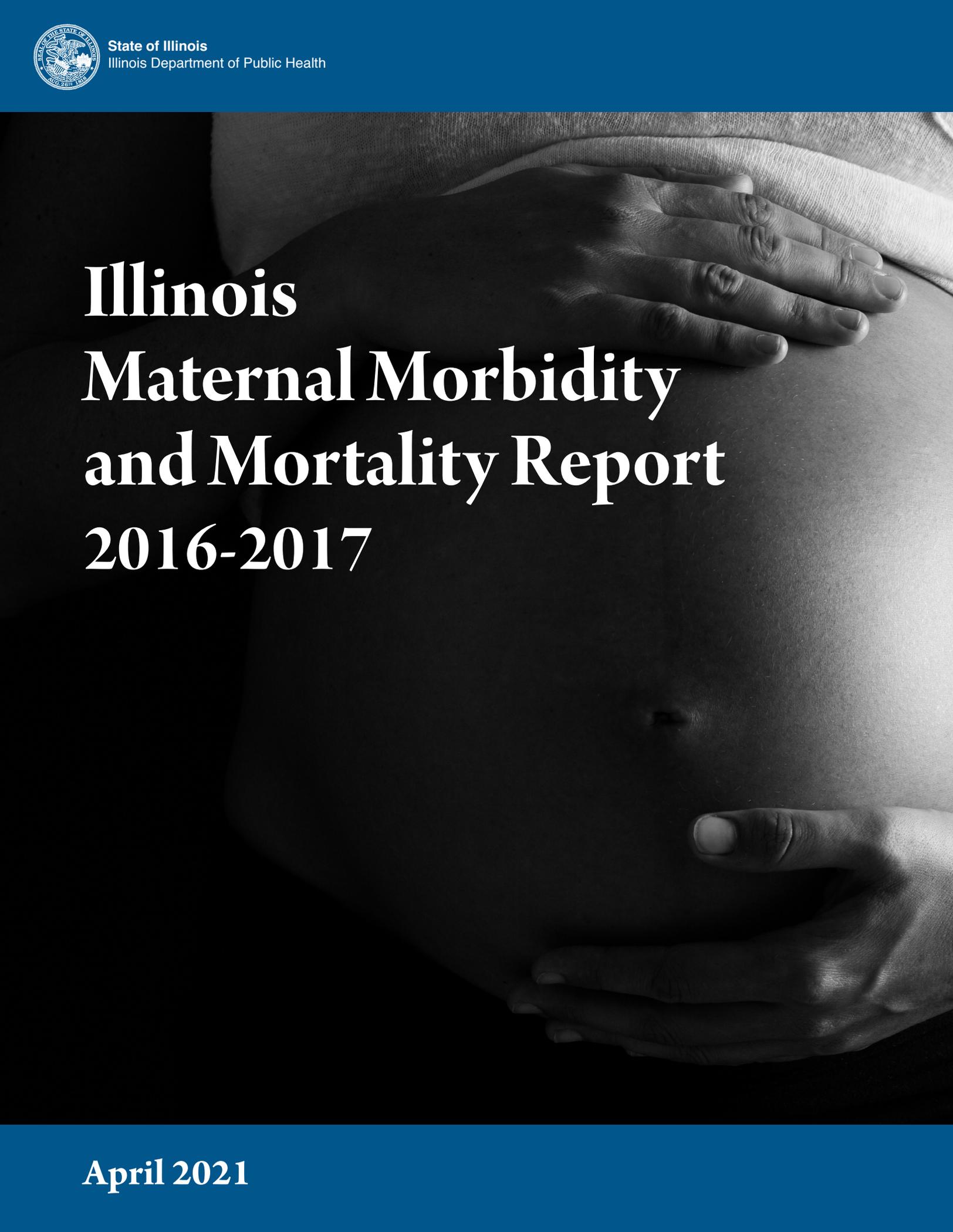




State of Illinois  
Illinois Department of Public Health

A black and white photograph of a pregnant woman's belly. Two hands are gently touching the skin of the abdomen. The lighting is soft, highlighting the texture of the skin and the fabric of the clothing.

# Illinois Maternal Morbidity and Mortality Report 2016-2017

April 2021



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The Illinois Department of Public Health would like to acknowledge the 175 Illinois women who died while pregnant or within one year of their pregnancy during 2016-2017 and their loved ones.

We hope our efforts to better understand the causes of maternal mortality in Illinois will help prevent other women from suffering a similar fate.

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**For more information:**

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**Suggested Citation**

Illinois Maternal Morbidity and Mortality Report, 2016-2017, Illinois Department of Public Health. (April 2021).

**Funding**

The work represented in this report was funded by the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE-MM) program of the Centers for Disease Control and Prevention, grant number 5 NU58DP006682-02-00.

**Other Support**

The Illinois Department of Public Health acknowledges the support provided by the Centers for Disease Control and Prevention’s Maternal and Child Health Epidemiology Program (MCHEP) in the implementation of the state maternal mortality review process, data analysis, and preparation of this report.

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Dear Colleagues,

The Illinois Department of Public Health (IDPH) is honored to share this second edition of the *Illinois Maternal Morbidity and Mortality Report*. This report builds on the important work of two IDPH committees, the Maternal Mortality Review Committee (MMRC) and the Maternal Mortality Review Committee for Violent Deaths (MMRC-V), which was captured in Illinois' first ever report on maternal morbidity and mortality and released in 2018. The first report included detailed statewide data and recommendations that would help prevent maternal morbidity and mortality, while also improving the overall health of women of reproductive age. We are humbled at the response to the first report. Elected officials, community leaders, medical providers, foundations, and everyday Illinoisans have raised their voices and become deliberate in their efforts to lift this work in a collaborative, focused way.

The goal of this second report is to continue identifying statewide patterns in maternal health and providing recommendations directed at key stakeholders to prevent maternal mortalities and morbidities. Additionally, this report expands the discussion to include factors that play a role in maternal health and contribute to the health disparities and inequities observed in Illinois' maternal health outcomes. This discussion, as difficult as it may be, is absolutely essential if we want to be serious about our mission to improve health outcomes for all women, children, and families.

IDPH recognizes the work is not by any means complete; in fact, we are just beginning. The MMRC and MMRC-V, which are subcommittees of the Perinatal Advisory Committee (PAC), an advisory board to IDPH, will continue their work and are currently reviewing the maternal deaths that occurred in 2018. They will continue identifying and examining the social determinants of health that detrimentally impact the health of women of color, and in particular Black women. We at IDPH are committed to a culture of health equity, and we are committed to working collaboratively with our partners to have Illinois be the healthiest state for all women.

IDPH cannot thank enough the dedicated volunteers who serve on the MMRC and the MMRC-V for devoting their time and expertise to this mission critical work. Working together, our efforts will continue to move Illinois forward in ensuring Illinois women have the best health outcomes possible.

In continuous service,

Ngozi Ezike, MD  
Director



## Executive Summary

Maternal mortality (death) is an important measure for assessing the overall health of a community. Given the increase over time and persistent racial/ethnic disparities in maternal mortality in the United States, it is vital that we better understand the causes of and contributors to this public health crisis.

Using a variety of data sources, the Illinois Department of Public Health (IDPH) identifies all deaths of women while pregnant or within one year of pregnancy (pregnancy-associated deaths). IDPH convenes two maternal mortality review committees (MMRCs), which review specific cases of maternal death to identify the causes of death, determine whether the deaths were pregnancy-related (occurred due to a pregnancy complication, a chain of events initiated by the pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy), determine whether the deaths were preventable, and develop recommendations to prevent future deaths. The two MMRCs reviewed 129 maternal deaths that occurred during 2016-2017 to develop the recommendations in this report.

### Key Findings:

An average of 75 Illinois women died while pregnant or within one year of pregnancy each year during 2008-2017, with the highest number recorded in 2017 (a total of 103 deaths).

In 2016-2017:

- 34% of women who died while pregnant or within one year of pregnancy died from a cause related to pregnancy.
- The leading cause of pregnancy-related death was mental health conditions, including substance use disorders, which comprised 40% of pregnancy-related deaths. The next three most common causes of pregnancy-related death were pre-existing chronic medical conditions that were exacerbated by pregnancy, hemorrhage, and hypertensive disorders of pregnancy.
- Black women were about three times as likely to die from a pregnancy-related condition as White women.
- Black women were more likely to die from pregnancy-related medical conditions while White women were more likely to die from pregnancy-related mental health conditions.
- One-third of pregnancy-related deaths occurred more than two months after pregnancy.
- The MMRCs determined that 83% of the pregnancy-related deaths were potentially preventable.
- 85% of the pregnancy-associated deaths by suicide and 35% of the pregnancy-associated deaths by drug overdose were determined to be pregnancy-related.
- The MMRCs determined that nearly all the pregnancy-associated homicide, suicide, and drug overdose deaths were potentially preventable.

### Highlights of Key Recommendations:

- Health insurance plans, including Illinois Medicaid, should reimburse for telehealth, including phone-based services, regardless of patient or provider location.
- The state and collaborating programs should expand and facilitate coordination of home visiting programs for pregnant and postpartum women with complex medical or mental health conditions, regardless of income, who could benefit from additional support or care coordination.
- The state should expand implementation of promising practices for improving maternal outcomes and empowering women to engage with health care providers, such as home visiting for all women within three weeks of giving birth and doula support.
- Hospitals should participate in the upcoming statewide birth equity quality improvement initiative with the Illinois Perinatal Quality Collaborative and should provide training and resources to staff on racism, implicit bias, stigma related to substance use disorder, and trauma-informed care.
- Hospitals should establish policies and protocols to ensure appropriate treatment of pregnant or postpartum women with substance use disorders and support opioid overdose prevention.
- Providers should ensure that following delivery, all women are discharged from the hospital with an appointment for an early postpartum visit with an obstetric care provider within the first three weeks postpartum, followed by a comprehensive postpartum visit no later than 12 weeks postpartum.
- Providers should seek consultation when prescribing, changing, or discontinuing anti-depressants or other psychotropic medications during pregnancy, and that they ensure the patient is connected to mental health services in addition to medication therapy.<sup>1</sup>
- Community-based organizations should educate women on the importance of getting prenatal care early in pregnancy to improve healthy pregnancy outcomes and increase opportunity to optimally parent her child.
- It is important that all women have an annual well-woman visit with a primary care provider to identify and manage any chronic conditions, and to discuss how to be as healthy as possible before or between pregnancies. It is also important for women with a recent pregnancy to reconnect with, or establish care with, a medical home for continued medical care beyond the postpartum visit.

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<sup>1</sup> Maternal Mental Health: Depression and Anxiety. (February 2016). Council of Patient Safety in Women's Health Care. Retrieved from <https://safehealthcareforeverywoman.org/patient-safety-bundles/maternal-mental-health-depression-and-anxiety/>

## Introduction

In 2018, the Illinois Department of Public Health (IDPH) released its first ever report on maternal morbidity and mortality.<sup>2</sup> This report described maternal deaths in Illinois, including where they occurred, what caused them, and who was most affected. The report also specifically highlighted the unacceptably high rates of pregnancy-related deaths for Black women. Since the release of that report, there has been an increased focus on maternal mortality in Illinois:

- The General Assembly introduced several bills incorporating recommendations from the report, and many were signed into law by Gov. JB Pritzker.
- Illinois was the first state in the nation to extend full Medicaid benefits from 60 days to 12 months postpartum, following the federal Centers for Medicare & Medicaid Services (CMS) approval in April 2021. The Illinois Department of Healthcare and Family Services (HFS) submitted an Medicaid 1115 demonstration waiver to permit continuous eligibility through 12 months postpartum. CMS approval of the waiver enables federal matching dollars to implement this Medicaid expansion. This was a key recommendation from the first *Illinois Maternal Morbidity and Mortality Report* to improve continuity of care for women.
- Using data and recommendations from the report, entities in the state were awarded highly competitive national grants aimed at improving maternal health outcomes. More details about these grants are provided in the “Building Momentum in Maternal Health” section of this report.
- Birthing hospitals incorporated recommendations from the report into quality improvement initiatives to improve maternal health outcomes.
- IDPH staff members and Maternal Mortality Review Committee (MMRC) leadership presented maternal mortality data and recommendations to local, state, and national audiences, reaching approximately 1,500 people. The objective of these presentations was to increase awareness of opportunities to improve maternal health outcomes.

This report will build upon the first report by presenting updated data on maternal deaths and providing specific recommendations that the MMRCs developed when reviewing deaths occurring during 2016-2017. This report will also provide additional context to the many factors involved in maternal mortality in Illinois. It is important to note that some of the findings from this report are not directly comparable to findings from the first report due to changes in methods. More details are provided in each section and are available in Appendix D.

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<sup>2</sup> *Illinois Maternal Morbidity and Mortality Report*. (October 2018). Illinois Department of Public Health.

## The Importance of Maternal Health

Maternal health, or the health of a woman<sup>3</sup> during pregnancy, childbirth, and the postpartum period, is important because of the rapid physical and psychological shifts during this time that can have longstanding effects on a woman's life. For example, chronic conditions can be exacerbated by the physiologic stress of pregnancy and new pregnancy-related health conditions may arise. Women typically have more interaction with health care providers during pregnancy and increased access to health and social services during pregnancy. Therefore, pregnancy and the postpartum period provide an opportunity to identify, treat, and manage conditions to improve a woman's overall health.

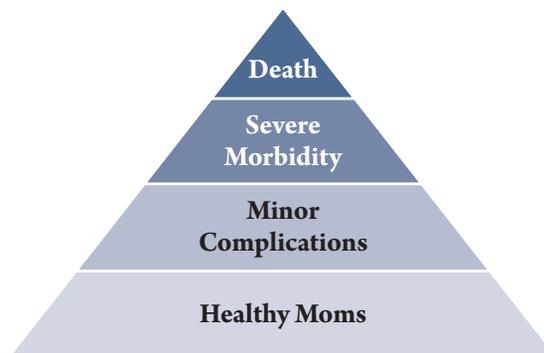
### Maternal Health in Illinois

According to the July 2019 American Community Survey, Illinois is the sixth most populous state in the United States with 12.7 million residents, including 2.5 million women of reproductive age (15-44 years).<sup>4</sup> Illinois women deliver approximately 140,000 births annually. The state is racially and ethnically diverse, with approximately 54% of births to non-Hispanic White women, 17% to non-Hispanic Black women, 21% to Hispanic<sup>5</sup> women, and 8% to non-Hispanic women of other races. It is also geographically diverse, with both large urban areas and sparsely populated rural communities, each with unique barriers to health care.

### Maternal Health as a Continuum

Health outcomes during the perinatal and postpartum period occur across a continuum (Figure 1). Most women are healthy during pregnancy, meaning they experience a typical outcome with no complications. However, some women experience pregnancy complications, which may be minor or severe, and may cause significant short- and/or long-term consequences to a woman's health. Severe complications are rare, with a relatively small number of women experiencing the most severe complication: death.

**Figure 1: The Continuum of Maternal Health**



<sup>3</sup> IDPH understands and recognizes that not all people who have been pregnant or given birth identify as being a "woman." This report uses the term "women" instead of "people" or "persons" as an intentional device to highlight the vulnerability of people who society typically identifies as being female. The use of "women" is not intended to exclude or silence those who do not identify as female, but to draw attention to the ways pregnant or postpartum people are discriminated against because of their female gender assignment at birth.

<sup>4</sup> *Annual Estimates of the Resident Population for Selected Age Groups by Sex for Illinois: April 1, 2010 to July 1, 2019* (2020) United States Census Bureau American. Retrieved February 18, 2021 from <https://www.census.gov/data/tables/time-series/demo/popest/2010s-state-detail.html>

<sup>5</sup> IDPH acknowledges that multiple terms may be used to describe the Hispanic population, including Latino or Latinx. A Pew Research Center study in 2020 reported that 69% of U.S. adults with Hispanic or Latino origins prefer the term "Hispanic," 29% preferred "Latino" and 4% preferred "Latinx" (<https://www.pewresearch.org/hispanic/2020/08/11/views-on-latinx-as-a-pan-ethnic-term-for-u-s-hispanics/>). IDPH has opted to use "Hispanic" throughout this report because it was the most preferred term.

Maternal morbidity (pregnancy complications) and maternal mortality (death) are two indicators often used to assess the overall health status of a community. Although still relatively rare, maternal mortality in the United States has been increasing and is 3 to 4 times higher than other developed nations.<sup>6</sup> However, not all women are at equal risk of dying. In the United States, between 2014-2017 pregnancy-related mortality ratios were three times higher for Black women than White women.<sup>7</sup>

While health insurance and availability of services can be major barriers to care, many other social and systemic issues affect the health gap between Black and White persons. It is now recognized that health is not merely the result of an individual's biology or genetics, but is influenced by a myriad of other factors, such as education, wealth, and racism. Opportunities and access to information can affect decision-making and the health behaviors of women. Laws and policies can create unequal distribution of resources and power that may leave some groups of people disadvantaged. The social, political, and economic structures that produce inequities, combined with the lived, everyday experiences of individuals, are known as "social determinants of health." Examples of social determinants of health that deeply affect a woman's ability to thrive and to be healthy include poverty, quality of education, health literacy, employment, housing, availability of child care, transportation, community support, and neighborhood safety.

It is particularly important to note that structural racism is a driving force of the social determinants of health. Structural racism is defined as "normalization and legitimization of an array of dynamics – historical, cultural, institutional, and interpersonal – that routinely advantage Whites while producing cumulative and chronic adverse outcomes for people of color."<sup>8</sup> Structural racism affects many aspects of society, including the health care system. The next section will provide one specific example of how structural racism affects the quality of life and health of Black women in Chicago through a practice called "redlining."

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<sup>6</sup>Kassebaum, N. J., Barber, R. M., Bhutta, Z. A., Dandona, L., Gething, P. W., Hay, S. I., ... & Lopez, A. D. (2016). Global, regional, and national levels of maternal mortality, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*, 388(10053), 1775-1812.

<sup>7</sup>Centers for Disease Control and Prevention (2018). Pregnancy Mortality Surveillance System. Retrieved from <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-mortality-surveillance-system.htm>

<sup>8</sup>Lawrence, K., & Keleher, T. (2004). Chronic disparity: Strong and pervasive evidence of racial inequalities. Retrieved from <http://www.intergroupresources.com/rc/Definitions%20of%20Racism.pdf>

## Redlining: Structural Roots Of Inequity In Chicago

Approximately two-thirds of Illinois' population resides in the Chicago metropolitan area, and Chicago is one of the most racially segregated cities in the country.<sup>9</sup> Chicago also has one of the largest life expectancy gaps between neighborhoods: residents of Englewood (a majority low-income Black neighborhood) live an average of 60 years while residents of Streeterville (a majority upper-income White neighborhood) live an average of 90 years.<sup>10</sup>

It is important to understand the long-standing oppressive systems and policies that have led to the inequitable distribution of resources and poor health outcomes in Chicago. This context is especially important when discussing disparities in maternal health outcomes, because reducing these disparities will require systemic changes beyond improving the quality of health care and will require involvement of partners from sectors outside the clinical and public health fields.

### The History of Redlining

Chicago's history of segregation and inequity is rooted in the policy of "redlining," a practice that began in the early 1930s. Shortly after the Great Depression, the Home Owner's Loan Corporation (HOLC) was set up by the federal government to rescue defaulted mortgages to boost the housing market. The HOLC used maps of White and Black populations to rate the housing market in different cities and neighborhoods, and then offered financial resources to people they deemed worthy.

In Chicago, predominantly Black communities were rated as "undesirable" and were outlined in red (Figure 2), thus the origin of the term "redlining."<sup>11,12</sup> The HOLC withheld mortgages from or charged significantly higher interest rates to Black residents. Less than 2% of the HOLC's national lending between 1934 and 1962 went to Black residents, regardless of where they lived.<sup>13</sup>

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<sup>9</sup> Frey, W. (2018). Black-white segregation edges downward since 2000, census shows. Washington, DC: The Brookings Institution. Retrieved from <https://www.brookings.edu/blog/the-avenue/2018/12/17/black-white-segregation-edges-downward-since-2000-census-shows/>

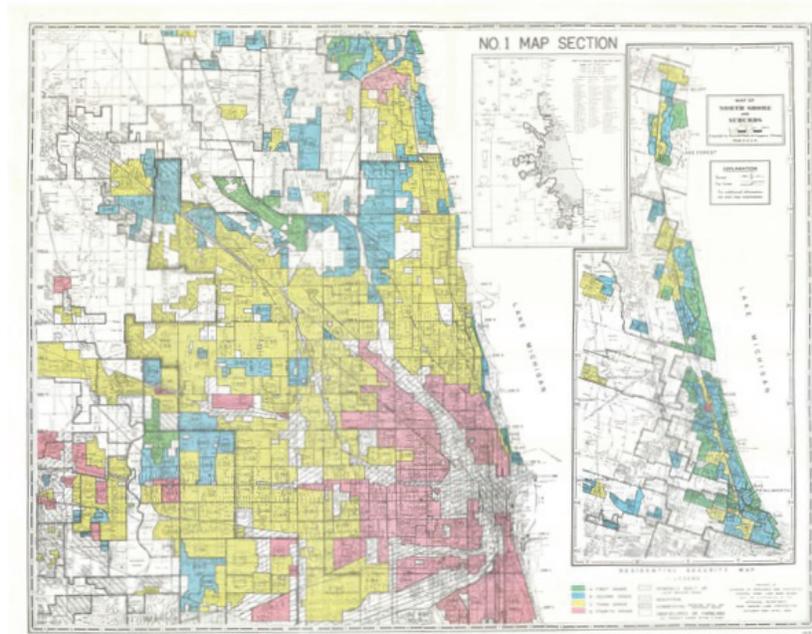
<sup>10</sup> *City Value for Life Expectancy in Chicago, IL*. (2019). City Health Dashboard. Retrieved from <https://www.cityhealthdashboard.com/>

<sup>11</sup> Aaronson, D., Hartley, D., & Mazumder, B. (2017). The Effects of the 1930s HOLC "Redlining" Maps. Federal Reserve Bank of Chicago, 2017(12).

<sup>12</sup> *Mapping Inequality: Redlining in New Deal America*. Retrieved from <https://dsl.richmond.edu/panorama/redlining/>

<sup>13</sup> Ansell, D. A. (2017). *The death gap: How inequality kills*. University of Chicago Press.

Figure 2: Original Redlined Map of Chicago, created by the Home Owner’s Loan Corporation<sup>14</sup>



Green: Level A, “best”	Blue: Level B, “still desirable”
Yellow: Level C, “definitely declining”	Red: Level D, “hazardous”

### Effects of Redlining Today

An analysis by the Federal Reserve Bank of Chicago found that the HOLC maps led to reduced credit access and higher borrowing costs which, in turn, contributed to disinvestment in poor urban neighborhoods with long-term repercussions.<sup>15</sup> In Chicago, redlining resulted in racial disparities in home-ownership, wealth attainment, housing deterioration, and abandonment, and to inequitable declines in property values. This led to further residential segregation over time as lending practices reinforced the boundaries where people of various races were able to secure housing. While the Fair Housing Act of 1968 made redlining illegal, the principle continued to be practiced throughout the mid-1990s by banking and insurance industries.<sup>16</sup> The effects of redlining continue to be seen in Chicago through a two-tiered housing market with “prime” vs. “subprime” categories. Black and Hispanic people are more likely to pay higher interest rates, premiums, and fees compared to Whites with equal credit.<sup>17</sup> Without loans or insurance available, redlined communities have been unable to grow and flourish.

<sup>14</sup> Heppler, J. A. (2017). *American Panorama: An Atlas of United States History*. Retrieved from <https://dsl.richmond.edu/panorama/>

<sup>15</sup> Aaronson, D., Hartley, D., & Mazumder, B. (2019). *The Effects of the 1930s HOLC “Redlining” Maps*. WP 2017-12 Retrieved from <https://www.chicagofed.org/publications/working-papers/2017/wp2017-12>

<sup>16</sup> Hunt, B. (2005). Redlining. *The electronic encyclopedia of Chicago*. *Chicago Historical Society*. Retrieved from <http://www.encyclopedia.chicagohistory.org/pages/1050.html>

<sup>17</sup> Henricks, K., Lewis, A. E., Arenas, I., & Lewis, D. G. (2018). A tale of three cities: The state of racial justice in Chicago report. Retrieved from [http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP\\_StateOfRacialJusticeReport-1.pdf](http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP_StateOfRacialJusticeReport-1.pdf)

Compared to other areas of the United States, cities in the Midwest, like Chicago, have the highest percentage of historically redlined “hazardous” areas that are currently low-income neighborhoods. These patterns demonstrate that the inequities created by redlining have a lasting impact over time.<sup>18</sup> Historically, redlined neighborhoods have become more isolated over time and are more likely to lack essential resources, like healthy food. Even in today’s Black communities in Chicago, there continues to be limited access to grocery stores and more access to fast food chains, than in other communities. Because of this, Black communities have higher rates of diabetes than other Chicago neighborhoods.<sup>19</sup>

Redlined communities also suffer from a lack of high-quality education. The most recent closings of Chicago’s public schools have been located on the south and west sides of Chicago, the very same areas that were redlined in the 1930s. Approximately 42,000 Black teenagers in the south and west neighborhoods of Chicago have been affected by school closings since the 1980s.<sup>19</sup> The lack of quality education greatly affects health literacy and has been linked to shorter life expectancy and increased mortality rates.

The effects of redlining are also seen in the availability of health care providers and facilities. The north side of Chicago, which is more racially and culturally diverse, has close to 10 times as many health care providers available as Black communities on the south side.<sup>20</sup> This difference can also be seen in the case of “trauma deserts,” or areas without a nearby level I or II trauma hospital. Black-majority neighborhoods in Chicago are more likely to be in a trauma desert than White-majority neighborhoods. These trauma deserts correspond with the Black communities that were originally deemed “hazardous” by the HOLC. Ultimately, the lack of accessibility to trauma centers has led to higher mortality rates in Black communities.<sup>21</sup>

Not only are there fewer hospitals serving redlined communities, but the hospitals that predominantly serve people of color are often subject to cash and capital shortages that limits the types and quality of care they provide.<sup>22</sup> For example, these facilities are less likely to have specific types of radiology and dedicated physicians who specialize in reading those images.<sup>23</sup> Hospitals treating a majority of Black patients also have higher surgery-related mortality rates.<sup>24</sup> The lack of health care resources makes both diagnosing and treating disease increasingly difficult, contributing to poorer health outcomes in Black-majority communities.

If Black individuals residing in redlined communities do see a physician, it may be challenging for them to pick up prescriptions as historically redlined communities also suffer from lack of access to pharmacies, or “pharmacy deserts.” A 2014 study found that 5% of segregated White communities in Chicago were pharmacy deserts, compared to 54% of segregated Black communities and 34% of percent of segregated Hispanic communities. Approximately 1 million Chicago residents live in pharmacy deserts, and 53% of these persons live in segregated Black communities.<sup>25</sup>

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<sup>18</sup> Mitchell, B., & Franco, J. (2018). HOLC “redlining” maps: The persistent structure of segregation and economic inequality. *NCRC Research*. Retrieved from [https://ncrc.org/wp-content/uploads/dlm\\_uploads/2018/02/NCRC-Research-HOLC-10.pdf](https://ncrc.org/wp-content/uploads/dlm_uploads/2018/02/NCRC-Research-HOLC-10.pdf)

<sup>19</sup> Henricks, K., Lewis, A. E., Arenas, I., & Lewis, D. G. (2018). A tale of three cities: The state of racial justice in Chicago report. Retrieved from [http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP\\_StateOfRacialJusticeReport-1.pdf](http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP_StateOfRacialJusticeReport-1.pdf)

<sup>20</sup> Henricks, K., Lewis, A. E., Arenas, I., & Lewis, D. G. (2018). A tale of three cities: The state of racial justice in Chicago report. Retrieved from [http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP\\_StateOfRacialJusticeReport-1.pdf](http://stateofracialjusticechicago.com/wp-content/uploads/IRRPP_StateOfRacialJusticeReport-1.pdf)

<sup>21</sup> Tung, E. L., Hampton, D. A., Kolak, M., Rogers, S. O., Yang, J. P., & Peek, M. E. (2019). Race/Ethnicity and Geographic Access to Urban Trauma Care. *JAMA network open*, 2(3), e190138-e190138.

<sup>22</sup> Ansell, D. A. (2017). *The death gap: How inequality kills*. University of Chicago Press.

<sup>23</sup> Ansell, D., Grabler, P., Whitman, S., Ferrans, C., Burgess-Bishop, J., Murray, L. R., ... & Marcus, E. (2009). A community effort to reduce the black/white breast cancer mortality disparity in Chicago. *Cancer Causes & Control*, 20(9), 1681.

<sup>24</sup> Ansell, D. A. (2017). *The death gap: How inequality kills*. University of Chicago Press

<sup>25</sup> Qato, D. M., Daviglus, M. L., Wilder, J., Lee, T., Qato, D., & Lambert, B. (2014). ‘Pharmacy deserts’ are prevalent in Chicago’s predominantly minority communities, raising medication access concerns. *Health Affairs (Project Hope)*, 33(11), 1958–1965.

Perinatal health care access on Chicago's South Side has historically been shaped by hospital closures. At the beginning of 2019, Chicago had 19 hospitals with obstetric units, with six located on the South Side. During 2019-2020, several obstetric units on the South Side faced temporary and permanent closures, due to economic resources and COVID-19. These closures left only three birthing hospitals on the South Side, compared to the six each on the North and West sides of Chicago. The lack of health care resources in some communities could contribute to poor maternal and infant outcomes. One study in Chicago found that Black-majority communities with a history of redlining had higher preterm birth rates than Black-majority communities that were not historically redlined.<sup>26</sup>

In addition to these obstetric unit and hospital closures, increasingly competitive funding for community health organizations and federally qualified health centers reduced lactation services. For South Side neighborhoods such as Englewood and Roseland, addressing the barriers to breastfeeding is essential. Both neighborhoods are majority Black, with breastfeeding initiation rates of only 1.4% and 6.8%, compared to the state breastfeeding initiation rate of 84.2%.<sup>27</sup>

While maternal health is a multi-faceted and complicated problem, it is important to recognize how systematic racism such as redlining policies has negatively impacted communities of color by creating barriers to health, and how these barriers directly influence a woman's ability to have a healthy pregnancy. Addressing these barriers will be essential to ensuring equitable care for women.

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<sup>26</sup> Matoba, N., Suprenant, S., Rankin, K., Yu, H., & Collins, JW. (2019). Mortgage discrimination and preterm birth among African American women: An exploratory study. *Health & Place*, 59 (9), 102193.

<sup>27</sup> Butler, M., Allen, J. A., Hoskins-Wroten, J., Sanders-Bey, T., Venegas, R. N., Webb, I., & Ragland, K. (2021). Structural Racism and Barriers to Breastfeeding on Chicagoland's South Side. *Breastfeeding Medicine*, 16(2), 10.1089/bfm.2020.0311.

## Chronic Disease During Pregnancy

Chronic diseases are any health conditions that last one or more years and require ongoing medical attention or limit activities of daily living.<sup>28</sup> Chronic diseases are increasing among women of reproductive age in the United States, and more women are entering pregnancy with conditions that may be undiagnosed or uncontrolled. Common chronic diseases, including obesity, hypertension, and diabetes, can increase the risk of pregnancy complications<sup>29</sup> and maternal death.<sup>30</sup> Therefore, it is important to consider how chronic disease may be affecting maternal health and maternal mortality in Illinois.

This section of this report will focus on three common chronic diseases: obesity, hypertension, and diabetes.

**Obesity** is having a weight higher than what is considered healthy for a given height. The American Medical Association passed a resolution in 2013 recognizing obesity as a chronic disease in an effort to promote improved medical prevention and treatment approaches, while also reducing stigma.<sup>31</sup> Being obese carries risks of both infant and maternal complications during pregnancy and birth, including pregnancy loss, birth defects, preterm birth, stillbirth, preeclampsia, and gestational diabetes. Losing weight prior to pregnancy is the best way to decrease the risk of problems caused by obesity and improve maternal health, which may result in a healthier pregnancy.<sup>32</sup>

**Hypertension**, or high blood pressure, occurs when the pressure in the arteries is too high. When high blood pressure develops during pregnancy or during the postpartum period and is accompanied by organ damage, it is called preeclampsia. Hypertension and preeclampsia can cause pregnancy complications, including premature birth, low birthweight, and placental abruption (the placenta separates from the wall of the uterus before birth).<sup>33</sup> Hypertension that remains after pregnancy and into the postpartum period can cause fluid in the lungs, blood clots, seizures, and/or stroke. The data on hypertension in this section includes chronic hypertension or pregnancy-induced hypertension.

**Diabetes** is a condition in which a person's cells cannot use the sugar from their diet because a hormone called insulin is not produced (type I diabetes) or the body doesn't adequately respond to insulin (type II diabetes). Gestational diabetes is diabetes that develops during pregnancy, but the blood sugar may return to normal after pregnancy. Any type of diabetes during pregnancy can increase the baby's risk of birth defects, stillbirth, or preterm birth, as well as increasing the chances of the mother needing a cesarean delivery.<sup>34</sup> Gestational diabetes may increase the woman's risk of high blood pressure and pre-eclampsia, as well as diabetes later in life.<sup>35</sup> The data on diabetes in this section includes any of these types of diabetes.

<sup>28</sup> About Chronic Diseases. (October 2019). Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/chronicdisease/about/index.htm>

<sup>29</sup> Maternal Health: Advancing the Health of Mothers in the 21st Century at a Glance 2016. (October 2017). Retrieved from <https://www.cdc.gov/chronicdisease/resources/publications/aag/maternal.htm>

<sup>30</sup> Nelson, D. B., Moniz, M. H., & Davis, M. M. (2018). Population-level factors associated with maternal mortality in the United States, 1997–2012. *BMC Public Health*, 18(1), 1007.

<sup>31</sup> AMA House of Delegates Adopts Policy to Recognize Obesity as a Chronic Disease. (June 2013). Obesity Medicine Association. Retrieved from <https://obesitymedicine.org/ama-adopts-policy-recognize-obesity-disease/>

<sup>32</sup> Frequently Asked Questions: Obesity and Pregnancy. (April 2016). The American College of Obstetricians and Gynecologists. Retrieved from <https://www.acog.org/Patients/FAQs/Obesity-and-Pregnancy>

<sup>33</sup> High Blood Pressure During Pregnancy. (July 2015). March of Dimes. Retrieved from <https://www.marchofdimes.org/complications/high-blood-pressure-during-pregnancy.aspx>

<sup>34</sup> Diabetes During Pregnancy. (June 2018). Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/diabetes-during-pregnancy.htm>

<sup>35</sup> Gestational Diabetes. (April 2017). Mayo Clinic. Retrieved from <https://www.mayoclinic.org/diseases-conditions/gestational-diabetes/symptoms-causes/syc-20355339>

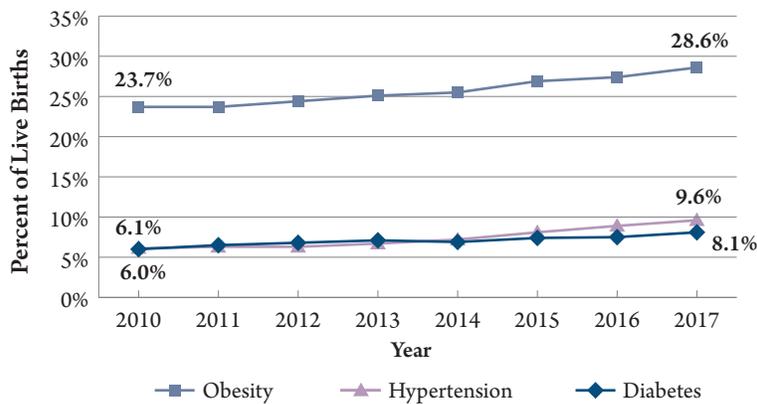
**Chronic Disease During Pregnancy**

During 2010-2017, there were significant increases in the percent of Illinois live births to women with obesity, hypertension, and diabetes (Figure 3). The percent of births to women with:

- Obesity increased 21% from 23.7% in 2010 to 28.6% in 2017.
- Hypertension increased 57% from 6.1% in 2010 to 9.6% in 2017.
- Diabetes increased 35% from 6.0% in 2010 to 8.1% in 2017.

Some women may have presented with more than one of the three chronic conditions described in this section, therefore percentages in the figures in this section are not mutually exclusive.

**Figure 3: Percent of Illinois Births to Women with Obesity, Hypertension, and Diabetes, 2010-2017**



In the following figures, rates of these chronic diseases are compared for different groups of Illinois women. For these analyses, two years of data were combined (2016-2017) to make these analyses similar to the morbidity and mortality data reported later in this report.

**Obesity**

During 2016-2017 in Illinois, 28.0% of live births were to women with obesity (Figure 4). Within their respective demographic categories, obesity was highest among women who were Black (38.9%), age 40 years and older (32.4%), had a high school education or less (32.2%), resided in rural counties (32.6%), and had Medicaid insurance (33.1%).

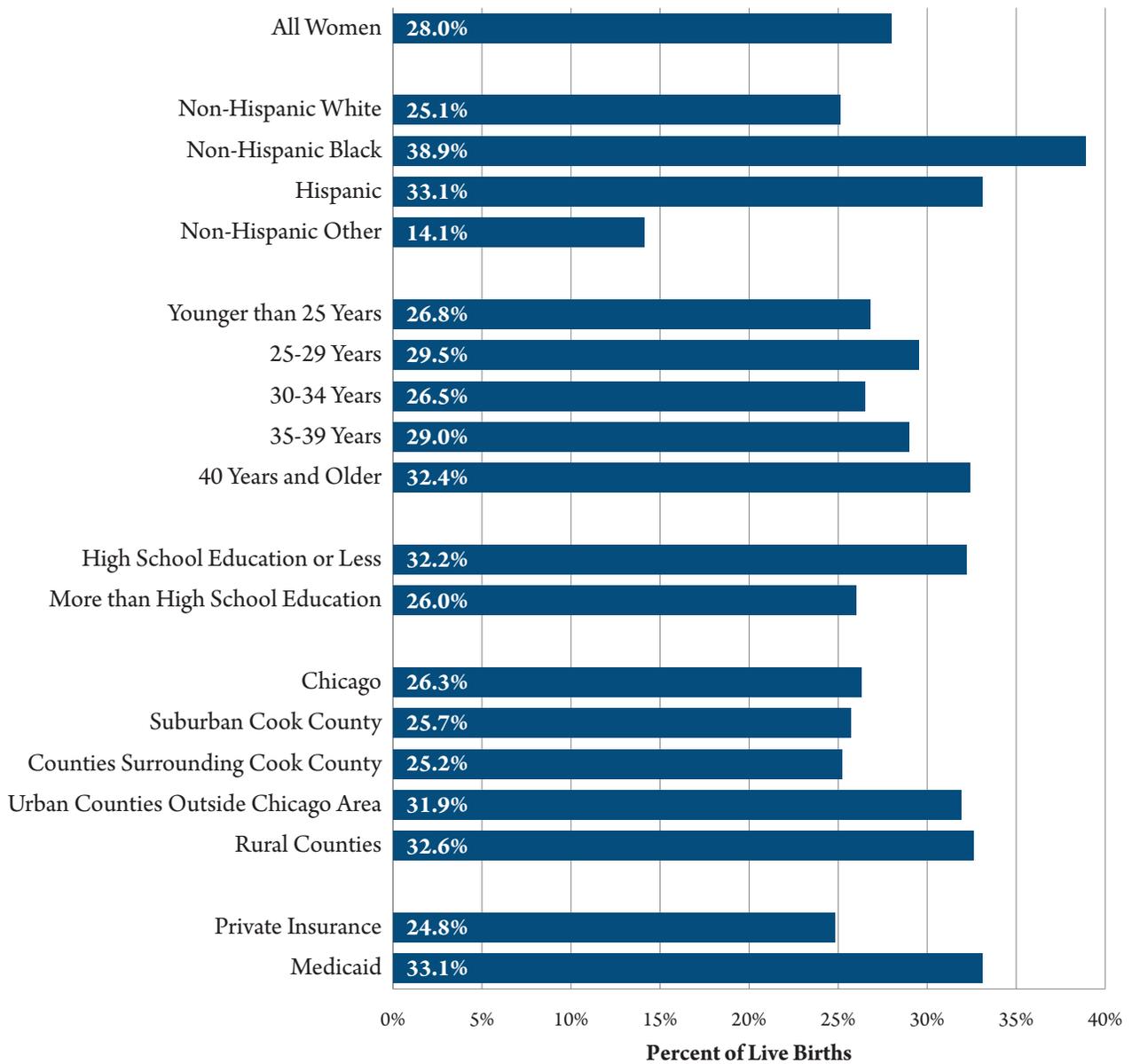
**Hypertension**

During 2016-2017 in Illinois, 9.2% of live births were to women with hypertension (Figure 5). Within their respective demographic categories, hypertension was highest among women who were Black (12.5%), age 40 years and older (15.2%), had more than a high school education (9.6%), resided in rural counties (10.4%), had private insurance (9.5%), and were obese (16.4%).

**Diabetes**

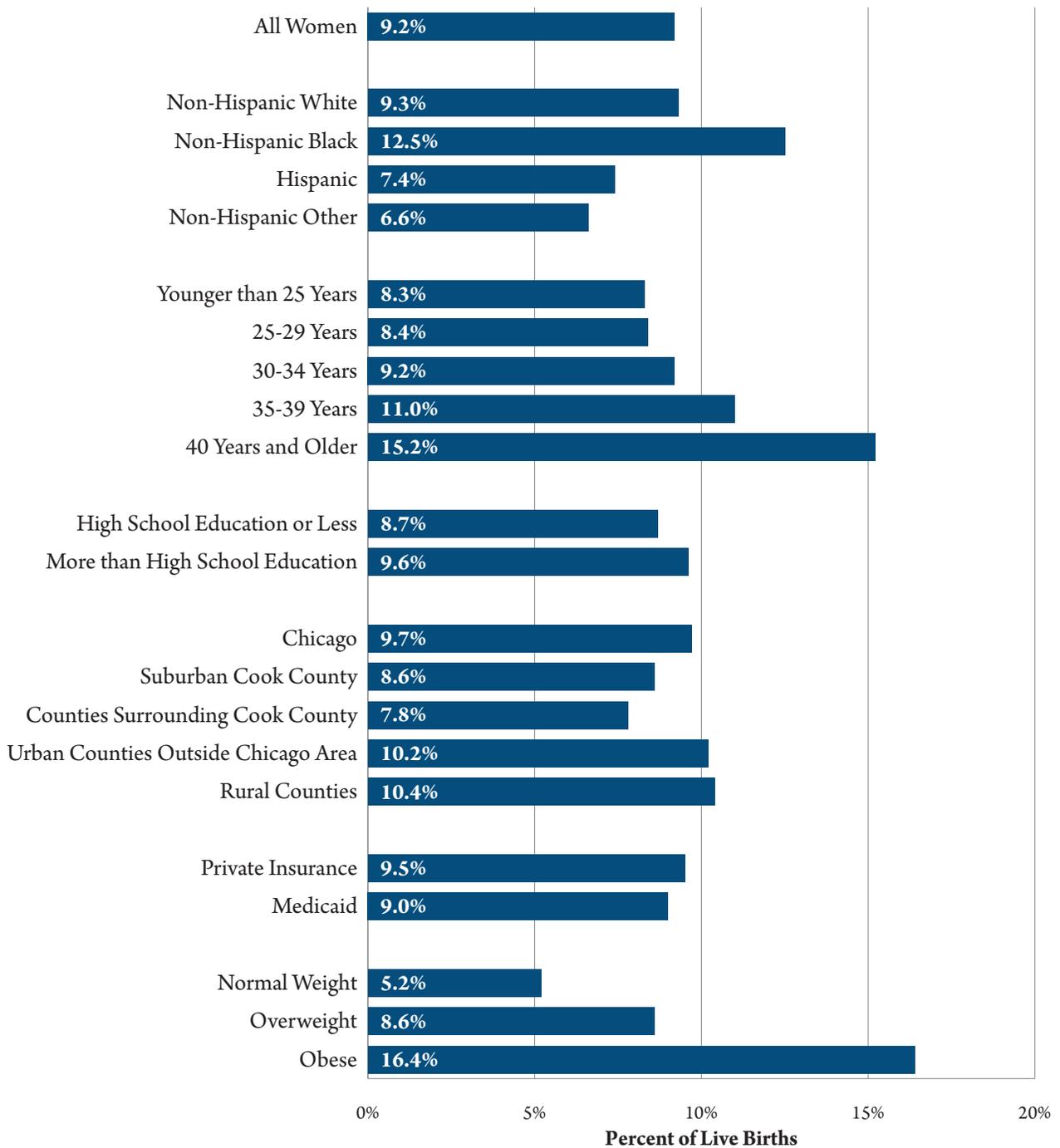
During 2016-2017 in Illinois, 7.8% of live births were to women with diabetes (Figure 6). Within their respective demographic categories, diabetes was highest among women who were “Other” races (not White, Black, or Hispanic) (12.1%), age 40 years and older (17.5%), Suburban Cook County residents (8.6%), and obese (14.1%). There were not substantial differences in diabetes by educational level or insurance type.

Figure 4: Percent of Illinois Live Births to Women with Obesity, by Demographics, 2016-2017



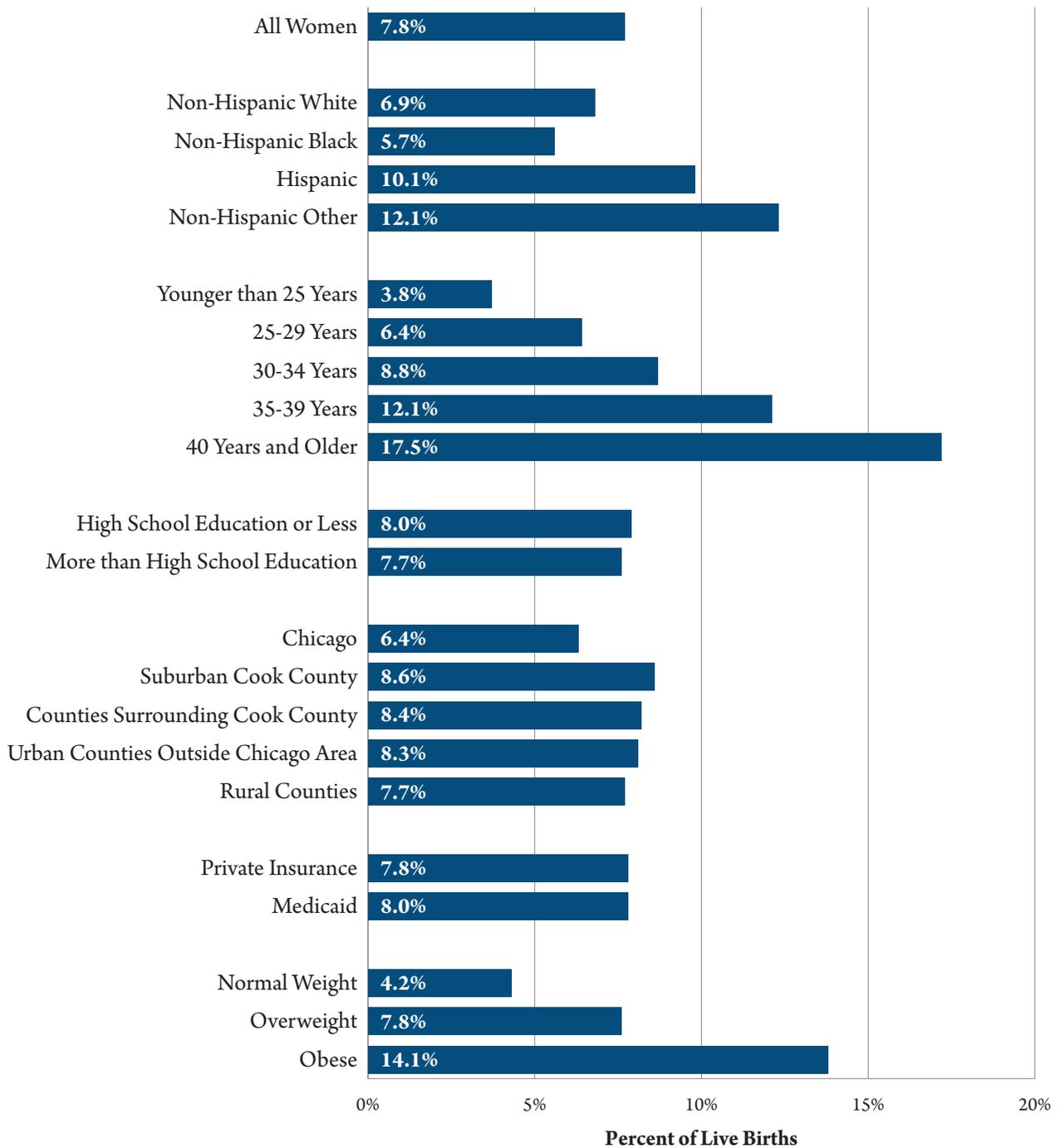
**Data interpretation example:** The bar on the chart referring to women with a High School Education or Less means that among live births occurring to women with a high school education or less, 32.2% were obese.

Figure 5: Percent of Illinois Live Births to Women with Hypertension, by Demographics, 2016-2017



**Data interpretation example:** The bar on the chart referring to obese women means that among live births occurring to obese women, 16.4% had hypertension.

Figure 6: Percent of Illinois Live Births to Women with Diabetes, by Demographics, 2016-2017



**Data interpretation example:** The bar on the chart referring to Hispanic women means that among live births occurring to Hispanic women, 10.1% had diabetes.

## Chronic Disease Prevention

Given the relationship between chronic disease and adverse maternal health outcomes, it is vitally important that all women of reproductive age have access to routine preventive health care to help them be as healthy as possible before pregnancy. Women with chronic health conditions, especially those seeking to become pregnant, should also receive care from appropriate specialists to ensure their chronic conditions are properly managed.

Most chronic diseases can be prevented or improved by eating healthy foods, being active, and maintaining a normal weight status. However, many of the root causes of chronic disease are attributable to the social determinants of health<sup>36</sup> and a person's ability to effectively control chronic conditions is greatly influenced by factors such as economic insecurity.<sup>37</sup>

Improving the health of reproductive-aged women will require systems that improve health care for women outside of pregnancy to incorporate chronic disease screening and interventions into routine women's health visits, while improving community-based health promotion and education.<sup>38</sup> Improving the health of reproductive-aged women will also take a systemic approach to address the social determinants of health that prevent women from accessing routine health care.

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<sup>36</sup> Cockerham, W. C., Hamby, B. W., & Oates, G. R. (2017). The social determinants of chronic disease. *American Journal of Preventive Medicine*, 52(1), S5-S12.

<sup>37</sup> Berkowitz, S. A., Meigs, J. B., DeWalt, D., Seligman, H. K., Barnard, L. S., Bright, O. J. M., ... & Wexler, D. J. (2015). Material need insecurities, control of diabetes mellitus, and use of health care resources: results of the Measuring Economic Insecurity in Diabetes study. *JAMA Internal Medicine*, 175(2), 257-265.

<sup>38</sup> Barfield WD, Warner L. Preventing chronic disease in women of reproductive age: opportunities for health promotion and preventive services. *Prev Chronic Dis* 2012; 9: 110281. DOI: <http://dx.doi.org/10.5888/pcd9.110281>

## Severe Maternal Morbidity

The term “severe maternal morbidity” represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. Some types of severe maternal morbidity may cause long-lasting health problems that extend beyond the pregnancy.

A woman was classified as having severe maternal morbidity if any of 20 categories of severe complications were listed on the record for her delivery hospital stay. For more information about how severe maternal morbidity was calculated for this report, see Appendix D.

### Severe Maternal Morbidity Data

Illinois’s severe maternal morbidity rate for 2016-2017 was 75.4 per 10,000 deliveries. This means that about 1 in 150 women who delivered a baby experienced a severe maternal morbidity. The top five most common severe maternal morbidity complications in Illinois during 2016-2017 were hysterectomy, disseminated intravascular coagulation (DIC), acute renal failure, sepsis, and adult respiratory distress syndrome (ARDS).

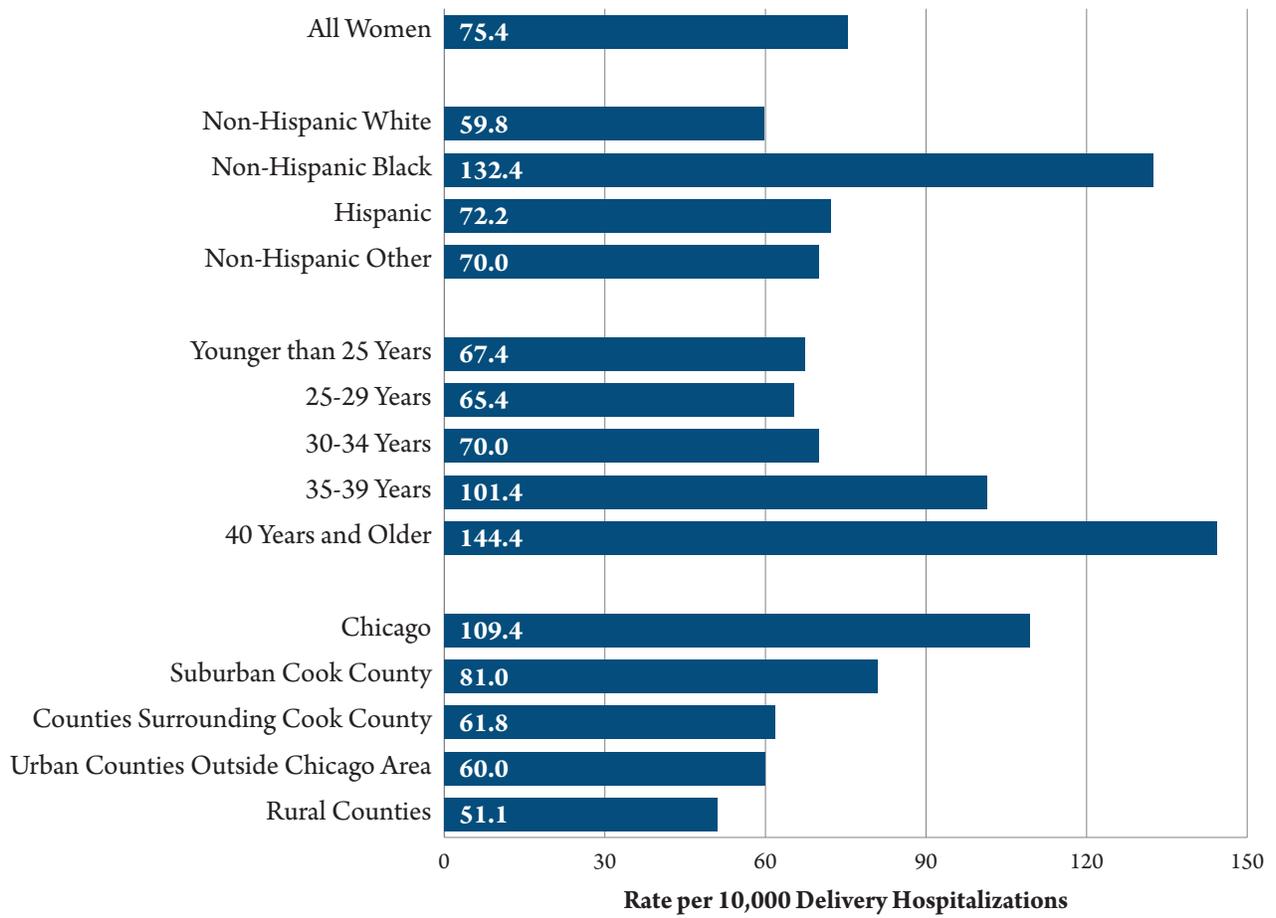
To better understand how severe maternal morbidity impacts certain subgroups of Illinois’ population, the severe maternal morbidity rate was calculated separately by characteristics of interest, including maternal age, race and ethnicity, county of residence, and hypertension status.

Black women had the highest rate of severe maternal morbidity in Illinois during 2016-2017 with a rate of 132.4 per 10,000 deliveries (Figure 7). This is more than two times as high as the rate for White women. Hispanic and Other race women had rates of severe maternal morbidity that were approximately 20% higher than White women.

Women over the age of 40 years had the highest rate of severe maternal morbidity (144.4 per 10,000 deliveries) during 2016-2017 (Figure 7). Women between the ages of 35 and 39 years had the next highest rate of severe maternal morbidity (101.4 per 10,000 deliveries). Women younger than 35 all had similar rates of severe maternal morbidity to each other (rates ranging from 65.4-70.0 per 10,000 deliveries).

Women who lived in Chicago had the highest rate of severe maternal morbidity (109.4 per 10,000 deliveries) (Figure 7). Women who lived in rural counties had the lowest rate of severe maternal morbidity (51.1 per 10,000 deliveries).

Figure 7: Severe Maternal Morbidity Rates among Illinois Delivery Hospitalizations, by Demographics, 2016-2017



## Maternal Mortality

Maternal mortality is the death of a woman during pregnancy, childbirth, or the postpartum period, and it serves as a sensitive indicator of the quality of the health and health care of a community. Many different definitions of maternal mortality are used to track and analyze deaths in different contexts, but Illinois uses the following standard definitions from the Centers for Disease Control and Prevention (CDC):<sup>39</sup>

*Pregnancy-Associated Death* = The death of a woman during pregnancy or within one year of the end of a pregnancy from any cause.

*Pregnancy-Related Death* = The death of a woman during pregnancy or within one year of the end of a 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.

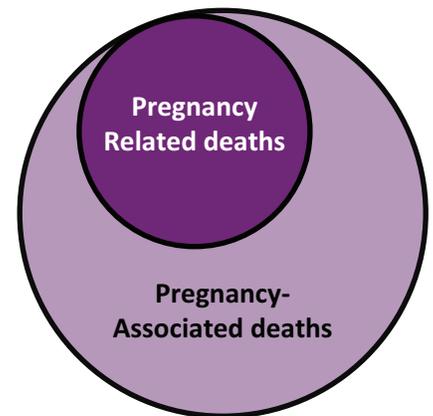
Women who experience pregnancy-related deaths are therefore a subset of women who experience pregnancy-associated deaths (Figure 8).

The first step to tracking and understanding maternal mortality is to identify all pregnancy-associated deaths from a variety of public health data sources. After cases are identified, IDPH and the two MMRCs review the deaths to closely examine the cause of death and determine whether it was pregnancy-related. The review process also identifies factors that influenced the death and informs the development of recommendations for preventing future deaths.

The process Illinois uses to identify pregnancy-associated deaths, collect information, and review cases was described in detail in the 2018 version of the *Illinois Maternal Morbidity and Mortality Report*.<sup>40</sup>

The “pregnancy-associated mortality ratio” (PAMR) and “pregnancy-related mortality ratio” (PRMR) are reported throughout this section. The PAMR and PRMR are interpreted as the number of deaths that occurred for every 100,000 live births within a specific group of women. Because they standardize the population size, the PAMR and PRMR are more meaningful than case counts for comparing the likelihood of death for different groups.

**Figure 8: Relationship Between Pregnancy-Associated and Pregnancy- Related Deaths**



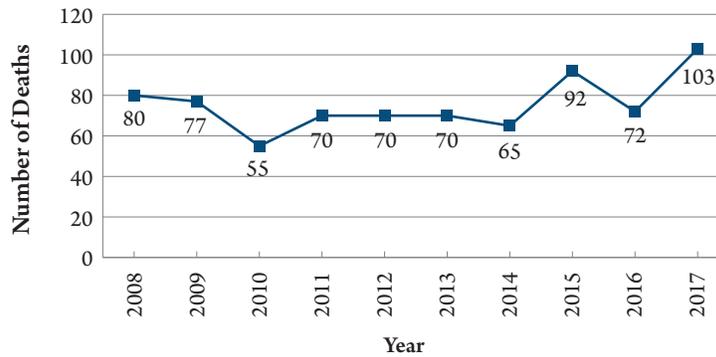
<sup>39</sup> *Maternal Mortality Review Committee Facilitation Guide*. (2019). Centers for Disease Control and Prevention. Retrieved from <http://reviewtoaction.org/rsc-ra/term/80>

<sup>40</sup> *Illinois Maternal Morbidity and Mortality Report*. (October 2018). Illinois Department of Public Health.

**Pregnancy-Associated Deaths**

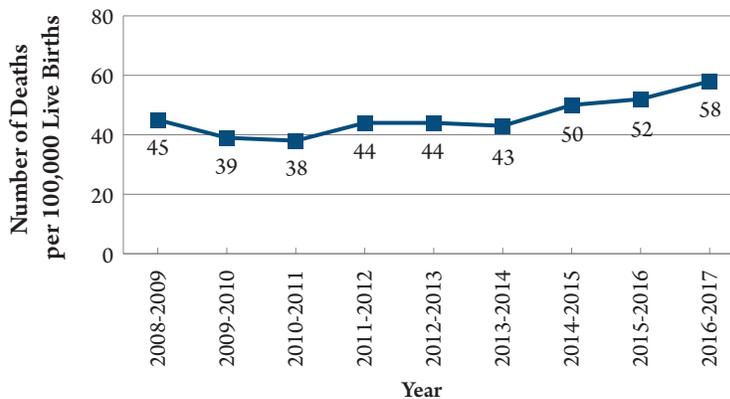
During 2008-2017, a total of 754 Illinois women died while pregnant or within one year of pregnancy. The average annual number of women who died while pregnant or within one year of pregnancy was approximately 75 women. Figure 9 shows that the fewest deaths occurred during 2010 (55 deaths) and the most deaths occurred during 2017 (103 deaths).

**Figure 9. Number of Pregnancy Associated Deaths, Illinois 2008-2017**



While there is no obvious trend when looking at the case counts each year, a different picture emerges when looking at two-year averages in the pregnancy-associated mortality ratio (PAMR). Figure 10 shows the change in PAMR over time and demonstrates a steady increase over the last several years, with 2016-2017 having the highest PAMR on record for Illinois. The Illinois PAMR during 2016-2017 was 50% higher than the lowest PAMR during 2010-2011. This increase over the last several years calls for further examination into the factors driving pregnancy-associated mortality in Illinois.

**Figure 10. Pregnancy Associated Mortality Ratio, Illinois 2-Year Averages**

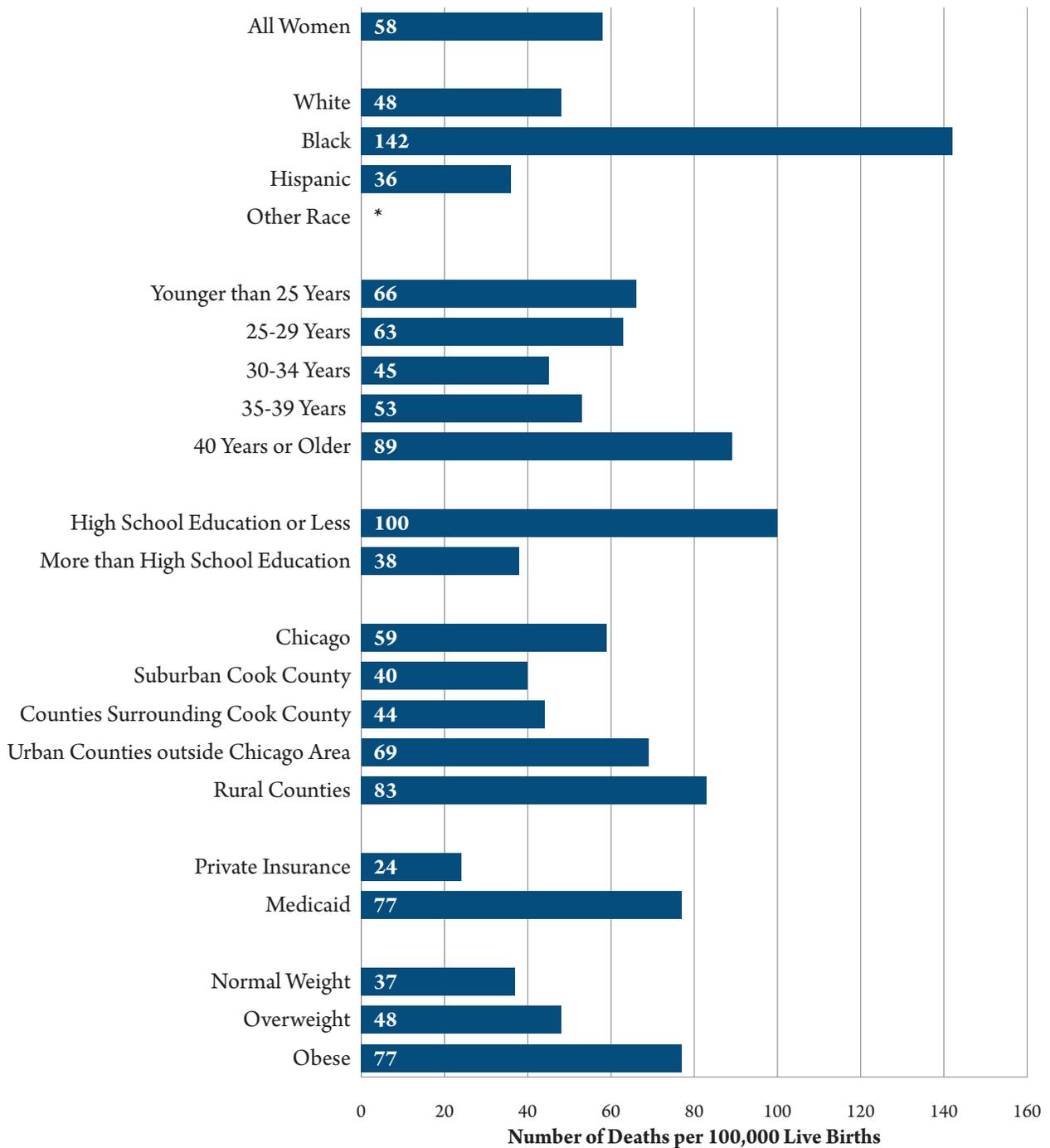


During 2016-2017, there were 175 pregnancy-associated deaths, which translated to 58 pregnancy-associated deaths for every 100,000 live births in Illinois. However, pregnancy-associated mortality is not equally experienced by all groups of women. Figure 11 shows there are significant differences in the PAMR for women based on their race/ethnicity, age, education level, location of residence, insurance type, and body mass index (BMI).

- Black women were nearly three times as likely to die within one year of pregnancy as White women.
- Women ages 30-34 had the lowest PAMR. Women younger than 25 years old had about 50% higher risk of death within one year of pregnancy than women 30-34 years old. Women 40 years old or older were twice as likely to die within one year of pregnancy as women who were 30-34 years old.
- Women with a high school education or less were two and a half times as likely to die within one year of pregnancy as women who had more than a high school education.
- The PAMR was highest for women living in rural counties. Women who lived in Suburban Cook County and the counties surrounding Cook County had the lowest PAMR.
- Women on Medicaid during pregnancy were three times as likely to die within one year of pregnancy as women with private insurance.
- A higher body mass index (BMI) was related to a higher PAMR; obese women were more than twice as likely as normal weight women to die within one year of pregnancy.

Understanding the differences in pregnancy-associated mortality is an important first step in understanding who is most affected by this public health problem, and how to target interventions and resources.

Figure 11. Pregnancy-Associated Mortality Ratio (PAMR),  
By Demographics, Illinois 2016-2017



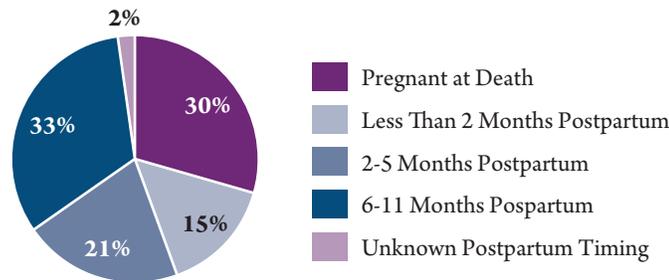
\* Not reported due to small sample size (fewer than 5 deaths for group)

**Data interpretation example:** The bar on the chart referring to Black women means that for every 100,000 live births among Black women, 142 Black women experienced a pregnancy-associated death.

Of the pregnancy-associated deaths that occurred during 2016-2017, 30% (52 deaths) occurred to women while they were pregnant, 15% (26 deaths) occurred less than two months postpartum, 21% (36 deaths) occurred 2-5 months postpartum, and 33% (57 deaths) occurred 6-11 months postpartum (Figure 12). For 2% of pregnancy-associated deaths (4 deaths), the women were known to have had a pregnancy within the last year, but the exact postpartum timing was unknown.

These data demonstrate the importance of tracking maternal deaths to one year postpartum, as approximately half of pregnancy-associated deaths occur more than two months after pregnancy.

**Figure 12. Timing of Pregnancy-Associated Deaths in Relation to Most Recent Pregnancy, Illinois 2016-2017**



*Due to rounding, percentages in this figure do not add up to 100%*

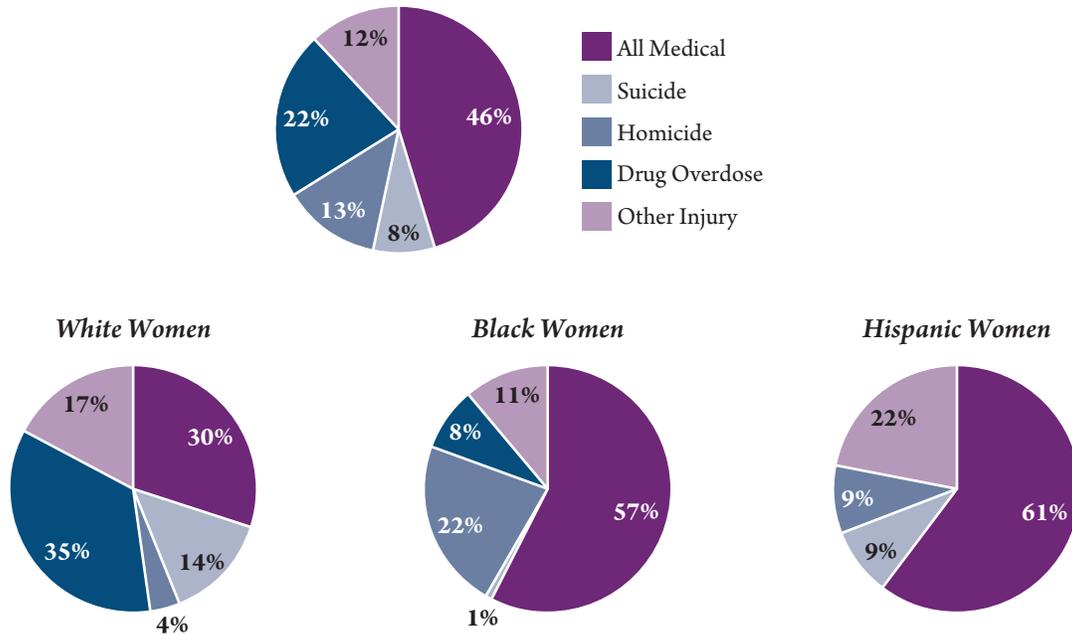
The “underlying cause of death” is the event or condition that initiated the chain of events that eventually led to the death. Based on death certificate information and MMRC reviews, the underlying cause of death is used to identify different categories of deaths. Deaths are generally classified as medical causes (including hemorrhage, infection, cardiac conditions, cancer, diabetes, etc.), suicide, homicide, drug overdose, or other types of injury (mostly motor vehicle crashes).

For the pregnancy-associated deaths that occurred during 2016-2017, 46% (80 deaths) were related to medical causes, 8% (14 deaths) were due to suicide, 13% (22 deaths) were due to homicide, 22% (38 deaths) were due to drug overdose, and 12% (21 deaths) were due to other injuries (Figure 13). Together, the “violent deaths” due to suicide, homicide, and drug overdose accounted for 42% (74 deaths) of all pregnancy-associated deaths. Violent pregnancy-associated deaths are further explored later in this report.

During 2016-2017, the most common causes of pregnancy-associated deaths differed by race/ethnicity (Figure 13):

- Medical pregnancy-associated deaths comprised a larger proportion of pregnancy-associated deaths for Black (57%) and Hispanic women (61%) than they did for White women (30%).
- Suicide accounted for approximately 14% and 9% of pregnancy-associated deaths among White and Hispanic women, respectively, but was a very rare cause of pregnancy-associated death for Black women (1%).
- Homicide accounted for 22% of pregnancy-associated deaths among Black women but was a very rare cause of pregnancy-associated death for White (4%) and Hispanic women (9%).
- Drug overdose was the most common cause of pregnancy-associated deaths for White women, comprising 35% of pregnancy-associated deaths. Drug overdose accounted for a smaller proportion of pregnancy-associated deaths among Black (8%) and Hispanic (22%) women.

**Figure 13. Underlying Causes of Pregnancy-Associated Death, By Race/Ethnicity, Illinois 2016-2017**



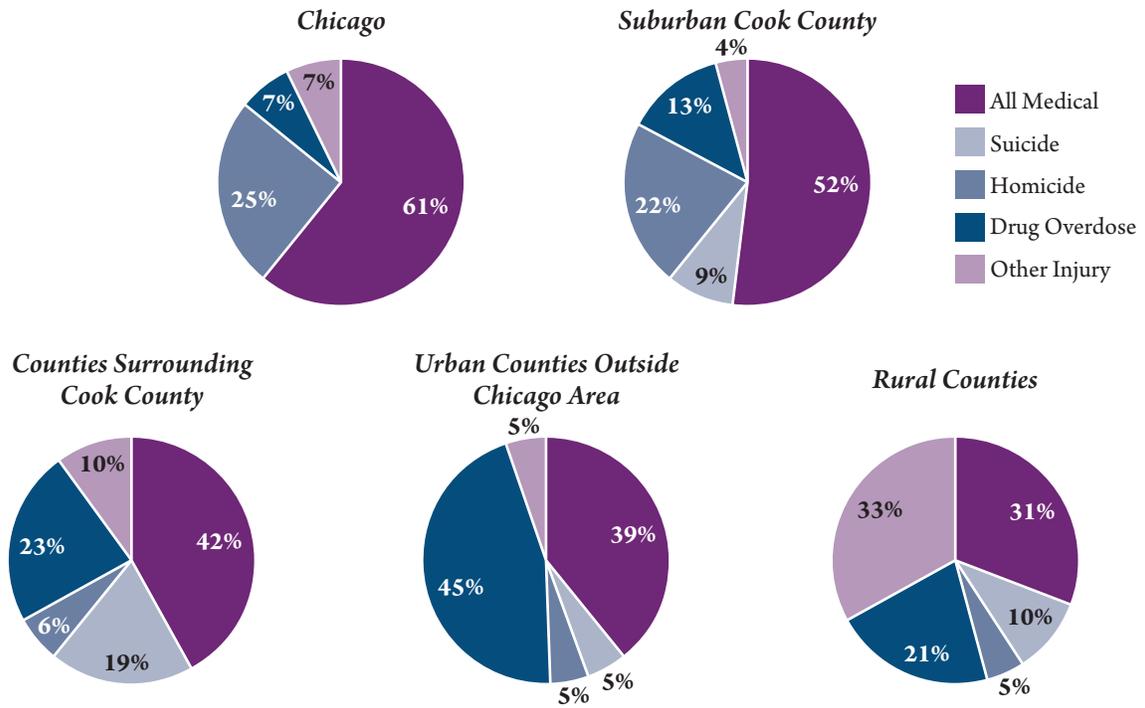
Due to rounding, percentages in this figure do not add up to 100%

During 2016-2017, the most common causes of pregnancy-associated deaths also differed by the county of residence for Illinois women (Figure 14):

- Medical causes comprised 61% of pregnancy-associated deaths among Chicago residents, but only 31% of pregnancy-associated deaths among residents of rural Illinois counties.
- Suicide comprised 19% of pregnancy-associated deaths among residents of the counties surrounding Cook County, but zero pregnancy-associated deaths among residents of Chicago.
- Homicide comprised 25% of pregnancy-associated deaths among Chicago residents and 22% of pregnancy-associated deaths among residents of suburban Cook County, compared to only 5-6% for other areas of the state.
- Drug overdose comprised 45% of pregnancy-associated deaths among residents of urban counties outside the Chicago metropolitan area, but only 7% of pregnancy-associated deaths among Chicago residents.
- Other injuries were a relatively rare cause of pregnancy-associated death for most geographic areas in Illinois. The one exception was among rural county residents where other injuries comprised 33% of pregnancy-associated deaths. Most of the deaths in this category are due to motor vehicle crashes, which are known to pose a greater health burden in rural areas.<sup>41</sup>

<sup>41</sup> *Motor Vehicle Safety in Rural America*. (2018). Centers for Disease Control and Prevention. Retrieved from: <https://www.cdc.gov/ruralhealth/MotorVehicleSafety.html>

**Figure 14. Underlying Causes of Pregnancy-Associated Death, By County of Residence at Time of Death, Illinois 2016-2017**



*Due to rounding, percentages in this figure do not add up to 100%*

The variation in the leading causes of death by race/ethnicity and geography raises additional questions about why these differences occur and how to prevent deaths effectively in different communities. These questions draw attention to the need for a comprehensive review of certain types of pregnancy-associated deaths.

### Reviewing and Assessing Maternal Deaths

The CDC recommends review of maternal deaths by a multidisciplinary committee as a means of gathering additional information about how the woman died, whether the death was preventable, and how to prevent future maternal deaths. Illinois has two state committees that review maternal deaths: the Maternal Mortality Review Committee (MMRC), which first met in 2001, and the Maternal Mortality Review Committee for Violent Deaths (MMRC-V), which first met in 2015.

- The MMRC reviews all pregnancy-associated deaths from medical conditions that are potentially related to pregnancy.
  - Examples: deaths due to postpartum bleeding, high blood pressure during or after pregnancy, or complications of asthma during pregnancy
- The MMRC-V reviews all pregnancy-associated deaths due to homicide, suicide, unintentional drug overdose, or other drug-related conditions.
- Deaths that do not fall within the scope of the committee reviews are still counted as pregnancy-associated deaths but are not reviewed by either state committee.
  - Examples: deaths related to cancer or motor vehicle crashes

Beginning with the review of 2015 deaths, IDPH implemented new processes to align the MMRC and MMRC-V with national best practices and to ensure consistency across the two committees. Every year, IDPH staff review the records gathered for each pregnancy-associated death and assign the cases for committee review.

Prior to case review, skilled abstractors prepare case summaries (called “abstracts”) by reviewing medical records and other information, such as police or autopsy reports. The abstract includes key information on the woman’s medical and social histories and outlines the sequence of events leading to her death. As part of the abstract, IDPH uses a social determinants of health checklist to capture information about the woman’s social and community context, education and language, health care barriers, and economic stability. This checklist allows the committee to specifically identify social, economic, and environmental factors that may have contributed to the death and to develop data-driven policy recommendations to address them. Addressing social determinants of health is critical for promoting health equity. Together, the medical and social information in the abstracts is used by the MMRCs to make key decisions about the case.

Beginning in 2020, the case abstracts have included a community vital signs dashboard developed by Emory University, Rollins School of Public Health. The dashboard presents information about the woman’s community (based on her last known address) compared to the average of other neighborhoods in Illinois and the United States. The dashboard includes indicators related to general health, reproductive health, behavioral health, neighborhood social stability, social support, housing, transportation, and socioeconomic groups. This dashboard enables the MMRCs to gain a sense of the general social and community context in which the woman lived, and to consider how these social determinants may have affected her health. This new and innovative tool has helped deepen conversation around social determinants of health during case review and helped the committees to identify community and systems factors that contributed to the death. More information about the community data will be included in future reports once the MMRCs have used the information for a complete year of case reviews.

To guide the case review discussion, both the MMRC and MMRC-V use a standardized data collection form developed by the CDC called the “Committee Decision Form.”<sup>42</sup> This form walks the MMRCs through key questions about each death, including the following:

1. What was the cause of death?
2. Was the death related to pregnancy?
3. Was the death potentially preventable?
4. What factors contributed to the death?
5. What recommendations could be implemented to prevent future deaths?

During 2019 and 2020, the Illinois MMRCs completed reviews of pregnancy-associated deaths that occurred during 2016 and 2017. During those years, 175 Illinois residents died while pregnant or within one year of pregnancy, with 46 of those deaths being of non-violent causes that were unrelated to pregnancy. A total of 129 pregnancy-associated deaths of Illinois residents were reviewed, 57 by the MMRC and 72 by the MMRC-V (Figure 15).

**Figure 15: Pregnancy-Associated Deaths to Illinois Residents during 2016-2017, by Review Type**



The next section of this report presents case review data for the deaths of Illinois women that occurred during 2016 and 2017. This builds upon the data presented in the first state report by presenting the most recent two years of data and by expanding upon the themes identified in the first report. The two-year combined estimates provide larger case counts and improve the reliability of the statistical analyses, allowing this report to present a more detailed analysis of issues related to racial inequities and causes of death.

<sup>42</sup> *Maternal Mortality Review Committee Decisions Form.* (2017). Centers for Disease Control and Prevention. Retrieved from <https://reviewtoaction.org/rsc-ra/term/68>

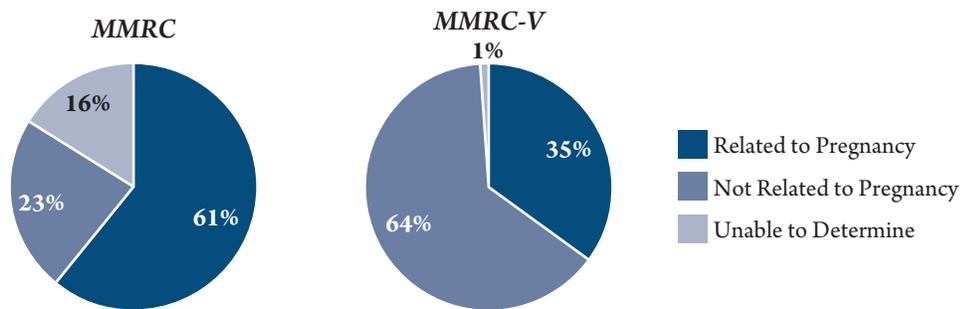
**Pregnancy-Related Deaths**

Pregnancy-related deaths are deaths where the MMRCs determined that the cause of death was related to the pregnancy. In the first Illinois Maternal Morbidity and Mortality Report, the definition of “pregnancy-related” deaths also included deaths for which the relationship to pregnancy was unable to be determined (due to incomplete information) so a relationship to pregnancy was not definitely ruled out. We have since changed our definition to align with the CDC and enable comparison with national reports. Therefore, this report’s data for pregnancy-related deaths are not comparable to the data in the first report.

The MMRC reviewed 57 deaths that occurred during 2016-2017 and determined that 61% (35 deaths) were related to pregnancy and 23% (13 deaths) were not related to pregnancy (Figure 16). For 16% (9 deaths), the MMRC was not able to determine whether it was related to pregnancy, usually due to incomplete information in the medical records, or uncertainty about the woman’s cause of death.

The MMRC-V reviewed 72 deaths that occurred during 2016-2017 and determined that 35% (25 deaths) were related to pregnancy and 64% (46 deaths) were not related to pregnancy (Figure 16). For 1% (1 death), the MMRC-V was not able to determine whether the death was related to pregnancy due to incomplete information about a woman’s past medical and social histories.

**Figure 16: Relationship to Pregnancy for Reviewed Maternal Deaths, Illinois 2016-2017**

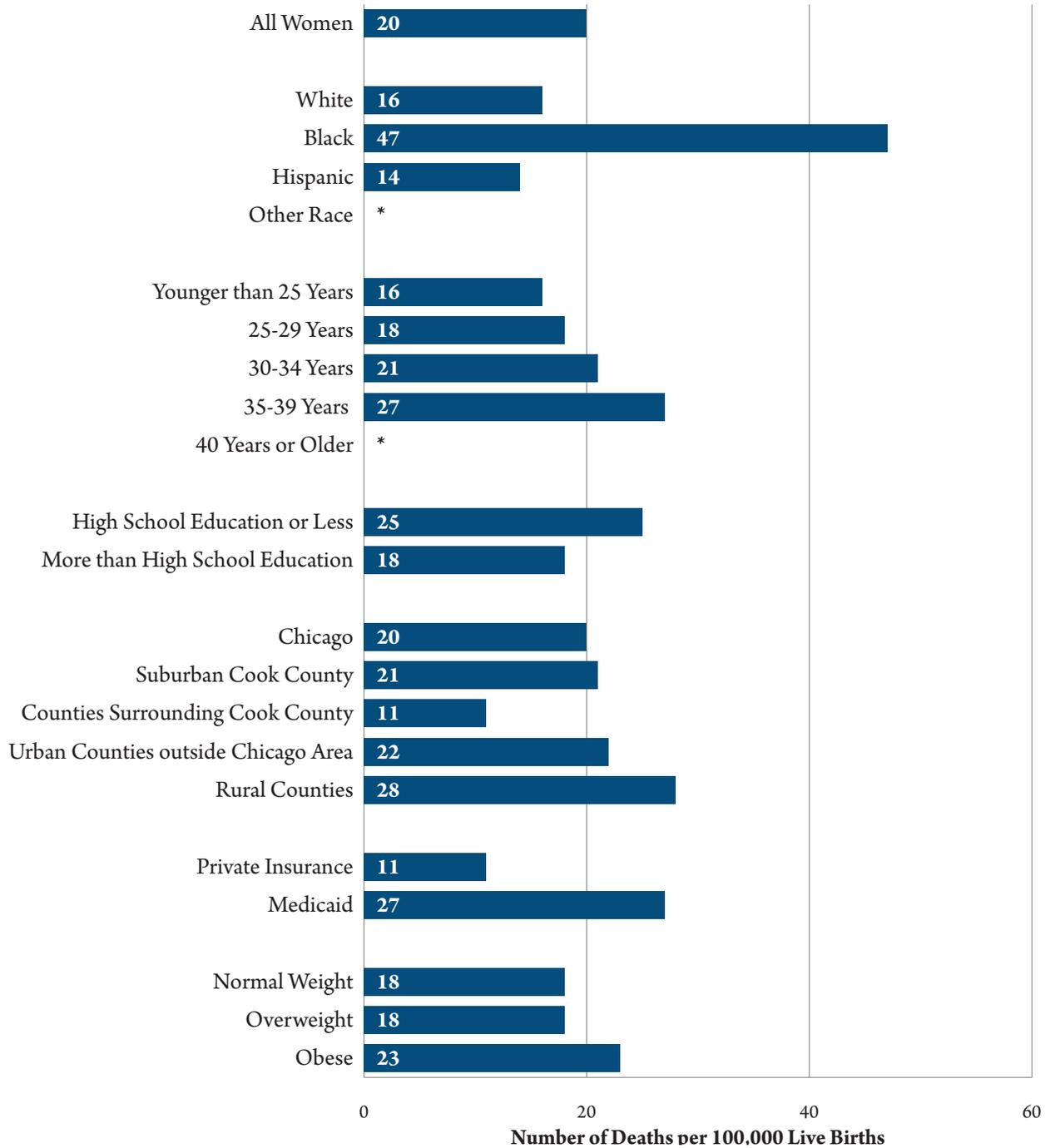


There were a total of 60 pregnancy-related deaths during 2016-2017, accounting for approximately 34% of all pregnancy-associated deaths. This translates to 20 pregnancy-related deaths for every 100,000 live births for Illinois residents.

Pregnancy-related mortality is not equally experienced by all groups of women. Figure 17 shows there are substantial differences in the PRMR for women based on their race/ethnicity, age, education level, location of residence, insurance type, and body mass index (BMI).

- Black women were three times as likely as White women to die from a pregnancy-related cause.
- The PRMR increased with age, with women 35-39 years old or older being approximately 70% more likely to die from a pregnancy-related cause than women younger than 25 years old.
- Women with a high school education or less were more likely to die from a pregnancy-related cause than women with more than a high school education.
- The PRMR was highest for residents of rural counties and lowest for residents of the counties surrounding Cook County.
- Women on Medicaid during pregnancy were twice as likely to die from a pregnancy-related cause as women with private insurance.
- Obese women had a slightly higher PRMR than normal weight and overweight women.

Figure 17. Pregnancy-Related Mortality Ratio (PRMR),  
By Demographics, Illinois 2016-2017

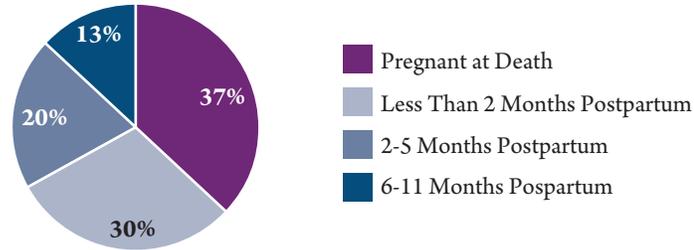


\* Not reported due to small sample size (fewer than 5 deaths for group)

**Data interpretation example:** The bar on the chart referring to Chicago women means that for every 100,000 births among Chicago residents, 20 Chicago women experienced a pregnancy-related death.

Of the pregnancy-related deaths that occurred during 2016-2017, 37% (22 deaths) occurred to women while they were pregnant, 30% (18 deaths) occurred less than two months postpartum, 20% (12 deaths) occurred 2-5 months postpartum, and 13% (8 deaths) occurred 6-11 months postpartum (Figure 18). These data demonstrate the importance of considering tracking maternal deaths to one year postpartum, as approximately one-third of pregnancy-related deaths occur at least two months after pregnancy.

**Figure 18. Timing of Pregnancy-Related Deaths in Relation to Most Recent Pregnancy, Illinois 2016-2017**



To better understand pregnancy-related deaths, the underlying cause of death was classified as either “injury,” “mental health conditions,” or one of 10 medical conditions defined by the CDC’s Pregnancy Mortality Surveillance System (PMSS): hemorrhage, infection, amniotic fluid embolism, thrombotic pulmonary embolism, hypertensive disorders of pregnancy, anesthesia complications, cerebrovascular accident, cardiomyopathy, other cardiovascular conditions, and other non-cardiovascular conditions. We further divided “other non-cardiovascular deaths” into two sub-categories for our analysis: one that identified deaths related to pre-existing chronic medical conditions, and a separate group that identified other conditions unique to pregnancy.

Table 1 shows the top four categories of the underlying causes of pregnancy-related death. The most common underlying cause of pregnancy-related deaths was mental health conditions (including substance use disorders), which caused 24 deaths over the two-year period. The next most common causes of pregnancy-related deaths each accounted for five deaths over the two-year period: pre-existing chronic medical conditions, hemorrhage, and hypertensive disorders of pregnancy. Together, these top four causes accounted for 65% of pregnancy-related deaths. All other causes of death combined accounted for 21 deaths, or 35% of pregnancy-related deaths.

**Table 1. Top Four Underlying Cause of Death Categories for Pregnancy-Related Deaths, Illinois 2016-2017**

Cause of Death Category	Number of Pregnancy-Related Deaths	Percent of Pregnancy-Related Deaths
Mental Health Conditions*	24	40%
Pre-existing Chronic Medical Condition**	5	8%
Hemorrhage	5	8%
Hypertensive Disorders of Pregnancy	5	8%
All Other Causes Combined***	21	35%

*Due to rounding, percentages in this figure do not add up to 100%*

\* Includes deaths due to depression, schizophrenia, and substance use disorder

\*\* These deaths were related to health conditions that women were known to have prior to pregnancy, including: lupus, sickle cell disease, and end-stage renal disease. These deaths are included as “non-cardiovascular deaths” by the CDC PMSS.

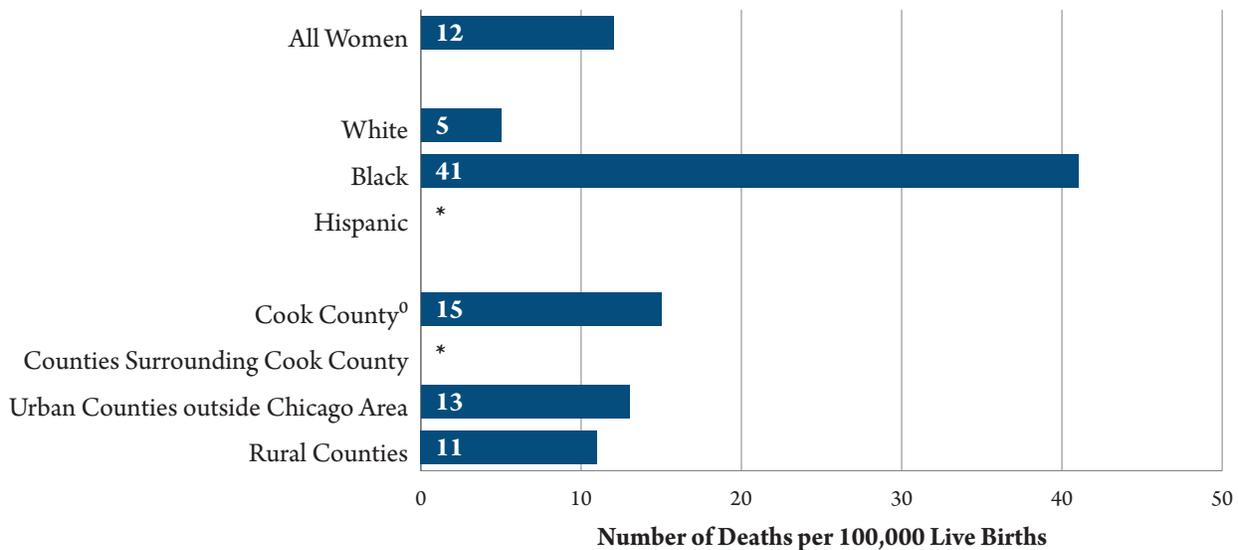
\*\*\* Each of the other cause of death categories accounted for fewer than five deaths during the two-year period and are not able to be reported individually.

Examination of the cause of death also revealed how the drivers of pregnancy-related mortality were different across racial/ethnic groups. There is a striking divide between the contribution of mental health conditions to the pregnancy-related deaths of different racial/ethnic groups. Mental health conditions caused 64% of the pregnancy-related deaths among White women, 56% of the pregnancy-related deaths among Hispanic women, but only 13% of pregnancy-related deaths among Black women.

Collectively, the other three top categories of cause of death in Table 1 (i.e., pre-existing chronic medical conditions, hemorrhage, and hypertensive disorders of pregnancy) accounted for only 3% of pregnancy-related deaths among White women but were responsible for 46% of pregnancy-related deaths among Black women and 33% of pregnancy-related deaths among Hispanic women. Importantly, all five deaths due to pre-existing chronic medical conditions occurred in Black or Hispanic women, and all five hemorrhage deaths occurred in Black women.

The breakdown in pregnancy-related deaths for those due to medical conditions compared to mental health conditions revealed important racial/ethnic and geographic patterns that were masked by the overall PRMR in Figure 17. Figure 19 shows the PRMR that is specifically due to medical conditions. Black women were eight times as likely to die from a pregnancy-related medical condition than White women. Of all the geographic areas in Illinois, women residing in Cook County had the highest risk of experiencing a pregnancy-related death caused by a medical condition. In contrast, Figure 20 shows the PRMR that is specifically due to mental health conditions, revealing opposite racial and geographic patterns. White women and those residing in rural counties in Illinois were most likely to die from a pregnancy-related mental health condition.

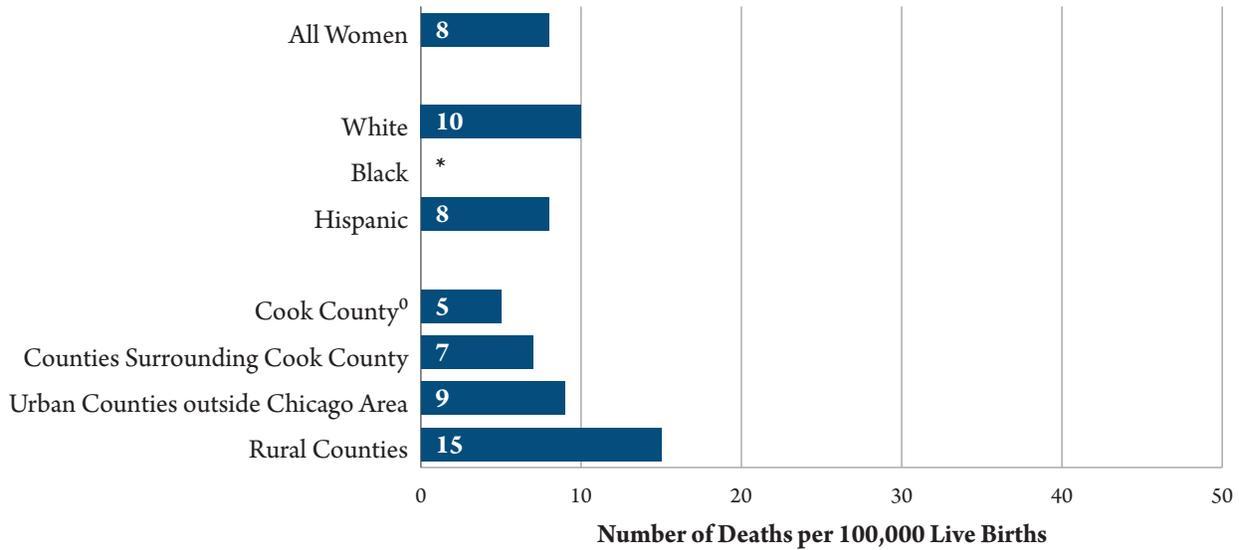
**Figure 19. Pregnancy-Related Mortality Ratio (PRMR) Due to Medical Conditions, By Demographics, Illinois 2016-2017**



\* Not reported due to small sample size (fewer than 5 deaths for group)

<sup>0</sup> Due to small case counts, Chicago and suburban Cook County have been combined for this chart to enable the estimate to be displayed.

**Figure 20. Pregnancy-Related Mortality Ratio (PRMR) Due to Mental Health Conditions, By Demographics, Illinois 2016-2017**



\* Not reported due to small sample size (fewer than 5 deaths for group)

<sup>0</sup> Due to small case counts, Chicago and suburban Cook County have been combined for this chart to enable the estimate to be displayed.

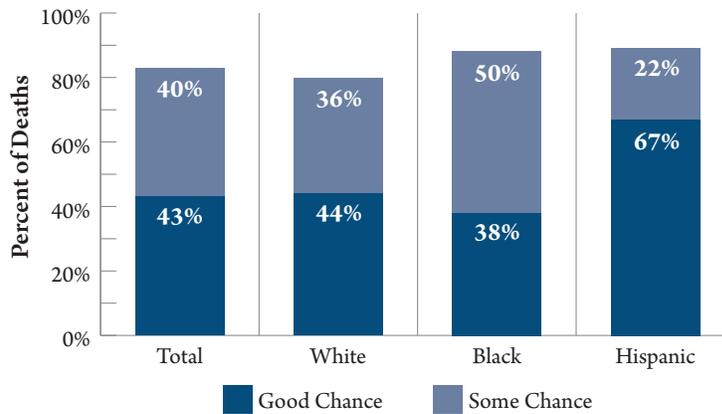
After discussion of the cause of death, the MMRCs determine whether the death was potentially preventable. Deaths are considered “preventable” if reasonable changes to provider, facility, patient, community, or system factors could have helped to prevent the death. However, it is important to recognize that among these preventable deaths, the chance of preventing that death can range from a “very good chance” to “slight chance.” The number and types of factors that contribute to each case greatly influence the chance of preventability.

For example, a death where the hospital did not have enough blood available to treat a hemorrhage might be considered to have a “good chance” of being prevented. On the other hand, the death of a woman with a complicated medical condition who was receiving some medical treatment, but did not receive a referral to a specialist, might have had only a “slight chance” of being prevented.

However, all preventable deaths have at least one issue that the MMRCs identified as a potential way to change the course of the woman’s health outcome. Deaths that are deemed “not preventable” are those where there were no factors identified that could have changed the sequence of events or medical condition that led to the woman’s death. An example of a death that was “not preventable” is a woman who suffers from a sudden brain bleed during pregnancy but had no known risk factors that would have reasonably led a health provider to start preventative treatment for this condition prior to its occurrence.

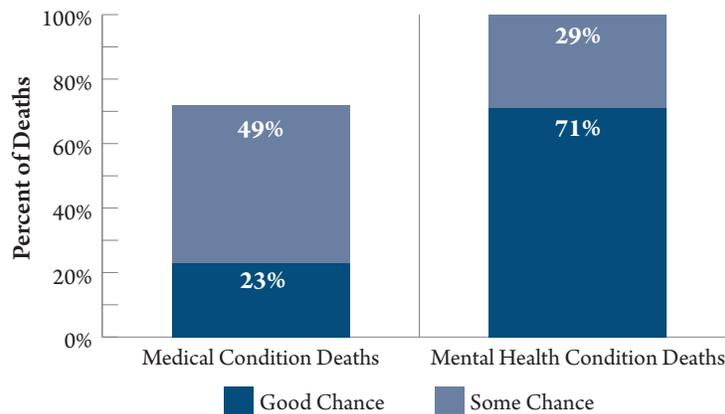
For 83% of pregnancy-related deaths, the MMRCs determined there was at least “some chance” of the death being prevented (Figure 21). The overall preventability of pregnancy-related deaths was similar across racial/ethnic groups, with 80% of deaths to White women, 88% of deaths to Black women, and 89% of deaths to Hispanic women being deemed preventable. Deaths with a “good chance” of being prevented made up 43% of all deaths, 44% of deaths to White women, 38% of deaths to Black women, and 67% of deaths to Hispanic women.

Figure 21. Percent of Pregnancy-Related Deaths That Were Preventable, By Race/Ethnicity, Illinois 2016-2017



The chances of preventing the death differed by the underlying cause of death (Figure 22). For pregnancy-related deaths caused by medical conditions, nearly 72% were potentially preventable, with 23% having a good chance of being prevented and 49% having some chance of being prevented. In contrast, 100% of pregnancy-related deaths due to mental health conditions were preventable, with 71% having a good chance of being prevented and 29% having some chance of being prevented.

Figure 22. Percent of Pregnancy-Related Deaths That Were Preventable, By Underlying Cause of Death, Illinois 2016-2017



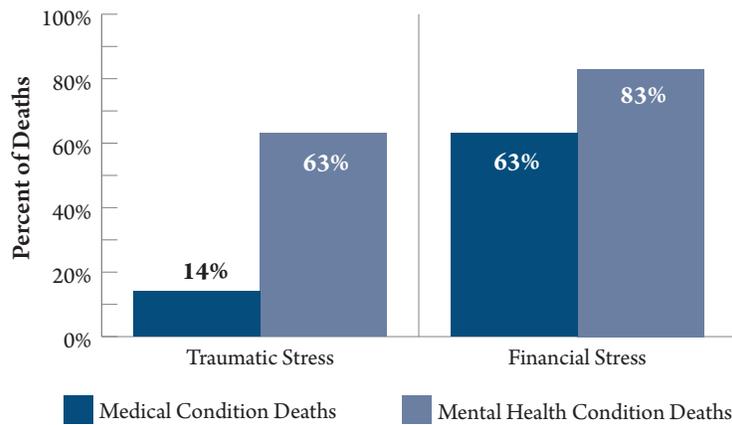
Information from the social determinants of health checklist was compiled to consider the social and economic experiences of women who died from a pregnancy-related cause. Women experienced “traumatic stress” if they had any current or past history of housing instability (including homelessness), incarceration or other justice system involvement, involvement with the Illinois Department of Children and Family Services (DCFS), community violence, domestic violence, or other trauma (such as sexual abuse). Women were classified as experiencing “financial stress” if they were on Medicaid, had no health insurance, were a participant in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), were unemployed, or had issues with food insecurity. More information about these data definitions are available in Appendix D.

Of the women who died from a pregnancy-related cause, 33% experienced traumatic stress and 76% experienced financial stress. However, there were differences in the experience of these stressors by the underlying cause of the death, with pregnancy-related deaths due to mental health conditions being more likely to have experienced each type of stressor (Figure 23).

Traumatic stress was experienced by 14% of women who died from pregnancy-related medical conditions and 63% of women who died from pregnancy-related mental health conditions. This demonstrates the importance of evaluating and addressing women’s trauma history along with mental health and substance use disorders.

Financial stress was experienced by 63% of women who died from pregnancy-related medical conditions and 83% of women who died from pregnancy-related mental health conditions. This high prevalence of financial stress among both groups highlights the need to improve the social services available to low-income pregnant and postpartum women.

**Figure 23. Percent of Pregnancy-Related Deaths Affected by Social Determinants of Health, By Underlying Cause of Death, Illinois 2016-2017**



The MMRCs concluded their case reviews with detailed discussions of the specific factors that contributed to each maternal death, along with recommendations for preventing future deaths due to those factors. More information about the types of factors involved in these preventable deaths is presented in the section “Opportunities for Prevention.”

**Violent Pregnancy-Associated Deaths**

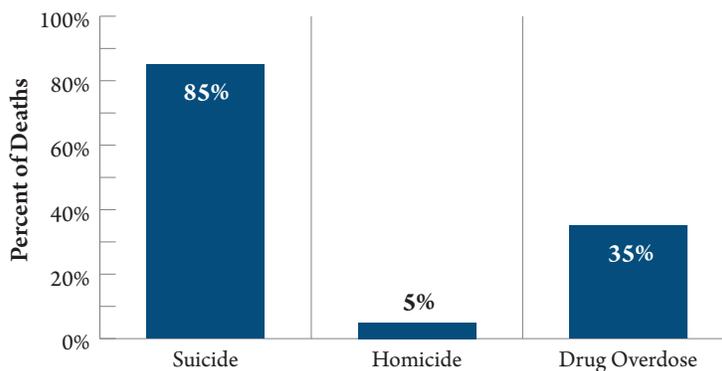
The MMRC-V reviews all pregnancy-associated deaths that are suspected to be the result of homicide, suicide, or unintentional drug use. It is important to review these deaths to better understand the experience of violence, mental health disorders, and substance use disorders on Illinois women. During pregnancy and the postpartum period, some women are interacting with the health care system frequently, so medical providers have a unique opportunity to identify concerns related to mental health, substance use, or violence and link women to needed services as well as provide necessary treatment. Given the rise in opioid overdose deaths among all women of reproductive age,<sup>43</sup> the reviews of pregnancy-associated overdose deaths are important for informing prevention and intervention efforts.

A total of 72 pregnancy-associated deaths occurring during 2016-2017 were reviewed by the MMRC-V to evaluate whether the causes of death were related to suicide, homicide, or drug overdose. Of these pregnancy-associated deaths, the MMRC-V determined 13 deaths were suicides, 21 deaths were homicides, 37 deaths were drug overdoses, and one death was an unintentional injury death (and therefore was not a true “violent death”). These categories are mutually exclusive, meaning that each case is classified as only one type, and cannot be placed into multiple categories. For example, in the case that a suicide was completed by intentionally overdosing on a drug or medication, this case is included in the “suicide” category, not both the “suicide” and “drug overdose” categories.

As already shown in Figures 13 and 14, the types of violent pregnancy-associated deaths experienced by women varies by their race/ethnicity and location of residence. Drug overdose was the most common type of violent death for White and Hispanic women, while homicide was the most common type of violent death for Black women. For women residing in Chicago and suburban Cook County, homicide was the most common type of violent death. For women residing in the counties surrounding Cook County, urban counties outside the Chicago area, or rural counties, drug overdose was the most common type of violent death.

Of the 71 violent pregnancy-associated deaths during 2016-2017, 35% (25 deaths) were pregnancy-related. The percent of violent deaths that were pregnancy-related varied by type of violent death (Figure 24); 85% of suicide deaths were pregnancy-related, compared to only 5% of homicides and 35% of drug overdoses.

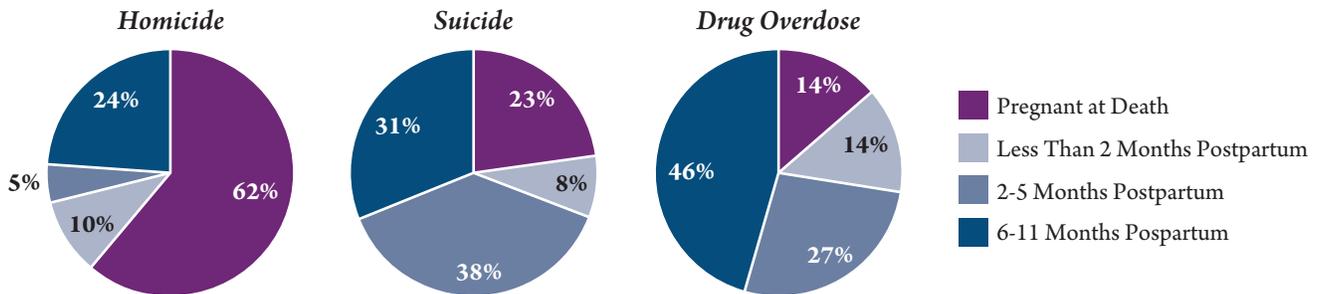
**Figure 24. Percent of Violent Pregnancy-Associated Deaths that Were Pregnancy-Related, Illinois 2016-2017**



<sup>43</sup> Data Snapshot: Opioid poisoning deaths among Illinois women of reproductive age. (2019). Illinois Department of Public Health. [http://www.dph.illinois.gov/sites/default/files/publications/opioid-deaths-among-women-repro-age\\_0.pdf](http://www.dph.illinois.gov/sites/default/files/publications/opioid-deaths-among-women-repro-age_0.pdf)

The timing of death in relation to pregnancy varied across homicide, suicide, and drug overdose pregnancy-associated deaths (Figure 25). More than 60% of homicide pregnancy-associated deaths occurred during pregnancy, compared to 23% of suicide and 14% of drug overdose deaths. For both suicide and drug overdose, almost three-quarters of deaths occurred two or more months postpartum, compared to only about one quarter of homicide deaths.

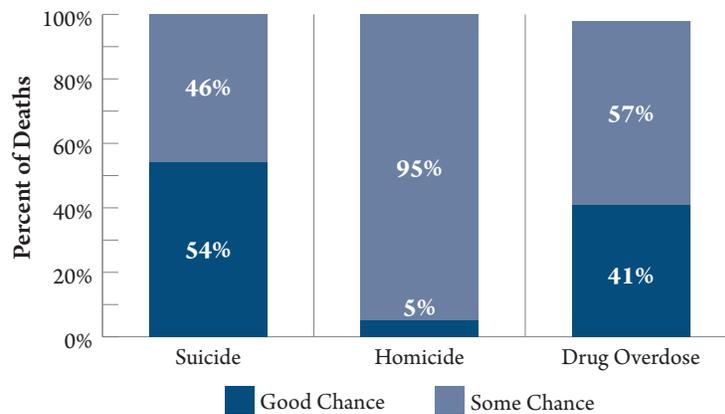
**Figure 25. Timing of Violent Pregnancy-Associated Deaths in Relation to Most Recent Pregnancy, Illinois 2016-2017**



Due to rounding, percentages in this figure do not add up to 100%

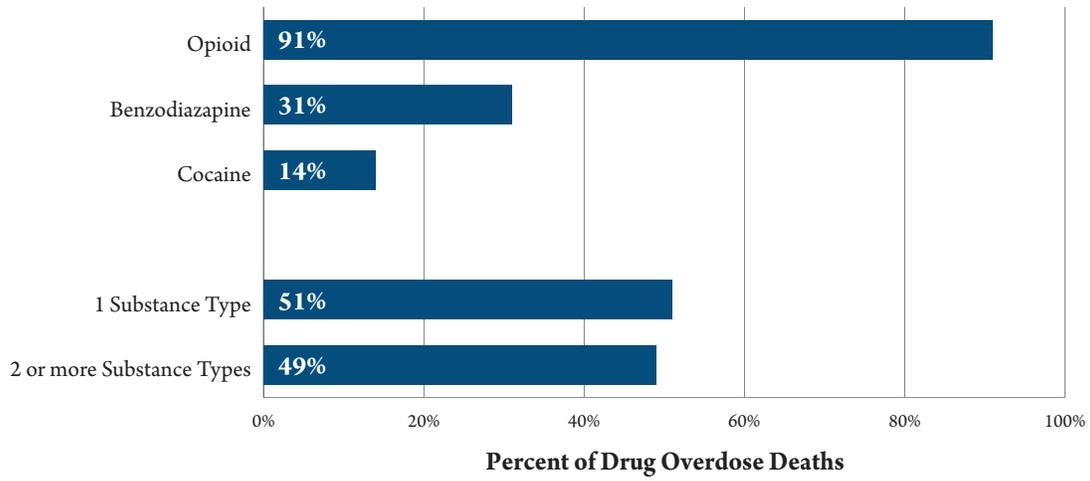
Virtually all the violent pregnancy-associated deaths were determined to be potentially preventable by the MMRC-V. Of the deaths during 2016-2017, 100% of suicides, 100% of homicides, and 98% of drug overdoses were potentially preventable (Figure 26). The MMRC-V also evaluates whether there was a “good chance” or “some chance” of potentially preventing the death. While 54% of suicides and 41% of drug overdose deaths had a good chance of being averted, only 5% of homicides had a good chance of being averted.

**Figure 26. Percent of Violent Pregnancy-Associated Deaths That Were Preventable, By Cause of Death, Illinois 2016-2017**



For drug overdose deaths, toxicology tests during an autopsy are used to determine the substances involved. For 35 out of the 37 drug overdose tests, toxicology results were available to the MMRC-V and a summary of the most common substances involved in the deaths is shown in Figure 27. Opioids were the most common substance involved in pregnancy-associated drug overdose deaths, with 91% of drug overdose deaths involving at least one type of opioid. The most common non-opioid substances involved in drug overdose deaths were benzodiazepines (31%) and cocaine (14%). A combination of multiple types of drugs accounted for 49% of overdose deaths. The most common multi-drug combination among the pregnancy-associated overdose deaths was opioids and benzodiazepines.

Figure 27. Percent of Pregnancy-Associated Drug Overdose Deaths that Involved Various Substance Types, Illinois 2016-2017



The following sections of this report include examples of real deaths experienced by Illinois women in 2016-2017, as well as the major opportunities for intervention and recommendations that were developed as a result of the case reviews by the MMRCs.

## Maternal Death Case Examples

The following section includes five real examples of Illinois women who died during 2016-2017 while pregnant or within a year of pregnancy. Although names have been changed and certain details have been omitted to maintain confidentiality and respect the privacy of the woman and her family, these case summaries stay true to the main events of each case.

Each case example led to rich discussion during the MMRC and MMRC-V meetings, and many important lessons were learned from each woman's death. These examples represent some of the major themes that were identified across reviewed cases. The examples were selected to illustrate the many factors that need to be addressed in preventing maternal mortality.

### Victoria's Story

Victoria was a Black woman in her 30s who immigrated to the United States one year prior to becoming pregnant. She had lupus, a chronic condition in which the body's own immune system attacks itself. She regularly saw a rheumatologist (a doctor specializing in immune diseases) to manage her disease. About one month before becoming pregnant, she stopped going to the rheumatologist and stopped taking her medications due to issues with her health insurance. Several months later, when she was halfway through pregnancy, her insurance was reinstated, and she went to her first prenatal care appointment. During a prenatal appointment, she mentioned having severe abdominal pain, and her prenatal care provider referred her to a maternal-fetal medicine (MFM) physician, a specialist for high-risk pregnancies, due to her abdominal pain and her lupus. However, she never saw this physician because she was admitted to the hospital for pain and shortness of breath due to her lupus. While in the hospital she was given medications to control her lupus, but these drugs also weakened her immune system. Her weakened immune system made her more susceptible to infections, and she developed sepsis, a bacterial infection in her blood stream, and severe bleeding. She died several days later in the hospital while pregnant.

### *What can we learn from Victoria's death?*

Pregnancy can make some chronic medical conditions worse, causing life-threatening health problems. With consistent medications and medical care, some medical conditions, such as autoimmune diseases, can often be treated and managed. The lack of or inconsistent access to insurance can create challenges in seeing a specialist or getting needed medications during pregnancy. In addition, insurance issues can affect a pregnant woman's ability to start prenatal care early in her pregnancy. Consistent insurance can facilitate continuity of care and better management of chronic medical conditions before and during pregnancy and help to prevent complications during pregnancy. It is important that women with chronic medical conditions, especially those seeking to become pregnant, receive ongoing medical care before and during pregnancy.

### Tiffany's Story

Tiffany was a Black woman in her 20s who had a history of asthma. She gave birth to a healthy baby with no complications during her pregnancy or delivery. About one week after birth, she went to a hospital emergency department for chest pain, shortness of breath, and a cough. The emergency department diagnosed her with an asthma exacerbation and prescribed her medications to reduce asthma symptoms and to treat an infection. Several weeks later, she went back to the same hospital with the same symptoms and was given another asthma medication. A few weeks after her second visit, Tiffany went back to the same hospital with the same symptoms for a third time. At this visit, she was found to be in heart failure from peripartum cardiomyopathy, a condition where the heart muscles are weakened and cannot pump blood efficiently. Tiffany was admitted to the hospital and treated but discharged a few days later with no cardiology follow-up appointment scheduled. Several months later, she passed away in her home from heart failure.

### *What can we learn from Tiffany's death?*

All providers within a hospital should be trained on the signs and symptoms of severe postpartum complications and should ask women whether they have been pregnant in the last year. If the emergency department providers are aware of a woman's recent delivery when evaluating her symptoms, they may consider the potential of other conditions, such as a heart condition (cardiomyopathy), and diagnose it earlier. An early diagnosis would allow them to provide treatment to reduce the severity of the condition and potentially save the woman's life. Additionally, once a woman is diagnosed with a heart condition, she should be directly connected to a cardiologist for follow-up. It is vital that hospitals provide "warm handoffs" to specialty providers who can continue to manage the patient's care outside of the hospital setting. A "warm handoff" is the transfer of care between two members of the health care team, where the handoff occurs in front of the patient and family.<sup>44</sup>

### Gabrielle's Story

Gabrielle was a Black woman in her 30s. She entered prenatal care at the start of her second trimester and had a normal pregnancy without complications. She knew she wanted to prevent future pregnancies and planned with her doctor to have a tubal ligation after delivery. She delivered a healthy baby by cesarean section and had the tubal ligation surgery completed at the same time. After surgery, Gabrielle complained of being unable to breathe and having a swollen abdomen. Her heart rate was high. There was a lack of close monitoring during this time. Several hours after her initial complaint, she was taken back to the operating room for the OB/GYN to re-open her abdomen and explore the cause of the pain. Upon reopening her incision, it was discovered that she had massive bleeding in her abdomen due to a cut in her fallopian tube. The cut was repaired, and many blood vessels were removed. She was in stable condition after surgery, and her nurse noticed minor swelling. Over the next several hours, her health deteriorated. Her pulse was weak, and she was given blood transfusions. She went into cardiac arrest. Gabrielle was pronounced dead from postpartum hemorrhage less than 24 hours after delivery.

### *What can we learn from Gabrielle's death?*

Postpartum hemorrhage is a life-threatening complication that must be immediately addressed. Despite complaining of pain and swelling in her abdomen, it took several hours before providers seriously considered her complaints and began to suspect a hemorrhage. Following delivery, appropriate and consistent monitoring is essential to timely and effective hemorrhage intervention. Providers need to listen to and properly address a woman's complaints. Hospitals can also benefit from adopting standardized hemorrhage protocols and ongoing hemorrhage education for all staff to ensure that any provider caring for pregnant or postpartum women can quickly identify and treat hemorrhage.

<sup>44</sup> Warm Handoff: Intervention. (December 2017). Agency for Health care Research and Quality. Retrieved from <https://www.aHRQ.gov/patient-safety/reports/engage/interventions/warmhandoff.html>

### Ana's Story

Ana was a Hispanic woman in her 20s. She had no postpartum depression or other mental health conditions during her previous pregnancies. She delivered her baby without complications and when she left the hospital, she told her health care providers that she had a great support system waiting for her at home. At a postpartum follow-up appointment, a couple of months after delivery, Ana told her physician she was feeling depressed and she had a very high depression risk screening score. Her obstetrician prescribed her an anti-depressant medication and gave her the phone number to a hospital with inpatient psychiatry services. The provider then sent Ana home with no follow-up appointments planned. Approximately three months later, Ana died by suicide.

#### *What can we learn from Ana's death?*

Postpartum depression can come on suddenly due to hormonal changes after delivery, even in women without prior mental illness. Although patients may have a good support system at home, they may specifically seek help from their physician to manage depression. While it is good clinical practice for an obstetrician to screen for depression, provide medication, and provide a phone number for further help, a severe depression score should trigger a "warm hand-off" to a mental health provider and frequent follow-up. Anti-depressants can sometimes increase feelings of suicide, so it is vital that persons taking these medications receive care from a mental health provider. In addition, providing friends and family members education on the signs of severe depression and where to find additional services may help them to recognize and to respond to any suicide warning signs that a patient may be showing.

### Jennifer's Story

Jennifer was a White woman in her 20s. She had a history of major depressive disorder and anxiety since childhood. Throughout her pregnancy, she saw an obstetrician for prenatal care, an MFM physician to manage her medications during pregnancy, and a psychiatrist to manage her chronic mental conditions. Both the obstetrician and MFM indicated that the patient's mental health concerns were the responsibility of the psychiatrist. However, both the psychiatrist and MFM made changes to psychiatric medications throughout pregnancy. Notes from all three physicians were not clear about who started, changed, or discontinued various medications for her depression and anxiety. Despite routinely getting care from all three physicians, it was not coordinated. Jennifer was found dead in her home a few months postpartum. There were more than two dozen psychiatric and pain medications found in her home; many of these medications were duplicate prescriptions or similar types of drugs. Her autopsy determined that her death was an accidental overdose due to a combination of medications.

#### *What can we learn from Jennifer's death?*

Coordination of care between multiple providers is critical, especially for women with mental health conditions. Women may be seeing the appropriate specialists regularly and receiving medications for physical and mental health conditions but a lack of discussion between providers about a woman's medication regimen may cause confusion about her medications and result in her taking multiples of certain types of medications. More actively managed and coordinated medication lists may prevent accidental overdoses.

### Taylor's Story

Taylor was a White woman in her late teens with a history of a substance use disorder. She had a strong support network that included both her parents. She began prenatal care early in her pregnancy with an obstetrician. During her multiple prenatal care visits, there was no record of her prenatal care physician evaluating her for a substance use disorder or discussing possible treatment and recovery services. When she went to the hospital for her delivery, Taylor tested positive for multiple substances. She received social work and psychology services while in the hospital. Taylor was instructed to follow up with a therapist. She did not receive a connection to a specific provider, nor help arranging an appointment. The hospital scheduled Taylor for a general postpartum checkup with an obstetrician six weeks after delivery, but she did not attend this appointment. A couple of months after delivery, Taylor died of a drug overdose involving multiple substances, including opiates.

### *What can we learn from Taylor's death?*

Lack of proper screening and coordination into treatment programs for pregnant and postpartum women continues to be an issue for Illinois women. Some women attend many prenatal care visits but are not screened for substance use with a validated tool, nor referred to additional care. Despite drug use being identified at delivery, some women are not provided treatment or a direct path to substance use treatment and recovery services. Care coordination can help women navigate the health care system to obtain the care needed. Furthermore, naloxone awareness and education may be beneficial for women's support system. In Illinois, anyone can buy naloxone at a pharmacy without a prescription. Health care providers and hospitals can educate patients with substance use disorder and their families about how and when to use naloxone.



## Opportunities For Prevention

An integral part of the maternal mortality review process is to determine whether the maternal death was preventable. For deaths that have at least some chance of being prevented, the MMRCs identify factors that contributed to the maternal death and corresponding action steps that could have prevented the death.

Contributing factors, as identified by the MMRCs, are modifiable factors that impacted a woman's health outcome in a meaningful way, even if they did not directly or solely cause the death. Contributing factors to a maternal death can happen at multiple levels, such as provider, clinic, hospital, system, community, family, or patient. Each maternal death is unique, and thus, the contributing factors vary by case. Across the deaths occurring during 2016-2017, the MMRCs identified several common contributing factors. The most common contributing factors to pregnancy-related deaths included lack of clinical knowledge, poor quality of care, poor standardization of care, poor coordination of care, lack of referrals, limited patient education, lack of appropriate policies, and poor access to care. The most common contributing factors to violent pregnancy-associated deaths included substance use, mental health, lack of assessment and screening, poor coordination of care, and poor access to care and treatment.

The contributing factors identified by the MMRCs are summarized into broad themes below, which can inform maternal mortality prevention efforts. All the themes and factors listed below must be addressed using a racial and ethnic equity lens, as is evident from the case review data that the burden of maternal deaths occurring in Illinois is not equally distributed across racial and ethnic groups.

### 1. Quality of Care

Following clinical standards of care is important for maximizing the quality of care and improving maternal outcomes. Many pregnant and postpartum women presented to hospitals with risk factors for poor maternal outcomes, but were not properly identified, screened, diagnosed, treated, or resuscitated. Health care facilities need to identify a woman's pregnant or postpartum status during all health care visits to properly diagnose and manage her health. Many institutions lacked a formal curriculum on obstetric best practices for all providers who treat women who are or may become pregnant, including emergency physicians and subspecialists. These factors highlight a clear need for an evidence-based standard of care for pregnant and postpartum women across all hospital settings and specialties. Furthermore, there is a need for providers, hospitals, and health systems to conduct quality improvement initiatives to work towards reducing adverse maternal outcomes. The MMRCs' recommendations address several ways to improve the quality of maternal care through implementations of specific clinical best practices and quality improvement initiatives.

### 2. Care Coordination

The coordination of care between health care providers and hospital systems is an integral part of ensuring each woman receives adequate and comprehensive medical treatment. The MMRCs found that necessary referrals to a specialist were often delayed or absent and that women were frequently treated at facilities without the resources and personnel to accommodate their medical needs. Inadequate or absent communication between hospital systems, especially between the inpatient and outpatient settings, contributes to poor maternal outcomes. By referring to appropriate specialists (including social workers, substance use treatment centers, bariatric services, medical subspecialists, and mental health professionals), especially through "warm hand-offs" to those specialists, women will receive more comprehensive and medically appropriate care. The MMRCs developed recommendations to address strategies for improving the care coordination of pregnant and postpartum women.

### 3. Postpartum Follow-Up and Support

The postpartum period can be a challenging time for women, both physically and emotionally. Women can experience pregnancy-related complications for up to one year postpartum, and thus, can benefit from enhanced medical and social services during the year after pregnancy. While the traditional definition of “postpartum” is 42 days after pregnancy, the data from our reviews shows the importance of expanding that window to the first year after pregnancy, as one-third of pregnancy-related deaths from 2016-2017 occurred more than two months after pregnancy. Once pregnancy is over, women usually have less contact with the health care system and may have only one postpartum visit if they receive one at all. Additionally, eligibility for some programs and services may be reduced in the postpartum period, such as Medicaid pregnancy coverage ending at 60 days postpartum.

The MMRCs also identified that patients were not properly educated on warning signs of potentially severe pregnancy complications and therefore delayed or did not seek medical attention when it was needed. By the time these women sought health care, their medical conditions were often too far advanced for treatment to be effective. It is the responsibility of everyone in the health care field to promote women’s participation in their own health care, and to educate both women and their families about postpartum health. Several of the MMRCs recommendations focus on key actions that can be taken to improve the postpartum support system for women and their families.

### 4. Mental Health

Maternal health incorporates not only physical health, but mental health as well. Appropriate management of mental health conditions is critical during and after pregnancy to promote the best possible outcomes for both the woman and her infant. Many pre-existing mental health conditions may be exacerbated by hormonal changes and stressors during pregnancy. However, women with no history of mental health conditions may also develop mental health conditions around the time of pregnancy, such as postpartum depression. Several of the MMRCs’ recommendations address ways to ensure that pregnant and postpartum women are properly screened for mental health conditions, have access to comprehensive mental health treatment, receive appropriate medication management, and receive coordinated care between physical and mental health providers.

### 5. Substance Use

Substance use disorders are a growing problem for women of reproductive age, particularly in the context of the opioid crisis. Access to appropriate substance use treatment, particularly for pregnant women, continues to be a challenge. In multiple cases, women wanted to enter treatment but did not have the knowledge or resources to navigate the health care system. Some women were not seen by hospital social workers because the hospital staff were “too busy,” while others were denied access to treatment because of insurance or their pregnancy status. Other women lacked transportation to and from treatment centers. Due to these numerous barriers, women were unable to gain access to needed substance use disorder treatment.

The MMRCs also identified inadequate follow-up as a concern for women with substance use disorders. Providers sometimes began medication-assisted recovery but did not schedule a follow-up appointment to closely monitor the woman’s treatment. When women tested positive for various drugs and alcohol at the time of delivery, some were sent home with no follow-up or referrals regarding their substance use. It is critical that women with substance use disorders are identified early in their pregnancies, so they can be linked to substance use treatment and additional social services as soon as possible. The availability of such services needs to be expanded, and services need to be designed in a way that meets the needs of women and their families. For women who are in recovery, it is vital to receive the follow-up support services necessary to maintain recovery. Recommendations from the MMRCs emphasized the importance of helping women navigate the health care system, as well as addressing ways to prevent, to identify, and to treat substance use

disorders by utilizing all the various services available in the hospital and clinic. These resources include social work, case managers, and substance use treatment teams.

### **6. Social Determinants of Health**

There are many social and systemic factors that profoundly affect the ability of women to be healthy. These “social determinants of health” include poverty, racism, quality of education, employment, housing, child care, transportation, neighborhood safety, and violence. These issues affect a woman’s physical and mental health directly through cumulative stress and influence her ability to seek, receive, and adhere to health care treatment. Access to transportation and child care, as well as inflexible workplaces (e.g., hourly positions or lack of paid sick leave), prevent numerous women from accessing adequate prenatal or postpartum care.

In general, health care providers are not routinely screening for trauma or addressing the social determinants of health. For example, most of the reviewed cases did not have any documentation of an intimate partner violence screening. Some charts labeled women as “non-compliant,” but did not include notes about the reasons behind her decision and whether there were major barriers preventing her from seeking or receiving care. On the other hand, some facilities and providers did document specific issues, such as a lack of transportation, and worked to support their patient in overcoming those barriers. Addressing the social and structural barriers that many women experience will require a comprehensive social assessment coupled with the integrated partnership of social workers, case managers, and peer counselors to connect these women with assistance. It is important to assess all women for social determinants of health, rather than only selecting women perceived as having barriers. This is especially important as providers’ perceptions may be based on their own preconceived notions and biases. Several recommendations from the MMRCs promote health equity by suggesting systemic changes to help all women achieve optimal health.

## Recommendations

During the review of each maternal death, the MMRC and MMRC-V developed specific, actionable recommendations that could have prevented death. IDPH recorded recommendations developed in response to each reviewed case, which totaled more than 200 recommendations for the two years of reviews. The two MMRCs then reviewed and prioritized these recommendations based on importance, feasibility, and potential impact.

Recommendations were specifically tailored towards hospitals, health care providers, health insurance plans and managed care organizations, state government, community-based organizations, and women and their families and friends. All of these groups have a shared role in the promotion of women's health and the prevention of maternal mortality.

### Recommendations for Hospitals

Hospital practices and policies greatly affect maternal mortality and racial equity in maternal health outcomes; therefore, hospitals are key players in maternal mortality prevention. Hospitals should promote a climate of culturally responsive, patient-centered care to optimize every woman's health, and should ensure their policies promote health equity. The MMRCs found many opportunities to prevent maternal mortality through the improvement of hospital practices, protocols, and policies. Lack of communication within and between hospitals led to fragmented, poor quality care for some women. Hospitals also were not routinely incorporating formal assessments and screening tools for substance use, mental health disorders, and interpersonal violence. The MMRCs also emphasized the hospital's role in helping women navigate the health care system by coordinating referrals and consultations across specialties, and by developing multi-disciplinary treatment teams that include social work, case managers, and substance use disorder treatment providers.

Specifically, the MMRCs recommend:

1. Hospitals should implement evidence-based best practices and conduct continuous quality improvement for the care of pregnant and postpartum women. Best practices should include participation in regional and statewide quality improvement initiatives, the use of patient safety bundles,<sup>45</sup> interpretive services, peer review, facility-level interdisciplinary morbidity and mortality reviews, and the routine use of validated screening tools for mental health, suicide, substance use, and intimate partner violence.
2. Hospitals should participate in the upcoming statewide birth equity quality improvement initiative with the Illinois Perinatal Quality Collaborative, which will support implementation of the patient safety bundle for the "Reduction of Peripartum Racial/Ethnic Disparities." Hospitals should provide training and resources on racism, implicit bias, stigma related to substance use disorder, and trauma-informed care. Hospitals should develop resources to confirm providers, nurses, and staff are providing culturally informed care with the opportunity for consultations, as needed, along with feedback and discussion to optimize care.<sup>46</sup>
3. Hospitals should have a policy for all units, including emergency departments, to request consultation from an obstetric care provider prior to the discharge of pregnant and postpartum women who have conditions or symptoms associated with potential complications and/ or adverse outcomes.

<sup>44</sup> Patient Safety Bundles. (2019). Council on Patient Safety in Women's Health Care. Retrieved from Retrieved from <https://safehealthcareforeverywoman.org/patient-safety-bundles>.

<sup>45</sup> Howell, E. A., Brown, H., Brumley, J., Bryant, A. S., Caughey, A. B., Cornell, A. M., ... & Mhyre, J. M. (2018). Reduction of peripartum racial and ethnic disparities: a conceptual framework and maternal safety consensus bundle. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 47(3), 275-289.

4. Hospitals should develop systems for connecting pregnant and postpartum women to care coordination and to social services prior to discharge, including ensuring that all women are discharged following delivery with an appointment for an early postpartum visit with an obstetric care provider within the first three weeks postpartum.
5. Hospitals should have a policy that aligns with current evidence-based best practices for the resuscitation of pregnant women, including Advanced Cardiovascular Life Support (ACLS), management of suspected pulmonary embolism, and transfusion protocols, and should ensure that emergency department staff are knowledgeable of this policy.
6. Hospitals should establish policies and protocols to ensure appropriate treatment of pregnant and postpartum women with substance use disorders and to support opioid overdose prevention. Hospital obstetric and emergency departments should train providers on best practices for treating patients with substance use disorder, including how to:
  - Start patients on medication-assisted recovery (MAR) and linking patients to outpatient treatment and to recovery services.
  - Establish protocols for using risk-based, patient-centered validated screening tools for substance use, brief intervention, and referral to treatment.
  - Ensure a “warm handoff” to appropriate specialists and care coordination by helping their patients schedule an appointment.
  - Create policies to ensure appropriate postpartum pain management and opioid prescribing practices.<sup>47</sup>
  - Distribute patient education materials on harm reduction techniques, including naloxone.
  - Prescribe naloxone for patients who use opioids and counsel these patients and their families on the use of naloxone.<sup>48</sup>
  - Integrate the Illinois Prescription Monitoring Program into the electronic medical record.<sup>49</sup>
7. Hospitals should implement guidelines for assessing the needs of pregnant and postpartum women with complex medical or social issues. Hospitals should employ a social worker or case manager who can conduct and document a psychosocial needs assessment that includes social determinants of health prior to delivery hospital discharge to identify potential barriers to care and to connect women to resources and postpartum case management. Hospitals should educate providers on the necessity of a timely social work assessment for ensuring women’s access to health care services.
8. Hospitals should ensure that both providers and patients are knowledgeable of the warning signs for potential postpartum complications through the first year postpartum. All hospital units should ask women if they have been pregnant within the last year and should evaluate symptoms with recent/current pregnancy status in mind. All providers within a hospital, including emergency departments, should receive education on risk factors, symptom presentation, diagnostic tests, and appropriate management of postpartum complications and conditions associated with increased risk during the first year postpartum.

<sup>47</sup> Opioid use and opioid use disorder in pregnancy. Committee Opinion No. 711. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2017;130:e81–94.

<sup>48</sup> Naloxone. Illinois Department of Public Health. Retrieved from <https://www.dph.illinois.gov/naloxone>

<sup>49</sup> Illinois Prescription Monitoring Program. Retrieved from <https://www.ilpmp.org/index.php>

9. Patient education materials on potential warning signs of complications through the first year postpartum should address a variety of teaching methods, be appropriate for patients with low literacy, be written in a patient's native language, and list specific symptoms for which postpartum women should seek urgent care.

### Recommendations for Health Care Providers

Health care providers who see women before, during, and after pregnancy have an important role to play in maternal mortality prevention. Importantly, providers should address racial and ethnic bias, stereotypes, stigma, and discrimination in the health care setting, and should promote equitable practices and services. The MMRCs found several key opportunities for health care providers to prevent maternal mortality, including ensuring coordinated, high-quality care, conducting appropriate risk screenings, and optimizing provider-to-provider communication, including “warm hand-offs” where the provider directly assists the patient in making an appointment with a referral. It is important that providers identify all patients’ social service needs and integrate service delivery to remove barriers to health care. It is also imperative that providers actively engage and listen to women and their family members and patient advocates when seeing patients, in order to have the woman or advocate’s perspective.

Specifically, the MMRCs recommend:

1. Providers should follow evidence-based best practices for maternal care and implement practices that support high-quality care for pregnant and postpartum women, such as those outlined in the patient safety bundles developed by the Council on Patient Safety in Women’s Health Care.
2. Providers should review resources that discuss the impact of racism, implicit bias, stigma related to substance use disorder, and trauma on health care outcomes, seek out continuing education on health equity, and assess how their own unconscious biases may influence their treatment of patients.<sup>50</sup>
3. Providers should ensure pregnant/postpartum women with complex medical or mental health conditions are referred to the appropriate specialists and should ensure a “warm handoff” to, and ongoing coordinated care with, these specialists. Timely postpartum follow-up should occur not only with an obstetric care provider, but also with appropriate medical specialists. It is especially important that providers seek consultation when prescribing, changing, or discontinuing anti-depressants or other psychotropic medications during pregnancy, and that they ensure the patient is connected to mental health services in addition to medication therapy.<sup>51</sup>
4. Providers should follow the American College of Obstetricians and Gynecologists’ (ACOG’s) guidance on optimizing postpartum care<sup>52</sup> by ensuring that all women are discharged from the hospital with an appointment for an early postpartum visit with an obstetric care provider within the first three weeks postpartum, followed by a comprehensive postpartum visit no later than 12 weeks postpartum.
5. Providers should follow evidence-based best practices for the resuscitation of pregnant women, including ACLS, management of suspected pulmonary embolism, and transfusion protocols.
6. Providers should follow best practices for the identification and treatment of substance use disorders among pregnant and postpartum women. Providers treating pregnant and postpartum women in obstetric or emergency care should:

<sup>50</sup> Project Implicit. (2011). Retrieved from <https://implicit.harvard.edu/implicit/education.html>

<sup>51</sup> Maternal Mental Health: Depression and Anxiety. (February 2016). Council of Patient Safety in Women’s Health Care. Retrieved from <https://safehealthcareforeverywoman.org/patient-safety-bundles/maternal-mental-health-depression-and-anxiety/>

<sup>52</sup> Optimizing postpartum care. ACOG Committee Opinion No. 736. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2018;131:e140–50.

- Adopt a universal, validated, self-reported screening tool for substance use at the first prenatal care visit, on admission for delivery, and during postpartum visits.
  - Give a brief intervention and referral to treatment for those with a substance use disorder, and specifically educate patients who use opioids and their families on harm reduction strategies, such as naloxone.
  - Prescribe naloxone for patients who use opioids and counsel these patients and their families on the use of naloxone.
  - Assess readiness to begin MAR and educate women on the importance of MAR to improve healthy pregnancy outcomes, reduce risk of overdose death, and increase opportunity to optimally parent her child.
  - Ensure a “warm handoff” to a behavioral health/ recovery treatment provider who can continue care during and after pregnancy.
  - Follow ACOG’s guidelines for pain management and safe opioid prescribing and consider how other medications may interact with opioids (e.g., benzodiazepines).<sup>53</sup> Health care providers must, by Illinois law, use the Illinois Prescription Monitoring Program to review patients’ past prescriptions and identify potential dependence and drug-seeking behavior.<sup>54</sup>
7. Providers should follow the U.S. Preventive Services Task Force recommendation to screen all women of reproductive age for intimate partner violence and connect women who screen positive with ongoing support services to address the intersections of intimate partner violence, mental health, and substance use disorders.<sup>55</sup>
  8. Providers should conduct and document comprehensive contraceptive counseling, review and provide access to the full range of contraceptive options, including long-acting reversible contraception, while discussing effectiveness of each option, and promote reproductive justice through shared medical decision-making. Providers should consult the U.S. Medical Eligibility Criteria for Contraceptive Use<sup>56</sup> to ensure women with medical conditions are given contraceptive methods that are safe for their conditions.

### Recommendations for Health Insurance Plans and Managed Care Organizations

Because health insurance plans, including Illinois Medicaid and managed care organizations, provide opportunities for pregnant and postpartum women to access a range of medical services, they also have an important role in adopting policies that promote maternal health and prevent maternal mortality. The MMRCs noted that the majority of the 2016-2017 pregnancy-associated deaths occurred more than two months after pregnancy, which demonstrates the need for continuous, extended postpartum care. It is also important that payers increase access to all necessary medical services during the first year postpartum, including ensuring sufficient specialist networks. The MMRCs also emphasized that payment for non-traditional services, such as doula support and telehealth services, can ensure all women receive comprehensive health care during and after pregnancy.

<sup>53</sup> Postpartum pain management. ACOG Committee Opinion No. 742. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2018;132. DOI: 10.1097/AOG.0000000000002683. Epub 2018 May 18.

<sup>54</sup> Opioid use and opioid use disorder in pregnancy. Committee Opinion No. 711. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2017;130:e81–94.

<sup>55</sup> Curry, S. J., Krist, A. H., Owens, D. K., Barry, M. J., Caughey, A. B., Davidson, K. W., ... & Kubik, M. (2018). Screening for intimate partner violence, elder abuse, and abuse of vulnerable adults: US Preventive Services Task Force final recommendation statement. *Jama*, 320(16), 1678-1687. <https://jamanetwork.com/journals/jama/fullarticle/2708121>

<sup>56</sup> Curtis KM, Tepper NK, Jatlaoui TC, et al. U.S. Medical Eligibility Criteria for Contraceptive Use, 2016. *MMWR Recomm Rep* 2016;65(No. RR-3):1–104. DOI: <http://dx.doi.org/10.15585/mmwr.rr6503a1>.

Specifically, the MMRCs recommend:

1. Health insurance plans, including Illinois Medicaid, should encourage a continuum of postpartum care and allow reimbursement for multiple postpartum visits for all women.
2. Health insurance plans, including Illinois Medicaid, should cover intensive case management and outreach and non-medical support services (such as doulas) for women with complex medical and mental health conditions while pregnant and up to one year after delivery.
3. Health insurance plans, including Illinois Medicaid, should reimburse for telehealth regardless of patient or provider location, including phone-based services, for clinical services not widely geographically available in Illinois, including, but not limited to cardiology, pain management, psychiatry, substance use treatment, and counseling services.

### **Recommendations for State Agencies and Partners**

State agencies play an essential role in creating and maintaining the social environments in which women live and work. For example, the state administers social service programs, regulates hospitals, and passes legislation that affects local communities. The state, through programs, policies, and leadership, must offer equitable approaches to improving maternal health, and must address systematic injustices that affect women's health. Based on the deaths occurring in 2016-2017, the MMRCs identified several key opportunities for the state to improve the systems and services that support pregnant and postpartum women.

Specifically, the MMRCs recommend:

1. The state should increase designated funding for the administrative perinatal centers and the Illinois Perinatal Quality Collaborative to support statewide, evidence-based quality improvement initiatives related to the care of pregnant and postpartum women.
2. The state and collaborating programs should expand and facilitate coordination of home visiting programs for pregnant and postpartum women with complex medical or mental health conditions, regardless of income, who could benefit from additional support or care coordination. The state should expand implementation of promising practices for improving maternal outcomes and empowering women to engage with health care providers, such as home visiting for all women within three weeks of giving birth and doula support.
3. IDPH should continue to work on establishing hospital maternal levels of care to promote and ensure risk-appropriate care for pregnant women.
4. The state should continue to support and fund trainings to increase the number of providers who have a waiver to provide buprenorphine.
5. The Illinois Department of Human Services (IDHS) should increase access to substance use and mental health services for pregnant and postpartum women, including medication-assisted recovery, peer recovery support services, and integrated prenatal care and substance use treatment, particularly in areas outside the Chicago metropolitan area. Programs should address stigma and interpersonal violence, be gender-responsive and trauma-informed, serve women with young children, and prioritize justice-involved women. IDHS should enhance technical assistance to substance use treatment providers to ensure they are effectively providing services to pregnant and postpartum women.

6. DCFS should provide education to hospitals, providers, and the public about supportive, intact services for women with substance use disorder. DCFS also should develop intensive family services for at least the first year after birth to support maternal recovery and to ensure the safety of the infant. Intensive family services are family-focused, community-based crisis intervention services designed to maintain children's safety in their homes and prevent the unnecessary separation of families.
7. The state should expand financial support for evidence-based models of community violence prevention, such as violence interruption, peer counseling, and positive youth development programs.<sup>57,58</sup>

### Recommendations for Community-Based Organizations

Community-based organizations are a powerful resource because of their direct interactions with women and their families. Because of the trust they establish within their community, these organizations are uniquely able to share information in culturally-appropriate ways and to empower women to engage with their providers in shared medical decision-making. These community-based organizations can amplify community voices and advocate for changes that will improve health equity.

Specifically, the MMRCs recommend:

1. Community-based organizations providing home visiting, case management, or care coordination services should increase public awareness of these programs, conduct outreach to connect women to available services, and ensure continuity of care across programs to connect women to the program that best fits their needs.
2. Community-based organizations should educate women on the importance of getting prenatal care early in pregnancy to improve healthy pregnancy outcomes and to increase the opportunity to optimally parent her child. Community-based organizations should disseminate public education materials to increase awareness of postpartum warning signs,<sup>59</sup> including postpartum depression, and should develop supportive programs to help women get the care they need.
3. Community-based organizations should disseminate public education materials to increase awareness of warning signs for postpartum depression and psychosis and should develop supportive programs to help women get the care they need, especially when suicidal ideation is disclosed.
4. Community-based organizations should share information within their communities about available evidence-based substance use treatment services, such as medication-assisted recovery. For those who use opioids, community-based organizations can help community members learn how to use harm reduction interventions to prevent opioid overdose, including:
  - How to get and use naloxone to save the life of someone overdosing on opioids.
  - How to ensure you are not alone when using substances.
  - How to use fentanyl test strips to check heroin.
5. Community-based organizations should educate the public on how to provide support for family and friends in intimate partner violence situations, and help women develop safety plans.

<sup>57</sup> Delgado, S. A., Alsbahi, L., Wolffe, K., Alexander, N., Cobar, P., & Butts, J. A. (2018). The Effects of Cure Violence in the South Bronx and East New York, Brooklyn. 2017.

<sup>58</sup> Milam, A. J., Buggs, S. A., Furr-Holden, C. D. M., Leaf, P. J., Bradshaw, C. P., & Webster, D. (2016). Changes in attitudes toward guns and shootings following implementation of the Baltimore Safe Streets intervention. *Journal of Urban Health*, 93(4), 609-626.

<sup>59</sup> Post-Birth Warning Signs Education Program. (2019). Association of Women's Health, Obstetric and Neonatal Nurses. Retrieved from <https://www.awhonn.org/education/hospital-products/post-birth-warning-signs-education-program/>

## Recommendations for Women and Their Families and Friends

During case reviews, the MMRCs are conscious of not blaming women for their own deaths, recognizing that there are many factors that influence a woman's health status and whether she is able to seek, to receive, and to adhere to care. However, the MMRCs identified several opportunities for improving public awareness of risk factors for maternal mortality. It is important that women and their families and friends know when and how to seek out health care for symptoms of severe pregnancy complications. Family and friends can empower women to engage with their providers and make active decisions about their care.

Specifically, the MMRCs recommend:

1. It is important that all women have an annual check-up visit with a primary care provider to identify and to manage any chronic conditions, and to discuss how to be as healthy as possible before or between pregnancies. It is also important for women with a recent pregnancy to reconnect with, or establish care with, a medical home for continued medical care beyond the postpartum visit.
2. When women seek medical care, including at emergency departments and urgent care clinics, it is important that they always tell their health care providers if they are currently pregnant or have been pregnant within the last year.
3. It is important that pregnant and postpartum women identify new health symptoms to their health care providers, even if they think the symptoms are unrelated to pregnancy or not significant.<sup>60</sup>
4. Friends and family of pregnant or postpartum women can support those they love by encouraging them to attend their medical appointments, to discuss symptoms with a health care provider, and to identify signs and symptoms of postpartum complications.
5. Friends and family of pregnant and postpartum women can support those they love by learning the signs and symptoms of depression, anxiety, and mood changes, and by helping their loved ones get mental health care when they need it.<sup>61</sup>
6. Friends and family of pregnant and postpartum women can support those they love by learning the signs and symptoms of substance use, and by helping their loved ones get substance use treatment.<sup>62</sup> Anyone can obtain naloxone at Illinois pharmacies without a prescription. By learning how and when to use naloxone, they could save the life of someone overdosing on opioids.

*\* See Appendix A for more information about services and programs available to the public. \**

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<sup>60</sup> Post-Birth Warning Signs Education Program. (2019). Association of Women's Health, Obstetric and Neonatal Nurses. Retrieved from <https://www.awhonn.org/education/hospital-products/post-birth-warning-signs-education-program/>

<sup>61</sup> *Postpartum Depression in Illinois*. (2017). Illinois Department of Public Health. Retrieved from [http://www.dph.illinois.gov/sites/default/files/publications/publicationsowhfsppostpartum-depression-factsheet\\_1.pdf](http://www.dph.illinois.gov/sites/default/files/publications/publicationsowhfsppostpartum-depression-factsheet_1.pdf)

<sup>62</sup> *Recognizing an Addiction Problem*. (2016). Healthline. Retrieved from <https://www.healthline.com/health/addiction/recognizing-addiction#later-stages>

## IDPH Commitment to Health Equity

The stark differences in maternal mortality between White and Black women in Illinois are unacceptable and alarming. They represent unfair distributions of health in the population – often referred to as “health inequities.” Such inequities are present not only in maternal deaths, but in a multitude of maternal and infant outcomes, as well as many outcomes related to chronic disease, infectious disease, and environmental exposures.

The American Public Health Association (APHA) defines health equity as “everyone [having] the opportunity to attain their highest level of health.”<sup>63</sup> The World Health Organization (WHO) shares this definition, but further stated, “... that no one should be disadvantaged from achieving this potential.”<sup>64</sup> Margaret Whitehead, head of the World Health Organization Collaborating Centre for Policy Research on the Social Determinants of Health, has stressed that for policy discussions, health inequities need to be defined as “differences in health which are not only unnecessary and avoidable but in addition, are considered unfair and unjust.”<sup>65</sup>

The lack of health equity affects not only women, but families, the broader community, and the entire state. IDPH is committed to health equity and the elimination of health disparities in Illinois. The IDPH Health Equity Council affirmed this commitment by stating that “All Illinoisans deserve to live long, healthy lives, free of modifiable differences in health status and outcomes.”<sup>66</sup>

IDPH recognizes that in order to advance health equity, it must address the social determinants of health, including race/ethnicity, gender, employment, housing, education, public safety, food security, and access to care. There is an inherent requirement that state leadership, staff, and partners acknowledge that racism (implicit, explicit, and structural), classism, sexism, and other longstanding social inequities remain pervasive in society and influence health equity.

IDPH seeks to address health equity issues through increased coordination between Illinois leadership, programs, and strategic partnerships. More specifically, IDPH is committed to promoting health equity in all programs and policies, including the development of the public health and health care workforce. To do so, IDPH will employ a multiprong approach, which includes the following strategies:

### *Health Equity Council*

- Continuing to support the IDPH Health Equity Council (HEC), established in 2018. This council seeks to:
  - support the development of department-wide standards to enhance health equity as it relates to the mission, vision, values, and priorities of IDPH;
  - support a culturally competent IDPH workforce; and
  - promote statewide efforts and support public health partners in research and evidence-based best practices related to reducing health inequities.

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<sup>63</sup> *Health Equity*. (2018). American Public Health Association (APHA). Retrieved from <https://www.apha.org/topics-and-issues/health-equity>

<sup>64</sup> *Health Equity* (2018). World Health Association (WHO). Retrieved from [https://www.who.int/topics/health\\_equity/en/](https://www.who.int/topics/health_equity/en/)

<sup>65</sup> Whitehead M. (1992). The concepts and principles of equity and health. *Int J Health Serv*, 22:429–45.

<sup>66</sup> *Minority Health* (2020). Illinois Department of Public Health (IDPH). Retrieved from <http://www.dph.illinois.gov/topics-services/life-stages-populations/minority-health>

### *Diversity, Equity, and Inclusion Committee*

- Continuing to support the IDPH Diversity, Equity, and Inclusion Committee. This committee seeks to promote awareness around diversity, equity, and inclusion within the agency in order to better serve the residents of Illinois by developing and promoting strategies and best practices within the realms of racial, social, sexual, and gender diversity. To that end, the committee has drafted a Diversity, Equity, and Inclusion Plan with the following goals:
  - create a trained and knowledgeable staff with a penchant to reduce or eliminate implicit/explicit/cultural bias within and outside of IDPH;
  - develop a comprehensive program to reduce or eliminate health disparities among diverse communities; and
  - ensure diversity, equity, and inclusion are embedded in the State Health Improvement Plan.

### *Provider Education and Training*

- Encouraging and supporting health provider education and training on racial equity, implicit bias, gender bias, anti-racism, and human rights and the effect these issues have on the delivery of care and health outcomes.
- Supporting the implementation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in health and promoting cultural humility among health care providers.

### *Delivery of Care*

- Providing resources to help the health care and public health workforces understand the social determinants of health. For example, a team led by the IDPH Office of Women's Health and Family Services developed a web-based infant mortality toolkit to provide resources and tools to address social determinants of health and infant mortality disparities.
- Encouraging integrated service delivery and connections between different providers, including those that provide social services.
- Promoting tools, such as patient decision aids, patient-centered birthing plans, and clinical conversion guides, that can assure respectful communication and information accessibility during visits between women and providers.
- Encouraging the participation of doulas, birth workers, community health workers, and patient advocates to support maternal health.
- Promoting the establishment of policies that are supportive of the use of telemedicine to reduce geographic barriers to care and to ensure all Illinois communities have access to care.

### *Partnerships and Collaborations*

- Identifying and including diverse partners/stakeholders to serve on committees, advisory councils, and workgroups. These stakeholders are to be diverse in race/ethnicity, gender, sexual orientation, religion, disabilities, and areas of professional expertise.
- Collaborating with external partners to ensure health care providers are aware of resources to address social determinants of health, which serve as barriers and conditions that hinder health care access and availability.
- Actively listening to community voices and acknowledging community strengths through Maternal and Child Health Family Councils and other IDPH community engagement activities.

### *Workforce*

- Cultivating a diverse health care workforce by exploring opportunities to support individuals from under-represented backgrounds in pursuing careers in primary care and public health professions.
- Supporting the role of community health workers in improving maternal health and exploring opportunities for training and certifications.

IDPH recognizes that achieving health equity is an ongoing process and will not be accomplished overnight. It will take dedication and persistence to overcome generations of institutionalized racism, sexism, and classism. IDPH remains committed to the actions that are necessary to achieve long, healthy lives, free of modifiable differences in health status and outcomes for all Illinoisans.

## Coronavirus Disease 2019 and Maternal Health Outcomes

During 2020, the landscape of maternal health and health care has shifted immensely due to the coronavirus 2019 disease (COVID-19) pandemic. Although information regarding the impact of COVID-19 on maternal outcomes is still emerging, below is a summary of what is currently known from research conducted in the United States.

Though the absolute risk is low, pregnant women with COVID-19 appear to be at higher risk for severe illness and death than infected nonpregnant women and uninfected pregnant women.<sup>67,68</sup> The CDC found that symptomatic pregnant women were more likely than symptomatic nonpregnant women to be admitted to the intensive care unit, receive invasive ventilation, receive extracorporeal membrane oxygen, and die.<sup>69</sup> Pregnant women with underlying medical conditions, particularly diabetes and obesity, and older pregnant women were at even higher risk of severe illness.<sup>70,71,72,73</sup>

It is uncommon for infants born to mothers with COVID-19 to test positive for the COVID-19 virus. Limited data suggest that vertical transmission of the COVID-19 virus from an infected pregnant person to their fetus or baby during pregnancy or delivery may be possible, but the main concern is transmission to the newborn after birth from infectious respiratory droplets.<sup>74,75,76</sup> While there is no evidence of changes in preterm birth rates nationally,<sup>77</sup> limited data suggest that pregnant women with COVID-19 might be at increased risk for preterm birth.<sup>78,79</sup>

<sup>67</sup> Brandt, J.S., Hill, J., Reddy, A., Schuster, M., Patrick, H.S., Rosen, T., ... & Ananth, C.V. (2020). Epidemiology of coronavirus disease 2019 in pregnancy: risk factors and associations with adverse maternal and neonatal outcomes. *American Journal of Obstetrics and Gynecology*, S0002-9378(20), 31134-0;

<sup>68</sup> Zambrano, L.D., Ellington, S., Strid, P., Galang, R.R., Oduyebo, T., Tong, V.T., ... & CDC COVID-19 Response Pregnancy and Infant Linked Outcomes Team. (2020). Update: Characteristics of Symptomatic Women of Reproductive Age with Laboratory-Confirmed SARS-CoV-2 Infection by Pregnancy Status — United States, January 22–October 3, 2020. *Morbidity and Mortality Weekly Report*, 69, 1641–1647.

<sup>69</sup> Zambrano, *et al.* (Same as 68)

<sup>70</sup> Brandt, *et al.* (Same as 67)

<sup>71</sup> Grechukhina, O., Greenberg, V., Lundsberg, L.S., Deshmukh, U., Cate, J., Lipkind, H.S., ... & Reddy, U.M. Coronavirus disease 2019 pregnancy outcomes in a racially and ethnically diverse population. (2020) *American Journal of Obstetrics and Gynecology MFM*. 2(4), 100246

<sup>72</sup> Panagiotakopoulos, L., Myers, T.R., Gee, J., Lipkind, H.S., Kharbanda, E.O., Ryan, D.S., ... & Weintraub, E.S. (2020). SARS-CoV-2 Infection Among Hospitalized Pregnant Women: Reasons for Admission and Pregnancy Characteristics — Eight U.S. Health Care Centers, March 1–May 30, 2020. *Morbidity and Mortality Weekly Report*, 69, 1355–1359

<sup>73</sup> Zambrano, *et al.* (Same as 68)

<sup>74</sup> Adhikari, E.H., Moreno, W., Zofkie, A.C., MacDonald, L., McIntire, D.D., Collins, R.R., Spong, C.Y. (2020). Pregnancy Outcomes Among Women With and Without Severe Acute Respiratory Syndrome Coronavirus 2 Infection. *JAMA Network Open*, 3(11), e2029256

<sup>75</sup> Kotlyar, A.M., Grechukhina, O., Chen, A., Popkhadze, S., Grimshaw, A., Tal, O., Taylor, H.S., Tal, R. (2020). Vertical transmission of coronavirus disease 2019: a systematic review and meta-analysis. *American Journal of Obstetrics and Gynecology*, S0002-9378(20), 30823-1.

<sup>76</sup> Walker, K.F., O'Donoghue, K., Grace, N., Dorling, J., Comeau, J.L., Li, W., Thornton, J.G. (2020). Maternal transmission of SARS-COV-2 to the newborn, and possible routes for such transmission: a systematic review and critical analysis. *BJOG*, 127(11), 1324-1336.

<sup>77</sup> National Center for Health Statistics, Centers for Disease Control and Prevention (2020). Provisional Estimates for Selected Maternal and Infant Outcomes by Month, 2018 – 2020. Retrieved from: <https://www.cdc.gov/nchs/covid19/technical-notes-outcomes.htm>

<sup>78</sup> National Center for Health Statistics, Centers for Disease Control and Prevention (2020). Maternal and Infant Characteristics Among Women with Confirmed or Presumed Cases of Coronavirus Disease (COVID-19) During Pregnancy. Retrieved from: <https://www.cdc.gov/nchs/covid19/technical-linkage.htm>

<sup>79</sup> Woodworth, K.R., Olsen, E.O., Neelam, V., Lewis, E.L., Galang, R.R., Oduyebo, T., ... & CDC COVID-19 Pregnancy and Infant Linked Outcomes Team. (2020). Birth and Infant Outcomes Following Laboratory-Confirmed SARS-CoV-2 Infection in Pregnancy — SET-NET, 16 Jurisdictions, March 29–October 14, 2020. *Morbidity and Mortality Weekly Report*, 69, 1635–1640.

COVID-19 has led to unexpected changes in prenatal care and birth plans for many women as providers have reduced in-person prenatal visits, limited support persons and visitors during delivery, and increased isolation protocols that may have led to separation of mothers and newborns if either one was identified as infected or likely infected.<sup>80</sup> The long-term effects of these changes on maternal health still need to be assessed. Additionally, the indirect effects of COVID-19 on maternal health, such as overburdened health care systems, increased unemployment and food insecurity, and higher rates of mental health issues, also need to be measured.

The direct and indirect impact of COVID-19 remains higher among pregnant women of color. Multiple studies around the U.S. have found that Black and Hispanic pregnant women are disproportionately affected by and have higher rates of severe disease due to COVID-19 virus infection.<sup>81,82,83,84,85,86</sup> A survey examining racial differences in the impact of the COVID-19 pandemic found that Black pregnant women had the following: (1) a higher likelihood of having their employment negatively impacted; (2) more worries regarding their prenatal care, birthing experience, and access to essential items; and (3) a higher prevalence of depression compared to White women.<sup>87</sup>

When the MMRCs review the deaths occurring during 2020 and 2021, they will consider the contributing role of infection with the COVID-19 virus and the indirect effects of the broader COVID-19 pandemic.<sup>88</sup> For maternal deaths where COVID-19 virus infection played a role, additional experts with specialized skills and knowledge of critical care and respiratory disease will be recruited to participate in the MMRCs' reviews. For all deaths during 2020 and 2021, it will be even more important to discuss the social determinants of health that impacted each woman's death – such as access to care, finances, employment, and social support – and how these factors were affected by the societal changes brought on by the pandemic.

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<sup>80</sup> Gildner, T.E. and Thayer, Z.M. (2020). Birth plan alterations among American women in response to COVID-19. *Health Expectations*, 23, 969 – 971.

<sup>81</sup> Adhikari, *et al.* (Same as 74)

<sup>82</sup> Brandt, *et al.* (Same as 67)

<sup>83</sup> Grechukhina, *et al.* (Same as 71)

<sup>84</sup> Gur, R.E., White, L.K., Waller, R., Barzilay, R., Moore, T.M., Kornfield, S., ... & Elovitz, M.A. (2020). The Disproportionate Burden of the COVID-19 Pandemic Among Pregnant Black Women. *Psychiatry Research*, 293, 113475

<sup>85</sup> Sakowicz, A., Ayala, A.E., Ukeje, C.C., Witting, C.S., Grobman, W.A., Miller, E.S. (2020). Risk factors for severe acute respiratory syndrome coronavirus 2 infection in pregnant women. *American Journal of Obstetrics and Gynecology MFM*, 2(4), 100198

<sup>86</sup> Zambrano, *et al.* (Same as 68)

<sup>87</sup> Gur, *et al.* (Same as 84)

<sup>88</sup> Metz, Torri D. MD, MS; Collier, Charlene MD; Hollier, Lisa M. MD, MPH Maternal Mortality From Coronavirus Disease 2019 (COVID-19) in the United States, *Obstetrics & Gynecology*: August 2020 - Volume 136 - Issue 2 - p 313-316.

## Building Momentum to Improve Maternal Health

The content of the state's first Illinois Maternal Morbidity and Mortality Report<sup>89</sup> served as a powerful tool to demonstrate the state's capacity to monitor these important health indicators and solidify Illinois' commitment to improving maternal health by reducing racial and social inequities.

Since this report was published, there have been many efforts across Illinois to improve maternal health through the implementation of the recommendations put forward. Some key initiatives include:

### *Securing Additional Funding to Improve Maternal Health in Illinois*

- The data and recommendations from the first report were used to secure three major grants to improve maternal health in Illinois. Efforts are underway to collaborate, to align, and to leverage these funding opportunities for optimal population health improvement:
  - IDPH received \$450,000 per year for five years through the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE-MM) program funded by the Centers for Disease Control and Prevention.
  - The University of Illinois at Chicago (UIC) Innovations to ImPROVe Maternal Outcomes in Illinois (I PROMOTE-IL) received \$1.9 million per year for five years from the Health Resources and Services Administration to improve maternal health and to create a state Maternal Health Task Force, which is co-chaired by the IDPH Title V director, Dr. Kenya McRae. This initiative is being implemented in partnership with IDPH.
  - The city of Chicago, Everthrive Illinois, and AllianceChicago partnered to create the Chicago Collaborative for Maternal Health, which was one of nine cities to receive funding through the Safer Childbirth Cities funded through Merck for Mothers.

### *Expanding Medicaid to One-Year Postpartum*

- Illinois was the first state in the nation to extend full Medicaid benefits from 60 days to 12 months postpartum, following the federal Centers for Medicare & Medicaid Services (CMS) approval in April 2021. The Illinois Department of Healthcare and Family Services (HFS) submitted an Medicaid 1115 demonstration waiver to permit continuous eligibility through 12 months postpartum. CMS approval of the waiver enables federal matching dollars to implement this Medicaid expansion. This was a key recommendation from the first Illinois Maternal Morbidity and Mortality Report to improve continuity of care for women.

### *Improving Clinical Practice and Provider Education*

- IDPH and I PROMOTE-IL are providing funding and support to the Illinois Perinatal Quality Collaborative (ILPQC) to implement the Birth Equity Initiative, which aims to support hospital capacity to facilitate systems and culture change to achieve birth equity.
- IDPH is supporting the Administrative Perinatal Centers to provide training to all birthing hospitals on obstetrical hemorrhage through the implementation of an obstetric hemorrhage toolkit.
- I PROMOTE-IL is partnering with ILPQC to provide ongoing education about obstetric hemorrhage and hypertension to providers across the state.
- I PROMOTE-IL is assessing protocols for pregnant and postpartum persons seeking care in emergency departments and designing emergency department provider training.

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<sup>89</sup> Illinois Maternal Morbidity and Mortality Report. Illinois Department of Public Health. (October 2018).

- IDPH formed a new Severe Maternal Morbidity Sub-Committee in 2019 under the Statewide Quality Council and Perinatal Advisory Committee. The aim of this sub-committee is to review cases of severe maternal morbidity, identify clinical quality improvement opportunities, and ultimately recommend best practices for reviewing these cases in the hospital setting.

### *Increasing Funding to Improve the Health of Women of Reproductive Age:*

- IDPH is funding local organizations, such as local health departments and non-profits, that serve women in various capacities to create and to implement plans to increase the number of women of reproductive age receiving well-woman exams.

### *Addressing Maternal Mental Health and Substance Use*

- IDPH is expanding funding and increasing awareness of the state perinatal depression hotline (MOMS line at NorthShore University HealthSystem), which provides perinatal depression crisis interventions, consultations, resources, education, and referrals for women who have screened positive for symptoms of perinatal depression.
- IDPH provided funding to UI Health and the Winnebago County Health Department to increase the number of obstetric providers in Illinois birthing hospitals that are trained in MAR and establish a network of support for trained providers.
- IDPH is collaborating with UIC to implement a pilot project to expand the capacity of perinatal health care providers to screen, to assess, to refer, and to treat pregnant and postpartum women for depression and related behavioral health disorders.
- I PROMOTE-IL worked with Illinois DocAssist to conduct mental health and substance use trainings for birthing hospitals and obstetrical providers.
- IDHS is piloting the Illinois Families in Recovery (IFR) program to address the needs of pregnant and postpartum women with substance use disorders (SUD) and their families in central Illinois. IFR will include outpatient SUD services and individual family support plans that may include case management, home visiting, parenting coaching, doula services, recovery services, and wrap-around services, such as transportation and child care.

### *Coordination of State Workgroups and Advisory Committees*

- Multiple state advisory committees advise IDPH on issues of maternal health and perinatal care. IDPH coordinates the efforts of these groups to increase their collective impact through ensuring communication with workgroup chairpersons, facilitating joint meetings between committees, and ensuring there is not duplication of projects.
  - Perinatal Advisory Committee (PAC): Advises IDPH on all issues related to perinatal health and the regionalization of perinatal health care. All of the committees listed report to the PAC as an overarching body and collectively counsel IDPH on the establishment and implementation of policies.
  - Statewide Quality Council: Identifies, recommends, and implements quality projects to improve and expand upon perinatal health care across the state.
  - Severe Maternal Morbidity Sub-Committee: Reviews select cases of women who had an unplanned admission to the intensive care unit during or after childbirth. The committee then uses their reviews to inform recommendations to hospitals on how to improve their internal morbidity reviews.

- Maternal Mortality Review Committee (MMRC): The MMRC reviews all pregnancy-associated deaths from medical conditions that are potentially related to pregnancy and issues recommendations to prevent such deaths.
- The MMRC-V reviews all pregnancy-associated deaths due to homicide, suicide, unintentional drug overdose, or other drug-related conditions, and issues recommendations to prevent such deaths.
- Hospital Facilities Designation Sub-Committee: Provides guidance to IDPH and PAC on the compliance of institutions that provide perinatal services in accordance with Illinois' Regionalized Perinatal Health Care Code.
- Task Force on Infant and Maternal Mortality Among African Americans was created by the state legislature under Public Act 101-0038 and charged with identifying key strategies to decrease infant and maternal mortality among African Americans in Illinois. The task force has three subcommittees that include members from the other state workgroups and advisory committees and seeks to align efforts across groups and with the Illinois Title V program (Maternal and Child Health Services Block Grant).
- In addition to these formal advisory bodies, IDPH also ensures coordination and collaboration with other private workgroups, such as the Illinois Maternal Health Task Force and Chicago Collaborative for Maternal Health.

IDPH remains committed to identifying and reviewing maternal deaths and morbidities and will build upon this report's findings and recommendations over the coming years. IDPH welcomes efforts to disseminate and implement these data and recommendations and looks forward to engaging diverse partners through the planning and hosting of the state's first Maternal Health Summit in September 2021.



## APPENDIX A: Resources for Women and Their Families and Friends

### *If you or someone you know is having suicidal thoughts, immediately contact:*

National Suicide Prevention Lifeline	800-273-TALK (8255)
National Suicide Crisis Text Line	Text HOME to 741-741

### *For help with depression or other mental health concerns:*

Illinois Perinatal Depression MOMsline	866-364-MOMS (6667)
Postpartum Support International “warmline”	800-944-4PPD (4773)
Postpartum Depression Alliance of Illinois	847-205-4455

### *To find treatment for substance use disorders or for questions about naloxone:*

Illinois Helpline for Opioids and Other Substances:	833-2-FIND-HELP
SAMHSA’s National Hotline:	800-662-HELP (4357)

### *For support and services related to domestic violence:*

Illinois Domestic Violence Helpline	877-863-6338
National Domestic Violence Hotline	800-799-7233

### *For concerns regarding human trafficking:*

National Human Trafficking Hotline	888-373-7888 (Text: 233733)
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### *To find birth control or women’s health services:*

Illinois Women’s Health Line	888-522-1282
Planned Parenthood	Text PPNOW to 774636

### *For other postpartum questions, concerns, and support:*

4th Trimester Project Self-Care Resource	<a href="https://www.newmom.health">https://www.newmom.health</a>
La Leche League International (for breastfeeding)	877-452-5324

### *To determine whether you or your family qualify for state programs:*

Medicaid, WIC, or Food Stamps (SNAP)	800-843-6154
Temporary Assistance for Needy Families (TANF)	773-522-8370
Child Care Assistance Program (CCAP)	312-823-1100
Illinois Cares RX (assistance with medications)	800-226-0768
Home Visiting	<a href="http://igrowillinois.org">http://igrowillinois.org</a>

### *For emergency, short-term child care:*

Crisis Nurseries	<a href="http://www.dhs.state.il.us/page.aspx?item=55909">http://www.dhs.state.il.us/page.aspx?item=55909</a>
Safe Families	<a href="https://safe-families.org/get-help">https://safe-families.org/get-help</a>

## APPENDIX B: Resources for Health Care Providers and Hospitals

### *For consultation about mental health and substance use concerns for perinatal patients:*

Illinois DocAssist	866-986-ASST (2778)
Postpartum Support International <a href="https://www.postpartum.net">https://www.postpartum.net</a>	800-944-4773, ext. 4
MCPAP for Moms <a href="https://www.mcpapformoms.org/Toolkits/Toolkit.aspx">https://www.mcpapformoms.org/Toolkits/Toolkit.aspx</a>	855-MOM-MCPAP (666-6272)
The Joint Commission's Toolkit on detecting suicidal ideation <a href="https://www.jointcommission.org/assets/1/18/SEA_56_Suicide.pdf">https://www.jointcommission.org/assets/1/18/SEA_56_Suicide.pdf</a>	

### *For questions regarding safe medications during pregnancy and breastfeeding:*

Infant Risk Center	806-352-2519
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### *For questions regarding best practices for birth control options:*

U.S. Medical Eligibility Criteria (MEC) for Contraceptive Use <a href="https://www.cdc.gov/mmwr/volumes/65/rr/rr6503a1.htm?s_cid=rr6503a1_w">https://www.cdc.gov/mmwr/volumes/65/rr/rr6503a1.htm?s_cid=rr6503a1_w</a>	
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### *For information about participation in statewide perinatal quality initiatives:*

Illinois Perinatal Quality Collaborative <a href="http://www.ilpqc.org">http://www.ilpqc.org</a>	
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### *For information on maternal patient safety bundles, toolkits, and quality care standards:*

National Council on Patient Safety in Women's Health Care <a href="https://safehealthcareforeverywoman.org">https://safehealthcareforeverywoman.org</a>	
National Center on Domestic Violence, Trauma, and Mental Health – Coercion toolkit <a href="http://www.nationalcenterdvtraumamh.org/publications-products/coercion-related-to-mental-health-and-substance-use-in-the-context-of-intimate-partner-violence-a-toolkit">http://www.nationalcenterdvtraumamh.org/publications-products/coercion-related-to-mental-health-and-substance-use-in-the-context-of-intimate-partner-violence-a-toolkit</a>	
Joint Commission <a href="https://www.jointcommission.org/assets/1/6/New_Perinatal_Standards_Prepub_Report.pdf">https://www.jointcommission.org/assets/1/6/New_Perinatal_Standards_Prepub_Report.pdf</a>	

### *To learn about naloxone and get patient education materials:*

Illinois Department of Public Health <a href="http://dph.illinois.gov/naloxone">http://dph.illinois.gov/naloxone</a>	
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### *For screening women for the social determinants of health:*

American Academy of Family Physicians' recommended SDOH screening tool <a href="https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf">https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf</a>	
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### *For materials to support warm handoffs:*

Agency for Healthcare Research and Quality Warm Handoff Intervention tools <a href="https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html">https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html</a>	
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## Appendix C: Medical Terminology

### Adult Respiratory Distress Syndrome

Adult respiratory distress syndrome (ARDS) is a serious lung condition that causes low blood oxygen. People who develop ARDS are usually ill due to another disease or a major injury, commonly sepsis. ARDS occurs when fluid leaks into the lungs, causing difficulty breathing and low oxygen levels. This can deprive other organs of the oxygen they need to function and result in organ damage.

### Amniotic Fluid Embolism

An amniotic fluid embolism is a life-threatening condition in which some of the fluid that surrounds the baby enters the mother's blood stream. This can lead to an immune system response, resulting in flooding of the lungs with fluid (making breathing difficult). This may result in heart failure.

### Body Mass Index

Body mass index (BMI) is a measure to look at body weight proportional to body size. BMI equals weight (in kilograms) divided by height (in meters) squared. A BMI of 18.5-24.9 is considered normal weight, a BMI of 25.0-29.9 is considered overweight, and a BMI of 30.0 or higher is considered obese.

### Cardiomyopathy

Cardiomyopathy is a condition in which the chambers of the heart can no longer pump blood like they normally do, leading to heart failure. Peripartum related cardiomyopathy is defined as heart failure occurring towards the end of pregnancy or within five months following delivery. The cause is currently unknown, but risk factors include age greater than 30 years, pregnancy with multiple fetuses, African descent, and maternal cocaine use.

### Cerebrovascular Accident

A cerebrovascular accident is also known as a stroke, and just as a heart attack is a lack of oxygen flow to the heart, a cerebrovascular accident is a "brain attack." This occurs when oxygen is not properly delivered to the brain, resulting in temporary or permanent damage depending on how long the brain is deprived.

### Diabetes

Diabetes is a condition in which insulin is not produced (type I diabetes) or the body doesn't respond to insulin well (type II diabetes), preventing the cells in the body from using the sugar a patient eats in their diet. This results in sugar remaining in the blood rather than being taken into the cells. People with diabetes must monitor their blood glucose frequently and take insulin injections or other medications to make sure their blood sugar stays in a normal range to prevent long-term health complications.

### Disseminated intravascular coagulation

Disseminated intravascular coagulation (DIC) is when abnormal clumps of thickened blood (clots) form in the blood stream. This uses up the clotting factors in the blood and makes other parts of the body more susceptible to uncontrolled bleeding. The cause of DIC is usually infection or inflammation.

## Hemorrhage

Hemorrhage is major blood loss, and there are two major types that happen more frequently in pregnant/postpartum women:

1. *Intracranial hemorrhage* is bleeding from a blood vessel into the brain. This causes major blood loss, but also causes the brain to shift, or herniate, as the blood fills the space in skull. The shifting of the brain can lead to death.
2. *Postpartum hemorrhage* is massive blood loss during delivery. In 2017, ACOG defined postpartum hemorrhage as either a cumulative blood loss of greater than 1,000 mL or bleeding associated with signs/symptoms of low blood volume within 24 hours of giving birth, regardless of delivery method.

## Hypertensive Disorders of Pregnancy: Hypertension, Preeclampsia, and Eclampsia

These three conditions fall on a spectrum. Hypertension is high blood pressure, which can be present before, during, or after pregnancy. When high blood pressure develops during pregnancy or during the postpartum period and is accompanied by organ damage, most commonly to the liver or kidneys, it is called preeclampsia. Damage to the kidneys results in protein being discarded in the urine. Eclampsia occurs when a woman with preeclampsia begins to have seizures. This is a life-threatening emergency and warrants immediate delivery of the baby.

## Hysterectomy

A hysterectomy is an operation to remove the uterus, which may be necessary if a woman experiences massive bleeding during or after pregnancy.

## Maternal Morbidity

A maternal morbidity is a complication from pregnancy that results in significant short- or long-term consequences to a woman's health.

## Maternal Mortality

A maternal mortality is the death of a woman during pregnancy or close in time to pregnancy.

## Opioids

Opioids are compounds similar in structure to opium, an addictive drug made from poppies. It is a narcotic and, in medicine, is used as a pain reliever.

## Opioid Use Disorder

Opioid use disorder is a pattern of opioid use that leads to significant impairment of daily life or distress. A person may be diagnosed with an opioid use disorder if they have cravings for opioids, a persistent desire to cut down on opioid use, and/or a failure to fulfill major obligations at school, work, or home.

## Postpartum Mental Health

Because of hormonal changes during and around the time of pregnancy, it is normal for women to feel "down" or sad after delivery, sometimes called the postpartum blues. These may last up to four weeks postpartum. However, when certain symptoms, such as sleep disturbance, lack of interest, feelings of guilt, low energy, poor concentration, or altered appetite, persist after four weeks, a woman may be diagnosed with postpartum depression. Some women with postpartum depression may also have feelings of wanting to hurt themselves (self-harm) or wanting to die (suicidal ideation). Rarely, a condition called postpartum psychosis develops, in which a woman may develop delusions, hallucinations they see or hear, and rapid mood swings.

## **Pregnancy-Associated Death**

The death of a woman during pregnancy or within one year of the end of pregnancy, regardless of the cause of death.

## **Pregnancy-Related Death**

The death of a woman during pregnancy or within one year of the end 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.

## **Preventable Death**

A death is considered preventable if the MMRC/MMRC-V determines that there was at least some chance of the death being averted by one or more reasonable changes to patient, family, provider, facility, system and/or community factors.

## **Renal Failure**

Renal failure, or kidney failure, is a condition when the kidneys are no longer able to remove waste from the blood. This can result in a build-up of potentially harmful substances and chemical imbalances in the blood. Chronic diseases like diabetes can cause renal failure, but a common cause of renal failure among pregnant and postpartum women are hypertensive disorders of pregnancy.

## **Sepsis**

When the body is exposed to an infection, it sends many chemicals into the body that damage various organ systems. If a woman enters septic shock, her blood vessels become unable to adequately pump blood and blood pressure drops dramatically. Without the pressure propelling the blood to organs, many organs die from oxygen starvation.

## **Severe Maternal Morbidity**

The term “severe maternal morbidity” represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. It is sometimes referred to as “near miss” morbidity, meaning that the woman came very close to dying from her condition.

## **Thrombotic Pulmonary Embolism**

A deep venous thrombosis is a blood clot formed in the body, usually the legs, that has the potential to break off and travel through the body. If this clot travels to the lungs, it becomes a pulmonary embolism and can lead to severe breathing problems as parts of the lung lose access to oxygen. Pregnancy is a condition that makes moms more prone to blood clots, so proper precautions should be taken in pregnant and postpartum women to prevent a deep venous thrombosis and pulmonary embolism.

## **Warm Hand-Off**

A “warm handoff” is the transfer of care between two members of the health care team, where the handoff occurs in front of the patient and family. This transparent handoff of care engages patients in communication, giving them the opportunity to clarify or correct information or ask questions about their care.<sup>90</sup>

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<sup>90</sup> Warm Handoff: Intervention. (December 2017). Agency for Health care Research and Quality. Retrieved from <https://www.ahrq.gov/patient-safety/reports/engage/interventions/warmhandoff.html>

## Appendix D: Methods Notes for Statistical Analyses

### Demographic Definitions

#### *Race/Ethnicity*

In each of the data sources used in this report, race and ethnicity are collected as two separate fields, in alignment with the U.S. Census. For the purposes of this report, women were classified into one of four racial/ethnic groups: non-Hispanic White, non-Hispanic Black, Hispanic, and non-Hispanic Other race (includes Asian, Pacific Islander, American Indian, Alaska Native, and multi-racial women). The shorthand of “White”, “Black”, “Hispanic” and “Other Race” is used throughout this report. There were very few deaths to non-Hispanic Other race women, so this sub-group is not shown for maternal mortality.

#### *Location of Residence*

Only information on women who were Illinois residents at the time of death are presented in this report. A woman's location of residence was used to group women into one of five geographic categories:

- **Chicago:** Residential ZIP code within Chicago boundary
- **Suburban Cook County:** Residence in Cook County, but ZIP code not within Chicago boundary
- **Counties Surrounding Cook County:** Residence in DuPage, Kane, Lake, McHenry, or Will counties
- **Urban Counties Outside Chicago Area:** Residence in Champaign, DeKalb, Kankakee, Kendall, McLean, Macon, Madison, Peoria, Rock Island, Sangamon, St. Clair, Tazewell, or Winnebago counties
- **Rural Counties:** Residence in all other counties not referenced above (93 counties)

#### *Insurance Status*

Insurance status was classified based on the payer for delivery as recorded on the live birth certificate. For the mortality analysis, if the insurance information was not available from the birth certificate, medical records were used to identify insurance during pregnancy.

#### *Body Mass Index*

Pre-pregnancy body mass index (BMI) was classified based on the pre-pregnancy height and weight listed on the live birth or fetal death certificate for the most recent pregnancy. If the height and weight information were not available on the birth or fetal death certificate, medical records were used to identify the pre-pregnancy height and weight. If pre-pregnancy height and weight were not available in medical records, height and weight from the earliest known point in pregnancy were used.

### Chronic Disease Data Methods

The data in this section come from live birth certificates for Illinois residents. In addition to information about the baby, the birth certificate records a variety of demographic and health related information about the mother. Chronic diseases were identified from the birth certificates in the following ways:

**Obesity:** Pre-pregnancy height and weight as recorded on the birth certificate were used to calculate body mass index (BMI) using the formula  $\text{weight (kg)} / \text{height}^2 (\text{m}^2)$ . BMI is categorized into the following categories: underweight (<18.5), normal (18.5-24.9), overweight (25.0-29.9) and obese (30.0 or higher). The data shared in this section focuses on women with an obese BMI.

**Hypertension:** Women with hypertension diagnosed prior to pregnancy, hypertension diagnosed during pregnancy (including pregnancy-induced hypertension or preeclampsia), or severe preeclampsia were defined as having hypertension.

**Diabetes:** Women with diabetes diagnosed before or during pregnancy were defined as having diabetes.

To identify trends in these conditions, single-year estimates were calculated for 2010-2017. The revised Illinois birth certificate was implemented in 2010, so it is not possible to obtain comparable data from older birth certificates.

To better understand how chronic disease impacts different subgroups of Illinois women, the percent of live births to women with hypertension, diabetes, and obesity was calculated separately by various demographic characteristics on the birth certificate. When looking at demographic comparisons of chronic conditions, two years of data (2016-2017) were combined to increase the reliability of the estimates.

### Severe Maternal Morbidity Methods

The term “severe maternal morbidity” represents a group of potentially life-threatening unexpected maternal conditions or complications that occur during labor and delivery. The Centers for Disease Control and Prevention (CDC) developed a standard method to identify severe maternal morbidity from International Classification of Diseases, Version 10 (ICD-10) diagnosis and procedure codes representing 21 types of pregnancy complications associated with high risk of maternal death.

To align with recent changes in the definition of the severe maternal morbidity indicator used by CDC and the Maternal and Child Health Bureau, this report does not include blood transfusion as a severe maternal morbidity condition and no longer incorporates the length of delivery hospital stay to determine whether cases were truly instances of severe maternal morbidity. Therefore, the data presented in Figure 7 are not comparable to severe maternal morbidity data in the previous report.

For this report, 2016 and 2017 Illinois hospital discharge data were combined to identify deliveries with any of the 20 severe maternal morbidity categories. Hospitalization records for more than 280,000 deliveries to Illinois residents were included in this analysis.

Severe maternal morbidity rates were calculated by dividing the number of severe maternal morbidity cases by the number of total deliveries and multiplying by 10,000. This gives a rate that represents the number of women experiencing severe maternal morbidity out of every 10,000 deliveries.

### Pregnancy-Associated and Pregnancy-Related Mortality Methods

The data presented throughout this section come from multiple sources, including death certificates, birth certificates, fetal death certificates, medical records, autopsy reports, coroner reports, police reports, and MMRC decision forms.

In this report, two years of mortality data are presented together to improve the reliability of the statistics. Because maternal mortality is a relatively rare event, case counts from a single year may be too small to draw meaningful conclusions, especially if the data are broken down into specific subgroups. Because of the small case counts, there may be random fluctuation from year to year; interpretation is improved when multiple years are combined.

The “pregnancy-associated mortality ratio” (PAMR) and “pregnancy-related mortality ratio” (PRMR) are displayed to allow for comparisons of the likelihood of mortality for different groups. The PAMR is calculated by dividing the number of pregnancy-associated deaths by the number of live births and then multiplying by 100,000. The PRMR is calculated by dividing the number of pregnancy-related deaths by the number of live births and then multiplying by 100,000. The

PAMR and PRMR are interpreted as the number of deaths that occurred for every 100,000 live births within a specific group of women. Because they standardize the population size, the PAMR and PRMR are more meaningful than case counts for comparing the likelihood of death for different groups.

### Social Determinants of Health Methods

IDPH completes a social determinants of health checklist to capture information about the social and community context, education and language, health care barriers, and economic stability for each death that is reviewed by the MMRCs. This checklist allows the committee to specifically identify social, economic, and environmental factors that may have contributed to the death and to develop data-driven policy recommendations to address them. However, because medical records are not designed to capture detailed social histories, it is likely that the checklist underestimates the true experience of these issues. The data from these checklists therefore represent a conservative estimate of the extent to which each factor affected maternal deaths.

The social determinants of health checklists for pregnancy-related deaths were used to identify two categories of stressful life events: traumatic and financial. These categories were conceptually developed based on combinations of stressful life events present in the Pregnancy Risk Assessment Monitoring System.<sup>91</sup>

**Traumatic stress** was defined as the presence of any of the following experiences: current or past history of housing instability (including homelessness), incarceration or other justice system involvement, involvement with DCFS, community violence, domestic violence, or other documented trauma (such as sexual abuse).

**Financial stress** was defined as having no health insurance, being enrolled in Medicaid (as a marker for being low-income), participating in the WIC nutrition program, being unemployed, or having issues with food insecurity.

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<sup>91</sup> Ahluwalia, I.B., Merritt, R., Beck, L.F., & Rogers, M. (2021). Multiple lifestyle and psychosocial risks and delivery of small for gestational age infants. *Obstetrics and Gynecology*, 97(5), 649-656.





