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FINAL REPORT

State Data for Conducting Patient-Centered Outcomes Research to Improve Maternal Health: Stakeholder Discussions Summary Report

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

by
NORC at the University of Chicago and AcademyHealth

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Office of the Assistant Secretary for Planning and Evaluation

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EXECUTIVE SUMMARY

This report presents a summary of discussions with stakeholders conducted to identify key components of successful state-based maternal health data linkage initiatives, to recognize the gaps in implementing such initiatives including data use for research and finally to understand the current status of existing linkages of state-level data with other data sources and with electronic health records. Discussants were selected from each of the following stakeholder groups: 1) Researchers working at the state-level to identify quality improvement opportunities, including academic and non-academic institutions, individuals that use data from a particular state or group of states, and networks of Medicaid researchers; 2) State Medicaid Medical Directors; 3) Data stewards, such as individuals or organizations that are involved in collecting, processing and transmitting diverse state-level data to data repositories or to researchers or research networks; 4) State Maternal Mortality Review Committee (MMRC) members; and 5) Perinatal Quality Collaborative (PQC) members.

This report was produced by AcademyHealth and NORC at University of Chicago under a contract with the Office of the Secretary's Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) which is administered by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) for the United States Department of Health and Human Services (HHS).

The stakeholder discussions highlighted several advanced state data infrastructure characteristics such as having the capacity to blend multiple data resources, iterative development of data processes, ability to overcome technical challenges and the facility to explore the use of health information exchanges (HIEs) to access clinical records on women's pre-pregnancy health. Stakeholders also provided information on funding mechanisms of state data initiatives on MM/SMM. Furthermore, the discussions revealed several data-related challenges faced by state initiatives such as concerns about the quality of data on race/ethnicity, challenges in formulating data use agreements (DUAs) for data linkages and having limited ability to link data on mothers with their babies. Stakeholders provided insight on future goals of their state's initiatives on MM/SMM. Finally, stakeholders mentioned several considerations on future actions that may contribute to improving the health and well-being of women nationwide.

INTRODUCTION

Maternal mortality (MM) rates in the United States are higher than in other developed nations.[1] Within the U.S., maternal mortality rates differ by state, influenced by care quality structures and Medicaid coverage policy among other factors[2], which can explain the increasing trend of severe maternal morbidity (SMM) rates.[3] Further, states vary in their data capacity including the ability to collect, link, and surveil relevant data. To understand their own MM/SMM rates, states use a variety of federal, state, and private resources. Despite challenges encountered, states have continued to play an essential role and serve as the catalyst for prior federal initiatives to combat the maternal health crisis through cross-agency collaborations at the national and state (e.g., between state public health and Medicaid agencies) levels.

In early 2020, the U.S. Department of Health and Human Services (HHS) announced the "Improving Maternal Health in America" initiative with a focus on reducing poor pregnancy and postpartum outcomes. One of the goals outlined under this initiative is to "improve data and bolster research to inform future interventions."[4] HHS's Office of the Assistant Secretary for Planning and Evaluation (ASPE) commissioned NORC and AcademyHealth to explore state-level maternal health initiatives focused on improving maternal health outcomes and understanding the data systems required to conduct such efforts. There is a plethora of literature on MM/SMM; however, there are gaps in our understanding of how data relevant to MM/SMM are used in research and quality improvement, and the challenges encountered therein. Furthermore, strong evidence on promising practices to identify and address MM/SMM disparities through data linkage is currently lacking. This report helps to address those gaps by providing multi-stakeholder perspectives on state data systems, state data capacity, data linkage, timeliness of data, and quality of data.

METHODS

In collaboration with ASPE and NORC, AcademyHealth developed semi-structured discussion guides[a] for hour-long conversations with five stakeholder[b] groups with maternal health expertise: Medicaid Medical Directors (MMDs), Maternal Mortality Review Committees (MMRCs), Perinatal Quality Collaboratives (PQCs), researchers, and data stewards. Informed by our project's literature review of current state maternal health initiatives, these stakeholders were selected based on the unique perspective each group brought to state-based maternal health care delivery and/or research. MMDs and data stewards provided perspectives based on their roles in maternal health-focused state programmatic and administrative responsibilities. MMRC and PQC members represented a more diverse composite, ranging from community providers to state officials, which taken together had a deep interest and evolving understanding of the issues impacting maternal morbidity and mortality. Maternal health researchers, as the ultimate translators of data to useful information, contributed valuable insights on the challenges and opportunities existing data sources and infrastructure. MMDs and PQCs were most often involved in applying the information gained from these analyses to comprehensive maternal health initiatives. In addition, feedback was sought from Technical Expert Panel (TEP) members[c], including internal HHS experts who work on MM/SMM prevention and related quality improvement initiatives. Our partners and stakeholders reviewed and provided input on the discussion guides that aimed to: 1) capture key components of state maternal health data initiatives, 2) understand use of existing state-level data, 3) identify challenges in data system implementation, and 4) capture the association of data systems with quality improvement efforts.

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[a] Discussion guides are available upon request

[b] See appendix B for a list of discussants

[c] See appendix C for a list of TEP members

We sourced recommendations for discussants from ASPE, NORC, the TEP, AcademyHealth's Evidence-Informed State Health Policy Institute (ESHPI) contacts from the Medicaid Medical Directors Network (MMDN) and the State-University Partnership Learning Network (SUPLN), and PQC and MMRC member lists published by the Centers for Disease Control and Prevention (CDC). The goal was to seek a diverse set of perspectives along multiple dimensions, including geographic location, Medicaid non-expansion and expansion states, and relative development stage of maternal health initiatives in the state. Of note, this project used a convenience sample of stakeholders and was not a complete survey of states.

State maternal health initiatives bring together individuals and organizations that otherwise would not meet or share improvement ideas. These include medical providers, hospitals, public health officials, Medicaid officials, data specialists, university researchers, and individuals representing patients and communities.

We facilitated 26 semi-structured discussions (representing 21 states and 59.8% of births in the US[5]) over the course of five weeks in summer 2020. We then coded the discussion transcriptions using qualitative data analysis software, NVivo 10, to extract pertinent information, which aligned with the key themes addressed in the specific stakeholder discussion guides. Stakeholder responses were synthesized to develop this report.

FINDINGS

These findings are a snapshot of statewide maternal health initiatives from stakeholder discussions. Revealed are promising and best practices that leverage data infrastructure, data linkages, and data capacity to address MM/SMM to inform ASPE and support patient-centered outcomes research (PCOR) on maternal health. The project team used a set of five domains to describe and compare state maternal health initiatives: *1) state initiative characteristics; 2) funding structures; 3) data infrastructure; 4) data linkage processes; and 5) data use for quality improvement*. The discussants who participated in this project were instrumental in launching their state initiatives and calling the attention of state leadership. They represented perspectives from university-based perinatal researchers, clinicians, and state officials.

1. State Initiative Characteristics

The genesis of maternal health quality improvement initiatives and use of state data systems to address MM/SMM varies widely by each state's administrative structure and policy focus. While some states, like Delaware and Colorado, created initiatives to review maternal mortality as far back as the 1960s, most state programs are less than 20 years old, with the last decade seeing an increased focus by states due to the rising rates of MM/SMM. In many states, Governors and legislatures recognized MM as a priority through patient experiences and preliminary data.

When exploring the founding of their state's programs, discussants explained that building internal trust within the program and with external agencies/partners was vital for quality improvement. State maternal health initiatives bring together individuals and organizations that otherwise would not meet or share improvement ideas. These include medical providers, hospitals, public health officials, Medicaid officials, data specialists, university researchers, and individuals representing patients and communities.

We found that advanced or rapidly developing initiatives shared characteristics such as: 1) creating and maintaining coalitions with a variety of stakeholders; 2) focusing on locally important maternal health issues such as substance use disorder (SUD) treatment or depression screening for mental illness; 3) appreciating the value of effective and timely data feedback to front line providers to improve care; 4) understanding data system development; and 5) communicating effectively with decision makers (e.g., submitting MMRC and PQC annual reports to legislature).

While focusing on using data to address MM/SMM, state data initiatives vary in nature in terms of where the data are housed, how the data are collected, the ability to link data, the clinical focus of the data system, and the level of support received from policymakers. In many states, discussants had developed or were forming partnerships with one or more major state universities. State-university partnerships can draw in expertise and provide data capacity that is often not otherwise available to state agencies. These partnerships support data quality, timely input of data, linkage, analysis, and provision of data to providers. Additionally, PQCs are primarily located within universities with close ties to state government and provider organizations, though some are located within state agencies. For example, Kentucky's PQC program is funded by state and federal sources and housed in the Department of Public Health (DPH), while Illinois's PQC program is grant-funded and housed outside of a state agency. State Medicaid programs, like California's Medi-Cal, support PQCs with funding for operations, but also through other quality improvement initiatives (e.g., managed care organization (MCO) incentives).

In addition to state-university partnerships, technical support from federal agencies has been instrumental in improving maternal health quality initiatives. Most states commented that their use of the CDC Maternal Mortality Review Information Application (MMRIA) database for compiling MM data enabled them to track metrics and evaluate MM efforts more easily. Smaller states commented that sharing their MM data with the CDC MMRIA system allowed them to enhance their own maternal mortality reviews, which were limited in size, by being able to compare their cases with a larger set of cases from other states. A few states also noted their active participation in the Centers for Medicare and Medicaid Innovation (CMMI) technical assistance grant[6] to support data linkage of vital records to Medicaid claims. Finally, a few states participate in CMMI's Maternal Opioid Misuse (MOM) model and described how it provides supplemental assistance to their quality improvement efforts by targeting additional resources to improve care delivery for those beneficiaries, both pre- and postnatal, who receive treatment for opioid use disorder (OUD).

2. Funding of State Maternal Health Initiatives

States utilize various funding streams for their maternal health initiatives; the most common funding streams discussed by participants were Title V block grant funding[d], Medicaid funds, and state appropriations based on legislative support. *Table 1* illustrates the prominent funding mechanisms states use for maternal health initiatives, as cited by discussants. Most states used Title V block grant funding as the principle funding to establish initiatives. Some states were able to leverage federal Medicaid funding to develop effective data quality systems. States receive federal funds, referred to as Federal Medical Assistance Percentage or FMAP to match state Medicaid funds for program administration including data systems and quality improvement. The FMAP for each state is based on a formula that provides higher reimbursement to states with lower per capita incomes relative to the national average[e].

Medicaid Information Technology Architecture (MITA) provides an enhanced (90%) federal match for state data systems enhancements and was used by one state we interviewed. In most states MITA is being designed to enhance enrollment and claims processing capacity with the downstream goal of using this architecture for quality systems. States that used MITA match had quality linked to MITA and developed strong relationships between perinatal quality initiatives and state Medicaid enrollment and claims systems. Most states did not have these relationships and therefore, did not consider this option.

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[d] Title V is a key source of support for promoting and improving the health and well-being of the nation's mothers, children, including children with special needs, and their families.

[e] Matching Rates, Medicaid and CHIP Payment and Access Commission, www.macpac.gov/subtopic/matching-rates/

In addition, several states participate in the Health Resources and Services Administration's (HRSA)-funded Alliance for Innovation on Maternal Health (AIM), which assists state-based teams in developing and implementing maternal safety bundles. State agency discussants referenced the CDC's Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) program as a valuable resource in their states' efforts to improve their overall data system infrastructure as well as data linkage and analysis capabilities. State MM/SMM initiatives combine these funding streams with a variety of state and local resources to create sustained and comprehensive initiatives.

Table 1: Prominent Funding Mechanisms for State Maternal Health Initiatives[++]

						Federal			State	Private
	States	Title V	CDC (staffing, ERASE MM, other grants)	CDC Funded PQC's^	HRSA (AIM)+	Medicaid Match^^	CMMI MOM* grant	CMS IAP**	State appropriations via legislature or in agency budget	Private funding
1	AL	X							X	X
2	CA	X	X		X				X	X
3	CO	X	X	X	X		X		X	
4	DE	X	X	X	X			X		
5	FL	X	X	X	X	X				
6	GA	X		X	X	X				
7	IL	X	X	X	X					X
8	KS	X	X							
9	KY	X				X		X	X	
10	MA	X		X	X			X		
11	MD	X			X	X	X	X		
12	ME	X					X			
13	MI	X			X	X				X
14	NH	X	X		X		X			
15	OH	X	X		X	X			X	
16	PA	X	X		X				X	
17	SC	X			X	X				
18	SD	X								
19	TX	X	X		X		X		X	
20	WA	X	X		X					
21	WV	X			X		X			X

**Defined as Maternal Opioid Misuse Model*
***Defined as Medicaid Innovation Accelerator Program*
^The CDC also funds the National Institute for Children's Health Quality (NICHQ, which serves as the coordinating center for state PQCs.
^^ The Federal Medical Assistance Percentages (FMAPs) are used in determining the amount of matching funds for state expenditures for assistance payments.
[+] *Not every AIM state is receiving funding. This notes their participation in the program.*
[++] *This tables refers to those significant funding mechanisms states use to support their state maternal health initiatives, as identified by discussants based on their working knowledge. It is not meant to be comprehensive.*

3. State Data Infrastructure and Stewardship

Stakeholder discussions with data stewards[f] and researchers revealed that the agency location, function, and responsibility of state data stewards vary markedly, which has an impact on state data capacities. Data stewards range from state maternal and child health (MCH) directors or epidemiologists with primary surveillance management responsibilities to university research institutions with full oversight of state data

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[f] For the purposes of identifying appropriate data stewards for our discussions, we defined data stewards as those responsible for utilizing the data governance processes to ensure the appropriateness of data elements throughout the system. A data steward is responsible for the quality of defined/assigned dataset on a daily basis.

warehouses, including data storage, quality assurance, and linkage responsibilities for a comprehensive repository of data sources (i.e., vital records, hospital discharge data, emergency department records, Medicaid claims and encounter data).

Notably, data steward roles vary with respect to data ownership versus data management, with one not necessarily indicating responsibility for the other. Data stewards who oversee large data warehouses or repositories noted they are not the data owners, but rather manage the data. For example, the University of South Carolina's Institute for Society and Families manages a data warehouse comprised of key data sources like hospital discharge data (HDD), vital records, and Medicaid claims. However, the warehouse does not own the data, but rather acquires and manages different data sources either through a state contract or legislative mandate.

Kentucky established a centralized office within the Cabinet for Health and Family Services (CHFS) to serve as an "honest broker," which functions not as the data owner, but rather the provider of data quality oversight who is principally responsible for storing and linking data based on agency requests. Other states, such as Maryland, use a regional health information exchange (HIE) like the Chesapeake Regional Information System for our Patients (CRISP), which primarily serves as a centralized data repository of several major data sources in Maryland for participating providers. Data stewards such as MCH directors have responsibilities and may be granted access to specific data (i.e., birth defects screening, Medicaid claims) based on their roles. Some data stewards also assist with reviewing data requests. For example, researchers in South Carolina submit data requests to a committee within the data warehouse that vets research applications. Once the committee reviews the data request and makes its recommendation to the Medicaid agency, the data steward reviews the recommendation with the Medicaid agency to provide guidance in the final approval decision. In most states, data ownership and decisions about data use are maintained by the state agency responsible for the particular data set (e.g., Medicaid claims with Medicaid, hospital discharge claims with facilities or aggregated to the hospital association, vital records with the State Registrar or Vital Records office).

Some data stewards also provide key quality assurance responsibilities, by which they both explore the data for inconsistencies and advise the agency on the integrity of the data. As an example, while Kentucky's centralized data office outsources the collection of their entire state's HDD to the Kentucky Hospital Association, it provides data quality assurance to ensure accuracy and submits the data to the Agency for Healthcare Research and Quality (AHRQ) for the Health Care Utilization Project (HCUP)[g]. New Hampshire's MCH epidemiologist shared that the state established a Birth Data Quality Committee where data quality enhancements are made. For example, recognizing an increase in SUD-related maternal deaths, the committee added items to the birth certificate related to prenatal substance exposure. The epidemiologist explained that previously these maternal deaths were classified as pregnancy-associated deaths, but with this additional information, more deaths could be counted as pregnancy-related deaths.

Discussants shared challenges regarding the collection of race, ethnicity, and other self-reported demographic data. Medicaid discussants universally indicated their interest in improving their knowledge of race, ethnicity, and language by improved collection of this data or linking Medicaid data to better-populated sources. Most discussants reported that vital records were the most reliable source of information on race, ethnicity and other demographic data. Title 42 §435.907 of the electronic Code of Federal Regulations (eCFR) only requires Medicaid to collect information from an applicant that is necessary to make an eligibility determination. Race

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[g] Currently, Kentucky's data center follows documented procedures by which an analyst conducts quality checks on the data, but the office is currently transitioning to the use of commercial products to automate the process, including master data management (MDM) and the use of unique identifiers to allow for improved integration across different data sources.

and ethnicity are optional fields during enrollment, and collection processes vary by front-line workers. As an exception, Kentucky captures race and ethnicity data in the Integrated Eligibility and Enrollment System (IEES).

Other states noted efforts that they are undertaking to improve demographic data. Massachusetts' Medicaid program, MassHealth, explained that the state's DPH extracts race and ethnicity information from the HDD for reference when calculating their SMM rates. Due to the poor reporting of race and ethnicity in Medicaid claims, MassHealth also needs access to the state's HDD for conducting SMM analyses specific to Medicaid beneficiaries. This step requires a data request to their state's sister agency, the Center for Health Information and Analysis (CHIA), which serves as the data warehouse for the state's providers and payers and can conduct the data linkage.

4. Data Linkage Capacity

Both researchers and data steward discussants reported conducting data linkage, often a key responsibility of the entity in charge of data quality assurance. Discussants varied in the data sources that they currently link for MM/SMM, but commonly cited linkages between HDD and vital records. Discussants mentioned that linkages between vital records and Medicaid claims are preferred because they show a more complete picture of health care access (e.g., prenatal care) than HDD alone, but are also more challenging due to time lags and limited analytic capacity.

Discussants identified several challenges with data linkages, such as the requirement of separate data use agreements (DUAs) for each state agency, which delays data sharing. As an example, one discussant explained that their state's DPH includes both the vital records office and the MCH office. The State's Medicaid and DPH agencies have a formal interagency DUA; however, in order for the DPH's MCH epidemiologist to review linked birth certificates with Medicaid claims, each agency requires their own DUA. This results in an onerous process for both DPH's MCH epidemiologist as the requestor and Medicaid as the claims data owner, which then needs to request access to the data for any review of linked claims. Other data linkage challenges relate to the data owners and any changes they may make to their own data sets and/or infrastructure. For example, a few discussants noted that hospital mergers often lead to delayed HDD submissions due to a change in electronic health record (EHR) vendors. Data linkage may also be more complex due to a limited number of identifiers to facilitate accurate linkages.

Many stewards cited the necessity of DUAs and memorandums of understanding (MOUs) with data owners to authorize data linkage. Significant time and resources (i.e., legal staff) are dedicated to establishing these DUAs and MOUs between state agencies and between state agencies and external partners (usually universities). States with more robust maternal health initiatives tend to create MOUs and/or DUAs for ongoing linkages (rather than discrete projects) through cooperative agreements between the partner agencies. Mature data sharing agreements are long-term contracts (usually five years) and based on agreed-upon procedural steps for data linkages (i.e., the order of operations). For example, Maine's MCH director found that an MOU between her Office of Child and Family Services and the state's Medicaid program, MaineCare, was somewhat streamlined because her role as Title V director already required her to have an MOU with the state's Medicaid office. Her office leveraged this requirement to establish its ability to conduct data analyses and data linkages for the next five years.

South Carolina's data warehouse relied on its longstanding relationship with Medicaid to establish MOUs across the vital records and HDD entities, enabling a three-way linkage. Through these data linkages, a more complete maternal health care profile is captured. Such a linkage reveals information on prenatal care, pregnancy history, chronic conditions, and patients' residential location. These collective linkages enable South Carolina to build and now apply the Palmetto small area deprivation index[7] to assign risk scores based on the mother's geographic community. Kentucky has also overcome common data linkage obstacles through strong state executive-level buy-in. Because linked data are critical for reviewing the extent of the OUD and SUD-related MM rates, Kentucky's Cabinet for Health and Family Services (CHFS) designated linking these data as "a standard process."

Timeliness of data feeds for record linkage is also a common challenge. The timing varies depending on the data infrastructure and completeness of the data sources, but on average, HDD and birth certificate data are available monthly for data stewards and/or researchers responsible for data linkage. For MCH officials, access to vital records varies from daily to monthly depending on the dataset (i.e., birth certificates, death certificates). With respect to timeliness in fulfilling data requests some states like California can provide feedback to clinical providers through their rapid-cycle data center and others like Ohio have developed capacity to respond promptly to specific queries. Kentucky shared that they can usually respond to a request from their PQC lead for information within two days to two weeks, depending on the complexity of the request. New Hampshire can expect a cut of Medicaid claims data in two to four weeks. Maine's MCH director can access MCH department data (e.g., blood spot data, newborn screening) daily, birth certificate data weekly, and death data monthly.

5. Data Use for Quality Improvement

In states that have documented improvement in MM/SMM outcomes such as California and Illinois, local data are integral to implementation of maternal reviews and quality improvement. Advanced data programs are able to feed data back to providers and other systems at the local level to improve care. Discussants spoke of local-level process measures that are associated with decreased morbidity outcomes (e.g., time to hypertension

STATE SPOTLIGHT: BEST PRACTICE

The Commonwealth of Kentucky's Cabinet for Health and Family Services (CHFS) formed the Office of Health Data and Analytics' Division of Analytics in 2019 *"to provide oversight and strategic direction and be responsible for coordinating the data analysis initiatives for the various departments that regulate health care and social services…"*

RESPONSIBILITIES

The Division is principally responsible for:

- facilitating data integration by "initiating and maintaining data-sharing agreements in order to improve inter-agency and cross-cabinet collaboration."
- reviewing data analyses conducted by the CHFS departments within the cabinet "to ensure the consistency, quality, and validity of the analysis,"
- reviewing and responding to all public data requests received by the CHFS, and
- assuring the privacy of individual data via the chief privacy officer.

FUNDING

The Division is funded through state appropriations, Medicaid (including FMAP), Medicaid Management Information System (MMIS), and other grant resources.

DATA

The Division currently manages the integration of six data sets, with additional sources anticipated shortly:

- MMIS claims and encounters, all beneficiaries except the 1915c waiver population (claims) are in management care (encounters)
- Office of Vital Statistics (OVS) birth and death certificates
- Kentucky All Schedule Prescription Electronic Reporting (KASPER), the state's Prescription Drug Monitoring Program (PDMP)
- Hospital Discharge Data System
- Kentucky Cancer Registry (KCR)
- Neonatal Abstinence Syndrome (NAS) Registry

SUSTAINING AND EXPANDING THE STATE INTEGRATED DATA STRUCTURE

This strategic infrastructure has enabled Kentucky to adopt data linkage processes as standard procedures, allowing them to quickly operationalize cross-agency data initiatives, including responding to the COVID-19 public health emergency. Kentucky's COVID-19 response has hastened the addition of the Kentucky Health Information Exchange (KHIE) to the integrated data structure. In turn this new data source, can be utilized for their state's MM/SMM project to identify many more births and access EHRs to capture prenatal and/or postnatal care.

treatment under one hour associated with decreased risk of stroke). Several state discussants pointedly spoke of data use in these quality improvement cycles as part of public health practice and data-driven quality improvement. For example, Ohio associated maternal health process measures to infant mortality by linking Medicaid claims to vital records (birth and death certificates) to better understand these correlations. All state discussants had an understanding of quality improvement processes and the need for timely linked data to contribute to improvement cycles.

When asked about specific data measures used or needed to analyze and improve MM/SMM, many discussants spoke in depth about measures related to obstetric hemorrhage, hypertension, and SUD. Some states, such as Texas and Colorado, are working to address these issues through participation in the AIM Program with the American College of Obstetricians and Gynecologists (ACOG). States that are part of AIM report on outcome and process measures within four categories: readiness, recognition and prevention, response, and reporting/systems learning.[8] For instance, the Illinois PQC (ILPQC) measures treatment of hypertension within 60 minutes, patient education at discharge on warning signs of preeclampsia, and follow-up visits scheduled within seven to 10 days. The ILPQC also includes a process measure on debriefing (e.g., a huddle) after birth.

STATE SPOTLIGHT: BEST PRACTICE

The Delaware Fetal and Infant Mortality Review (FIMR) recently began reviewing all fetal deaths annually. This has allowed them to take a closer look at SMM based on FIMR cases using CDC criteria over the past two years. The data for these cases come from the National Center for Fatality Review and Prevention, although the Delaware FIMR does its own quality assurance to flag SMM, as it is not easily identifiable or standardized in the database. The Delaware MMRC is considering expanding its SMM definition to better understand the severe complications that arise during pregnancy that may be due to behavioral issues, chronic conditions, and other factors not included in the traditional definition of SMM.

Some states focus on improvement directed by the findings of their MMRCs. The Missouri Pregnancy-Associated Mortality Review (PAMR) looks at cases of maternal mortality to identify which deaths could have been preventable, in particular they reviewed cases of maternal hypertension—treatment plan, associated SUD, location and timeliness of treatment, if medication is prescribed, and other health care quality measures to make recommendations for improved treatment protocols.

According to the National Institute for Children's Health Quality (NICHQ), many PQCs receive neonatal data that can be used to measure MM/SMM from hospitals through elective delivery, breastfeeding, and preterm labor metrics. Multiple discussants acknowledged this challenge—that MM and SMM analyses have traditionally focused on obstetric complication measures, rather than factors such as behavioral health, social determinants of health, and chronic health conditions such as cancer and hypertension. Some MMRCs have difficulty assigning a cause of mortality due to a lack of linked or timely data for pregnant and postpartum patients, and limitations on access to records that identify chronic diseases and social risks. The Colorado Department of Public Health and Environment has addressed this issue through a program called Health eMoms,[9] which incentivizes mothers to take an annual survey until their child's third birthday. The survey covers a range of questions regarding postpartum health and wellness, which the Colorado MMRC then uses to look back and understand why SMM may have occurred.

Similar to MMRCs, depending on their data structure and data validity, PQCs have different priorities for interventions to improve maternal health. See *Table 2* for examples of PQC maternal health interventions. Most PQCs disclosed how their initial quality improvement work on MM/SMM was an addition to their work to reduce infant mortality. Quality improvement projects were chosen based on local identification of SMM challenges. Most states had a focus on pregnancy-related morbidity and mortality, specifically focusing on medical management of hypertension and postpartum hemorrhage. The Illinois, California, and Florida PQCs adapted the AIM maternal safety bundles and reported significant improvements in maternal health when using these bundles with an integrated data feedback process. Texas reinterpreted the AIM bundles to create an initiative to identify maternal early warning signs overall.[10] States more deeply affected by the opioid crisis were more likely to choose initiatives that aimed to help pregnant mothers with OUD and SUD, while a number of states that identified maternal mental health as a key issue targeted depression screening. Virtually all states expressed interest in expanding their understanding of racial and ethnic disparities in MM/SMM in their communities, often beginning with better data collection. MMRC analyses were used as part of the decision-making for specific state PQC efforts; however, due to the lag in the collection and reporting of data, MMRCs' recommendations more often supported PQC quality improvement programs and the enhancement of data systems.

Table 2: Examples of PQC Maternal Health Interventions

Intervention Type	Examples
Medical Health Interventions	• Hypertension bundle • Postpartum hemorrhage bundle • Use of PP LARC
Mental Health Interventions	• Depression screening • Treatment of SUD/OUD during and after pregnancy
Social Risk Factor Interventions	• Community health worker referral • Housing support • Prenatal doula programs • Programs targeting specific racial/ethnic populations

At the conclusion of all discussions, we asked discussants about their aspirations and goals for using data to understand their state's MM/SMM rates and to support programmatic improvements. Most discussants identified improvements in data reporting and quality to better inform non-medical services and actions towards social and health care equity for the mother and child, which can influence follow-up care. In addition, discussants underscored the importance of a broader picture of the lifestyle and risks a mother might face. See *Table 3* for shared data use goals for MM/SMM by stakeholders.

Table 3: Future Goals Mentioned by Stakeholders[h]

	Future Goals					
Stakeholder Type	**Improve** Data Reporting	Improve Data Quality	Increase Non-Medical Services (SDOH)*	Life Course Approach	Increase Workforce (Doulas and Community Health Workers)	Care Transitions and Follow-Up
MMDs	5	4	3	2	3	2
Data Stewards	2	1	1	0	0	0
Researchers	5	4	2	3	1	3
MMRCs	0	1	2	3	3	1
PQCs	2	3	3	2	1	2
Total	**14**	**13**	**11**	**10**	**8**	**8**

** SDOH is an abbreviation for social determinants of health.*

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[h] This table represents specific goals that were mentioned the most by discussants based on stakeholder group. Other goals mentioned by a smaller amount of discussants were extending postpartum coverage, increasing MM/SMM funding, and providing access to OUD/SUD treatment.

DISCUSSION

AcademyHealth conducted these multi-stakeholder discussions to identify more recent, less formalized state-based MM/SMM initiatives that otherwise may not be captured in grey literature and peer reviewed publications. These targeted discussions addressed how states leverage data sources and analytic capacity through collaboration with cross-state agencies, data warehouses, and university researchers, to study MM/SMM and inform policy decision-making related to maternal health outcomes. Similar to the literature findings, our discussions identified MM/SMM research efforts across states that focus on quality via the use and linkage of vital records, hospital discharge data and Medicaid claims. University researchers were instrumental in monitoring maternal health outcomes, managing data sources, and facilitating data linkages. Findings from discussions demonstrated opportunities where states could align efforts across systems (e.g., Medicaid programs, health plans, hospitals) to understand the health and wellbeing of their perinatal populations through data sharing and data quality improvements. We found variability in the strength of data infrastructure and data stewardship. Improvements could facilitate better data standardization and integration and help to ensure sustainability and continuity of MM/SMM data initiatives. States emphasized the value of having a strong leader and team that are responsible for combining resources to produce robust integrated state data systems. These states also had champions that were effective at building coalitions with clinical leaders, policymakers, academia, and social services partners.

Discussions identified states' use of both federal agency technical support and federal and state funding streams (i.e., ERASE MM, PQCs, CMMI IAP technical assistance, MITA, Title V, etc.) to bolster states' MM/SMM monitoring and quality improvement infrastructure, which together influenced the robustness of MM/SMM efforts. Most often, these initiatives were initially federally funded and later supplemented with state resources. Successful states had inter-agency and cross-agency collaborations that better positioned them to align funding from non-competitive Title V block grants with other federal sources such as CDC grants, the National Institute on Drug Abuse (NIDA) awards, and Medicaid matching funds. State official discussants appreciated federal programs (i.e., ERASE MM, PQCs, AIM) that support infrastructure and capacity building. Discussants acknowledged the value of federal surveillance products and support, but sought more flexibility to give them the opportunity to align federal products with existing systems. Discussants also noted the potential benefits of having longer-term federal funding cycles to provide sustained support for infrastructure. States varied in their capacity to assume program operations after federal grant cycles were completed.

ADVANCED DATA INFRASTRUCTURE CHARACTERISTICS

States with advanced data infrastructure shared similar characteristics:

1. A capacity to blend resources;
2. The iterative development of a data process that is effective in data collection, analysis, and feedback to users;
3. The ability to overcome technical, administrative, and legal barriers to sharing data; and
4. The facility to explore the use of HIEs to access additional clinical records regarding a woman's pre-pregnancy and prenatal health, and/or *incorporate* geographic and social service data (e.g., child protection) to consider the full life course

There was marked variation with respect to where the data are housed, the type of data sources collected and linked, the clinical focus/primary use of data, and policymaker involvement. Most states cited linking HDD, vital records, and Medicaid claims as essential for informing comprehensive MM/SMM initiatives. Legal and ethical considerations, limited resources to navigate data sharing agreements, and the disparate timeliness of the data sets were challenges that these states overcame to link data.

Our report has several limitations. First, we used a convenience sample of state maternal health stakeholders in five unique roles (MMDs, PQCs, MMRCs, researchers, and data stewards). Second, our review of 21 states, while representative of 59.8% of births in the US, is limited in scope and depth. Individual discussants shared their knowledge of their state, which was often comprehensive, but sometimes limited in perspective depending on the question asked. Despite these limitations, this report offers ASPE and HHS a broader understanding of the current status of state MM/SMM data initiatives and potential opportunities to advance federal support of these efforts. This report is a distillation of over 25 hours of interviews and associated background research, which is a strength. Another strength is the use of a semi-structured interview process to assure discussion uniformity and the coding of all discussions via qualitative analysis software NVivo 10 to limit bias.

CONCLUSION AND CONSIDERATIONS FOR FUTURE ACTIONS

Based on our discussions, states that have an integrated and sustainable data infrastructure and a trusted data steward that bridges data owners and maternal health researchers are better positioned to align funding resources and leverage data linkage capacity to improve maternal health. With heightened awareness of the importance of data systems that provide valid, timely and linked information, the federal government has the opportunity to further align its support to states to strengthen maternal health initiatives.

Our discussions revealed several considerations to develop the infrastructure to improve the collection, analysis (including linkage) and use of maternal health data by states. First, in order to support sustainable state programs, both funding and technical support opportunities could be considered. These considerations include funding support for all states to innovate data systems from their current status to enhance capabilities including data linkage and timely feedback for quality improvement. Such federal funding sources could be aligned and enhanced to support program continuity over time. To assist states in building their analytic capacity, both direct technical assistance to states and support via an interstate learning collaborative can be established. This comprehensive approach could enable states to improve data quality, link data, use data to inform quality improvement and address technical, administrative and legal barriers to data linkage. Finally, specific technical support and funding to enhance the collection and use of data on race, ethnicity and social determinants is a major consideration revealed by the discussants. Modernizing MM/SMM initiatives through these and other considerations about data standardization, integration and interoperability will contribute to improving the health and well-being of women nationwide.

APPENDIX A. STATE BIRTH AND MATERNAL MORTALITY RATES

	2018 State Birth and MM Rates	
States	**Total Births**	**Maternal Mortality Rates**[*,^]
AL	57,761	36.4
CA	454,920	11.7
CO	62,885	X[^]
DE	10,621	X
FL	221,542	15.8
GA	126,172	27.7
IL	144,815	9.7
KS	36,261	X
KY	53,922	40.8
MA	69,109	17.4
MD	71,080	14.1
ME	12,311	X
MI	110,032	16.4
NH	11,995	X
OH	135,134	14.1
PA	135,673	14
SC	56,669	27.7
SD	11,893	X
TX	378,624	18.5
WA	86,085	15.1
WV	18,248	X
Total for discussant states	*2,265,752*	X
Total in U.S.	*3,791,712*	*17.4*

[*] *Maternal mortality rates are per 100,000 live births. This is public data extracted from: https://www.cdc.gov/nchs/maternal-mortality/MMR-2018-State-Data-508.pdf*

[^] *Data suppressed due to confidentiality restrictions*

APPENDIX B. LIST OF DISCUSSANTS

Stakeholder Groups				
Medicaid Medical Directors (MMDs)	Maternal Mortality Review Committees (MMRCs)	Perinatal Quality Collaboratives (PQCs)	Researchers	Data Stewards
Mary Applegate, MD (OH)	Brie Thumm, MD (CO)	Patricia Heinrich (NICHQ)	Bill Sappenfield, MD (University of South Florida)	Maryann Harakall (Maine MCH Director)
Monica Le, MD (MA)	Anne Pedrick (DE)	Elliott Main, MD (CA Maternal Quality Care Collaborative)	Michelle Menegay (Ohio State Government Resource Center)	Maik Schutze (Kentucky Office of Health Data and Analytics)
Jim Becker, MD (WV)	Leticia Hernandez, PhD (FL)	Patricia (Patti) Lee King, PhD, MSW (IL)	Jessica Smith, PhD (Georgia Health Policy Center)	David LaFlamme, PhD (University of NH)
Judy Zerzan, MD (WA)	Manda Hall, MD (TX)	Devika Maulik, MD (KS)	Marian Jarlenski, PhD (University of Pittsburgh)	Ana Lopez DeFede, PhD (SCBOI)
Mary Carpenter, MD (SD)		Connie White, MD (KY)	Kara Zivin, PhD (University of Michigan)	Marc Rabner, MD (CRISP)
Elizabeth Brown, MD (DE)		Martha Wingate, DrPH (AL)		

NOTE: The views expressed by discussants were personal not of the organizations they represent.

APPENDIX C. LIST OF TEP MEMBERS

Technical Expert Panel (TEP): State Data for Conducting Patient-Centered Outcomes Research to Improve Maternal Health

Name	Organization	Contact
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