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Perinatal Substance Use Data Linkage Project: Multi-Year Strategic Research Agenda

REPORT HIGHLIGHTS:

- **Senate Bill (SB) 19-228 authorized the Perinatal Substance Use Data Linkage Project** for the purposes of planning, implementation, and evaluating public health actions to improve outcomes for families impacted by substance use during pregnancy.
- **SB21-137 created annual state investments in the project**, providing a unique opportunity to think strategically on research priorities that respond to emergent needs and opportunities of stakeholders across child welfare, health care, and prevention spaces.
- This **multi-year research agenda outlines a strategy for leveraging the data linkage project** to guide state investments and decision-making in policies and practices positioned to improve family health and well-being.

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Table of Contents

Introduction1

Development of the Multi-Year Research Agenda2

Priority Research Areas2

 Area 1: Generate Population Estimates 2

 Area 2: Explore System Utilization and Correlates with Health and Child Welfare Outcomes 3

 Area 3: Capacity Building for Evaluation of Policies and Programs 4

Key Design Considerations.....4

 1. Flexibility and Responsiveness 4

 2. Informed by Qualitative Study 5

 3. Data Access 5

 4. Data Partners 5

 5. Characteristics of Maternal-infant Dyads..... 5

 6. Stakeholder Engagement 5

Next Steps5



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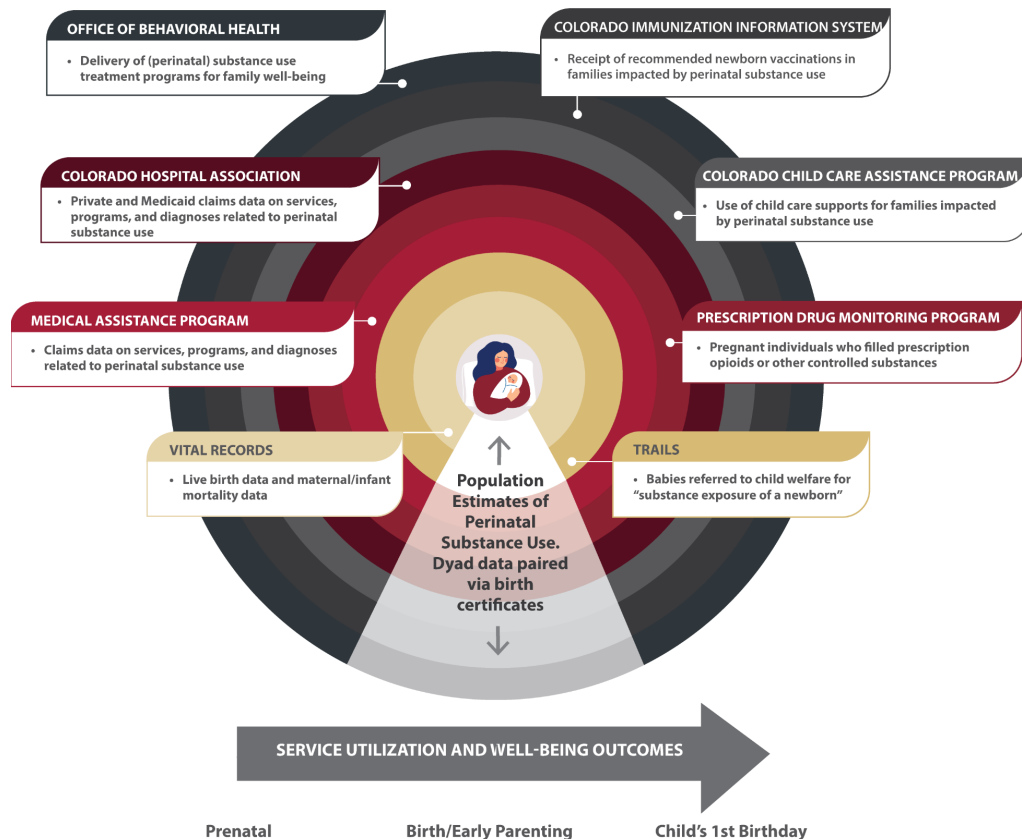


Introduction

The goal of the perinatal substance use data linkage project is to inform policy and practice efforts aimed at strengthening families impacted by perinatal substance use and substance use disorders (SU/SUD). The project is unique in Colorado because it centers maternal-infant dyads, their health outcomes, and services received prenatally through the first year of life. As such, this study can bring into focus opportunities for prevention, treatment, and support of dyads impacted by SU/SUD during the perinatal period. This multi-year research agenda outlines a strategy for leveraging the data linkage project to guide state investments and decision-making in policies and practices positioned to improve the health and well-being of families impacted by substance use during pregnancy.

Senate Bill (SB) 19-228 authorized the Perinatal Substance Use Data Linkage Project for the purposes of planning, implementation, and evaluating public health actions to improve outcomes for families impacted by substance use during pregnancy. The project aims to generate annual population estimates of perinatal substance use, trends in health outcomes, and service utilization patterns for impacted maternal-infant dyads. Experts from Colorado’s state agencies, universities, medical providers, the Substance Exposed Newborns Steering Committee (now SuPPoRT Colorado) of the Attorney General’s Substance Abuse Trend and Response Task Force, advocacy groups, and families recommended a set of core state administered data systems for inclusion in this project. These data sources are authorized for access and linking in the data linkage project through SB21-137, as illustrated in Figure 1, serving as the roadmap for this multi-year research agenda.

Figure 1. Data Linkages authorized under SB21-137





Development of the Multi-Year Research Agenda

This agenda was informed by cross-system stakeholder dialogue, study findings to date, the current evidence base, leading legislation, and state decision-maker priorities for data-informed investments:

- [SuPPoRT Colorado](#): Supporting Perinatal substance use Prevention, Recovery, and Treatment in Colorado, as well as the SuPPoRT Data and Research Advisory Group and Family Advisory Board
- [Plans of Safe Care Policy Brief](#) outlining data-informed recommendations for cross-system policy and practice investments
- [Part One Study Findings](#) on protective and risk factors for child welfare involvement
- [Part One Supplemental Findings](#) on maternal and infant mortality in the first year of life
- Existing research evidence on perinatal substance use and family strengthening
- State and national legislation related to child welfare, health care, and prevention for perinatal SU/SUD

Priority Research Areas

Three priority research areas guide this multi-year strategic agenda.

Area 1: Generate Population Estimates

Goal 1: Develop a sustainable and replicable approach to estimating the number of maternal-infant dyads impacted by substance use during pregnancy in Colorado. Generate baseline data on population estimates to serve in future trend analysis. To achieve this goal, it is necessary to fully engage medical claims data and the Prescription Drug Monitoring Program (PDMP) as data partners in the Linked Information Network of Colorado (LINC). Table 1 illustrates progress toward onboarding the essential data partners necessary to achieve Goal 1.

Research Question 1: What is the size of the population of maternal-infant dyads with prenatal SU/SUD?

Table 1. Progress Toward Onboarding Goal 1 Essential Data Partners

Data Source	Current Status	Next Steps Toward Fully Engaged
Medical Assistance Program	Partially Engaged: A limited Medicaid dataset has been identified and requested, with a plan to connect 2019 birth records (inclusive of prenatal and postnatal periods) to other state administered data sources.	The limited dataset requested will provide valuable information on feasibility of linking data and the conditions needed for the Colorado Department of Health Care Policy and Financing (HCPF) to participate as a full data partner in LINC. Lessons learned from this dataset will be used to guide next steps needed towards full engagement.



Data Source	Current Status	Next Steps Toward Fully Engaged
Colorado Hospital Association	Exploratory: Initial feasibility conversations about onboarding Colorado Hospital Association (CHA) data into LINC for this project have started. CHA data are inclusive of private pay and Medicaid data. Further, it has information on claims that were submitted but not reimbursed.	Continue feasibility conversations about onboarding CHA, with a focus on what data CHA can contribute, the value of these data to the project, and the conditions needed for CHA to participate as a fully engaged data partner in LINC.
Prescription Drug Monitoring Program Data	Partially Engaged: Approval has been granted to connect a limited dataset for 2018 to 2019 live birth records (inclusive of prenatal and postnatal periods) to other state administered data sources.	The limited dataset requested will provide valuable information on feasibility of linking data and the conditions needed for PDMP to participate as full data partners in LINC. Lessons learned from this dataset will be used to guide next steps needed towards full engagement.

Note. All-Payer Claims Data is not in this strategic research agenda because it does not include substance use claims.

Area 2: Explore System Utilization and Correlates with Health and Child Welfare Outcomes

Goal 2: Improve cross-system care coordination by identifying patterns of health and human service system utilization, including: a) service touch points commonly utilized, b) underutilized service touch points, and c) service touch points that are associated with improved health and child welfare outcomes. To achieve this goal, it is necessary to onboard the Colorado Child Care Assistance Program (CCCAP), the Colorado Immunization Information System, and the Colorado Department of Human Services’ Office of Behavioral Health (CDHS/OBH) into LINC. This is in addition to ensuring full engagement of medical claims data (HCPF, CHA) and PDMP as data partners in LINC. Table 2 illustrates priority sequencing in onboarding the additional data partners necessary to achieve Goal 2 and their value to the project.

- Research Question 2: What are the characteristics of maternal-infant dyads that are identified in administrative data sources as impacted by substance use during a pregnancy or at risk of substance use during a pregnancy?**
- Research Question 3: What is the association between health and human service utilization patterns and maternal-infant health outcomes in the perinatal period among dyads impacted by prenatal SU/SUD?**
- Research Question 4: What are the prevalence and predictors of child welfare referral, response, and involvement among dyads impacted by prenatal SU/SUD?**



Table 2. Progress Toward Onboarding Goal 2 Additional Data Partners

Data Source	Value	Onboarding Sequence
Colorado Child Care Assistance Program	New parents need support in caring for the infant so that prevention, treatment, and recovery services can be fully accessed and used. This is especially important for families with medically fragile infants, where respite care may be needed frequently. Child care assistance program data can help inform the picture of protective factors and correlates with health and child welfare outcomes.	After medical claims data and PDMP data partners are fully engaged in LINC.
Colorado Immunization Information System	Newborn immunizations are part of well-baby care, a preventative measure that is important for a healthy start to life. Immunization data can help inform the picture of health care outcomes in the first year of life and correlates to health and child welfare outcomes.	After medical claims data and PDMP data partners are fully engaged in LINC.
Office of Behavioral Health	Several prevention, treatment, and recovery programs for perinatal SU/SUD are administered through CDHS/OBH. Identifying program receipt patterns can inform the picture of protective factors and correlates with health and child welfare outcomes.	After CCCAP, Colorado Immunization Information System, medical claims, and PDMP data partners are fully engaged in LINC.

Note. We will continue to explore additional data sources and partners that can expand the picture of service utilization patterns for improving cross-system care coordination.

Area 3: Capacity Building for Evaluation of Policies and Programs

Goal 3: Build capacity to leverage these innovative data linkages to inform evaluation of policies and programs designed to strengthen families impacted by perinatal SU/SUD. To achieve this goal, the data partners illustrated in [Figure 1](#) must be fully onboarded to LINC. This will allow for state agencies and researchers to request these data for evaluation of policies and programs and, if approved, receive access to those data in a timely manner. For example, CDHS is resourcing a four-year pilot program for Plans of Safe Care (POSC) and the health and safety outcomes of interest are broader than child welfare involvement. By onboarding all data partners, inputs and outcomes of the POSC pilot can be more comprehensively assessed.

Research Question 5: What perinatal SU/SUD policy and program evaluations can be informed and strengthened by the perinatal substance use data linkage project?

Key Design Considerations

Six study design considerations will be centered as this strategic research agenda unfolds.

1. Flexibility and Responsiveness

The strategic research agenda is intended to be flexible and responsive to new policy and practice opportunities, decision-making goals, and community and family needs. As such, we anticipate refining



the three priority research areas based on emergent issues and during ongoing stakeholder engagement, co-design, and data partnerships.

2. Informed by Qualitative Study

The Office of State Planning and Budgeting has provided funding for a two-year qualitative research study with families impacted by perinatal SU/SUD. This qualitative study will elevate family voice, add contextual understanding to the data linkage project, and yield more holistic and constituent-informed intervention and prevention strategies. The study is planned for State Fiscal Year (SFY) 2023 through SFY2024; findings and lessons learned from the qualitative study will inform this multi-year agenda.

3. Data Access

To fully realize the goals of the data linkage project, additional work is needed to onboard necessary data partners (see [Table 1](#) and [Table 2](#)). Answering research questions is likely to be an iterative process. As new data sources are onboarded to LINC or the years or breadth of data within a data source (e.g., Medicaid) is expanded, more analyses can be conducted.

4. Data Partners

In addition to those data partners named in [Figure 1](#), additional data partners may be explored for onboarding and inclusion in the project. This multi-year agenda will be amended to include these data partners and the value they bring to the project.

5. Characteristics of Maternal-infant Dyads

The characteristics of maternal-infant dyads (e.g., race/ethnicity, socioeconomic status, maternal age), the type of substance use, and the system that flagged risk of or evidence of impacts of SU/SUD can inform tailored policy and practice solutions. Research Question 2 will help us elucidate, through the statistical method of Latent Class Analysis, groups of maternal-infant dyads with shared characteristics. Dyad characteristics are essential for promoting culturally responsive solutions, creating a data-informed understanding of inequities, and right-sizing strategies toward modifiable risk and protective factors.

6. Stakeholder Engagement

We will continue to engage stakeholders in the design, execution, meaning-making, and application of this multi-year research agenda. This includes stakeholders from Colorado's state agencies, universities, medical providers, the SuPPoRT Colorado Steering Committee of the Attorney General's Substance Abuse Trend and Response Task Force, advocacy groups, and families.

Next Steps

This strategic research agenda is anticipated to unfold over the next three to five years. Activating this agenda will be done in collaboration with study partners and in alignment with Colorado's practice, policy, and fiscal investments in promoting well-being for families impacted by substance use during pregnancy.