Fetal and Infant Mortality Data Report

September 2024





Illinois Department of Public Health Office of Women's Health and Family Services *Women's Health Line* 888-522-1282 The Illinois Department of Public Health would like to acknowledge the families and communities who have experienced the profound devastation of infant death, stillbirth, and pregnancy loss.

As we honor your suffering, we remain committed to expanding our understanding of the factors leading to infant death. We are dedicated to leveraging data-driven insights to prevent similar tragedies.

Acknowledgements

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For more information, contact the Office of Women's Health and Family Services at <u>DPH.MCH@illinois.gov</u>.

Notes about Language used in this Report:

"Women"

This report describes the experiences and outcomes of pregnant and postpartum "women". IDPH recognizes that not all people who have been pregnant or given birth identify as a woman and acknowledge the diversity of gender identities among those who may become pregnant or give birth. This report uses the term "woman" intentionally based on the definitions used in the data sources. Additionally, the use of "women" is used to underscore the specific vulnerabilities and gender-related challenges faced by individuals identified as female at birth. Importantly, that this usage is not meant to disregard or silence those who identify differently but aims to focus attention on societal disparities linked to gender assignment at birth.

<u>"Hispanic"</u>

IDPH acknowledges that multiple terms can be used to describe the Hispanic population, including Latino/Latina or Latinx. A 2021 Gallup study of U.S. adults with Hispanic or Latino origins found that 57% preferred the term "Hispanic," 37% preferred "Latino" and 5% preferred "Latinx". IDPH has opted to use "Hispanic" throughout this report because it was the most preferred term.

Race/Ethnicity Classification

When addressing health inequities throughout this report, the social construct of race is used as a proxy for racism, which has negative consequences for health outcomes and healthcare access and utilization. Race does not have a biological basis and is confounded by characteristics such as socioeconomic status, nationality and ethnicity, which makes it an imperfect proxy for racism that should be considered within the context of the data and population of interest.

Additionally, this report draws on secondary data sources (i.e., data collected outside if IDPH) thus our analyses are limited to predefined variables and categorization. In this report, those identifying as non-Hispanic American Indian/Alaska Native, Asian, Native Hawaiian or other Pacific Islander, Multiracial, are included in overall rate estimates, but are often not shown independently due to these groups being too small in Illinois to provide stable statistical estimates. See the Appendices for detailed information on how race/ethnicity categories are defined.

Estimates for non-Hispanic Black and Hispanic persons are compared to those of non-Hispanic White persons not to reinforce White persons as a dominant group or because their outcomes are the most desirable, but rather to highlight unacceptable racial/ethnic inequities in outcomes across the population. In the absence of good methodologic alternatives, we use this imperfect approach of comparing to non-Hispanic White persons. Keeping in line with continuous efforts to improve accuracy of race/ethnicity information¹, IDPH identifies American Indian/Alaskan Native race first when categorizing racial groups to best properly classify this population to include in surveillance reports. See Appendix B for detailed notes on race/ethnicity classification.

¹ Lee, N. T., Harris, A. P., & Frey, W. H. (2024, May 30). Why the federal government needs to change how it collects data on Native Americans. Brookings. https://www.brookings.edu/articles/why-the-federal-government-needs-to-change-how-it-collects-data-on-native-americans/

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Executive Summary

Infant mortality is defined as the death of an infant before their first birthday. In addition to being a tragic loss for families and communities, infant mortality is an important indicator of the overall health of a society.

In the landscape of public health, the issue of infant mortality in Illinois remains a critical focal point, underscored by persistent inequities across social, demographic, and health indicators. This report builds upon previous editions and presents a comprehensive analysis of current infant mortality trends in the state. It highlights profound disparities that persist despite longstanding state and national efforts, particularly evident in outcomes categorized by race and ethnicity. By illuminating these disparities, the report seeks to guide targeted prevention efforts and inform the development of effective public health programs aimed at enhancing infant health outcomes statewide. This evidence-based approach identifies key areas where interventions can have the greatest impact, fostering a more equitable landscape for infant health in Illinois.

Key Findings

- In 2021, the infant mortality rate in Illinois was 5.6 deaths per 1,000 live births; slightly higher than the U.S. national rate of 5.4.
- In 2021, Illinois had the 28th lowest state infant mortality rate out of the 50 US states.
- In the last ten years, the overall infant mortality rate in Illinois has slowly declined.
- The leading causes of infant in Illinois are effects of prematurity and fetal malnutrition, birth defects, sudden unexpected infant death (SUID) and pregnancy/ delivery complications. These conditions make up nearly 70% of all infant deaths.
- In Illinois, the infant mortality rate among infants born to Black women is nearly three times that of infants born to White, Hispanic, and Asian women.
- If the fetal and infant mortality rate among infants born to non-Hispanic Black women was reduced to rates among infants born to low-risk White women, 204 Black fetal and infant deaths would be prevented each year.
- The Black-White inequity in infant mortality is heavily influenced by trends in deaths due prematurity and SUID. In 2021, non-Hispanic Black infants were more than four times as likely to die of SUID than non-Hispanic White and Hispanic infants.

Introduction

Infant mortality is defined as the death of an infant before their first birthday, and the infant mortality rate (IMR) is the number of infant deaths before one year of age for every 1,000 live births² in a population. Using the IMR to measure infant mortality allows a direct comparison between groups and geographic areas with different population sizes. IMR is an important indicator of the overall health of a community, as factors that influence infant mortality can also impact the wider community, such as living conditions, economic development, and quality and access to medical care³.

Figure 1: In 2021, 31 states including Illinois had *not* met the Healthy People 2030 goal of no more than 5.0 infant deaths per 1,000 live births.



A lack of overall progress toward improving maternal and infant health outcomes coupled with persistent inequities has prompted a surge in national public attention⁴, and a key area of prioritization at the state and federal level. Many benchmarks for improving the health of a population across states are based on the objectives set by the *Healthy People 2030 (HP2030)* initiative⁵. HP2030 aims for all US states to achieve an IMR less than or equal to 5.0 infant deaths per 1,000 live births by 2030. As of 2021,

² Centers for Disease Control and Prevention. (2023). *Infant Mortality*. Retrieved from <u>https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm</u>

³ Barfield, W., D'Angelo, D., Moon, R., et al. (2013). CDC grand rounds: public health approaches to reducing US infant mortality. *Morbidity and Mortality Weekly Report*, *62*(31), 625.

⁴ Rabin, R. C. (2023, November 1). Infant Deaths Have Risen for the First Time in 20 Years. *New York Times*. <u>https://www.nytimes.com/2023/11/01/health/infant-mortality-rate-rise.html</u>

⁵ Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved from <u>https://health.gov/healthypeople/objectives-and-data/social-determinants-health</u>

31 states, including Illinois, have yet to achieve this goal (Figure 1). In 2021 the IMR in Illinois was approximately 5.6 deaths per 1,000 live births; this is slightly higher than the corresponding national rate of 5.4 deaths per 1,000 live births during the same year. However, some groups of Illinoisians have benefitted from this improvement more than others, as inequities across in infant health outcomes persist.

To maximize the impact of public health efforts, it is essential to consider the unique healthcare needs across the vastly different landscapes Illinoisans live in. Geographically, Illinoisians represent a mix of populated urban areas such as Chicago and the suburban collar counties, several mid-sized cities, and rural areas of the central and southern parts of the state. In 2021, there were over 132,000 live births to Illinois residents, with 54.6% born to White women, 21.7% to Hispanic women, 15.8% to Black women, 6.3% to Asian women, <1% to American Indian/Alaska Native women, <1% to Native Hawaiian or Pacific Islander women, and <2% to non-Hispanic women of other races (includes other race and multiple-race women).

This report presents inequities in Illinois infant mortality across multiple characteristics, especially highlighting the differences in IMR by race and ethnicity. Recognizing racism as a driving force behind the social determinants of health and a barrier to achieving health equity and optimal health for all individuals is crucial. The impact of racism on health outcomes is especially pertinent for Illinois, a racially and ethnically diverse state that remains highly segregated. The causes and solutions for the inequity in infant mortality rates are broad and complex. Previous research has suggested that racial inequities in infant mortality are mediated through systemic racism and chronic stress, healthcare access and quality, education and economic stability, and neighborhood and built environment exposures⁶.

⁶ Jang, C. J., & Lee, H. C. (2022). A Review of Racial Inequities in Infant Mortality in the US. *Children (Basel, Switzerland)*, 9(2), 257. <u>https://doi.org/10.3390/children9020257</u>



In 2021, 743 Illinois residents died before their first birthday (5.6 deaths per 1,000 live births). On average from 2012-2021, the infant mortality rate declined (Figure 2).

During this time period there was some fluctuation in year-to-year infant mortality rates by geographic area, but there was no significant change in one direction for any group (Figure 3). During most of this period, residents of urban counties outside the Chicago metropolitan area, including the metro areas of Springfield, Peoria, and the Illinois suburbs near St. Louis, had the highest infant mortality rate, while residents of 5 the suburban counties surrounding Cook County ("collar counties") had the lowest infant mortality rate. The collar counties are the only area in Illinois currently meeting the HP 2030 goal for infant mortality of less than 5.0 infant deaths per 1,000 live births. See Appendix B for a full list of Illinois counties in each category.



Figure 3: Infant mortality in Illinois is lowest in the suburban "collar counties" and highest in the city of Chicago and urban centers outside of the Chicagoland area.

Data Source: Illinois Death Certificates, 2012-2021

Illinois has long-standing racial inequities in infant mortality. Across all years during 2012-2021, non-Hispanic Black infants had an IMR two to four times that of non-Hispanic White, Hispanic, and Asian/Pacific Islander infants.

Over the same period, the infant mortality rates for non-Hispanic White, non-Hispanic Black, and Hispanic did not substantially change. In contrast, the infant mortality rate for Asian/Pacific Islander infants decreased on average by 6.4% annually between 2012 and 2021. In 2021, Asian/Pacific Islander infants have the lowest infant mortality rate of any group, with 2.4 deaths for per 1,000 live births (Figure 4).



Figure 4: From 2012-2021, IMR among Black infants has remained

Data Source: Illinois Death Certificates, 2012-2021

Timing and Causes of Infant Death

In 2021, approximately two-thirds of all infant deaths occurred during the first four weeks of life, called the neonatal period (Figure 5). Examining infant mortality by timing of death can give insight into where public health efforts can be focused for the biggest impact. Trends in timing of infant deaths have remained stable since 2012 (not shown).



Figure 5: Approximately two-thirds of all infant deaths occurred in the first four weeks of life.

In 2021, birth defects (20%) and prematurity/fetal malnutrition (20%) were the leading causes of infant death. Sudden unexpected infant death (SUID) was the third leading cause of infant death (18%), followed by pregnancy/delivery complications (9%). The top four causes of death make up 67% of all infant deaths in Illinois (Figure 6).

Figure 6: Leading Causes of Infant Mortality in Illinois, 2021



Since 2012, infant mortality due to prematurity and fetal malnutrition has declined

significantly, from 1.8 deaths per 1,000 live births in 2012 to 1.1 deaths per 1,000 live births in 2021 (Figure 7). In other works, there was an average decrease of 3.6% per year. The death rates from the other three major causes of death have not changed significantly since 2012.



Non-Hispanic Black infants have the highest IMR across all leading causes of infant death (Figure 8). The largest racial/ethnic inequity was for SUID deaths, for which Non-Hispanic Black infants were almost five times as likely to die as Non-Hispanic White infants. Rates for Asian/Pacific Islander infants are not displayed due to low sample size.



Figure 8: Black infants have the highest IMR across all leading causes of infant death.

Data source: Illinois Death Certificates, 2021

Risk Factors: How does infant mortality vary for different groups of Illinoisians?

While the cause of death explains the immediate reason for an infant's passing, risk factors and risk markers provide important context for public health action. *Risk factors* are characteristics or conditions that are associated with an increased likelihood (or risk) of developing a particular disease or condition. In contrast, risk markers do not directly cause the outcome but rather serve as indicators that the outcome is more likely to occur.

Identifying and addressing these factors is crucial for preventing infant mortality on a larger scale; these factors are essential for developing effective public health interventions aimed at reducing infant mortality rates and ensuring effective allocation of limited resources to those who need it most.

Linked birth and death certificate data files for the 2021 birth cohort were analyzed to compare maternal and infant characteristics among cases of infant mortality⁷. The infant mortality rates of different sub-groups were compared to identify groups at greater risk by a variety of characteristics.

Figure 9 shows differences in the rate of infant mortality by maternal characteristics. Major findings include:

- **Race/Ethnicity:** The infant mortality rate among infants born to Non-Hispanic Black women occurs at nearly 3x the rate of infants born to Non-Hispanic White women.
- **Payer for Delivery:** The infant mortality rate was highest among infants born to women covered by Medicaid, compared to infants born to women covered by private insurance or other payment plans.
- **Previous Poor Pregnancy Outcome:** The infant mortality rate was higher among infants born to women who had a previous negative pregnancy outcome, such as prior preterm birth, perinatal death, or intrauterine growth restriction.
- **Prenatal Care:** The infant mortality rate was highest among infants born to women who did not receive any prenatal care. The infant mortality rate decreased as adequacy of prenatal care increased. The exception was women who received "adequate plus" prenatal care (more than the expected number of prenatal care visits). These women likely had higher-risk pregnancies, leading them to receive more prenatal care than is typical, but also contributing to increased risk for infant mortality.

Maternal Education: The infant mortality rate decreased as mother's education level increased.

⁷ 2021 births is the most recent year of data in this report due to the availability of cohort linked infant death files at the time of publication. This data requires the availability of finalized infant death records from 2021 and 2022, so a lag in this expanded source of information is expected.

Figure 9: Illinois Infant Mortality Rate (IMR) by Maternal and Infant Characteristics, 2020-2021 Birth Cohort



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Source: Linked Infant Birth and Death Certificates, 2020-2021

Fetal Mortality

Fetal mortality describes the death of a fetus at any time during pregnancy⁸. Sometimes, fetal deaths occurring later in pregnancy are called stillbirths. There is much less known about fetal mortality compared to infant mortality due to the discrepancies in terminology, categorization and reporting across jurisdictions and disciplines. Federal law requires national data collection of fetal death. Most US states, including Illinois, define fetal death as the death of a fetus at least 20 weeks gestation and weighing at least 350 grams. Although fetal deaths have not been included in past Illinois infant mortality data reports, IDPH has added this to call attention to these deaths as we incorporate fetal death prevention efforts into maternal and child health programs and funding opportunities.

Figure 10 shows the fetal mortality rate (FMR) in Illinois over the last ten years. Notably, there has been some variation in FMR across this time period including a slight increase from 2020-2021. However, there has been no significant change in the FMR overall during this time period.



Data source: Illinois Death Certificates, 2012-2021

Figure 11 shows differences in rate of fetal mortality by maternal characteristics:

Maternal Age: Women less than 20 years old had a higher fetal mortality rate than older women.

Race/Ethnicity: Non-Hispanic Black women had the highest fetal mortality rate of all racial groups.

- **Previous Poor Pregnancy Outcome:** The fetal mortality rate was higher among mothers who had a previous negative pregnancy outcome, such as prior preterm birth, perinatal death, or intrauterine growth restriction for fetus/infant.
- **Prenatal Smoking Status:** The fetal mortality rate was higher among women who smoked cigarettes during pregnancy than women who did not smoke cigarettes during pregnancy.

⁸ Centers for Disease Control and Prevention, National Center for Health Statistics. (2022). *Fetal Deaths*. Retrieved from https://www.cdc.gov/nchs/nvss/fetal_death.htm

Prenatal Care: The fetal mortality rate was highest among women who did not receive any prenatal care. The fetal mortality rate decreased as adequacy of prenatal care increased. The exception was women who received "adequate plus" prenatal care (more than the expected number of prenatal care visits). These women likely had higher-risk pregnancies, leading them to receive more prenatal care than is typical, but also contributing to increased risk for fetal mortality.

Infant's Sex: Male infants had a slightly higher fetal mortality rate than female infants.

Plurality: The fetal mortality rate was higher for twin or higher multiple births than singleton births.

Figure 11: Illinois Fetal Mortality Rate (FMR) by Maternal and Infant Characteristics, 2020-2021 Birth Cohort

	All Fetal Deaths	5.5
Maternal Age	<20 years of age 20-24 years of age 25-29 years of age 30-34 years of age 35+ years of age	6.9 5.7 5.1 4.9 6.4
Maternal Race/Ethnicity	Non-Hispanic White Non-Hispanic Black Hispanic Asian/Pacific Islander Multiple/Other	4.3 9.9 5.6 3.8 7.1
Maternal Education	Less than high school education High school graduate Some college, but no bachelor's Bachelor's or higher	6.5 6.1 4.7 3.3
Maternal Residence	Chicago Suburban Cook County Collar counties Other urban counties Rural counties	6.3 5.7 5.2 5.1
Maternal Birthplace	US Born Foreign Born	5.2 6.4
Parity	0 previous live births 1-2 previous live births 3+ previous live births	5.2 4.9 9.9
Previous Poor Outcome	Previous poor pregnancy outcome No previous poor pregnancy outcomes	21.6 4.4
Maternal Smoking	No smoking during pregnancy Smoked during Pregnancy	5.2 9.6
Prenatal Care	Inadequate PNC or No PNC Intermediate PNC Adequate PNC Adequate PINC	7.4 3.8 2.8 8.2
Multiple Gestation	Singleton birth Twins or higher multiple	5.3 43.6
Source: F	etal Death Certificates, 2020-2021	0 5 10 15 20 25 30 35 40 45 50 FMR (per 1,000 live births)

Perinatal Periods of Risk Analysis

The Perinatal Periods of Risk (PPOR) analysis is an analytical framework developed by CityMatCH to quantify inequities in fetal and infant death⁹. This approach clarifies how fetal and infant mortality differ between demographic groups for various "periods of risk" and identify opportunities for ways to reduce inequities. PPOR can be used to investigate any inequity, but given the context of infant mortality in Illinois, we chose to look further into the race/ethnicity gap.

In a PPOR analysis, a "reference" population – typically the group with the best birth outcomes – is compared to a "focus" population – typically the group with the worst birth outcomes. Differences between the reference and focus groups are examined within each period of risk to identify actions steps that could reduce overall inequities¹⁰. This approach can be tailored to fit the parameters of any group, making it useful for informing community specific interventions and priorities.

In alignment with standard PPOR methodology, this analysis included Illinois residents with a fetal or infant loss at least 24 weeks gestation and at least 500 grams at delivery. Fetal and infant deaths for these two populations are broken down into four "periods of risk", or specific times during the perinatal period where a change in care received or public health intervention may prevent a death: maternal health and prematurity, maternal care, newborn care, and infant health period (Figure 12). Fetal and infant loses at 500-1499g birthweight are attributed to maternal health/prematurity period regardless of gestation, fetal loses up to 24 weeks gestation are attributed to the maternal care period, neonatal infant deaths up to 27 days old are attributed to the newborn care period and post neonatal deaths from 28 days to one year old are attributed to the infant care period.

The breakdown of deaths by these periods of risk highlights opportunities for reducing racial inequities in fetal and infant mortality rates. The Perinatal Periods of Risk approach designates a set of focus for action. Deaths occurring in the maternal health/prematurity period of risk are heavily influenced by the woman's health prior to pregnancy. Areas to focus public health programs to address this period of risk include pre-/inter-conceptional health, prenatal substance use, and specialized perinatal care for very low birth weight infants. For women who must travel farther to receive necessary care, transportation and childcare can act as additional barriers to getting needed health care. Focusing on increasing the availability and use of health services would not necessarily benefit all women equitably, so additional community-based investigation into these barriers is needed. To truly address the systemic factors that influence a woman's ability to be healthy and to have a healthy pregnancy, including poverty, education/literacy, discrimination, and systemic racism.

⁹ City MatCH. (2021). *Perinatal periods of Risk Approach*. Retrieved from https://www.citymatch.org/perinatalperiods-of-risk-approach/

¹⁰ Peck, M. G., Sappenfield, W. M., & Skala, J. (2010). Perinatal periods of risk: A community approach for using data to improve women and infants' health. *Maternal and Child Health Journal*, *14*, 864-874.

Table 12. Perinatal Periods of Risk Model

		Fetal Death Fetal loss >24 weeks gestation	Neonatal Death 0-27 days old	Post-neonatal Death 28 days- 1 year old
veight	500-1499 grams	Ma Fetal or infant deaths	aternal Health / Prematurit occurring at 24 weeks gesta birthweight	y: tion or later; very low
t		Maternal Care:	Newborn Care:	Infant Health:
Bi	1500 grams or more	Fetal deaths occurring at 24 weeks gestation or later; low or normal birthweight	Infant deaths occurring within the first 27 days after birth; born low or normal birthweight	Infant deaths occurring 28-364 days after birth; born low or normal birthweight

Age at death

For this analysis, infants born to Black women were the focus population. The reference group was infants born to White women who were at least 20 years old and who had at least 13 years of education at the time of their infant's birth because this group has the lowest IMR. For the remainder of this section this reference group will be referred to as "low-risk White".

For infants born to low-risk White women during 2020-2021, the overall fetal-infant mortality rate (FIMR) was 3.4 deaths per 1,000 live births overall, 1.2 per 1,000 live births during the maternal health/prematurity period of risk, 1.1 in the maternal care period, 0.3 in the newborn care period, and 0.3 in the infant health period (Table 13a).

For infants born to Black women during 2020-2021, the overall fetal-infant mortality rate was 12.3 per 1,000 live births overall, 3.8 deaths per 1,000 births in the maternal health/prematurity period, 3.1 in the maternal care period, 1.8 in the newborn care period, and 3.6 in the infant health period (Figure 13b).

Table 13a: Fetal and Infant Mortality by Perinatal Period of Risk, Among infants born to Low-Risk, non-Hispanic White Women*, 2020-2021

(Reference Group)

	Fetal Death Fetal loss >24 weeks gestation	Neonatal Death 0-27 days old	Post-neonatal Death 28 days- 1 year old		
Birthweight 500-1499 grams	Ma (128 deaths / 10	nternal Health/Prematu 19,939 total births + feta = 1.2 deaths per 1,000	rity I deaths) * 1,000		
Birthweight 1500 grams or more	Maternal Care (117/) * 1,000 = 1.1 per 1,000	Newborn Care (32/109,939) * 1,000 = 0.3 per 1,000	Infant Health (34/109,939) * 1,000 = 0.3 per 1,000		

Table 13b: Fetal and Infant Mortality by Perinatal Period of Risk,Among infants born to non-Hispanic Black women 2020-2021 (FocusGroup)

	Fetal Death Fetal loss >24 weeks gestation	Neonatal Death Post-neonatal Death 0-27 days old 28 days- 1 year old					
Birthweight 500-1499 grams	M a 42,983	aternal Health/Prematu (164 deaths / 3 total births + fetal deat = 4.1 deaths per 1,000	rity ths) * 1,000				
Birthweight 1500 grams or more	Maternal Care (132/ 42,983) * 1,000 = 3.1 per 1,000	Newborn Care (78 / 42,983) * 1,000 = 1.8 per 1,000	Infant Health (155/ 42,983) * 1,000 = 3.6 per 1,000				

If we compare the PPOR results among the reference group (Figure 13a) with the focus group (13b), it is clear that the fetal-infant mortality rate was higher for Black women than for low-risk White women for all periods of risk. The difference between the IMR for these groups is called the *excess mortality rate*. In the 2020-2021 birth cohort, the overall *excess* mortality rate among Black fetuses and infants was 9.5 deaths per 1,000 live births. In other words, if the IMR for infants born to Black women was the same as the IMR of infants born to low-risk white women, an average of 204 Black fetal and infant deaths could be avoided per year.

Table 13c shows the number of *excess* deaths for each of the four periods of risk. The excess mortality rate among Black fetuses and infants was the greatest for the infant health period of risk, which had an excess mortality rate of 3.3 deaths per 1,000, or 71 excess Black deaths per year. The maternal health period of risk had the second highest excess mortality rate of 2.7 deaths per 1,000, or 57 excess Black deaths per year. The maternal care period of risk had the third highest excess mortality rate of 2.0 deaths per 1,000, or 43 excess Black deaths per year. The newborn care period of risk had the lowest excess mortality, at 1.5 deaths per 1,000 or 33 excess Black deaths per year.

Table 13c: Excess Mortality Among Black Fetuses and Infants, 2020-2021

	Fetal Death Fetal loss >24 weeks gestation	Neonatal Death 0-27 days old	Post-neonatal Death 28 days- 1 year old		
Birthweight 500-1499 grams	M Excess mortal Excess nu	aternal Health/Prematu ity rate = 2.7 deaths per mber of deaths = 57 dea	u rity 1,000 live births I ths per year		
Birthweight 1500 grams or more	Maternal Care 2.0 per 1,000 live births 43 deaths per year	Newborn Care 1.5 per 1,000 live births 33 deaths per year	Infant Health 3.3 per 1,000 live births 71 deaths per year		

(Illinois Black women compared to Low-Risk White women)

Most excess deaths occurring in the infant health period of risk are related to Sudden Unexpected Infant Death (SUID) and other injuries (such as assault/homicide and motor vehicle accidents). Prevention effort for the infant health period could focus on infant safe sleep, breastfeeding, injury prevention, and infant access to a medical home.

Figure 14: Contribution of Perinatal Periods of Risk to Excess Black Fetal-Infant Mortality, 2020-2021



Safe Sleep and Sudden Unexpected Infant Death (SUID)

Sudden Unexpected Infant Death (SUID) is a sudden, unexpected death to an infant less than 1 year of age, and whose cause of death is not immediately obvious before investigation¹¹. The underlying cause of SUIDs can vary widely, however most SUIDs occur during sleep or are related to the environment. SUID can be accidental or non-accidental and is sometimes related to underlying medical conditions.

A major contributor to the stagnation of infant mortality in Illinois is due to SUID deaths among Black infants. A major barrier to improvement of infant mortality in Illinois is due to stark racial inequities, especially for SUID deaths among Black infants. Compared to White infants in Illinois, Black infants are more than 4 times as likely to die from Sudden Unexpected Infant Death (SUID) when compared to infants born to non-Hispanic White women. The inequity in SUID death by race/ethnicity has persisted over the last 10 years and continues to be a topic of focus for Illinois.

In 2021, non-Hispanic Black infants were than four times of likely to die of SUID than non-Hispanic White and Hispanic infants. This inequity has persisted over the last 10 years; the SUID rate did not change significantly between 2013 to 2021 for non-Hispanic White, non-Hispanic Black, or Hispanic infants (Figure 10).



Figure 15: Non-Hispanic Black infants have experienced a consistently higher rate of Sudden Unexpected Infant Death than non-Hispanic White and Hispanic infants.

Data source: Illinois vital records, 2012-2021

¹¹ Illinois Department of Human Services. (2023). *Infant Safe Sleep.* Retrieved from https://www.dhs.state.il.us/page.aspx?item=146357

The good news is, engaging in and promoting consistent safe sleep practices has been shown to drastically prevent SUID deaths. IDPH and partnering state agencies encourage the use of the recommendations for safe sleep published by the American Academy of Pediatrics:



While most infants are placed on their back to sleep this is substantially lower among non-Hispanic Black infants compared to non-Hispanic White. (Figure 16) Furthermore, only about half of infants are placed in a safe sleep environment without loose bedding and just over one third of infants are placed on a separate sleep surface. Inequities in safe sleep practices exist by race and ethnicity, maternal age, maternal education level, insurance type and parity (Figure 16-18).

Data from the Illinois Pregnancy Risk Assessment Monitoring System (PRAMS) highlight how the use of safe sleep practices is not an "all or nothing" approach; in the last 5 years there has been an improvement in some safe sleep practices when assessed independently but not improvements in all practices. Thus, more detailed analyses were needed to understand the context in which families were adopting certain safe sleep practices.

Figure 16: Most infants in Illinois are put to sleep on their back, but there are differences by mom's race/ ethnicity, age, education and type of insurance. % of infants put to sleep on thier back (2021)



Percent (%)

Figure 17: Just over one in three Illinois infant are put to sleep alone, on a separate sleep surface. This differs by mom's race/ethnicity, age, education and type of insurance



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Figure 18: About half of Illinois infants are put to sleep with no loose bedding or objects in the sleep space, and this differs by mom's race/ ethnicity, age, education and type of insurance



Impact of COVID-19 on Infant Mortality

In the wake of the COVID-19 epidemic, infant mortality in Illinois decreased substantially from 2018 to 2019 and has remained stable since then. Death rates for each major cause of death were statistically similar when comparing 2019 to 2020-2021. The COVID-19 pandemic and its recovery therefore did not have a substantial impact on the overall trend of infant mortality, nor on any major cause of infant mortality such as prematurity and fetal malnutrition. From 2020 to 2022, COVID-19 was a factor in 10 infant deaths in Illinois, the majority occurring in 2022.

However, COVID-19 infection in the mother or infant can pose a serious risk to the infant's health.¹² Although most infants infected with COVID-19 experience mild illness, COVID-19 can cause severe infection, hospitalization, and death in infants.

In addition, the downstream effects of the pandemic may impact infant mortality through other ways that maternal COVID-19 infection affects infant health. Some national studies have found an increased risk of preterm birth among women infected with COVID-19, especially during the third trimester of pregnancy¹³. Research has also demonstrated a relationship between maternal COVID-19 infection and neonatal respiratory morbidity¹⁴. Maternal COVID-19 infection may have contributed to additional infant deaths due to prematurity, respiratory morbidity, or other effects in Illinois. As our understanding and data sources for COVID-19 in the perinatal period continue to develop, ongoing surveillance and analysis may uncover additional impacts of COVID infection on the entire maternal and child health population.

Data to Action: Current Activities

The data in this report demonstrate how efforts to reduce infant mortality have shown mixed progress over the last several years. Persistent inequities in race/ethnicity and geographic location have been challenges that contribute to the slowing of progress.

Strong partnerships representing a diverse set of perspectives across Illinois is essential to improving infant health outcomes. IDPH leverages its unique position to convene stakeholders, disseminate data, fund and implement best practice programs, and address structural health care system challenges. State and federal funding are invested in services across areas of maternal and child health, while keeping health equity at the forefront of its priorities. **Currently, programs and initiatives aimed at improving infant health and reducing infant mortality supported by IDPH and other State of Illinois Agencies include**:

Illinois Regionalized Perinatal System

The Illinois Regionalized Perinatal System ensures hospital quality monitoring and appropriate care for high-risk pregnant women and infants. Each birthing facility in the state is assigned a perinatal level based on neonatal care capabilities. Regional perinatal centers, based in hospitals with the highest level of care designation, serve as data hubs and support systems. The regionalization model aims to improve birth outcomes through training, technical support, consulting on complex cases, and facilitating transfers to higher-level care.

Illinois Perinatal Quality Collaborative (ILPQC)

¹² Centers for Disease Control and Prevention (CDC). (2023). Retrieved from <u>https://www.cdc.gov/covid/hcp/clinical-care/for-pediatric-hcp.html</u>.

¹³ Neelam, V., Reeves, E. L., Woodworth, K. R., et. al. (2022). Pregnancy and infant outcomes by trimester of SARS-CoV-2 infection in pregnancy–SET-NET, 22 jurisdictions, January 25, 2020–December 31, 2020. *Birth Defects Research*, *115*(2), 145–159. doi:10.1002/bdr2.2081

¹⁴ Man, O. M., Azamor, T., Cambou, M. C., et. al. (2024). Respiratory distress in SARS-COV-2 exposed uninfected neonates followed in the covid outcomes in mother-infant pairs (comp) study. *Nature Communications*, 15(1). doi:10.1038/s41467-023-44549-5

The Illinois Perinatal Quality Collaborative (ILPQC) is a nationally recognized statewide network of hospital teams, perinatal clinicians, patients, public health leaders, and policymakers committed to improving health care and outcomes for mothers and babies across Illinois. They have partnerships and engage stakeholders working with the IDPH Regionalized Perinatal System, state health agencies, associations, and advocacy groups to improve obstetric and neonatal care to end maternal and infant mortality.

Fetal and Infant Mortality Review (FIMR)

The Fetal and Infant Mortality Review (FIMR) program aims to reduce infant mortality by using infant and fetal death case review to inform the implementation of community-based interventions and policies. Multidisciplinary committees analyze non-medical factors associated with fetal and infant mortality and identify areas for intervention. FIMR is supported by the American College of Obstetricians and Gynecologists (ACOG), FIMR is a nationwide framework focusing on eliminating inequities in perinatal, infant, and maternal health. It focuses on improving access to comprehensive health services, particularly for high-risk women, and directs resources toward addressing underlying issues. IDPH currently supports FIMRs in Chicago and Southern Illinois (St. Clair/Madison County).

Illinois Safe Sleep Support Campaign

Multiple state agencies (DHS, CDPH, DCFS, and IDPH) began collaborating in 2022 to develop a statewide safe sleep campaign. The campaign includes safe sleep awareness communication and messaging activities that are culturally accessible and focused on safe sleep practices, breastfeeding, and injury prevention. In addition, the campaign has a component that focuses on resources, such as free cribs and safe sleep prevention kits.

Family Connects Chicago

IDPH directly supports the Chicago Department of Public Health (CDPH) in implementation of Family Connects Chicago to ensure nurse home visits for all babies and parents immediately following birth and linkage to a network of community supports to assist with longer term, family identified needs. Family Connects considers services for the entire family and relies on community alignment for optimal functioning. Chicago has adapted the model to six regions, each with its community alignment board, to cater to the city's diversity and scale.

Case Management and Home Visiting Programs

IDPH collaborates with Department of Human Services (DHS) on an array of programs that support pregnant and postpartum women and infants at risk for poor birth outcomes across the state to align strategies and collaborate on initiatives. Often these programs are administered in collaboration with other state agencies such as the Illinois Department of Human Services (DHS) Maternal, Infant and Early Childhood Home Visiting (MIECHV) program.

Healthy Start

Illinois has multiple locally focused programs funded under the federal Healthy Start Initiative. The purpose of Healthy Start is to improve health outcomes before, during, and after pregnancy and reduce the well-documented racial/ethnic differences in rates of infant death and adverse perinatal outcomes. Healthy Start S is intended to support projects in communities and populations experiencing the greatest disparities in maternal and infant health outcomes.

Safe Sleep Program

The Baby-ZZZ Safe Sleep Program seeks to partner with maternal and child health community stakeholders to expand community-based promotion of safe sleep practices and employ a risk reduction approach to improve sleep environments for all Illinois infants.

Conclusions: What Next?

IDPH continues to use the data presented in this report to inform evidence-driven decision making for all perinatal programs and services, including efforts to reduce infant mortality, and continuously evaluate programs for their efficacy and impact, especially in the communities facing the biggest inequities. For additional resources available to families, caretakers and health care providers in Illinois, See Appendix B at the end of this report.

This report demonstrates how inequities in infant mortality, especially among racial groups, continue to persist in Illinois. Since 2012, infants born to non-Hispanic Black women have had an IMR approximately three times that of infants born to non-Hispanic White women. What's more, infants born to non-Hispanic Black women have a higher death rate for each of the leading causes of infant death and across periods of risk throughout the first year of life compared to all other racial groups in Illinois. Although the population in Illinois is too small to provide stable estimates, national data demonstrate significantly higher infant mortality rates among American Indian/Alaskan Native communities as well.

As we continually use updated data to inform future activities, many of the analyses shown can be expanded upon. Future studies should continue to expand upon the data analyses described in this report, such as analyzing factors associated with preterm birth and infant safe sleep behaviors. By better understanding the factors contributing to infant mortality, especially those due to preterm births and SUID, Illinois may be able to propel the reduction of infant mortality overall while also narrowing inequities across the state.

Appendix A: Resources for Illinois Parents, Families and Caregivers

Newborn and infant health support:

Baby Care Basics – Going home with new baby chicago.gov/city/en/sites/onechifam/home/infant-care/baby-basics.html

Birth to Five Illinois (Early Childhood Education and Care) birthtofiveil.com

Chicago Family Connects

chicago.gov/city/en/sites/onechifam/home/family-wellness/family-connects.html OR Contact <u>fcc@cityofchicago.org</u>

Erikson Institute's Fussy Baby Network erikson.edu/fussy-baby-network 888-431-2229

Everthrive Illinois

everthriveil.org

Federally Qualified Health Centers

<u>npidb.org/organizations/ambulatory_health_care/federally-qualified-health-center-fqhc_261qf0400x/il/=</u>

Illinois Early Intervention: Resources for Families of Premature Infants eiclearinghouse.org/guides/parents-premature-infants/

Immunization Program and I-Care

Start Early (Previously Ounce of Prevention) startearly.org

Safe sleep support and SUID prevention:

Illinois Safe Sleep Support Campaign infantsafesleep.illinois.gov

AAP Patient Care Safe Sleep Resource Hub aap.org/en/patient-care/safe-sleep/

Safe Sleep Information for Child Care Providers childcareta.acf.hhs.gov/safe-sleep-information-child-care-providers

Grief and bereavement resources for those impacted by infant loss:

SIDS of Illinois sidsillinois.org FIMR Chicago <u>https://www.fimrchicago.org/bereavement-and-grief-resources</u> OR contact fimr@bsd.uchicago.edu 217-785-1455

Heartlight Support*	(312) 227-3930
luriechildrens.org/en/patients-visitors/resources-suppor	rt-services-for-families/bereavement-
support OR contact <u>heartlight@luriechildrens.or</u>	<u>rg</u>
Star Legacy	952-715-7731
starlegacyfoundation.org	552 715 7751
5 //	
Maternal health support:	
Congenital Syphilis/Perinatal HIV warm line	800-243-2437
Illinois Perinatal Depression Hotline	866-364-MOMS (866-364-6667)
Caring for Yourself After Delivery – Information on Postpartum Chicago.gov/city/en/sites/onechifam/home/pregnancy- health/caring-for-yourself-after-delivery.html	Care -sexual-parental-health/parental-
4th Trimester Project Self-Care Resource – general info for new	parents
For emergency, short-term childcare:	
Child Care Assistance Program (CCAP)*	312-823-1100
Crisis Nurseries	
dhs.state.il.us/page.aspx?item=55909	
Safe Families <u>safe-families.org/get-help/</u> <u>To determine whether you or your family qualify for state prop</u>	grams:
Medicaid Insurance Eligibility and Enrollment	
Women, Infants and Children (WIC)	800-843-6154
All Kids (healthcare coverage)	866-255-5437
Temporary Assistance for Needy Families (TANF)*	800-843-6154
Illinois Cares RX (assistance with medications)	800-252-8966
Illinois Home Visiting Collaborative http://igrowillinois.org/	312-793-1476
*Available in Spanish	

***Family Connects Chicago is intended for foster parents, adoptive parents and families who already have other children

Appendix B: Definitions

Fetal and Infant Mortality

- Fetal mortality: the death of a fetus (at least 20 weeks gestation) prior to delivery.
- Infant mortality: the death of an infant before their first birthday.
 - *Neonatal mortality:* the death of an infant between 0-28 days after birth.
 - *Early-neonatal mortality:* the death of an infant between 0-7 days after birth.
 - Late-neonatal mortality: the death of an infant between 8-28 days after birth.
 - *Post-neonatal mortality:* the death of an infant between days 29-364 after birth.
- Infant Mortality Rate (IMR): the number of infant deaths before their first birthday per 1,000 live births among the population of interest.
- Sudden Infant Death Syndrome (SIDS): the death of a seemingly healthy infant less than a year old which remains unexplained after a thorough case investigation.
- Sudden Unexpected Infant Death (SUID): the sudden and unexpected death of an infant less than 1 year old in which the cause was not obvious before investigation (includes SIDS, accidental suffocation and strangulation in bed, and unknown cause).

Infant/Fetal Characteristics

- **Preterm:** infant born with gestational age less than 37 weeks.
- Full term: infant born with gestational age of at least 37 weeks.
- Very low birthweight: an infant's first recorded weight after birth less than 1500g.
- Low birthweight: an infant's first recorded weight after birth less than 2500g.
- Normal birthweight: an infant's first recorded weight after birth at least 2500g.

Maternal Characteristics

- **Pre-existing maternal chronic condition:** presence of diabetes, chronic hypertension, or obesity prior to pregnancy.
- **Prenatal care:** as defined by the Kotelchuck adequacy of prenatal care utilization index which classifies prenatal care into categories based on the timing of first prenatal care initiation and number of visits.
- **Previous poor pregnancy outcome:** history of previous preterm birth and/or history of previous poor birth outcomes (i.e., previous infant death).
- **Smoking:** refers to any cigarette smoking during pregnancy.

Race/Ethnicity

In this report race/ethnicity refers to either the mother's race and ethnicity fields on the birth certificate or infant's race and ethnicity fields on the death certificate, depending on what was available for analysis. The US Census defines these Race & Ethnicity Categories as:

• American Indian or Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

- Hispanic or Latino: A person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino."
- Native Hawaiian or Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands.
- Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam.
- Black or African American: A person having origins in any of the Black racial groups of Africa.
- White: A person having origins in any of the original peoples of Europe, the Middle East or North Africa.

Geography

Based on county and ZIP code of residence.

- Cook County was divided into "Chicago" and "Suburban Cook County."
- **Collar counties:** counties surrounding Cook County, including Lake, McHenry, Kane, DuPage, and Will
- **Other urban counties:** include Winnebago, DeKalb, Kendall, Kankakee, Rock Island, Peoria, Tazewell, McLean, Champaign, Macon, Sangamon, Madison, and St. Clair
- Rural counties: includes all other counties in Illinois.

Cause of Infant Death Classification

Causes of infant death are based on ICD (International Classification of Diseases) codes. The National Center for Health Statistics (NCHS) provides detailed instructions on how to group ICD codes to accurately classify and report causes of death, including specific guidelines for infant mortality. These guidelines ensure consistency and comparability of mortality data within each country and internationally.

Data Sources

This report uses data from birth certificates, death certificates, and fetal death certificates from the IDPH Division of Vital Records. All vital records used in this report are certified/final data. This report includes births through 2021. This was the most recent year available for all the sources presented at the time of publication. By utilizing data across multiple sources, we can conduct more detailed analyses and identify important context not found on the death certificate.

General Statistical Notes

- Analyses were limited to births and deaths for Illinois residents.
- All analyses were conducted in SAS version 9.4 and with a significance level of p<0.05 unless otherwise mentioned.

Cross-Sectional Infant Mortality Analyses

Analyses on pages 7-12 assessed infant mortality using cross-sectional data. This approach uses number of births during a calendar year and the number of infant deaths during that same year. In this type of analysis, infant death certificates are not linked to their corresponding birth certificates.

In cross-sectional analyses, IMR is defined as:

 $\frac{\# of infants who died during year A}{total \# of live births during year A} * 1,000$

The following analyses were done using cross-sectional infant mortality data.

- Time trend analyses were conducted in Joinpoint Trend Analysis Software to test trends from 2012-2021 and identify timepoints when statistically significant changes in trends occurred.
- Cause of death information was compared by race/ethnicity.

Cohort Infant Mortality Analyses

Analyses examining maternal risk factors and the PPOR assessed infant mortality using **cohort** data. Cohort data compares infant mortality rates for a specific group of infants born during a given year; this approach requires infant death certificates to be linked to the corresponding birth certificates to identify infant deaths before their first birthdays. Cohort analysis allows for more in-depth examination of risk factors and risk markers for infant mortality because the birth certificate contains much more detailed demographic and medical information than the death certificate.

In cohort analyses, IMR is defined as: # of infant born in year A who died within 1 year total # of live births during year A * 1,000

The following analyses were done using birth cohort data of infants born in 2020 or 2021.

• Bivariate analyses were conducted to test whether certain maternal or infant characteristics were associated with infant mortality. The chi-square test statistic was used to test for statistical significance.

Appendix D: Detailed Tables for Infant Mortality Trend Analyses

Table 1: in Illinois Infant Mortality by Timing of Death (corresponds to Figure 3)

						Early-	Early-	Late-	Late-	Post-	Post-
	Live	Infant	Infant	Neonatal							
Year	Births	Deaths	MR	Deaths	MR	Deaths	MR	Deaths	MR	Deaths	MR
2013	156,918	942	6.0	639	4.1	533	3.4	106	0.7	303	1.9
2014	158,522	1,044	6.6	756	4.8	638	4.0	118	0.7	288	1.8
2015	158,101	952	6.0	667	4.2	550	3.5	117	0.7	285	1.8
2016	154,467	984	6.4	697	4.5	595	3.9	102	0.7	287	1.9
2017	149,391	912	6.1	629	4.2	534	3.6	95	0.6	283	1.9
2018	144,828	943	6.5	661	4.6	541	3.7	120	0.8	282	1.9
2019	140,145	790	5.6	531	3.8	446	3.2	85	0.6	259	1.8
2020	133,304	737	5.5	522	3.9	443	3.3	79	0.6	215	1.6
2021	132,228	743	5.6	476	3.6	406	3.1	70	0.5	267	2.0

MR = Mortality Rate

Table 2: Trends in Illinois Infant Mortality by Geography of Residence (corresponds to Figure 5)

Year	Chicago			Suburban Cook County			Collar Counties			Other Urban Counties			Rural Counties		
	Live	Infant	Infant	Live	Infant	Infant	Live	Infant	Infant	Live	Infant	Infant	Live	Infant	Infant
	Births	Deaths	MR	Births	Deaths	MR	Births	Deaths	MR	Births	Deaths	MR	Births	Deaths	MR
2013	39,612	257	6.5	29,288	167	5.7	36,024	185	5.1	28,407	195	6.9	23,587	138	5.9
2014	40,137	284	7.1	29,389	183	6.2	36,678	195	5.3	28,630	231	8.1	23,688	151	6.4

2015	39,269	311	7.9	29,524	168	5.7	36,370	149	4.1	28,737	174	6.1	24,201	150	6.2
2016	37,999	269	7.1	28,760	204	7.1	36,098	170	4.7	27,843	202	7.3	23,767	139	5.8
2017	36,321	241	6.6	28,037	153	5.5	34,895	145	4.2	27,075	229	8.5	23,063	144	6.2
2018	34,857	245	7.0	26,930	173	6.4	34,041	168	4.9	26,526	193	7.3	22,474	164	7.3
2019	32,880	207	6.3	26,147	121	4.6	33,232	166	5.0	25,845	173	6.7	22,041	123	5.6
2020	31,082	162	5.2	25,025	133	5.3	31,425	135	4.3	24,778	181	7.3	20,994	126	6.0
2021	28,909	185	6.4	25,206	145	5.8	32,336	123	3.8	24,665	154	6.2	21,112	136	6.4

MR = Mortality Rate

Table 3: Trends in Illinois Infant Mortality by Race/Ethnicity (corresponds to Figure 6)

Year	Non	-Hispanic V	/hite	Non-Hispanic Black				Hispanic		Asian/Pacific Islander		
	Live	Infant	Infant	Live	Infant	Infant	Live	Infant	Infant	Live	Infant	Infant
	Births	Deaths	MR	Births	Deaths	MR	Births	Deaths	MR	Births	Deaths	MR
2013	84,295	362	4.3	25,976	330	12.7	33,352	178	5.3	9,206	40	4.3
2014	84,674	451	5.3	26,162	325	12.4	33,700	198	5.9	9,508	38	4.0
2015	84,487	366	4.3	26,406	327	12.4	33,789	187	5.5	9,768	29	3.0
2016	81,732	383	4.7	25,357	342	13.5	32,530	203	6.2	9,982	32	3.2
2017	78,245	343	4.4	25,403	338	13.3	31,296	167	5.3	9,580	38	4.0
2018	76,717	382	5.0	24,271	333	13.7	30,244	160	5.3	9,421	35	3.7
2019	73,938	295	4.0	23,087	257	11.1	29,835	160	5.4	8,937	27	3.0
2020	70,644	264	3.7	22,222	278	12.5	28,656	143	5.0	8,372	17	2.0
2021	71,668	288	4.0	20,709	244	11.8	28,423	162	5.7	8,197	20	2.4

MR = Mortality Rate