Project Report

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

Final Report

Sara Heins, Zachary Predmore, Emily Hoch, Sangita Baxi

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About This Project Report

Medicaid pays for nearly half of all births in the United States, including most births by Black and Hispanic women. To assess the health outcomes of and the maternity-related services received by the Medicaid population, data linkages between Medicaid data, birth certificates, and other data sources must be made. State agencies have developed various methods of linking the records of mothers and/or infants with Medicaid insurance with the infants' birth certificates, and these methods vary in performance. The project aims described in this report are as follows: (1) develop a better understanding of the current landscape of state-based policies and activities linking Medicaid claims with birth certificates and other data sources; (2) document existing state capacity for conducting and validating these linkages (including expanding the linkages to other data, such as All-Payer Claims Databases [APCD] where available); (3) describe the barriers and gaps preventing these data linkages from being used more widely; and (4) explore the use of these linked databases for patient-centered outcomes research in the field of maternal and infant health. The findings will inform future efforts to create data structures that allow for evidence-based evaluations of ongoing and future U.S. Department of Health and Human Services (HHS) investments in maternal and infant health, including efforts to address observed racial and ethnic disparities.

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RAND Health Care Communications
1776 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138
(310) 393-0411, ext. 7775
RAND_Health-Care@rand.org

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Disclaimer

Executive Summary

Medicaid pays for nearly half of all births in the United States, and Medicaid claims are a rich source of longitudinal data on peripartum maternal and infant diagnoses and health care utilization. However, Medicaid claims often lack key sociodemographic data and may underreport certain maternal and infant clinical information. Linking Medicaid claims with birth certificates can provide a more complete picture of maternal and infant health. In addition, it can facilitate linkages with additional data sources that are already linked to birth certificates.

There is considerable interest in using linked data to conduct maternal and infant health longitudinal research to plan and evaluate interventions, inform funding priorities, and target interventions. Despite this interest, linkage efforts vary greatly by state, and there is not a consistent set of standard methodologies to make these data available for research at the national level.

Approach

To develop a better understanding of state efforts to link Medicaid claims with birth certificates and other data sources, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) contracted with the RAND Corporation to

- conduct a structured literature review of peer-reviewed and gray literature
- develop an inventory of data linkage efforts for all U.S. jurisdictions (defined as including all states, territories, and the District of Columbia) and detail characteristics of the data used, linkage processes, and applications
- facilitate semistructured group discussions with representatives involved in these data linkage efforts from nine states to learn more details of the technical aspects of the data linkages, cross-agency processes and communications, and barriers and facilitators.

Results

Key findings from the structured literature review and group discussions included the following:

- We identified 45 studies published between 2017 and 2022 that used Medicaid claims linked with birth certificates and/or other data sources from 22 states to conduct maternal and infant health research.
- Most jurisdictions (39) had conducted state-level linkages between Medicaid claims and birth certificates and/or other sources of data (e.g., electronic health records, newborn screening data).
- States varied considerably with regard to the types of data they linked with Medicaid claims.

- Discussion participants noted that linked data were mainly used for policy and program evaluation, though some states noted their use in targeting individual-level interventions.
- Participants also reported that strong relationships among state agencies and streamlining of the data use agreement process helped facilitate linkages, while major challenges included establishing policies and processes for sharing data and working across agencies.

Considerations

Many states are successfully linking Medicaid claims with birth certificates and other data. These states' efforts include innovative practices that may inform other states interested in developing new linkage efforts or expanding upon existing efforts. States looking to implement these linkages should consider the following actions:

- strengthening relationships among state agencies and developing policies to simplify the data linkage processes; these may include using a universal data use agreement or developing master patient indices with identifiers that can be used across agencies
- collaborating across states to share resources and best practices
- leveraging existing data infrastructure and processes (e.g., health information exchanges, all-payer claims databases)
- outsourcing technical tasks when needed; states can contract with external organizations experienced in performing these types of linkages or can consider using existing software developed to facilitate linkages.

Federal policymakers could consider the following practices:

- supporting states by offering grant funding or technical assistance
- establishing learning collaboratives or networks to leverage states' expertise and their longstanding efforts in implementing linkages while providing expert advice on overcoming challenges and identifying best practices for developing national data linkage strategies.

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Chapter 1. Introduction

Background

Medicaid is the payer for almost half of all births in the United States, including more than half of all births by non-Hispanic Black and Hispanic women (Martin, Hamilton, and Osterman, 2020). Maternal and infant claims (a term that we use throughout this report to refer to both fee-for-service claims and records generated from managed care encounters) contain information on diagnoses and health care utilization, but these data alone sometimes do not provide enough information and must be linked with other data to conduct high-impact longitudinal patient-centered outcomes research on maternal and infant health that can inform policies and programs.

Birth certificates, for instance, contain key information not captured in claims (e.g., parents' educational attainment) or captured inconsistently in claims (e.g., low birth weight). In addition, once claims are linked to birth certificate data, linking to other types of data is possible. For example, birth certificates are used to create the sample for the Pregnancy Risk Assessment Monitoring System (PRAMS)—a large survey on maternal and infant health administered in 46 states, the District of Columbia, and two U.S. territories (Centers for Disease Control and Prevention, 2021)—and allow PRAMS to be linked to claims (Hawkins et al., 2022; DeSisto et al., 2021). Other data that some states may regularly link with live birth certificate data include death certificates and hospital discharges.

However, efforts to link Medicaid claims with birth certificates and other data sources have been fragmented and typically conducted at the state level, with some states developing comprehensive, regularly updated databases while others complete annual data linkages manually. Across these linkage efforts, there is also substantial variation in (1) data sources linked to Medicaid claims (e.g., birth certificates, hospital discharge data, prescription drug management programs, electronic health records); (2) linkage methods (probabilistic record linkage, deterministic record linkage, or combination of both); (3) variables used for linkage (e.g., names, dates of birth, Social Security numbers, mothers' information); (4) match rates; and (5) uses of these linked databases (e.g., patient care, research, quality improvement). A national initiative assessing these disparate linkage efforts may identify best practices and scale them up for future data linkages across all states and territories.

Purpose

The aims of this project were to

- develop a better understanding of the current state of state-based policies and activities linking Medicaid claims with birth certificates and other data

- 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
- describe barriers that hinder these linkages and facilitators and strategies for improving linkage efforts
- 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 (e.g., 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.

Overview of Approach

We have taken a three-pronged approach to achieve these aims:

- Structured literature review: We completed a structured literature review of peer-reviewed articles to identify published research that used these linkages or described these linkage efforts.
- Inventory of state and territory efforts: We reviewed gray literature for each state and territory to develop an inventory of state linkage efforts.
- Semistructured discussions: We conducted nine semistructured group discussions with representatives from nine states to capture information on data linkage efforts. Each discussion focused on a single state and was inclusive of leaders responsible for implementing and using these linked databases.

Organization of the Report

This report begins with a discussion of the structured literature review (Chapter 2), describes the inventory of state and territory efforts (Chapter 3), presents the results of the semistructured group discussions (Chapter 4), and concludes with a summary and considerations (Chapter 5).

Chapter 2. Structured Literature Review of Peer-Reviewed Literature

We conducted a structured literature review to find examples of peer-reviewed literature using linked Medicaid data for the purpose of maternal and infant health. We abstracted information to assess trends in data linkage methodology and topics covered, as well as to identify states for inclusion in the discussions in Chapter 4.

Methods

In consultation with a RAND Corporation health care research librarian and with the Office of the Assistant Secretary for Planning and Evaluation (ASPE), we developed a list of search terms and literature databases (Table 2.1) to identify five years of recent peer-reviewed articles using Medicaid claims linked with birth certificates or other sources of data. The RAND librarian conducted an initial title and abstract search of the peer-reviewed academic literature published between February 28, 2017, and March 1, 2022. Articles were retained for screening if they contained at least one relevant data term, linkage term, and maternal/infant health term (Table 2.1).

Table 2.1. Databases and Search Terms

Databases	Search Terms
PubMed, Academic Search Complete, CINAHL, Scopus, Web of Science	**Linkage terms**: link*, join*, merg* **Data terms**: Medicaid, “claims data,” “administrative claims,” “administrative data,” “All-payer,” “Birth certificate,” “Death certificates,” “medical record,” “health record,” “Prescription Drug Monitoring Program,” “Prescription Monitoring Program,” PMP, PDMP, “Pregnancy Risk Assessment Monitoring System,” PRAMS **Maternal and infant health terms**: health AND maternal, child, infant, prenatal, postpartum, antenatal, pregnancy, pregnant, neonatal, perinatal, newborn, fetal

NOTE: PDMP = prescription drug monitoring program.

Two researchers independently screened a 5-percent sample of articles to determine whether they met inclusion criteria, then assessed agreement and clarified the inclusion criteria as needed. The two researchers then split up and screened the remaining articles, with articles adjudicated and discussed when necessary. The final study inclusion criteria are presented in Table 2.2. Briefly, these were original, empirical peer-reviewed articles that used Medicaid claims or all-payer claims data (APCD) containing Medicaid claims individually linked with birth certificates and/or other data sources. Only state- or territory-wide linkages were considered, meaning that linkages involving an area smaller than a state or territory (e.g., a single county or health system) were not included. Similarly, linkages performed at the national level were not included. Articles were required to address or have a clear application to a maternal and/or infant health topic and include in the study population pregnant women, postpartum women, and/or infants younger than one year of age.

Table 2.2. Study Inclusion Criteria

Domain	Inclusion Criteria
Publication dates	February 28, 2017–March 1, 2022
U.S. data	Uses data from U.S. states and/or territories
Study type	Original, empirical peer-reviewed research article. Editorials, commentaries, systematic reviews, and qualitative research studies were not included in the review, but relevant articles from these excluded types were flagged for background information purposes.
Maternal and infant health topic	Article must address maternal and infant health topic, and the study population must include pregnant women, postpartum women, and/or infants <1 year of age.
Data used	• Medicaid or APCD including Medicaid claims linked at the individual level with data from – birth or death certificates – electronic medical records or health information exchanges (HIEs) – PDMPs – social services (e.g., Supplemental Nutrition Program for Women, Infants and Children; Child Protective Services; Housing Vouchers) – PRAMS – hospital discharges – registries (e.g., birth defects, cancer)
Geographic scope of LInkage	Data linked for one or more states or territories. Linkages involving a single commercial insurer, county, or health system are not included. Linkages performed at the federal level (e.g., Medicaid Analytic Extract linked with National Health Interview Survey) are not included.

After the list of included articles was finalized, the two researchers coded articles using Google Forms based on the following categories: state(s), years of data linked, types of data linked, details of linkage process, maternal and infant topics, health disparities examined, linkage challenges, and information about data access. Information in each category was coded using a mixture of structured and free-text data, and code sets were iteratively discussed and updated. Table 2.3 summarizes the final coding guide. Some studies conducted secondary analyses of previously linked data sets. If these studies provided citations of articles describing the original linkages, we also included information from the cited articles in the data abstraction.

Table 2.3. Final Coding Guide

Category	**Questions**	**Response Types**
States	For which states or territories were data linked?	State or territory abbreviations or note if not specified
Years	What were the first and last years of linked data? Note noncontinuous time frames or differences in years used by data set.	Year range and free-text notes
Types of data sets linked	What type of claims, enrollment, or encounter data set was linked?	Multiple choice: Medicaid, All-Payer Claims Database
	What type(s) of other data sets were linked?	Checkbox: Birth certificates, death certificates, PDMPs, EMR/EHR/HIE, social services, state maternal health program enrollment, PRAMS, registries, other (free-text)
	Are mother and infant claims linked?	Multiple choice: yes, no, not specified, other (free-text)
Details of linkage process	What type of record linkages were used?	Multiple choice: deterministic (i.e., an exact match on one or more unique identifiers, such as Social Security number [SSN]), probabilistic (i.e., partial matches on multiple non-unique identifiers, such as name and birth date), both, other (free-text), not specified
	Which variables were used in the linkages?	Checkbox: Child DOB, mother DOB, delivery date, child SSN, mother SSN, medical record or enrollment number, name, geographic information (e.g., address, zip code), child sex, race, not specified, other (free-text)
	What was the match rate of each linkage? (may provide multiple)	Percentage match and free-text description of match type (e.g., percentage of infant Medicaid claims linked to birth certificate) or not specified
	How, if at all, were matches validated?	Checkbox: manual review, comparison with other data source, other (free-text), not specified
Maternal and infant health topics	Which maternal and infant health risk-factors, protective factors, and outcomes were examined?	Checkbox: diabetes, hypertension, prenatal care or other pregnancy-related service, labor and delivery complications (e.g., sepsis, hemorrhage), infant mortality, neonatal abstinence syndrome, maternal mental health, breastfeeding, maternal substance use, preterm birth or low birth weight, Medicaid expansion, social services use, other (free-text)
Health disparities	Which health disparities were examined?	Checkbox: race, ethnicity, rurality, education level, other (free-text)
Linkage challenges	What linkage challenges were noted?	Free-text
Author affiliations	With what types of organizations were the authors affiliated?	Checkbox: academic, state government, federal government, other (free-text)
Access for researchers	What information do the authors provide about data sharing or access for other researchers?	Free-text

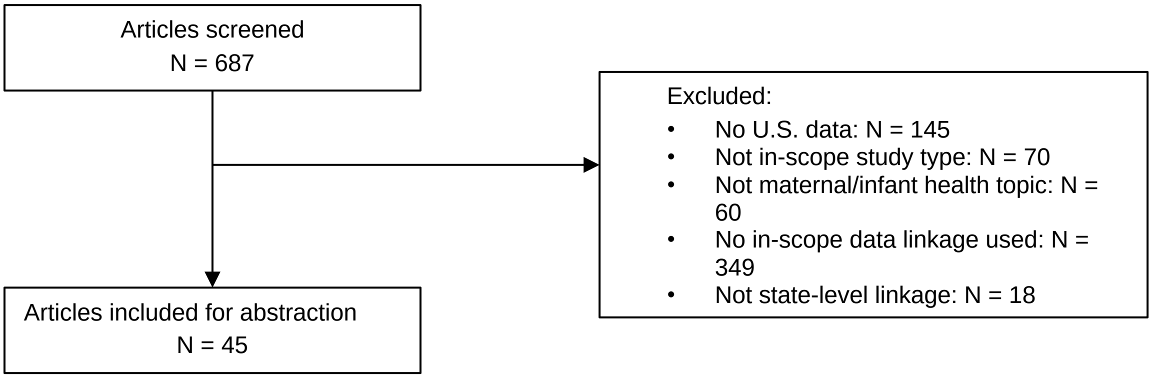
NOTE: DOB = date of birth; EHR = electronic health record; EMR = electronic medical record.

Results

Screening Results

A total of 687 articles were identified in the literature search (Figure 2.1). After screening, 45 articles were found to meet all inclusion criteria and were retained for abstraction. The most common reason for exclusion was that no in-scope data linkage was used (N = 348). The 45 included studies can be found along with their corresponding state in the Appendix.

Figure 2.1. Article Screening Results



NOTE: Exclusion criteria were applied sequentially in the order shown (e.g., an article that did not use U.S. data was not further evaluated for additional exclusion criteria)

Characteristics of Linked Data

The 45 included studies used data from 22 different states. Four studies used data from multiple states, including one study that used data from three unspecified states (Clemans-Cope et al., 2019). Oregon was the most frequently represented state in the literature with six studies, followed by Massachusetts, South Carolina, and Wisconsin, each with five studies, and Missouri, Ohio, and Tennessee, each with three studies. States used data from 2000–2019, with most studies using data from 2015 or earlier.

Additional characteristics of linked data are shown in

Table 2.4. Most studies (93.3 percent) linked only Medicaid data to other data sets, though we did identify three studies that used APCD data. Studies linked claims to many different types of data sets, and claims were often linked to multiple data sets in the same study.

Birth certificate data were the most common type of other data linked with claims data and were included in 75.6 percent of studies. Other data sets that were commonly linked to claims were social services (15.6 percent of studies), maternal or infant death certificates (13.3 percent of studies), state maternal health program enrollment (8.9 percent of studies), EHRs or HIEs (8.9 percent of studies), registries, such as birth defect or cancer (6.7 percent of studies), and hospital discharge (6.7 percent of studies).

Social services data were linked with Medicaid data in some studies we reviewed because Medicaid enrollees are often eligible for and utilize social services, and use of these services may have important implications for maternal and infant health. Examples of social services data linked in the studies we reviewed were child protective services data in Washington (Arthur et al., 2018) and Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) data in South Carolina (Bersak and Sonchak, 2018). Many states have large maternal and child health (MCH) programs that provide supplemental, targeted care to high-risk mothers and infants. We found studies that linked Medicaid claims, birth certificates, and enrollment data for these types of programs, such as the Ohio Infant Mortality Reduction Initiative (Swoboda et al., 2018), the University of Arkansas telemedicine program for high-risk pregnant women (Sung et al., 2021), and the Michigan Maternal and Infant Health Program (Raffo et al., 2021). Finally, we noted many other examples of infrequently linked data, including from PRAMS, criminal justice, PDMP, and education.

We also examined whether mother and infant claims were linked to each other, in addition to being linked to an outside data source. Mother and infant claims data can usually be linked through a Medicaid family identifier in combination with infant date of birth and mother delivery codes (Palmsten, Huybrechts, et al., 2013). Claims data provide richer longitudinal data on mother and infant diagnoses and service use than are provided on birth certificate data, but mother-infant claims linkages introduce an additional potential source of error (e.g., if mother and infant are mismatched), may reduce cohort size given that not all infants will match to a mother (and vice-versa), and potentially introduce selection bias if linked individuals are different from unlinked individuals (Palmsten, Huybrechts, et al., 2013). Because birth certificates provide some data on both maternal and infant health, researchers may choose to link this data source with only maternal claims or only infant claims, depending on their specific research questions. We found that 44.4 percent of studies used linked mother and infant claims (N = 20), 40.0 percent did not link mother and infant claims (N = 18), and the remaining 15.6 percent did not provide enough information about the data used to determine whether linked mother and infant claims were used (N = 7).

Table 2.4. Characteristics of Linked Data (N = 45 studies)

Data Characteristic	Number of Studies (%)
Claims data set linked	
Medicaid	42 (93.3)
All-payer claims (including Medicaid)	3 (6.7)
Other data sets linked to claims[a]	
Birth certificates	34 (75.6)
Social services data	7 (15.6)
Death certificates	6 (13.3)
State MCH program enrollment	4 (8.9)
EHR/HIE data	4 (8.9)
Registries	3 (6.7)
Hospital discharge data	3 (6.7)
Other	7 (15.6)
Mother and infant claims linked	
Yes	20 (44.4)
No	18 (40.0)
Unable to ascertain	7 (15.6)

[a] The sum of frequencies exceeds 100 percent because some studies linked claims to multiple types of data sets.

Processes for Linking Data Sets

Details of the linkage processes used in studies are detailed in Table 2.5. Just over half of studies specified a linkage type. Fifteen studies (33.3 percent) used deterministic linkage only, three studies (6.7 percent) used probabilistic matching only, and seven (15.6 percent) used both (e.g., used deterministic linkage to link two data sets and then probabilistic to link an additional data set or used staged linkages to link two data sets). Some studies also used an additional step of manually reviewing probabilistic matches. Child date of birth was the most commonly used linkage variable (28.9 percent of studies), followed by mother's date of birth (24.4 percent), name (31.1 percent), geographic identifiers (13.0 percent), and mother's Social Security number (13.3 percent). Names often included close matches, such as closely spelled or sounded names, and could include infant names. Examples of geographic identifiers used were county, zip code, and address. Other variables used in linkages included race, provider number, and telephone number.

Most studies (53.3 percent) did not specify a match rate, defined as the percentage of individuals from one data set matched to individuals in another data set. Interpreting match rates is highly dependent on the specific type of match, and low rates may be acceptable in some contexts. For example, a study by Sung et al. (2021) examined linkages between maternal Medicaid claims for delivery and birth certificates, as well as between Medicaid claims for pregnancies and birth certificates. Including pregnancy claims instead of just delivery claims can increase the percentage of birth certificates that are matched to maternal claims but will result in a lower percentage of maternal claims matched to birth certificates because some of these pregnancies will result in miscarriage or early termination and will not generate a birth certificate. Examples of match rates reported in included studies were 42.6 percent of all birth certificates (not just for Medicaid births) linked to a maternal Medicaid delivery claim (Mallinson and Ehrenthal, 2019) and 96.1 percent of maternal Medicaid enrollment records matched to a birth certificate (Luck et al., 2020). Only four of the studies reviewed mentioned any type of validation study (e.g., manually reviewing a sample of matches for accuracy), and none of the studies provided results of the validation exercises.

Table 2.5. Details on Linkage Process (N = 45 studies)

Linkage Characteristic	Number of Studies (%)
Types of linkages used	
Deterministic only	15 (33.3)
Probabilistic only	3 (6.7)
Both	7 (15.6)
Not specified	20 (44.4)
Variables used in linkages[a]	
Child date of birth	13 (28.9)
Mother date of birth	11 (24.4)
Delivery date	3 (6.7)
Child Social Security number	4 (8.9)
Mother Social Security number	6 (13.3)
Mother and/or child name	14 (31.1)
Health record or enrollment number	4 (8.9)
Geographic identifier	6 (13.3)
Other	4 (8.9)
Not specified	20 (44.4)
Match rate	
At least one match rate provided	21 (46.7)
No match rate specified	24 (53.3)
Validation analyses	
Analyses described	4 (8.9)
No analyses described	41 (91.1)

[a] The sum of frequencies exceeds 100 percent because some studies linked claims to multiple types of data sets.

Topics Studied Using Linked Data

Studies examined a wide range of maternal risk factors, service utilization, policies, MCH outcomes, and health disparities (Table 2.6).

The most commonly examined maternal risk factor was substance use during pregnancy (40.0 percent of studies), followed by diabetes and hypertension (each 20.0 percent of studies). Examples of other maternal risk factors examined were asthma, prescription medication exposure during pregnancy, and anxiety or depression diagnosed during pregnancy.

The most commonly examined service or policy was prenatal care or other pregnancy-related service use (46.7 percent of studies), social service use (11.1 percent of studies), and Medicaid expansion (8.9 percent of studies). Examples of other services or policy changes were care coordination programs, postpartum contraceptive use, and type of Medicaid (e.g., managed care versus fee-for-service).

The most commonly examined mother and infant health outcomes examined were delivery complications (17.8 percent of studies), followed by preterm birth or low birth weight (13.3 percent) and infant mortality (11.1 percent). Examples of other mother and infant health outcomes were birth defects and miscarriage.

Most studies examined differences in MCH service use and/or health outcomes by race and ethnicity (82.2 percent and 71.1 percent, respectively), and nearly half of studies (42.2 percent) examined differences by urban or rural residence.

One example of a study that examined the relationship between a maternal risk factor and infant outcomes looked at the association between maternal opioid use during pregnancy and congenital malformations (Wen et al., 2021). In this study, the authors identified a dose-dependent relationship between maternal prescription opioid use during the third trimester and birth defects in the musculoskeletal system (Wen et al., 2021). An example of a study that examined the effect of a policy on infant outcomes looked at the effect of WIC participation on birth outcomes (Chorniy, Currie, and Sonchak, 2020). The study found that participation of pregnant women in the program decreased risk of low birthweight for babies and that these decreases were larger among African American women than among non-Hispanic White women (Chorniy, Currie, and Sonchak, 2020).

Table 2.6. Applications of Linked Data (N = 45 studies)

Topic Examined[a]	Number of Studies (%)
Maternal risk factors	
Substance use	18 (40.0)
Diabetes	9 (20.0)
Hypertension	9 (20.0)
Other	7 (15.6)
Service utilization or policy change	
Prenatal care or other pregnancy-related service use	21 (46.7)
Medicaid expansion	4 (8.9)
Social services use	5 (11.1)
Other	15 (33.3)
Mother and infant health outcomes	
Infant mortality	5 (11.1)
Preterm birth or low birth weight	6 (13.3)
Neonatal abstinence syndrome	4 (8.9)
Delivery complications	8 (17.8)
Breastfeeding	3 (6.7)
Other	8 (17.8)
Health disparities	
Race	37 (82.2)
Ethnicity	32 (71.1)
Rurality	19 (42.2)
Education	4 (8.9)

[a] The sum of frequencies exceeds 100 percent in some cases because some studies investigated multiple health topics and disparities.

Challenges and Researcher Access

We collected information on challenges noted related to data linkage in each of the studies. Surprisingly, only 13 studies (28.9 percent) explicitly discussed linkage challenges. Incomplete data was the most commonly discussed challenge. For example, one study noted that delivery claims were often missing from Medicaid managed care plans (Lynch et al., 2021).

Other researchers noted that missing data on variables used for linkages was a major limitation. These included missing unique identifiers, such as Social Security number, used for deterministic linkages, and missing demographic variables, such as race, used in combination with other variables for probabilistic linkages (Whitmore et al., 2021). Other challenges noted were a lack of continuous Medicaid enrollment and patient migration, which can censor longitudinal data, and lag time in the availability of data, which prevents acting on timely and relevant information.

The lag time in data availability and time needed for the peer-review publishing process may also have been why most studies used data prior to 2015. Similarly, few studies provided information on how researchers not on the study team might access data. While most articles provided general information about the source of the data (often a state agency or a contractor of a state agency), information about data use agreements, contact information for obtaining data, or data application processes were rarely provided. However, author affiliations provided some insight into how data may have been accessed. In particular, we noted that 12 studies (26.7 percent) included at least one author from a state government, which may have facilitated the study team's access to data. Additionally, 42 studies (93.3 percent) included at least one author from an academic institution, six studies (13.3 percent) included at least one author from the federal government, and 19 studies (42.2 percent) included at least one author with another type of affiliation, such as a health system, commercial data provider, insurance company, or nonacademic research institution. Statements about the availability of programming code for performing linkages were also rarely available.

Summary

We examined peer-reviewed studies published from 2017 to 2022 and identified 45 studies that used state Medicaid claims linked with other data sources to conduct maternal and infant health research. Of note, most studies examined disparities in risk factors, service utilization, or health outcomes by race and ethnicity.

Historically, Medicaid claims—and other types of health care claims data—have suffered from high rates of missing race and ethnicity data (Polubriaginof et al., 2019; Li et al., 2018). Linking claims with birth certificate data can help to reduce missingness in race and ethnicity data and may allow for a more robust study of maternal and infant health disparities (Smith et al., 2010).

Studies used data from many different states and examined a wide range of MCH topics. In general, studies often lacked sufficient details on the matching process for outside researchers to replicate. While most studies provided basic information on years of data, data sets used, and variables used in linkages, less than half of studies specified a match rate and even fewer reported results of validation exercises. Very few studies explicitly discussed linkage challenges or provided information on how researchers outside state governments could access linked data.

These results point to opportunities to better document data linkage methods and develop academic and state government partnerships to conduct maternal and infant health research with linked data. These opportunities will be explored further in Chapter 4, which reports on semistructured group discussions with relevant state representatives.

Chapter 3. Inventory of State and Territory Linkage Efforts

We compiled an inventory of linkage efforts by state and territory to assess the landscape of linkages nationally. We then used this inventory to ascertain patterns in the data sources used in these linkages, as well as to note any challenges in establishing or maintaining linkages and identify states for inclusion in group discussions (Chapter 4).

Methods

Many state agencies have performed linkages between Medicaid claims, birth certificates, and other data sources. However, these states may not always have the time or resources to publish their efforts in the peer-reviewed literature. Thus, in the next phase of the project, we conducted a search of state agency websites for all 50 states, eight U.S. territories, and the District of Columbia (hereafter referred to as *jurisdictions*) to identify additional information not found in the peer-reviewed literature.

Two researchers conducted searches of each jurisdiction's Medicaid agency, vital records and statistics, and health department websites using the linkage and data terms described in Table 2.1. The team also conducted targeted searches of state APCD websites, where they existed, to identify whether Medicaid claims in the APCD had ever been linked with vital records or other data sources.

We also note that Health Resources & Services Administration (HRSA) Title V MCH Services Block Grants are a key source of federal funding provided to each jurisdiction annually. The primary goal of these grants is to provide funding for MCH services, but these grants also support state MCH data linkage efforts. Thus, we also reviewed each state's MCH Title V Block Grant Fiscal Year 2022 Application/2020 Annual Report (hereafter *Title V MCH Report*) for names and descriptions of potential linkage activities (U.S. Department of Health and Human Services [HHS], 2020). This was the most recent Title V MCH Report available at the time of review and the first yearly report for which information on data linkages was systematically reported by grantees through a required form ("Form 12"). In previous annual reports, several states voluntarily provided information on linkage efforts in narrative form. When vital records were indicated as being linked to Medicaid on Form 12, we considered the state to have an in-state linkage, even if additional details on the linkage were not available in the report or elsewhere in our search. Where states did not report linking Medicaid and birth certificate data on Form 12 in their 2020 Title V MCH Report, we reviewed reports from 2017–2019 to determine whether data linkage efforts were previously reported. We also closely examined information from the Title V MCH Report on State Systems Development Initiatives (SSDI), which are HRSA grants that provide funding to "develop, enhance, and expand state and jurisdictional Title V MCH data capacity for its needs assessment and performance measure reporting" (HRSA, 2017). HRSA publishes annual snapshots of states that have linked Medicaid claims to birth records, and we used the 2020 annual snapshot to validate our desk research efforts and ensure we captured all relevant HRSA-funded efforts (HRSA, 2021).

As in the review of peer-reviewed literature in Chapter 2, we abstracted information on several predetermined categories developed in consultation with ASPE on in-scope linkages for each jurisdiction. Linkages were considered in-scope using similar criteria as for the peer-reviewed literature: Linkages had to involve individually linking Medicaid or APCD (inclusive of Medicaid) claims with birth certificates or other data sources. When an in-scope linkage was identified for a specific jurisdiction, we abstracted information on types of data linked to Medicaid claims, years of data linked, frequency of linkages, linkage type (probabilistic, deterministic, or both), fields used to create linkages, applications of linked data to MCH research, availability of data to researchers, linkage challenges noted, and plans to link additional data in the future. Potentially relevant key informants for the group discussions (Chapter 4) were also noted for states of interest. When no in-scope linkages were found, researchers recorded a brief free-text summary of other types of linkage efforts (e.g., linking birth certificate and hospital discharge data) but did not abstract any further information.

Results

Characteristics of Linked Data and Information on Linkage Process

We identified several in-scope linkages through our searches of Title V Reports and state agency websites. The characteristics of linked data are summarized in Table 3.1, and a full inventory of each jurisdiction's linkage efforts is provided in the Appendix.

In total, these searches identified 33 jurisdictions with in-scope data linkage efforts (excludes peer-reviewed literature). Jurisdictions linked Medicaid claims to a variety of different data sources, which are detailed in the Appendix. All in-scope data linkage efforts involved linking Medicaid claims to birth certificates, with the exception of Maryland, which does not link Medicaid claims to birth certificates but links Medicaid claims with EHRs, PDMP, and other data sources (Maryland Health Care Commission, 2022). We also noted that 14 articles from the peer-reviewed literature were from six states that did not have publicly available information on current, in-scope state-level data linkage efforts (California, Florida, Missouri, New Jersey, South Carolina, Tennessee). Some of these articles used older data, while others may have linked data solely for a specific research project. These articles are listed under their corresponding state in the Appendix. In total, 39 jurisdictions had in-scope data linkage efforts when considering both the peer-reviewed and gray literature.

When considering only the 33 jurisdictions identified through Title V Reports and state agency websites, 28 (47.4 percent) jurisdictions mentioned a Medicaid–to–birth record linkage in their Title V MCH Reports. Five jurisdictions (two of which did not have an in-scope linkage noted in the Title V MCH Report) mentioned an APCD (inclusive of Medicaid claims)–to–vital record linkage. We also noted four jurisdictions with separate in-scope linkages not described in the Title V MCH report (two of which had no in-scope linkages described in the Title V MCH report) (Table 3.1).

Other commonly reported linked data sets included death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data. Examples of other not-so-common sources of data linked to Medicaid claims included child welfare drug affected infant reports, child maltreatment reports, coronavirus disease 2019 (COVID-19) contact tracing, and Behavioral Risk Factor Surveillance System (BRFSS) data.

Although it was a key resource for this inventory, we noted that the structured data on the 2020 Title V MCH Report sometimes has contradicting information about linkages. For example, Montana noted no vital records–to–Medicaid linkage in Form 12 but described a current data linkage between vital records and Medicaid claims in its fiscal year 2022 application, possibly indicating that the data linkage effort began after 2020 or is not finalized. By contrast, Arkansas's Form 12 noted linkage between vital records and Medicaid, but elsewhere in the report noted that vital records were linked only with aggregated Medicaid data, indicating an out-of-scope linkage for the report. We also noted one state (Illinois) that reported linking vital records to Medicaid claims on Form 12, but communications with multiple state representatives indicated that Illinois does not conduct these linkages at the state level. It is possible that the question about data linkages was interpreted differently by Title V representatives (e.g., linkages were conducted for a smaller cohort of women receiving Title V services). If a vital record–to–Medicaid linkage was noted anywhere in the Title V MCH report, we erred on the side of inclusion but noted the conflicting information in the Appendix. Examining Title V MCH reports from 2017–2019 for states without an in-scope linkage noted in 2020 did not yield any additional in-scope linkages. However, we did find that a few states noted plans in their 2017–2019 reports to link Medicaid data with birth certificates and other data sources in the future, sometimes noting these plans for several reports in a row. These details are included in the Appendix.

In general, we found limited publicly available information on linkage details in the Title V MCH Report. However, we did find information on linkages from some jurisdictions, mostly outside of Title V MCH Reports and more commonly for the APCD or other linkage efforts. Of the 33 jurisdictions (excluding peer-reviewed articles) that had in-scope linkages, 11 had information on years of linked data, four had information on linkage type, and four had information on the match rate.

Table 3.1. Characteristics of Linked Data and Details on Linkage Process

Data Characteristic	Number (%)
Claims linkage types[a]	N = 59 total jurisdictions
Medicaid in-scope linkages (reported in Title V MCH Report)[b]	28 (47.4)
APCD in-scope linkages	5 (8.5)
Other in-scope linkages not reported in Title V MCH Report	4 (5.1)
Data used in peer-reviewed article	22 (37.3)
No in-scope linkages identified	20 (33.9)
Details of in-scope linkage available[a]	N = 33 jurisdictions with in-scope linkage (excluding peer-reviewed articles)
Years of linked data	11 (33.3)
Linkage type (probabilistic, deterministic, both)	4 (12.1)
Fields used to create linkages	4 (12.1)
Match rate	4 (12.1)

[a] The sum of percentages may exceed 100 because states' categories are not mutually exclusive.

[b] All in-scope linkages except for Maryland's involved linking Medicaid claims with birth certificate data.

Applications of Linked Data

In the Title V MCH Reports, states generally noted only that linked data were used for reporting MCH metrics and MCH monitoring, without providing more detail. However, some states provided specific examples of how they used Medicaid data linked with other sources. For example, Iowa's Title V MCH Report noted that linked data have been used to evaluate access to prenatal care, tobacco use, and postpartum contraceptive access (HHS, 2020). Utah's Title V MCH Report noted that its linked data were used to assess prenatal care delivery, maternal morbidities, and birth outcomes (HHS, 2020). Another data linkage effort not included in the Title V MCH Report detailed how linked data were used to analyze rates of prenatal care, maternal risk factors such as diabetes and hypertension, and newborn outcomes, such as preterm birth and rates of neonatal abstinence syndrome (NAS) (Colorado Department of Health Care Policy and Financing, 2019).

Challenges, Researcher Access, and Jurisdictions' Future Plans

Each Title V MCH Report includes information on challenges faced by the MCH program during the reporting period. The challenges discussed in these reports were usually not specific to data linkages; however, there were common themes noted with potential implications for data linkages. Several states noted staff turnover and lack of staff expertise needed to develop and maintain data infrastructure to create or maintain linkages as salient challenges. The COVID-19 pandemic was also cited as diverting resources from MCH activities. For example, Hawaii noted that it would not pursue plans to link additional data sets to birth certificates because of lack of staff and COVID-19 related priorities (HHS, 2020).

Another common challenge noted was difficulty obtaining interagency access to data, even within the same state. For example, Kentucky's Title V MCH Report noted that state programs are often siloed but that the creation of a program support branch within the division has helped mitigate this challenge and facilitate interagency data access (HHS, 2020).

One challenge specific to data linkage was noted by the Arkansas APCD, maintained by the Arkansas Center for Health Improvement. While some APCDs are able to link to birth certificates using Social Security number, the Arkansas APCD does not have this information and deterministically links enrollees using a combination of last name, date of birth, and sex (Arkansas Healthcare Transparency Initiative, 2022). Given that this is not a unique combination within a state, multiple individuals in a state may have the same identifier. Conversely, those with name changes may have multiple identifiers within the system (Arkansas Healthcare Transparency Initiative, 2022).

Overall, most state linkage efforts we identified were focused on internal use of linked data by state government users for the purposes of Title V MCH block grant activities. Most states did not provide publicly available information on access to linked data for researchers not affiliated with the state government. However, a few states did provide this information. In general, APCDs tended to have more-transparent processes for researchers obtaining access to linked data than did state health departments or other state agencies. For example, the Oregon and Vermont APCDs provided detailed information on available data, access procedures, purchase cost, and acceptable data use (Oregon Health Authority, 2022; Vermont Green Mountain Care Board, 2018).

Several Title V MCH Reports noted plans to improve data infrastructure, including linking Medicaid and birth certificate data. For example, Connecticut noted that it had linked Medicaid and birth certificate data prior to 2012 but then lost funding to perform the linkages and is currently working to obtain new interagency agreements to resume these linkages (HHS, 2020). Another example of future plans to link Medicaid claims with other data is the California Health and Human Services Agency (CHHS) Research Reconciliation and Research Data Hub (Children's Data Network, 2020). This data hub is not yet available but will eventually link California Medicaid claims with a wide range of vital statistics and social services data.

Summary

We identified 39 out of 59 jurisdictions with any in-scope linkages across the peer-reviewed literature, Title V MCH Reports, state APCDs, and other web data sources. This includes 33 jurisdictions with current, in-scope linkages identified through Title V MCH Reports, state APCDs, and other web data sources and six states where linkages were identified only in the peer-reviewed literature. Jurisdictions are linking a wide variety of data sets, and several more plan to link additional data in the future. We also noted several recent efforts to develop more-centralized data repositories linking APCD data with birth certificates and other sources of data. APCD data sets tended to have more public-facing documentation on linkages and information about access for researchers as compared with other sources of linked data. Common challenges noted were obtaining access to data across agencies or departments within a state and finding time and resources to improve data infrastructure. Technical and legal barriers to linking data were not as commonly discussed but will be explored further in the Chapter 4 group discussions.

Chapter 4. Semistructured Group Discussions

We conducted in-depth discussions with representatives from states that had implemented linkages to help put the results of the structured literature review and inventory in context and better understand the origins of these linkages, the linkage methods used, and any barriers or facilitators that states had encountered while developing or maintaining linkages.

Methods

We conducted nine semistructured group discussions with representatives responsible for creating, maintaining, and using Medicaid claims linked with birth certificates and other data sources. Each discussion focused on a single state and included one or more representatives from that state. We identified states for inclusion according to the results of the literature review. To be eligible for a group discussion, the state needed to link Medicaid claims with birth certificates or other data sources and have more than 50,000 live births in 2020 (National Center for Health Statistics, 2021). We sought to include states of varying population sizes from all regions of the country. We recruited participants via email using publicly available information about who was responsible for a linkage in a state, including state registrars, Medicaid directors, contacts in MCH departments, SSDI coordinators, and authors from papers in our literature review. We also followed up via phone with states that did not respond to emails. In email exchanges with state representatives, we identified the appropriate participants for each discussion.

We developed a semistructured discussion guide that included questions about the technical specifications of the linkage; the origins of the linkage; the uses of the data for research, policy, and practice; any barriers to implementation; and any future plans for data linkages. The guide was informed by findings from the literature review and input from an ASPE-led technical expert panel and was focused on linkages between Medicaid and birth certificate data, though probes allowed us to capture other data sources linked to Medicaid claims that states had implemented. Discussions were conducted via videoconference using zoom.gov and typically lasted one hour. Discussions were recorded, transcribed, and analyzed using a conventional content analysis approach in Dedoose. Participants provided oral consent to participate and be recorded. These discussions were deemed exempt from human subjects review by the RAND Human Subjects Protection Committee.

Results

States That Participated in Discussions

Between May and July 2022, we held semistructured group discussions with representatives from the following states: California, Colorado, Louisiana, Kentucky, Maryland, Michigan, New York, North Carolina, and Ohio. A summary of the states we did and did not speak with is included in Table 3.1.

Table 3.1. State Participation in Group Discussions, by Literature Review Findings Category

Literature Review Findings Category	States Included in Group Discussions	States Not Included in Group Discussions
Peer-reviewed literature only	N/A	FL, NJ, MO, TN, SC
Gray literature only	MD, KY	AK, AR, DE, KS, MN, MS, MT, NE, NV, OK, PR, UT, WA
Both peer-reviewed and gray literature	CA, CO, LA, MI, NY, NC, OH	IA, IL, IN, MA, ME, NH, OR, RI, TX, VT, WA, WI
No linkage noted	N/A	AS, AL, AZ, CT, DC, FM, GA, GU, HI, ID, MI, NM, ND, MP, PW, PA, SD, VI, VA, WY

The number of participants from each state ranged from two to seven. Participants in discussions varied by state but included staff from state Medicaid agencies (e.g., directors, evaluation leads, analysts), vital records agencies (e.g., directors, managers), MCH divisions (e.g., epidemiologists, SSDI program coordinators), public health departments (e.g., managers of housing services, directors of social services), and APCDs (e.g., directors, project managers). In some discussions, we also included researchers who had used the linked data (both inside and outside the state government) and contractors responsible for linking the data.

Origins of Linkage Efforts

Many of the linkage efforts originated from the need to answer a single research question or evaluate an existing program or pilot initiatives and had grown since then. The need or desire to look at birth, prenatal, or neonatal outcomes of Medicaid populations often drove partnerships between vital records agencies and either departments of public health or health care financing.

> Some state efforts to link Medicaid claims and birth certificates were very recent endeavors, while others date back nearly 40 years; one state that we spoke with had been linking Medicaid claims and birth certificates since 1985, and another had just started in 2017.

One participant stated,

> a common problem such as severe maternal morbidity or mortality can force those agencies to work more cooperatively.

Using the linked data to answer a motivating research question, such as determining the prevalence of NAS, often demonstrated the value of linking data, built interest from other agencies, and led to added capacity, allowing linkages to be conducted more frequently and with different data sources.

The COVID-19 pandemic was also cited by some states as a motivation for an increased emphasis on data linkages. These linkages also tended to expand beyond their initial scope. Once health departments began using claims linked with birth certificates for a specific purpose, states began viewing linked data as having other uses for public health and started incorporating additional data sources (e.g., immunization data, WIC program data).

A handful of states described their linkages between Medicaid and birth certificates as originating from statewide initiatives to build data warehouses or other large databases that could be used across the state government to conduct research, evaluate programs, and inform policy.

Data Linked

States predominantly linked Medicaid claims with birth and death certificates. Some states linked Medicaid claims to EHRs, hospital discharge data, social services (e.g., WIC program participation) data, and other data sources and registries as needed. Some states also linked Medicaid claims with immunization records, data from the PRAMS, admission/discharge/transfer (ADT) messages from hospitals, HIEs, and state-specific pregnancy intake forms or surveys. A handful of states linked data through an APCD, so birth certificates would be linked to claims from all payers, not just Medicaid. Michigan also linked Medicaid data with housing and homelessness data, as well as education data, through its data warehouse. Ohio linked with foster children records in the state child welfare system and prison data from its Department of Rehabilitation and Corrections.

Apart from birth certificates, linking Medicaid data with death certificates was also a common data linkage; it has been used to support COVID-19 surveillance, study opioid use disorder, and construct a 30-day mortality measure for hospital regulation. In states with a robust HIE in which health care providers can securely share patient health information, the HIE sometimes served as the basis for the linkage, especially if the HIE used a master patient index (MPI) to link data. An MPI, also known as a client or patient registry, is a centralized database for individual-level health information linked to an individual patient. One participant with experience linking data in multiple states summed this up:

> In most states where there’s significant health data involved in the cross-sector integration effort, the HIE is a key player. So, there are some states where these efforts are more closely aligned to the HIE’s data backbone and other places where the HIE is one partner who’s maybe contributing an extract for certain projects.

In states with an established MPI, demographic information, immunization history, and hospital records can be linked for targeted outreach and analysis. MPIs have helped states transition from ad-hoc linkage efforts to silo-breaking partnerships.

Several states recommended that linkages should be done separately for both infants and mothers (in addition to linkage for a maternal/infant dyad), as some infants, especially those who die in the perinatal period, may never be enrolled in Medicaid.

Data Stewardship and Ownership

Most states conduct their linkages within a specific state agency—usually the agency responsible for MCH or the Medicaid agency. A few of the states subcontracted the linkage to a local university or government contractor. Leaders shared their pride in developing interest and capacity within state agencies, with one describing the in-house expertise as “a luxury.” Expertise varied not only at state vital statistics and public health agencies but also at Medicaid agencies, some of which have data scientists on staff who develop their own analysis plans while others are limited to producing state-mandated reports and reports for federal funding. In those states with advanced capacity for analysis, other state agencies often request detailed linked data for analyses. One discussion participant explained the need for processes to balance these potentially overwhelming requests:

> And having processes set up, not just to do the routine pieces but where, for instance, a specific question comes up either internally or externally, or a research need, a formal research need, having mechanisms in place to facilitate those, I think, is critical as well to ensuring success of this type of work.

Linkage Process

Linkage Methods

States were evenly divided between those that used probabilistic and those that used deterministic methods:

1. The deterministic approach was successful for state agencies that have access to a Social Security number of the child and mother, birth certificate, and Medicaid file, and can attempt a one-to-one match.
2. The flexibility associated with the probabilistic approach was the major reason states cited for using it; one participant noted that match rates improved after they transitioned away from a deterministic methodology.

Many states used a combination of deterministic and probabilistic approaches to matching records.

States varied in how frequently they ran linkages (e.g., annually, quarterly, monthly). States that linked additional data, including immunization records, sometimes linked their data daily. Time frames varied by necessity, data availability, staff resources, stakeholder data use agreements (DUAs), and funding. In states where the process is largely automated, matches can be done in almost real time, whereas others find it to be a significant effort that can be undertaken only annually. Additionally, many states made use of a preliminary linked file to begin unofficially using the data (e.g., for research, for program evaluation) based on initial Medicaid and birth certificate data; once those data sets are finalized for a year (typically between six and nine months later), the final linked file can be created and used for official purposes.

Software and Tools

Most states used off-the-shelf software, such as Link Pro (LinkPro Technologies Inc., 2021) or Link Plus (Centers for Disease Control and Prevention, 2022), that allows states to easily deploy a pre-built linkage algorithm, but some performed custom analysis using statistical analysis software, such as SAS. California developed an open-source algorithm that it has promoted for different states to do their own linkages. This open-source probabilistic linkage algorithm incorporates machine learning to iteratively validate findings (Foust et al., 2021).

Some states use MPIs to manage and link clients across services and data sets. Two states that used MPIs used the IBM Initiate product, and one used IDQ from Informatica to manage their MPIs.

Variables Used for Linkage

Matching mother and/or child Medicaid claims with birth certificate data typically involves the mother’s and/or child’s name, date of birth, and Social Security number where available. Many participants described complications with matching on the mother’s name, including the use of a maiden name versus a married name, the presence of a middle name, and the use of nicknames or other abbreviations. Most states used the mother’s and/or child’s date of birth, and only a few cited problems, with one saying that, for some mothers, a missing date of birth in claims data was sometimes coded as January 1. Social Security number was used by about half of the states. When Social Security number was available, it was described as a key variable for deterministic linkages and a variable with a lot of weight for probabilistic ones. However, some states cited state laws that prevented Social Security numbers from being used in the matching process, and others had large numbers of noncitizen mothers who did not have Social Security numbers. Colorado included a mother’s Medicaid ID number on the birth certificate, which greatly increased match rates. A few states used race and ethnicity data for linkage, though discussion participants noted that race and ethnicity data were not often collected reliably, as some data sources included self-reported race, while others had physician or administrator assessment of a person’s race. Some used child sex for matching as well but noted that it provided only a marginal benefit when added to more powerful variables, such as name and date of birth.

Other variables often used for the manual review after the probabilistic match included addresses, county of residence, and phone number.

Linked Data Quality and Validation

Participants noted that linked data sets were of generally high quality and were relatively complete. However, some issues were highlighted by respondents. Some participants mentioned data quality issues. For example, sometimes Medicaid claims for the newborn were billed under the mother's Medicaid ID number; as one participant explained,

> Mom has a clear record and a [Medicaid] number, baby gets born, baby doesn't necessarily get a Medicaid identifier right away, so some of baby's services get billed under mom's number. So doing that linkage for the baby can be more problematic.

This can be challenging if the linkage program relies on using a delivery date from infant claims to link to the birth date on the birth certificate and the claim is associated with the mother instead of the infant. Cases of adoption and foster care, in which the woman who gave birth may not be listed as the mother on the birth certificate, also complicated the linking process.

States reported match rates varying from 65 percent to 99 percent, though most states reported match rates over 90 percent. Some states noted that there are several different ways to calculate a match rate, including which population is used as the denominator (e.g., percentage of mother's Medicaid delivery claims matched to a birth certificate). As noted in the literature review section, depending on the uses of the linked data, a lower match rate may be acceptable in certain contexts.

Participants from one state noted that in counties on the state border, mothers were more likely to give birth in neighboring states. This meant that while the state had the Medicaid claims for those mothers, the state was missing the birth certificate information for those children.

Using last names as a linking variable has been particularly challenging because of naming and spelling conventions that differ from English (e.g., Slavic languages, Spanish naming customs) and data entry errors. Louisiana uses not only the first and last name but also the pronunciation to counteract potential spelling errors.

Most states using a probabilistic approach automatically matched records with a probability higher than a set cutoff score and have some sort of manual review for those close to the cutoff score to resolve any errors and review potential matches. To improve performance, North Carolina switched to a probabilistic method and had two staff members review the findings to confirm whether matches scoring just below a cutoff were legitimate. However, for states with large numbers of annual births or large data warehouses with millions of records, the time burden associated with manual review of near matches was prohibitive. One participant explained the need for this manual validation:

> Twins with similar first names can be really challenging because they have the same address, the same birthday, and very similar names, and so we have a team that's reviewing—kind of running data quality checks and reviewing that and trying to merge or split individuals as appropriate to make sure that the data integrity stays high.

Outputs

The most common use of the linked data was to look at pregnancy and birth outcomes across the state, usually at the county or other regional level. Most states described using these data to inform state Medicaid policy and MCH policy. Linked data inform disparities analyses, public health programming, policy and budget discussions, and other use cases. Specific topics covered included birth outcomes, preterm birth monitoring, opioid use, and COVID-19–related questions. For example, one state respondent indicated having used the linked data

> to assess the WIC program as well to see if there were differential outcomes for WIC participants, particularly Medicaid cost related. It's also used by the Medicaid program just in general to gauge things like low birth weight, infant mortality, prenatal care received.

In one state where analyses using linked data had recently been presented as part of a public report on maternal and infant health outcomes, one participant described

> using this data to drive requests. It's always a tender balancing act to ask for expensive items but having this kind of report gives us the leverage to do that. So we are working on some bigger requests that we have to wait for our budget process to talk through, but that have been heavily informed by this report, and are really giving us the leverage to ask for things that I don't think we could've asked for two years ago.

Only a few states used linked data sets for individual outreach to patients; Louisiana used the linked data to offer women with previous preterm births additional services during pregnancy. Maryland used the linked claims data set to reach out to individuals who had not completed COVID-19 vaccination (not specific to MCH but accomplished using linked claims). Linking specific ICD-10 codes has also strengthened surveillance of birth defects and facilitated enrollment into state MCH programs.

External Partnerships

All states had a process to allow external researchers to access the linked data, almost always requiring sign-off from each department contributing data to the linked data set that the researcher had requested. This process typically involved an external researcher submitting a detailed proposal describing what data were needed, what analyses were planned, and the desired outputs (e.g., peer-reviewed publications). These proposals were then typically routed through multiple approvals within the state government, including by the data owners and often an institutional review board (IRB) in the state government.

Three states reported having public portals where interested researchers could submit data requests and download certain public data files.

State protocols for data access varied. California has developed an interoperable data hub for which linkage keys could be issued to allow analysts to study the data in a closed environment.

Some states may have more stringent DUA processes, such as Colorado, where data requests require review and approval by the Colorado Department of Health Services, IRB, and the Vital Statistics Advisory Committee can take up to four months. The urgent need for COVID-19 surveillance and immunization data expedited linkages and partnerships in states including Maryland, where the portal expanded from "the core hospital HIE to being more of a kind of a public health data utility." For external researchers, having an existing relationship with the data owners in state government and having conversations about how to submit data requests can also expedite approval of IRB requests. However, despite all states offering access, not all states had successfully shared data with external researchers.

Facilitators

The most commonly cited facilitator for creating and maintaining Medicaid data linked to other sources was having strong relationships between staff working in Medicaid and vital records agencies. These relationships were often easier to establish when Medicaid and vital records staff were a part of the same division or department within the state government. When these agencies are separate, these relationships can take a long time to establish; one state said that it took four years there to form connections between agencies, establish the DUAs, and begin sharing data. It is also important that once the relationship is established, it is upheld:

> We work hard to maintain and keep that relationship on a positive note. We're very respectful of their data. We do not re-release it without their permission.

Another researcher with experience working with linked data in multiple states said,

> If there's not a good relationship [between] your Department of Public Health and your Medicaid agency, that's a huge problem for the state, certainly for a researcher. There tend to be . . . ownership problems.

States that were successfully linking data had made the linkages a priority of their MCH programs. There was agreement among many participants that the linked data were key to successful implementation and evaluation of many of the other MCH efforts that were happening in the state.

As one participant stated,

> It's a priority. A lot of what we do hinges upon those data linkages and helping to determine if we're succeeding in meeting our goals and objectives or if we need to redesign a program, so it's also utilized for evaluation purposes.

Often, discussion participants could cite a specific person, whether a high-ranking state health care policymaker or a dedicated MCH leader, who was able to drive forward and maintain enthusiasm for what could be a multiyear project.

> I think that issue of having a strong champion or champions for the importance of really looking at the data sources you have and that you can leverage to better answer the questions you have, or forecast what some of the needs are of the

> population you’re serving, is sort of the moral of the story, or one of the great facilitators.

Another participant agreed:

> It’s so important to have the folks that will really go out and sell [the linkage] so that people really understand what you can do with it.

Challenges

Discussion participants were nearly unanimous that the major challenges associated with linking Medicaid and birth certificate data were not technical but rather related to the organizational and operational aspects of establishing the linkages. For instance, staffing was a common challenge for many states. As one discussion participant said,

> Having dedicated staffing is often the hardest part of all of this, having staff with the knowledge and the time, particularly of the Medicaid data. . . . That is probably the biggest challenge that we have, in terms of the timeliness and just pulling off matches like this, is having staffing resources.

States that subcontract data linkages to external entities did not need to hire as many staff; as a result, they reported fewer challenges with hiring staff with technical skills and keeping data expertise in-house. However, this approach led to states having less capacity to conduct their own analyses using the data.

In addition to turnover among staff responsible for building and maintaining linkages, leadership turnover was also cited as a challenge for states. New agency leaders take time to develop relationships with other leaders in state government or have different priorities for the government. One state cited shifting state government priorities, saying that the state government diverted MCH analyst staff time toward COVID-19 tracking and prevention efforts, which slowed progress on the Medicaid and birth certificate data linkage.

The need to establish DUAs with internal state agencies and external researchers was another common challenge for states. While these DUAs were often not very complex, they required coordination between multiple state agencies and often had to go through multiple layers of approval. The DUAs also had to specify the nature of what the user hoped to do with the data, including whether the results would be made public. One participant described that,

> for researchers a challenge is making sure that the data use agreement covers the territory of the variables of the data that’s needed but also allows for research that can be published. I think that’s a huge limitation.

Kentucky has established a global memorandum of understanding (MOU) across the state government to enable easier data sharing between departments and agencies.

States faced several challenges around the legality of data sharing when implementing these linkages. State laws around privacy and data protection mostly focused on potentially identifying data, such as Social Security numbers and such sensitive data as substance use history (protected federally under 42 CFR Part 2), so these data needed to be treated with extra caution and shared only when needed. To protect against the accidental leakage of personally identifiable information (PII), California has created a large data network across multiple state agencies in which each individual is given a unique source ID and encrypted linkage key. PII is then stripped from the individual's file, and only the source ID is shared between agencies when linking data. As previously discussed, there were some data quality and completeness issues with names, addresses, Social Security numbers, and other variables used for linking, but all states that we spoke to were able to establish linkages despite these issues with data quality.

A few states raised that, in states that had not expanded Medicaid (or states that were matching data from years before Medicaid expansion), mothers may be covered by Medicaid insurance for only a very short time. This limited eligibility meant that research using the claims data presented a limited picture of the health service use by a mother before and after birth. Several states that had established other linkages to Medicaid claims noted that birth certificates and other vital records data were relatively high-quality data sources, especially when compared with social service data and other programmatic data from various state agencies.

Summary

We spoke with representatives from nine states about their experiences developing and maintaining linkages between Medicaid claims and birth certificates, including the technical aspects of those linkages, relationships between different stakeholders, uses of the linked data for research, and facilitators and challenges associated with establishing these linkages. States had varying degrees of data linkage, with some conducting linkages only between Medicaid and birth certificates and others establishing large data warehouses that linked data from many departments and agencies across the state. The data were mainly used for policy and program evaluation, with a handful of states using them to target individual-level interventions. Strong and long-standing relationships between state agencies, including the use of department level DUAs or MOUs, helped facilitate linkages, as did departmental support in the form of a strong champion or other leader to drive the projects forward. Almost all participants deemphasized the challenges associated with the technical aspects of these linkages; many used off-the-shelf products that seemed to work well. Instead, the major challenges that participants faced were related to establishing policies and processes for sharing data and working across agencies that might have differing priorities.

Chapter 5. Report Summary and Considerations

In this report, we described state efforts to link Medicaid claims with birth certificate data and other data sources to support maternal and infant health. These linked data can enable longitudinal patient-centered outcomes research on maternal and infant health, which can inform the development of policies and programs to promote maternal and infant health and address health care disparities. First, we reviewed academic peer-reviewed literature, Title V MCH reports, and publicly available information on state agency websites and extracted information on details of linkage efforts for each state. Next, we conducted nine group discussions that included representatives from state agencies, contractors with experience linking data, and academic researchers who have used the linked data. The following are key findings from this study:

- Thirty-nine of 59 jurisdictions (66.1 percent) linked Medicaid claims to birth certificates or other data sources.
- Birth certificates were the type of data most commonly linked to Medicaid claims, followed by social services data and death certificate data. This was echoed in our discussions with states, though multiple states also noted recent efforts to link immunization data and Medicaid data.
- We found relatively few papers describing validation of the linked data sets but note that many states we spoke with have processes for data validation.
- Several recent efforts to develop more centralized data repositories linking APCD data with birth certificates and other sources of data or creating HIEs across state agencies are under way and progressing.
- Some states performed linkages within the state health department or Medicaid agency, while others subcontracted the linkage to a local university or government contractor.
- Some states were making efforts to create central data hubs to facilitate quick-turnaround analysis projects using linked data.
- Common challenges noted were obtaining access to data across agencies or departments within a state and finding time and resources to improve data infrastructure. These challenges were expanded upon during our group discussions.
- States cited the additional challenges of privacy laws limiting the use of Social Security numbers for deterministic linkages and finding staff with dedicated time to perform linkages and use the linked data.

Our group discussions also noted several facilitators to data linkage efforts, including strong relationships between staff working in different agencies and institutional buy-in to the importance of building and maintaining data linkage capacity.

We note several limitations of these results. While we restricted our search to studies used in the past five years, lags in analyzing and publishing data meant that some of the data used in the studies were much older. Data linkages are rapidly evolving in scope and sophistication, and some of the linkages using older data from the studies may no longer be relevant. Second, states may not consistently report on linkage efforts, and we noted some instances in which reports gave conflicting information and discussions with states led to the identification of additional linkages beyond what was described in reports and articles. This suggests that states may be performing additional linkages beyond what we found in our inventory. Finally, we note that our group discussions were limited to larger states with ongoing data linkage efforts and with representatives who had availability to speak with us. This allowed us to have richer conversations on methods related to large-scale linkages but limits generalizability to other states and territories.

Considerations

Based on the structured literature review, inventory of state and territorial efforts, and semistructured discussions, we have identified several potential steps for states developing data linkages and for federal policymakers supporting states' efforts to build their data capacity. We do not make any specific recommendations around the methodological approach for these linkages, since our study has found examples of successful linkages that use a variety of methods (e.g., probabilistic versus deterministic), linkage software, and frequency of linkage.

Develop and Maintain Relationships Among Stakeholders

Every discussion participant agreed that identifying staff within each agency with the right expertise and developing strong and sustainable relationships among state agencies are key for setting data linkages' goals and processes. That necessary expertise includes experience preparing DUAs, familiarity with good practices for linking and sharing data, and using the linked data for longitudinal research, patient-centered outcomes research, programs, and policy.

Build on Existing Infrastructure

Many states have existing APCDs or HIEs, which are large databases or data structures that permit the transfer of health information that can be used as the basis for Medicaid and birth certificate data linkages. A few others have data warehouses making possible data linkages with birth certificate and other vital records data for additional insights into the health and well-being of their residents, mothers and infants included. In addition, these initiatives likely have staff with technical expertise, as well as collaborations with other entities, supporting data standards, linkages, and implementation of technology solutions when needed.

Outsource Technical Tasks

Exploring other options and implementing different strategies are necessary when state resources are insufficient. There are state or national entities (i.e., academic institutions, nonprofit or private government consulting groups) that have and can retain staff with expertise in data linkages. Several states participating in the discussion had to contract with such nongovernment entities to successfully link Medicaid claims and birth certificates data.

Dedicate Additional Resources and Technical Expertise for States

Building data capacity and maintaining it, data linkages included, requires funding, technical staff, and support from division and agency leadership. Many states have built their data linkages to monitor MCH outcomes by using limited SSDI funds or other state MCH resources. More information about state financial resources can be found in a previous ASPE report on state data for conducting patient-centered outcomes research to improve maternal health (ASPE, HHS, 2020). Additional federal support for state data capacity-building efforts could take the form of federal funds or technical assistance, including help with staffing and/or expert resources needed to implement data linkages. With this additional federal support, states will also be able to expand their current data linkage efforts beyond program-specific requirements, specifically to patient-centered outcomes research that is needed to continuously inform decisions on program strategies and policymaking.

Establish Learning Collaboratives

Not all states have expertise around linking Medicaid claims and birth certificate data, which in turn limits the use of these data at the national level. Coordination and collaboration among states and national experts will help consolidate the linkage methods and allow compilation of state linked data into national files for longitudinal studies, patient-centered outcomes included, that could inform federal programs and policymaking.

The federal government has established learning collaboratives or networks before, but these were time-limited and, sometimes, not sufficiently resourced for sustainability. Our findings indicate that relatively few states had consulted with other states, even though there is the potential for knowledge-sharing among interested stakeholders. Considering the current status of knowledge in data and technology, the federal government may create a new collaborative—well-resourced and with clear goals—consisting of experts at the national level, as well as representatives from states that have operationalized linkages and states that are looking to build these linkages. State representatives could meet regularly to present progress, gather input on best practices, or get advice on how to overcome challenges they encounter while establishing linkages. With input from national experts, states will be able to jointly conduct complex validation studies to decide on the linkage methods that can be used across all states and also jointly learn and adopt technology solutions, which will ultimately allow compilation of state data into national files.

Conclusions

This study adds valuable information to the landscape of state-based activities linking Medicaid claims with birth certificates and other data. More than half of jurisdictions (66.1 percent; 39 out of 59 included in the review process) were identified as performing data linkages. Although the linkage origins, methodologies, and uses vary across jurisdictions, 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. Well-resourced national learning collaboratives can facilitate knowledge-sharing and decisionmaking on best practices to consolidate linkage processes and methods across states with the aim of developing national linked data for research, programs, and policies.

Appendix. Inventory of State and Territory Linkage Efforts

Summary of 39 jurisdictions with in-scope linkages

Alaska

- 2020 Title V MCH Report notes Medicaid claims linkage with birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020)
- Note use of both probabilistic and deterministic linkages (HHS, 2020).
- Provides annual reports on topics such as infant mortality, low birth rate, cigarette smoking during pregnancy, and rates of cesarean section births (HHS, 2020).
- No information was available on obtaining linked data for outside researchers, but may be possible for researchers to perform linkages themselves—researchers may request individual-level vital records data and identifiers for linkages with outside data source (Chalmers et al., 2021).
- No information available on first year of data linkage, fields used for matching, match rates, or linkage challenges.

Arkansas

- 2020 Title V MCH Report notes Medicaid claims linkage with birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020); however, the report also notes that the Arkansas Department of Health is working on an agency data sharing agreement to access Medicaid data and that the Arkansas Title V Program currently has access to only limited aggregate data, so this particular linkage is not in-scope.
- Arkansas has also developed an APCD that includes Medicaid data and has been linked to birth and death certificate, hospital discharge, Arkansas cancer registry, medical marijuana cardholder, and workers' compensation data (Arkansas Healthcare Transparency Initiative, 2022).
- The APCD includes linked data 2013–2020 and is deterministically linked via a hashed identifier combining an enrollee's last name, date of birth, and gender (Arkansas Healthcare Transparency Initiative, 2022).
- A challenge is that enrollees with the same last name, birth date, and gender may receive the same study ID, or someone with a name change may have multiple study IDs (Arkansas Healthcare Transparency Initiative, 2022).
- The APCD has been used to study the association of Medicaid expansion in Arkansas with pregnancy-related services and racial disparities (Steenland et al., 2021).
- Data are available to outside researchers who complete the application process, pay the access fee, and gain approval (Arkansas Center for Health Improvement, 2022).
- No information was available on match rates between any of the sources.
- We identified one peer-reviewed article linking Arkansas Medicaid claims with birth and death certificate data and participation in a University of Arkansas telemedicine program for high-risk pregnant women (Sung et al., 2021).

California

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, CHHS has devoted resources to developing the CHHS Research Reconciliation and Research Data Hub (Children's Data Network, 2020). This data hub is not yet available but will eventually link California Medicaid data with a wide range of vital statistics and social services data.
- We identified one peer-reviewed article that linked California Medicaid data with birth certificate and hospital discharge data (Palmsten et al., 2021).

Colorado

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, the 2019 Health First Colorado Maternal Report described a linkage from a birthing parent's Medicaid ID to the newborn's birth certificate for the first time and notes plans to link EHR data and release annual MCH reports in the future (Colorado Department of Health Care Policy and Financing, 2019).
- Report says that 83 percent of Medicaid births listed on birth certificates were linked to the mother's Medicaid claims.

- Linked data were used to analyze rates of prenatal care; such maternal risk factors as diabetes and hypertension; and newborn outcomes, such as preterm birth and rates of NAS (Colorado Department of Health Care Policy and Financing, 2019).
- No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, linkage challenges, or access for outside researchers.
- We identified one peer-reviewed article that used Colorado Medicaid data linked with birth certificate data (Gordon et al., 2022).

Delaware

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, hospital discharge, and PRAMS or PRAMS-like data.
- The report notes contract with Forward Consultants to conduct data linkages and epidemiologic research, more broadly, but does not provide specific information on process of linking Medicaid with other data sets.
- No information available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers.

Florida

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, we identified one peer-reviewed article that used Florida Medicaid data linked with EHR data (Mkuu et al., 2021).

Illinois

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, hospital discharge, PRAMS or PRAMS-like data, and the BRFSS (HHS, 2020). However, based on emails with several representatives of Illinois state agencies, we believe that this report was inaccurate and that Medicaid and birth certificate data are not currently being linked.
- No information available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, applications of linked data, or access for researchers for linkages with Medicaid data specifically; details on type of linkage and match rates are provided for links between infant birth and death certificates.
- We identified one peer-reviewed article that used Illinois Medicaid data linked with social services and incarceration data (Goerge and Wiegand, 2019).

Indiana

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, the 2022 SSDI application noted completion of the Family and Social Services Administration Medicaid Data Integration Project that linked Medicaid data with social services data in that year.
- No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers.

Iowa

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- Iowa has linked Medicaid and birth certificate data annually since 1989 (Children’s Health Care Quality Measures Core Set Technical Assistance and Analytic Support Program, 2014).
- These linked data have been used to evaluate access to prenatal care, tobacco use, and postpartum contraceptive access (HHS, 2020).
- No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers.
- We identified one peer-reviewed article linking Iowa and Louisiana Medicaid data with birth certificate data (Okoroh et al., 2018).

Kansas

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like data, birth defect registry, BRFSS, and Youth Risk Behavior Surveillance System data (HHS, 2020).
- Data have been linked annually from 2014–2020.
- The report noted that staff turnover was a challenge to maintaining infrastructure (HHS, 2020).

- No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, or access for researchers.

Kentucky

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like data, NAS registry, and the Kentucky Health Access Nurturing Development Services (HANDS) home visitation program data (HHS, 2020).
- The report noted that siloed programs within the state can be a challenge to improving data infrastructure but that the creation of a program support branch within the division has helped mitigate this challenge (HHS, 2020).
- No information available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, or access for researchers to linkages.

Louisiana

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like data, BRFSS, and National Violent Death Reporting System (HHS, 2020).
- Analyzes Medicaid data through a partnership with the University of Louisiana.
- No information available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, applications of linked data, or access for researchers to linkages.
- We identified two peer-reviewed articles: one article linking Medicaid claims from Louisiana, Missouri, New Jersey, and South Carolina with birth certificate data (Howell, Johnson, and Cross-Barnet, 2020) and one article linking Iowa and Louisiana Medicaid data with birth certificate data (Okoroh et al., 2018).

Maine

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like data, home visiting program data, child welfare drug-affected infant reports, and child maltreatment reports (HHS, 2020).
- Medicaid and vital statistics data linkage was completed in spring 2021, and Maine’s MCH program is working to gain access to the linked data set (HHS, 2020).
- No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, applications of linked data, or access for researchers to linkages.
- We identified one peer-reviewed study linking Maine and Massachusetts APCD data (including Medicaid claims) with birth certificate and PRAMS data (Hawkins et al., 2022).

Maryland

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, Maryland has a HIE (Maryland Health Care Commission, 2022) that links Medicaid claims with other data sources, such as EHR data, vaccination data, and COVID-19 testing data.

Massachusetts

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources but does note linkage of birth certificate data to the Massachusetts Public Health Data (PHD) Warehouse, which includes APCD data (including Medicaid claims) (HHS, 2020).
- The public data warehouse incorporates hospital discharge, addiction treatment services, disease surveillance, death certificate, social services, PDMP, and WIC data (Massachusetts Department of Public Health, 2021).
- Linked APCD data are available from 2014–2018, but other data sets are available for broader time frames (ranging from 2011 to 2019).
- The data warehouse uses both probabilistic and deterministic matching on last name, date of birth, Social Security number, sex, and Zip code (Bernson, 2020).
- The warehouse was originally developed to inform response to the opioid epidemic but has been applied to MCH topics, such as disparities in use of medication to treat opioid use disorder among pregnant women (Schiff et al., 2020).
- Researchers may apply to conduct research with PHD data, but study must be conducted on site with publication restrictions (Massachusetts Department of Public Health, 2021).
- No information was available on linkage rates or linkage challenges.

- We identified five peer-reviewed articles: three linking Massachusetts Medicaid data with social services data (Clark et al., 2018; Clark et al., 2019a; Clark et al., 2019b), one linking APCD data (including Medicaid claims) with birth certificate, PDMP, hospital discharge, and state-funded addiction treatment data (Schiff et al., 2020), and one peer-reviewed study linking Maine and Massachusetts APCD data (including Medicaid claims) with birth certificate and PRAMS data (Hawkins et al., 2022).

Michigan

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- The report also notes in-development efforts to link Medicaid claims to birth defects registries and immunization records and to improve timeliness of linkages (HHS, 2020).
- Lack of MCH program staff to analyze data and difficulties using data from the Michigan Medicaid data warehouse are reported as challenges (HHS, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges, or access for researchers to linkages.
- We identified two peer-reviewed articles: one linking Michigan Medicaid data with birth certificate data and enhanced prenatal care program participation data (Roman et al., 2022) and one linking Michigan Medicaid data with birth certificate, EHR, and program data (Raffo et al., 2021).

Minnesota

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020).
- Years of data linkage are not provided; however, prior publication indicates that Medicaid and birth certificate linkages were performed using data from 1997 and that the match rate for this year was 93.2 percent (Gyllstrom et al., 2002).
- The publication using 1997 data noted that border counties had lower match rates, possibly indicating out-of-state births not being captured (Gyllstrom et al., 2002).
- No information was available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, applications of linked data, linkage challenges, or access for researchers to linkages.

Mississippi

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, and hospital discharge data (HHS, 2020).
- Future plans include improving timeliness of data and the quality of race and ethnicity data to conduct health disparities research (HHS, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges, or access for researchers to linkages.

Missouri

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, we identified three peer-reviewed articles: two linking Missouri Medicaid claims with EHR data (Herrick et al., 2019; Herrick et al., 2021) and one linking Medicaid claims from Louisiana, Missouri, New Jersey, and South Carolina with birth certificate data (Howell, Johnson, and Cross-Barnet, 2020).

Montana

- 2020 Title V MCH Report does not note linkage between Medicaid claims and other data sources in Form 12, which provides structured data on linkages (HHS 2020).
- However, elsewhere in the report, monthly linkages between Medicaid enrollment, birth records, and PRAMS are described—possibly a new initiative (HHS, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges, or access for researchers to linkages.

Nebraska

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020).

- Only mother claims (as opposed to infant claims or mother-infant dyads) are linked to birth certificate data (HHS, 2020).
- No information was available on current researcher access, but the report notes that proposed legislation will develop a set of comprehensive rules for disclosure and use of public health information (HHS, 2020).
- Future plans include development of a public health data warehouse called Data Nexus to provide timely and integrated data systems to the MCH program (HHS, 2020).
- No information available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges, or access for researchers to linkages.

Nevada

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- Researchers may request data from the Nevada Department of Health and Human Services Office of Analytics, but it is unclear whether it is possible to request linked data (Nevada Department of Health and Human Services Office of Analytics, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges, or access for researchers to linkages.

New Hampshire

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like data, commercial claims, drug and alcohol treatment, COVID-19 contact tracing, and disease surveillance data (HHS, 2020).
- Linked Medicaid and birth certificate data have been used to study such topics as early elective deliveries, maternal mortality, and severe maternal morbidity (HHS, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers to linkages.

New Jersey

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- However, we identified one article linking Medicaid claims from Louisiana, Missouri, New Jersey, and South Carolina with birth certificate data (Howell, Johnson, and Cross-Barnet, 2020).

New York

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- New York has begun implementing an APCD that includes information on enrollment, claims and encounter data, provider data, hospital discharge data, and vital records. Electronic health records and other data sources are planned to be integrated in the future (New York State Department of Health, 2020).
- Researchers are expected to be able to request linked data in the future, but policies to allow this are still in development (New York State Department of Health, undated).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers to linkages.
- We identified two peer-reviewed articles linking New York Medicaid claims with registry data (Kahn et al., 2021; Anderson et al., 2021).

North Carolina

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like, and birth defects registry data (HHS, 2020).
- No information was available on first year of linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers to linkages.
- We identified two peer-reviewed articles: one linking North Carolina Medicaid data with birth certificate data (Vladutiu et al., 2019) and one linking North Carolina Medicaid data with registry data (Nichols et al., 2021).

Ohio

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020).
- No information was available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers to linkages.
- Data are linked at least annually and are used to calculate infant mortality rates and other perinatal indicators.
- We identified three articles linking Ohio Medicaid claims with other data sets: one with birth certificate data and social services data (Crane et al., 2019), one with birth certificate data (Dunlop et al., 2020), and one with birth certificate data, death certificate data, Ohio Infant Mortality Reduction Initiative reports, and the Medicaid Women of Reproductive Age data set (Swoboda et al., 2018).

Oklahoma

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, and PRAMS or PRAMS-like data (HHS, 2020).
- Medicaid eligibility and birth certificate records were deterministically and probabilistically linked for 2015–2018 (Oklahoma State Department of Health, 2016).
- The linked data set is intended for such uses as identifying live births paid by Oklahoma Medicaid and conducting statistical analyses, assessing the maternal characteristics and behaviors prenatal and postnatal along with related birth outcomes, comparing pregnancy risks and birth outcomes between the Medicaid and non-Medicaid populations, among other uses (HHS, 2020).
- Future linkages include additional years and other data sources (e.g., PRAMS, WIC) to expand the information captured in the data set (HHS, 2020).
- Data can be obtained by special data request upon approval from the Oklahoma Health Care Authority and Oklahoma State Department of Health.
- Linkages and additional analyses will resume when a new MCH Medicaid Analyst is hired and trained (HHS, 2020).

Oregon

- 2020 Title V MCH Report notes no linkage between Medicaid claims and birth certificates (HHS, 2020).
- The Oregon All Payer Claims Database (APAC) can be linked to other data sources, and linked APAC–death certificate data are available on request (Oregon Health Authority, 2018).
- The APAC–death certificate linked data set includes annually “mixed methods” linked data from 2010–2018 matching on names, date of birth, and date of death. 91 percent of death certificates matched to APAC, while 86 percent of APAC matched to death certificate data (Oregon Health Authority, 2018).
- Matching challenges came from errors or differences in data sources and differences in matching algorithms.
- APAC data can be requested through the Office of Health Analytics; APAC–death certificate data also needs a death certificate record data request through the Oregon Center for Health Statistics (Oregon Health Authority, 2022).
- We identified six peer-reviewed articles: three linking Oregon Medicaid data with birth certificate data (Harvey et al., 2021b; Luck et al., 2020; Oakley et al., 2017), one linking Oregon Medicaid data with birth and death certificate data (Bui et al., 2019), one linking Oregon Medicaid data with birth certificate and hospital discharge data (Harvey et al., 2021a), and one linking Oregon and South Carolina Medicaid data with birth certificate data (Rodriguez et al., 2021).

Puerto Rico

- 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, and PRAMS or PRAMS-like data (HHS, 2020).
- Deterministic linkage of 2020 live births and Medicaid eligible participants was performed with 87.8 percent match (verified to be true matches) (HHS, 2020).
- No information was available on fields used for matching, linkage challenges, applications of linked data, or access for researchers for linkages.

Rhode Island

- 2020 Title V MCH Report notes linkages between Medicaid claims, birth and death certificates, and fetal death certificates. Medicaid data can be linked to MCH data through the RI Data Ecosystem for de-identified data analysis.
- Also available is KIDSNET, which links birth certificates, newborn screening (developmental risk, bloodspot, Critical Congenital Heart Disease, hearing), immunization, lead screening, home visiting, Child Outreach, WIC, Early Intervention, Early Childhood Developmental Screening, Foster Care, and Head Start for children; an interagency agreement is now in place for selected data to further link to Medicaid and state social services (HHS, 2020).

- No information was available on years linked, linkage type, fields used for matching, linkage challenges, applications of linked data, or access for researchers for linkages.
- We identified one peer-reviewed article linking Rhode Island Medicaid data to birth certificate data (Wen et al., 2021).

South Carolina

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- Vital statistics data are available to researchers but do not seem to be linked to other data sources (HHS, 2020). South Carolina cites staffing issues, including the need to redirect resources during the COVID-19 pandemic, as a barrier to these efforts (HHS, 2020).
- We still identified four peer-reviewed articles: two linking South Carolina Medicaid data to birth certificate and social services data (Bersak and Sonchak, 2018; Chorniy, Currie and Sonchak, 2020), one article linking South Carolina Medicaid data to birth certificate data (Liberty et al., 2020), and one article linking Medicaid claims from Louisiana, Missouri, New Jersey, and South Carolina with birth certificate data (Howell, Johnson, and Cross-Barnet, 2020).

Tennessee

- 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (HHS, 2020).
- The State Title V program does not have access to State Medicaid data (HHS, 2020). It cites challenges hiring staff to build data infrastructure with limited funding (HHS 2020).
- However, we identified three peer-reviewed articles linking Tennessee Medicaid data with other data sources: two with birth certificate data (Whitmore et al., 2021; Lopata et al., 2020) and one with birth certificate and education data (Fill et al., 2018).

Texas

- 2020 Title V MCH Report notes linkages between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- Several agreements are in place to enable at least annual linkage of vital records data with Medicaid administrative data (HHS, 2020).
- Data gaps are being assessed and identified, and additional data sets may be added in the future (HHS, 2020).
- Data capacity is an ongoing challenge for some populations, particularly for children (1–5 years) and neighborhood-level data; data quality has been a challenge, but improvements in maternal mortality, PRAMS, and Texas Early Hearing Detection and Intervention data are in process (HHS, 2020).
- No information was available on years linked, linkage type, fields used for matching, or access for researchers for linkages.
- We identified two peer-reviewed articles linking Texas Medicaid claims with birth and death certificate data (Leyenaar et al., 2021; Ganduglia Cazaban et al., 2019).

Utah

- 2020 Title V MCH Report notes linkages between Medicaid claims, birth and death certificates, WIC, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- The Data Resources Program links vital birth records at least annually with Medicaid eligibility data (HHS, 2020).
- The Department of Health Master Person Index (DOHMPI) project uses deterministic and probabilistic linkage to link information from birth and death certificates, Medicaid eligibility records, and the APCD (HHS, 2020).
- Linked data are used to assess prenatal care delivery, maternal morbidities, and birth outcomes (HHS, 2020).
- The DOHMPI project linked data may be accessible by contacting the Health Informatics Office, Center for Health Data, Utah Department of Health (Utah Department of Health, undated).
- No information was available on years linked, fields used for matching, or linkage challenges.

Vermont

- 2020 Title V MCH Report notes linkages between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020).
- The Vermont Child Health Improvement Program Heath Services Research team has access to Vermont's All-Payer Claims Database, Vermont Health Care Uniform Reporting and Evaluation System, linked to vital records through the University of Vermont Larner College of Medicine (UVM-LCOM).

- UVM-LCOM researchers provided first name, last name, Social Security number, date of birth, and gender, and the vendor applied a propriety hashing algorithm to identify vital records to be linked with VHCURES (Vermont Green Mountain Care Board, 2018).
- VHCURES access and data linkage can be requested through the Green Mountain Care Board (Vermont Green Mountain Care Board, 2018).
- No information was available on first year of data linkage, linkage type, applications of linked data, or linkage challenges.

Washington

- 2020 Title V MCH Report does not note linkages between Medicaid and other data sources (HHS, 2020).
- However, the Washington State Department of Social and Health Services Research and Analysis has maintained the Integrated Client Databases (ICDB) since the 1990s. The ICDB draws from over 30 state agencies, including vital statistics and Medicaid, but is not available to external researchers (Mancuso, Huber, and the Washington State Department of Social and Health Services Research and Data Analysis Division, 2021).
- The ICDB has reports on several recent projects using linked data. For example, one project evaluated predicting maternal well-being outcomes for the state's Temporary Assistance for Needy Families population. Another report examined the relationship between gestational age of prior deliveries and interpregnancy intervals and pre-term births among women with Medicaid coverage (Xing et al., 2021).
- No information was available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, or linkage challenges.
- We identified one peer-reviewed publication linking Washington Medicaid claims with birth certificate data, death certificate data, social services data, and criminal justice data (Arthur et al., 2018).

West Virginia

- 2020 Title V MCH Report notes linkages between Medicaid claims, birth and death certificates, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- A programmer analyst supports prioritized surveillance systems development and linkages.
- No information was available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers to linkages.

Wisconsin

- 2020 Title V MCH Report notes linkages between birth and death records, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020).
- It is noted that hospital discharge data are linked to Medicaid, but MCH doesn't appear to have access to Medicaid, and there are no further details about the linkage.
- The Office of Health Informatics provides hospital-based and linked patient-level health data to Wisconsin state and local agencies, and others can contact the Wisconsin Hospital Association Information Center (Wisconsin Department of Health Services, 2021).
- No information was available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, or linkage challenges.
- We identified four peer-reviewed articles linking Wisconsin Medicaid data with other data sets: three with birth certificate data (DeSisto et al., 2020; Rubenstein et al., 2021; Mallinson and Ehrenthal, 2019) and one with PRAMS data (DeSisto et al., 2021).

Summary of 20 jurisdictions with no in-scope linkages

American Samoa

Currently, links birth records only to death records and newborn hearing screening data (HHS, 2020). In their 2020 Title V MCH report, officials note that it is a long-term goal to link Medicaid and social services data with their existing SILAS electronic database.

Alabama

Links birth records only to death records (Hardy, 2021). Alabama notes challenges with timely reporting of data and lack of in-house expertise and time to develop data linkages (HHS, 2020).

Arizona

Links birth records only to death records and newborn bloodspot screening, newborn hearing screening, hospital discharge, PRAMS or PRAMS-like, and MEDSIS (Arizona's system for infectious disease reporting) data (HHS, 2020).

Connecticut

Connecticut does not currently link vital records to any other types of data (HHS, 2020). However, prior to 2012, the Connecticut Department of Social Services provided linked Medicaid and birth certificate data for MCH block grant activities through a subcontractor, who was later defunded. Connecticut is working to obtain new interagency agreements for this linked data.

District of Columbia

Links birth records only to death records, newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020). In 2017–2020 reports, noted plans to link Medicaid and vital statistics data, but this does not appear to have happened (HHS, 2020).

Federated States of Micronesia

Federated States of Micronesia (FSM) links birth records to death records, newborn hearing screening, hospital discharge data, and the MCH Data Matrix (HHS, 2020). In 2020, FSM was not eligible for Centers for Medicare and Medicaid Services programs, but data were collected from MiCare Health Insurance. It is not clear whether it is actively linked to other data sources.

Georgia

Links birth records only to death records, newborn bloodspot screening, newborn hearing screening, hospital discharge, and PRAMS or PRAMS-like data (HHS, 2020). Maternal death data are linked to Medicaid claims.

Guam

Guam currently does not link birth records to any other types of data (HHS, 2020). Guam MCH has access to most data elements but does not have access to Medicaid and PRAMS data, and it has been an ongoing challenge to obtain access to Medicaid data.

Hawaii

Links birth records only to death records. Hawaii has had limited epidemiological support for the past several years. There are currently no plans to establish any new data linkages without additional epidemiological support and while COVID-19 priorities are in competition (HHS, 2020).

Idaho

Links birth records only to death records, newborn bloodspot screening, and newborn hearing screening (HHS, 2020). Report also notes that the MCH program’s lack of access to hospital discharge data is a key challenge.

Marshall Islands

Marshall Islands does not currently link vital records to any other types of data (HHS, 2020). Data linkage of different systems is underway (vital records, special needs registry encounter and provider data), but implementation has been delayed because of the COVID-19 pandemic. In 2020, Marshall Islands did not have access to Medicaid.

New Mexico

Links Vital Records Birth data only with Vital Records Death, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020). 2017–2020 Title V MCH Reports discussed planned Medicaid claims and birth certificate linkages, but these do not appear to have happened (HHS, 2020). The long-acting reversible contraceptives evaluation team has planned linkages between Medicaid claims and birth certificates but is still waiting for the claims data as of 2020 (HHS, 2020). An APCD is scheduled for release in 2023 and may include linkages to other data sources from the New Mexico Department of Health, but it is unclear whether these will be individual or aggregate data linkages (Getner and Krapfl, 2021).

North Dakota

Links birth records only to newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020). A plan is under development and implementation for overcoming barriers to data linkage and increasing linkages of MCH data sets, but specific data sets are not mentioned. COVID-19 pandemic activities, particularly the use of real-time hospitalization data, have had priority over other efforts.

Northern Mariana Islands

Links birth records to death records, newborn hearing screening, and PRAMs or PRAMS-like data (HHS, 2020). Developing a data governance framework and a centralized public health data repository, but no other details are currently available.

Palau

Links birth records only to newborn hearing screening (HHS, 2020). In 2020, Palau did not have access to the State Children’s Health Insurance Program or Medicaid.

Pennsylvania

Links only birth and death records (HHS, 2020). Some efforts have been made to link claims data to birth certificate records, including the assembly of an administrative data set of linked birth certificates and claims for 4,781 Medicaid-covered 17P-eligible pregnancies between 2014 and 2016 (3 percent of Medicaid births) (HHS, 2020).

South Dakota

Links birth certificate data only to death certificate data, bloodspot screening, hearing screening, and PRAMS (HHS, 2020). In the 2019 Title V MCH Report, noted that the department of health was working to link Medicaid claims with birth and death certificate data, but there has been no further update on this effort (HHS, 2020).

U.S. Virgin Islands

The U.S. Virgin Islands does not currently link vital records to any other types of data (HHS, 2020). There are no current plans to explicitly link to Medicaid data, but that may be done to serve the changings needs of the population.

Virginia

Links birth certificate data only to death certificate data, newborn hearing screening, and PRAMS (HHS, 2020). The Title V MCH Report notes that the program uses Medicaid claims and APCD data, but access is not provided in the claims data sets to the identifiers needed to link these data to birth certificates (HHS, 2020).

Wyoming

Links only birth and death certificates, Newborn Blood Screening, newborn hearing screening, and PRAMS or PRAMS-like data (HHS, 2020). There is currently an effort to develop the linkage of the birth file to Medicaid claims data for MCH metrics. The Wyoming Department of Health is also developing the Wyoming Integrated Next Generation System (WINGS) that will replace the current state Medicaid Management Information System. This system will potentially include linkages to other systems, including public health and vital statistics (Wyoming Department of Health, 2022).

Abbreviations

ADT	admission/discharge/transfer
APCD	all-payer claims data(base)
ASPE	Assistant Secretary for Planning and Evaluation
BRFSS	Behavioral Risk Factor Surveillance System
CHHS	California Health and Human Services Agency
COVID-19	coronavirus disease 2019
DUA	data use agreement
EHR	electronic health record
HHS	U.S. Department of Health and Human Services
HIE	health information exchange
HRSA	Health Resources and Services Administration
IRB	institutional review board
MCH	Maternal and Child Health
MOU	memorandum of understanding
MPI	master patient index
NAS	neonatal abstinence syndrome
PDMP	prescription drug monitoring program
PII	personally identifiable information
PRAMS	Pregnancy Risk Assessment Monitoring System
SSDI	State Systems Development Initiative
WIC	Women, Infants, and Children

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