Franklin County
Fetal-Infant Mortality Review (FIMR)

Case Review Team Findings: Year Two

(January – December 2016)

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EXECUTIVE SUMMARY

Columbus Public Health (CPH) established the Franklin County Fetal-Infant Mortality Review (FIMR) Program in January 2014. At its core, FIMR is an evidenced-based continuous quality improvement process. The process starts with the detailed review of de-identified cases of fetal and infant death by a multidisciplinary Case Review Team (CRT). This group examines the significant social, economic, cultural, safety and health systems' factors associated with fetal and infant mortality, and proposes recommendations to support optimal birth outcomes. On an annual basis, the CRT shares its observations with a Community Action Team (CAT) which then determines how best to address barriers to care and gaps in service delivery and to "create social and physical environments that promote good health for all."[1]

Between January and December 2016, the CRT met monthly to review a total of 48 cases (29 fetal, 19 infant). Of these 48 cases, 26 included a full family interview and one included an abbreviated interview. The Franklin County FIMR CRT included experts from a variety of fields, including family violence, father involvement, grief support, housing, maternal mental health, neonatology, nutrition, obstetrics, perinatal home visiting, public health and social services. On average, the CRT spent 30-60 minutes discussing the themes and needs of each case. By design, cases with known risks were prioritized so we could learn more about our community's service system gaps.

Based on this detailed review, several themes emerged. For example, the CRT noted a lack of assessment of basic social determinants of health across client records. If a woman is not assessed whether she has food, housing or transportation, a woman cannot be assisted in meeting these basic needs and reducing her associated stressors. Further, the community will not grasp the scope of women's needs and will not be able to assess the community's capacity to meet them. The FIMR CAT should consider this trend, as well as the following recommendations, for future program planning and action.

PRECONCEPTON

- *Promote access to and use of effective birth control to avoid unintended pregnancy*

PREGNANCY

- *Conduct ongoing holistic assessment of pregnant women*
  - *Trauma history*
  - *Substance use*
  - *Mental health*
  - *Cognitive ability & health literacy*
- *Repeatedly assess pregnant women's nonmedical needs*
  - *Housing*
  - *Transportation*
  - *Hunger, income, employment*
- *Layer supports for pregnant women living with multiple stressors*
  - *Perinatal home visiting*
  - *Outreach to women not accessing prenatal care*
  - *After-hours care for pregnant women*
  - *Outreach to women using drugs*
- *Standardize fetal "kick-count" education*
- *Discuss postpartum birth control (PPBC) options, including the opportunity for tubal ligation, by the 24th week in pregnancy*

POSTPARTUM/INTERCONCEPTION

- *Assess women's family planning goals and offer PPBC, including long-acting reversible contraceptives (LARC), prior to delivery discharge*
- *Schedule postpartum follow up appointment prior to hospital discharge*
- *Assist opiate positive women to connect with treatment prior to discharge*
- *Develop more robust grief supports and engage families in grief support programming*
- *Educate families about the purpose, limitations and funding of autopsy*

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THE PROBLEM

Infant mortality — or the death of a baby before his or her first birthday — is a critical indicator of community health. Every year in Franklin County, approximately 150 babies die before their first birthdays. Fetal death — or the death of a fetus at any time during pregnancy — is not included in these infant mortality numbers. On average, there are 130 fetal deaths reported in Franklin County each year. With the average annual loss of 280 fetuses and infants,[2] people across our community are asking *why*.

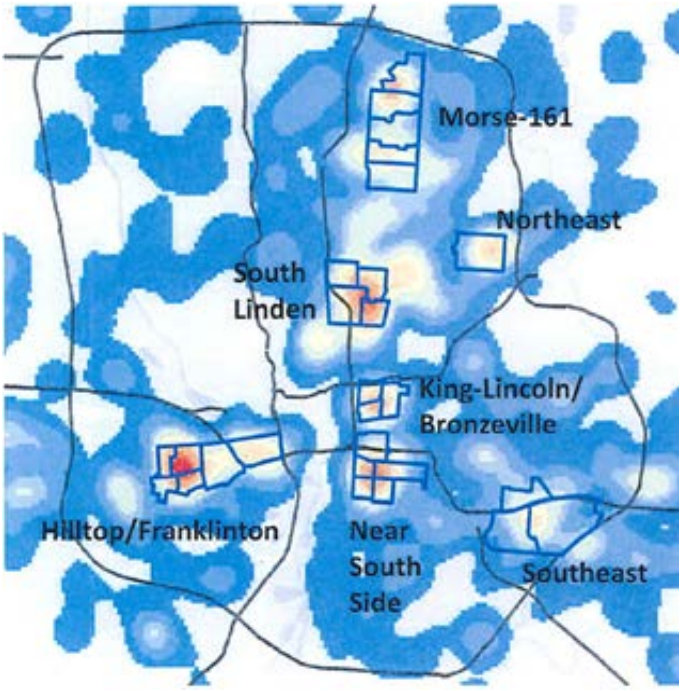
More than Just a Medical Issue

There is no single reason why some infants live to see their first birthday while others do not, nor is there an easy means of combatting this problem. However, research indicates solutions for reducing fetal and infant mortality and eliminating the disparities which exist in these outcomes must transcend individuals' characteristics and behaviors. A community's assets and liabilities, including its transportation systems, availability of affordable housing, and access to healthy foods and health care, among other items can either help "protect" women from adverse pregnancy outcomes or increase their "risk" of experiencing them.[3]

Where You Live Matters

Researchers have found that these assets and liabilities, along with the conditions in which people are born, live, learn, work, play and age — otherwise referred to as the social determinants of health — have a significant impact on health outcomes. Health is not something that happens solely in a medical setting. Health is in the air people breathe, the water they drink and the places they live.

***Figure 1*: Columbus Infant Mortality 'Hotspots'**



Franklin County has neighborhoods where homelessness, poor access to nutritious foods, higher rates of crime and unemployment, lower rates of graduation, limited access to health coverage, and late entry into prenatal care contribute to fetal demise, to babies being born too small or too soon, and to infants failing to thrive during their first year of life. Eight areas in Franklin County with the highest rates of infant mortality are deemed infant mortality high-priority neighborhoods. (Each one is exhibited in the map in **Figure 1**.)

CelebrateOne, a collective impact initiative established to improve birth outcomes and reduce disparities in infant mortality, believes that zip codes should not be a determinant of health. As CelebrateOne works with community leaders, residents and industries to enhance neighborhood social and economic conditions, FIMR has chosen to prioritize cases from the eight high-priority areas highlighted in Figure 1 to enhance the understanding of the life experiences of resident mothers, fathers and families affected by loss in these areas.[4]

THE FIMR MODEL

Columbus Public Health (CPH) established the Franklin County Fetal-Infant Mortality Review (FIMR) Program in January 2014. This program is patterned on an evidence-based model originally developed by the National FIMR (NFIMR) Program — a collaborative effort between the American College of Obstetricians and Gynecologists (ACOG) and the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration. NFIMR has since transitioned to the National Center for Fatality Review & Prevention (NCFRP). At its core, FIMR is a continuous quality improvement process. The process starts with a detailed review of de-identified cases of fetal and infant death by a multidisciplinary Case Review Team (CRT). This group examines the significant social, economic, cultural, safety and health systems' factors associated with fetal and infant mortality and proposes recommendations to support optimal pregnancy outcomes. On an annual basis, the CRT shares its observations with a Community Action Team (CAT) which then determines how best to address barriers to care, gaps in service delivery and other unmet needs.

Columbus Public Health oversees multiple fetal, infant and child death review processes in Franklin County. FIMR, however, is unique in exploring the qualitative (versus quantitative) nature of fetal and infant death, and in deeply exploring a well-defined subset of fetal and infant deaths (verses broadly describing the circumstances of all fetal and infant deaths in the county). In year one, FIMR reported on a total of 30 cases reviewed over the program's first 15 months. In year two, FIMR's themes and recommendations emerged from the review of 48 cases between January and December 2016. For more information about the differences between FIMR and other child death review models, see Appendix A.

CASE SELECTION PROCESS

Perinatal Periods of Risk (PPOR)[5]

Perinatal Periods of Risk (PPOR) is a comprehensive approach designed to help urban communities across the U.S. use local data to reduce fetal and infant mortality. The initial analysis divides fetal and infant deaths into four "Perinatal Periods of Risk" based on birth weight and age at death (**Figure 2**). Because causes of death tend to be similar in each period, when a community finds that its problems lie in only one or two periods of risk, efforts can be focused on those periods. A mortality rate is calculated for each period to allow for comparisons of populations within and between jurisdictions and to examine temporal trends in fetal and infant death.

PPOR analyses build data capacity, promotes evidence-based decision making, strengthens partnerships, helps leverage resources and enables systems changes. Urban communities across the U.S., including Columbus, use PPOR as a way to monitor progress in fetal and infant mortality reduction, to guide public health planning and to prioritize prevention activities, including FIMR case selection.

Figure 2: Perinatal Periods of Risk (PPOR) Model

Age at Death

Birth Weight	**Fetal** ≥24 Weeks Gestation	**Neonatal** 0-27 Days	**Post-Neonatal** 28-364 Days
500 – 1499 grams	**Maternal Health/Prematurity** Chronic Disease Prevention Health Behavior Change Perinatal Care		
≥1500 grams	**Maternal Care** Prenatal Care High Risk Referral Obstetric Care	**Newborn Care** Perinatal Management Neonatal Care Pediatric Surgery	**Infant Health** Safe Sleep Injury Prevention Infection Prevention

AVAILABLE DATA

In 2016, Franklin County FIMR selected cases based on data found on documents produced by the Office of Vital Statistics. Infant information is reported on the "Birth Summary" and "Certificate of Death." Information for fetal deaths ≥20 weeks gestation is reported on the "Report of Fetal Death." Since families are not required to complete the "Report of Fetal Death" on fetal deaths which occur before 20 weeks gestation, FIMR has limited information about these earlier losses.

Guided by PPOR analyses, the CelebrateOne high-priority neighborhoods and vital statistics information, the Franklin County FIMR selected cases which fell into both of the following categories to review in depth. By design, cases with known risk factors were prioritized for the purpose of learning more about service system gaps within the community. Two additional bereaved families who did not meet case selection criteria asked to participate in a FIMR interview. FIMR abstracted these cases and brought them to the CRT for review as well.

Deaths from one of two PPOR categories

- "Maternal Health/Prematurity" (blue box)
  - Fetal death: 500-1499 grams at birth & ≥24 weeks gestation at death
  - Infant death: 500-1499 grams at birth & no minimum gestational age
- "Maternal Care" (pink box)
  - Fetal death: ≥1500 grams at birth & ≥24 weeks gestation at death

AND, with 3 or more maternal risk factors as reported by the Office of Vital Statistics

- Unmarried
- Less than a high school education/GED
- Birth spacing of less than 18 months
- Previous preterm birth
- Previous poor birth outcome
- Smoked within 3 months of pregnancy or while pregnant
- Teenager (<20 years of age at time of birth)
- Obesity pre-pregnancy (BMI ≥30)
- Enrolled in Women, Infants and Children (WIC) Food and Nutrition Service Program
- Non-Hispanic Black/African American
- Lived in a CelebrateOne high-priority neighborhood
  - Franklinton (43223, 43222), Hilltop (43204), Morse Rd/161 (43229, 43224), Near East (i.e., King-Lincoln/Bronzeville) (43203), Near South (43205, 43206), Northeast (43219), Linden (43211), Southeast (43232, 43227)

FAMILY INTERVIEW

Since the family's voice adds vital insight to each case, the Franklin County FIMR conducted extensive outreach to those affected by fetal or infant loss. Across the country, about half of all FIMRs seek family interviews as part of their case abstraction process. Among these programs, one-third of reviewed cases typically include a family interview.[6] However, of the 48 cases Franklin County FIMR reviewed in year two, 56% included an interview, 23% declined to participate and 21% were unresponsive. FIMR is grateful for the reflections shared by families who participate in the FIMR interview. They illustrate how significantly the social determinants of health can affect birth outcomes.

CASE PREPARATION

Once cases were selected, the FIMR staff abstracted all available medical and social service records. FIMR has a Memorandum of Understanding (MOU) with *Mount Carmel Health Systems*, *Nationwide Children's Hospital*, *OhioHealth*, *The Ohio State University Wexner Medical Center* and *PrimaryOne Health* which promotes medical records sharing with FIMR. If a family received care from a provider outside of these health systems, FIMR attempted to obtain a "Release of Information" (ROI) from the family to review those records. Whenever applicable, FIMR received a summary from Franklin County Children Services outlining a family's involvement as a perpetrator or victim of violence. Records from the Ohio Department of Rehabilitation and Correction and the Franklin County Municipal Court also were reviewed to learn about any legal matters, including outstanding warrants and family incarceration history. If the family had contact with CPH's Home Visiting, Perinatal Hepatitis B or WIC programs, those records were also reviewed.

FIMR integrated the information from the medical records with the details gathered from the family interview, and then de-identified all abstracted information related to the family, decedent, providers and facilities. Finalized de-identified abstracts were shared via secure server with the CRT approximately one week before cases were formally reviewed.

CASE REVIEW TEAM (CRT)

The success of the FIMR process is directly linked to the active participation of the CRT. Members have expertise in a variety of areas related to maternal and child health including, but not limited to, family violence, father involvement, grief support, housing, maternal mental health, neonatology, nutrition, obstetrics, perinatal home visiting, public health and social services. A full list of active 2016 CRT members is available in Appendix B.

The CRT is a closed team that meets monthly. It typically reviews three cases at each two hour meeting. Starting in 2016, the CRT split into two smaller teams once per quarter to review six cases instead of the usual three. The CRT discussed each of the 48 abstracted cases for 30-60 minutes, identified each case's characteristics using a detailed list of present and contributing factor codes adapted from NFIMR's "Present & Contributing Variables" document (see Appendix C), and prioritized which variables seemed most influential in the outcome of the case. The group discussion and these codes became the basis of the FIMR findings and recommendations.

COMMUNITY ACTION TEAM (CAT)

FIMR presents its findings on an annual basis to its CAT. In year one, the CAT included the CelebrateOne Executive Committee, representatives of the Lead Entities and select others. In year two, CelebrateOne will invite a broader group of community stakeholders into the process so that insights gained from FIMR are more widely shared and acted upon.

PROFILE OF CASES REVIEWED

FIMR seeks to review all cases which meet selection criteria within a year of the death. Of the 48 cases reviewed in 2016, eight deaths occurred at the end of 2014, 30 in 2015 and 10 in 2016. FIMR aims to review cases within one year of death and on average the program was able to meet this goal. Delays in reviewing cases were due to the time it takes to obtain all available medical records, to outreach for family interviews, and to review backlogged cases.

Causes of death, as reported by vital statistics and compiled by FIMR, included:

- Prematurity and its sequelae (10 cases)
- Congenital anomalies such anencephaly, renal agenesis, hydrops, etc. (10 cases)
- Maternal complications such as diabetes, hypertension, obesity, etc. (9 cases)
- Intrauterine growth restriction (2 cases)
- Maternal substance use (2 cases)
- Other causes (2 cases)
- Unknown (13 cases)

Note: Leading causes of Franklin County infant deaths, as reported by vital statistics, for years 2012-2016 are available in Appendix D.

Table 1 presents a summary of the cases' fetal/infant characteristics. **Table 2** presents a summary of maternal characteristics.

Table 1: Fetal/Infant Characteristics of FIMR Cases Reviewed in 2016

Fetal/Infant Characteristic	% FIMR Fetal Deaths N=29	% FIMR Infant Deaths N=19	% Total FIMR Cases N=48	% Total Franklin County Deaths* N=286
Sex of Fetus/Infant				
Male	48.3	57.9	52.1	48.3
Female	51.7	42.1	47.9	48.6
Unknown	--	--	--	3.1
Plurality				
Singleton	96.6	89.5	93.8	86.4
Multiple Gestations	3.4	10.5	6.3	8.0
Unknown	--	--	--	5.6
Gestational Age (weeks)				
Extremely preterm (<28)	27.6	47.4	35.4	53.5
Very preterm (28 to <32)	27.6	26.3	27.1	9.1
Moderate/Late preterm (32 to <37)	20.7	26.3	22.9	12.9
Term (≥37)	24.1	0.0	14.6	21.3
Unknown	--	--	--	3.1
Birth Weight (grams)				
Extremely low birth weight (<1000)	37.9	47.4	41.7	45.1
Very low birth weight (1000-1499)	13.8	52.6	29.2	8.7
Low birth weight (1500-2499)	31.0	0.0	18.8	14.3
Normal birth weight (2500-3999)	13.8	0.0	8.3	17.1
High birth weight (≥4000)	3.4	0.0	2.1	2.1
Unknown	--	--	--	12.6
Congenital Anomaly†				
Present	10.3	47.4	25.0	11.5
Absent	89.7	52.6	75.0	71.0
Unknown	--	--	--	17.5

* Data for Franklin County include fetal & infant deaths for year 2015 only. FIMR cases reviewed in 2016 include deaths from years 2014-2016.
† Refers to the presence or absence of any anomaly, including those incompatible with life
Data Source: Vital Statistics, manually entered into FIMR database; analyzed by Office of Epidemiology

Table 2: Maternal Characteristics of FIMR Cases Reviewed in 2016

Maternal Characteristic	% FIMR Fetal Deaths N=29	% FIMR Infant Deaths N=19	% Total FIMR Cases N=48	% Total Franklin County Deaths* N=286
Race/Ethnicity				
Non-Hispanic White	24.1	52.6	35.4	35.0
Non-Hispanic Black/African American	51.7	47.4	50.0	40.2
Non-Hispanic Other	10.3	--	6.3	9.1
Hispanic/Latino	13.8	--	8.3	8.4
Unknown	--	--	--	7.3
Country of Origin				
U.S.-Born	69.0	84.2	75.0	72.7
Foreign-Born	27.6	15.8	22.9	21.3
Unknown	3.4	--	2.1	5.9
Age Group				
<20	10.3	21.1	14.6	8.4
20-24	13.8	10.5	12.5	22.4
25-29	34.5	26.3	31.3	22.4
30-34	24.1	26.3	25.0	29.7
≥35	17.2	15.8	16.7	16.8
Unknown	--	--	--	0.3
Education				
≤Grade 8	20.7	15.8	18.8	6.3
Grade 9-12, no diploma	34.5	31.6	33.3	15.0
High School/GED	17.2	26.3	20.8	21.0
Some College	13.8	15.8	14.6	19.2
Associates Degree	6.9	10.5	8.3	8.0
Bachelors, Masters or Professional Degree	3.4	--	2.1	22.0
Unknown	3.4	--	2.1	8.4
Pre-Pregnancy Weight				
Underweight (BMI <18.5)	3.4	5.3	4.2	2.8
Normal Weight (BMI 18.5-24.9)	27.6	10.5	20.8	32.2
Overweight (BMI 25.0-29.9)	10.3	36.8	16.7	21.7
Obese (BMI ≥30)	55.2	42.1	54.2	26.9
Unknown	3.4	5.3	4.2	16.4
Marital Status				
Married	24.1	15.8	20.8	40.9
Unmarried†	75.9	84.2	79.2	53.1
Unknown	--	--	--	5.9
Entry into Prenatal Care				
1st trimester (0-13 weeks GA)	65.5	63.2	64.6	54.5
2nd trimester (14-26 weeks GA)	6.9	21.1	12.5	12.6
3rd trimester (27-40 weeks GA)	3.4	--	2.1	2.8
No prenatal care	13.8	--	8.3	7.0
Unknown	10.3	15.8	12.5	23.1
Primary Method of Payment for Delivery				
Private Insurance	17.2	26.3	20.8	20.6
Medicare	--	--	--	1.4
Medicaid	72.4	73.7	72.9	19.9
Self-Pay/Indigent	10.3	--	6.3	4.2
Unknown	--	--	--	53.8
Other Characteristics				
First Pregnancy	10.3	26.3	16.7	17.5
Previous preterm birth‡	20.8	26.7	23.1	12.0
Previous poor birth outcome‡	16.0	13.3	15.0	7.2
Birth spacing <18 months‡	44.0	61.5	50.0	35.3
Smoked during/within 3 mo. of pregnancy	41.4	42.1	41.7	24.3
Enrolled in WIC with this pregnancy	55.2	63.2	60.0	29.3
Resident of CelebrateOne neighborhood	72.4	57.9	66.7	41.6

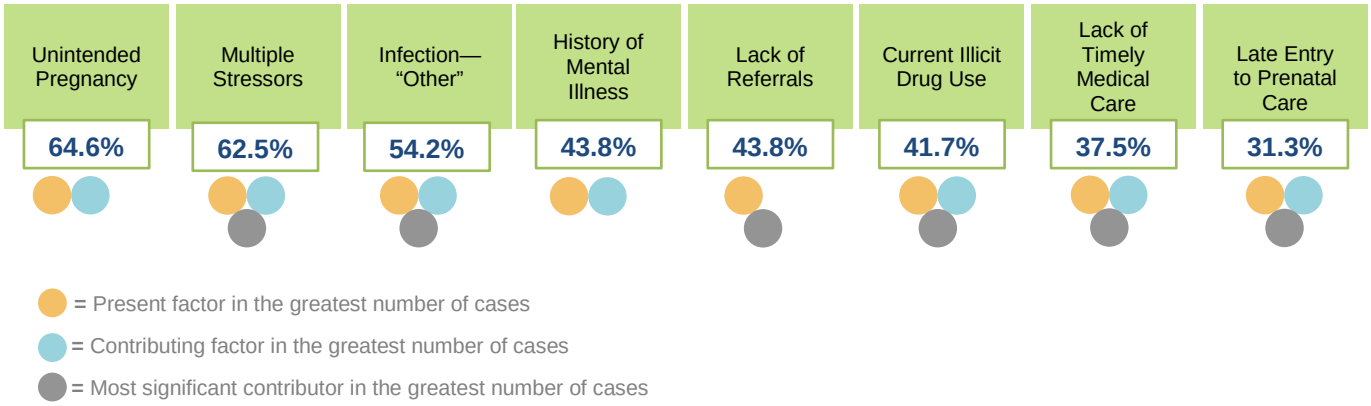
* Data for Franklin County include fetal & infant deaths for year 2015 only. FIMR cases reviewed in 2016 include deaths from years 2014-2016.
† Unmarried includes single (never married), divorced and widowed women
‡ Proportions exclude those with first pregnancies and unknown previous outcomes
Data Source: Vital Statistics, manually entered into FIMR database; analyzed by Office of Epidemiology

FINDINGS & RECOMMENDATIONS

To analyze case findings, factors from the detailed list of present and contributing factor codes — adapted from NFIMR's "Present & Contributing Variables" document (Appendix C) — were prioritized according to the following: 1) the factor was present in the greatest number of cases; 2) the CRT considered the variable to be a contributing factor in the greatest number of cases; and 3) the CRT deemed the factor to be one of the most significant contributors in the greatest number of cases. **Figure 3** highlights the factors that fall into at least two of these three categories. Boxed percentages represent the proportion of cases affected by these factors.

Information and themes identified through family interviews and CRT discussions were reviewed to understand how these variables related to women's real-world experiences with conception, pregnancy, delivery and loss. The CRT's recommendations are based on these findings and are organized in the following sections according to the preconception, pregnancy and postpartum/interconception periods. Though most recommendations center on changes in provider behavior and agency workflow, there could also be implications for interagency collaboration, legislation and patient behavior change.

Figure 3: Significant Present & Contributing Factors to Fetal/Infant Demise



PRECONCEPTION

PROMOTE ACCESS TO AND USE OF EFFECTIVE BIRTH CONTROL TO AVOID UNINTENDED PREGNANCY

> *"I had used the pill in the past but stopped taking it because I wasn't keeping up with it. I found out I was pregnant when I was about five weeks along. When I told my boyfriend [a 28-year-old man]… he told me, 'I don't want you to abort my baby. I want us to have this baby.' But when I first got the news I was shocked. I didn't know what I was gonna do. After a couple of days, I decided to keep the baby… to have him. I had to think about it though… if I was ready. It wasn't my plan, but [the father] wanted it and my mom is TOTALLY against abortion, so I decided to keep the baby."* — 18-year-old mother

Of the 48 cases FIMR reviewed, seven pregnancies (14.6%) were known to be intended and 31 (64.6%) were known to be unintended. Data on pregnancy intention was not available for 10 (20.8%) cases. Of the 31 pregnancies indicated as unintended, 12 (38.7%) were also known to be undesired and 14 (45.2%) were preceded by a short interpregnancy interval (<18 months). Given that Healthy People 2020 aims to increase the proportion of intended pregnancies to 56% and that unintended pregnancy is associated with a greater risk of health and social issues for mom and baby,[7] the CRT viewed access to family planning methods and education as a major need among the cases reviewed.

Family planning may prove particularly important for special populations such as opiate-addicted women and adolescents. Of the eight women who tested positive for opiates in pregnancy, only one reported that she had planned the pregnancy. Five reported the pregnancy as unintended. Pregnancy intention was unknown in the remaining two cases. Further, three of the four women who received no prenatal care were also using

opiates. Since opiate-using women were more likely than the majority group to experience both an unintended pregnancy and no prenatal care, these women may benefit by postponing pregnancy until they have addressed their addiction needs.

Family planning outreach is also important for young women. One-third of the cases reviewed were to women whose first pregnancy (which was not necessarily the pregnancy with the decedent) had occurred when she was 18 years of age or younger. Seven of the 48 reviewed cases had mothers who were teenagers (≤19 years old) at the time they conceived the decedent. Eight cases in the sample were first pregnancies. Of these, six losses were to young women between the ages of 17 and 21 years old. All six of these first pregnancies were unplanned.

FIMR recognizes that women need effective birth control to have planned, healthy pregnancies and optimal birth outcomes. Partnering with non-traditional providers may help families meet their family planning goals. Potential partners include harm reduction programs to assess family planning needs of substance-using women, pharmacists to administer Depo-Provera outside the traditional OB/GYN setting,[8] and mobile medical units to meet women's family planning needs within their own communities.

PREGNANCY

CONDUCT ONGOING HOLISTIC ASSESSMENT OF PREGNANT WOMEN

Since the CRT noted a lack of assessment of basic social determinants of health across client records, they thought the first step to meeting women's basic needs was to increase assessment in four key areas: trauma history, tobacco/drug use, mental health and comprehension. If a need is identified, pregnant women and families must be referred to the appropriate support services. However, if the community lacks the capacity to address the needs of pregnant women and families, capacity issues must also be addressed.

A) Trauma History

> *"We were poor. My mom died when I was 12 and me and my [10-year-old] brother had to move in with my dad. He didn't do much. He had a different woman every week moving in and moving out. I took care of my brother; he's blind and mentally retarded. He has cerebral palsy… Then we moved in with my grandma (maternal grandmother)… I was in the special [education] classes in school. I don't think I had the attention span for school. I was too busy thinking about what was going on outside school. Also, I was bullied about my weight… I did 12th grade two times, but I dropped out… I got pregnant when I was 21… but I left [my boyfriend] when I was four months pregnant… he tried to choke me and punch me. He tried to kill me and the baby… My son [now 7-years-old] lives with my grandma who raised me. I asked her to keep him stable-like… he knows I'm his mother. I see him, but he lives there… His father committed suicide last year."* — 28-year-old mother

Twenty-six of the 48 mothers were noted to have a "life-course factor" in her history. Factors included:

- Being a victim of past physical, sexual or verbal abuse (15 women)
- Experiencing childhood neglect (9 women)
- Growing up in extreme poverty (8 women)
- Having a history of childhood homelessness (7 women)
- Being in foster care as a child (6 women)
- Displacement to a refugee camp as a child (4 women)

Most women reported these events were traumatic, leaving them feeling vulnerable, angry or hyper-vigilant. However, these experiences were rarely documented by providers. On occasion, these disclosures emerged at a time of crisis when a mother met with a social worker who documented her struggles, but generally they were not part of the medical record and were revealed during the FIMR interview. This suggests that families like those reviewed by FIMR underreport traumatic life course factors.

When trauma was assessed, providers tended to focus on the trauma of current exposure to domestic violence. Women in 44 of the 48 cases reviewed by FIMR were asked about current violence at least once during their pregnancies; 8% of these assessments were completed during their prenatal care appointments, 22% during ER visits and 58% during delivery. Three of the 48 women reported abuse to their provider while pregnant with the decedent, though the FIMR interview identified five additional women who actually experienced abuse during their pregnancies with the decedent (four women denied being abused when assessed by providers; one woman was never documented as being assessed for domestic violence).

FIMR recommends assessing all women for a history of trauma and screening women for domestic violence at every visit regardless of whether previous safety assessments have been negative. Further, providers should offer education and referral for support services as needed.

B) Substance Use

> *"[Using drugs] made me feel normal and happy growing up… [and] helped me cope with my abuse. I [drank alcohol] because I was tired of how I was feeling … I smoked 10-20 cigarettes a day the whole time I was pregnant … I even went to one prenatal care appointment tipsy because I'd been up all night drinking hard lemonade."* — 32-year-old mother

Current and historical tobacco use was a variable or "risk factor" used for case selection: 24 of the losses reviewed by FIMR were to women who smoked in the three months prior to becoming pregnant or during their pregnancy with the decedent. Tobacco use is often self-reported at the time of the first assessment. Subsequent assessment of tobacco use varies by provider. While half of the deaths were to women who smoked cigarettes, only 12 of these women received tobacco cessation education from their prenatal care providers. Eight of the 24 smokers reported decreasing their tobacco use during pregnancy (four of these women received tobacco cessation education and four did not).

Assessment of other drug use is completed with a combination of self-report and drug testing. Of the 48 cases reviewed, 36 women received a drug test at some time in her pregnancy (21 at a prenatal care or ER visit; 25 at delivery) and 18 tested positive. Of the 12 women who received no drug test, two had used substances during the pregnancy (one reported marijuana use and one was arrested on a drug charge) suggesting that drug testing alone does not fully capture women's drug use in pregnancy. In all, 20 women were found to have used at least one type of illicit drug during pregnancy with the decedent, and seven of these women were polysubstance users.

- Marijuana (13 women)
- Opiates (6 women)
- Oxycodone (5 women)
- Cocaine (2 women)
- Benzodiazepines (2 women)
- Methamphetamine (1 woman)
- Barbiturates (1 woman)
- Non-prescribed methadone (1 woman)

Since women who use alcohol in pregnancy often face stigma, it is likely that alcohol use in pregnancy is also underreported. One 19-year-old woman who denied using any substances during her pregnancy — and produced two negative drug tests — revealed in her FIMR interview that she frequently drank to excess while pregnant. She said, "I need to forget things" and "feel like a butterfly and float away."

FIMR recognizes that because of the stigma and underreporting of substance use in pregnancy, women may benefit from comprehensive drug use assessment, non-judgmental cessation education, support in accessing treatment and vigorous follow-up.

C) Mental Health

> *At 20 weeks gestation, [mom] sought care at an ER for abdominal pain, shortness of breath and "not feeling right." ER notes stated "symptoms resolved without treatment." However, the mother refused to leave when discharged saying, "I feel like I wasn't taken care of properly, so I'm not leaving! I'm not signing these [discharge] papers. I'm not leaving. Something's wrong with me!" This mother asked to speak to her doctor's supervisor. He left and returned with two uniformed police officers. They restrained this mother, charged her with "trespassing and resisting at the ER" and jailed her overnight. The ER notes stated, "[the mother] was escorted out of ER in handcuffs, resisting and kicking bedside cart on the way out of room." While jailed, she missed an ultrasound appointment. When she attended the rescheduled appointment, the mother disclosed suicidal ideation. She was referred to the ER but, "she stated that she had been there and did not get the help she needed."* — 19-year-old mother with history of trauma and mental illness

Twenty-one women had a history of at least one mental illness; 16 of these women had two or more mental illnesses. Diagnoses included:

- Depression (18 women)
- Anxiety (10 women)
- Suicidal ideation (6 women)
- Bipolar disorder (5 women)
- Post-traumatic stress disorder (4 women)
- Suicide attempts (4 women)
- Other mood disorders (3 women)
- Panic disorders (2 women)
- Obsessive compulsive disorder (1 woman)
- Borderline personality disorder (1 woman)
- Visual/auditory hallucinations (1 woman)

Of these women, 13 received a referral for mental health treatment while pregnant with the decedent and 10 reported being seen at least one time. However, many of these women did not continue with recommended treatment after the initial appointment. Five of the 21 women with a known mental illness declined needed mental health treatment. The CRT identified 6 additional women who they suspected had an undiagnosed, untreated mental illness.

FIMR review revealed significant unmet and undertreated mental health needs and suggests women would benefit from additional assessment, care coordination and ongoing support.

D) Cognitive Ability & Health Literacy

> *"I really think the insulin had something to do with it, even though I didn't do the autopsy. And I think I should have. But at that time, with everything that was going on, I just wanted everything over. At first, I thought I did it. And I kept saying, 'I think I killed my own baby. I think I killed my own baby 'cause of eating [my diabetic diet] and the way I lay.' Sometimes I lay on my side. You know, I really, seriously think I did it."* — 42-year-old mother

Six women appeared to have limitations that affected their understanding of standard prenatal care education, recommended treatment options, the decedent's prognosis and/or cause of death. In only one case was there a note about a patient's cognitive ability; it stated "patient is mildly retarded." In the remaining cases, there was no notation about the mothers' cognitive abilities or special learning needs, and it was clear the parent and the provider had very different understandings of the course of treatment or the cause of death. This affected the mothers' ability to be fully engaged in their own care while pregnant or the decedents' care before death. Holding on to misinformation affects women's subsequent health status and potential future pregnancies as well. For example, following her son's death, the woman quoted above discontinued all her diabetes and hypertension medicines and became very ill. She blamed the medicines for the demise, so she stopped them. Several other women attributed their children's deaths to standard medicines used in pregnancy, including the Tdap vaccine, the Glucola blood sugar

drink or steroids administered for fetal lung maturity. Each of these women stated they would decline these tests or therapies in the future.

FIMR suggests that asking women how they like to learn at the onset of care may promote better communication between providers and patients. Additionally, asking families to describe their understanding of complex medical information being presented to them may help providers clarify misinformation as it occurs and bolster patients' satisfaction with their care.

REPEATEDLY ASSESS PREGNANT WOMEN'S NON-MEDICAL NEEDS (E.G., HOUSING, TRANSPORTATION AND INCOME)

Families had many non-medical needs that affected their health and ability to engage in medical care, including housing, transportation, hunger, income and employment. When mentioned in the medical records, if at all, these items were often listed on the patient's "face sheet," a single-page biographical summary. Under housing, for example, the face sheet might indicate "apartment" or "lives with 2-year-old." Under employment, it might say "full-time" or "fast food restaurant." While seemingly informative, much of this information was actually out-of-date or incomplete.

A) Housing

> *This mother, the father and three of the mother's children lived together in an $850+/month apartment throughout her pregnancy with the decedent. She reported she "liked the apartment" but said the landlord "wouldn't fix anything." The list of maintenance problems included broken and missing windows, crumbling ceiling, lack of insulation, frozen pipes that burst and a clogged tub drain. She said they had to empty the tub with a bucket for nearly eight months and eventually paid to have it fixed themselves. The mother said she felt comfortable in the neighborhood, but also described it as "full of hookers and junkies."* — 39-year-old mother

Only 18 women had any notation about housing on their "face sheets," in social worker notes or anywhere else in their charts. Of these, 17 were assessed to have stable housing and one woman was listed as "homeless." The remaining 30 cases had no indication of a woman's housing situation. However, after talking with these families, FIMR found 12 women who had significant problems with housing. Nine women struggled with issues, including bug infestations, disconnected utilities for months at a time, lack of kitchen appliances and major safety problems such as leaking bathroom pipes and a collapsed roof. Three additional women disclosed they were homeless at some point in their pregnancies. In addition, 16 women had "frequent or recent moves" immediately before, during or after the pregnancy or while the child was alive.

FIMR recommends all women be repeatedly assessed for stable housing throughout the pregnancy and receive housing supports as needed.

B) Transportation

> *"I probably went to the emergency room 20 times. Mostly I went there because I could get a ride (via ambulance)."* — 19-year-old mother

> *"I didn't try [to schedule rides through my HMO transportation] because my friends said, "They gonna make you wait a long, long time to pick you up.'"* — 18-year-old mother

Transportation was another area where providers lacked useful information about their patients. Twenty-four cases listed a woman's primary method of transportation as "car," "bus," "ride with friend," etc. Of these cases, two women had no means of getting home after delivering the decedent and they were given bus passes at discharge. Two additional women had a method of transport listed on the "face sheet" but reported transportation barriers during the FIMR interview. In these cases, one woman's vehicle was so

unreliable she could not use it and the other woman depended on others for rides, but says they often "refused." The remaining 24 cases had nothing in their charts about transportation. FIMR interviewed 14 of these families and discovered that seven of them had transportation challenges, including a lack of driver's license, vehicle, gas money and car insurance; limited access to a vehicle; and dependence on others for rides. In all, there were 11 women who indicated a transportation difficulty either on their "face sheet" or during the FIMR interview. Of these, nine had insurance through a Medicaid HMO which typically includes a transportation benefit, though only one woman used that benefit. Women cited a number of reasons for not using this benefit, including lack of awareness, limitations to the number of times it can be used, excessive wait times, and limited flexibility for pick up and drop off locations.

FIMR review indicates a need to assess the effectiveness of current transportation services. FIMR recommends all women's transportation needs be repeatedly assessed throughout pregnancy.

C) Hunger, Income, Employment

> *"Stress is just life in general. You always run out of something. Right now we run out of food and we don't get paid 'till Thursday. We're always hitting [food] pantries, but it's hard walking. We got hot dogs frozen now, but that's it (opens the freezer to show how empty it is)." When asked if [mom] is enrolled in WIC for her 4-year-old or for herself she said, "I don't have nowhere to put it. I don't have a fridge for the milk. I only got a freezer. And anyway, I can't get there. I don't even know where the closest one is."* — 28-year-old mother

WIC is the only common measure of socioeconomic status located on both the "Birth Summary" and "Report of Fetal Death." While not all women who qualify for this supplemental nutrition program are enrolled, FIMR identified women who lived at or below 185% of the federal poverty limit by monitoring this variable. In all, 28 of the 48 cases reviewed had mothers enrolled in WIC during their pregnancy with the decedent. Medicaid is another measure of socioeconomic status; 40 women received Medicaid at some point in their pregnancies. In addition, FIMR interviews revealed that 23 families felt "concerned about having enough money" during this pregnancy. Three of these women reported skipping meals to save money, two of which had WIC. Of the 32 women who worked at some point of their pregnancy, 18 reported work problems (e.g., no breaks, scheduling problems, conflicts with boss or co-worker) and five were fired. Again, almost none of this information was in any part of the women's charts. Yet, families reported that their low or unpredictable incomes affected their family stability, access to food, health insurance, prenatal care attendance, stress levels and overall health.

FIMR recommends that women's income be repeatedly assessed and that providers partner with social workers and community organizations to more fully support clients in need.

LAYER SUPPORTS FOR PREGNANT WOMEN LIVING WITH MULTIPLE STRESSORS

> *"I'm tired of my life, period… [My primary stressor is] disappointment in myself. I can barely get [my toddler's] dad to do anything for her and I went and got pregnant with him again. I was just fired because the cook put his hands on me and I pulled a knife ... I'm like a mother to my siblings (aged 18, 16, 13, 11) [I've had] suicidal thoughts for several years now."* — 19-year-old mother

Of the 48 cases reviewed, 30 were identified as having "multiple stressors," and for 12 of these cases, "multiple stressors" was noted as one of the top needs. Stressors included, but were not limited to:

- Social isolation
- Generational poverty
- Poorly managed chronic health conditions
- Domestic violence
- Complicated grief from previous pregnancy/infant loss or losing parental rights of previous children
- Unmet mental health needs

- Unreliable housing
- Job insecurity
- Drug use by parents or other people in the household
- Lack of childcare
- Lack of transportation
- Incarceration

One 26-year-old mother of three said that she felt unsupported and isolated during her pregnancy because her mother provided childcare for the children of her "drug-addicted siblings while they're incarcerated or high, but not for my children when I'm working or caring for [the decedent] in the NICU." This woman, like so many in our sample, juggled competing demands and had a limited social safety net. Despite being smart and hard-working, creative and resilient, she felt like she could never get ahead. Instead, she was forced to navigate from one crisis to the next.

FIMR suggests several ways to layer supports for families like these ones, including bolstering perinatal home visiting, outreach to women not accessing prenatal care, after-hours prenatal care, and outreach to women using drugs.

A) Perinatal Home Visiting

Of all the cases reviewed, FIMR could only find one — a teen mother who self-referred — that had any contact with a perinatal home visiting program. However, the CRT indicated that at least 10 of these families were good candidates for perinatal home visiting support.

B) Outreach to women not accessing prenatal care

Many women from this sample received scant prenatal care and four received no prenatal care at all. Women frequently cited transportation or childcare difficulties and/or feelings of ambivalence about the pregnancy among the reasons for not engaging in prenatal care. One 19-year-old mother indicated she felt unsure about the pregnancy, but entered prenatal care at eight weeks and completed three visits at a private prenatal care clinic. She stopped attending her prenatal care appointments when she decided to terminate the pregnancy. Being unable to afford the abortion, she tried to re-engage her initial prenatal care provider only to learn the clinic had discharged her for "no showing." Ultimately, this mom sought the bulk of her care (eight visits) at the ER before enrolling at a new prenatal care clinic in her third trimester. She only completed one visit there before experiencing the fetal demise. The CRT questioned how this mother's life would have been impacted had she received better support through her pregnancy, how her life trajectory might have changed had she been able to afford the termination she desired, and how the birth outcome might have been improved with consistent prenatal care.

C) After-hours care for pregnant women

Two-thirds of the women in this sample worked during part or all of their pregnancies. Many of these women stated they could not afford to miss work to attend scheduled prenatal care appointments, so they skipped appointments or sought care at the ER instead. In all, 17 cases were coded as having "inappropriate use of the ER." Providing options for care during non-traditional hours may help some of these women improve their prenatal care attendance.

D) Outreach to women using drugs

There was an association between women's drug use and entry into prenatal care (see **Table 3**). Namely, those with current or past substance use were more likely to forgo prenatal care or to establish care later in pregnancy than those who were not substance users. Some of these substance-using women stated the pregnancy was unplanned or unwanted so they postponed care. Others reported their life lacked stability when they were using drugs, so it was difficult to engage in prenatal care. Though not explicit, some women may likely fear the legal repercussions or social stigma of testing positive for illicit drugs during a prenatal care visit, especially if they were raising other children at home. Unfortunately, many of

these women did not participate in the FIMR interview, so questions remain about the factors impacting substance-using women's prenatal care initiation.

Table 3: Timing of Prenatal Care Entry by History or Current Substance Use

Timing of Prenatal Care Entry	History of Substance Use* (%) N=22	No History of Substance Use* (%) N=24	Current Substance Use† (%) N=21	No Current Substance Use† (%) N=19
1st Trimester (0-13 weeks GA)	36.4	87.5	33.3	84.2
2nd Trimester (14-26 weeks GA)	50.0	8.3	47.6	10.5
3rd Trimester (≥27 weeks GA)	0.0	4.2	0.0	5.3
No Prenatal Care	13.6	0.0	19.0	0.0

* 2 cases had an unknown drug history; 1 entered prenatal care during the 2nd trimester, 1 had no prenatal care
† 8 cases had unknown current drug use; 6 entered prenatal care during the 1st trimester, 2 entered during the 2nd trimester

STANDARDIZE FETAL "KICK-COUNT" EDUCATION

> *"Next time [I'm pregnant], I don't think I would do like with this baby when I crawl in bed and go to sleep. Next time I will rush to the hospital if there are signs, so the hospital could be aware and help me with whatever is going on… I was learning with this pregnancy… I feel like I will not neglect my health the way I did. I had a lot of signs that I didn't listen to … Those were the days I should have gone to the hospital. That happened because of lack of knowledge."* — 25-year-old mother

Decreased fetal movement is often considered an indicator of fetal compromise. Recognized by the American Congress of Obstetricians and Gynecologists (ACOG), fetal movement counting (also called "kick counts") is a simple test that involves counting the amount of time it takes to feel ten kicks, flutters or rolls. Though this activity can be done by women at home, providers are responsible for teaching their patients to do these counts, how often to do them, and when to seek care.[10]

In the FIMR sample, 18 women did not seek timely medical care following the onset of what they deemed a concerning pregnancy-related symptom. Of these, 13 reported a decrease in fetal movement. The delay between the onset of decreased movement and the time women sought care ranged from as little as six hours to as much as six days, but averaged about 50 hours. All of these women were subsequently diagnosed with an intrauterine fetal demise (IUFD). When interviewed, two women indicated they had reported the decrease in movement to their providers, were checked and sent home. When the decrease continued they thought it must be normal because they had already been checked. Others said they noticed the decrease in movement at the time, but delayed seeking care because of lack of transportation or childcare, or feeling unsure that the decreased movement was a problem. Still other women said they didn't typically monitor fetal movements and hadn't noticed the decreased movement until they were asked to think back to the last time they felt movement.

Of the 13 women who experienced decreased fetal movement and delayed seeking care, only half received "kick-count" education. Five of the seven women who received no "kick-count" education were non-English speakers. In all, less than one-third of the cases reviewed in 2016 included any documentation or parent report of fetal "kick-count" education.

FIMR recommends standardizing fetal "kick-count" education and encouraging patients to contact their providers when they first suspect decreased fetal movement. This messaging is essential for all women, especially those whose first language is not English.

DISCUSS POSTPARTUM BIRTH CONTROL (PPBC), INCLUDING TUBAL LIGATION, BY THE 24TH WEEK IN PREGNANCY

"I been trying to get my tubes tied since 2000 when I had my son. But I can't do that because of my blood pressure high and they say I can't stay open (in surgery) that long. I was on depo one time after he born but it make me drink Pepsi so I stopped. After that… I lost two other kids. But them didn't affect me like [the decedent] did. Them didn't go as far. The first one I lost — it was a girl — in 2011… I had a D&C. And then I lost one in 2012. It was still in the sac. He just fall out. I didn't know I was pregnant for either one of those… Now, I'm on nothing… I didn't get no birth control shot because it will kill my kidneys. My plan was to get my tubes tied but they say I can't, so I'm on nothing." — 42-year-old mother

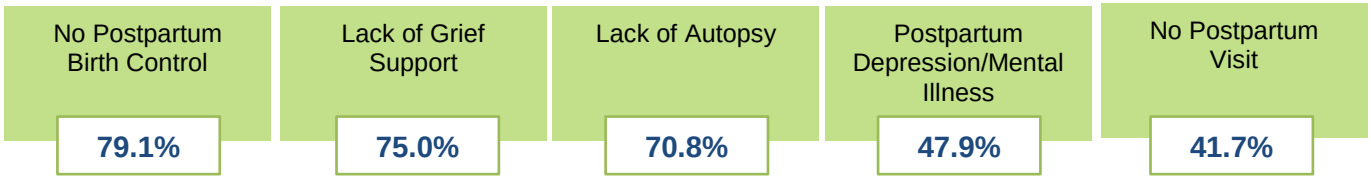
Discussion in the prenatal period of a woman's PPBC plans varied from woman to woman and from site to site. Mothers in six cases explicitly expressed an interest in or signed consent for tubal ligation prenatally and all six continued to say they did not desire pregnancy after delivering the decedent. Yet, only one of these women received any type of PPBC prior to her delivery discharge. She had signed a consent form for tubal ligation at 24 weeks gestation, so she was able to receive the procedure before being discharged. The remaining five women left the hospital with no PPBC. One of these women, having signed a consent form for the procedure at 38 weeks, was told she would need to be re-admitted for the procedure at a later date due to the mandatory 30-day wait period that follows signing the consent form. In the end, this woman received one dose of Depo-Provera at her 6-week postpartum visit and has had no contraceptive coverage since. She continues to say she does not want to have any more children. Another woman said she'd hoped to have the procedure during her delivery admission because she would be unable to get the time off of work to have it done at a later date. However, she was discharged with a referral to schedule the procedure at another time. At the time of interview, she stated she still desired a tubal ligation but had been unable to complete it due to work commitments and was not using any other form of contraception.

Because of the risk of unplanned pre-term delivery, delivery at hospitals that do not routinely offer tubal ligation, or use of a health insurance plan with strict parameters surrounding tubal ligation consent, FIMR recommends discussing PPBC throughout pregnancy, and offering tubal ligation consent paperwork by the 24th week of pregnancy. That way, women have access to a broad selection of reproductive options at delivery.

POSTPARTUM/INTERCONCEPTION

To identify the challenges women and families face after a fetal or infant demise, FIMR also examined the "Present & Contributing Variables" document for factors relevant to the postpartum period. **Figure 4** presents those factors that were prevalent in the greatest number of cases. Again, information and themes identified through family interviews and CRT discussions were reviewed to understand how these variables related to women's experiences with loss and their subsequent medical and non-medical needs.

Figure 4: Significant Needs Following a Fetal/Infant Demise



ASK "ONE KEY QUESTION," THEN PROVIDE DESIRED BIRTH CONTROL, INCLUDING LONG-ACTING REVERSIBLE CONTRACEPTIVES (LARC), PRIOR TO HOSPITAL DISCHARGE

"We didn't plan this pregnancy; we didn't want it. I used Depo or the pill in the past but I never remember to take them on time. I considered getting an abortion for this pregnancy but I couldn't go through with a third abortion." (This mother has had seven pregnancies and has four living children. She does not desire any future pregnancy, but was given no PPBC before discharge.) — 32-year-old mother

"I got the shot after every pregnancy because I was hoping for more time in between… but it never works." (This mother has had 12 pregnancies and has nine living children. She does not desire any future pregnancy, but was given no PPBC before discharge.) — 39-year-old mother

Women reported feeling a variety of emotions following the birth of the decedent. Some were adamant they would try to conceive again immediately, while others were certain they never wanted to be pregnant again. FIMR interviews revealed that women felt bereft, confused, guilty or conflicted about their loss and their future family planning needs. It is a delicate time and women's family planning desires can be under-assessed or left unaddressed. For example, though 16 women reported they did not desire pregnancy after the loss, only two of these women left the delivery hospital with PPBC. Another 16 women had no notation in their chart that family planning had been assessed at all prior to a woman's delivery discharge. For those who did receive PPBC prior to discharge, the methods tended to be short-term. See below:

- Depo-Provera (7 women)
- Prescription for birth control pills (1 woman)
- Planned tubal ligation (1 woman)
- Emergency hysterectomy (1 woman)

The *One Key Question Initiative* encourages providers to ask, "Would you like to become pregnant in the next year?" to learn about a woman's future family planning goals.[11] Asking the "one key question" of all postpartum women, including those who have recently suffered a demise, invites a conversation about family planning. This, in turn, prompts providers to review accurate information on the full menu of reproduction options with women and, if desired, provide access to the effective PPBC method of her choice.

FIMR recommends assessing all women's family planning goals and offering PPBC, including LARC, prior to delivery discharge.

SCHEDULE POSTPARTUM APPOINTMENT PRIOR TO DELIVERY DISCHARGE

"I don't remember being told to make a postpartum appointment, so I never went to one." — 28-year-old mother

FIMR tracked women's referral to and completion of postpartum obstetric appointments. This routine visit is a particularly important touchpoint for newly bereaved mothers. Not only does it offer an opportunity to address physical symptoms a woman may have following birth, but it is a time to assess postpartum depression, grief, vaccination status and family planning needs. It can also be a time to discuss the decedent's delivery, answer questions about the autopsy or refer the family to a genetic counselor or other maternal health specialists.

Of the 21 women who received a scheduled appointment for their postpartum check-up before being discharged from the hospital, 17 (81%) completed this visit. Of the 24 women who were counseled to schedule their own postpartum check-up, 11 (46%) completed this visit. Three women had no documentation in their charts about scheduling a postpartum check-up, and none of these women completed a postpartum visit.

FIMR recommends scheduling women for a postpartum appointment before their delivery discharge.

ASSIST OPIATE-POSITIVE WOMEN TO CONNECT WITH TREATMENT PRIOR TO DELIVERY DISCHARGE

This mother was caught smoking heroin in her hospital room after delivery; her dealer had brought the drugs to her in the hospital. Nursing notes reported the mother said, "I smoke my drugs to help my pain and no one ever told me I couldn't smoke heroin in here"… then "she asked very tearfully for support to get off

heroin." The nurse contacted a social worker who gave the mother a phone number for drug treatment. The social worker explained "it is protocol" for the mother to make the call for this service. It's unknown if she ever made that call for treatment. However, records indicate this mother was hospitalized for detox after being arrested for felony drug possession seven months after delivery. — 25-year-old mother

Eight women tested positive for opiates at some point in their pregnancy with the decedent. However, only one woman received specialized prenatal care to address both her obstetrical and addiction needs. This woman's drug test was negative at delivery and she engaged in addiction support services within two weeks of her delivery.

Six women tested positive for opiates at delivery (opiates-5, oxycodone-4). None of these women received an appointment for drug treatment prior to her delivery discharge and, within months of discharge, two of these six women were incarcerated for drug-related crimes. The CRT viewed this as a missed opportunity. For some women, the emotional toll of losing a child may exacerbate drug use. For others, it may be a catalyst for recovery. Either way, offering support and referral for treatment during this sentinel event may help some opiate-positive women alter the course of their drug use.

FIMR recommends opiate-positive women meet with a drug counselor prior to hospital discharge to assess readiness for treatment and to assist women to engage with the appropriate treatment options. FIMR suggests assessing barriers that preclude a smooth transition from delivery admission to drug treatment.

DEVELOP MORE ROBUST GRIEF SUPPORTS

"I was pretty depressed for a while [after he died] … When I came home from the hospital it was really sad. I had my own house, but I didn't even want to stay in the house by myself. I couldn't come home 'cause I had all his baby stuff here. So I had to stay with my mom for two weeks until my boyfriend cleaned out the baby's room. It was really depressing having to plan a funeral when I was supposed to be celebrating his life. It was sad. I still think about him a lot. (crying) Like a LOT, a lot. I thought about talking with other parents [who had lost a baby] but I didn't really have any resources. They had given me resources at the hospital but I don't know what I did with it." —18-year-old mother

"They didn't give us any resources. [The baby's father] is having a difficult time. He does not talk about the baby's death and is taking it very hard. He used to be happy … stayed home … made time for everybody. Now he doesn't. He comes home to sleep. It's like he lost his whole entire life. He will not speak on the subject for nothin'. He just gave up." — 38-year-old mother

Though 42 families were seen by the hospital chaplain and 31 families were seen by a hospital social worker during a mother's delivery admission, reports varied about how useful these in-house services felt to the families. While the majority of families described the chaplain or social worker as a good touchpoint in the hospital setting, some families had concerns. For example, several stated the chaplain was more focused on completing the disposition paperwork than attending to their spiritual needs. This may point to a misunderstanding of the chaplain's role in the hospital setting. Others said the chaplain made critical errors in documentation such as identifying the wrong cemetery for burial or misspelling the decedent's name. These errors undermined the family's trust in the hospital and had a lasting impact on their experience of their child's death.

Franklin County has several grief groups designed for families who have experienced pregnancy loss or the death of an infant, and 18 families were notified about these options prior to hospital discharge. However, "lack of grief support" was noted in 36 of the reviewed cases and 29 families received no grief referral beyond what was offered during the delivery admission. Some families (especially young women, women of color and women who felt ambivalent about their pregnancies prior to the demise) said they were not interested in attending a traditional grief group for support, opting instead to seek support from friends, family or a faith community. Other families, underestimating the scope of their grief, reported they

initially declined community grief referrals, but later wished they had accepted them. Still others said they did not feel comfortable accessing grief supports so far from home.

FIMR recommends offering every family a referral to local bereavement resources, following up with families who initially decline referral, and expanding grief group meeting locations into CelebrateOne neighborhoods. In addition, FIMR suggests the creation of new supports, marketed to those who are not interested in or cannot get to a traditional grief group (e.g., those with transportation challenges, the incarcerated, etc.). Lastly, FIMR recommends all families who experience fetal or infant loss receive a home visit to assess women's physical and mental health, postpartum birth control plans, grief support needs, etc., and to offer support and referral as appropriate.

EDUCATE FAMILIES ABOUT THE PURPOSE, LIMITATIONS AND FUNDING OF AUTOPSY

> *This mother declined autopsy due to cost, but "regrets" not learning everything possible about the demise. She reports the hospital chaplain said the autopsy was not covered by insurance, so she viewed it as "just another cost." The mother remembers being told there was a "50 percent chance the autopsy wouldn't reveal anything and thought, 'Why would we spend this money and have such a low chance of them even being able to discover what happened?' But when we found out about the staph infection later, we were like 'Oh, maybe we should have gotten it.'"* — 32-year-old mother

> *"They never discussed autopsy with me. I didn't know that was a choice I had."* — 26-year-old mother

Conducting an autopsy can reveal more about some deaths and may give parents insight into the success of future pregnancies. Fourteen of the 48 FIMR cases included an autopsy (fetal autopsy, 28%; infant autopsy, 32%). Though some families were disappointed that a cause of death could not be determined by this process, none of these families expressed regret about consenting to the autopsy. Autopsy was not completed in the remaining 34 cases for a variety of reasons. Twenty-four families declined autopsy due to financial constraints, religious practices, not wanting to put their loved one through the procedure, and doubting that it would reveal new information. In seven cases, autopsy was not discussed with the family. In one case, autopsy was ordered but not done. In two cases, there was no information about why an autopsy was not conducted.

FIMR recommends educating all families about the value of autopsy including the benefits and limitations of this procedure. In addition, FIMR suggests clarifying payment expectations so all families are given accurate information about funding supports if they cannot otherwise afford this service.

IN CLOSING

Summary

The in-depth FIMR review of 48 cases of fetal and infant death to “at risk” Franklin County residents in 2016 uncovered trends and insights which may lead to improved systems of care for families, and hopefully, a lower rate of fetal and infant mortality in the future. This report organized these findings based on the preconception, pregnancy and postpartum/interconception periods of a woman’s life. Themes included the need for family planning, ongoing holistic assessment of medical and non-medical needs, “scaffolding” women with multiple stressors, “kick-count” education, post-partum follow-up, treatment for opiate-positive women, grief support and autopsy. The FIMR CAT should consider these recommendations for future program planning and action.

Future Reviews

“Infection – other” was a high scoring variable present in 26 cases. In 12 of these cases, two or more kinds of "other" infections were present while the mother was pregnant with the decedent. Infections included:

- UTI (18 cases)
- Group beta strep, yeast infection (5 cases of each)
- MRSA (3 cases)
- Bacterial vaginosis, hydradenitis, chorioamnionitis (2 cases of each)
- Sinusitis, hepatitis A, hepatitis C, strep pharyngitis, gastroenteritis, abdominal wall abscess, parvovirus, folliculitis, listeria, pneumonia, bronchitis, colitis (1 case of each)

Further, 14 cases had at least one STI in pregnancy including:

- Chlamydia (7 cases)
- Herpes (5 cases)
- Trichomonas (4 cases)
- Human papilloma virus, genital warts, hepatitis B, cytomegalovirus, syphilis (1 case of each)

Though frequently present, FIMR did not develop a recommendation related to the “infection-other” variable. If infections continue to be present with a high frequency moving forward, FIMR may benefit from collaborating with CPH’s Office of Infectious Disease Investigation and others to explore the impact of these infections on pregnancy outcomes.

In addition, between January and December 2017, FIMR will review a total of 48 cases with the CRT and continue conducting enhanced outreach to bereaved families in order to obtain FIMR interviews. Lastly, CPH’s Office of Epidemiology will update Franklin County PPOR analyses which may alter the scope of FIMR reviews in 2018.

APPENDIX A: CPH DEATH REVIEWS

Columbus Public Health

Death Reviews

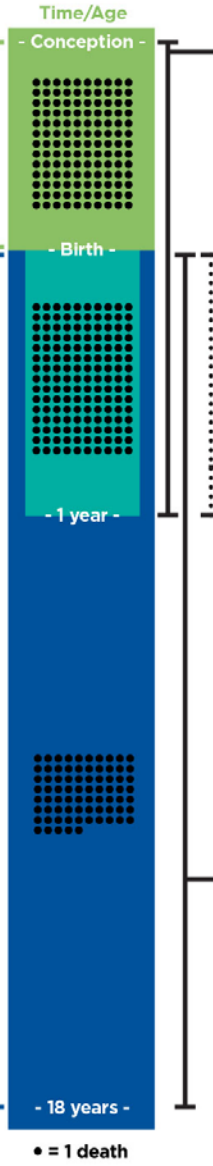
Columbus Public Health oversees multiple death review processes of infants and children in Franklin County, including the Fetal-Infant Mortality, Sudden Unexpected Infant Death, and Child Fatality reviews. The graph below shows how the reviews relate to one another and community data on child deaths.

Death (Mortality) Data Categories

Fetal Mortality
~130 deaths per year
- Includes all fetal losses 20 weeks gestation-birth
- Includes voluntarily reported fetal losses <20 weeks gestation

Infant Mortality
~150 deaths per year
- First breath to 364 days
- Includes **Sudden Unexpected Infant Deaths (SUID)** ~ 25 deaths per year

Child Mortality
~225 deaths per year
- First breath to 17 years and 364 days
- Includes infant mortality



Death Review Processes

The Franklin County Fetal-Infant Mortality Review (FIMR)

Includes Fetal & Infant Mortality Data (typically 20 weeks gestation to 364 days after birth)

An action-oriented quality improvement process that assesses, monitors and works to improve service systems and community resources for women, infants and families. Research shows FIMR is an effective perinatal systems intervention. The FIMR Case Review Team (CRT) reviews a **subset of the roughly 280 cases of fetal and infant deaths** and shares its findings with the Community Action Team (CAT) annually for intervention planning and implementation.

**Fetal deaths are not included in the Franklin County Infant Mortality Rate.*

The Sudden Unexpected Infant Death (SUID) Review

Includes Sudden and Unexpected Infant Deaths (first breath to 364 days after birth)

A subcommittee of the Franklin County Child Fatality Review (FCCFR) that reviews, analyzes and reports on all **deaths of infants less than 1 year of age that occur suddenly and unexpectedly,** and whose cause of death is not immediately obvious before investigation. Most SUIDs are reported as one of three types: Sudden Infant Death Syndrome (SIDS); Accidental Suffocation or Strangulation in Bed (ASSB); or unknown cause. **All sleep-related infant deaths are reviewed by the SUID Review.**

The Franklin County Child Fatality Review (FCCFR)

Includes Child Deaths (first breath to 17 years & 364 days)

An ongoing community planning process in which a team of community experts from various systems and agencies convenes to review, analyze and report on the circumstances around the **deaths of children under 18 years of age**. The mission is to reduce the incidence of preventable child deaths. The FCCFR reviews all cases of infant deaths and SUIDs, but does not review fetal deaths.

5/19/2017

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THE CITY OF COLUMBUS
ANDREW J. GINTHER, MAYOR
COLUMBUS PUBLIC HEALTH

APPENDIX B: ACTIVE CRT MEMBERS IN 2016

Name	Title*	Organization*
Jada Brady	Policy Analyst	Franklin County Department of Job & Family Services
Rochelle Chambliss, DTR	Dietetic Technician, Registered	Women, Infants & Children
Sheryl Clinger	Director of Advocacy/Policy and Community Engagement	The Center for Family Safety and Healing
Mark Dodley	Program Coordinator, Father to Father Program	Columbus Urban League
Brian Ellair, RHIT	Health Information Technician (HIT)	Columbus Public Health
Jennifer Fears-Volley, LISW-S	Maternal Mental Health Clinical Program Director	Catholic Social Services
Raquel Fuentes	Program Managed-West Side	CelebrateOne
Tonya Fulwider	Program Director MHAFC & Founder of Perinatal Outreach and Encouragement for Moms (POEM)	Mental Health America Franklin County
Pat Gabbe, MD, MPH	Clinical Professor, Pediatrics Director, Moms2B	Nationwide Children's Hospital OSU Wexner Medical Center
Erin Heinzman	Administrative Office	Franklin County Department of Job & Family Services
Jay Iams, MD	Maternal Fetal Medicine	Ohio Perinatal Quality Collaborative OSU Wexner Medical Center
Derrick Lewis	Chief Operating Officer	Men of Courage
Marianne Marinelli, MSN, RNC, CLC	Women's Health Outcome Manager	Grant Medical Center
Arnitta Mason	Supervisor	Franklin County Jobs and Family Services
Octavia Mercado	Supportive Service Liaison	Columbus Metropolitan Housing Authority
Sonia Murphy, RD, CLS, MICS, LD	Dietician Supervisor & Certified Lactation Specialist	Women, Infants & Children
Apurwa Naik, MD	Neonatologist	Central Ohio Newborn Medicine
Marc Parnes, MD	Retired OBGYN	Previously worked at Riverside & St. Ann's
Maureen Provenzale, RN	POEM Program Coordinator	Mental Health America of Franklin County
Lauren Rose-Cohen, RN	FIMR Coordinator	Columbus Public Health
Katherine Schiraldi	Associate Director at Intake & Assessments	Franklin County Children Services The Center for Family Safety and Healing
Lynnette Schroeder, M. Div.	NICU & Bereavement Chaplain, Pastoral Care Department	Nationwide Children's Hospital
Janet Taylor, LSW, CPS,CLC	Social Worker, My Baby & Me	Columbus Public Health
Sharla Teets, RN	Maternal Child Health Section Chief	Columbus Public Health
Cynthia Ward, LISW-S	Social Worker, Wellness on Wheels	OhioHealth
Stacie Williamson, RN	Supervisor, Children with Medical Handicaps Program	Franklin County Public Health
Amanda Zabala, MPH	Epidemiologist	Columbus Public Health

*CRT members' titles and organizational affiliations at the time of their CRT involvement.

APPENDIX C: PRESENT & CONTRIBUTING FACTORS

Each of these variables is from the detailed list of present and contributing factor codes, adapted from NFIMR's "Present & Contributing Variables" document. Numbers represent the cases in which the factor was present. Note: some variables may be underreported due to missing information in available records.

1. Preconception/Interconception Care

0	Preconception care
28	Postpartum visit kept
12	Pregnancy planning/BC education
4	Dental/oral care
10	Chronic disease control education
0	Weight management/dietician
44	Bereavement referral (includes referral for hospital chaplain at delivery)

2. Medical: Mother

7	Teen pregnancy (≤19)
8	Pregnancy > 35 years
5	Cord problem
6	Placental abruption
0	Placenta previa
4	Chorioamnionitis
2	Preexisting diabetes
3	Gestational diabetes
1	Incompetent cervix
2	Infection—bacterial vaginosis
14	Infection—STI: _____
26	Infection—other: _____
3	Multiple gestation
36	Weight pre-pregnancy (BMI <18.5 or >25)
10	Insufficient/excess weight gain
10	Poor nutrition
15	Pre-existing hypertension
7	Pregnancy induced hypertension: pre-eclampsia/eclampsia
14	Preterm labor
19*	Pregnancy <18 months apart
7	PROM/PPROM/prolonged rupture of membrane
7	Dental/oral issues
8*	Previous voluntary termination of pregnancy
19*	Previous spontaneous abortion
14	Oligohydramnios/polyhydramnios
6*	Previous fetal loss
3*	Previous infant loss
12*	Previous low birth weight delivery
15*	Previous preterm delivery
13*	Previous C-section: #_____
3*	Previous ectopic pregnancy: #_____
16	First pregnancy <18 yrs. old
11	≥4 Live births
0	Assisted reproductive technology

3. Family Planning

7	Intended pregnancy
31	Unintended pregnancy
12	Unwanted pregnancy
23	No birth control
2	Failed contraceptive
3	Lack of knowledge: methods
0	Lack of resources

4. Substance Use

18	Positive drug test
12	No drug test
26	Tobacco use: history
24	Tobacco use: current
12	Alcohol use: history
5	Alcohol use: current
20	Illicit drug use: current—Type:
16	Illicit drug use: history—Type:
2	Use of unprescribed meds—Type:
1	Over the counter drug/prescription:

5. Prenatal Care/Delivery

8	Standard of care not met
5	Inadequate assessment
4	No prenatal care
15	Late entry to prenatal care
21	Lack of referrals
13	Missed appointments
4	Multiple providers/sites
3	Lack of dental care
17	Inappropriate use of ER: #_____

6. Medical: Fetal/Infant

1	Non-viable fetus
9	Low birth weight <2500 g
21	Very low birth weight <1500 g
13	Extremely low birth weight <750 g
6	Intrauterine growth restriction
12	Congenital anomaly
13^	Prematurity (excludes induced labors)
4^	Infection/sepsis
0^	Failure to thrive
0^	Birth injury
0^	Feeding problem
4^	Respiratory distress syndrome
0^	Developmental delay
0^	Inappropriate level of care
1^	Positive drug test

7. Pediatric Care

2^	Standard of care not met
0^	Inadequate assessment
0^	No pediatric care
0^	Lack of referrals
0^	Missed appointments/immunizations
1^	Multiple providers/sites
1^	Inappropriate use of ER

8. Environment

10	Unsafe neighborhood
10	Substandard housing
5	Overcrowding
18	Secondhand smoke
1^	Little/no breastfeeding
0^	Improper or no car seat use
0^	Unsafe sleep location
0^	Infant overheating
0^	Not back sleep positioning
0^	Apnea monitor misuse
0^	Lack of adult supervision

9. Injuries

0	Motor vehicle occupant
0	Abusive head trauma

10. Social support

13	Lack of family support
13	Lack of neighbor/community support
15	Lack of partner/FOB support
12	Single parent
7	Living alone
25	≤12th grade education/no GED
2	Special education
6	Physical or cognitive disability

11. Partner/FOB/Caregivers

23	FOB Employed
2	History of mental illness
13	Substance/tob use/abuse: current
9	Substance/tob use/abuse: history

12. Family Transition

16	Frequent/recent moves
4	Living in a shelter/homeless
1	Concerns regarding citizenship
12	Divorce/separation
3	Multiple partners
6	MOB: prison/parole/probation
8	FOB: prison/parole/probation
4	Major illness/death in family

13. Maternal Mental Health/ Stress

21	History of mental illness
23	Depression/mental illness postpartum
30	Multiple stresses
14	Social chaos
32	MOB employed
23	Concern about enough money
18	Work/employment problems
5	Child/children with special needs
8	Problems with family/relatives
36	Lack of grief support

14. Family Violence/Neglect

15	History of abuse to MOB
7	Current abuse to MOB
4	History of abuse—decedent
3	History of abuse—other child
0	Current child abuse—decedent
1	Current child abuse—other child
0	History of child neglect—decedent
5	History of child neglect—other child
7	Multiple CPS referrals
8	Multiple police reports

15. Culture

9	Language barriers
3	Beliefs regarding pregnancy/health

16. Payment for Care

10	Private
0	Medicare
41	Medicaid
3	Self-pay/medically indigent

17. Services Provided

28	WIC
3	Mother/child not eligible
5	Poor provider communication
12	Client dissatisfaction—prenatal
11	Client dissatisfaction—hospital
1	Client dissatisfaction—pediatric
3	Dissatisfaction—support services
4	Lack of child care

18. Transportation

0	No public transportation
12	Inadequate/unreliable

19. Documentation

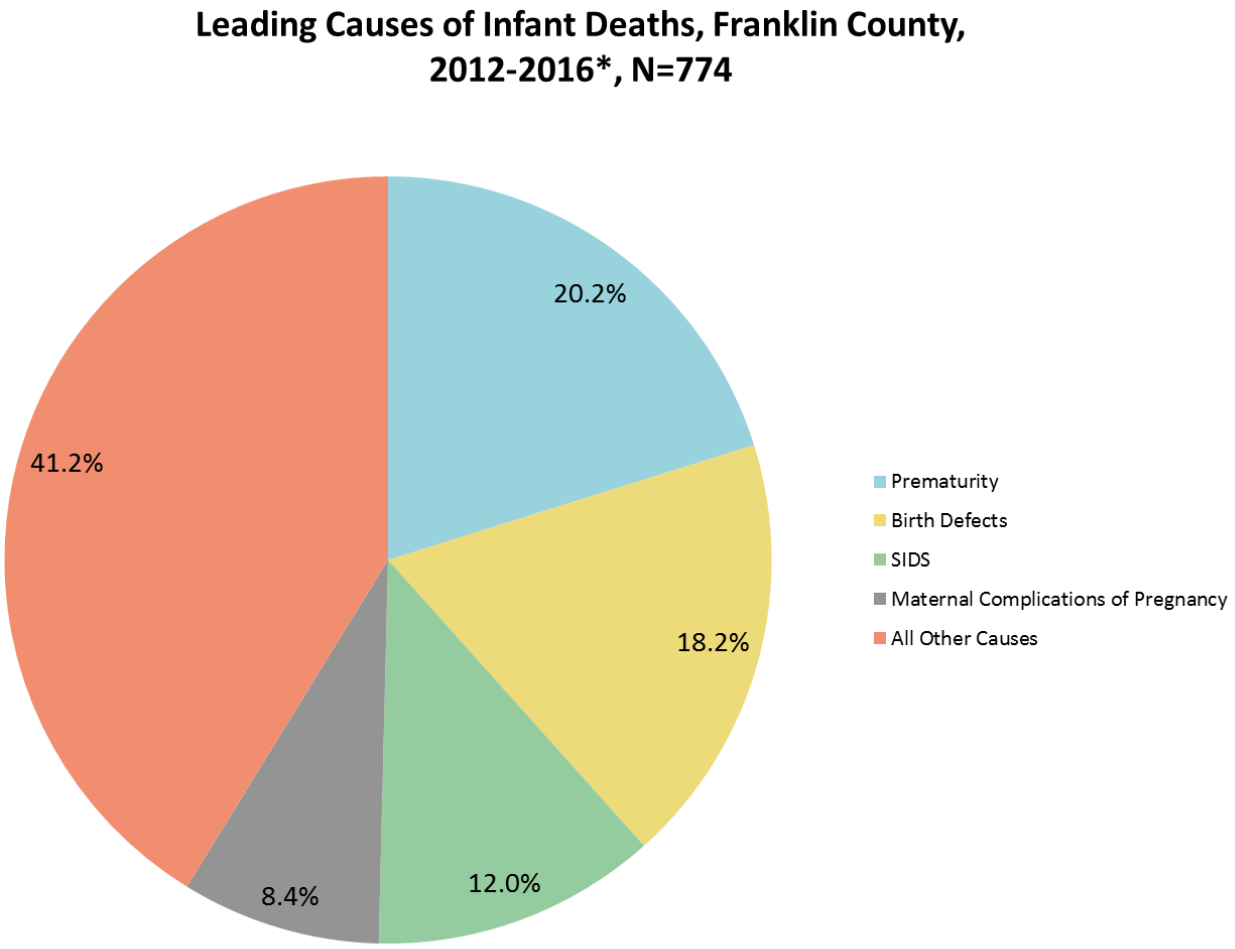
2	Inconsistent unclear information
5	Inconsistent vital records data
10	Missing data
0	No death scene investigation
0	No doll reenactment

20. Added variables

11	History of homeless as a child (includes displacement to a refugee camp)
9	History of neglect as a child
8	Declined/not engaged in needed mental health services
33	Inadequate assessment of non-medical needs
2	No placental pathology
7	Lack of referrals for known lethal condition
4	Inflexible/ineffective prenatal education
26	History of trauma
14	Declined social services: _____
3	Delivery outside hospital
34	No autopsy
21	History of other chronic disease
6	Tried but unable to follow med. advice
4	No domestic violence screening
18	MOB did not seek timely medical care
8	Cultural barriers
5	Possible un-dx mental illness
38	No postpartum birth control

All cases are out of 48 unless otherwise noted (i.e., the full sample)
**Indicates a denominator of 40 (i.e., all cases with previous pregnancy)*
^Indicates a denominator of 19 (i.e., all cases of infant death)

APPENDIX D: LEADING CAUSES OF INFANT DEATHS, FRANKLIN COUNTY, 2012-2016



*2016 Data is Preliminary
Source: Ohio Department of Health Vital Statistics Data Analyzed by Columbus Public Health

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