Online Appendix 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,” PRAMSMaternal and Infant Health Terms: health AND maternal, child, infant, prenatal, postpartum, antenatal, pregnancy, pregnant, neonatal, perinatal, newborn, fetal |

Online Appendix 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 articles. 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 All-Payer Claims Database (APCD) including Medicaid claims linked at the individual level with data from:
	+ Birth or death certificates
	+ Electronic medical records or health information exchanges (HIEs)
	+ Prescription drug monitoring programs
	+ Social services (e.g., Supplemental Nutrition Program for Women, Infants and Children, Child Protective Services, Housing Vouchers)
	+ Pregnancy Risk Assessment Monitoring System (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. |

Online Appendix 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 non-continuous timeframes 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? What type(s) of other data sets were linked?Are mother and infant claims linked? | Multiple choice: Medicaid, All-Payer Claims DatabaseCheckbox: Birth certificates, death certificates, Prescription drug monitoring programs, EMR/EHR/Health Information Exchange, Social services, State maternal health program enrollment, PRAMS, registries, other (free-text)Multiple choice: Yes, no, not specified, other (free-text) |
| Details of linkage process | What type of record linkages were used?Which variables were used in the linkages?What was the match rate of each linkage? (may provide multiple)How, if at all, were matches validated? | Multiple choice: Deterministic (i.e., an exact match on one or more unique identifier such as social security number), probabilistic (i.e., partial matches on multiple non-unique identifiers, such as name and birth date), both, other (free-text), not specifiedCheckbox: 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)Percent match and free-text description of match type (e.g., percent of infant Medicaid claims linked to birth certificate) or not specifiedCheckbox: 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 |

**Online Appendix 4. State Selection for Discussions**

Selected for discussion

N=9

|  |  |
| --- | --- |
| **Larger half\*****(n=4)**  | **Smaller half\*****(n=5)**  |
| Northeast (n=1) | Northeast (n=0) |
| Midwest (n=1) | Midwest (n=1) |
| South (n=1) | South (n=3) |
| West (n=1) | West (n=1) |

Eligible data linkage

N=21

|  |  |
| --- | --- |
| **Larger half\* (n=10)** | **Smaller half\* (n=11)** |
| Northeast (n=2) | Northeast (n=1) |
| Midwest (n=2) | Midwest (n=5) |
| South (n=4) | South (n=4) |
| West (n=2) | West (n=1) |

More than 50,000 live births per year

N=26

All jurisdictions

N=59

**\*To determine the larger half of states, we ranked the 21 eligible states by number of births and identified the 10 states with the most live births. The remaining 11 states were deemed the smaller half of states.**

**Online Appendix 5: Discussion Guide**

1. First, can you tell me what your role is in terms of linking Medicaid data to birth certificates or using this type of linked data in your state?
	* Probes: What is your position at your organization? How long have you been working with these types of data? How often do you use linked data?
	* Are there additional people who were key to linking data who are not on this call?
	* What agencies were involved in this effort? Who was the leading agency or organization? Were there any academic institutions, private organizations, or foundations involved in this effort?
2. What types of data do you currently link to Medicaid data within your state? (For researchers) What types of linked data do you use in your research?
	* Probes: How many years of data do you have linked? How frequently are the data updated?
	* Does this linkage include an APCD?
	* What is the process for linking data? What variables do you match on? Is it a probabilistic or deterministic approach?
3. How are the linked data being used? For research, policymaking, clinical practice, social services?
	* Can you provide example use cases for the data?
	* Can you describe the process for external researchers or organizations to access these data? Approximately how many researchers have accessed it?
	* What research questions can be addressed with these linked data?
	* What research questions are you interested in that would require additional data linkages?
	* Are the linked data being used in quality improvement initiatives?
	* Being used to inform policy and practice?
4. How did the idea to link data come about? Tell me the “story” of your data linkage efforts
	* Probes: Who were the key people involved? What were the original goals or motivations?
	* How does this effort compare to other linkage efforts the state has taken on (APCD efforts)?
	* How does the data linkage fit within the state’s priorities for maternal and child health?
5. What are the biggest challenges with linking data or using linked data? Are there any characteristics of your state, policies, or the structure of your Medicaid program that make linking data or using linked data especially challenging?
	* Probes: technical, regulatory, legal
	* What data quality issues have you encountered? How have you addressed issues with data quality?
	* What about data completeness?
	* Accessing data – permission, data use agreements, willingness to share data?
	* How have you overcome these barriers?

1. What future data linkage efforts are you envisioning? Are there ongoing efforts or planned efforts?
	* Probes: what are the timelines for these linkage efforts? Who is involved? What data sources are being considered?
	* Anything else that we haven’t discussed that you think is important for us to know?

**Online Appendix 6. Article Screening Results**

Articles screened

N=687

Articles included for abstraction

N=45

Excluded:

* No U.S. data: N=145
* Not in-scope study type: N=70
* Not maternal/child health topic: N=60
* No in-scope data linkage used: N=349
* Not state-level linkage: N=18

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**Online Appendix 8**. 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/PRAMS-like data (Title V MCH Report)
* Note use of both probabilistic and deterministic linkages (Title V MCH Report).
* Provide annual reports on topics such as infant mortality, low birth rate, cigarette smoking during pregnancy, and rates of cesarean section births (Title V MCH Report).
* No information 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 (Alaska Department of Health and Social Services, 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/PRAMS-like data (Title V MCH Report); 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 only has access to 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 data, hospital discharge data, 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).
* 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 application process, pay access fee, and gain approval (Arkansas Center for Health Improvement, 2022).
* No information on match rates between any of the sources.
* 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 (Title V MCH Report).
* However, California’s Health and Human Services Agency (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.
* 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 (Title V MCH Report).
* However, the 2019 Health First Colorado Maternal Report described a linkage from a birthing parent’s Medicaid ID and the newborn’s birth certificate for the first time and notes plans to link electronic health record data and release annual maternal and child health reports in the future (Colorado Department of Health Care Policy & Financing, 2019).
* Report 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, 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 & Financing, 2019).
* No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, linkage challenges, or access for outside researchers.
* 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/PRAMS-like data.
* 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 (Title V MCH Report).
* However, 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/PRAMS-like data, and the Behavioral Risk Factor Surveillance System (BRFSS) (Title V MCH Report). However, based on e-mails 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.
* 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 (Title V MCH Report).
* However, the 2022 SSDI application noted completion of the Family and Social Services Administration (FSSA) Medicaid Data Integration Project that linked Medicaid data with social services data this 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/PRAMS-like data (Title V MCH Report).
* 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 (Title V MCH Report).
* No information available on type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, linkage challenges, or access for researchers.
* 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/PRAMS-like data, birth defect registry, BRFSS, and Youth Risk Behavior Surveillance System (YRBSS) data (Title V MCH Report)
* Data have been linked annually from 2014–2020.
* Noted that staff turnover was a challenge to maintaining infrastructure (Title V MCH Report).
* 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/PRAMS-like data, NAS registry, and the Kentucky Health Access Nurturing Development Services (HANDS) home visitation program data (Title V MCH 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 (Title V MCH Report).
* 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/PRAMS-like data, BRFSS, and National Violent Death Reporting System (Title V MCH Report).
* 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.
* 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/PRAMS-like data, home visiting program data, child welfare drug affected infant reports, and child maltreatment reports (Title V MCH Report).
* 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 (Title V MCH Report).
* 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.
* 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 (Title V MCH Report).
* However, Maryland has Health Information Exchange (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) (Title V MCH Report).
* The public data warehouse incorporates hospital discharge, addiction treatment services, disease surveillance data, 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).
* Uses both probabilistic and deterministic matching on Last Name, DOB, SSN, Sex, and Zip Code (Bernson, 2020).
* Originally developed to inform response to opioid epidemic, but has been applied to maternal and child health 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 must be conducted on site with publication restrictions (Massachusetts Department of Public Health, 2021).
* No information on linkage rates or linkage challenges.
* Identified four peer-reviewed articles: two 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/PRAMS-like data (Title V MCH Report).
* Report also notes in-development efforts to link Medicaid claims to birth defects registries and immunization records and to improve timeliness of linkages (Title V MCH Report).
* Lack of MCH program staff to analyze data and difficulties using data from the Michigan Medicaid data warehouse are reported as challenges (Title V MCH Report).
* 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.
* 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).
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| **Minnesota*** 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, newborn bloodspot screening, newborn hearing screening, and PRAMS/PRAMS-like data (Title V MCH Report).
* Years of data linkage 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).
* 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 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.
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| **Mississippi*** 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, and hospital discharge data (Title V MCH Report).
* Future plans include improving timeliness of data and the quality of race and ethnicity data to conduct health disparities research (Title V MCH Report).
* 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.
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| **Missouri*** 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (Title V MCH Report).
* However, 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).
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| **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 (Title V MCH Report).
* However, elsewhere in the report, monthly linkages between Medicaid enrollment, birth records, and PRAMS are described—possibly a new initiative (Title V MCH Report).
* 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.
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| **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 (Title V MCH Report).
* Only mother claims (as opposed to infant claims or mother-infant dyads) are linked to birth certificate data (Title V MCH Report) .
* No information on current researcher access, but report notes that proposed legislation will develop a set of comprehensive rules for disclosure and use of public health information (Title V MCH Report).
* Future plans include development of a public health data warehouse called Data Nexus to provide timely and integrated data systems to the MCH program (Title V MCH Report).
* 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.
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| **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 (Title V MCH Report).
* 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 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
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| **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 (Title V MCH Report).
* Linked Medicaid and birth certificate data have been used to study topics such as early elective deliveries, maternal mortality, and severe maternal morbidity (Title V MCH Report).
* No information 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.
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| **New Jersey*** 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (Title V MCH Report).
* However, **i**dentified one article linking Medicaid claims from Louisiana, Missouri, New Jersey, and South Carolina with birth certificate data (Howell, Johnson and Cross-Barnet, 2020).
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| **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 (Title V MCH Report).
* 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).
* No information 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.
* Identified two peer-reviewed articles linking New York Medicaid claims with registry data (Kahn et al., 2021; Anderson et al., 2021).
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| **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 (Title V MCH Report).
* No information 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.
* 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).
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| **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 (Title V MCH Report).
* 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 to linkages.
* Data are linked at least annually and are used to calculate infant mortality rates and other perinatal indicators.
* 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 dataset (Swoboda et al., 2018).
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| **Oklahoma*** 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, and PRAMS or PRAMS-like data (Title V MCH Report).
* 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 uses such as: identifying live births paid by Oklahoma Medicaid and conducting statistical analyses, assessing the maternal characteristics and behaviors during pre- and post-natal along with related birth outcomes, comparing pregnancy risks and birth outcomes between the Medicaid and non-Medicaid populations, among others (Title V MCH Report).
* Future linkages include additional years and other data sources (e.g., PRAMS, WIC) to expand the information captured in the data set (Title V MCH Report).
* Data can be obtained by special data request upon approval from OHCA and OSDH.
* Linkages and additional analyses will resume when a new MCH Medicaid Analyst is hired and trained (Title V MCH Report).
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| **Oregon*** 2020 Title V MCH Report notes no linkage between Medicaid claims and birth certificates (Title V MCH Report).
* 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/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).
* 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).
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| **Puerto Rico*** 2020 Title V MCH Report notes linkage between Medicaid claims, birth and death certificates, WIC, and PRAMS or PRAMS-like data (Title V MCH Report).
* Deterministic linkage of 2020 live births and Medicaid eligible participants was performed with 87.8 percent match (verified to be true matches) (Title V MCH Report).
* No information available on fields used for matching, linkage challenges, applications of linked data, or access for researchers for linkages.
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| **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, CCHD, hearing), immunization, lead screening, home visiting, Child Outreach, WIC, Early Intervention, Early Childhood Developmental Screening, Foster Care, and Head Start for children; an inter-agency agreement is now in place for selected data to further link to Medicaid and state social services (Title V MCH Report).
* No information available on years linked, linkage type, fields used for matching, linkage challenges, applications of linked data, or access for researchers for linkages.
* Identified one peer-reviewed article linking Rhode Island Medicaid data to birth certificate data (Wen et al., 2021).
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| **South Carolina*** 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (Title V MCH Report).
* Vital statistics data are available to researchers but do not seem to be linked to other data sources (SSDI report). South Carolina cites staffing issues, including the need to redirect resources during the COVID-19 pandemic, as a barrier to these efforts (Title V MCH Report).
* However, 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).
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| **Tennessee*** 2020 Title V MCH Report does not note linkage between Medicaid claims and vital records or other data sources (Title V MCH Report).
* The State Title V program does not have access to State Medicaid data (Title V MCH Report). They cite challenges hiring staff to build data infrastructure with limited funding (SSDI Report).
* However, 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).
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| **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 (Title V MCH Report).
* Several agreements are in place to enable at least annual linkage of vital records data with Medicaid administrative data (Title V MCH Report).
* Data gaps are being assessed and identified, and additional data sets may be added in the future (Title V MCH Report).
* 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 TEHDI data are in process (Title V MCH Report).
* No information available on years linked, linkage type, fields used for matching, or access for researchers for linkages.
* Identified two peer-reviewed article linking Texas Medicaid claims with birth and death certificate data (Leyenaar et al., 2021; Ganduglia Cazaban et al., 2019).
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| **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 (Title V MCH Report).
* The Data Resources Program (DRP) links vital birth records at least annually with Medicaid eligibility data (Title V MCH Report).
* 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 (Title V MCH Report).
* Linked data are used to assess prenatal care delivery, maternal morbidities, and birth outcomes (Title V MCH Report).
* 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).
* No information 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 (Title V MCH Report).
* The VCHIP Heath Services Research team has access to Vermont’s All-Payer Claims Database VHCURES linked to vital records through the University of Vermont School 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 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 (Title V MCH Report).
* However, the Washington State Department of Social and Health Services (DSHS) Research and Analysis (RDA) 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 (Washington State Health and Human Services, 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 TANF 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 available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, or linkage challenges.
* 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).
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| **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 (Title V MCH Report).
* A programmer analyst supports prioritized surveillance systems development and linkages.
* 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 to linkages.
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| **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 (Title V MCH Report).
* 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 available on first year of data linkage, type of linkage (e.g., probabilistic, deterministic), fields used for matching, match rates, applications of linked data, linkage challenges.
* 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).
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| *Summary of 20 jurisdictions with no in-scope linkages* |
| **American Samoa** Currently, only links birth records to death records and newborn Hearing Screening data (Title V MCH Report). In their 2020 Title V MCH report, they note that it is a long-term goal to link Medicaid and social services data with their existing SILAS electronic database. |
| **Alabama** Only links birth records 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 (Title V MCH Report). |
| **Arizona**Only links birth records to death records, newborn bloodspot screening, newborn hearing screening, Hospital Discharge, PRAMS/PRAMS-like, and MEDSIS (Arizona’s system for infectious disease reporting) data (Title V MCH Report). |
| **Connecticut**Connecticut does not currently link vital records to any other types of data (Title V MCH Report). 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**Only links birth records to death records, newborn bloodspot screening, newborn hearing screening, and PRAMS/PRAMS-like (Title V MCH Report). In 2017–2020 reports, noted plans to link Medicaid and vital statistics data, but this does not appear to have happened (Title V MCH Report). |
| **Federated States of Micronesia**Federated States of Micronesia link birth records to death records, newborn hearing screening, hospital discharge data, and the MCH Data Matrix (Title V MCH Report). In 2020, FSM was not eligible for CMS programs but data were collected from MiCare Health Insurance. It is not clear if it is actively linked to other data sources. |
| **Georgia**Only links birth records to death records, newborn bloodspot screening, newborn hearing screening, Hospital Discharge, and PRAMS/PRAMS-like data (Title V MCH Report). Maternal death data are linked to Medicaid claims. |
| **Guam**Guam currently does not link birth records to any other types of data (Title V MCH Report). Guam MCH has access to most data elements but does not have access to Medicaid and PRAMS data, and it has been an ongoing challenging to obtain access to Medicaid data. |
| **Hawaii** Only links birth records 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 (Title V MCH Report).  |
| **Idaho**Only links birth records to death records, newborn bloodspot screening, and newborn hearing screening (Title V MCH Report). Report also notes that the MCH program’s lack of access to hospital discharge data is a key challenge. |
| **Marshall Islands**Marshall Islands do not currently link vital records to any other types of data (Title V MCH Report). Data linkage of different systems are underway (vital records, special needs registry encounter and provider data), but implementation has been delayed as a result of the COVID-19 pandemic. In 2020, Marshall Islands did not have access to Medicaid. |
| **New Mexico**Only links Vital Records Birth data with Vital Records Death, newborn hearing screening, and PRAMS or PRAMS-like data (Title V MCH Report). 2017–2020 Title V MCH Reports discussed planned Medicaid claims and birth certificate linkages, but these do not appear to have happened (Title V MCH Report). The long-acting reversible contraceptives (LARC) evaluation team has planned linkages between Medicaid claims and birth certificates but is still waiting for the claims data as of 2020 (Title V MCH Report). An All-Payer Claims Database (APCD) is scheduled for release in 2023 and may include linkages to other data sources from NM DOH but it is unclear whether these will be individual or aggregate data linkages (Getner and Krapfl, 2021) |
| **North Dakota**Only links birth records to newborn bloodspot screening, newborn hearing screening, and PRAMS or PRAMS-like data (Title V MCH Report). 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**Only links birth records to death records, newborn hearing screening, and PRAMs or PRAMS-like data (Title V MCH Report). Developing a data governance framework and a centralized Public Health data repository, but no other details are currently available. |
| **Palau**Only links birth records to newborn hearing screening (Title V MCH Report). In 2020, Palau did not have access to SCHIP or Medicaid. |
| **Pennsylvania**Only links birth and death records (Title V MCH Report). 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) (Title V MCH Report).  |
| **South Dakota**Only links birth certificate data to death certificate data, bloodspot screening, hearing screening, and PRAMS (Title V MCH Report). In 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 (Title V MCH Report). |
| **US Virgin Islands**The U.S. Virgin Islands does not currently link vital records to any other types of data (Title V MCH Report). There are no current plans to explicitly link to Medicaid data but may do so to serve the changings needs of the population. |
| **Virginia**Only links birth certificate data to death certificate data, newborn hearing screening, and PRAMS (Title V MCH Report). Notes that the program uses Medicaid claims and APCD data, but they do not have access in the claims datasets to the identifiers needed to link these data to birth certificates (Title V MCH Report). |
| **Wyoming**Only links birth and death certificates, Newborn Blood Screening, newborn hearing screening, and PRAMS or PRAMS-like data (Title V MCH Report). 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 MMIS. This system will potentially include linkages to other system, including public health and vital statistics (Wyoming Department of Health, 2022). |