ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

OFFICE OF THE SECRETARY
PATIENT-CENTERED OUTCOMES RESEARCH TRUST FUND

PROJECT REPORT

Linking Medicaid Claims, Birth Certificates, and Other Data Sources to Advance Maternal and Child Health

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health & Human Services

By
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The Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of the U.S. Department of Health and Human Services (HHS) on policy development in health, disability, human services, data, and science; and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

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ASPE Executive Summary

Improving maternal health outcomes is an ongoing priority for the U.S. Department of Health and Human Services (HHS). For example, the White House in June of 2022 released a Blueprint for Addressing the Maternal Health Crisis that describes the Administration's vision for decreasing rates of maternal morbidity and mortality, reducing disparities, and improving the experiences of birthing people. One of the five goals included in the Blueprint is about data capacity (Goal 3: Advance data collection, standardization, transparency, research, and analysis).

Focusing on improving prenatal care alone is not sufficient for improving pregnancy outcomes and reducing maternal mortality. Data standardization and interoperability will facilitate data linkages and longitudinal research to understand behavioral and social risks for adverse pregnancy outcomes occurring before pregnancy and to identify the set of interventions focused on modifying these risks through prevention and management. Examples of these modifiable risks include pregnancy intendedness, exposure to substances (alcohol, smoking and illicit drugs), and chronic disease management and control (i.e., diabetes, cardiovascular diseases, depression, hypothyroidism). Women with pre-existing chronic conditions are at higher risk for pregnancy complications and adverse pregnancy outcomes including severe maternal morbidities and maternal death as well as long-term poor health outcomes.

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) builds data capacity for conducting patient centered outcomes research (PCOR). It was enacted in the Affordable Care Act in 2010 and reauthorized for another decade in 2019, with maternal health research included as one of its priorities. PCOR is especially critical to reducing disparities in maternal health outcomes as it helps us understand the particular risks that women face and creates a framework to consider all relevant factors across the life course. Projects focused on improving the use of Electronic Health Records (EHRs) and claims for PCOR on maternal health are included in the portfolio of OS-PCORTF intradepartmental projects coordinated by the Office of the Assistant Secretary for Planning and Evaluation (ASPE). Data standardization and linkages are at the core of these projects, with a particular focus on access to Medicaid claims as Medicaid covers nearly half of the live births in the US, and linking these data with other data sources. In 2021, OS-PCORTF Maternal Health Consortium was created to facilities knowledge sharing and collaboration among these projects and across HHS agencies respectively.

Linkages of Medicaid claims with other data sources have been performed at the state level, using methods that vary in complexity and match rate, which makes it difficult to create a national data source for PCOR on maternal health. To identify potential next steps for a consolidated approach to performing these data linkages, while leveraging long standing state efforts, ASPE contracted with RAND Health Care to:

1. Develop a better understanding of the current state of state-based policies and activities linking Medicaid claims and live birth certificate data
2. Identify examples of states that have conducted and validated these linkages, as well as states that have expanded these linkages to include other data sources such as all-payer claims databases
3. Describe barriers that hinder these linkages, and facilitators and strategies for improving linkage efforts
4. Explore the use of these linked databases for patient-centered outcomes research in the field of maternal and infant health. Examples of use cases may include impact of pre-pregnancy existing health conditions (i.e., diabetes, cardiovascular, mental health) on maternal health during pregnancy and pregnancy outcomes; utilization of health care services during postpartum period and impact on interpregnancy interval

Structured literature reviews (peer-reviewed and grey) and discussions with select states were conducted. The results revealed that many states are successfully linking Medicaid claims with birth certificates and other data. More than half jurisdictions (66.1%; 39 out of 59 included in the review process) were identified as performing these data linkages. Although the linkage origins, methodologies, and uses vary across, similarities were found in linkage processes and challenges encountered, mostly related to coordination among multiple agencies; securing resources and staffing; and establishing policies for data sharing.

Overall, the findings from this project add valuable information about state-based activities linking Medicaid and birth certificate data that could inform creation of national learning collaboratives to facilitate knowledge sharing and decision making on best practices to consolidate linkage processes and methods across states with the aim of developing national linked data for research, programs and policies.