

US Maternal and Infant Health Data:
**Pregnancy Risk Assessment
Monitoring System (PRAMS) in Crisis**

National PRAMS Convening, June 3, 2026, A Summary Report



The Harvard Center for Population
and Development Studies

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Acknowledgements

The National PRAMS Convening was supported by the Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health care issues and makes grants to improve health care practice and policy. The Convening was also supported by Rollins School of Public Health at Emory University through support from the O. Wayne Rollins Foundation.



Disclosures

Rita Hamad: I have no conflicts of interest to disclose.

Arden Handler: I have no conflicts of interest to disclose.

Philip Hastings: My research firm, Far Harbor LLC, is under contract to the CDC Foundation to clean, weight, and deliver final PRAMS datasets for the 2024-2025 data years to CDC, and to produce the public use research files for 2023, 2024 and 2025.

Holly Shulman: I serve as a paid consultant for Far Harbor on the PRAMS weighting contract with the CDC Foundation.

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Executive Summary

The **Pregnancy Risk Assessment Monitoring System (PRAMS)** is one of the nation’s most important sources of population-based information on pre-pregnancy, pregnancy, postpartum experiences, and maternal and infant health. For nearly four decades, PRAMS has enabled federal and jurisdictional (state, territorial, and city) public health agencies, researchers, policymakers, and advocates to monitor health outcomes and inequities, guide programs and policies, and evaluate progress. Its standardized methods and broad geographic coverage make it uniquely valuable, not only enabling national population research on pregnancy and the postpartum period, but also providing the insights necessary for jurisdictional decision-making and local action.

This critical infrastructure has been severely disrupted since January 2025. After federal actions that halted data collection and removed access to PRAMS data and project materials, the entire Centers for Disease Control and Prevention (CDC) PRAMS team was placed on administrative leave in April 2025 and remains so as of the writing of this report. The recent short-term funding renewals for jurisdictional data collection by PRAMS sites, combined with outsourced contracts for certain data-processing activities, represent modest positive progress. Yet these stopgap measures do not resolve the loss of national coordination or the uncertainty surrounding PRAMS’s future. Continued disruptions include the following:

- The centralized scientific and technical support at CDC that sustained the system for decades has been almost entirely eliminated.
- The public portal containing nearly 40 years of multi-site PRAMS data remains offline and unavailable.
- PRAMS sites—which already lacked sufficient federal funding to fully support PRAMS—face uncertainty due to insufficient capacity and resources related to staffing, data collection and processing, data analysis, and dissemination.

In response, over 40 invited experts participated in a virtual National PRAMS Convening on June 3, 2026, hosted by the Harvard Center for Population and Development Studies. Participants included former federal PRAMS staff and current and former site PRAMS staff, academic researchers, nonprofit and advocacy organizations, and private foundations. The goals were to identify the most urgent threats to PRAMS; develop actionable short- and medium-term recommendations to ensure PRAMS continuity; and assess the infrastructure, staffing, and funding needed to preserve the system.

Participants’ overarching recommendations were to:

1. Fully restore CDC’s leadership, oversight, and staffing for this critical component of national public health surveillance as soon as possible; and,
2. Provide stable, long-term funding for PRAMS at both the federal and site levels.

At a minimum, federal staffing of PRAMS must be restored to the levels prior to the 2025 disruptions to ensure capacity for high-quality technical assistance and centralized coordination as in prior years. At the same time, convening participants agreed that **immediate stopgap support for sites to help backfill lost capabilities is critical** for sustaining PRAMS, pending the restoration CDC’s scientific leadership.

As such, participants identified the need for a **democratized coordinating entity**, provisionally named “*Friends of PRAMS*.” This entity would bring together representation from PRAMS sites and other interested parties to coordinate activities, facilitate peer learning, advance the policy and funding agenda, and support functions no longer managed by CDC. Its work should complement existing efforts, avoid duplication, and remain responsive to changes in federal capacity. Dedicated funding is necessary to sustain the coordinating entity and its working groups. While the primary goal of this entity would be to coordinate implementation of the recommendations below, there was recognition that even if CDC staff are fully restored, such an entity could continue to play a support and champion role, ensuring that implementation of PRAMS remains robust and true to its mission.

The Convening focused on three interconnected areas, each corresponding to a potential *Friends of PRAMS* working group. Recommendations reflected the urgency of preserving current PRAMS operations and the need to build sustainable infrastructure.

1. Participants discussed the **loss of real-time technical and scientific assistance** to PRAMS sites, including support for sampling, data-collection protocols, operational problems, analysis, and shared methods. They emphasized that differences in site capacity increase the risk of departures from standardized protocols, which could undermine data quality and comparability.
Recommendation: assess sites’ needs and available expertise, develop a technical triage plan, and **establish a technical assistance hub** to provide coordinated support and maintain shared resources.
2. Participants examined the **loss of access to existing multi-site PRAMS data** and the absence of infrastructure for disseminating future data. This discussion highlighted the legal, logistical, and governance challenges involved in creating a non-CDC data-sharing mechanism, particularly because PRAMS data incorporate information from birth certificates and are subject to jurisdiction-specific requirements.
Recommendation: expand the existing multi-site dashboard (created by sites themselves during the past year) as a near-term source of aggregate indicators and, over the longer term, pursue data use agreements between sites and an **independent data repository** capable of housing and disseminating individual-level multi-site data.
3. Participants considered **policy and funding challenges**, including the (possibly permanent) elimination of federal PRAMS staffing, insufficient resources at the site level, and the instability created by the current approach of annual rather than multi-year funding to sites.
Recommendation: **seek support from multiple funding sources** for national and site-level functions, pursue a dedicated federal budget line item for PRAMS, and develop a template and technical assistance toolkit to help sites seek funding within their jurisdictions.

Importantly, participants cautioned against permanently shifting core governmental responsibilities to an entity outside government for the long term. There was a strong sense that national public health surveillance efforts are a core function of federal public health efforts.

This report presents the full findings and recommendations of the National PRAMS Convening. Section 1 begins with the history and function of PRAMS, the events and challenges of the current crisis, and the rationale and goals for the Convening. Next, Sections 2–4 summarize the discussions, recommendations, and implementation considerations related to the three focal areas mentioned above. Section 5 concludes with the case for action and proposed next steps for establishing Friends of PRAMS, organizing its working groups, securing the resources needed to sustain them, and implementing the recommendations over the next several years.

1. Background and Timeline of Events

1.1 PRAMS History and the Current Context

The Pregnancy Risk Assessment Monitoring System (PRAMS) represents one of the nation’s most critical public health surveillance tools. Established in 1987, PRAMS is a jurisdiction-based population survey of pre-pregnancy, pregnancy, and postpartum experiences. In recent years, the survey covered more than 80% of all U.S. births across 46 states as well as Puerto Rico, the Northern Mariana Islands, New York City, and the District of Columbia (hereafter referred to as “sites”).¹ As the only long-term national U.S. dataset specifically designed to capture pre-pregnancy, prenatal, and postpartum experiences, PRAMS serves as an essential resource for understanding maternal and infant health trends at both the national level and within each participating site.

PRAMS data have enabled policymakers, researchers, public health organizations, and advocates to track key maternal and infant health indicators including patterns of health insurance coverage, postpartum depression, experiences during prenatal care, contraceptive use, infant sleep practices, and maternal complications.²⁻⁴ With its link to birth certificates, this data infrastructure has been instrumental in identifying inequities in maternal and infant health outcomes, as well as building the evidence base for targeted interventions and population-level policies to improve maternal health (see **Appendix A**).⁵⁻⁸ State, territorial, and local health departments rely on PRAMS to design public health strategies and to measure progress toward maternal and child health goals. PRAMS is a core data source for reporting on the Maternal and Child Health Block Grant, a federal-state partnership program authorized under Title V of the Social Security Act to improve the health and well-being of women, mothers, infants, children, and families.⁹ In just one example of impact, the National Academies of Science, Engineering, and Medicine relied on data from PRAMS for its recent recommendations on breastfeeding in the United States.¹⁰ The dataset’s consistency, comparability, and population-based design make it uniquely valuable for national-level trend analyses all the way down to site-level decision-making.

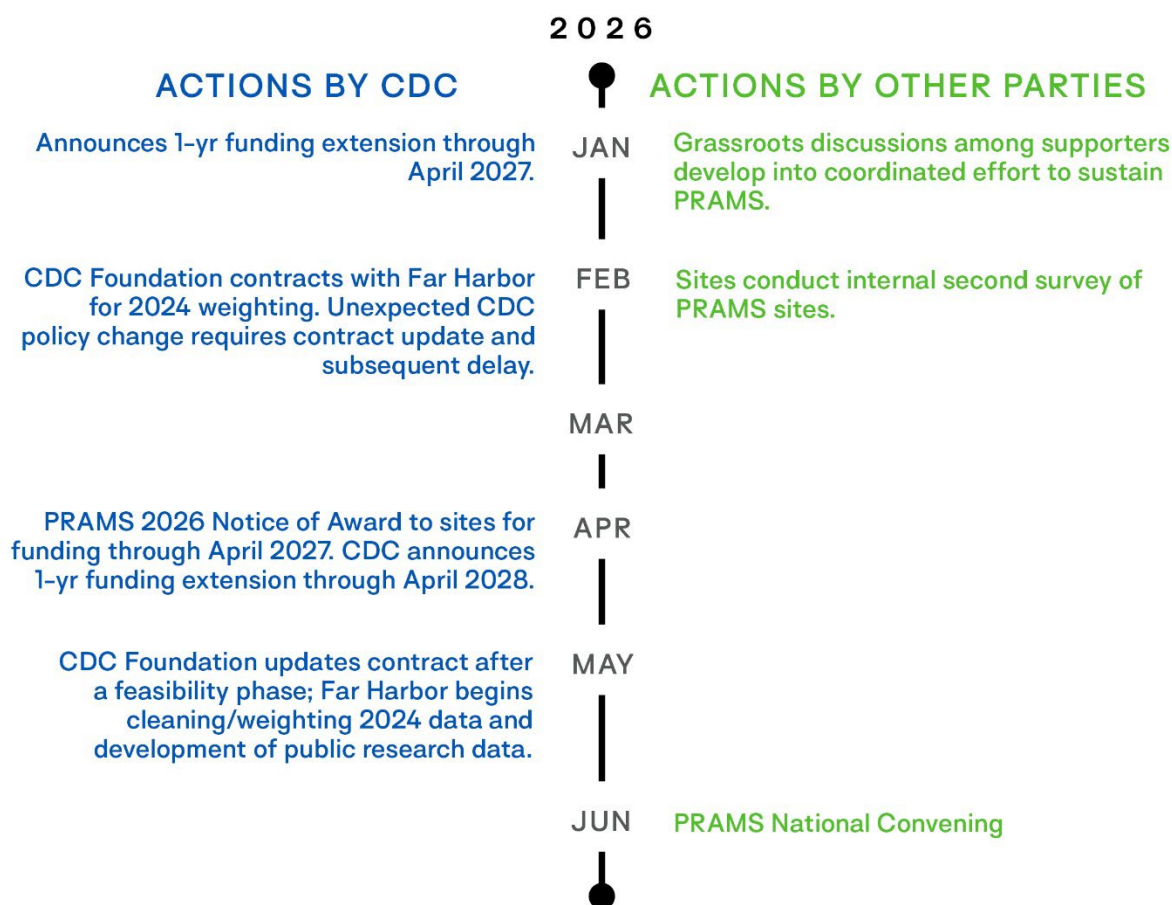
For decades, CDC staff have worked collaboratively with sites on PRAMS implementation. CDC provides funding for sites to conduct data collection and analyze and disseminate site-specific data. CDC staff have historically been responsible for coordinating activities across all sites, providing scientific and technical assistance, and engaging with national partners. Federal funding has historically not been sufficient to cover all PRAMS costs, and sites have to supplement with other funding sources. For the past 15 years, each site has only received \$175,000 annually to support data collection, representing less than half of operating costs for many sites. At the same time, sites have always depended on CDC PRAMS staff to coordinate critical ongoing tasks, such as to:

1. Develop, test, and implement survey questions that are validated and consistent across sites.
2. Standardize methodology across sites.
3. Create sampling designs for annual data collection and monitor their implementation.
4. Launch the questionnaire across sites and troubleshoot implementation problems.
5. Calculate survey weights to enable data interpretation.
6. Compile, clean, harmonize, and disseminate multi-site data for researchers, policymakers, and the public.
7. Produce key annual indicators of maternal and infant health, overall and by site.

This critical infrastructure is now at risk after a series of federal actions (see **Figure 1**).¹¹

Figure 1: PRAMS timeline of events





On January 20, 2025, the Trump Administration issued Executive Order 14168, "Defending Women From Gender Ideology Extremism and Restoring Biological Truth to the Federal Government."¹² This federal directive required a purge of gender identity language in all federally supported activities. To be in compliance, CDC halted PRAMS data collection, took down access to all PRAMS public use data (1988–present), and removed access to project materials for participating sites (with the intent of reinstating everything once targeted language was removed).¹³ However, a second major blow came in April 2025 when the entire CDC PRAMS team was slated for termination and placed on administrative leave as part of broad-scale reductions in the federal workforce.¹⁴ This action eliminated the centralized oversight, data management, and dissemination infrastructure that has sustained the system for decades. A coalition of 19 states and Washington, DC, filed a lawsuit in May 2025 challenging the layoffs.¹⁵ At the time of this report's dissemination, staff remain on paid administrative leave while the lawsuit works its way through the federal court system.

To address the leadership and communication vacuum, sites began coordinating monthly calls to discuss and coordinate project activities. Far Harbor, a former long-time CDC PRAMS contractor, set up a secure file-sharing and communications platform for sites to utilize in the interim. In May 2025, CDC awarded funding to sites to continue data collection for another year but with the caveat that CDC would no longer provide technical or scientific support. While the PRAMS tracking software (PRAMS Integrated Data System, PIDS¹) was brought back online in June for sites to conduct 2025 data collection, the absence of central coordination has created a

cascading crisis with multiple major disruptive impacts on participating sites, the quality of the data, and PRAMS data users. Because the amount of funding provided to sites has never been sufficient, sites were already supplementing federal funding with alternative funding sources in order to carry out PRAMS functions. Most sites are unable to cope with the additional responsibilities created by this crisis (see **Box 1**).

In the last year, there have been a few positive developments. The CDC announced a series of one-year funding renewals that could keep PRAMS sites operating through April 2028 (i.e., 2026 and 2027 data collection). In early 2026, the CDC Foundation, on behalf of CDC, contracted with Far Harbor to investigate feasibility for restarting the data cleaning and weighting process. By May 2026, Far Harbor had completed the feasibility analysis within the CDC network and began weighting the PRAMS 2024 data, with plans to produce the public use data files for 2023 and 2024. In October 2026, the CDC Foundation amended and extended the Far Harbor contract to include 2025 data weighting and creation of the public use research files when the raw data become available from the CDC.

Box 1: Surveys of PRAMS sites to understand disruptions since 2025

Two successive surveys of PRAMS sites were conducted to better understand the impacts of these disruptions.¹⁸ According to the first survey conducted in August 2025 (n=37 sites), only three-quarters of sites had access to PRAMS data collection software systems, resulting in average delays of 3.3 months for 2025 collection (see **Figure 3**). The second survey was conducted three-quarters of the way through the 2025 data collection period,¹⁹ in February 2026. It found that only about half (54.8%) of responding sites (n=42 sites) expected to collect a full year of data in 2025 (see **Figure 4**).

Figure 3: Challenges faced by sites after dismantling of CDC PRAMS team (Survey 1, n=37)

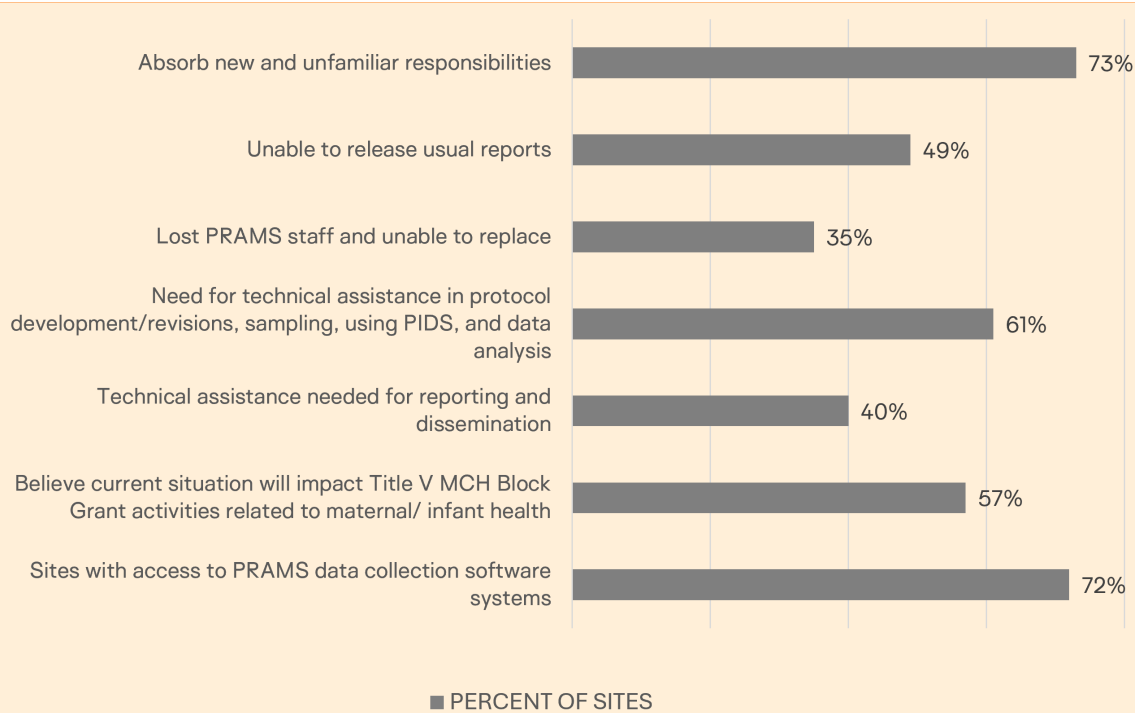
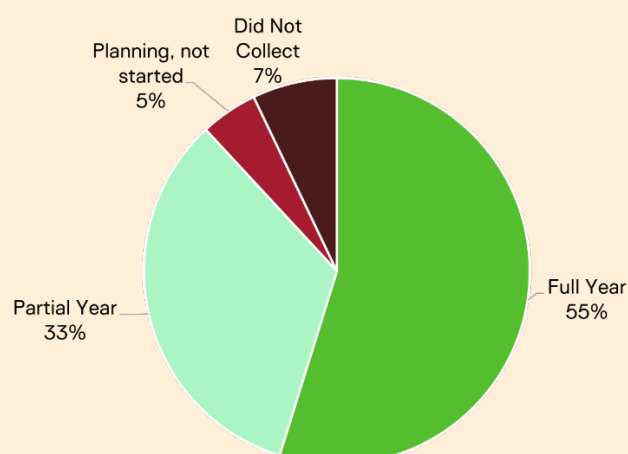


Figure 4: Site expectations for 2025 data collection (Survey 2, n=42)



Despite this partial progress, expert CDC PRAMS staff remain on paid administrative leave while not being allowed to carry out their duties. Data access has still not been restored, and the future of data collection remains uncertain. A handful of substitute staff at the CDC with no prior PRAMS experience have been assigned to distribute funds to sites for data collection, manage the contract for the PIDS tracking system, and receive birth file submissions from sites. These tasks were assigned on top of their existing full-time (non-PRAMS) duties.

Figure 2 summarizes the key disruptions to PRAMS and their impact. Per official CDC communication to sites in April 2025,^a there will no longer be any centralized or coordinated scientific expertise provided to sites. Without this technical assistance and more certainty about the future, sites remain at high risk of drifting away from a standardized protocol. Some sites are considering leaving the national PRAMS project entirely, which would be damaging to the comparability and continuity of data collection across sites and over time, further weakening this important source of public health information. Individual sites have faced barriers to continuing data collection. According to two recent surveys of site staff (see **Box 1**), some sites ceased collection for the entire 2025 surveillance year. CDC’s online portal (Automated Research File, ARF) that provided access to nearly 40 years of data is still offline, having just been launched in 2024 (see **Section 3**).¹⁶ Consequently, researchers, policymakers, and the public have lost access to both historical and current data, not to mention the loss of public infrastructure after such a substantial investment.¹⁷ Because CDC has only announced single-year funding extensions (instead of the typical 5-year awards), sites face significant uncertainty, putting at risk each site’s staffing and vendor contracts. All these disruptions create administrative and methodologic uncertainty that threatens the continuity and quality of current and future data collection, maternal and child health (MCH) program planning and operations, as well as access to decades of existing data for researchers, policymakers, and the public. These disruptions also mean that data from these years will be less comparable to other years,

^a “CDC can no longer provide the scientific, technical, and information technology assistance resources as described in the Notice of Funding Opportunity RFA-DP-21-001 for the Pregnancy Risk Assessment Monitoring System (PRAMS). CDC will share guidance for revision of workplans and budget documents for the Year 5 budget period starting May 1, 2025 through April 30, 2026 soon.” Excerpt from a CDC email notification to all participating PRAMS sites on April 30, 2025.

making it difficult to understand MCH trends during this period. Smaller sample sizes also mean that it will be difficult to examine trends among smaller subgroups (e.g., rural populations, racial/ethnic minorities).

Figure 2: Disruptions to PRAMS and their impacts

BEFORE 2025	NOW	IMPACT
Full-time CDC PRAMS team of 20 to coordinate • Technical assistance • Sampling, weighting • Standard protocol and methodology	Limited CDC substitute resources assigned (no prior PRAMS experience) • Scant ad-hoc technical support • No scientific support for sites • Tightly limited communication	⚠ Threatens data quality ⚠ Risk to comparability across sites & time
Dissemination of multi-site data through ARF portal	ARF portal shut down with no public data access	⚠ Historical multi-site PRAMS data is unavailable ⚠ Researchers must request data from each site ⚠ Sites must deal with many more data requests
Centralized survey question development & coordination	No CDC staff to develop & coordinate survey questions	⚠ Risks to survey consistency ⚠ Stagnation, no new topics/questions
Funding through 5-year cooperative agreements	1-year funding extensions, currently through April 2028	⚠ Staff layoffs in some sites because of funding uncertainties ⚠ Some vendors have terminated contracts with sites
Ongoing data collection by all participating sites	2024 data: Partial year (9 mos) for all sites 2025 data: Delays in data collection for most sites, no data collection for a few sites 2026 data: Some sites started collecting data, with delays	Threats to sites' capacity for: ⚠ Monitoring MCH trends ⚠ MCH decision-making ⚠ Program evaluation ⚠ Monitoring Title V MCH Block ⚠ Grant activities ⚠ Reduced statistical power for data analysis

1.2 Rationale and Goals for National PRAMS Convening and Report

The consequences of these disruptions have been extremely detrimental to research and policy efforts aimed at improving maternal and infant health. Overburdened states lack the capacity to measure progress on critical maternal health goals, identify emerging risks, or process requests for data sharing. Policymakers cannot track maternal and infant health trends in real time. Researchers cannot access the data necessary to study health inequities or evaluate relevant policies. Advocates lose a key evidence base for making systemic changes to prevent maternal and infant mortality and morbidity—particularly among marginalized communities. Mississippi, where PRAMS data collection was disrupted during 2024 and 2025, serves as a clear illustration of these losses. In August 2025, the state’s health department announced an infant mortality crisis; PRAMS data would have been ideally suited to help investigate the causes and potential solutions.¹⁷

To address the immediate challenges facing PRAMS, a core group of academic researchers and former CDC team members engaged in conversations with a variety of knowledgeable experts and interested parties, including former federal PRAMS staff and current and former site PRAMS staff, academic users of PRAMS data, non-profit organizations, and private foundations. These conversations highlighted the urgency of a coordinated national response to preserve this vital data source and to establish sustainable infrastructure for future PRAMS data access, coordination, and dissemination. Many of these interested groups indicated a strong desire to work together, since the conversations and actions to that point were happening without coordination.

This need for a coordinated rescue of PRAMS motivated a National Convening on June 3, 2026, which brought together partners to discuss ongoing challenges and develop actionable recommendations. The specific goals of this Convening were to:

1. Understand key barriers to the continuation of PRAMS surveillance system, including current and future PRAMS data collection, weighting, and cleaning; and sharing existing and future data.
2. Identify ways to bridge immediate gaps, including providing technical guidance to PRAMS sites; ensure long-term viability of PRAMS data collection and data dissemination; and showcase the value of PRAMS data to provide evidence on the need for restoring this critical data resource.
3. Develop recommendations regarding short- and long-term strategies to address these challenges, including plans for technical assistance to sites, data dissemination to the research and practice community, and ways to encourage the restoration of federal staffing and support for PRAMS.
4. Identify funding, infrastructure, and staffing needs to ensure continuity of the effort beyond the Convening.

The National PRAMS Convening involved 46 invited experts who were selected to participate based upon their MCH and policy experience. They represent diverse perspectives across federal and state government, academia, the non-profit sector, and private foundations (see **Appendix B**). The event was hosted virtually on June 3, 2026, by the Harvard Center for Population and Development Studies, with funding from the Commonwealth Fund and the Rollins Family Foundation at Emory University.

The National PRAMS Convening opened by sharing information about the history of PRAMS, its role in the U.S. MCH public health system, and the changes to PRAMS since January 2025 (see **Appendix C**). Then, participants

were divided into three breakout groups to address the topics identified as the greatest substantive areas of concern. These groups were charged with developing actionable recommendations in the areas of:

- **Data and Technical Assistance to PRAMS Sites:** How to provide technical assistance to ensure the credibility and continuity of site PRAMS data collection.
- **Use and Dissemination of PRAMS Data:** How to create the logistical and legal infrastructure to collect and share existing and future PRAMS data.
- **Policy and Funding:** How to build the evidence base and promote networking to support the continuation of PRAMS at the site and national levels.

After the breakout sessions, all participants regrouped in a joint plenary session. Each breakout group presented their recommendations followed by a general discussion. After the Convening, participants had the opportunity to complete a follow-up worksheet to share additional thoughts on the recommendations as well as ideas related to the future support of PRAMS.

The proceedings of this National PRAMS Convening, including participant input from follow-up worksheets, are summarized in this report. Sections 2–4 summarize the discussions and conclusions of each of the three breakout groups within the substantive areas above, and Section 5 provides an overview of conclusions and next steps.

One cross-cutting recommendation that emerged across all three breakout groups was to develop a democratized coordinating entity positioned as “Friends of PRAMS.” This non-governmental supporting entity could serve as a central coordinating body for important PRAMS matters that are no longer directed or managed by CDC. This body of experts would facilitate further convenings, peer-to-peer connections, development of best practices, and shared learning. The entity could also be a long-term place for absorbing, contracting, or directing essential scientific and other support temporarily undertaken by volunteers trying to aid sites in navigating these challenges. If at some point the CDC PRAMS team is restored (as Convening experts strongly recommend), then the Friends of PRAMS could aid in a smooth transfer of knowledge and perhaps continue to engage in a more targeted role as a public champion for this treasured and critical national resource.

2. Focus Area I: Data and Technical Assistance

2.1 Overview

As described briefly in Section 1, all PRAMS participating sites are navigating severe uncertainty with a minimum of technical support from CDC. Even if CDC maintains its current trajectory with the provision of basic site funding, PIDS access for data collection, and survey data processing, there is a strong need for real-time scientific and technical support. Without such technical assistance, the sites remain at risk of not using a standardized protocol or withdrawing from the national PRAMS project entirely, which would damage the comparability and continuity of data collection across sites (see **Figure 2** above).

This section focuses on the technical and operational challenges facing sites today. We conclude this section with recommendations to address the gaps in real-time technical support and the shared knowledge infrastructure.

2.2 Key Findings Regarding Challenges

Participants in the Data and Technical Assistance breakout session identified the following key challenges affecting sites.

2.2.1 Technical Operations and Methods Support

The current lack of real-time technical assistance means that sites are left to make critical, urgent operational decisions on their own, which they are not equipped, trained, or staffed to handle.

The following are a few of the many examples of these types of issues:

- Sampling errors and how to address them (e.g., duplication of mothers or mailings across batches).
- Protocol guidance for special circumstances, (e.g., communication with mothers who experienced infant death, adoption, incarceration).
- Necessary adjustments to sampling plans (e.g., when sampling is interrupted; when a site receives significantly more or less surveys than planned; if state births decline; when stratification approach must change).
- Violations of protocol and how to remediate such incidents (e.g., accidental disclosure of pregnancy status and/or other personally identifiable information during outreach).
- Changes made to outreach, incentives, or other methods for contacting mothers.
- Updates in site vital statistics systems that cause sampling program failures.

Currently, even when sites submit help tickets to CDC for technical support, they can experience several weeks of delay and sometimes receive no response at all.

2.2.2 Historical Archives and Communications Infrastructure

Prior to 2025, CDC functioned as the repository for historical documents (via the Inside PRAMS SharePoint site), multi-site public use data (via the ARF portal), and a hub of communications among all sites (via the PRAMS listserv). The loss of this historical and collaboration infrastructure meant that sites were effectively cut off from the critical resources and one another, creating hurdles to accessing even the most basic self-help and peer-help resources.

Soon after the infrastructure blackout in early 2025, participating sites organized a “PRAMS All-Site” virtual call, using old lists of emails. This meeting evolved to become a monthly occurrence among sites, serving as a lifeline for sharing challenges and ideas for salvaging operations. A former PRAMS statistical contractor (Far Harbor) was invited to join these monthly meetings; later, the firm donated infrastructure and technical staff time to help bridge the gaps in communications. A portal with a companion listserv was created and deployed as a stopgap solution for site member communications and peer-sharing of historical documents, such as codebooks, methods, and protocols. Grassroots technical guidance and site collaborations now occur regularly via this interim platform. Unfortunately, several sites report that their agency firewalls prevent access to this independent resource.

Although the interim platform has become a valuable communications hub for most participating sites, any technical questions requiring deeper PRAMS expertise are answered on an ad-hoc basis by a group of volunteers. This situation is not sustainable, since these volunteers cannot provide the same level of support as the dedicated CDC scientists who once ensured a common protocol. Absent an entity with the mandate (and funding) to maintain standards over time, the system is already at risk of losing the cross-site comparability, validity, and quality that makes PRAMS a premier data source.

2.2.3 Analytic and Scientific Support

CDC scientists once offered clear guidance on best practices for analyzing data and presenting results. Quick questions from researchers about analytic strategies were often fielded by internal CDC standing committees. Sites were also required each year to showcase “Data to Action” stories that revealed the underlying value of the PRAMS system, using examples from CDC-developed statistical code and reporting templates.⁸ When sites wanted to alter their outreach and recruitment methods, CDC staff would help sites develop experiments to test changes and evaluate what works best. Staff at CDC would also evaluate how changes to survey items and response rates could affect estimates. All that expertise is now unavailable. Most sites report that they do not have internal capacity or time to pursue even the most basic methodological and analytic questions, let alone take on the technical operations that CDC had provided.

2.2.4 Diverse Environments, Needs, and Capabilities

Across PRAMS sites, there exists a wide variability in public health infrastructure, leadership support, legal and political systems, budgets, and operational capabilities. Thus, potential solutions are not likely to work with a one-size-fits-all approach. For example, when CDC notified sites that PIDS was reactivated and instructed them to resume data collection, several sites were ready to immediately restart operations; whereas other sites were told by their attorneys general to cease PRAMS operations due to litigation in progress. Similarly, the highest-

functioning sites often leverage outside funding, have robust staffing, and maintain strong regional partnerships, while other sites struggle to maintain their operations within a bare minimum of CDC and health department support. Therefore, recommendations for future technical assistance support should consider this variability. Solutions might need to focus on the most at-risk sites in the short term.

2.3 Recommendations

Friends of PRAMS

As noted above, one cross-cutting recommendation that emerged from all three breakout groups was the creation of a *Friends of PRAMS* coordinating entity to continue championing PRAMS beyond this Convening. Participants in our session recommended a structure that resembled the previous PRAMS All-Site Working Group, which nominated regional site representatives to attend regular coordinating meetings. Other structural analogues might be Institutional Review Boards or Federal Advisory Committees. As with this Convening, the representation should be diverse and interdisciplinary to capture a variety of perspectives and types of expertise. One point was repeatedly emphasized: staff from PRAMS sites must be involved via genuine representation to share perspectives and shape solutions. Transparency and consensus-building will be critical to the eventual success of such an organization.

We note here that a final decision was not made about which specific organization or type of organization would work best in this role, nor the specific governance or decision-making structure. Ideas ranged from the creation of a new nonprofit entity, to naming an affiliated partner as a host organization such as the [Association of State, Territorial and Health Officials \(ASTHO\)](#) or the [Association of Maternal & Child Health Programs \(AMCHP\)](#), to funding a Center of Excellence connected to a School of Public Health (e.g., Harvard, Emory, or Columbia). In addition, there are currently several regional consortia of sites pooling resources and talent to envision a future for PRAMS (e.g., the Northeast Public Health Collaborative). These efforts should be coordinated together with whatever entity arises to avoid duplication of effort. The development of the National Asset Map (see additional recommendations below) should include all of these diverse groups under the *Friends of PRAMS* umbrella.

The recommendations are written below with the assumption that *Friends of PRAMS*, with appropriate funding, would lead many of these efforts. Its role would also adapt based on whether CDC PRAMS staff are restored, as described throughout the report.

Specific Actions: Technical Support for Sites

Recommendations for this section focus on high-impact, simple solutions that could address the sites' frequent needs for operational and technical support in the absence of CDC assistance and leadership. These activities have the potential to be implemented rapidly, without requiring approval from CDC, the US Department of Health and Human Services (HHS), or participating sites. Much like a triage unit, solutions may not be perfect but could help "keep the patient alive" in the interim. Ideally, these solutions would be temporary until CDC offers this function again. However, if the loss of the CDC PRAMS team becomes permanent, at some point in the future a purpose-built organization or network could perhaps absorb these critical functions. Attempting to design the perfect structure now might delay interested sponsors and partners from providing the immediate

help needed; thus, the following recommended steps could be implemented quickly and provide immediate relief to sites. These efforts would require funding to ensure sustainability and accountability.

1. Conduct a **Site Needs Analysis**. An in-depth analysis of unmet operational and technical support needs from the sites' perspectives is the critical first step toward developing solutions. Specific and detailed examples of these needs would ensure that appropriate expertise can be identified. Examples of such site needs might include: technical assistance on protocol questions; statistical sampling fraction updates; phone vendor contracting; advice for reducing cost of outreach methods; consultations on analysis methods; and fixing errors in sampling programs. After surveying sites, the list of needs should be categorized by *importance* and *urgency*. Each identified need should also be categorized by how much it might overlap with an ongoing CDC-managed function in order to assess the feasibility of addressing the need without CDC involvement or approval. ASTHO already initiated a first step in needs analysis during a PRAMS all-site monthly meeting and documented some ideas from the sites.
2. Create a **National Asset Map** in parallel with the Needs Analysis in #1. Execute a scan of existing resources and expertise within the entire network. Include all sites and their partner organizations to identify who might provide peer mentorship in areas like operations, outreach, incentives, data processing, and analysis. Develop a detailed directory of aligned experts, organizations, funders, and vendors, along with their capability for support. In a related resource table, identify all available data and document repositories, platforms for communication, websites, and other tools and software that might be leveraged for site support.
3. Create a clear **Plan for Technical Triage**. Based on the Needs Analysis and Asset Maps from #1-2, create an actionable plan for delivering the critical functions that are not currently provided by CDC. Leverage existing resources where practical (e.g., all-PRAMS listserv, file shares, portal, etc.).
4. Build and deploy a **Technical Assistance Hub**. Create a coordinated team platform for a PRAMS helpdesk and repository, where members provide expert triage to connect sites to resources and offer real-time technical and operational assistance. Maintain an efficient communications infrastructure and file repository, and conduct periodic evaluations to ensure site needs are met.

Although the focus at the Convening was on addressing the immediate crisis facing PRAMS, participants also mentioned several long-term recommendations if CDC PRAMS staff are restored and new opportunities emerge to improve upon PRAMS. These are described in **Appendix D**. All participants agreed that major innovations during this time of uncertainty would be difficult and not realistic in the short term.

2.4 Implementation Considerations

Successful implementation of any of these recommendations must pair funding, institutional memory, and expertise with external operational capacity. Some former CDC staff and those currently on forced administrative leave possess the necessary institutional expertise, yet they may be prohibited from helping in this effort for various reasons (e.g., legal). Within PRAMS sites, staff with 5+ years of PRAMS knowledge are fast becoming scarce due to retirements and layoffs. Yet these very resources are critical to help bridge emerging gaps.

Financial stability for PRAMS sites also remains a significant hurdle to long-term sustainability. Sites typically augment CDC funds by 200–300% using state or other agency dollars. If a supporting organization were to

undertake some of the prior CDC coordinating functions, then dedicated funding assistance—potentially from philanthropic sources—might help to incentivize continued site participation. One idea that emerged from the breakout group was that regional sponsors might be able to support individual sites or regions without necessarily trying to replace the CDC’s national role.

2.5 Risks and Contingency Planning

There are several potential risks in starting up a new technical assistance operation to fill the current void. First, the CDC might view such an effort as competitive to its funding and oversight role. Another risk is that a successful rollout might jeopardize the chances of CDC bringing back the dedicated staff and research scientists who once delivered technical support. Lastly, there is a risk that even with the injection of funding to provide technical and operational support, such an effort could be seen as illegitimate, burdensome, or ineffective by sites, so that a gradual erosion of the PRAMS network and protocol ensues. Below are some ideas for mitigating those risks.

Position the effort as temporary. Participants emphasized that any immediate technical assistance solution, whether through a foundation or academic entity, should be positioned as a temporary stopgap effort (e.g., 2 years). Most Convening participants believe that the primary goal remains the restoration of federal research scientists and oversight and a dedicated federal line item for PRAMS to ensure the long-term integrity of the nation's maternal and infant health data (see **Section 4**).

Articulate a clear return on investment: Engage allies like ASTHO, AMCHP, and the Maternal & Child Health Appropriations Alliance (MCHAA) to orient all collaborators (including the sites) about the value of standardized technical support and a common protocol for data quality and comparability. Continue to articulate value with CDC and HHS and establish clear service boundaries to avoid any overlap with CDC. Establish a way to share any necessary coordinating information with CDC when technical assistance intersects with these boundaries. Provide ad hoc expertise and knowledge, if requested, to the remaining CDC staff who were assigned to manage functions for CDC PRAMS.

Build an efficient, peer-led, site-focused service model. Draw upon the existing talent within sites and strengthen it. Offer educational and training opportunities for sites interested in building their own capacity. Partner with former CDC and other expert staff to ensure strong institutional memory. Encourage regular feedback from sites about what is and is not working. Conduct regular iterative improvements of the service delivery model to ensure timeliness and accuracy.

Ensure legal compliance: Any external support structure will eventually need to accommodate data use agreements (DUAs) for situations where data must be shared to investigate and resolve technical issues. Ensure there is a resource available for handling legal questions and/or DUAs, as required.

3. Focus Area II: Use and Dissemination of PRAMS Data

3.1 Overview

The CDC PRAMS ARF portal went live in January 2024 to streamline the dissemination of multi-site PRAMS data from 1988 to the present. Prior to establishing the public use ARF portal, CDC required researchers to submit a proposal describing how they plan to use the data. Each proposal was reviewed by staff at CDC and each site, and sites could choose to have their data excluded from a research project on a case-by-case basis. Although this allowed the strictest sites to apply their own approval processes, it was time-consuming for researchers, CDC staff, and site, and limited dissemination of the data.

Because the PRAMS surveys are linked to birth certificate data and birth certificate variables are part of the analytic datasets, there are additional legal considerations that must be taken into account that are not applicable to most surveys. Each site has laws regulating the use of vital statistics data to protect the privacy of the individuals and confidentiality of the information. All sites authorize the use of birth certificate data for public health research, but some sites interpret the rules more stringently by way of the protections they impose. At the extreme end, some sites require separate human subjects Institutional Review Board (IRB) review and approval of each proposed research project using birth certificate data.

When it was decided to transition to the PRAMS ARF portal from the original PRAMS data request process, it took over three years of planning and preliminary efforts before the public use data was first released. After agreeing on the set of birth certificate variables that could be included, by far the most time-consuming process was entering into DUAs with each of the PRAMS sites. There were IRBs, privacy officers, legal offices, and vital statistics offices all reviewing and weighing in on the agreements. Many sites required modifications to the PRAMS DUA, which had to be negotiated between the respective legal offices. Forty-six of the 50 sites ultimately signed DUAs to have their data included in the public use datasets. The agreements gave CDC permission to release the sites' data to anyone who completed the application process and signed a researcher data sharing agreement. The four sites that chose not to allow their data to be released in the public use dataset, due to their strict interpretations of vital records laws, continued to be responsible for fulfilling researcher requests for their PRAMS data.

The ARF required a major investment in infrastructure by American taxpayers and represented an important improvement in transparency. Yet it was taken down one year later as part of the 2025 disruptions (see **Section 1**). This leaves researchers, policymakers, advocates, and the general public with no easy access to present or past PRAMS data. Instead, prospective data users must secure approvals for individual data use from 50 separate sites, creating a time- and resource-intensive process for both data requesters and sites themselves. Moreover, many sites have no processes or infrastructure to manage data requests, and even those with established processes have insufficient capacity to handle the increased volume of requests.

3.2 Key Findings Regarding Challenges

Discussions in the Use and Dissemination breakout group highlighted both the urgency and complexity of restoring and sustaining broad access to PRAMS data. A centralized, multi-site data resource increases the value of PRAMS for national and comparative research. Participants repeatedly returned to three cross-cutting themes: (1) the need to establish solutions both for existing PRAMS data and for future data; (2) the legal and logistical challenges of moving away from a CDC-centered model; and (3) the tradeoffs between start-up time, effort required, data utility, and long-term sustainability.

3.2.1 Considerations for Existing and Future Data

Participants in the breakout group noted that “existing” versus “future” PRAMS data represent distinct problems. Existing data—spanning decades of PRAMS data in which data users have high confidence—are at immediate risk since they are effectively inaccessible for research and policy use. With the ARF portal offline and federal PRAMS staff on indefinite administrative leave, there is no clear, active mechanism to ensure that these historical data remain available in a form that is both legally compliant and analytically useful. Participants agreed that re-establishing access to these existing data is a high priority.

At the same time, for current (2025 and 2026) and future PRAMS data (2027), short-term funding has been announced to support sites’ data collection.^b Yet, infrastructure at the CDC that once supported standard data processing, harmonization, and dissemination is no longer available. As a result, there is a risk that any new data collected will become fragmented across sites, with variable formats, documentation, and sharing rules. Participants stressed that any new dissemination solution will need to grapple not only with where data are housed, but also with who is responsible for ensuring comparability over time and across sites.

3.2.2 Legal and Logistical Considerations for Reestablishing Data Access

Participants in this breakout group analyzed the legal and logistical barriers that constrain what can be done in the near term, especially in the absence of CDC leadership and infrastructure. CDC had invested substantial effort to put in place DUAs that allowed construction of a public use dataset; these agreements were with CDC, not with third-party entities. Participants noted that any new repository or platform that aims to host PRAMS data would almost certainly have to repeat this work—negotiating fresh DUAs with every site—unless a residual authority at CDC could authorize data sharing under existing agreements.

This legal context framed a broader discussion of potential models for hosting PRAMS data while the ARF CDC portal is unavailable. The group considered the role of academic-based third-party repositories such as the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan, the Integrated Public Use Microdata Series (IPUMS) at the University of Minnesota, or other established data archives. These organizations have considerable experience housing sensitive public health and social survey data and could, in

^b “CDC is excited to share that a second supplement opportunity available to current PRAMS recipients will be offered in winter 2026/2027. This opportunity will provide funding for the project/budget period from May 1, 2027, through April 30, 2028.” Excerpt from a CDC email notification to PRAMS sites on June, 2026.

principle, serve as a centralized home for PRAMS files. However, participants underscored that such an arrangement would still require: (1) clarity about who is authorized to transmit the data to the repository; (2) new or amended DUAs with sites if the original agreements are tethered to CDC; and (3) substantial legal, administrative, and staffing resources at both the sending and receiving institutions. While this path could ultimately provide a robust and sustainable dissemination mechanism, it would demand dedicated legal and governance work, likely over several years.

There were also concerns that not all sites might participate in the process to establish a new data repository, just as some had opted out of the ARF portal. This highlights the need to ensure strong involvement across a broad spectrum of sites from the outset. For example, hesitant sites could be reassured that they would then be less burdened with data requests themselves, if the process is centralized.

Relatedly, there was a shared sense that any dissemination approach should learn from analogous efforts in other domains (e.g., data rescue initiatives, existing multi-state health datasets hosted at academic or nonprofit institutions, and sites that had set up alternative avenues to disseminate data outside of the ARF). Participants suggested reviewing these precedents to avoid reinventing solutions for issues such as secure access, de-identification standards, documentation, and user support.

The breakout group members quickly ruled out another near-term but more legally complex possibility: allowing an entity that already holds downloaded PRAMS data from the former portal to share those files. Participants noted that the individual or organization that shared data in this way would likely be violating their DUA, and that this would undermine trust.

3.2.3 Considering Tradeoffs Posed by Different Solutions

The breakout group participants explored tradeoffs between speed, data utility, and long-term sustainability across different possible solutions. A recurring theme was that some users—particularly policymakers and program staff—can meet many of their needs using a well-designed data dashboard of aggregate-level data, whereas researchers and evaluators often require individual-level microdata.

This distinction surfaced in the discussion of a near-term option to expand an existing PRAMS dashboard—created by one of the sites' epidemiologists—that currently presents aggregate indicators.²⁰ Scaling up such a dashboard could restore rapid access to at least a subset of indicators across sites, thereby enabling many descriptive and advocacy-oriented uses of PRAMS. Providing additional support for this solution—which is currently being maintained by just one individual and is therefore at risk of not being sustainable—could ensure more robust infrastructure and broader use of this dashboard. However, this approach would not by itself meet the needs of those conducting policy evaluations, equity analyses, or complex multivariable research projects that depend on individual-level data.

In contrast, as noted above, the most sustainable and useful long-term solution identified by the group centered on re-establishing DUAs directly between sites and a third-party repository, with strong site involvement in design and oversight. Under this model, sites would formally authorize a non-CDC entity to hold and disseminate their data, with clear conditions on data access, confidentiality protections, and use. Participants viewed this as the most durable legally sound foundation for a non-CDC dissemination architecture and one that could

potentially be combined with a broader advisory or governance structure for PRAMS. At the same time, they acknowledged that negotiating and implementing such agreements across all participating sites would be a major undertaking, requiring substantial time, staff capacity, and legal expertise. Finally, the group reflected on the inherent tension between setting up a data repository and infrastructure outside of the CDC—a critical need at this time to minimize the loss of institutional knowledge and data quality—and the general agreement that these functions should ideally reside centrally within the federal government at the CDC. As one participant put it, “A workaround can solve today's problem while making tomorrow's restoration of governmental public health infrastructure less likely.” Participants highlighted the need for providing this support in the short term (and possibly longer), while not undermining the push to restore federal capacity, an echo of participants’ concerns across breakout groups. Participants did not resolve this tension but recognized it as a core challenge for any future infrastructure.

Taken together, these discussions underscored that the central challenge for use and dissemination is not merely technical. It is fundamentally about governance, legal authority, and the allocation of responsibilities between sites, federal agencies, and potential third-party partners—both for safeguarding the legacy of existing PRAMS data, and for ensuring that future data can be collected, processed, and shared in ways that maximize their public health impact.

3.3 Recommendations

The following two recommendations emerged. Participants noted that, in implementing these recommendations, there should be close involvement and buy-in from staff across PRAMS sites, legal expertise to ensure compliance, and technical support to ensure operational feasibility.

Short-term Recommendation. To increase short-term access to existing PRAMS data, scale up the existing multi-site PRAMS dashboard created in the last year,²⁰ which would provide aggregate data similar to the CDC WONDER dashboard for vital statistics data.²¹ This dashboard would not have the capacity to provide individual-level data, but could be more quickly rolled out.

Medium-term Recommendation. To support longer-term sharing of existing and future PRAMS data with external users across the nation, ask sites to develop DUAs with an independent data repository to house and disseminate the data. This process could be expedited if the existing DUA between the CDC and each site is used as a blueprint.

Also, participants acknowledged the need to remain nimble and prepared to adjust strategies if federal support for centralized data sharing is restored. For example, the group discussed another possibility: gaining access to the existing CDC ARF portal and reactivating it to ensure data access. Multiple participants felt pessimistic that this was a feasible approach, given the lack of dedicated PRAMS staff at the CDC in the current moment.

Additional long-term recommendations are described in **Appendix D**.

3.4 Implementation Considerations

As noted in Section 1, participants envisioned that these recommendations would ideally be implemented by a *Friends of PRAMS* entity. Resource needs include initial staff time to undertake a new process of establishing DUAs (including individuals with legal and data-sharing expertise), financial support for infrastructure, and longer-term staff time to maintain the DUAs and data repository, including staff time to manage ongoing data requests from data users.

4. Focus Area III: Policy and Funding

4.1 Overview

This session focused on the future of PRAMS amid federal staffing reductions, funding uncertainty, and broader challenges to public health infrastructure. The goal was to identify strategies and potential funding and policy changes that will ensure the future of PRAMS. While there was widespread concern about the dismantling of federal capacity supporting PRAMS and conversations about PRAMS preservation, the discussion also included reimagining and strengthening the system for the future.

4.2 Key Findings Regarding Challenges

4.2.1 Immediate Policy and Funding Challenges faced by PRAMS

The Policy and Funding breakout discussion noted that wide-ranging support for PRAMS has emerged from many sectors over the recent challenging period, including not only from the PRAMS sites themselves but many academic partners and national public health and MCH organizations. The role of local health departments, which in some states have pushed state legislators to support their PRAMS programs, was also acknowledged. In addition, there was recognition that supporters of MCH data systems may not always be confined to those ordinarily expected, and as such, participants stressed the importance of thinking outside the box to build additional support for PRAMS.

Participants noted that at the current time, PRAMS supporters and partners want not only stable but increased funding, as well as restoration of federal oversight functions. Understanding current funding and administrative challenges can assist in considering what is needed to ensure the stability of PRAMS. Specific challenges for the full restoration of PRAMS relate to: 1) staffing and oversight at the federal level, and 2) funding at both the site and national levels. (Note: in this section, we use the word “federal” when referring to governmental oversight by CDC, and “national” when referring to oversight across sites but not necessarily by the federal government).

4.2.1.1 Staffing Challenges

With respect to the staffing of PRAMS, as indicated in Section 1, the entire CDC staff responsible for managing PRAMS was placed on administrative leave in April 2025.¹⁴ Without federal oversight and support of PRAMS, the breakout group acknowledged that the risk of PRAMS becoming a site-only initiative clearly increases, and uncertainty for the future of PRAMS as a multi-site maternal and infant public health surveillance system heightens.

4.2.1.2 Funding Challenges

Considering the funding landscape for PRAMS, breakout group participants indicated that funding for PRAMS at the **site level** has never been sufficient, with various sites needing to provide additional funding from other funding streams including from vital statistics budgets, Health Resources and Services Administration (HRSA) Title V Maternal and Child Health Block Grant dollars, HRSA State Systems Development Initiative (SSDI) funds, state general revenue funds, etc. It was also acknowledged that add-on surveys associated with PRAMS, such as

PRAMS for Dads and follow-up postpartum and toddler surveys, require additional support and, to date, have relied heavily on philanthropic funding for implementation.²² As sites get a better handle on what they can and cannot do without federal oversight and support, the fragility of funding and support provided at the site level is of great concern with increasing resource strain for the sites, both in terms of funding and personnel.

At the **federal level**, there is continued budget uncertainty with the domestic discretionary budget. The year-to-year funding uncertainty for US domestic programs leads to a lack of stability for sites, given their need to plan for each data collection and implementation year. Even without the current funding unpredictability, PRAMS has never had its own line item in the federal budget or unique authorizing legislation. Currently, PRAMS is funded through the CDC Safe Motherhood bundle, but like other surveillance systems such as the Behavioral Risk Factor Surveillance System, PRAMS does not have an individual line item, making it extremely difficult to advocate for PRAMS in the federal budget. Rather, PRAMS is primarily authorized through Section 301 of the Public Health Service Act (42 U.S. C. §241), which is the general authorizing legislation for HHS and CDC, but how that funding is allocated to specific activities such as PRAMS is at the discretion of HHS. Data collection and surveillance activities were formally codified into law by the 2026 PREEMIE ACT (PL 109-450) which mandates federal support for PRAMS but does not provide funding.²³ Specifically, the PREEMIE Reauthorization Act was signed into law to “renew and strengthens the federal government’s commitment to preventing preterm birth, the leading contributor to infant mortality in the U.S.” Supported activities including reauthorizing the CDC’s research and programs on preterm birth, and improved national data tracking including PRAMS as part of the Safe Motherhood Initiative.

Given these federal funding challenges, funding for the federal administration of PRAMS in addition to site-level operations is left to the discretion of CDC/HHS leadership at any point in time. This is problematic because, while Congressional budgets may continue to ensure that sites receive funds for data collection, there is no requirement that funds be used at the federal level to ensure national oversight and implementation of PRAMS. In addition, although sites have received renewed PRAMS funding to collect 2025 and 2026 data with anticipated funding for 2027, this funding was delayed and has been provided on an annual basis rather than through the typical continuous five-year Cooperative Agreement mechanism. While Cooperative Agreements have never provided long-term permanent funding and come with their own challenges including requiring annual reporting and renewal applications, these agreements did provide a significant level of stability to PRAMS sites because they were multi-year agreements.

To fill in funding gaps over the last two years when PRAMS funding has been delayed and appropriated only annually, philanthropy and funding from state-level programs such as the Title V Block Grant have in some cases provided additional fiscal support to PRAMS. However, this approach is not sustainable and does not provide the level of predictability that PRAMS sites need to plan and retain critical resources including staff. In fact, state budgets are under a significant amount of financial strain because of the 2025 “One Big Beautiful Bill Act” (H.R. 1) effects on their Medicaid and Affordable Care Act populations, and due to major cuts to programs such as the Supplemental Nutrition Assistance Program (SNAP).^{24 25} States also face issues related to funding being delayed or not provided by the federal government for ongoing programs such as Head Start or planned infrastructure projects (e.g., transportation), and the general requirement that states have balanced budgets without accumulating deficits, unlike the federal government.

In sum, although funding has been provided by the U.S. Congress to sites to implement PRAMS, staffing losses and administrative barriers at the federal level (i.e., CDC) have led to an almost complete elimination of federal PRAMS functions (see **Section 1**). The year-to-year funding approach for sites leaves them in a precarious position with respect to current and future PRAMS implementation, leading to disruptions in staffing that have reduced capacity and institutional knowledge to continue PRAMS data collection.

4.3 Recommendations

As noted in Section 1, this breakout group also concluded that there is a need for a *Friends of PRAMS* entity to ensure ongoing support for PRAMS and to develop a funding and policy agenda. In addition to the functions of this group outlined in Sections 2–3, the funding and policy agenda should include the following:

- Seek funding from a variety of sources at both the national and site levels to support national oversight functions, a mechanism to distribute multi-site data to external partners, and to ensure site-specific implementation of PRAMS.
- Pursue an explicit line item for PRAMS in the federal budget. While the ultimate goal is a PRAMS or PRAMS look-alike surveillance system in every state/jurisdiction, with ongoing mandatory funding, pursuing an explicit line item within the CDC Safe Motherhood bundle funded is necessary to ensure PRAMS continuity.
- Provide a template and technical assistance toolkit to assist sites as they seek funding for PRAMS from their state/jurisdictional budgets. Such a template could delineate potential funding sources at the state/jurisdictional level and could also help sites in their messaging with respect to the importance of PRAMS to maternal and infant health in their states/jurisdictions.

Additional long-term recommendations are described in **Appendix D**.

4.4 Implementation Considerations

A significant portion of the implementation discussion focused on whether the previous federal responsibilities for PRAMS should remain at the CDC (i.e., federal) or remain national, but not necessarily at the CDC. There was agreement about the importance of a national entity in the implementation of PRAMS (e.g., *Friends of PRAMS*). Participants emphasized that a true national public health surveillance system requires national coordination and that leadership at a national level provides legitimacy and consistency for sites' efforts. Likewise, this national oversight is needed to ensure the comparability of data across sites and the distribution of multi-site data to external partners.

The controversial issue that emerged in the discussion was whether “national” means restoration of CDC functions (i.e., federal) or whether these functions should be provided by some other “national” entity (i.e., quasi-governmental) in the short term given the current turmoil within the federal government and HHS, in particular. Most breakout group members cautioned against permanently shifting core governmental responsibilities to an entity outside government for the long term. As in the other breakout groups, there was a strong sense that national surveillance efforts are a core function of federal public health efforts and that it was important to continue to have this expectation of the federal government's involvement, if not in the near term, at least in the longer term.

There was concern that restoration of CDC PRAMS staff—and the support they offer—may not occur any time soon, and that in the current tumultuous climate, this strategy may not be ideal. There was also agreement that if federal level PRAMS staff are restored, with some or all CDC PRAMS staff positions reinstated (with former PRAMS staff or new hires), in the short term, there will still likely be a need to contract out some functions that CDC has historically performed to support PRAMS, given the potential lack of expertise in that office, especially if staff are new to PRAMS. These functions include data weighting, data cleaning, providing technical assistance, and serving as a national data resource for external partners (see **Sections 2–3** for additional details). There was also recognition by breakout group participants that if funding was not provided to the CDC for directly delivering or subcontracting core PRAMS federal functions, it might be necessary to position an outside entity (e.g., *Friends of PRAMS* or a similar entity) to receive funding for national oversight of PRAMS, likely from non-governmental sources.

5. Conclusion and Next Steps

5.1 The Case for Action

PRAMS is an indispensable resource for maternal and infant health practice, policy, and research. For nearly four decades, it has provided consistent population-based information that sites and national partners use to identify emerging needs, monitor inequities, guide programs and policies, and evaluate progress. The disruptions that began in 2025 now threaten not only current data collection, but also the quality and comparability of future data and access to decades of existing data.

The findings from this Convening demonstrate the urgency of coordinated action. Sites are operating without the centralized scientific and technical support on which they have historically relied. Differences in local staffing, resources, and capacity increase the risk of divergence from standardized protocols. Researchers, policymakers, and practitioners remain unable to access multi-site data. At the same time, year-to-year funding has left sites without the stability to retain personnel, maintain contracts, and plan future data collection. The loss of federal PRAMS staff has left sites without the necessary expertise to troubleshoot implementation problems or to obtain real-time technical assistance. After placing the CDC's own trained experts in data processing on administrative leave, CDC now is funding outside entities for the implementation of core functions typically performed by PRAMS staff, including data cleaning and weighting. Although sites and other partners have developed valuable interim solutions, volunteer efforts and short-term funding cannot sustainably replace national coordination and infrastructure.

5.2 Proposed Structure and Next Steps for a PRAMS Coordinating Entity

A recommendation that emerged across all three breakout groups was the formation of a democratized coordinating entity, provisionally described as *Friends of PRAMS*. This entity should bring together genuine representation from PRAMS sites, current and former government employees, academic partners, nonprofit and advocacy organizations, and others with relevant technical, legal, data-sharing, policy, and funding expertise. Its structure should emphasize transparency, shared governance, and consensus-building, with PRAMS sites playing a central role in identifying needs and shaping solutions.

Friends of PRAMS would serve as a supporting initiative for coordinating activities that are no longer being directed or managed by CDC. Its work should complement existing site, regional, organizational, and federal efforts, with clear boundaries to avoid duplication or competition. The entity should remain prepared to adjust its role if CDC staffing and functions are restored. In that circumstance, *Friends of PRAMS* could transfer activities back to CDC, and continue to support coordination and shared learning. It could champion PRAMS as a critical national resource without displacing the federal government's central responsibility for public health surveillance.

The three Convening focus areas provide a natural structure for ongoing working groups within a *Friends of PRAMS* entity. A Data and Technical Assistance group could guide the development of the site needs analysis,

national asset map, technical triage plan, and the creation of a newly formed technical assistance hub. A Use and Dissemination group could support expansion of the existing aggregated statistics dashboard and lead the longer-term work required to establish DUAs with an independent data repository. A Policy and Funding group could coordinate the funding and policy agenda, including efforts to stabilize national and site-level funding, pursue a federal budget line item for PRAMS, and develop a funding template and technical assistance toolkit for PRAMS sites.

5.3 Follow-Up Actions

Immediate actions: During the next one year, an initial startup group should establish the *Friends of PRAMS* coordinating structure, define its relationship to CDC and existing partners, and organize the three working groups. Immediate priorities should include assessing site needs and available assets, developing a plan for technical triage, supporting the existing communications and peer-learning infrastructure led by PRAMS sites, and identifying the resources required to sustain these activities. In parallel, collaborators should begin strengthening the multi-site dashboard and advancing the funding and policy agenda.

Medium-term actions: Over the following one to three years, the coordinating entity and its working groups should move toward sustained operation of the technical assistance hub, shared governance and peer networks, and a legally sound mechanism for disseminating existing and future PRAMS data. Progress should be assessed through indicators already central to the recommendations: broad site participation; consistent operation of the coordinating entity and working groups; production and use of technical assistance resources; expanded availability of multi-site data; policy advances, including progress toward a dedicated federal budget line item; and greater funding stability for both site implementation and national functions.

Need for funding to ensure success and sustainability: Critically, launching and sustaining *Friends of PRAMS* and its working groups will require dedicated funding rather than continued reliance on volunteer labor and in-kind contributions. Resources will be needed for staff time, coordination, technical and legal expertise, communications and data infrastructure, and meaningful site participation. Funding should therefore be sought from a variety of sources to support the entity's initial development and ongoing operations, ensuring that it has the stability and accountability needed to carry out the recommendations described above.

5.4 Conclusion

There is an immediate need to stabilize funding for PRAMS and preserve the critical functions needed to sustain PRAMS at both the site and national levels. Achieving that vision will require coordinated action from sites, government, researchers, nonprofit and advocacy organizations, funders, and other partners. Their collective engagement can protect the continuity and value of PRAMS now while advancing the long-term goal of stable, mandatory funding and restored federal responsibility for this essential public health infrastructure.

References

1. Shulman HB, D'Angelo DV, Harrison L, Smith RA, Warner L. The Pregnancy Risk Assessment Monitoring System (PRAMS): Overview of Design and Methodology. *Am J Public Health*. Oct 2018;108(10):1305-1313. doi:10.2105/ajph.2018.304563
2. Karasek D, Collin DF, Hamad R, Jackson K, Gemmill A. Perinatal Health and Healthcare Utilisation During the COVID-19 Pandemic: A Nationwide Interrupted Time Series Analysis. *Paediatr Perinat Epidemiol*. May 2025;39(4):373-384. doi:10.1111/ppe.70000
3. Hamad R, Collin DF, Gemmill A, Jackson K, Karasek D. The Pent-Up Demand for Breastfeeding Among US Women: Trends After COVID-19 Shelter-in-Place. *Am J Public Health*. Aug 2023;113(8):870-873. doi:10.2105/ajph.2023.307313
4. Bruce K, Stefanescu A, Romero L, et al. Trends in Postpartum Contraceptive Use in 20 U.S. States and Jurisdictions: The Pregnancy Risk Assessment Monitoring System, 2015-2018. *Women's Health Issues*. Mar-Apr 2023;33(2):133-141. doi:10.1016/j.whi.2022.10.002
5. Pulvera R, Collin DF, Hamad R. The effect of the 2009 WIC revision on maternal and child health: A quasi-experimental study. *Paediatr Perinat Epidemiol*. Nov 2022;36(6):851-860. doi:10.1111/ppe.12898
6. Wells WM, White JS, Collin DF, Wang G, Modrek S, Hamad R. Effects of US state paid family leave policies on perinatal and postpartum health: a quasi-experimental analysis. *Am J Epidemiol*. Jan 8 2026;195(1):246-254. doi:10.1093/aje/kwaf010
7. Eliason EL, Daw JR, Allen HL. Association of Medicaid vs Marketplace Eligibility on Maternal Coverage and Access With Prenatal and Postpartum Care. *JAMA Netw Open*. Dec 1 2021;4(12):e2137383. doi:10.1001/jamanetworkopen.2021.37383
8. U.S. Centers for Disease Control and Prevention. PRAMS Data to Action Success Stories. <https://archive.cdc.gov/#/results?q=prams%20success%20stories>
9. Health Resources & Services Administration. Title V Maternal and Child Health (MCH) Services Block Grant. Updated May 2026. Accessed September 1, 2026. <https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-services-block-grant>
10. National Academies of Sciences E, Medicine, Division of B, et al. The National Academies Collection: Reports funded by National Institutes of Health. In: Young M, Caswell JA, Asiodu I, eds. *Breastfeeding in the United States: Strategies to Support Families and Achieve National Goals*. National Academies Press (US).
11. Bleich SN, Handler A, Shulman H. Losing Our Lens on Maternal and Infant Health—The Consequences of Disrupting PRAMS. *American Medical Association*; 2026:e263235-e263235.
12. The White House. Defending Women From Gender Ideology Extremism And Restoring Biological Truth To The Federal Government. Accessed September 1, 2026. <https://www.whitehouse.gov/presidential->

[actions/2025/01/defending-women-from-gender-ideology-extremism-and-restoring-biological-truth-to-the-federal-government/](#)

13. Handler AS, Johnson K, Rankin KM, Velonis AJ, James AR, Kotelchuck M. Shuttering the Pregnancy Risk Assessment Monitoring System (PRAMS): A Dangerous Attack on US Mothers and Infants. *Am J Public Health*. Jun 2025;115(6):848-850. doi:10.2105/ajph.2025.308107
14. Gratas S. Public health workers reflect on a year since mass layoffs at the CDC. Georgia Public Broadcast. Accessed September 1, 2026. <https://www.gpb.org/news/2026/02/11/public-health-workers-reflect-on-year-mass-layoffs-at-the-cdc>
15. Olsen E. Judge allows states' lawsuit over HHS restructuring to move forward. Healthcare Dive. Accessed September 25, 2026. <https://www.healthcaredive.com/news/judge-allows-states-lawsuit-hhs-restructuring-layoffs-move-forward/817087/>
16. U.S. Centers for Disease Control and Prevention. PRAMS Automated Research File Data Portal Access Form. Accessed September 25, 2026. <https://www.cdc.gov/prams/php/data-research/arf-data-access-form.html>
17. Carter S. Mississippi declares infant deaths emergency as CDC program that could have helped is halted. The Guardian. <https://www.theguardian.com/us-news/2025/sep/16/mississippi-infant-deaths-cdc-prams>
18. Handler A, Rankin, K, Boateng, J. *PRAMS Surveillance of Maternal and Infant Health: The Effect of Changes at the Federal Level Since 2025*. 2026. March 2026. <https://maternalchild.uic.edu/wp-content/uploads/sites/614/2026/03/Handler-Rankin-Boateng-PRAMS-report-March-2026-url.pdf>
19. Presentation at May 6, PRAMS All-Site Meeting [virtual].
20. PRAMS Data Visualization Tool. Parrish Analytics and Epidemiology Consulting & Holck Consulting. Accessed September 1, 2026. <https://holckconsulting.com/PRAMS/#>
21. U.S. Centers for Disease Control and Prevention. CDC WONDER. Accessed September 25, 2026. <https://wonder.cdc.gov/>
22. Garfield CF, Simon CD, Harrison L, et al. Pregnancy Risk Assessment Monitoring System for Dads: Public Health Surveillance of New Fathers in the Perinatal Period. *Am J Public Health*. Oct 2018;108(10):1314-1315. doi:10.2105/ajph.2018.304664
23. March of Dimes. March of Dimes Applauds PREEMIE and PMDA in FY26 Funding Package. March of Dimes. Accessed September 25, 2026. <https://www.marchofdimes.org/about/news/march-dimes-applauds-preemie-and-pmda-fy26-funding-package>
24. Alker J, Schneider A. One Big Beautiful Bill Act: Winners and Losers in the Medicaid Provisions. September 25, 2025. <https://ccf.georgetown.edu/2025/06/26/one-big-beautiful-bill-act-winners-and-losers-in-the-medicaid-provisions/>

25. Food Research & Action Center. The Far-Reaching Harmful Impacts of the Reconciliation Bill — on Families, Older Adults, Immigrants, and State Budgets. Food Research & Action Center. Accessed September 25, 2026. <https://frac.org/wp-content/uploads/Budget-Reconciliation-2025-Impacts-Fact-Sheet.pdf>
26. Interagency Council on Statistical Policy. Standard Application Process. Accessed 25 September, 2026, <https://sap.nsf.gov/>

Appendix A. Examples of High-Impact PRAMS Studies

Citation	Public Health Importance
Panel A: Peer-reviewed Literature	
Holicky, A., et al. (2025). " Patterns of Infant Sleep and Care Practices: 2016-2020 ." <i>Pediatrics</i> 156(4).	Only 19.3% of new mothers reported all 6 infant sleep and care practices recommended to prevent sleep-related infant deaths. These data provide improved understanding of how infant sleep recommendations are followed to inform intervention strategies.
Kortsmit, K., et al. (2021). " Workplace Leave and Breastfeeding Duration Among Postpartum Women, 2016-2018 ." <i>Am J Public Health</i> 111(11): 2036-2045.	Women with less than 3 months of leave reported shorter breastfeeding duration than did women with 3 or more months of leave. This study informs employers, policymakers, and community members of the role that leave plays on the ability of women with a recent live birth to meet breastfeeding recommendations.
Haight, S. C., et al. (2021). " Frequency of cannabis use during pregnancy and adverse infant outcomes, by cigarette smoking status - 8 PRAMS states, 2017 ." <i>Drug Alcohol Depend</i> 220: 108507.	Prenatal cannabis use was more common among women who smoked cigarettes during pregnancy and high frequency cannabis use was associated with low birthweight delivery. This suggests that healthcare providers can implement substance use screening, evidence-based counseling, and cessation services to help pregnant women avoid tobacco and cannabis use.
Wells, W. M., et al. (2026). " Effects of US state paid family leave policies on perinatal and postpartum health: a quasi-experimental analysis ." <i>Am J Epidemiol</i> 195(1): 246-254.	State paid family leave policies led to increased breastfeeding duration and decreased depressive symptoms and mixed results for birth outcomes. This work informs the implementation and design of national and state paid policies.
Dore, E. C., et al. (2026). " Trends in Poverty and Birth Outcomes in the US ." <i>JAMA Pediatrics</i> 180(5): 583-585.	There are stark disparities in birth outcomes by poverty status, with inequities growing in recent years. These findings point to the need for more support during pregnancy and birth for low-income families.
Panel B: Governmental Reports	
Adams, E. K., et al. (2013). " Expansion of Medicaid covered smoking cessation services: maternal smoking and birth outcomes ." <i>Medicare Medicaid Res Rev</i> 3(3).	Medicaid coverage of cessation services before pregnancy can lead to modest reductions in smoking, and that tobacco control policies, such as higher taxes, measured here through higher prices, can also be effective in reducing smoking.
Ko, J. Y., et al. (2017). " Trends in Postpartum Depressive Symptoms - 27 States, 2004, 2008, and 2012 ." <i>MMWR Morb Mortal Wkly Rep</i> 66(6): 153-158.	Despite the observed decline in prevalence of postpartum depressive symptoms (PDS), one in nine women experience PDS, with higher prevalence in certain states and subgroups of women. These data can be used to monitor progress toward meeting nationwide health promotion and disease prevention goals.
DeSisto, C. L., et al. (2014). " Prevalence estimates of gestational diabetes mellitus in the United States, Pregnancy Risk Assessment Monitoring System (PRAMS), 2007-2010 ." <i>Prev Chronic Dis</i> 11: E104.	Gestational diabetes prevalence (9.2%) is high in the US, and no evidence of change between 2007 and 2010. Findings are important for understanding the future burden of related diseases (e.g., type 2 diabetes) and related health care costs.

Citation	Public Health Importance
Tong, V. T., et al. (2009). "Trends in smoking before, during, and after pregnancy - Pregnancy Risk Assessment Monitoring System (PRAMS), United States, 31 sites, 2000-2005." <i>MMWR Surveill Summ</i> 58(4): 1-29.	Efforts to reduce smoking prevalence among female smokers before pregnancy have not been effective, while efforts targeting pregnant women have met some success as rates have declined during pregnancy and after delivery. This informs strategies to reduce smoking in the perinatal period.
D'Angelo, D. V., et al. (2015). "Patterns of Health Insurance Coverage Around the Time of Pregnancy Among Women with Live-Born Infants--Pregnancy Risk Assessment Monitoring System, 29 States, 2009." <i>MMWR Surveill Summ</i> 64(4): 1-19.	One third of women reported lacking health insurance or transitioning between types of health insurance coverage around the time of pregnancy. The majority of women who changed health insurance status obtained coverage for prenatal care, delivery, or both through Medicaid. This study can be used to design policies to optimize health insurance coverage among women around the time of pregnancy.
Panel C. State Reports	
Maine PRAMS (2023). Helping Maine become a healthier place for parents and babies.	PRAMS data have been used to support policy change such as extending MaineCare (the state Medicaid program) to 1 year postpartum and to support arguments for paid family leave. PRAMS data were also used to conduct policy evaluations such as assessing the Maternal Child Health Program's progress towards meeting their Title V priorities.
New Jersey PRAMS (2024). Reducing infant mortality in Black communities.	PRAMS was used to identify factors linked to infant mortality among Black families. Prompted state health commissioner to allocate \$4.7 million/year to community-based case management approaches to reduce Black infant mortality, including free prenatal care and community doulas in neighborhoods with the largest racial gaps in maternal health.
Pennsylvania Maternal and Child Health Services Title V Block Grant (2016). 2014 Annual Report.	PRAMS data were used to identify urgent need to reduce sudden infant death syndrome and shape public campaigns and education. This resulted in increased safe sleep practices from 2016 to 2022.
West Virginia WVOW Radio (2025). West Virginia leads nation in reduction of women smoking while pregnant.	PRAMS data showed high rates of smoking in the state. This prompted interventions leading to a decrease in in percent of women reporting smoking from 25.1 percent in 2016 to 18.2 percent in 2021, the largest decrease of any state in the country.

Appendix B. Convening Participant List

Name	Organization
Amanda Bennett	University of Illinois Chicago; formerly CDC
Amy Zapata	Louisiana Title V
Anonymous Participant	PRAMS Site
Arden Handler	University of Illinois Chicago, Emerita
Ashleigh Sutphen	CityMatCH
Ayesha Lampkins	Oklahoma PRAMS
Catherine Vladutiu	University of North Carolina at Chapel Hill
Craig Garfield	Lurie Children's Hospital, Northwestern
Dave Goodman	Mercer University; formerly CDC
Denise Pecha	University of Nebraska Medical Center
Holly Shulman	Venture Analytics LLC; retired CDC
Jared Parrish	Alaska PRAMS
Jess Maksut	The Commonwealth Fund
Jill Hardy	Michigan PRAMS
John Kubale	University of Michigan ICPSR
Joia Crear-Perry	National Birth Equity Collaborative
Karen Hacker	Emory University; formerly CDC
Karen Howard	Crossover Partners; National Healthy Start Association
Katherine Dixon Hert	Alabama Title V
Kay Johnson	Johnson Policy Consulting
Ken Rosenberg	Oregon Health Sciences University
Kristen Marchi	University of California at San Francisco
Kristin Rankin	University of Illinois at Chicago
Laurie Zephyrin	The Commonwealth Fund
Laurin Kasehagen	Mississippi PRAMS; formerly CDC
Lee Warner	Lee Warner Coaching & Consulting LLC; retired CDC
Lynda Kellam	Data Rescue Project
Meagan Robinson Maynor	Association of Maternal and Child Health Programs
Michael Warren	March of Dimes
Nan Ruffo	Lurie Children's Hospital of Chicago; formerly CDC

Name	Organization
Peggy Brozicevic	Vermont PRAMS
Philip Hastings	Far Harbor, LLC
Rita Hamad	Harvard University
Russell Kirby	University of South Florida
Sanaa Akbarali	Association of State and Territorial Health Officials
Sarah Blake	Emory University
Sara Bleich	Harvard University
Sarah Stone	Massachusetts PRAMS
Sherry Glied	New York University
Stephen Patrick	Emory University
Theresa Chapple-McGruder	University of Pittsburgh

Appendix C. Agenda of PRAMS Convening

National Convening on PRAMS Agenda

June 3, 2026, 11:00 am – 3:00 pm ET

11:00–11:15 a.m. Welcome Remarks from Hosts and Sponsors

- Rita Hamad, MD, PhD, Harvard Center for Population and Development Studies
- Laurie Zephyrin, MD, MPH, MBA, The Commonwealth Fund
- Stephen Patrick, MD, MPH, MS, FAAP, Rollins School of Public Health, Emory University

11:15–11:45 a.m. Background on PRAMS and Current Challenges

- PRAMS in Crisis: Overview of Recent Actions, Presenter **Holly Shulman**, MA, Venture Analytics; retired CDC
- Changes to PRAMS at the Federal Level: Effect on States' PRAMS Efforts, Presenter **Arden Handler**, DrPH, University of Illinois School of Public Health
- Early Brainstorming: Ideas & Cautions, Presenter **Phil Hastings**, PhD, Far Harbor

11:45 a.m.–Noon Preparation for Breakout Groups

- Overview of topics and group assignments

Noon–1:00 p.m. Breakout Groups: Generating Solutions to Respond to Challenges Facing PRAMS

1. **DATA & TA:** How to provide technical assistance to ensure the credibility and continuity of state PRAMS data collection (co-leads: **Phil Hastings & Jill Hardy**)
2. **USE & DISSEMINATION:** How to create the logistical and legal infrastructure to collect and share existing and future PRAMS data (co-leads: **Rita Hamad & Holly Shulman**)
3. **POLICY:** How to support the continuation of PRAMS at both the state and national levels (co-leads: **Arden Handler & Sarah Blake**)

1:00–1:15 p.m. Break and transition back to full group Zoom room

1:15–1:45 p.m. Reports on Recommendations from Breakout Groups

- Focus on top 3 recommendations for action or potential responses to challenges (10 minutes per group)

1:45–2:45 p.m. Group Discussion of Recommendations for Action, Facilitator Kay Johnson, Johnson Policy Consulting

2:45–3:00 p.m. Next Steps: Rita Hamad

Appendix D. Long-Term Recommendations

While the focus of the Convening was on addressing the immediate crisis facing PRAMS, participants also mentioned several long-term recommendations, assuming that CDC PRAMS is restored and new opportunities emerge to improve upon PRAMS. These are listed below, organized by the same themes of technical assistance, data dissemination, and policies and funding. There was also broad agreement that any changes to the underlying methodology or protocol would need expert input, consensus building, and significant updates to the underlying data collection infrastructure that is currently maintained by the CDC.

D.1. Data and Technical Assistance

In the long term, participants suggested that the current crisis might provide an opportunity to rethink a methodology that—except for the web mode—has operated largely unchanged since 1988. Yet participants also noted that a revision of the existing questionnaire or methodology should not be an immediate priority, given that the questionnaire is currently meeting sites' needs, and additional flux in this time of crisis would not be advisable. Below are some suggestions that emerged during this breakout session and in follow-up surveys, for later consideration. These recommendations could also be explored and implemented by CDC if the PRAMS scientific team is restored.

- **Reducing cost.** Participants noted that stratified, multi-mode data collection is expensive. For instance, many sites find that mail and phone modes are increasingly expensive compared to the web, and phone contractors are difficult to procure. For Massachusetts, phone interviews contribute up to one-third of responses and are essential for equity (e.g., reaching Spanish-speaking populations). Other sites are eager to shift resources toward the web mode to reduce delays and costs from other modes. Economies of scale might also be achieved by negotiating with a single contractor to coordinate phone surveys for all interested sites.
- **Increasing flexibility.** PRAMS has historically been slow to implement changes or innovations requested by collaborators, due to the complexity of operations and management across diverse jurisdictions with different vendors and infrastructure. Some participants consider PRAMS to be behind the curve in regard to new technology or outreach methods that might improve response rates and quality. The data collection system at CDC was developed using disparate technologies over many years. Specialized contractors must maintain and secure the system so that any feature changes tend to be onerous and costly. One participant suggested that PRAMS could be classified as routine public health surveillance, similar to the Behavioral Risk Factor Surveillance System (BRFSS), which would eliminate the redundant federal and local Institutional Review Board (IRB) requirements of research and streamline approvals.
- **Improving timeliness.** Historically, the CDC has been relatively slow to return weighted data to sites; some of this delay is a result of the protocol itself (collecting data across the entire year, thus leaving data collection open until June of the following year). A number of ideas for improving timeliness have been proposed over the years (e.g., shorter data collection periods, or creating early “provisional” data) yet have not been enacted for various reasons.
- **Connecting populations and time points.** Innovations have been occurring independently at some sites across several dimensions. These include “family unit” or “fatherhood” surveys; follow-up surveys to capture

immediate postpartum and children at the toddler stage; and special or emerging topics added via supplements. Offering more family-centered surveillance approaches might help to ensure the ongoing integrity and reputation of PRAMS, potentially boosting reliability and validity. A future version of PRAMS might re-envision sampling approaches and outreach methodologies to ensure representative samples across jurisdictions. In addition to flexibility, connecting these related populations and timeframes could create new possibilities for funding and sustainability.

- **Strengthening qualitative data collection and analysis.** Enhancing the qualitative data within PRAMS might be another focus for the future. Participants noted that qualitative PRAMS data have been invaluable for understanding women's and families' experiences, documenting inequities in the women's/maternal and infant health delivery systems, and in informing the development of maternal health policy and advocacy strategies. Collecting and analyzing qualitative data in a more intentional way could enhance the value and richness of the PRAMS surveillance system.

D.2. Data Use and Dissemination

Some participants expressed the idea that a third-party repository is likely an inefficient use of resources. They voiced support for an idealized data repository that houses multiple interconnected and interoperable sources of government data on maternal and child health and other related resources. This could be a more robust version of the Standard Application Process portal used by other government agencies.²⁶

D.3. Policy and Funding

Breakout participants welcomed the opportunity to rethink implementation of PRAMS in the future and noted that PRAMS should receive sufficient resources to reflect actual operational costs. Although it was acknowledged that not all US states and jurisdictions currently have a PRAMS program, the concept of supporting PRAMS or a PRAMS look-alike program as "routine" in all states and jurisdictions was endorsed. This requires mandatory rather than discretionary funding with a specific line item for PRAMS in the federal budget to include funds for both federal oversight and site-specific implementation.

Participants supported the ongoing implementation and integration of multiple MCH surveillance systems including PRAMS, Maternal Mortality Review Committees (MMRCs), Fetal and Infant Mortality Review (FIMR), Child Death Review (CDR), and other essential MCH surveillance systems (e.g., National Survey of Children's Health) as part of permanent public health infrastructure rather than as part of discretionary programs requiring continual advocacy for funding. This recommendation clearly requires a policy and advocacy agenda beyond PRAMS, but in an effort to build back better systems, consideration of partner surveillance systems and how best to position PRAMS is a natural outgrowth of these discussions.

Additionally, while endorsing the stabilization of PRAMS as an essential first step, participants supported the expansion of a number of innovations and add-ons related to PRAMS including follow-up surveys of toddlers and inclusion of fathers through implementation of *PRAMS for Dads*. However, it was recognized that broad implementation of additions to PRAMS including toddler surveys and *PRAMS for Dads* will require additional resources, which will need to be included in the funding and policy agenda.