# Phase One Supplemental: Maternal & Infant Mortality in the First Year of Life

**Maternal and infant mortality outcomes in the first year of life for mother-infant dyads with child welfare involvement**

## REPORT HIGHLIGHTS:

This study creates a **baseline understanding** of infant and maternal mortality outcomes for families involved in child welfare and impacted by perinatal substance use:

- The **pregnancy-associated mortality rate** for mothers who were involved in child welfare and impacted by perinatal substance use was approximately 4% lower than the pregnancy-associated mortality rate for all Colorado mothers.

- The **leading cause of maternal death** for mothers involved in child welfare and impacted by perinatal substance use was accidental drug overdose, mirroring statewide maternal death trends.

- The **mortality rate for infants** involved in child welfare and impacted by perinatal substance use was over two times higher than Colorado's infant mortality rate in 2013 and 6.3% higher than the state average in 2016.

- In the **most recent study years**, the **mortality rate for infants** involved in child welfare and impacted by perinatal substance use **has declined** and the trend is now below the state average.

- **Results inform policy and practice aimed at preventing unnecessary deaths in the first year of life**, including the need for Plans of Safe Care; ensuring accessible treatment services; and leveraging new policies and funding streams.

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# Executive Summary

Comprehensively addressing perinatal substance use in Colorado requires robust data-informed policy and practice. The Colorado Legislature's Study Committee on Opioid and Other Substance Use Disorders responded to this need with SB19-228, a data linkage project aimed at using administrative records to inform and advance state policies and programs that strengthen families impacted by perinatal[i] substance use and substance use disorders (SUD).

> This data linkage project is a first of its kind in Colorado because it considers the health and well-being of mothers and infants as a unit—even during times when they may be physically separated for medical care, safety, or permanency.[ii]

The goal of linking data across state administrative data systems is to advance lawmaker, practitioner, and advocates understanding of trends and outcomes in perinatal substance use for Colorado families. Multiple contextual factors influence substance use during pregnancy and national research has found that perinatal substance use variably impacts women of all races, incomes, education and employment levels, and geographic regions. Young women and those living in poverty experience the highest prevalence rates, often due to multiple social inequities and structural factors.[1, 2, 3] In Colorado, the state health department reported a 98% increase in newborns exposed to opioids prenatally between 2012 to 2018.[4] Beyond opioids, the Substance Abuse and Mental Health Services Administration estimates that prenatal exposure to alcohol or illicit drugs affects 10-11% of all births.[5] Understanding the geographic and cultural variability associated with perinatal substance use in Colorado and how mother-infant dyads are engaging with health care, prevention, and public benefit systems can inform policies and practices aimed at improving family health and well-being.

*"It is not possible to fully promote the health and well-being of a child without supporting their caregiver, particularly during the perinatal period. Integrated data on mothers and their children are needed to understand how to best support families in Colorado."*

**- Kathryn (Kathi) Wells, M.D., Co-chair of SEN Steering Committee; Associate Professor, Department of Pediatrics, University of CO School of Medicine; Executive Director of the Kempe Center**

This report supplements the first phase of the data linkage project, which examined the risk of infant removal by child welfare shortly after a birth event due to a referral of substance exposure, by examining mortality data following a live birth through the first year of life for these mother-infant dyads.[iii] Baseline understanding of mortality outcomes for this population is critical to advancing efforts that prevent unnecessary deaths. Moreover, because involvement in child welfare can lead to increased family stress and separation of the mother-infant dyad and can heighten mental and behavioral health issues, understanding mortality data for child welfare-involved dyads is central to considerations of equity and to informing practice and policy recommendations for families experiencing heightened vulnerability.

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[i] In this report, we use the term "perinatal" to refer to the time before (i.e., pregnancy) through the first year after the birth.

[ii] Permanency in this context is "a legally permanent nurturing family" consistent with the Child Welfare Family Services Review definition.

[iii] The full Part One report for the data linkage project can be found [here](#).

## About the Data Linkage Project

To better understand perinatal substance use in Colorado, the legislature called for a statewide perinatal substance use data linkage project (SB19-228). The goal of this legislative mandate was to better use data to inform public health and human service actions and improve outcomes. Most existing research on perinatal substance use is focused on a singular system (e.g., health care or child welfare). The data linkage project creates a more robust understanding of perinatal substance use by focusing on the intersection of health, public assistance, and child welfare.

The data linkage project uses a mother-infant dyad approach, recognizing that infants and mothers are interconnected, their health and safety are intertwined and, therefore, engagement and outcomes are best understood when information is paired. During pregnancy, mother and infant are viewed and treated as one unit; however, following birth, the care, treatment, and support for mothers and infants are most often separated. A more holistic approach that centers the dyad after birth as well as during pregnancy can help to strengthen and coordinate early and ongoing care across systems.

**Phase One of the Data Linkage Project:** Phase One of the data linkage project focuses on mother-infant dyads involved in child welfare and opportunities to prevent the need for infant removal from the home for families impacted by prenatal substance use. Specifically, the study population includes mothers and infants who were Colorado residents at the time of the child's birth (2013-2019) and met the definition of "substance exposure of a newborn" during the prenatal period, as substantiated by a child welfare agency. As noted in the Methods section of the report, the sample consists primarily of births where the primary payment method for delivery was Medicaid. Part Two and beyond will expand the sample to include mother-infant dyads where substance use during pregnancy is evidenced in health care records. This subsequent phase will be made possible through recent passage of the Behavioral Health Recovery Act, SB21-137, which requires Medicaid and Prescription Drug Monitoring Program data to be used in this data linkage project.

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**Phase One Supplemental**

As a supplement to Phase One, mortality data following a live birth through the first year of life were obtained for mother-infant dyads involved in the original sample. This report examines trends in mortality data and contributing factors as well as compares these rates to the general population. The goal of this report is to create a baseline understanding of infant and maternal mortality outcomes for families involved in child welfare and impacted by perinatal substance use, to inform policy and practice aimed at preventing unnecessary deaths in the first year of life.

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## Phase One Supplemental Study Findings

Results of this supplemental analysis shed light on the mortality outcomes of mothers and infants with involvement in the child welfare system due to prenatal substance use. Key findings include:

- The **pregnancy-associated mortality rate** for mothers who were involved in child welfare and impacted by perinatal substance use **was approximately 4% lower** the pregnancy-associated mortality rate for all Colorado mothers.[iv]

- The **leading cause of maternal death** for mothers who were involved in child welfare and impacted by perinatal substance use was **accidental drug overdose**, mirroring statewide trends in maternal mortality.

- The **mortality rate of infants** who were involved in child welfare and impacted by perinatal substance use was **over two times higher** than Colorado's rate in 2013 and **6.3% higher** than the state average in 2016.

- In the **most recent study years**, **the mortality rate for infants** who were child welfare involved and impacted by perinatal substance use **has declined** and the trend is now below the state average.

These rates are for mother-infant dyads who were referred to child welfare shortly after a birth event for substance exposure of a newborn and that referral was substantiated. Future studies will calculate mortality rates for the broader population of mother-infant dyads impacted by perinatal substance use, who may not have been referred to child welfare.

## Study Implications

Study findings place a spotlight on the need to advance cross-system policy and practice in Colorado that prevent unnecessary deaths among maternal-infant dyads impacted by perinatal substance use. Below we highlight several implications of baseline findings established in this study and recommend leveraging the national research and practice expertise of the Colorado Maternal Mortality Review Committee and the Centers for Disease Control and Prevention Review to Action to inform these advancements.

- **Develop Plans of Safe Care.** The development of Plans of Safe Care should begin as soon as a mother-infant dyad is recognized as being impacted by substance use during the pregnancy and should continue to serve as the coordinated approach to health and well-being through the first year postpartum. Plans of Safe Care have a crucial role to play in preventable deaths given the complex origins and impacts of perinatal SUD and the need for diverse wraparound services for families (e.g., behavioral health, new parent social support, peer recovery support, SUD treatment, obstetric care, concrete supports).

- Prenatally, health care providers can work together with pregnant people and their families to create a Plan of Safe Care and introduce services that can support the health and well-being of mother-infant dyads over the long term (e.g., home visiting programs, Maternal Opioid Misuse model, co-located services). Birthing providers can partner with families to update these plans to reflect the medical and behavioral health needs of dyads after the birth. Prior research from this data linkage project demonstrated the medical fragility of infants affected by prenatal substance use, who may require additional clinical care after birth as well as bolstered support, education, and resources for family members caring for the higher-needs infant. [6] Continued implementation and

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[iv] Although the pregnancy-associated death rate is the best comparison group for the definition of maternal morality used in this study, it is an imperfect comparison group for this sample. The pregnancy-associated rate includes maternal deaths during pregnancy and the first year postpartum. For this sample, mortality was examined among mother-infant dyads following a live birth, meaning the mother survived at least until the birth event.

tailoring of the Plan of Safe Care can be done by caseworkers, community-based supports, and social service and health care providers throughout the first year of life.

- **Establish a State Intermediary for Implementation of Plans of Safe Care.** A state intermediary could be positioned to support development and implementation of Plans of Safe Care throughout the perinatal period, regardless of whether a family is or becomes child welfare involved. In 2016, the Child Abuse Prevention and Treatment Act (CAPTA) was amended by Congress with a requirement that states utilize a Plan of Safe Care for an infant born with and identified as being affected by substance use, withdrawal symptoms, or fetal alcohol spectrum disorders. The Plan of Safe Care is intended to ensure the safety and well-being of an infant impacted by prenatal substance use following release from a health care provider. Importantly, states are given flexibility in implementation of this CAPTA requirement and a cross-system, collaborative approach to meet the wide-ranging needs of infants and their families is recommended. As part of this flexibility, the plan can be initiated prenatally by a designated community organization, since child welfare cannot become involved with the family due to prenatal substance exposure until after the birth event.

  Given this preferred option to initiate prenatally, the importance of tailoring the plan ongoing to meet emergent needs and strengths, and the importance of cross-system coordination, establishing a state intermediary (outside of the child welfare system) for the implementation of Plans of Safe Care in Colorado may prove to be a high return investment in meeting CAPTA requirements and cultivating health and well-being for families, including prevention of unnecessary maternal and infant deaths due to perinatal substance use. Given the pregnancy-associated death rate for this sample was approximately 4% lower than the Colorado statewide rate, findings may indicate that families involved in child welfare receive more services and supports that meet their needs and contribute to this lower rate. As such, bolstering Plans of Safe Care for child welfare involved families *and* expanding access to Plans of Safe Care for families not involved in child welfare is a promising approach for leveraging services inside and outside of the child welfare system and reducing mortality rates in Colorado.

- **Ensure Substance Use Disorder and Behavioral Health Treatment Services are Accessible for Mothers of Infants.** Prevention of unnecessary maternal and infant deaths requires coordinated care services that begin prenatally and continue through the first year of life. This need is particularly pronounced when considering accidental drug overdose was the leading cause of maternal death in this study. The recommendation to establish a state intermediary for Plans of Safe Care that is outside of the child welfare system may help reduce the fear some mothers have that if they seek SUD treatment services, they will lose their baby.[7] Following, accessibility of services involves taking a comprehensive look at barriers and facilitators to accessing treatment. This study sample was primarily made up of a Medicaid-eligible population, showing the need to ensure Medicaid coverage extends postpartum and includes services that can promote accessible and effective treatment. The passage of SB21-194 (Maternal Health Providers) is an important start to ensuring expanded and effective coverage, with one of the provisions requiring the Colorado Department of Health Care Policy and Financing to seek an amendment to the state's Medical Assistance Plan to provide 12 months of postpartum medical benefits to individuals who qualified for benefits during pregnancy. Efforts can also be catalyzed by community-based programs that aim to reduce barriers to treatment engagement and build protective factors for birthing parents, including the vital need for social support and connection with their child in the womb and into early parenting. For instance, Illuminate Colorado is currently conducting a statewide pilot program to provide child care and

other support services to families experiencing a SUD, and Cultura Cura Belly is a new Denver-based program providing doula care and healing arts support to pregnant persons who have been impacted by substance misuse or addiction. Investment in such programs has the potential to significantly catalyze accessible and effective treatment, moving perinatal substance use treatment efforts further upstream to prevent unnecessary deaths and build early wellness that helps to avoid deleterious downstream implications.

- **Leverage New Policies and Funding Streams in Preventing Unnecessary Deaths and Achieving Birth Equity.** The 2021 Colorado Legislative Session resulted in the passage of several critical, intersecting bills by the General Assembly that can direct and advance practice and policy aimed at preventing unnecessary maternal and infant deaths among families impacted by perinatal SUD. For instance, in addition to extending Medicaid coverage 12-months postpartum, SB21-194 also has several provisions related to aligning data and systems to improve equity in perinatal health and care – provisions that can reduce the unacceptable disparities in maternal and infant mortality and morbidity observed for Black, Indigenous, and People of Color (BIPOC).[8] In addition, SB21-137 (Behavioral Heath Recovery Act) includes several provisions related to programming and funding for peer recovery and support efforts, which can be further catalyzed by stimulus funding from the American Rescue Plan, including $5.28 million allocated for peer-based recovery support services through the Block Grant funding stream, $4.9 million for workforce supports, including training for peer specialists and efforts to advance inclusion of BIPOC communities in the behavioral health field, and $2.6 million for connecting pregnant and parenting persons to treatment and recovery. Opioid Settlement Funds can also be leveraged in these efforts and Illuminate Colorado has issued guidance on a recommended framework for dedicating opioid settlement funds to children and families impacted by perinatal substance use, informed by the Colorado Substance Exposed Newborns Steering Committee as well as the Colorado Family Advisory Board. SB21-137 also includes $26 million for a statewide care coordination infrastructure, which is the overarching recommendation arising from both the full Part One study of this data linkage project as well as this supplemental focus on preventable deaths.
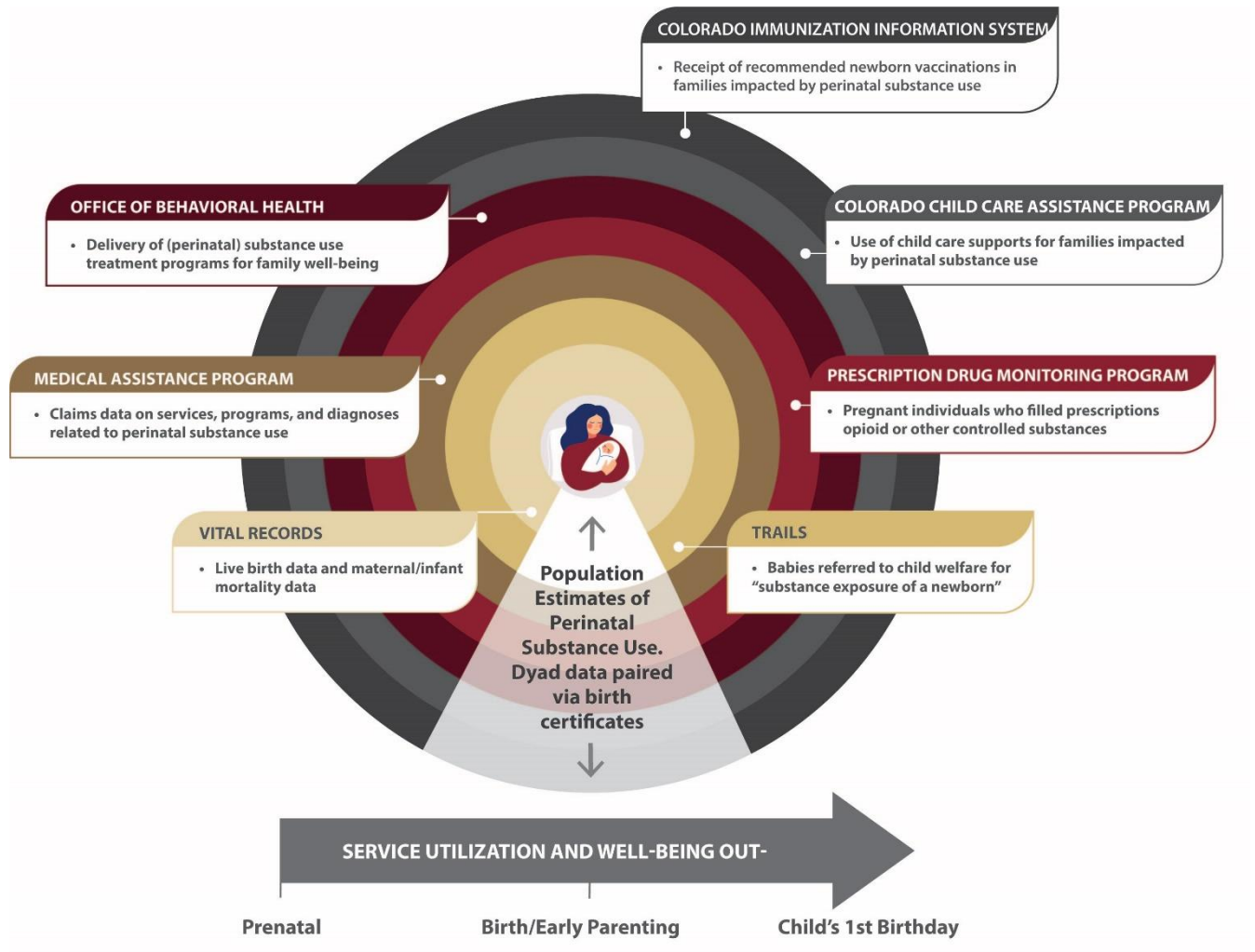
These implications are in addition to and deepen implications from the full Part One study and are situated within national literature and leading best practices for the prevention, treatment, and support of families impacted by perinatal substance use.

## Next Phases of Research

The Behavioral Health Recovery Act (SB21-137), passed in the 2021 Colorado Legislative Session, authorized access to additional data sources for use in this data linkage project, as illustrated in the figure on the next page. The inclusion of health care records will build the capacity to routinely monitor population-level incident rates of prenatal substance use and health outcomes for mother-infant dyads throughout the perinatal period. The goal is to better understand the risk and protective factors pregnant people impacted by perinatal SUD experience in accessing adequate prenatal care; identify opportunities for more effective screening and treatment approaches; and inform systems and policy changes that can strengthen the health and life path of Colorado families. The Behavioral Health Recovery Act allocated resources to begin this next phase of research and the project team is actively seeking additional support through grant proposals.

Data Linkages Required under SB21-137



**COLORADO IMMUNIZATION INFORMATION SYSTEM**
- Receipt of recommended newborn vaccinations in families impacted by perinatal substance use

**OFFICE OF BEHAVIORAL HEALTH**
- Delivery of (perinatal) substance use treatment programs for family well-being

**COLORADO CHILD CARE ASSISTANCE PROGRAM**
- Use of child care supports for families impacted by perinatal substance use

**MEDICAL ASSISTANCE PROGRAM**
- Claims data on services, programs, and diagnoses related to perinatal substance use

**PRESCRIPTION DRUG MONITORING PROGRAM**
- Pregnant individuals who filled prescriptions opioid or other controlled substances

**VITAL RECORDS**
- Live birth data and maternal/infant mortality data

**TRAILS**
- Babies referred to child welfare for "substance exposure of a newborn"

Population Estimates of Perinatal Substance Use. Dyad data paired via birth certificates

SERVICE UTILIZATION AND WELL-BEING OUT-

Prenatal          Birth/Early Parenting          Child's 1st Birthday

# Acknowledgements

# Suggested Citation

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# Study Partners

The Colorado Perinatal Substance Use Data Linkage Project was designed in partnership with the Center for Prescription Drug Abuse Prevention, Illuminate Colorado, the Substance Exposed Newborns Steering Committee, and experts from state agencies, non-profits, families with lived experience, and the academic community. The project ensures decision-makers across sectors have access to routine and rigorous Colorado-specific data that can inform further advancements in policy and practice.

**Center for Prescription Drug Abuse Prevention** coordinates Colorado's response to the misuse of medications such as opioids, stimulants, and sedatives. They address this major public health crisis in partnership with many agencies, organizations, and community coalitions, working together to educate, conduct public outreach and research, and improve safe disposal and treatment.
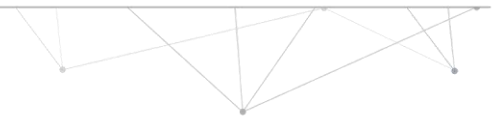
**Illuminate Colorado** is dedicated to strengthening families, organizations, and communities to prevent child maltreatment in Colorado. Holding five national affiliations and serving as backbone support for four statewide coalitions, including the Substance Exposed Newborns Steering Committee, Illuminate leverages

its cross-system connections to push forward multi-level efforts aimed at increasing resources and support for families impacted by or at risk of perinatal substance use.

**Substance Exposed Newborns Steering Committee** is working to identify and implement strategies to reduce the number of families affected by perinatal substance use in Colorado and improve outcomes for impacted parents/caregivers, children, and families across the lifespan. As a committee of the Substance Abuse Trend and Response Task Force, the Committee is co-chaired by the executive directors of Illuminate Colorado and the Kempe Center for the Prevention & Treatment of Child Abuse and Neglect.

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# Introduction

Comprehensively addressing perinatal substance use in Colorado requires robust data-informed policy and practice. The Colorado Legislature's Study Committee on Opioid and Other Substance Use Disorders responded to this need with SB19-228, a data linkage project aimed at using administrative records to inform and advance state policies and programs that strengthen families impacted by perinatal[v] substance use and substance use disorders (SUD).

> **This data linkage project is a first of its kind in Colorado because it considers the health and well-being of mothers and infants as a unit—even during times when they may be physically separated for medical care, safety, or permanency.[vi]**

The goal of linking data across state administrative data systems is to advance lawmaker, practitioner, and advocates understanding of trends and outcomes in perinatal substance use for Colorado families. Multiple contextual factors influence substance use during pregnancy and national research has found that perinatal substance use variably impacts women of all races, incomes, education and employment levels, and geographic regions. Young women and those living in poverty experience the highest prevalence rates, often due to multiple social inequities and structural factors.[9, 10, 11] In Colorado, the state health department reported a 98% increase in newborns exposed to opioids prenatally between 2012 to 2018.[12] Beyond opioids, the Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that prenatal exposure to alcohol or illicit drugs affects 10-11% of all births.[13] Understanding the geographic and cultural variability associated with perinatal substance use in Colorado and how mother-infant dyads are engaging with health care, prevention, and public benefit systems can inform policies and practices aimed at improving family health and well-being.

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**About Gender-Inclusive Language**

Although we primarily use the term "mother" and/or "mother-infant dyad" and/or "pregnant/postpartum women" in this report to refer to those experiencing pregnancy, birth, and the early postpartum period, we acknowledge and validate all gender identities that experience childbearing. Because data reported in this study use administrative datasets that only capture sex assigned at birth, we have no way of knowing the gender identities of participants. We honor that pregnancy, birth, and family formation are experienced by individuals across the gender continuum.

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## About the Data Linkage Project

To better understand perinatal substance use in Colorado, the legislature called for a statewide perinatal substance use data linkage project (SB19-228, with additional resources and authorizing legislation under SB20-28 and SB21-137). The goal of this legislative mandate was to better use data to inform public health and human service actions and improve outcomes. Most existing research on perinatal substance use is focused on a singular system (e.g., health care or child welfare). The data linkage project creates a more

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[v] In this report, we use the term "perinatal" to refer to the time before (i.e., pregnancy) through the first year after the birth.

[vi] Permanency in this context is "a legally permanent nurturing family" consistent with the Child Welfare Family Services Review definition.

robust understanding of perinatal substance use by focusing on the intersection of health, public assistance, and child welfare.

The mother-infant dyad approach used in this study recognizes that infants and mothers are interconnected, their health and safety are intertwined, and therefore engagement and outcomes are best understood when information is paired. During pregnancy, mother and infant are viewed and treated as one unit; however, following birth, the care, treatment, and support for mothers and infants are most often separated. A more holistic approach that centers the dyad after birth as well as during pregnancy can help to strengthen and coordinate early <u>and</u> ongoing care across systems.

> *"When families impacted by substance use disorders have information and access to resources without fear and stigma, we strengthen the foundation for families and communities to thrive."*
>
> **- Jade Woodard, Executive Director, Illuminate Colorado**

**Phase One of the Data Linkage Project** focuses on mother-infant dyads who were referred to child welfare shortly after a birth event for substance exposure of a newborn and that referral was substantiated. During child welfare involvement, an infant may be removed from the home when there is imminent concern for the child's safety or health. Separating an infant from their mother can disrupt early bonding and healthy development, while also creating stress for the postpartum mother and entire family.[14, 15] By focusing on the subset of child welfare-involved mother-infant dyads, this research offered unique insights into how health care, public assistance, and child welfare systems can coordinate efforts to strengthen families, prevent family separation, and decrease foster care placement for these Colorado babies. However, the data in Phase One remain limited because the dataset only included those dyads for whom a referral was made to child welfare and the referral was substantiated. Additionally, the sample consists primarily of births where the primary payment method for delivery was Medicaid. Part Two and beyond will expand the sample to include mother-infant dyads where substance use during pregnancy is evidenced in health care records.

**Phase One Supplemental** (i.e., this report) supplements the full Part One report by exploring mortality data following a live birth through the first year of life for mother-infant dyads in the original sample. This report examines trends in mortality data and contributing factors as well as compares these rates to the general population. The goal of this report is to create a baseline understanding of infant and maternal mortality outcomes for families involved in child welfare and impacted by perinatal substance use, to inform policy and practice aimed at preventing unnecessary deaths in the first year of life.

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**About the Study Sample**

The mother-infant dyads included in this study were referred to child welfare for "substance exposure of a newborn" and that referral was substantiated. This means that either the infant tested positive at birth for a schedule I controlled substance, as defined in section 18-18-203, C.R.S., or a schedule II controlled substance, as defined in section 18-18-204, C.R.S., unless the child tests positive for a schedule II controlled substance as a result of the mother's lawful intake of such substance as prescribed OR when there are observable effects of substance exposure in the infant (e.g., inability to eat, sleep, and soothe).

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**Research Aims for Phase One Supplemental**

> **Describe trends in infant and maternal mortality (focus: pregnancy-associated deaths) following a live birth and through the first year of life for families impacted by perinatal substance use and involved in child welfare.**
>
> **Compare infant and pregnancy-associated death rates for this sample to general population rates of maternal and infant mortality in Colorado.**

## Phase One Supplemental Findings

Results of this supplemental analysis shed light on the mortality outcomes of mothers and infants with involvement in the child welfare system due to prenatal substance use. Key findings include:

- Averaged across all years of the study, the **pregnancy-associated mortality rate** identified in this sample was **approximately 4% lower** than the Colorado rate in 2016.[vii]

- The leading cause of maternal death identified in this sample was **accidental drug overdose**, mirroring statewide trends in maternal mortality.

- The **infant mortality rate** identified in this sample was **over two times higher** than Colorado's rate in 2013 and **6.3% higher** than the state average in 2016.

- In the **most recent study years**, the **infant mortality rate** in this sample **has declined** and the trend is now below the state average.

These rates are for mother-infant dyads who were referred to child welfare shortly after a birth event for substance exposure of a newborn and that referral was substantiated. Future studies will calculate mortality rates for the broader population of mother-infant dyads impacted by perinatal substance use, who may not have been referred to child welfare.

## Study Implications

Study findings place a spotlight on the need to advance cross-system policy and practice in Colorado that prevent unnecessary deaths among maternal-infant dyads impacted by perinatal substance use. Below we highlight several implications of baseline findings established in this study and recommend leveraging the national research and practice expertise of the Colorado Maternal Mortality Review Committee and the Centers for Disease Control and Prevention Review to Action to inform these advancements.

- **Develop Plans of Safe Care.** The development of Plans of Safe Care should begin as soon as a mother-infant dyad is recognized as being impacted by substance use during the pregnancy and should continue to serve as the coordinated approach to health and well-being through the first year postpartum. Plans of Safe Care have a crucial role to play in preventable deaths given the complex origins and impacts of perinatal SUD and the need for diverse wraparound services for families (e.g., behavioral health, new parent social support, peer recovery support, SUD treatment, obstetric care, concrete supports).

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[vii] Although the pregnancy-associated death rate is the best comparison group for the definition of maternal morality used in this study, it is an imperfect comparison group for this sample. The pregnancy-associated rate includes maternal deaths during pregnancy and the first year postpartum. For this sample, mortality was examined among mother-infant dyads following a live birth, meaning the mother survived at least until the birth event.

Prenatally, health care providers can work together with pregnant people and their families to create a Plan of Safe Care and introduce services that can support the health and well-being of mother-infant dyads over the long term (e.g., home visiting programs, Maternal Opioid Misuse model, co-located services). Birthing providers can partner with families to update these plans to reflect the medical and behavioral health needs of dyads after the birth. Prior research from this data linkage project demonstrated the medical fragility of infants affected by prenatal substance use, who may require additional clinical care after birth as well as bolstered support, education, and resources for family members caring for the higher-needs infant. [16] Continued implementation and tailoring of the Plan of Safe Care can be done by caseworkers, community-based supports, and social service and health care providers throughout the first year of life.

- **Establish a State Intermediary for Implementation of Plans of Safe Care.** A state intermediary could be positioned to support development and implementation of Plans of Safe Care throughout the perinatal period, regardless of whether a family is or becomes child welfare involved. In 2016, the Child Abuse Prevention and Treatment Act (CAPTA) was amended by Congress with a requirement that states utilize a Plan of Safe Care for an infant born with and identified as being affected by substance use, withdrawal symptoms, or fetal alcohol spectrum disorders. The Plan of Safe Care is intended to ensure the safety and well-being of an infant impacted by prenatal substance use following release from a health care provider. Importantly, states are given flexibility in implementation of this CAPTA requirement and a cross-system, collaborative approach to meet the wide-ranging needs of infants and their families is recommended. As part of this flexibility, the plan can be initiated prenatally by a designated community organization, since child welfare cannot become involved with the family due to prenatal substance exposure until after the birth event.

  Given this preferred option to initiate prenatally, the importance of tailoring the plan ongoing to meet emergent needs and strengths, and the importance of cross-system coordination, establishing a state intermediary (outside of the child welfare system) for the implementation of Plans of Safe Care in Colorado may prove to be a high return investment in meeting CAPTA requirements and cultivating health and well-being for families, including prevention of unnecessary maternal and infant deaths due to perinatal substance use. Given the pregnancy-associated death rate for this sample was approximately 4% lower than the Colorado statewide rate, findings may indicate that families involved in child welfare receive more services and supports that meet their needs and contribute to this lower rate. As such, bolstering Plans of Safe Care for child welfare involved families *and* expanding access to Plans of Safe Care for families not involved in child welfare is a promising approach for leveraging services inside and outside of the child welfare system and reducing mortality rates in Colorado.

- **Ensure Substance Use Disorder and Behavioral Health Treatment Services are Accessible for Mothers of Infants.** Prevention of unnecessary maternal and infant deaths requires coordinated care services that begin prenatally and continue through the first year of life. This need is particularly pronounced when considering accidental drug overdose was the leading cause of maternal death in this study. The recommendation to establish a state intermediary for Plans of Safe Care that is outside of the child welfare system may help reduce the fear some mothers have that if they seek SUD treatment services, they will lose their baby.[17] Following, accessibility of services involves taking a comprehensive look at barriers and facilitators to accessing treatment. This study sample was

primarily made up of a Medicaid-eligible population, showing the need to ensure Medicaid coverage extends postpartum and includes services that can promote accessible and effective treatment. The passage of SB21-194 (Maternal Health Providers) is an important start to ensuring expanded and effective coverage, with one of the provisions requiring the Colorado Department of Health Care Policy and Financing to seek an amendment to the state's Medical Assistance Plan to provide 12 months of postpartum medical benefits to individuals who qualified for benefits during pregnancy. Efforts can also be catalyzed by community-based programs that aim to reduce barriers to treatment engagement and build protective factors for birthing parents, including the vital need for social support and connection with their child in the womb and into early parenting. For instance, Illuminate Colorado is currently conducting a statewide pilot program to provide child care and other support services to families experiencing a SUD, and Cultura Cura Belly is a new Denver-based program providing doula care and healing arts support to pregnant persons who have been impacted by substance misuse or addiction. Investment in such programs has the potential to significantly catalyze accessible and effective treatment, moving perinatal substance use treatment efforts further upstream to prevent unnecessary deaths and build early wellness that helps to avoid deleterious downstream implications.

- **Leverage New Policies and Funding Streams in Preventing Unnecessary Deaths and Achieving Birth Equity.** The 2021 Colorado Legislative Session resulted in the passage of several critical, intersecting bills by the General Assembly that can direct and advance practice and policy aimed at preventing unnecessary maternal and infant deaths among families impacted by perinatal SUD. For instance, in addition to extending Medicaid coverage 12-months postpartum, SB21-194 also has several provisions related to aligning data and systems to improve equity in perinatal health and care – provisions that can reduce the unacceptable disparities in maternal and infant mortality and morbidity observed for Black, Indigenous, and People of Color (BIPOC).[18] In addition, SB21-137 (Behavioral Heath Recovery Act) includes several provisions related to programming and funding for peer recovery and support efforts, which can be further catalyzed by stimulus funding from the American Rescue Plan, including $5.28 million allocated for peer-based recovery support services through the Block Grant funding stream, $4.9 million for workforce supports, including training for peer specialists and efforts to advance inclusion of BIPOC communities in the behavioral health field, and $2.6 million for connecting pregnant and parenting persons to treatment and recovery. Opioid Settlement Funds can also be leveraged in these efforts and Illuminate Colorado has issued guidance on a recommended framework for dedicating opioid settlement funds to children and families impacted by perinatal substance use, informed by the Colorado Substance Exposed Newborns Steering Committee as well as the Colorado Family Advisory Board. SB21-137 also includes $26 million for a statewide care coordination infrastructure, which is the overarching recommendation arising from both the full Part One study of this data linkage project as well as this supplemental focus on preventable deaths.

These implications are in addition to and deepen implications from the full Part One study and are situated within national literature and leading best practices for the prevention, treatment, and support of families impacted by perinatal substance use.

# Literature Review

- Maternal mortality
- Infant mortality
- Mortality rates and substance use disorders

# Literature Review

## Comprehensive Literature Review on Prenatal Substance Use

The Part One report of this data linkage project, available [here](#), includes a comprehensive literature review related to:

1. The impacts of substance use during pregnancy,

2. Trends in the use of opioids and other substances in Colorado and nationwide, and

3. Factors associated with prenatal substance use and substance use disorders.

In this supplemental report, a brief synthesis of the literature on infant and maternal mortality rates is presented. The rates in this literature review are presented with the intent of contextualizing study findings. For the purposes of this supplemental report, we do not engage a deep dive review of the broader considerations around maternal and infant mortality, including the health, social, and structural factors that influence this complex topic. We intend to engage this deeper dive during Part Two of the study.

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**Best Practices in Quantifying and Understanding Maternal Mortality**

This report uses the term "maternal mortality" to refer to deaths during pregnancy (after 20 weeks gestation), childbirth, and up to 1 year postpartum. We draw on definitions provided by *Review to Action* – a nationally leading resource supported through partnership between the Association of Maternal and Child Health Programs and the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality administered by the Centers for Disease Control and Prevention. *Review to Action* promotes the state-based maternal mortality review process as the best way to quantify and understand maternal mortality and prioritize interventions to improve maternal health. Colorado's Maternal Mortality Review Committee (MMRC) is administered by the state's Maternal Mortality Prevention Program and Colorado's MMRC is a network affiliate of *Review to Action.*

- **Pregnancy-associated death**: Death while pregnant or within 1 year of the end of the pregnancy, regardless of cause. This measure is reported as a ratio per 100,000 births. These deaths encompass the broadest definition of maternal mortality. Accidental drug overdose and behavioral and mental health issues are counted under pregnancy-associated deaths. As such, ***the focus of this study is on pregnancy-associated deaths.***

- **Pregnancy-related death**: Death during pregnancy or within 1 year of pregnancy from a [pregnancy complication](#), a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy. This measure is reported as a ratio per 100,000 births.

- **Maternal death**: Death during pregnancy or within 42 days of the end of pregnancy, regardless of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. This measure is reported as a ratio per 100,000 births. This definition is used by the National Center for Health Statistics and the World Health Organization.

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# Maternal Mortality

**Maternal Mortality**

The World Health Organization (WHO) defines a "maternal death" as the death of a woman during pregnancy or within 42 days after a pregnancy from any cause related to or aggravated by the pregnancy, and maternal mortality rates are calculated as the number of maternal deaths per 100,000 live births.[19] In the United States (U.S.), the maternal mortality rate rose from 17.4 deaths per 100,000 live births in 2018 to 20.1 per 100,000 live births in 2019.[20] The maternal mortality rate for Black women was almost 2.5 times higher than the rate for White women (44.0 compared to 17.0, respectively), and rates consistently increased with maternal age.[21] Women living in rural areas were also at a higher risk of maternal mortality than those in urban areas, due to a combination of health and care challenges (e.g., lack of specialists, workforce shortages, rising opioid use) and to social determinants of health (e.g., poverty).[22] This national picture demonstrates the massive health disparities experienced in childbirth and the vital necessity for policies and practices that advance birth equity.

The Centers for Disease Control and Prevention (CDC)'s National Center for Health Statistics (NCHS) implemented a change in the way maternal mortality was coded beginning in 2018 to address the underreporting of maternal deaths based on vital records. The change involved using the pregnancy status checkbox, which was added to the standard U.S. death certificate in 2003, in combination with the underlying cause of death to code maternal deaths.[23] The NCHS had previously not published official estimates of maternal mortality since 2007 to allow states sufficient time to adopt the addition of this checkbox on their death certificates.

Similarly, the Colorado Department of Public Health and Environment (CDPHE) identifies maternal deaths based on death certificates with the pregnancy status checkbox marked, an ICD-10 obstetric cause of death, linkage to live birth or infant death certificates, and the National Violent Death Reporting System.[24]

**Pregnancy-associated Death**

The Colorado MMRC, comprised of health care providers and public health professionals, examines each maternal death that occurs in the state with the goal of understanding the preceding events and preventing future maternal deaths.[25] In alignment with the *Review to Action* recommendations, the Colorado MMRC examines cases up to 1 year postpartum for a more comprehensive understanding of the contributing factors to each death.

The rate of pregnancy-associated deaths in Colorado was 47.4 per 100,000 live births in 2016, up from 24.0/100,000 in 2008.[26] Between 2014-2016, there were a total of 94 pregnancy-associated deaths in Colorado, with mental health or substance use contributing to nearly six out of 10 deaths.[27] Of these, the Colorado MMRC determined that **75.6% of these deaths were preventable.**

From 2014-2016, the leading causes of pregnancy-associated deaths in Colorado were suicide, drug overdose, injury, homicide, and cardiac conditions.[28] Pregnancy-associated deaths in Colorado fall into ten categories, as listed below:

1. Suicide
2. Homicide
3. Drug overdose

4. Sepsis/infection

5. Injury (including motor vehicle crashes)

6. Cerebrovascular accidents (stroke)

7. Cardiac conditions

8. Thrombotic pulmonary embolism

9. Other obstetric complications, including amniotic fluid embolism, hypertensive disorder, ruptured ectopic pregnancy, and uterine rupture

10. All other medical non-obstetric conditions, including cancer, autoimmune disorders, respiratory conditions, and others

**Pregnancy-related Death**

Pregnancy-related deaths have been on the rise in the U.S. over the past several decades, which stands in stark contrast to the declining rates in other high-income countries.[29] The pregnancy-related death rate was 17.3/100,000 births in 2017, up from a rate of 7.2 in 1987.[30] Part of the reason for the increase over time may be due to improved identification of pregnancy-related deaths. A study of pregnancy-related deaths in the U.S. between 2011-2015 found that approximately 60% of these deaths were preventable and did not differ significantly by race or ethnicity, although there were racial disparities in overall pregnancy-related death rates, similar to maternal mortality rates.[31,32] The CDC's Pregnancy Mortality Surveillance System, which codes and tracks pregnancy-related deaths, differs from state and local MMRCs in that the latter perform the most comprehensive reviews of deaths using information beyond what is available in vital records and are able to make determinations about pregnancy-related deaths that draw from both medical and non-medical data sources. From 2014-2016, Colorado's MMRC found that 65.8% of pregnancy-related deaths were caused by medical conditions and 34.2% were attributed to non-medical causes, such as suicide, homicide, and drug overdose.[33] An example of how a suicide may be considered pregnancy-related is if the MMRC determines that a person experienced depression for the first time during pregnancy and the suicide was a result of deteriorating mental health due to pregnancy.

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**Future Studies**

Pregnancy-associated deaths is the broadest aspect of maternal mortality and the focus of this phase one supplemental study. As the data linkage study expands beyond the population of mother-infant dyads who were referred to child welfare to also include those with heath care claims or patterns of filling prescription drugs that suggest substance misuse during the pregnancy, the sample size of the study will increase. This will allow us to also examine the narrower definition of pregnancy-related deaths, which can include intersections with substance use, as well as maternal mortality within the more strictly defined 42 days of the birth event.

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## Infant Mortality

The CDC defines infant mortality as the death of an infant after a live birth, but before their first birthday, and the infant mortality rate is calculated as the number of infant deaths for every 1,000 live births.[34] In 2019, the national infant mortality rate was 5.58 deaths per 1,000 live births.[35] The infant mortality rate in Colorado fell below the national rate at 4.7 deaths per 1,000 live births.[36] Nationally, the leading causes of infant deaths in 2019 were congenital malformations, deformations, and chromosomal abnormalities;

preterm birth and low birth weight; and unintentional injuries (e.g., burns, falls, airway obstruction).[37] Mirroring the racial disparities in maternal mortality trends, the infant mortality rate of non-Hispanic Black infants was almost double the rate of the general population (10.8/1,000), followed closely by infants identified as Native Hawaiian or Other Pacific Islander (9.4/1,000) and American Indian or Alaska Native (8.2/1,000).[38] These national statistics on infant mortality amplify the urgent need for policies and practices that address birth equity.

## Mortality Rates and Substance Use Disorders

In Colorado, accidental drug overdose was the leading cause of maternal mortality between 2004-2012 and the second leading cause between 2013-2016.[39, 40, 41] In particular, opioids are one of the greatest contributors to maternal mortality in Colorado.[42] The Colorado MMRC found that 85% of the cases they reviewed between 2008-2013 were, in fact, not pregnancy-related.[43] The leading causes of death for these cases were identified as injury (e.g., motor vehicle accidents and homicide), mental health conditions (e.g., suicide, recreational drug abuse, and prescription drug abuse), and other health conditions (e.g., cancer and cardiovascular conditions). Toxic levels of prescription and recreational drugs were found in 28.3% of the non-pregnancy-related cases. Between 2014-2016, substance use contributed to almost a third of both pregnancy-associated deaths (30 deaths) and pregnancy-related deaths (12 deaths). Overall, mental health conditions contributed to nearly one in four deaths.[44]

While the research on substance use and mortality outcomes of mothers in the postpartum period is limited, these findings—in combination with the Part One report—support the practice of enhancing coordinated care services between SUD treatment providers; birthing, neonatal, and pediatric care providers; early intervention services; home visiting programs; behavioral and mental health providers; public assistance programs (e.g., WIC); and other community-based services such as peer support recovery networks. Such enhanced service coordination must be delivered early and often in pregnancy and into the postpartum period through the first year of life. Coordinated approaches are especially vital given the documented gaps in postpartum care and the increased vulnerability the postpartum period can bring due to social isolation and perinatal mood disorders, exacerbated in recent times by the COVID-19 pandemic.[45, 46, 47]
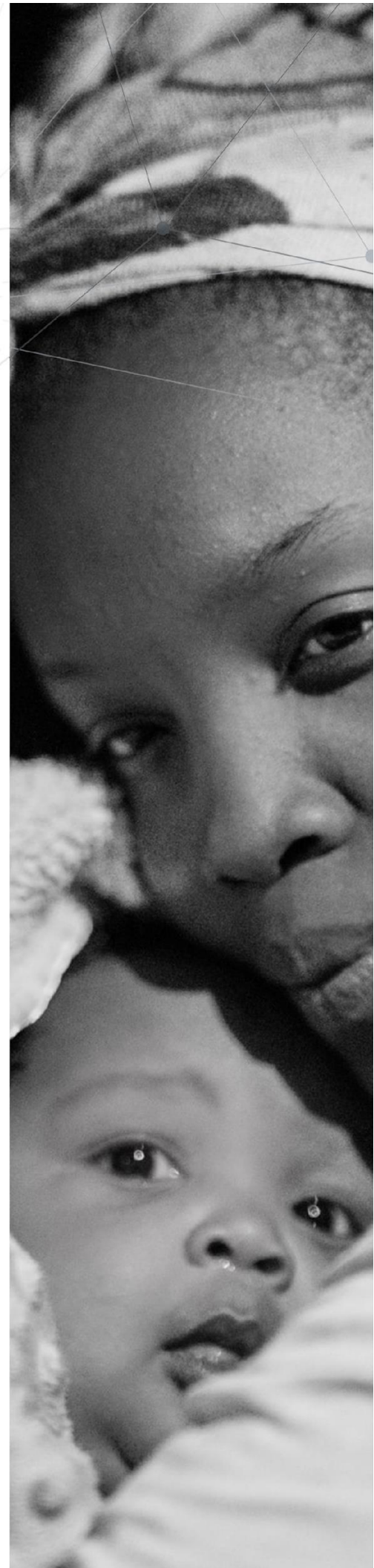
# Methods

- Establishing cohorts
- Sampling strategy
- Linking child welfare records to vital records
- Measurement of constructs
- Data analysis

# Methods

## Detailed Methods

The full Part One report of the data linkage project, available here, includes detailed methods on:

1. Establishing cohorts,

2. Sampling strategy,

3. Linking child welfare data to vital records,

4. Measurement of constructs, and

5. Data analysis.

## Establishing Cohorts

The cohort of focus includes all mother-infant dyads who were Colorado residents at the time of the child's birth (2013-2019) and met the definition of "substance exposure of a newborn" during the prenatal period, as substantiated by a child welfare agency. For the purposes of this supplemental report, we analyzed data for a subsample of mother-infant dyads in this cohort who died following a live birth and within the first year of life. The study uses linked child welfare, birth certificate, and death certificate data for live births that occurred between January 1, 2013 through December 31, 2019 with examination of deaths through December 31, 2020 (to account for the 12-month period following a 2019 birth).

## Sampling Strategy

> **Substantiated child welfare referrals for substance exposure of a newborn were used to create the sample for this first phase of the project.**

Anyone can call the Colorado Child Abuse and Neglect Hotline, 844-CO-4-Kids, to report potential child abuse or neglect. Medical providers, and other mandatory reporters, are required to notify child welfare agencies of suspected child maltreatment. Medical providers may identify prenatal substance use and/or substance exposure of a newborn, and it is then the role of county child welfare agencies to determine if a referral for substance exposure of a newborn requires an assessment of the allegations. The Colorado Children's Code that applied during the study period (2013-2019) specified that a child welfare substantiation of abuse should be made for:

> "Any case in which a child tests positive at birth for either a schedule I controlled substance, as defined in section 18-18-203, C.R.S., or a schedule II controlled substance,[viii] as defined in section 18-18-204, C.R.S., unless the child tests positive for a schedule II controlled substance as a result of the mother's lawful intake of such substance as prescribed."[48]

Referrals could also be substantiated when there is evidence of effects of substance exposure in the infant, such as the inability to eat, sleep, or be soothed.

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[viii] Schedule I substances include a range of substances with high potential for abuse and no currently accepted medical use, such as heroin, LSD, PCP, and psilocybin. Schedule II substances include substances with high potential for abuse but that do have accepted medical uses, such as oxycodone, methamphetamine, and morphine. See the full list of Schedule I and Schedule II substances via this link.

## Linking Child Welfare Data to Vital Records

The data integration and de-identification work for this study was accomplished by the Linked Information Network of Colorado (LINC). LINC is a public-private collaborative among the Colorado Lab and state and local data owners in Colorado that rely upon a data linking hub in the Governor's Office of Information Technology. LINC is available on a fee-for-service basis to link and de-identify data approved by the data owners for research and analytics. The LINC Data Scientist performing the functions of the linking hub has technical expertise in identity resolution and has met all certification and background check requirements that permit the handling of protected health records.

This study is a LINC project approved by the Colorado Department of Human Services (CDHS) Office of Children, Youth, and Families as well as CDPHE's Center for Health and Environmental Data. Child welfare data come from the state's administrative database, Trails (or the Colorado Comprehensive Child Welfare Information System), as maintained by CDHS. Vital Records data on live births and deaths are maintained by CDPHE. The child welfare data that were linked to vital records was a broader sample than what was ultimately used in this study. The purpose of this broader linkage was to facilitate a long-term research agenda. Thus, the numbers of records matched was substantially larger than the sample reported in the results section. Table 1 delineates data sources, date ranges, and other data restrictions.

Table 1: Linked Data Sources

| Data Source Received | Organization | Data Date Ranges | Other Data Restrictions |
|---|---|---|---|
| **Trails Child Welfare Extract (15,417 Records)** | CDHS, Office of Children, Youth, and Families | Trails clients with referrals between 1/1/2013 to 12/31/2019 which satisfied any one of three criteria: (1) Referral record flagged as Substance Exposed Newborn, regardless of findings; (2) Substantiated substance abuse by mother or removal for mother's substance abuse and action initiated before child's first birthday; or (3) Removal of child for case with substance abuse when child was less than one year of age. *Note.* The analytic sample was later limited to substantiated substance abuse by mother or removal for mother's substance abuse and action initiated before child's first birthday. | Utilized LINC Trails extract, rather than a direct pull from Trails. After identity resolution, substance abuse by mother was restricted to actions initiated within 0-2 days of the date of birth. |
| **Colorado Vital Records Birth Records Extract (452,347 Records)** | CDPHE, Center for Health and Environmental Data | All Colorado live births (including maternal and infant information) and infant death data from 1/1/2013 to 12/31/2019. | Only mother/child identifiers were provided for identity resolution with other data. Once identity resolution was performed, Vital Records at CDPHE provided additional approved data on the matches to be used in the study. |

| Data Source Received | Organization | Data Date Ranges | Other Data Restrictions |
|---|---|---|---|
| **Colorado Vital Records Death Records Extract** | CDHPE, Center for Health and Environmental Data | All death certificate data that were matched to the original study sample from 1/1/2013 to 12/31/2020. | This linkage was performed by CDPHE. |

See the Part One report for additional details on the data linkage process.

# Measurement of Constructs

All health-related measures were based on information reported on the birth certificate. All child welfare involvement data were based on information reported in Trails. For these constructs the measurement strategy is detailed in the full Part One report, linked here. All mortality-related measures were based on information reported on the death certificate.

## Maternal Mortality

The broadest definition of maternal mortality was used in this study, which is often referred to as pregnancy-associated death.[49] This aligns with the definition of maternal mortality typically used by CDPHE in their reports as well as recommendations from *Review to Action*. Analyses were based on death of the mother following a live birth and up to 1 year postpartum. See the Literature Review section for a deeper dive into the definitions associated with maternal mortality.

## Maternal Manner and Cause of Death

The manner of death was listed on the death certificate as one of the following six categories: Natural, Suicide, Homicide, Accident, Pending Investigation, or Undetermined Manner/Could not be determined. ICD-10 codes listed on the death certificate were used to identify the underlying cause of death for all mothers and each additional cause of death where multiple causes were identified.

## Infant Mortality

Infant mortality was defined as death of the infant after a live birth through 1 year following the birth event.

## Infant Cause of Death

ICD-10 codes listed on the death certificate were used to identify the underlying cause of death for all infants and each additional cause of death where multiple causes were identified.

# Data Analysis

All data were analyzed on a secure sever at the Colorado Evaluation and Action Lab. Prior to removing any output from the server, output was reviewed to ensure compliance with data privacy standards outlined in the Data Use License for this project.

Statistical software applications were used to explore data descriptively. Statistical code is documented and available upon request.

# Sample

Description of demographic characteristics

# Sample

Infants born between January 1, 2013 and December 31, 2019 who had a substantiated child welfare referral for substance exposure of a newborn and their birthing parent were included in this study. For health outcomes, the study sample was further limited to infants for whom the referral was made within six weeks of their birth (97.7% of full sample). Approximately two-thirds of these referrals (68.3%) occurred within the first three days following the birth event. This length of time aligns with standard hospital stays, and almost all of the infants included in this study were born in a hospital (97.8%).

> **4,178 unique dyads of mothers and infants were included in this study, providing a robust sample to explore trends in infant and maternal mortality within the first year of life following a live birth.**

*This sample is a subset of the population of families impacted by substance use during pregnancy. Future studies aim to expand the sample to include mother-infant dyads facing perinatal substance use based on mother and infant care claims and filling of prescription drugs. Read more in the CO SB19-228 legislative report.*

Colorado mothers of infants with a substantiated referral for substance exposure of a newborn were primarily lower income (57.6%) with an annual household income of less than $15,000, never married (51.4%), White (79.4%), and experienced lower educational attainment with 62.7% holding a high school education or less. At the time of the birth, the average age of mothers was 28.0 years old and the average age of fathers was 31.3 years old. The primary source of payment was Medicaid for 83.4% of the deliveries, private insurance for 9.1% of the deliveries, and self-pay or other for 7.5% of the deliveries.

> **46.2% of mothers participated in WIC during the pregnancy; household income data suggest that more were eligible.**

## About the Study Sample

The mother-infant dyads included in this study were referred to child welfare for "substance exposure of a newborn" and that referral was substantiated. This means that either the infant tested positive at birth for a schedule I controlled substance, as defined in section 18-18-203, C.R.S., or a schedule II controlled substance, as defined in section 18-18-204, C.R.S., unless the child tests positive for a schedule II controlled substance as a result of the mother's lawful intake of such substance as prescribed OR when there are observable effects of substance exposure in the infant (e.g., inability to eat, sleep, and soothe).

Table 2: Description of the Sample

| | Mother | Father | Household |
|---|---|---|---|
| **Age at Time of Birth** | | | |
| 12 to 17 | 1.6% | 0.4% | |
| 18 or 19 | 5.0% | 1.4% | |
| 20 to 24 | 28.1% | 14.5% | |
| 25 to 29 | 31.8% | 20.4% | |
| 30 to 34 | 20.8% | 16.3% | |
| 35 to 39 | 9.3% | 9.6% | |
| 40+ | 3.4% | 9.7% | |
| Unknown | 0.2 % | 27.7% | |
| **Race** | | | |
| White | 79.40% | 49.71% | |
| Black or African American | 10.39% | 9.70% | |
| American Indian or Alaska Native | 3.09% | 2.08% | |
| Other | 3.65% | 3.72% | |
| Unknown | 3.48% | 34.79% | |
| **Highest Level of Education** | | | |
| 8th grade or less | 1.91% | 1.60% | |
| 9th-12th grade, no diploma/GED | 25.40% | 12.90% | |
| High school graduate/GED | 35.37% | 29.90% | |
| Some college, no degree | 26.35% | 15.40% | |
| Associate's degree | 5.22% | 4.50% | |
| Bachelor's degree | 2.47% | 1.80% | |
| Master's / Advanced degree | 0.44% | 0.50% | |
| Advanced degree | 0.00% | 0.20% | |
| Unknown | 2.82% | 100.00% | |
| **Household Income** | | | |
| < $15,000 | | | 57.6% |
| $15,000 - $24,999 | | | 14.1% |
| $25,000 - $34,999 | | | 6.5% |
| $35,000 - $49,999 | | | 4.5% |
| $50,000 - $74,999 | | | 2.3% |
| $75,000+ | | | 1.2% |
| Unknown | | | 13.8% |

# Results

Describe trends in infant and maternal mortality following a live birth and through the first year of life for families impacted by perinatal substance use and involved in child welfare.

Compare infant and maternal mortality rates for this sample to general population rates of maternal and infant mortality in Colorado.

# Results

Two research aims were designed to create shared understandings of infant and maternal mortality outcomes for families impacted by perinatal substance use, with the long-term goal of preventing unnecessary death and creating early "upstream" wellness to avoid "downstream" deleterious effects.

## Research Aims for Phase One Supplemental

> **Describe trends in infant and maternal mortality (focus: pregnancy-associated deaths) following a live birth and through the first year of life for families impacted by perinatal substance use and involved in child welfare.**
>
> **Compare infant and pregnancy-associated death rates for this sample to general population rates of maternal and infant mortality in Colorado.**

## Maternal Mortality Trends and Characteristics

Averaged across all years of the study, the pregnancy-associated mortality rate identified in our sample was slightly approximately 4% lower than the Colorado rate of 47.4/100,000 in 2016.[50] Maternal mortality is an incident rate that is typically reported out of every 100,000 live births. Because our sample was only made up of approximately ~4,000 mother-infant dyads, the number of maternal deaths was too small to be reported in accordance with our cell suppression policy to protect study participant confidentiality. As such, we report rounded rates per year and percentages for aggregate sample findings.

> **Averaged across all years of the study, the pregnancy-associated mortality rate identified in this sample was approximately 4% lower than the Colorado rate in 2016.**

Mothers ranged from 19 to 40 years old, with an average age at the time of death of 28.5 years old. Compared to the demographics of the sample as a whole, mothers who identified as American Indian or Alaska Native were disproportionately represented among those who died—over 20% of maternal mortality cases despite making up only 3.1% of the sample. All mothers resided in Colorado at the time of death, with a roughly equal dispersion across Jefferson, Denver, El Paso, Pueblo, and Adams Counties. Table 3 depicts maternal deaths that occurred each year since the beginning of the study period through 2020, based on the infant's year of birth (2013-2019), with descriptive comparison to statewide rates.

Table 3: Comparison of Pregnancy-Associated Rates in the Study Sample to Colorado Pregnancy-Associated Death Rates

| Year | Pregnancy-Associated Death Rate – Study Sample* | Pregnancy-Associated Death Rate – Colorado [51] |
|------|------------------------------------------------|------------------------------------------------|
| 2013 | 25 per 100,000 | 45.6 per 100,000 |
| 2014 | 50 per 100,000 | 52.5 per 100,000 |
| 2015 | 50 per 100,000 | 40.0 per 100,000 |
| 2016 | 25 per 100,000 | 47.4 per 100,000 |
| 2017 | 25 per 100,000 | N/A |
| 2018 | 50 per 100,000 | N/A |
| 2019 | 98 per 100,000 | N/A |

*These are incident rates reported out of every 100,000 live births and are rounded to mask cell size.
Note. Colorado pregnancy-associated deaths for 2017 and beyond are not yet available as they are currently under review by the Colorado MMRC.

As illustrated in Figure 1, the most frequently reported manner of death on the death certificate for mothers in our sample was accidental, followed by natural causes, suicide, and homicide.

Figure 1: Manner of Maternal Death (across all years)
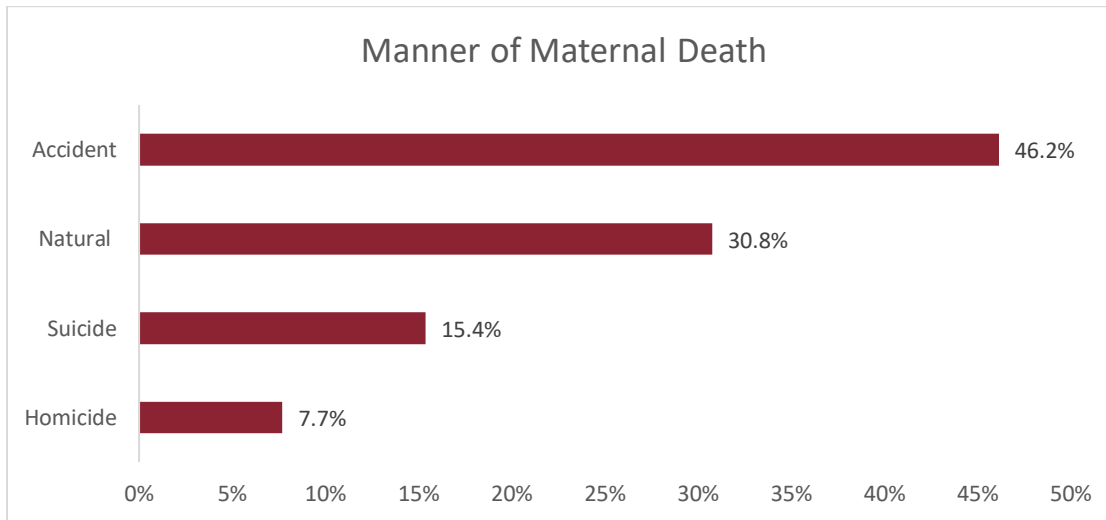


In addition to manner of death, death certificates include ICD-10 codes to identify the cause (or causes) of death. An underlying cause of death was determined for each mother based on the ICD-10 codes listed in Table 4. The leading cause of maternal death in this sample was accidental drug overdose, mirroring statewide trends in maternal mortality.

Table 4: ICD-10 Codes for Underlying Cause of Mother's Death

| Cause of Death | ICD-10 |
|---|---|
| Accidental poisoning by and exposure to other and unspecified drugs, medicaments and biological subs* | X44 |
| Accidental poisoning by and exposure to narcotics and psychodysleptics, not elsewhere | X42 |
| Other psychoactive substance abuse | F191 |
| Intentional self-poisoning by and exposure to other and unspecified drugs, medicaments and biological | X64 |
| Intentional self-harm by jumping or lying in front of moving object | X81 |
| Assault by hanging, strangulation and suffocation | X91 |
| Meningitis | G039 |
| Other and unspecified asthma | J459 |
| Death from direct obstetric cause | O960 |
| Death from indirect obstetric cause | O961 |

*This cause of death was reported four times more frequently than the other causes listed here.

## Infant Mortality Trends and Characteristics

The aggregate infant mortality rate identified in this sample was over two times higher than Colorado's rate in 2013 and 6.3% higher than the state average in 2016. In the most recent study years, the infant mortality rate in this sample fell below the statewide average. Table 5 presents the infant mortality rates for each year of the study. Infant mortality is an incident rate that is typically reported out of every 1,000 live births. Because our sample was only made up of approximately ~4,000 mother-infant dyads, the number of infant deaths was too small to be reported in accordance with our cell suppression policy to protect study participant confidentiality. As such, we report rounded rates per year and percentages for aggregate sample findings.

> **The aggregate infant mortality rate identified in this sample was over two times higher than Colorado's rate in 2013 and 6.3% higher than the state average in 2016.**
>
> **In the most recent study years, the infant mortality rate has declined and the trend is now below the state average.**

Table 5: Comparison of Infant Mortality Rates in the Study Sample to Colorado Infant Mortality Rates

| Year | Infant Mortality Rate – Study Sample* | Infant Mortality Rate – Colorado[52] |
|---|---|---|
| 2013 | 11 per 1,000 | 5.1 per 1,000 |
| 2014 | 2 per 1,000 | 4.8 per 1,000 |
| 2015 | 4 per 1,000 | 4.7 per 1,000 |
| 2016 | 5 per 1,000 | 4.8 per 1,000 |
| 2017 | 4 per 1,000 | 4.5 per 1,000 |
| 2018 | 4 per 1,000 | 4.8 per 1,000 |
| 2019 | 1 per 1,000 | 4.7 per 1,000 |

*These are incident rates reported out of every 1,000 live births and are rounded to mask cell size.

An underlying cause (or causes) of death was determined for each infant based on the ICD-10 codes listed in Table 6. The leading cause of infant death in this sample was pneumonia.

Table 6: ICD-10 Codes for Underlying Cause of Infant's Death

| Cause of Death | ICD-10 |
| --- | --- |
| Pneumonia* | J18 |
| Leukemia | C959 |
| Unspecified chronic respiratory disease originating in the perinatal period | P279 |
| Newborn affected by breech delivery and extraction | P030 |
| Bacterial sepsis of newborn | P369 |
| Newborn (suspected to be) affected by maternal use of drugs of addiction | P044 |
| Atresia of bile ducts | Q442 |
| Congenital malformation, unspecified | Q899 |
| Unspecified threat to breathing | W84 |
| Ill-defined and unknown cause of mortality | R99 |
| Unspecified event, undetermined intent, home | Y34 |
| Assault by hanging, strangulation and suffocation | X91 |
| Assault by other unspecified means | Y069 |

*This cause of death was reported two times more frequently than the other causes listed here.

## Limitations

The results of this descriptive study are limited to Colorado mother-infant dyads impacted by substance use during pregnancy for whom there was a referral made to child welfare and that referral was substantiated. The mortality rates cannot be generalized to the full population of mother-infant dyads in Colorado impacted by perinatal substance use as incorporating more data sources is needed to reach that goal (e.g., health care claims, prescription drug monitoring program data). Additionally, data were analyzed for a subsample of mother-infant dyads in this cohort who died following a live birth and within the first year of life; this means that maternal mortality during pregnancy and labor, as well as intrauterine fetal deaths after 20 weeks gestation but prior to a live birth, are excluded. The comparisons to Colorado rates of pregnancy-associated deaths is thus imperfect and underestimates the complete death rate for mothers. Expanding the sample to include the broader universe of mother-infant dyads impacted by perinatal substance use and examining the full spectrum of mortality for this broader sample is an important next step in this study.

## Next Phases of Research

Realizing the full potential of the data linkage project will require addressing barriers to data sharing and securing additional resources. The Colorado legislative report submitted by the Center for Prescription Drug Abuse Prevention to the Health and Insurance Committee and the Public Health Care and Human Services Committee of the House of Representatives and the Health and Human Services Committee of the Senate in December 2020 is linked here. SB21-137 (Behavioral Health Recovery Act) was passed in the 2021 Colorado Legislative Session and provides the authorization necessary to address data limitations in this study (see Figure 2).

Future phases of the data linkage project will build the capacity to routinely monitor population-level incident rates of prenatal substance use and health outcomes for maternal-infant dyads throughout the perinatal period. A companion qualitative study will engage pregnant people impacted by perinatal substance use to elicit their lived experiences on processes, barriers, stigmas, and supports that influence access to and successful navigation of SUD prevention and treatment, engagement with social services, and health care utilization.

The collective goal of these studies is to better understand the risk and protective factors pregnant people impacted by SUD experience in accessing adequate prenatal care; identify opportunities for more effective screening and treatment approaches; and inform systems and policy changes that can strengthen the health and life path of Colorado families. The Behavioral Health Recovery Act allocated resources to begin this next phase of research and the project team is actively seeking additional support through grant proposals.

Figure 2: Data Linkages Required under SB21-137
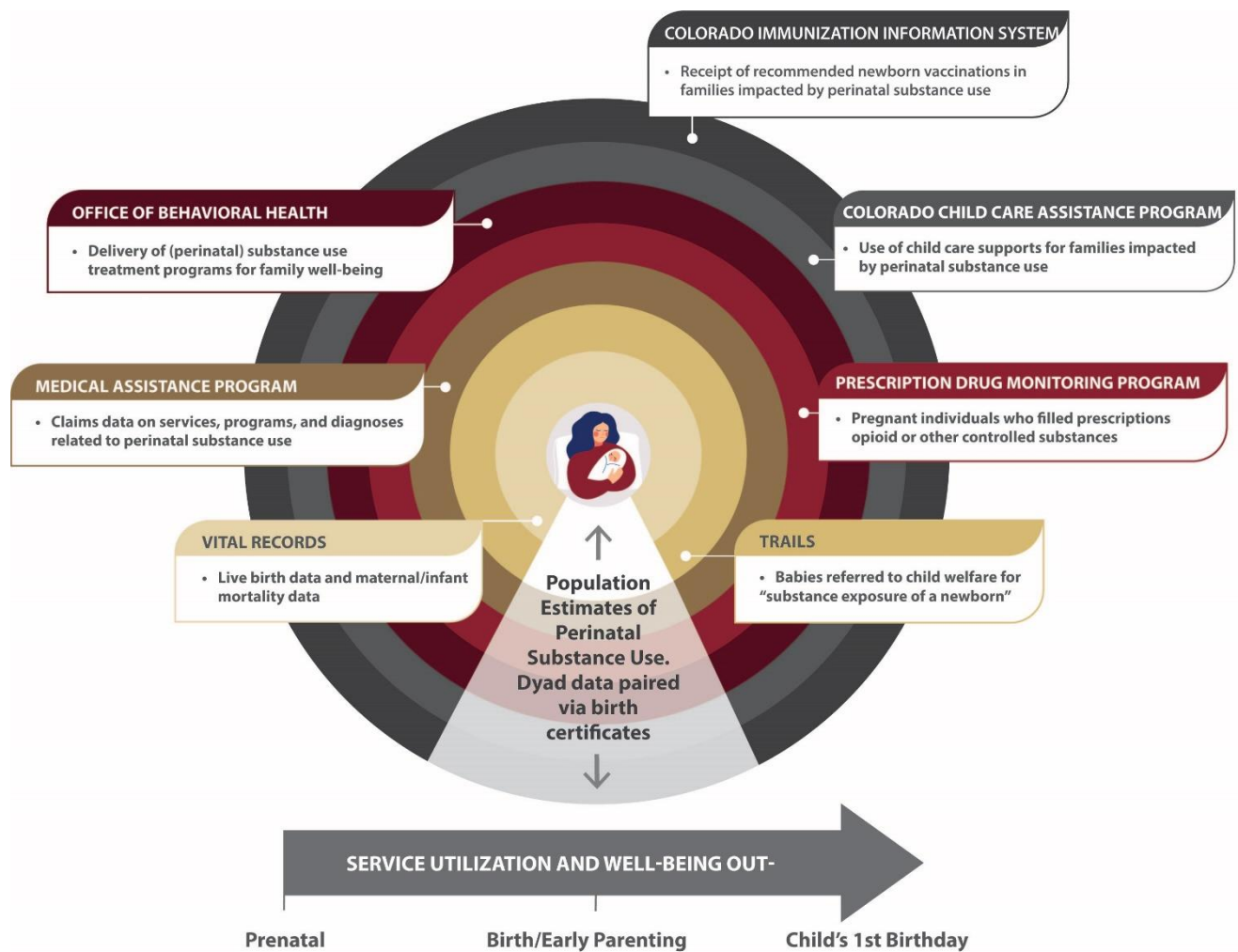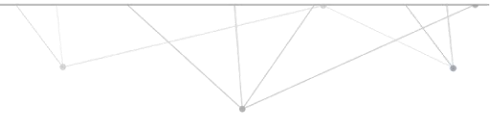
# Conclusion

This study spotlights trends in infant and maternal mortality for child welfare-involved mother-infant dyads impacted by perinatal substance use. In establishing a baseline understanding of mortality outcomes for this population, we provide critical information to inform cross-system efforts in Colorado that prevent unnecessary maternal and infant deaths. The national research and practice expertise of the Colorado MMRC and the CDC's Review to Action are recommending starting places to inform such policy and practice advancements.

# Endnotes

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