ST. LOUIS FETAL-INFANT MORTALITY REVIEW
Findings from 2003-2013

March 2017
Letter from Executive Director

Generate Health STL (formerly known as Maternal, Child and Family Health Coalition (MCFHC)) is proud to have founded in 2003 the first Fetal Infant Mortality Review (FIMR) program in the state of Missouri. Many volunteers dedicated several years to see this program become successful in St. Louis. Their resolve has been steadfast and it has been rewarded with the promise of improvements to the systems of care for women and babies.

This report is more than a compilation of the data collected and the insights generated over the first 10 years of active reviews and recommendations for improvements. This report is the story of losses suffered by too many families in our community, and the hope is that by telling these stories we can prevent the suffering of others.

While the breadth and depth of issues contributing to fetal and infant death can seem overwhelming and difficult to impact, FIMR challenges and inspires us to keep trying everything in our power, no matter how long it takes. FIMR reveals that we all have a responsibility for the health and wellbeing of moms and babies. As you review the findings, take time to commit to any actions, big or small, that you personally or your organization can take to improve the care of women and infants. It will make a difference.

The findings and recommendations from FIMR have shaped and will continue to inform Generate Health’s priorities and initiatives. This collection of data and insights was used by FLOURISH St. Louis to inform their priority focus areas. FLOURISH St. Louis is an initiative that aims to significantly reduce infant deaths by bringing the community together in new ways to address the complex problem of why so many babies are dying before they reach their first birthday. And in the future, FIMR will continue to provide a critical source of data for the FLOURISH Think Tank.

For more information about Generate Health and how to get involved, visit our website at www.generatehealthstl.org.

Warmest regards,

Kendra Copanas
Executive Director
Generate Health STL
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Purpose of Fetal Infant Mortality Review (FIMR)
The purpose of the Fetal Infant Mortality Review (FIMR) is to enhance the health and well-being of the community’s women, infants and families through reviewing cases of fetal and infant deaths and making recommendations to improve community resources and service delivery systems.

Purpose of Report
This report attempts to explain multi-faceted factors that contribute to infant mortality in St. Louis. The most significant findings, statistics, and recommendations are laid out in the following pages. Infant mortality is a complex issue resulting from a multitude of interwoven causes, and is affected by multiple social and societal determinants of health.

Often, causes of infant mortality extend beyond medical care. Systemic issues such as socioeconomic status, education, transportation, and employment all affect health. These systemic factors are referred to as social determinants of health, or “conditions in the environment in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risk” (Healthy People 2020). Social determinants impact health, just as risk factors like smoking use, drug use, past medical history and family medical history all impact health. It is also important to note that the health of fetuses and infants are tied to the health of their mothers. So, the social determinants of health that impact a pregnant woman also impact her unborn child. Therefore, it is important not only to determine a given population’s infant mortality rate, but also to examine the underlying causes and risk factors that contribute to that rate.

The FIMR model incorporates this framework through its extensive review of services the mother accessed both prenatally and during the postpartum period. Through the inclusion of a home interview that examines the mother’s social environment, FIMR incorporates findings associated with both traditional medical care as well as social determinants of health.
National FIMR

The National Fetal-Infant Mortality Review (NFIMR) was developed in 1990 by the American College of Obstetricians and Gynecologists (ACOG) and the Health Resource and Service Administration (HRSA), Maternal Child Health Bureau (MCHB), as a community-based process to identify and address both medical and social factors that contribute to infant mortality. Research demonstrates that NFIMR is an effective perinatal systems intervention.

NFIMR assists state and local Fetal and Infant Mortality Review (FIMR) programs by offering advice, providing training and technical support, and developing the NFIMR resource center. Within the NFIMR resource center, many manuals, community guides, and toolkits are available to help local FIMR programs in all stages of program development, from initial start-up planning of brand new FIMR programs to fine-tuning specific aspects of well-established FIMR programs.

NFIMR is an action-oriented community process that works to continually assess, monitor, and improve service systems and community resources for women, infants, and families. The figure below demonstrates this continuous cycle of improvement.

NFIMR recommends separate staff complete the various stages of the process. FIMR staff members are responsible for medical abstraction and home interview (data gathering). A Case Review Team develops recommendations based on an exhaustive review of abstracted cases (case review). Finally, a Community Action Team uses the recommendations from the Case Review Team to develop interventions in the community (community action), which then lead to changes in community systems.
Brief History of FIMR in St. Louis

The St. Louis Fetal and Infant Mortality Review (FIMR) program was established in 2003 by the Infant Mortality Workgroup of Generate Health STL (formerly known as the Maternal, Child and Family Health Coalition) in order to better understand why babies die. After reviewing infant mortality data and risk factors in the St. Louis region, the Infant Mortality Workgroup planned and implemented a FIMR program modeled after the National FIMR program.

Originally funded by Generate Health’s Healthy Start grant through HRSA, the St. Louis FIMR program began in the three zip codes covered by Healthy Start in St. Louis City and County (63113, 63120, 63136). These zip codes were chosen for Healthy Start due to a combination of need and community capacity (FIMR Report, 2007). Generate Health staffed FIMR for data collection and management, and committee facilitation. The Missouri Department of Health and Senior Services (DHSS) provided vital statistics information via the Bureau of Genetics and Healthy Childhood with Institutional Review Board approval.

In 2005, Generate Health received funding from the Missouri Foundation for Health (MFH) to expand the St. Louis FIMR program from three zip codes to cover the entire City of St. Louis and St. Louis County (FIMR Report, 2006). In 2011, the DHSS transitioned its relationship with local FIMR programs from the Bureau of Genetics and Early Childhood to the Bureau of Vital Statistics.

“Despite the multitude of excellent providers and hospitals in St. Louis, infant mortality is too high. We look for issues that are amenable to community action and education to prevent such deaths. This is the essence of good public health.”

The late Corinne Walentik, M.D., MPH
Neonatologist, SSM Cardinal Glennon Hospital
Professor of Pediatrics, Saint Louis University School of Medicine

2007 FIMR Annual Report
Current St. Louis FIMR model

FIMR provides a community-based method to examine social, economic, health, educational, and environmental factors associated with fetal and infant deaths in St. Louis. The FIMR process begins when a fetal or infant death occurs. Staff collects and abstracts data from vital statistics, medical and social service records spanning from preconception care visits to postpartum follow up or the infant’s demise. When possible, a structured home interview is also conducted (with consent) to record the mother’s and family’s experiences with the support services available to them and care received during the prenatal, labor and delivery, and postpartum periods. All information is kept confidential. After all case data is collected, it is de-identified (all identifying information about the family, providers, and services are removed). Case information is then summarized and presented to the Case Review Team.

Death Occurs

Data Collection
(Vital, medical and social service record review and home interview with the mother)

Case Review

Recommendations for Community Action, Interventions and Changes in Community Systems and Resources

Improved Maternal & Infant Health
The Case Review Team (CRT) consists of a 25-person roster that is diverse both demographically and professionally. The majority of obstetric and neonatal hospital systems in the region are represented. Additionally, maternal and child health representatives from academic systems, federally qualified health centers and community organizations participate in the case review process. New CRT members are nominated by current members based on gaps in expertise and are then recruited by staff. New members are asked to base their decision to participate on a minimum commitment of two years of active participation in case review. Historically, there have been approximately 2-4 CRT meetings per year.

The primary focus of the CRT is to systematically review and discuss the case summaries. The CRT identifies patterns of factors that contribute to the fetal or infant death and that demand further attention and intervention to reduce fetal and infant deaths. Based on these trends, the Case Review Team makes recommendations for action. (FIMR Report, 2007).

The Community Action Team (CAT) was a committee designed by the National FIMR model and was initially formed by the Infant Mortality workgroup in St. Louis to put CRT recommendations into action. Since that time, Generate Health has ensured that CRT recommendations have been integrated into its workings appropriately. Various mechanisms for doing so have included the incorporation of recommendations into various initiatives, the development and implementation of community and provider trainings, and the development of white papers on issues impacting infant mortality.
Fetal and Infant Mortality in St. Louis

According to HRSA, “Infant mortality rates are used worldwide to gauge the health and well-being of populations, and growing evidence suggests that higher infant mortality within a population is linked to that population's overall health and development across the life course.” Definitions for fetal deaths and infant mortality measures are provided below. These are standard, widely-used, epidemiological terms and definitions that align with the Missouri Department of Health and Senior Services working definitions.

**Fetal Deaths** (also referred to as stillbirths) are deaths in utero at or beyond the 20th week of pregnancy, and weighing at least 350g.

\[
Fetal \text{ Death Rate} = \frac{\# \text{ fetal deaths}}{1,000 \text{ (live births plus fetal deaths)}}
\]

**Perinatal Deaths** are deaths at 20 or more week’s gestation (weighing at least 350g) plus neonatal deaths.

\[
Perinatal \text{ Death Rate} = \frac{\# \text{ fetal deaths (20 + weeks)} + \# \text{ neonatal deaths (≤ 27 days)}}{1,000 \text{ (live births plus fetal deaths)}}
\]

**Infant Deaths** are defined as infants born alive and dying before their first birthday.

\[
Infant \text{ Death Rate} = \frac{\# \text{ infants born alive, who died before first birthday}}{1,000 \text{ live births}}
\]

There are overlaps among the categories (for example, an infant dying on day 20 would be included in the perinatal death rate and infant death rate.) For clarity, a timeline is included below.
Table 1. Fetal, perinatal, and infant death rates for St. Louis City, St. Louis County, and Missouri.

<table>
<thead>
<tr>
<th></th>
<th>Fetal Deaths per 1000 2003-2013</th>
<th>Perinatal Deaths per 1000 2002-2012</th>
<th>Infant Deaths per 1000 2002-2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Louis City</td>
<td>8.8</td>
<td>16.2</td>
<td>11.2</td>
</tr>
<tr>
<td>St. Louis County</td>
<td>6.5</td>
<td>12.1</td>
<td>7.7</td>
</tr>
<tr>
<td>Missouri</td>
<td>5.7</td>
<td>10.5</td>
<td>7.3</td>
</tr>
</tbody>
</table>

Missouri Department of Health and Senior Services, Delivery Profile, Infant Health Profile. 2015.

According to the Centers for Disease Control and Prevention (CDC), the three leading causes of infant mortality in Missouri and the United States are congenital malformations, preterm birth and low birth weight, and Sudden Infant Death Syndrome (SIDS). These were closely followed by maternal complications. Nationally, infant mortality rates are decreasing (12% decrease from 2005 through 2011) and the state of Missouri mirrors that trend (NCHS Databrief No. 120 April 2013). However, St. Louis City and St. Louis County fetal and infant mortality rates remain higher than the Missouri rates, as indicated in Table 1. Nationally, fetal mortality rates were stable from 2006-2012. However, the overall perinatal mortality rate declined 4% nationally, and by more than 10% in Missouri (NCHS Databrief No. 169 November 2014 bn). Similar to infant mortality data, perinatal and fetal death rates are higher for St. Louis City and County than for Missouri as a whole (Table 1).
Findings: Complex factors contributing to infant mortality in the St. Louis region

The following narrative outlines a decade of Case Review Team findings and recommendations from review of FIMR cases, with an emphasis on underlying factors that contribute to infant mortality. These issues are placed in the context of St. Louis City, St. Louis County, and Missouri, using the most current local data when possible. The sections follow the general format detailed below:

Factors related to an issue that contributes to infant mortality

FIMR data\(^1\). This is the percentage of FIMR cases affected by the issue. In some instances, background information on the risks associated with the factors is presented here as well.

The next section details CRT discussion topics to provide some context for the data and for the CRT recommendations. These paragraphs are italicized in a different color to emphasize that the content is not based on population-based epidemiological data, but rather provides an overview of CRT discussions that led to specific recommendations.

Next, local and state data is presented, wherever available. This section serves to place the issues and occurrences identified in FIMR cases into a larger context and to provide evidence-based data that support the FIMR findings.

RECOMMENDATION: These are the specific recommendations made by the CRT. They highlight the need for specific services or systemic changes and are based on the FIMR data, maternal interviews, and CRT experiences.

Appendix A presents St. Louis FIMR findings and recommendations over its ten-year history. Some recommendations have repeated over the course of the program, which suggests that the issues contributing to fetal and infant mortality are persistent and pervasive, and require thoughtful action and sustained commitment to change. Appendix B presents a summary of the findings and recommendations in table format. These were compiled from 10 years’ worth of meeting agendas, notes, and summaries.

\(^1\) From 2003 to 2013, 121 FIMR cases were reviewed by the CRT. Of the 103 cases with available data, 31 include maternal interviews, 40 are fetal deaths and 40 are infant deaths. Percentages are calculated by the frequency of the indicator divided by 103 (or 40 in the cases of issues discussed in the ‘Factors related to infant health’ section.)
Factors Related to Fetal/Infant Health

Of the infant cases reviewed by FIMR, 47.5% were born with congenital anomalies. 40.0% had an infection. 65.0% were born prematurely.

As seen in Figure 1 below, the leading causes of infant mortality in Missouri are SUID (sudden and unexpected infant deaths), congenital anomalies (birth defects), and preterm-related (preterm birth and low birthweight). Because FIMR cases are selected at random (and therefore not a representative sample of the causes of infant mortality in the region) there is limited FIMR data related to injuries and other perinatal conditions.

**Figure 1. Causes of Infant Mortality in Missouri**

<table>
<thead>
<tr>
<th>Percent</th>
<th>Injury</th>
<th>Other Perinatal Conditions</th>
<th>SUID</th>
<th>Congenital Anomalies</th>
<th>Preterm-related</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7</td>
<td>11</td>
<td>16</td>
<td>22</td>
<td>33</td>
</tr>
</tbody>
</table>

Infant Mortality Data Summary Report for Region VII, MCHB/HRSA CoIN Initiative Meeting, July 2014

**SUID**
SUID (sudden and unexpected infant deaths), SIDS (Sudden Infant Death Syndrome) and sleep related causes of infant mortality are addressed later in this report.

**Congenital Anomalies**
According to the Physicians Committee for Responsible Medicine (PCRM), a birth defect is an “abnormal development of the fetus resulting in death, malformation, growth retardation, and functional disorders.” The most common birth defects include heart defects, cleft lip and cleft palate, Down syndrome and spina bifida. About 10% of birth defects can be linked to a specific agent such as an environmental toxin or nutritional factor – among this 10%, the leading preventable cause is Fetal Alcohol Spectrum Disorder (also known as Fetal Alcohol Syndrome (FAS)). About 20% of congenital anomalies are inherited or associated with chromosomal changes. The remaining 70% of birth defects are due to unknown causes. Although inherited and chromosomal causes may not be preventable, preconception and
interconception care can help families identify significant family medical history and environmental risks that can lead to congenital anomalies, and reduce some of the risks of morbidity and mortality from these conditions. Furthermore, while 70% of birth defects are due to unknown or undetermined causes, research indicates that the risk factors listed on the right greatly increase the risk of having a baby with a birth defect (CDC). Adjusting modifiable behaviors (such as smoking, drinking, uncontrolled diabetes, or certain medication use), and working with a physician to address others that cannot be changed (such as age, medical history, or family history) can lower the risk of having a baby with a birth defect.

### Risk Factors for Congenital Anomalies:
- Smoking, alcohol, or drug use during pregnancy
- Certain medical conditions (such as obesity or uncontrolled diabetes before and during pregnancy)
- Certain medications, such as isotretinoin (a drug used to treat severe acne)
- Family history of a birth defects
- Older maternal age (typically over the age of 34 years)

### Factors associated with Preterm Birth:

#### Social, Personal, Economic Characteristics:
- Low or high maternal age
- Black race
- Low maternal socioeconomic status

#### Medical and Pregnancy Conditions:
- Infection
- Prior preterm birth
- Carrying more than 1 baby
- High blood pressure during pregnancy

#### Behavioral:
- Tobacco and alcohol use
- Substance abuse
- Late prenatal care
- Stress

### Preterm Birth
Preterm birth (<37 weeks) and low birthweight (<2500g) are the leading cause of infant mortality. Unfortunately, the causes of preterm birth are complex issues that are not always well understood. Factors associated with preterm birth, according to the CDC, are listed to the left. Notably, all of these factors are associated with the pregnant woman rather than a medical condition of the fetus. In addition, many are modifiable behavioral risk factors. Clearly, the social determinants of health that affect a pregnant woman also strongly impact the health of her unborn child. Nearly all of these risk factors for preterm birth were significant findings discovered and decided upon by the CRT, and are discussed in the following pages of this report.
Factors Related to Maternal Health

Of the cases reviewed by FIMR, 33.0% of mothers went into preterm labor. 26.2% experienced premature rupture of membranes (PROM). 23.3% had a previous fetal loss.

Of the cases reviewed by FIMR, 34.0% of moms were obese. 20.4% had poor nutrition.

In 2011, the Case Review Team and FIMR Advancement Team identified weight management for women of childbearing age as a priority recommendation based on FIMR data on obesity, nutrition, and diabetes (discussed later in this report). Weight management is closely linked to and impacts other St. Louis FIMR recommendations, especially preconception health and diabetes management, both of which are discussed later in this report.

Of the cases reviewed by FIMR, 29.1% of moms had an infection during their pregnancy. 15.5% had an STI. 10.7% had diabetes. 1.9% had HIV.

In 2007-2008, the Case Review Team prioritized the care of pregnant women with HIV as a recommendation for community action. A workgroup developed the following recommendations to providers for effectively addressing HIV issues in African American women:

- Increase self-awareness of communications, subconscious thought processes and attachment of stigma
- Heighten awareness of the special social circumstances and cultural contexts that may contribute to HIV risks
- Take detailed personal histories to compliment the battery of medical histories taken by clinicians
- Actively pursue mediating services to address special needs of each woman and family
- Ensure culturally appropriate holistic approaches to both testing and case management services

From 2010-2013, no cases were reviewed in which the mother was HIV-positive.
According to Missouri DHSS data, at the end of 2013, the greatest proportion of heterosexual contact cases living with HIV disease were between the prime child-bearing years of ages 25-44 for black/African American females. According to the FIMR/HIV National Resource Center, 100-300 infants in the United States are infected with HIV annually. While the risk of perinatal or vertical transmission (mother-to-child transmission) is low, women who are HIV-positive are less healthy than their HIV-negative counterparts, and therefore more likely to have poorer birth outcomes. Furthermore, many poor women who are HIV-positive are likely to experience gaps in care – which could result in a lack of HIV screening for her infant, as well as a lack of care for her own health. ACOG’s recommendation for HIV testing during the prenatal/perinatal period was last reaffirmed in 2011².

² ACOG has since reaffirmed HIV testing during prenatal/perinatal period in 2015.
Factors Related to **Diabetes**

Of the cases reviewed by FIMR, 10.7% of moms had diabetes.

There are significant risks to both the mother and infant, including stillbirth, to women with a prenatal diagnosis of diabetes and uncontrolled blood glucose during pregnancy. These risks apply to not only women with gestational diabetes (diabetes diagnosed *during* pregnancy), but also to those with Type 1 and Type 2 diabetes (diabetes diagnosed *before* getting pregnant). Glucose management during preconception, pregnancy, and postpartum for women with diabetes is extremely important to the health of mother and fetus/infant. Maintaining appropriate glucose control *prior* to conception is incredibly important since it greatly reduces the risks for many adverse birth outcomes for women with existing diabetes.

<table>
<thead>
<tr>
<th>Diabetes</th>
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<tbody>
<tr>
<td>Some moms with gestational diabetes report being left without follow up for their diabetes due to losing prenatal insurance coverage after their baby is born (even though they still have diabetes).</td>
</tr>
</tbody>
</table>

Review of FIMR cases demonstrated that internists are not always addressing reproductive planning during preconception or inter-conception care periods for women with pregestational (Type 1 or Type 2) diabetes. Furthermore, review of FIMR cases revealed a lack of referrals to diabetes educators for moms with gestational diabetes. The CRT noted that this is partly due to the systematic decline of available diabetic educators, nutritionists, and other health care personnel for health education and case management in hospitals.
The following charts indicate how births to women with diabetes in St. Louis City and St. Louis County have changed since FIMR began in St. Louis in 2003. Rates of births to women with insulin-dependent diabetes has remained relatively stable for St. Louis County and for Missouri, but has increased significantly for St. Louis City (Figure 2). Rates of births to women with non-insulin-dependent diabetes has remained relatively stable for St. Louis City, St. Louis County, and Missouri, although there has been a slight decrease in St. Louis City (Figure 3).

RECOMMENDATION: Improve perinatal diabetes coordination.

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Birth certificates collect diabetes data based on insulin dependency, not type of diabetes. Therefore, it is impossible to separate women with Type 1 diabetes from women with Type 2. All women with Type 1 diabetes are insulin-dependent. Some women with Type 2 and some women with gestational are insulin dependent, and some are not. Therefore, it is impossible to separate these using current data.
Factors Related to **Health Care Access**

According to [Healthy People 2020](https://www.healthypeople.gov/), health care access refers to the timely use of personal health services to achieve the best health outcomes, and requires three distinct steps:

1. Gaining entry into the health care system
2. Accessing a health care location where needed services are provided
3. Finding a health care provider with whom the patient can communicate and trust.

**Cultural Competency**

While there is no one definition for cultural competency, within the context of FIMR, the following definition from Betancourt et al adequately sums up the concept:

“Cultural competence in health care describes the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.”

Cultural competency has recently become an important indicator for health care providers, and relates specifically to step #3 of health care access listed above (in that providers need to be able to understand and connect with their patients). Of the cases reviewed by FIMR, 10.7% of moms experienced or conveyed cultural barriers to care.

**CRT findings highlight the need for culturally competent providers and services.** Some examples of issues include: communication/language barriers (specifically a lack of available interpreters, especially for certain dialects), cultural beliefs regarding pregnancy and health, religious beliefs regarding life, and concern of citizen status. The presence of any one of these issues not only impacts a woman’s ability to receive quality health care, but also adds additional stress to her pregnancy.

<table>
<thead>
<tr>
<th>Provider perception of patients based on race and employment status</th>
</tr>
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<tbody>
<tr>
<td>Medicaid clients often feel they are treated harshly and differently than those with private pay – they experience disrespectful doctors and poor bedside manners due to their race and poverty. This common frustration and lack of knowledge about the patient right to request a different provider has led many women to opt to use the Emergency Room for care rather than schedule regular appointments.</td>
</tr>
</tbody>
</table>
A sampling of regional racial demographics:

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>St. Louis City</td>
<td>46.4%</td>
<td>47.9%</td>
<td>6.8%</td>
</tr>
<tr>
<td>St. Louis County</td>
<td>70.3%</td>
<td>23.7%</td>
<td>6.8%</td>
</tr>
</tbody>
</table>

US Census Bureau: St. Louis County & St. Louis City, 2015.

Healthy People 2010 defines disparities as “particular types of differences that are closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”

Racial disparities in fetal mortality and infant mortality in the St. Louis region mirror similar disparate outcomes around the United States (NCHS Databrief No. 74 Sept 2011, David & Collins, 2014, For the Sake of All). However, the St. Louis disparity rate of 3:1 is more severe than the national average of 2:1. Indeed, compared to about 50 other metro areas around the country, St. Louis has the 3rd worst black/white gap for infant mortality (Where We Stand).

St. Louis has a historically strong racial disparity between African Americans and whites, especially in regard to health, education, income, and geography (For the Sake of All). While progress has been made to reduce infant mortality for White and African American babies, the disparity has widened because White infant death rates improved much faster than black (Figure 4). Indeed, an African American infant is approximately 3 times more likely to die before their first birthday than a white infant – a significant increase in disparity from the 1950’s rate of 2 times (For the Sake of All). Using national infant mortality data trends, Loggins and Andrade determined that, at the current rate, racial parity would not be achieved until the year 2063. Using only Missouri data from the same data set, parity in Missouri would not be achieved until 2041. This is demonstrated in Figure 5 on the following page. Unfortunately, this data
cannot easily be broken down to St. Louis City and St. Louis County level by race, because there are typically less than 20 white infant deaths per year in St. Louis City. Such a low number of events in the numerator makes the rate unstable (as well as infringes on the confidentiality of the individuals who experience those events).

![Image](image_url)

United States Department of Health and Human Services, Centers of Disease Control and Prevention, National Center for Health Statistics, Division of Vital Statistics. 2016

Poverty

Of the cases reviewed by FIMR, 62.1% of moms lived in poverty at the time of delivery and/or during the maternal interview. Medicaid status is often used as a proxy indicator for poverty.

Figure 6 below shows the rates of women receiving prenatal Medicaid by race in 2013. There is a significant disparity between African American and White mothers for Missouri, St. Louis County, and St. Louis City. More than 70% of African American mothers received prenatal Medicaid, regardless of location. The highest rate is in St. Louis City, with 86.9% of African American mothers receiving prenatal Medicaid. Overall, the rate (and racial disparity) of mothers on prenatal Medicaid for St. Louis City and County has remained relatively unchanged since 2003.

![Image](image_url)

Missouri Department of Health and Senior Services, Prenatal Profile. 2014.
Transportation

The Case Review Team defines access to health care as both the ability to receive care through health insurance coverage, and the ability to attend prenatal care appointments based on transportation availability. Of the cases reviewed by FIMR, 9.7% of moms reported inadequate transportation.

More than one out of five (21.4%) occupied housing units in St. Louis City do not have a car. In St. Louis County, 6.8% of occupied housing units do not have a car. Public transportation may be an option for some families but variables such as walking distance, safety, and absence of shelter may be deterrents. Women on prenatal Medicaid can use Non-Emergency Medical Transportation (NEMT) at no cost, but restrictions such as scheduling the ride five days ahead of the appointment limit the utilization of this benefit. Women needing to receive obstetric care emergently are taken to the nearest hospital by EMS, even if there aren’t any obstetric providers there.

**RECOMMENDATION:** Improve options for transportation to hospital from prenatal care site based on medical need.

**RECOMMENDATION:** Update EMS protocol for pregnant women.
Factors Related to **Continuity of Care**

**Preconception and Interconception Care**

Preconception care is focused on efforts to improve health prior to pregnancy; interconception care focuses on improving health between pregnancies (Kotelchuck, 2013). FIMR cases are reviewed for maternal age, contraceptive use, and pregnancy intention.

Of the cases reviewed by FIMR, 7.8% were teen pregnancy cases. 9.7% were in women with advanced maternal age (>35).

Both of these age groups are at increased risk for adverse birth outcomes. As demonstrated in Figure 7 below, since 2001-2003, teen pregnancy rates have decreased significantly for St. Louis City (40.3%), St. Louis County (34.8%), and Missouri (38.8%). However, rates for St. Louis City remain significantly higher than those for St. Louis County and Missouri. As seen in Figure 8 below, since 2001-2003, the rate of pregnancies to women with advanced maternal age has decreased in St. Louis County (8.9%), and increased in St. Louis City (32%).

![Figure 7. Teen Pregnancy Rate (under age 18)](image)

![Figure 8. Rate of Pregnancies to Women Ages 35-39](image)

**Family Planning**

Of the cases reviewed by FIMR, 9.7% of moms never used any form of birth control. 2.9% did not use birth control and did not intend to get pregnant. 9.7% got pregnant as a result of failed contraception. 22.3% did not use birth control and intended to become pregnant.
Short intervals between pregnancies are associated with poor health outcomes and are a focus of interconception care. Although adverse effects resulting from inadequate intervals between pregnancies are well-established, most physicians are inclined to support very small inter-pregnancy intervals (less than six months) for parents who have experienced a previous perinatal death without a known cause (Gold, 2010). The researchers of this study note that “responses may reflect efforts to support parents emotionally while recognizing individuals vary in coping and clinical circumstances. However, this is a provocative finding since short intervals may confer greater fetal risks for poor outcomes.” While St. Louis City (14.4%), St. Louis County (10.8%), and Missouri (12.1%) rates are well below the 2013 national rate of 33.1%, birth spacing rates in St. Louis City and County have remained relatively unchanged over time (Figure 9).

**Figure 9. Birth Spacing Less Than 18 Months**

Missouri Department of Health and Senior Services, Birth MICA. 2016

**Prenatal Care**

Of the cases reviewed by FIMR, 14.6% of moms had no prenatal care. 21.3% experienced a late entry into prenatal care (after first trimester). 16.5% missed prenatal appointments. 8.7% visited multiple providers/sites.

**Issues regarding prenatal care have been identified based on pregnant women making multiple visits to different emergency rooms during the prenatal period with no follow-up to their prenatal or primary care providers regarding the visit, medical condition, outcomes, or services provided by the ER staff. Similarly, parents visiting multiple providers face difficulties with decision-making due to conflicting messages – this partially stems from a lack of communication among providers regarding the follow-up instructions they give to their patients. Additionally, the CRT noted a lack of documentation regarding pregnant women receiving referrals to address health issues such as smoking and drug use during pregnancy. While services may be available in the community, there seems to be a disconnect between those who need them and their accessing the services.**

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**GenerateHealth**

22
As seen in Figures 10 and 11 below, the percentage of women in Missouri and the St. Louis area who enter prenatal care late (after the first trimester) or do not get prenatal care at all has risen in recent years. Furthermore, there is an obvious racial disparity, with the percentage of African American women entering prenatal care late or not at all significantly higher than white women. There is also a geographical disparity, with the percentage of women entering prenatal care late or not at all significantly higher in St. Louis City compared to St. Louis County. This relationship is modified by race, meaning that the association is evident among both African American women and White women.

**RECOMMENDATION:** Improve communication on behalf of Emergency Department and prenatal providers.
CRT case review revealed many instances of women not receiving the referrals they needed. This is often related to inadequate prenatal care – women who enter prenatal care late (or not at all), or who miss appointments, do not have the opportunity to see providers for additional health needs. This also was noted to be an issue for follow up – many women received diagnoses, but then did not receive adequate follow up related to the diagnosis (for example, gestational diabetes and then not seeing a diabetes educator or dietitian, or being told their infant had a genetic defect and then not seeing a genetic counselor.

**RECOMMENDATION**: Increase appropriate referrals.

**Risk Assessments and Provision of Care**

Of the cases reviewed by FIMR, 19.4% of moms had no prenatal risk assessment performed, and 8.7% had an inadequate prenatal risk assessment completed, or one that was not followed. Prenatal risk assessments are conducted on pregnant woman to identify and mitigate (if possible) genetic, medical, or social risk factors for adverse birth outcomes.

The CRT discussed the issue of whether the appropriate professional staff is providing services to the mothers or pregnant women. In addition, the CRT case review revealed a lack of information available in the medical records about follow-up on assessments that were conducted. There was an overall lack of clarity on the manner in which the assessments were conducted. For example,

- How did the provider obtain assessments about depression, intimate partner violence, substance use, hunger, housing, etc.?
- Is the social assessment being conducted by a social worker, nurse, or physician?
- Was the person providing the service competent and qualified for the task?
- Did the individual providing the services document their name and credentials?

In addition, there was almost never any information in the medical record about follow-up with women who missed prenatal appointments.

**Need for referrals, counseling, and follow up:**

- Preconception care and counseling
- STIs
- HIV
- Mental health
- Drug use
- Smoking cessation
- Abuse screening
- Genetics (including follow up after delivery)
- Dietician
- Diabetes educator
The CRT also found that women often reported inconsistent messages from various providers, including home visiting case workers. Emphasizing consistent education can help mothers in future pregnancies.

The high percentage of inadequate prenatal assessments among cases reviewed by FIMR is disconcerting, but perhaps not surprising, with the current racial disparity in infant mortality rates. Improved coordination and documentation of care provided could help ensure that patients receive appropriate, adequate, and consistent care from appropriate providers.

**RECOMMENDATION:** Improve care coordination (follow up and case management) for patients with inadequate prenatal care.

**Pediatric Care Coordination**

CRT review of FIMR cases revealed a few specific issues that were not common, but nonetheless were significant.

- Care coordination on holidays
- Difficulty with scheduling appointments – appointments are generally made during hospital stays or at the end of an appointment. This demands moms to know their future schedules. If conflicts arise after appointments are made, it can be exceedingly difficult to reschedule.
- Lack of discharge planning, discussion of support measures, and parent-guardian education for discharges of high-needs infants from the NICU.

**Care Coordination**

Treating physician sent a sick infant to the ER on a holiday. The infant was sent home from the ER on the same day. Infant was rushed back to the ER and died the following day.

**Education from Providers**

Women report inconsistent messages from providers. For example, a home visiting nurse who informs the mother about *Back to Sleep*, yet places the baby into the crib face down.
Postpartum Care
The CRT noted a high frequency of missed six-week postpartum visits. This is a significant issue since case review revealed many related issues – especially with diabetes management (particularly for women with gestational diabetes), and a lack of counseling on family planning – which leads directly to interconception care.

**RECOMMENDATION:** Improve follow up at six-week postpartum visit.

**RECOMMENDATION:** Improve continuity of care to eliminate the need for multiple visits by different case workers following an unexpected death.

Overarching Needs
Review of FIMR cases revealed a need for improved referrals, counseling, and follow up for a variety of issues. Furthermore, the medical records did not always document the education that was provided, and often the education was not recalled by the mothers interviewed by FIMR. This indicates that the manner in which education is provided is not effective. Specific examples from FIMR cases are provided in the following box.

**Critical education not provided:**
- Birth control (and broader family planning education)
- Genetic counseling
- Weight management / nutrition counseling
- Smoking cessation
- Pre/inter-conception care for future pregnancies
- Fetal movement
- Safe sleep
- Early prenatal care
- Seeking care with accidents, injuries, falls
Factors Related to **Psychosocial Health**

The psychosocial section of the NFIMR data abstraction forms consists of questions related to mental health, substance use, interpersonal violence, and social stability (housing, support from friends and family, legal problems, etc.).

**Substance Abuse**

Of the cases reviewed by FIMR, 27.2% of moms reported tobacco use during pregnancy. 16.5% reported illicit drug use (most commonly marijuana). 7.8% reported alcohol use during pregnancy. 7.8% reported exposure to second hand smoke.

The CRT noted that a medical record may indicate that a pregnant woman or mother smokes, but there is no assurance from the record that the woman was counseled on the dangers of smoking, and/or referred to cessation classes in the community. Furthermore, the CRT felt that there is a lack of community awareness of community-based smoking cessation resources for pregnant women.

Smoking during pregnancy can cause premature birth, birth defects, and death ([CDC](https://www.cdc.gov)). As seen in the Figure 12 below, St. Louis City (9%) and St. Louis County (14.7%) rates are below that of Missouri (17.8%), though any percentage is too high. The smoking rates have remained constant for all three geographic areas, indicating that smoking during pregnancy is a persistent problem.

### Figure 12. Rate of Mothers who Smoke During Pregnancy

<table>
<thead>
<tr>
<th>Year</th>
<th>Missouri (%)</th>
<th>St. Louis City (%)</th>
<th>St Louis County (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>02-04</td>
<td>20</td>
<td>15</td>
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<td>06-08</td>
<td>17</td>
<td>15</td>
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<td>07-09</td>
<td>17</td>
<td>15</td>
<td>14</td>
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<tr>
<td>08-10</td>
<td>17</td>
<td>15</td>
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<tr>
<td>09-11</td>
<td>17</td>
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<tr>
<td>10-12</td>
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<td>15</td>
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<tr>
<td>11-13</td>
<td>17</td>
<td>15</td>
<td>14</td>
</tr>
</tbody>
</table>

**RECOMMENDATION:** Increase tobacco and marijuana education as well as cessation materials and referrals.
**Social Stability and Abuse**

Of the cases reviewed by FIMR, 8.7% of moms reported a lack of supportive friends/family. 13.6% reported negative influences of friends/family. 11.7% reported that the father of the baby was not supportive.

Of the cases reviewed by FIMR, 9.7% of moms reported intimate partner violence.

**RECOMMENDATION:** Reinforce and increase use of adequate intimate partner violence screening.

**RECOMMENDATION:** Increase use of in-depth psychosocial assessments (particularly related to abuse and neglect).

**RECOMMENDATION:** Advocate for proactive action with parents who use marijuana.

**Mental Health**

Of the cases reviewed by FIMR, 20.4% of moms were single. 12.6% had a history of mental illness. 9.7% had a diagnosed mental illness during pregnancy. 49.5% experienced multiple stresses during pregnancy.

The Case Review Team identified, by consensus, whether multiple stresses were present for each case. Determining factors include stable housing, social support, finances, and indicators of poverty such as government assistance, life changes, and self-identified stress.

Long periods of stress contribute to high blood pressure and heart disease. In addition, the relationship between stress and pregnancy is becoming clearer, and persistent stress has been demonstrated to have effects on birth outcomes. Specifically, stress increases the chance of premature birth and low birthweight (March of Dimes).

**RECOMMENDATION:** Increase mental health referrals.
Factors Related to **Safe Sleep**

Of the cases reviewed by FIMR, 17.5% of moms either reported or the CRT determined that issues related to safe sleep were present. Most issues involved improper infant bedding (sleeping with items in crib, sleeping in an adult bed, etc.), co-sleeping (sleeping with another person), or the infant not being placed on his/her back to sleep.

The CRT identified safe sleep education as lacking in 13.6% of cases reviewed by FIMR.

**RECOMMENDATION:** Increase safe sleep education and improve understanding of safe sleep decision-making by parents and caretakers.

**RECOMMENDATION:** Increase safe sleep messages and outreach.

Sudden Infant Death Syndrome (SIDS) is defined as the sudden death of an infant less than one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history (MDHSS [Data and Statistics](#)). In Missouri, every county is legislatively mandated to establish a multidisciplinary panel to review child deaths, the [Child Fatality Review Program](#), which includes review of all sudden unexplained deaths of infants from one week to one year for potential prevention services.
Nationally, SIDS is the third leading cause of infant mortality and the primary cause of postnatal mortality. Locally, the Case Review Team deliberates sudden and unexpected infant deaths (SUID) cases. SUID includes SIDS, accidental deaths (such as suffocation and strangulation), sudden natural deaths (such as those caused from infections, cardiac or metabolic disorders, and neurological conditions), and homicides – though, FIMR does not review any case that involves litigation of any kind. Prevention of SUID and SIDS cases involves reducing environmental risk factors – the most prominent of which is safe sleep, where the infant is placed on his or her back, rather than sides or stomach, on an appropriate sleeping surface. As indicated below, the rate of SIDS has steadily decreased in Missouri over the last decade (Figure 13). However, there is a significant racial disparity of SIDS cases in St. Louis City (Figure 14).

![Figure 13. SIDS Trendline for Missouri](image1)

Missouri Department of Health and Senior Services, Infant Health Profile. 2015.

![SIDS Rate, 2002-2012](image2)

Missouri Department of Health and Senior Services, Infant Health Profile. 2015.
Factors Related to **Community-Based Bereavement Services**

Of the cases reviewed by FIMR, 7.8% moms either reported or were identified by the CRT as having a bereavement-related issue.

Families grieving infant loss need community support systems to meet their specific needs. Many families turn to their faith leaders and faith community for support. Other families may turn to online support groups that may or may not be moderated by a parent organization with bereavement training.

<table>
<thead>
<tr>
<th>Bereavement</th>
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<tbody>
<tr>
<td>Attending bereavement services at the hospital where the loss occurred can be extremely difficult for grieving families.</td>
</tr>
</tbody>
</table>

_The CRT discovered that, while there are infant loss support groups available in the St. Louis region, there may be cultural, social, location-based, or financial barriers to participation._

The last question of the home interview asks, “What do you think needs to be done to help women and families who experience the death of an infant?” Of the families interviewed, many expressed a need for more community-based bereavement services.

**RECOMMENDATION:** Increase grief support specific to parents who made the decision to remove life support.

**RECOMMENDATION:** Increase community-based bereavement services.
Factors Related to Pathology

Of the cases reviewed by FIMR, 12.6% had no autopsy performed, 11.7% had no placental pathology performed, and 14.6% had no autopsy/pathology/placental exam results found in the medical record.

The CRT noted that documentation is not being found in medical records to substantiate whether placenta pathology was ordered, conducted, and outcomes of results. Placental pathology results are beneficial when abstracting medical records and reviewing FIMR case summaries. More importantly, however, pathology results can be incredibly important for families and their care providers in planning future pregnancies. The CRT found inconsistent placenta pathology practices and policies throughout the entire region. A universal placenta pathology guideline was then developed and distributed by the CRT (FIMR Report 2007). Ideally, placenta pathology should be conducted on all deliveries, and there should be improved coordination between the pathologist and obstetrician.

Pathology

Families should be made aware of the option of having an autopsy performed. The findings should be shared with the family and the mother’s primary care provider. These actions should be documented in the medical chart.

An autopsy is a very useful tool to the CRT in determining the physical factors related to fetal and infant death. In addition, the investigation of the possible causes of death is an important part in helping the family cope since the explanation can be therapeutic in easing feelings of guilt (Incerpi et al., 1998).

The CRT determined that permission to perform an autopsy should be routinely requested from the mother/family.

The American Congress of Obstetricians and Gynecologists (ACOG) recommend gross and microscopic examination of the placenta after every stillbirth (Sills et al., 2013). The College of American Pathologists issued additional guidelines for when pathological evaluation of the placenta should be conducted under three indications: maternal, fetal/neonatal, and placental (Sills et al., 2013).
Maternal indications — systemic disorders, preterm delivery, peripartum fever/infection, unexplained third-trimester bleeding, clinical concern for infection, severe oligohydramnios, unexplained or recurrent pregnancy complication, abruption, invasive procedure with suspected placental injury, nonelective pregnancy termination, and thick meconium.

Fetal/neonatal indications — infant admitted to other than a level-one nursery, stillbirth/perinatal death, compromised clinical condition, hydrops fetalis, birth weight less than the tenth percentile, seizures, infection or sepsis, major anomalies, discordant twin growth, and multiple gestations with same-sex twins.

Placental indications — placental abnormalities (infarct, mass, vascular thrombosis, retroplacental hematoma, amnion nodosum, abnormal coloration or opacification, malodor), small or large placenta, umbilical cord lesion, and cord length greater than 32 cm.

**RECOMMENDATION:** Improve communication and reporting of pathology reports (as well as implications for future pregnancies) between pathology and primary care providers/obstetricians.
Limitations
The most significant limitation to these findings is the low interview rate. Many important details are revealed during the maternal interview; therefore, issues identified by the CRT are most likely underreported. While important information regarding the mother’s medical history is found in medical records, information regarding the mother’s behaviors and reasons for certain behaviors are only revealed from the interview. For example: the medical records may indicate that a mother did not attend all recommended prenatal appointments, but the interview would reveal why the mother did not attend all appointments. Identifying the reasons behind patient and maternal noncompliance of recommended behavior is necessary to design and implement effective system changes.

Conclusion
This report identifies, with the best information available, statistics from FIMR cases as well as Case Review Team discussion topics and recommendations that have been made since the first meeting in November 2003. When possible, current data on the issue was presented so as to put the issue and recommendation into a larger context. Some of these findings and recommendations have repeated over the course of the program. This suggests that the issues contributing to fetal and infant mortality are persistent and pervasive, and require thoughtful action and sustained commitment to change.

FIMR does not exist in isolation. Other maternal child health review structures, including Perinatal Periods of Risk (PPOR), Pregnancy Risk Assessment Monitoring System (PRAMS), and perinatal quality collaboratives, are gaining popularity and are complementary to FIMR. FIMR provides unique opportunities: (1) to better understand relationships between entire maternal child health systems that impact birth outcomes and family experiences and (2) to act to improve the quality of these systems.

Just as the emphasis of case review is focused on social, economic, health, educational, and environmental factors that contribute to fetal and infant mortality, the capability to respond to and impact each domain is fundamental to FIMR’s success in St. Louis. Ultimately, this will contribute to the reduction of fetal and infant mortality and improve health outcomes for all families.
Acknowledgements

The data, findings, and recommendations in this report are the result of 10 years of data collection, interviews, and Case Review Team meetings. Many staff and volunteers have been involved from FIMR’s early stages and continue to participate – a testament to the dedication and investment of the maternal child health professional community in St. Louis. Generate Health is sincerely grateful for their time and support.

Moms and Families

Generate Health is most grateful to the moms and families who experienced fetal and infant loss and generously shared their stories to help increase understanding and prevent other families from experiencing the same tragedy. Sharing painful stories is never easy, but doing so has helped improve support services available to the pregnant women and new mothers in the St. Louis area.

Case Review Team

Generate Health is grateful to the Case Review Team members who shared their time and expertise in reviewing cases and providing recommendations to address systemic issues impacting infant mortality.

Case Review Team members include: Lori Behrens, LCSW (SIDS Resources); Saleh Bahati, MD, MPH, CPH; Glenn Barber, RNC-NIC (SSM Cardinal Glennon Children’s Hospital); Jim Bartelsmeyer, MD (St. John’s Mercy Medical Center); Lori Behrens, LCSW (SIDS Resources); Anne Bell, RD (Family Care Health Center); Huldah Blamoville, MD (Private Practice); Anne Boayue, MPH, MSW (St. Louis Children’s Hospital); Mary Bouman (Board of Probation and Parole); Rachael Bradshaw, MS (Saint Louis University, SSM Cardinal Glennon Children’s Hospital, SSM St. Mary’s Health Center); David S. Brink, MD (Saint Louis University School of Medicine); Yolette Brown, MD (Grace Hill Health Centers); Teresa Buehler, MSW, LCSW (SIDS Resources); Lee Burnett, LCSW (Queen of Peace Center); Amy Calico, RD (Family Care Health Center); Jen Jen Chang, PhD, MPH (Saint Louis University College for Public Health and Social Justice); Nancy Cibulka, MS, PhD (Barnes-Jewish Hospital); Catherine Cibulskis, MD (Saint Louis University SSM Cardinal Glennon Children’s Hospital); Sessions Cole, MD (Washing University School of Medicine, Department of Pediatrics); Robert Edmonds, MD (Grace Hill Neighborhood Services); Sandy Gipson, RN, BSN (BJK People’s Health Centers); Mary Alice Grady, CNM (Barnes Teen Clinic); Cindy Grieve, RN (Maternal, Child and Family Health Coalition); Aaron Hamvas, MD (St. Louis Children’s Hospital); Robert Hardy, Paramedic EMT (St. Louis City EMS); Kimberly Harrell (Pine Lawn Health Center); Cobi Ingram (March of Dimes); Lillie Jackson (City of St. Louis Department of Health); Betty Jefferson, RN, MSN, CHCEF (Affinia Healthcare); Gloria Johnson (Life Source Consultants); Lori Jones, MPH, RD, MS (Saint Louis University Nutrition and Dietetics; City of St. Louis); Gwen Jones (City of St. Louis Department of Health); Bill Keenan, MD (Cardinal Glennon Children’s Hospital); Deborah Kiel, RN (Barnes College of Nursing); Tine Lanius, RN (Healthy Start); Tom Lemp, LCSW (Catholic Family Counseling); Anna Lijowska, MD (St. Louis Children’s Hospital; Washington University School of Medicine); Mary Ann Maher, MSN, RNC (Mercy St. Louis); Jessica Mann,
Community Action Team and Program Planning Committee
Generate Health is sincerely grateful to the groups of people who took CRT recommendations and designed and implemented systemic changes to address and improve infant mortality. Past Community Action Team members developed and implemented hospital policy changes and community training sessions. Past Program Planning Committee members integrated CRT recommendations into existing Generate Health initiatives, and developed white papers on HIV and weight management. Furthermore, FIMR discussions and findings also heavily contributed to Generate Health’s focus on preconception/interconception health – which resulted in the Partnership for Preconception Health, a series of many needs assessments, and the production of the Women’s Health report and a community action plan.

Funding and Support
The data used in this document was acquired from the Missouri Department of Health and Senior Services (DHSS). The contents of this document including data analysis, interpretation, or conclusions are solely the responsibility of the authors and do not represent the official views of DHSS. Generate Health is grateful to the DHSS for the support and provision of vital statistics data and to the Missouri Foundation for Health, who provided the majority of the funding for this project. The Foundation is a resource for the region, working with communities and nonprofits to generate and accelerate positive changes in health. As a catalyst for change, the Foundation improves the health of Missourians through a combination of partnership, experience, knowledge and funding.
References and Resources


## Appendix A: FIMR Recommendations

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<th>RECOMMENDATIONS</th>
<th>2004</th>
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<td>Prenatal care coordination &amp; continuity of care</td>
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<td>High risk/Chronic disease perinatal management (including HIV, diabetes)</td>
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Appendix B:
Summary of CRT findings and recommendations from 2003-2013.

Note: Bolded ‘\textbf{NEED FOR}’ = CRT recommendation.

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>CONTEXT/RECOMMENDATIONS</th>
</tr>
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</table>
| Bereavement | - Need for grief support specific to parents who made decision to remove life support  
- Need for community-based bereavement services  
  - Returning to hospital for bereavement services at hospital of loss very difficult. Consider alternative locations/entrances |
| Safe Sleep | - co-sleeping present in many cases  
- Need for safe sleep education and better understanding of safe sleep decision – making by parents and care takers  
- Need for safe sleep messages and outreach  
  - (Generate Health standing recommendation to SIDS Resources) |
| Diabetes | - Lack of referrals to diabetes educators for moms with gestational diabetes  
- Internists are not addressing reproductive planning – during preconception/interconception care periods  
  - Glucose management during preconception, pregnancy, and postpartum (for Type 1, 2, and gestational)  
- Losing diabetic educators and nutritionists in hospitals  
- Lack of coordination and follow up, especially for women with gestational diabetes  
- Need for improved perinatal diabetes coordination  
  - Reimbursement for services (moms with gestational diabetes who have lost prenatal insurance coverage after baby is born)  
  - Availability of health care personnel for health education & case management |
| Transportation | - Women on Medicaid can use Non-Emergency Medical Transportation (NEMT) at no cost, but must be scheduled \textbf{five} days in advance  
  - No options when a health concern arises  
  - Women report that free transportation often arrives late or not at all  
- Need for improved options for transportation to hospital from prenatal care site based on current medical need  
- Need for updated EMS protocol for pregnant women.  
- Current EMS protocol dictates transport to nearest hospital – even if it does not have perinatal services and does not deliver babies |
| Care Coordination/Continuity of Care | - Issues regarding of continuity of care during the prenatal period have been identified based on pregnant women making multiple visits to multiple emergency rooms during the prenatal period with no follow-up to her prenatal or primary care physician regarding the visit, medical condition, outcomes and serves provided by the emergency room staff.  
- Need for improved communication on behalf of ER and prenatal care providers |
<table>
<thead>
<tr>
<th>Care Coordination/Continuity of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Late entry into prenatal care</td>
</tr>
<tr>
<td>• Missed prenatal appointments</td>
</tr>
<tr>
<td>• Clients complain of long waits in clinics and they do not stay to be serviced</td>
</tr>
<tr>
<td>• Additionally, the CRT would like to see assurance that pregnant women were given referrals to address health issues such as smoking and drug use during pregnancy. While services may be available in the community, there seems to be a disconnect between those who need them and their accessing the services</td>
</tr>
<tr>
<td>➔ Need for appropriate referrals</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Prenatal Triage</th>
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</thead>
<tbody>
<tr>
<td>➔ Need for discussion regarding the process of providing clear medical advice and information to patients during prenatal phone triage</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care Coordination</th>
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</thead>
<tbody>
<tr>
<td>➔ Need for improved care coordination for patients with inadequate prenatal care – follow up and case management</td>
</tr>
<tr>
<td>o Case management is not reimbursable</td>
</tr>
<tr>
<td>• Among different sites/providers, especially on holidays:</td>
</tr>
<tr>
<td>o Impact of Christmas holiday and lack of 24/7 care coordination on outcome for baby born with congenital anomalies. Treating physician sent to ER on 12/24. Infant sent home from ER same day. Infant rushed back to ER and died 12/25</td>
</tr>
<tr>
<td>• Need to make follow-up appointment for pediatric and OB before leaving hospital –</td>
</tr>
<tr>
<td>o (CC addition: difficult without knowing schedule. Rescheduling appointments from home can also be a major challenge and inconvenience)</td>
</tr>
<tr>
<td>➔ Discharge planning – need for discussion regarding support measures and parent-guardian education for discharge of high-needs infant from NICU</td>
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<table>
<thead>
<tr>
<th>Postpartum</th>
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<tbody>
<tr>
<td>➔ Need for improved follow up at six-week postpartum visit</td>
</tr>
<tr>
<td>o Diabetes management</td>
</tr>
<tr>
<td>o Family planning (preconception/interconception counseling)</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Communication among providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Information from ER/triage not getting back to primary care physician</td>
</tr>
<tr>
<td>• Multiple providers – difficulty for parent decision-making due to conflicting messages between providers/specialists</td>
</tr>
<tr>
<td>• Provider awareness of treating even other healthcare practitioners as patients rather than peers</td>
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<table>
<thead>
<tr>
<th>Documentation:</th>
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</thead>
<tbody>
<tr>
<td>• Gaps in CRT knowledge of content of prenatal care and communication between prenatal care provider and hospital</td>
</tr>
<tr>
<td><strong>Psychosocial Assessments</strong></td>
</tr>
<tr>
<td>-----------------------------</td>
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<thead>
<tr>
<th><strong>Substance Abuse</strong></th>
<th><strong>Tobacco</strong></th>
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<tbody>
<tr>
<td></td>
<td>• A medical record may indicate that a pregnant woman or mother smokes, but there is no assurance from the record that the woman was counseled on the dangers of smoking, and/or referred to cessation classes in the community.</td>
</tr>
<tr>
<td></td>
<td>• The CRT felt that determining the availability of smoking cessation resources for pregnant women in the community depends on community awareness of such services in addition to assurance that resources would be utilized</td>
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<thead>
<tr>
<th><strong>Illicit drug use</strong></th>
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<tbody>
<tr>
<td>• Cocaine exposure</td>
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<tr>
<td>• Universal drug testing?</td>
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<thead>
<tr>
<th><strong>Pathology Reporting</strong></th>
<th><strong>Placental Pathology</strong></th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• Documentation is not being found in medical records to substantiate whether placenta pathology was ordered, conducted, and outcomes of results. Placental pathology results are beneficial when abstracting medical records and reviewing FIMR case summaries. Currently, guidelines for visual inspection of the placenta by a pathologist and further histological examination vary by hospital.</td>
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<tr>
<th><strong>Autopsy</strong></th>
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<tbody>
<tr>
<td>• An autopsy is a very useful tool to the Case Review Team in determining the physical factors related to fetal and infant death. However, they should not be performed unless it is the wishes of the family. The CRT would like assurance that families are made aware of the option of having an autopsy performed and that the offer/request is documented in the medical chart.</td>
</tr>
<tr>
<td>• If an autopsy is performed, the finding should be shared with the family and the mother’s primary care provider. These actions should be documented in the medical record.</td>
</tr>
<tr>
<td>• The offering of an autopsy may vary by where the death occurs and the measures taken to assure that it is offered in all circumstances, i.e., home, emergency room, deliver room, etc.</td>
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<table>
<thead>
<tr>
<th><strong>Communication</strong></th>
<th><strong>Need for improved communication and reporting of results (as well as implications for future pregnancies) between pathology and OB.</strong></th>
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<tbody>
<tr>
<td></td>
<td>• Poor understanding of results and relevance to future pregnancies.</td>
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<tr>
<th><strong>Social Services</strong></th>
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<tbody>
<tr>
<td>• The issue is whether professionals who provide services and education for mothers provide the right and consistent message. An example is a home visiting nurse who informs the mother about <em>Back to Sleep</em>, yet places the baby back into the crib face down. Reinforcement of these issues can help the mother in future pregnancies</td>
</tr>
<tr>
<td>• The issue is whether the appropriate professional staff is providing the services to the mothers or pregnant woman. For example, is the social</td>
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</table>
assessment being conducted by a social worker, nurse or physician? Was the person providing the service competent and qualified for the task? Did the individual providing the service document their name and credentials?

- **Substance abuse** – need for discussion regarding the limited action that Child Protective Services takes with parents who use marijuana
- **Case worker home visits** – need for improved continuity of care to eliminate need for multiple visits by different case workers following an unexpected death

### Cultural Competency

- Communication/language barriers – lack of available interpreters, especially for certain specific dialects
- Cultural beliefs regarding pregnancy and health
- Catholic beliefs regarding life
- Concern regarding citizen status
- Provider perception of patient based on race/employment status

### Relationship with Provider

- Medicaid clients feel they are treated harshly and differently than private pay
  - Experience disrespectful doctors and poor bedside manner due to their poverty
- Women did not know they could request another doctor at the clinic (opt to use ER rather than schedule regular appointments)

### NEED FOR IMPROVED: DETAILS

<table>
<thead>
<tr>
<th>Referrals, counseling, and follow up</th>
<th>Need for referrals, counseling, and follow up for:</th>
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<tbody>
<tr>
<td></td>
<td>• Mental health</td>
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<td></td>
<td>• Drug use</td>
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<tr>
<td></td>
<td>• STIs</td>
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<tr>
<td></td>
<td>• Smoking cessation</td>
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<td></td>
<td>• Preconception care/ counseling</td>
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<td></td>
<td>• Abuse screening</td>
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<td></td>
<td>• Genetics → Need for consistent genetics follow up post delivery</td>
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<td></td>
<td>• Dietician</td>
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<td></td>
<td>• Celiac disease – for referral and thorough assessment by dietician even if well-controlled</td>
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<td></td>
<td>• Diabetes educator</td>
</tr>
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<td></td>
<td>• HIV</td>
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<thead>
<tr>
<th>Education</th>
<th>Critical information not provided:</th>
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<tbody>
<tr>
<td></td>
<td>• Birth control (and broader family planning education)</td>
</tr>
<tr>
<td></td>
<td>• Genetic counseling</td>
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<tr>
<td></td>
<td>• Weight management</td>
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</tbody>
</table>
- Smoking cessation
- Pre/inter-conception care for future pregnancies
- Fetal movement
- Safe sleep (including co-sleeping environment education for all family members and caretakers)
- Nutrition counseling
- Early prenatal care
- Seeking care with accidents, injuries, falls

<table>
<thead>
<tr>
<th>Documentation</th>
<th>Pathology</th>
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<tbody>
<tr>
<td></td>
<td>Record of placental pathology and/or autopsy orders/results frequently missing from medical record</td>
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<thead>
<tr>
<th>Prenatal Records</th>
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<tbody>
<tr>
<td>Prenatal records are in paper form and not readily available in electronic format, difficult to access</td>
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</tbody>
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<thead>
<tr>
<th>Communication among providers</th>
<th>Pathology reporting</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>➔ need for improved communication and reporting of placental pathology and autopsy results between pathology and OB/prenatal providers/primary care providers. Poor understanding of results and relevance to future pregnancies.</td>
</tr>
<tr>
<td></td>
<td>➔ Need for improved care coordination between providers and health care sites (information from ER/triage/hospitalization to prenatal care provider in a timely manner)</td>
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</table>