U.S. Department of
Health and Human Services
Enhancing the health and well-being of all Americans

OFFICE OF THE SECRETARY
PATIENT-CENTERED OUTCOMES
RESEARCH TRUST FUND

Better Data for Maternal Health Research

HHS Efforts to Strengthen Data Infrastructure for a Healthy America

Executive Summary

The maternal death rate in the United States (U.S.) remains alarmingly high at 22 deaths per 100,000 live births—far worse than in comparable countries.[1] To address this maternal health crisis, the U.S. Department of Health and Human Services (HHS) is building new data capacity so researchers can identify risks and study new approaches for improving health outcomes in pregnancy.

Through funding by the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF), HHS agencies are working together to improve the accessibility, transparency, and analytic capacity of research data for studying national health problems. HHS agencies collaborate on data projects to address conditions such as maternal mortality to improve the validity of research findings and the effectiveness of federal programs.

The OS-PCORTF portfolio strives toward the vision of better data and stronger evidence to inform the health care decisions facing patients, families, and their health care team. This report highlights several examples of OS-PCORTF maternal health projects that have made new types of research possible and the potential of these projects to improve health care for pregnant women.

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April 2025

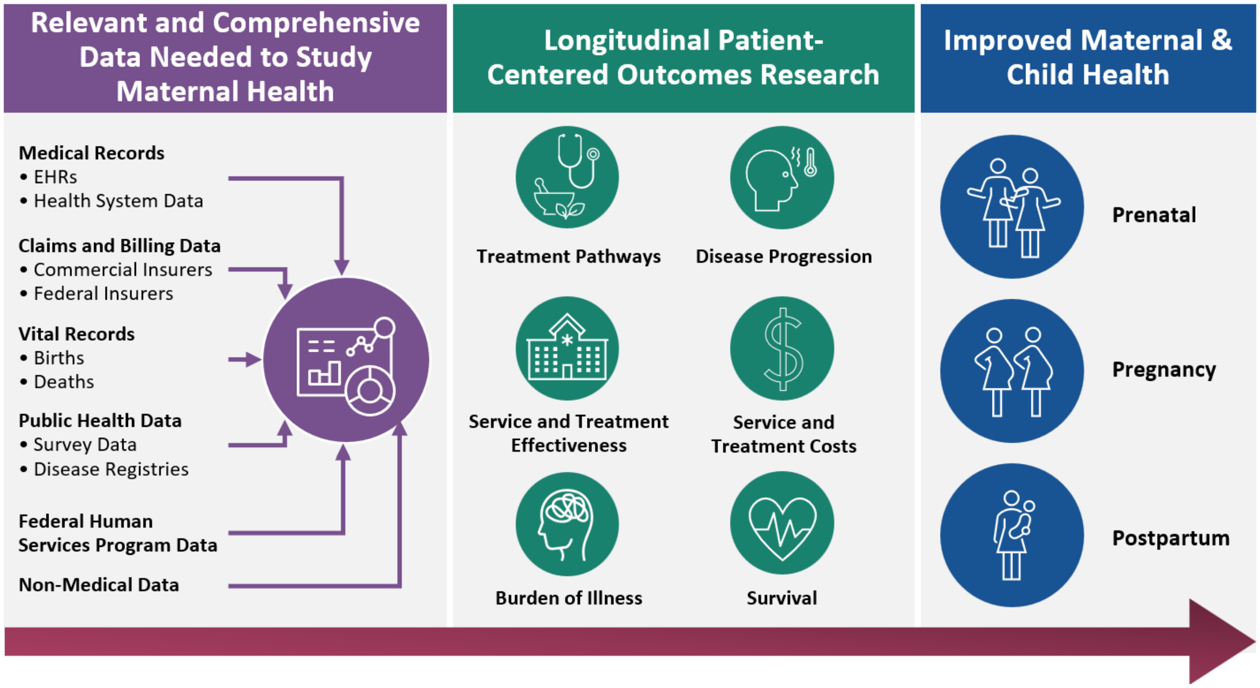
I. Background

HHS has supported several initiatives to address the maternal health crisis, striving to make the U.S. "one of the safest countries in the world for women to give birth".[2] Calls to action aim to reduce maternal mortality and morbidity in the U.S. through uptake of evidence-based practices, quality improvement, access to care, and better data for research.[2]

The OS-PCORTF was established by Congress to build data capacity for patient-centered outcomes research, which expands evidence about the effectiveness of health care interventions on patient outcomes. In 2019, the Further Consolidated Appropriations Act (P.L. 116-94) reauthorized the OS-PCORTF until 2029.[3] Under the reauthorization, addressing data infrastructure gaps to improve patient-centered outcomes research on maternal mortality was identified as a research priority.

The OS-PCORTF addresses the maternal health crisis by improving data infrastructure to support research and health care decision-making, improving access to electronic health record (EHR) data, linking key federal and state datasets, and fostering HHS partnerships to improve data for maternal health research. This report showcases the work of 11 OS-PCORTF projects that support reducing preventable pregnancy-related deaths, improving maternity care, studying substance use treatment for pregnant women, and representing all American mothers and children in health outcomes research.

OS-PCORTF Goals for Enhancing Data to Improve Maternal & Child Health Outcomes in the U.S.



II. Reducing Preventable Pregnancy-Related Deaths and Improving Maternity Care

The U.S. continues to have the highest maternal death rate among high-income countries, with over 80 percent of U.S. maternal deaths deemed preventable if changes are made to patient, community, clinician, health care, and other systems factors.[4] Decision makers need better data and evidence on effective maternal health care treatments and services to drive decisions and promote actionable change.

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OS-PCORTF projects
help researchers study the health of mothers and babies at every stage of care

The following five OS-PCORTF projects connect different types of health data, such as clinical records and insurance claims, to track health outcomes. These linked datasets can be used to strengthen evidence-based care and support healthier pregnancies and births.

1. Developing a Multi-State Network of Linked Pregnancy Risk Assessment Monitoring System (PRAMS) and Clinical Outcomes Data

The PRAMS is an ongoing, state-specific, population-based surveillance system designed to collect data from women with a recent live birth on maternal attitudes and experiences before, during, and shortly after pregnancy.[5]

To improve how states connect PRAMS data and provide better information for maternal health research, this project created a learning community of states to develop standard linking methods. **The goal of this project was to improve states' ability to link PRAMS data with clinical and administrative datasets, such as birth certificates, hospital discharge data, Medicaid claims, and all-payer claims databases.**

PROJECT OUTPUTS

A framework that state agencies can use to link PRAMS with administrative data sources

A final project report and project brief that contains insights and lessons learned to streamline data linkage processes

IMPLEMENTING AGENCY: CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Project Completed: December 2023

Key Outcomes: Twelve states participated in the PRAMS Data Linkage Learning Community, and 11 states successfully linked PRAMS data to other state data sources. States have used the linked data to support programmatic and surveillance activities. For example, one state will sustain PRAMS data linkages to better incorporate structural factors into the analysis of hospital discharge data, while another state will sustain data linkages to continue to assess risk factors for child maltreatment. Throughout implementation, the CDC project team met with state teams to provide technical assistance and subject matter expertise. By identifying best practices and addressing specific project challenges, these technical assistance sessions helped to increase efficiencies in data linkage, data sharing, and analysis across states.[6]

2. *Severe Maternal Morbidity and Mortality Electronic Health Record (EHR) Data Infrastructure*

Severe maternal morbidity includes unexpected labor, delivery, and postpartum outcomes that can significantly impact women's health in the short- and long-term. Data are needed to study the effect of medical conditions and interventions on pregnancy outcomes.

This project developed an open-source web application and implementation guide to help researchers link maternal and infant clinical EHR data with maternal mortality data from vital records. **The resulting data can be used to study the association between risk factors, pre-existing conditions, and the causes of severe maternal morbidity and pregnancy-related mortality, as well as adverse infant outcomes.**

PROJECT OUTPUTS

[MaternalHealthLink](#) application that automates extraction and exchange of clinical maternal and infant data

[HL7® Longitudinal Maternal & Infant Information for Research Implementation Guide](#) that helps researchers understand how to analyze clinical data to explore maternal and infant morbidity and mortality

IMPLEMENTING AGENCY: NATIONAL INSTITUTES OF HEALTH (NIH)

Project Completed: March 2024

Key Outcomes: Through public-private partnership, the NIH project team developed and pilot tested the MaternalHealthLink application and implementation guide at two data exchange marathons for testing information flow between health systems, using two real-world clinical data use cases: (1) pregnancy and subsequent death within a year, and (2) high blood pressure disorders of pregnancy (a leading cause of maternal morbidity affecting 1 in 7 pregnant women).[7,8] The data exchange marathons convened stakeholder experts including health information technology developers and health care organizations to test the implementation guide and identify potential implementation issues. The NIH project team incorporated stakeholder feedback as refinements to the guide. The pilot demonstrated the feasibility of using the implementation guide with clinical data from a regional health information exchange and making those data available to researchers.

3. *Making Medicaid Data More Accessible Through Standardized Data Formats*

The T-MSIS dataset is used by researchers for health outcomes studies in Medicaid. However, transforming T-MSIS data into a format that can be linked to clinical research datasets is time and resource intensive.

This project developed programming code to standardize T-MSIS data into two formats used nationally for research: (1) Observational Medical Outcomes Partnership (OMOP), and (2) Sentinel. This transformation produces T-MSIS data in a standard structure that can be more easily linked and aggregated across different

PROJECT OUTPUTS

Programming codes and user guides for converting T-MSIS data into the [OMOP](#) and [Sentinel](#) data formats

Publicly available [webinar training series](#) for researchers that describes how to use the new data transformation tools and communicates study findings to the research community

IMPLEMENTING AGENCIES: U.S. FOOD AND DRUG ADMINISTRATION (FDA) & NATIONAL INSTITUTES OF HEALTH/NATIONAL LIBRARY OF MEDICINE (NIH/NLM)

Project Completed: February 2025

research networks. This enables researchers to leverage analytic tools more easily for datasets formatted with OMOP or Sentinel. **Through standardization of data, this project increases the accessibility and efficiency of analyzing Medicaid data, a critical resource for studying populations served by one of the largest payers of maternal health care services.**

Key Outcomes: To demonstrate uses of the transformed T-MSIS data and maternal-infant linkage, the FDA and NIH project team formed a workgroup, consisting of federal and academic subject matter experts, to conduct a study on prenatal and congenital syphilis. The study assessed syphilis screening and treatment during pregnancy among publicly and commercially insured patients in the U.S.[9] Results of the study were submitted as a manuscript to a peer-reviewed journal. Additionally, the FDA will use the formatted Medicaid and Children's Health Insurance Program data available in the Sentinel Distributed Database for FDA-led demonstration projects evaluating different study designs to assess the safety of medications used during pregnancy.

4. Expanding Existing Data Standardization Resources for Maternal Health

There is large variability in both the availability and standardization of data important to study maternal outcomes across disparate sources, including EHRs, registries, public health surveillance data, and programmatic data.[10] The lack of standardized data used by federal agencies to study maternal health creates significant challenges to conducting research efficiently.

This project will develop a comprehensive set of standardized data elements through the United States Core Data for Interoperability Plus (USCDI+) program to improve the ability to exchange data between health care partners to ultimately improve the availability of data to study maternal health outcomes.

The goal of this project is to expand the USCDI+ Maternal Health Initiative, which will serve as a resource for maternal health care partners including patients, health care organizations, and researchers trying to unlock information that supports improved decision-making and ultimately lead to better outcomes. **Through refinement and further testing of the USCDI+ Maternal Health data elements list, the project will improve data standards for maternal health and provide guidance for standardized data collection and reporting.**

UPCOMING PROJECT OUTPUTS

Refined USCDI+ Maternal Health dataset with resources on how to leverage Certified Health Information Technology to advance exchange with minimal burden

IMPLEMENTING AGENCY: ASSISTANT SECRETARY FOR TECHNOLOGY POLICY/OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY (ASTP/ONC)

Expected Project Completion: October 2025

5. Quality of Care and Outcomes Data for Pregnant Medicaid Beneficiaries and Newborn Infants

Approximately 40 percent of all U.S. births are covered by Medicaid.[11] While Medicaid claims data provide information on enrollment, demographics, service utilization, and Medicaid payments, these data do not sufficiently capture clinical outcome measures. To study the effectiveness of service utilization on health outcomes, researchers need access to datasets that bring together maternal clinical characteristics, such as pregnancy history and risk factors, and health care outcomes data with maternal and infant Medicaid service utilization data.

UPCOMING PROJECT OUTPUTS

Linked longitudinal (i.e., observations collected over time) dataset of vital records and Medicaid data (2016-2020) for up to 20 states with descriptions of linkage methods

IMPLEMENTING AGENCY: CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS)

Expected Project Completion: February 2026

This project will link data from vital records birth certificates for Medicaid-covered pregnancies and births with claims data on mothers and infants from the Transformed Medicaid Statistical Information System (T-MSIS). **Linking birth certificate data to claims data will expand the ability of researchers to study the impact of care received during pregnancy on maternal and infant outcomes among Medicaid beneficiaries over time.**

III. Studying Substance Use Treatment Outcomes for Pregnant Women

In the last 15 years, the national prevalence of opioid use among pregnant women increased 333 percent.[12] Despite the availability of recommended medication, critical information is lacking about the risks and benefits of different treatment options for opioid use disorder (OUD) and how other factors, such as polysubstance use and access to treatment impact mother, child, and infant outcomes. In 2018, HHS laid out a five-point strategy to combat the opioid abuse crisis, which included supporting cutting-edge research to inform the development of new treatments and public health interventions to reduce negative health outcomes associated with opioid use.[13] HHS' strategy included improving research and disseminating findings on safe and effective OUD treatment during pregnancy, including the exploration of the risks and benefits of pharmacotherapy for mothers and infants.[14]

2

OS-PCORTF projects
addressed the priorities of the HHS five-point strategy to combat opioid abuse, misuse, and overdose

The following two OS-PCORTF awards led to the development and expansion of a surveillance system to improve data collection and analysis for the maternal and child health impacts of medication for opioid use disorder (MOUD).

1. MATernaL and Infant Clinical NetworK (MAT-LINK) Surveillance System to Understand Outcomes Associated with Treatment of Opioid Use Disorder (OUD) During Pregnancy

Clinicians and expectant mothers need better data to make decisions around substance use treatment during pregnancy. However, due to limitations in data collection and clinical trial enrollment for pregnant women, there are insufficient data available on: (1) maternal risks and outcomes with MOUD, and (2) long-term health outcomes of children prenatally exposed to opioids.

This project successfully created a surveillance network called MAT-LINK (the MATernaL and Infant clinical NetworK) to collect and link data from multiple medical centers across the country to study practice patterns and pregnancy, maternal, and child health outcomes associated with MOUD. When developing the network, the CDC project team ensured the interoperability of data through standardization efforts and the use of efficient data collection methodologies across multiple sites. In a second project, MAT-LINK2, the CDC project team expanded the network to four additional clinical sites. **Ultimately, MAT-LINK data can be used to identify differences in health care access and health care delivery that can inform clinical care and public health guidance.**

Key Outcomes: MAT-LINK became the first comprehensive surveillance system to collect health outcomes data on mothers and their children related to MOUD. The system collected data on pregnancies from 2014-2021 and found differences in the patient characteristics between women who received MOUD during pregnancy and those who did not; those who received treatment were more likely to be White, older, and use public insurance.[15] An assessment of the MAT-LINK system also demonstrated that the project improved the speed of data collection and analysis.[16]

2. Expansion of MATernaL and Infant NetworK (MAT-LINK2)

In the MAT-LINK2 expansion, the CDC project team added over 3,000 linked pregnant woman-infant pairs with OUD to the MAT-LINK dataset to enhance the comprehensiveness and representativeness of data in the MAT-LINK system. Additionally, the follow-up period endpoint for infants was extended from two years of age through six years of age, improving the robustness of data on the development of cognitive functions in children exposed to MOUD.[i] Inclusion of these data increased the availability of information on patient demographics, geography, insurance status, and conditions of interest for this population. MAT-LINK has been used across HHS, as well as clinical sites across the U.S., informing the clinical care of pregnant women with OUD on a national scale.[17]

PROJECT OUTPUTS

A MAT-LINK dataset consisting of more than 6,000 mother-infant pairs on 40 variables that cover maternal health history, pregnancy and postpartum outcomes, maternal delivery and neonatal birth outcomes, and child health history from seven sites across the U.S.[i]

Researchers can request a data dictionary that include the new child follow-up variables

IMPLEMENTING AGENCY: CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Projects Completed: December 2022 & February 2023

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[i] MAT-LINK2 received funding from multiple sources, including the OS-PCORTF, to expand data collection to multiple new sites, exposures, and child follow-up variables.

IV. Representing all American Mothers and Children in Research Data

From 2021 to 2022, the maternal mortality rate decreased significantly for Black non-Hispanic, White non-Hispanic, and Hispanic women, with reductions of 20, 7, and 11 deaths per 100,000 women, respectively.[18] However, differences in maternal mortality and severe maternal morbidity outcomes by patient demographics and geography persist. Addressing differences in access to care and other socioeconomic and structural factors are part of the solution to improving the nation's maternal health outcomes.

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OS-PCORTF projects
improve the representativeness of data available for maternal health research

The following three OS-PCORTF projects support federal efforts to improve the data available for research that identifies interventions and clinical care best practices for all maternal subpopulations.[19]

1. *Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with Federal Qualified Health Centers' (FQHC) Electronic Health Record (EHR) Visit Data*

Researchers need reliable and nationally representative data on maternal health visits for research on health care utilization and the relationship to patient characteristics, the care provided, and the outcomes of the visits. However, gaps exist in the clinical data available to understand the relationships between the care that expectant mothers receive and the outcomes of the visits.

This project increased the amount of data collected and processed from FQHCs that participate in the National Ambulatory Medical Care Survey (NAMCS) through two methods: (1) by collecting EHR data, which offers more detail on provided services in lieu of survey data, and (2) by increasing the total number of reporting sites to over 60. **This expanded data source provides researchers with more detailed data on the nature of care provided at FQHCs and its impact on maternal health outcomes.**

PROJECT OUTPUTS

A nationally representative NAMCS dataset with clinical EHR data for all FQHC maternal health visits in 2022 for sampled FQHCs, which includes variables on patient characteristics, clinical care provided, and health outcomes

A linked dataset of NAMCS health center data with death certificate data from the National Death Index (NDI), which can be used to study the association of health factors with mortality

A linked dataset of NAMCS health center data with U.S. Department of Housing and Urban Development (HUD) administrative data, which researchers can use to examine the association between housing support program participation and health outcomes

IMPLEMENTING AGENCY: CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Project Completed: December 2024

Key Outcomes: The resulting NAMCS health center dataset includes over 5.6 million visits from 64 health centers and enables the CDC National Center for Health Statistics to produce reliable, nationally representative estimates of patient health care utilization for FQHCs, which can be used to understand the needs and care provided in these settings. Additionally, this project evaluated the quality of the linkage of the FQHC data to NDI data and HUD administrative data. These data linkages, and resulting datasets, provide additional information on both mortality post-FQHC visit and the relationship of non-medical drivers to maternal health outcomes, which the CDC project team will use to study the impact of health care utilization on maternal health and other health-related outcomes.

2. Linking Federally Qualified Health Center (FQHC) Electronic Health Record (EHR) and Medicaid Data to Understand Maternal Health Care

In 2020, over 550,000 women received prenatal care within an FQHC, and almost half of those visits were for patients with Medicaid as their primary health insurer.[20] The population of individuals served by FQHCs are more likely to experience adverse maternal health outcomes, including increased maternal and infant mortality, preterm birth, and low birth weight.[21] As such, FQHCs are well positioned to address adverse maternal health outcomes among underserved populations through the delivery of evidence-based practices. Furthermore, research using insurance claims of state-run Medicaid programs can improve maternal health outcomes by informing improvements to the quality of preventive and treatment services provided by FQHCs.

UPCOMING PROJECT OUTPUTS

Linked dataset of 2021 NAMCS FQHC EHR data and 2020-2021 T-MSIS data

Technical report describing linkage methodology and guidance on how to use the dataset

IMPLEMENTING AGENCY: CENTERS FOR DISEASE CONTROL AND PREVENTION

Expected Project Completion: August 2025

This project will expand the linkage of FQHC EHR data from the NAMCS—the only source of nationally representative visit-level data on ambulatory health care services at FQHCs—to multiple years of T-MSIS data. The project builds upon the "Enhancing Surveillance of Maternal Health Clinical Practices and Outcomes with FQHCs' EHR Visit Data" project and will use the same linkage methodology to link NAMCS and T-MSIS data.[22] **This linkage will give researchers insight into the relationships between patient characteristics, health care service utilization, and outcomes for maternal health visits in FQHCs.**

3. Linking the Boston Birth Cohort and Pregnancy to Early Life Longitudinal Data System and Social Determinants of Health (SDOH) Databases: A Longitudinal Cohort of Mother-Child Dyads

There is a lack of longitudinal data in the U.S. linking data on mother and child health outcomes with data from other sectors to assess factors that influence maternal health, especially among medically underserved populations.[23]

UPCOMING PROJECT OUTPUTS

De-identified longitudinal dataset linking the Boston Birth Cohort (1998-2023), the Massachusetts Pregnancy to Early Life Longitudinal Data System (1998-2023), and the AHRQ SDOH Database (2009-2019/2020), available to federal and external researchers with a data user guide and technical report on the data elements, linkage, and quality

IMPLEMENTING AGENCY: HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Expected Project Completion: July 2027

Longitudinal data refers to data that are repeatedly collected over time from the same people. The project will link data from two longitudinal cohorts with data on mothers and their children—(1) the Boston Birth Cohort, a study to explore the causes and consequences of preterm birth that includes over 8,000 mother-child pairs, and (2) the Massachusetts Pregnancy to Early Life Longitudinal Data System, a population-based system with birth and hospital discharge records—with geographic census data available from the Agency for Healthcare Research and Quality (AHRQ) SDOH Database and other non-medical data from other sources. The resulting dataset will consist predominately of Black and Latinx women and those with lower socioeconomic status, and include genome data, medical records data, hospital discharge records, vital statistics, program data, and data on non-medical drivers of health. **This comprehensive data source will allow researchers to study health outcomes from a life course perspective.**

V. Looking Ahead

The portfolio continues to meet the OS-PCORTF reauthorization objective to address the maternal health crisis by improving data infrastructure to support research related to reducing preventable pregnancy-related deaths, improving maternity care, understanding substance use treatment outcomes for pregnant women, and improving the representation of all mothers and children in health outcomes research. The 11 highlighted projects improve maternal health data infrastructure by linking different sources of data, developing interoperable surveillance networks, and improving existing data standardization efforts. The OS-PCORTF portfolio will continue to improve data quality, provide more relevant and comprehensive data, enhance or create analytic resources for health outcomes research, and improve the access and use of data to further address the national research priority of reducing maternal mortality.

BUILDING ON FOUNDATIONAL OS-PCORTF WORK

In Fiscal Year 2025, the OS-PCORTF funded one new maternal health project to implement a new PRAMS supplement and follow-up survey across 12 jurisdictions, gathering data on respectful maternal care and maternal health experiences during pregnancy, delivery, and postpartum periods. **Ultimately, this data aims to inform the development of more effective maternal health care programs and policies.**

For more information about the OS-PCORTF projects described in this report, please reach out to **OSPCORTF@hhs.gov**

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