

DATA DICTIONARY

Version 6.0

National Fatality Review Case Reporting System

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Section L. Findings Identified During the Review

L1: Describe any significant challenges faced by the child, the family, the systems with which they interacted, or the response to the incident. These could be related to demographics, overt or inadvertent actions, the way systems functioned, or other environmental characteristics.

Some examples of different kinds of findings are highlighted below. **These are not exhaustive.** They are provided to illustrate a range of possible findings. Your team's findings may look different than those below. Please list any significant challenge you identify, even if it does not seem to fit neatly into one of the following categories.

- *Challenges faced by the child:* These could include a child's inability to read a warning label; congenital anomalies or developmental delays; living in a dangerous neighborhood; or facing discrimination based on race or sexual orientation.
- *Challenges faced by the family:* These could include poverty or lack of other resources such as mental health or medical resources; food or housing insecurity; lack of culturally-responsive prenatal care; low levels of health literacy; significant stress due to caregiving responsibilities; or lack of a social support network.
- *Systems-level challenges:* These could include lack of funding for needed education or intervention initiatives; structural racism; poor referral processes; collaboration; or communication between agencies/providers; failure to remove a child from a violent home; or inadequate available services within a jurisdiction.
- *Challenges with the response to the incident:* These could include a lack of available grief and bereavement resources; re-traumatization of a bereaved parent; challenges conducting an effective death scene investigation; or challenges communicating with a medical examiner's office.

L2: Describe any notable positive elements in this case. They could be demographic, behavioral, or environmental characteristics that may have promoted resilience in the child or family, the systems with which they interacted or the response to the incident.

Some examples of different kinds of findings are highlighted below. **They are not exhaustive.** They are provided to illustrate a range of possible findings. Your team's findings may look different than those below. Please include any significant positive element you identify, even if it does not seem to fit neatly into one of the following categories.

- *Demographic characteristics:* These could include intentional diversity on agency staff to help reflect a constituent community, such as with home visiting or child welfare; age-appropriate mental health interventions; presence of an LGBTQ resource center; a support group for teen childbearing parents; or effective language translation services.
- *Behavioral characteristics:* These could include wise decisions made by individuals, either in the family or within an agency such as seeking treatment for a substance use disorder; compliance with prenatal care provider recommendations; going to a shelter for domestic violence victims; a care provider who went above and beyond to meet a family's needs; or removing oneself or one's family from stressful situations.
- *Environmental characteristics:* These could include equitable and effective community-level emergency response services; thorough death scene investigation; effective

communication between agencies; a strong community support network, faith community, or school community; ongoing investment in community service systems; grief and bereavement support resources; or effective lead remediation in the family residence.

L3: List any recommendations and/or initiatives that could be implemented to prevent deaths from similar causes or circumstances in the future

Indicate the specific prevention strategies that **could be or have already been implemented** as a result of the review process. A recommendation means that the team made a formal statement that a specific strategy be implemented. Recommendations should be reasonable, achievable, and specific including a timeframe, geographic location, and who will take the lead on accomplishing the task. Recommendations may include changes to practices, policies, and procedures, as well as maintenance of current prevention activities.

L5: Could the death have been prevented

Team's conclusions regarding the preventability of the death. A child's death is considered to have been preventable if an individual or the community could reasonably have done something that would have changed the circumstances that led to the child's death. Consider preventability broadly and that most injury deaths are preventable. Examples of preventable deaths (**this list is not to be considered exhaustive**):

- *Unintentional injury deaths* of young children that occur under absent or poor adult supervision
- *Motor vehicle and other transport deaths* when fatal injuries are sustained due to failure to use appropriate restraints (child seat, seatbelt) in a motor vehicle, or failure to wear a helmet while riding a bicycle, motorcycle or ATV.
- *Deaths due to fire or burns* when fire caused by heating residence with a stove or children playing with matches.
- *Drowning deaths* when infant or toddler left unattended in a bathtub, lack of barriers around swimming pools or other bodies of water, failure to use mandated floatation devices.
- *Sleep-related deaths* when asphyxia results from bed-sharing or other unsafe infant sleep environment (e.g., place on couch, on pillow)
- *Weapon-related deaths* when firearm left loaded and/or unsecured.
- *Fall deaths* from balconies/windows.
- *Poisoning, Overdose, Acute Intoxication* unsecured prescription drugs or poisons.
- *Suicide* If parent or caregiver did not seek care for child when child had history of previous suicide attempts, mental illness, or indicated intent to commit suicide.
- *Medical Condition* if caregiver does not seek care or delays seeking care for a known medical condition or fails to follow prescribed care/treatment plan.

Examples of deaths that are not often typically preventable, if none of the above conditions are met and death is the expected outcome:

- Cardiovascular disease
- Congenital anomalies (birth defects)
- Prematurity and other perinatal conditions
- Other chronic medical conditions

O2. Issues Summary (present and contributing factors)

This section is meant to be used primarily for local teams to identify gaps in services and needs for improvement in care. Section O2 will only be completed by FIMR users.

Please use the following indicators:

- Present: Issue was present in this case
- Contributing: Review team felt that issue was a contributing factor in the death of the infant – not necessarily causative, but factor played a strong role in determining the outcome.

If the review team felt that the issue was present but unknown if contributing to the death, then select Present. If the issue was not a factor in the infant's death, then leave blank. Issues can be documented in more than one category for completeness of future case analysis. For example, No drug testing may be captured in category #6, Substance Use, as well as inadequate assessment in category # 4, Prenatal Care/Delivery.

1. Pre-, Inter-, and Post-conception Care

Note: The responses in this category are Yes, No and Unknown.

- Preconception care: Medical checkup before pregnancy documented including planning pregnancy.
- Postpartum visit kept: The childbearing parent received postpartum care within the first three weeks after delivery.
- Pregnancy planning/birth control education: The childbearing parent received any pregnancy planning or birth control education at any time before, during or after this pregnancy.
- Dental/oral care: The childbearing parent had a dental care provider and had been seen by a dental care provider before, during or after this pregnancy.
- Chronic disease control education: Had the childbearing parent received education about controlling any of their chronic diseases at any time before, during or after this pregnancy with appropriate referrals (if needed) made for control of chronic disease?
- Weight management/Dietician: Had the childbearing parent received education about controlling any weight issues, whether under- or over-weight, at any time before, during or after this pregnancy with appropriate referrals (if needed) made to a dietician.
- Bereavement referral: Referral to any bereavement program, hospital, pastoral care or local program given at any time

2. Medical: Childbearing parent

- Early teen: Childbearing parent age 17 years or less at time of conception.
- Late teen: Childbearing parent age 18 or 19 at time of conception.
- Pregnancy > 35 years: Childbearing parent age over 35 at time of conception.
- Cord problem: Evidence of cord torsion, nuchal cord, insufficient number of cord vessels, prolapsed cord, cord compression, or other documented problems relating to the umbilical cord.
- Placental abruption: A condition in which the placenta separates from the inner wall of the uterus before the baby is born.
- Placenta Previa: A placenta that is implanted in the lower uterine segment and covers all or part of the cervical opening. This should be clinically diagnosed.
- Chorioamnionitis: Infection of the membranes surrounding the fetus.
- Pre-existing diabetes: A condition in which levels of sugar in the blood are too high.
- Gestational diabetes: Diabetes that arises during pregnancy; it results from the effect of hormones and usually subsides after delivery.
- Cervical insufficiency: A weakened cervix that results in rapid and unexpected premature dilatation of the cervix and repeated spontaneous abortions, usually during second trimester. This should be clinically diagnosed.
- Previous abnormal PAP: A Pap smear, also called a Pap test, is a procedure to test for cervical cancer. An abnormal PAP means that there are early cell changes on the cervix might lead to cancer in the future. The cervix may be weakened depending on the course of treatment for an abnormal PAP.
- Infection, BV: Bacterial Vaginosis, an imbalance of the bacterial vaginal flora, detected prenatally or at delivery.
- Infection, Group B Strep: Group B Streptococcus also known as Group B Strep Infection (GBS) is a type of bacterial infection that can be found in a pregnant person's vagina or rectum. This bacteria is normally found in the vagina and/or rectum of about 25% of all healthy, adult women. A childbearing parent can pass GBS to the baby during delivery.
- Infection, Urinary Tract Infection: A urinary tract infection (UTI) is an infection in any part of the urinary system, including the bladder and kidneys. Without treatment, UTIs can cause serious

complications during pregnancy. Complications may include kidney infection, premature birth, and sepsis.

- STI: Sexually Transmitted Infection, any infection spread during sexual contact. Includes AIDS, herpes, gonorrhea, syphilis, chlamydia, papilloma virus (genital warts) and a number of others. Please specify the infection on line provided.
- Other source of infection: Any significant source of infection effecting the childbearing parent, including periodontal, UTI, etc. Please specify on line provided.
- Multiple gestation: Pregnancy with more than one fetus at conception: twins, triplets, etc.
- Weight: includes both Underweight – BMI (Body Mass Index) < 19.8 pre-pregnancy and Overweight – BMI 26.1 – 29 and obese—BMI 30+--pre-pregnancy.
- Insufficient/excess weight gain: Weight loss, little or not enough gain using the childbearing parent’s BMI and standards for nutrition during pregnancy put out by the Institute of Medicine
- Poor nutrition: Food intake insufficient for healthy pregnancy, given the childbearing parent ’s BMI – usually noted in the prenatal record or strongly suspected by the clinician(s) on the case review team.
- Pre-existing hypertension: A high blood pressure known to pre-date conception. Elevated Blood Pressure documented before pregnancy, B/P greater than 140/90, or greater than 10 mm above patient’s baseline B/P.
- Pregnancy-induced hypertension (PIH): Hypertensive states of pregnancy that have not been preceded by any chronic high blood pressure. Indicate if the childbearing parent experienced pre- or eclampsia.
- Pre-eclampsia: A pregnancy-specific hypertensive disease with multi-symptom involvement, usually occurring over 20 weeks gestation, and primarily defined by new-onset proteinuria.
- Eclampsia: The convulsive phase of the above disorder, among the most sever manifestation of the disease.
- Pre-term labor: Onset of Labor before 37 completed weeks gestation.
- Pregnancy <18 months apart: Current conception occurring less than eighteen months from the date of last delivery or pregnancy outcome.
- PROM: Premature Rupture of Membranes. Spontaneous rupture of the bag of waters any time before the onset of labor.
- PPROM: Preterm Premature Rupture of Membranes. Bag of waters ruptured before onset of labor and before 37 completed weeks of gestation.
- Prolonged Rupture of Membranes: Bag of waters has been ruptured greater than 24 hours before birth.
- Pre-existing dental/oral issues: Childbearing parent noted to have dental/oral issues – bleeding gums, cavities, abscesses, tooth loss, periodontal gum disease, poor dental hygiene etc.
- Oligo-/Polyhydramnios: Oligohydramnios: Smaller than normal amount of amniotic fluid. Polyhydramnios: Larger than normal amount of amniotic fluid, often associated with certain congenital disorders.
- Previous SAB or miscarriage: Previous pregnancy ending in a Spontaneous Abortion (SAB) Spontaneous Abortion or miscarriage is the non-induced loss of the infant before 20 weeks of gestation.
- Previous therapeutic abortion or voluntary abortion: Previous pregnancy ending in a therapeutic Abortion or a voluntary abortion. Therapeutic abortion refers to termination of pregnancy for medical indications such as the health of the childbearing parent or abnormalities in the fetus. A voluntary abortion describes the interruption of pregnancy before viability not for medical reasons.

- Previous fetal loss or infant loss: Previous pregnancy ending in a stillbirth (infant greater than 20 weeks gestation or greater than 400 grams) or previous pregnancy ending in the live birth of a child who did not survive to their first birthday, regardless of weight or gestation.
- Previous LBW delivery: Delivery of an infant less than 2500 grams, or 5 lb. 5 oz., birth weight prior to this birth.
- Previous preterm delivery: Delivery of an infant, either stillborn or live born, at less than 37 completed weeks gestation, prior to this birth.
- VBAC this pregnancy: (Vaginal Birth After C-section) The childbearing parent had a vaginal delivery of this fetus/infant after a cesarean section in a previous pregnancy.
- Previous C-Section: Delivery of a previous pregnancy by C-section
- C-Section this pregnancy: A cesarean section, or C-section, is a surgical operation for delivering a child by cutting through the wall of the childbearing parent 's abdomen.
- Previous ectopic pregnancy: Any pregnancy implanted outside of the uterine cavity
- First Pregnancy < 18 years old: Childbearing parent age less than 18 at conception of first pregnancy.
- >4 Live births: Five or more live births prior to this pregnancy.
- Assisted reproductive technology: Interventions to aid conception, including ovulation stimulation, fertility medications, GIFT, ZIFT procedures.

3. Family Planning

- Intended pregnancy: Childbearing parent wanted to be pregnant at the time of conception.
- Unintended pregnancy: Childbearing parent did not want to be pregnant at this time.
- Unwanted pregnancy: Childbearing parent did not want to be pregnant then or at any time in the future.
- No birth control: Neither the childbearing parent nor their partner used a family planning method prior to this pregnancy.
- Failed contraceptive: The childbearing parent and their partner used a family planning method but became pregnant anyway.
- Lack of knowledge, methods: The childbearing parent did not have knowledge or correct understanding of how to use family planning methods.
- Lack of resources: The childbearing parent did not know how to access resources for family planning methods, or some barrier existed that prevented them or their partner from obtaining services for family planning.

4. Substance Use

- Positive drug test: The childbearing parent had any positive toxicology screen for substances during pregnancy or at delivery.
- No drug test: The childbearing parent met criteria for complications known to be associated with drug use but was not tested.
- Tobacco use: history but not current: Any use by the childbearing parent of any tobacco product in the 12 months before the infant's conception. (Note: second hand smoke from any source in the home is noted in category #14, Environment).
- Tobacco use, current: Any use by the childbearing parent of any tobacco product during or after pregnancy up to the time of the infant's death. (Note: second hand smoke from any source in the home is noted in category #14, Environment).
- Alcohol use, history but not current: Any history of any alcohol use by the childbearing parent in the 12 months before the infant's conception.

- Alcohol use: current: Any use by the childbearing parent of any alcohol during or after the pregnancy, up until the time of the infant's death.
- Illicit drugs, history but not current: Any use by the childbearing parent of any illegal substance in the 12 months before the infant's conception.
- Illicit drugs, current: Any use by the childbearing parent of any illegal substance during or after the pregnancy, up until the time of the infant's death. *Specify the type(s) of drug if known.*
- Use of unprescribed medications: Any use by the childbearing parent of any prescription drug not prescribed for them during or after the pregnancy, up until the time of the infant's death. *Specify the type(s) of drug if known.*
- OTC/prescription drugs: Any use by the childbearing parent of over the counter or prescription drugs prescribed for the childbearing parent during or after pregnancy (up until the time of infant's death) and not under the apparent supervision of a physician. *Specify the type(s) of drug if known.*

5. Prenatal Care/Delivery

- Standard of care not met: Prenatal assessment or treatment did not meet commonly accepted obstetric practice standards.
- Inadequate assessment: Prenatal providers did not appropriately assess for certain conditions or circumstances.
- No prenatal care: Childbearing parent did not receive any prenatal care (*nurse visits in this category do not count as prenatal care*).
- Late entry to prenatal care: First prenatal visit (*excluding nurse visit*) occurred after 12th week of gestation.
- Lack of progesterone therapy: Childbearing parent did not receive progesterone therapy. Progesterone is a hormone secreted by the female reproductive system that functions mainly to regulate the condition of the inner lining (endometrium) of the uterus. Progesterone and related steroids such as 17-hydroxy progesterone (17P) may be used in pregnancy in the attempt to prevent spontaneous miscarriage, treat recurrent miscarriage, and prevent pre-term birth.
- Lack of referrals: Conditions or circumstances were identified in assessment, but no referral(s) made to existing appropriate services.
- Missed appointments: Missed prenatal appointments resulted in sporadic care.
- Multiple providers/sites: Childbearing parent received prenatal care from more than one provider, resulting in sporadic and fragmented care.
- Lack of dental assessment: A systematic collection, analysis, and documentation of the oral and general health status and patient needs was not done **during pregnancy**.
- Lack of dental care: The type of dental treatment required to either maintain or restore a patient's optimum dental health or dental condition was not received **during pregnancy**.
- Inappropriate use of ER: Multiple visits to the ER to treat conditions that could be handled by attending physician, either general practitioner or OB doctor.

6. Medical: Fetal/Infant

- Non-viable fetus: An expelled or delivered fetus which, although it is living, cannot possibly survive to the point of sustaining life independently, even with the support of available medical therapy.
- LBW: Low Birth Weight, any newborn, regardless of gestational age, whose weight at birth is less than 2500 grams, or 5lb. 5 oz. (5# 5 ounces)

- VLBW: Very Low Birth Weight, any newborn, regardless of gestational age, whose weight at birth is less than 1500 grams, or 3 lb. 5 oz.
- ELBW: Extremely Low Birth Weight, any newborn, regardless of gestational age, whose weight at birth is less than 750 grams, or 1 lb. 10 oz.
- Intrauterine Growth Restriction (IUGR): Birth weight of the fetus is below the 10th percentile of mean weight for gestational age.
- Congenital anomaly: Birth defects, malformations, chromosomal conditions, and other conditions noted prenatally, at delivery, or on autopsy.
- Prematurity: Infant delivered at less than 37 completed weeks gestation.
- Infection/sepsis: Infant shows clinical evidence or symptoms known to be associated with infection.
- Failure to thrive: An abnormal lag in growth and development of an infant resulting from conditions that interfere with normal metabolism, appetite, and activity. Causative factors may include chromosomal conditions, major organ system defects, disease or acute illness, physical deprivation or neglect.
- Birth injury: Insult or injury occurring to the fetus in the process of birth (ex. Hypoxia, fractured clavicle, cephalohematoma, etc.).
- Feeding problem: Infant exhibits inability or lack of desire to feed from breast or bottle.
- Respiratory Distress Syndrome (RDS): Acute lung disease of the newborn caused by progressive respiratory failure resulting from inadequate surfactant function – also called Hyaline Membrane Disease.
- Developmental delay: Infant falls below the norm in any one of these five areas: gross motor control, fine motor control, social interaction, language, or self-help.
- Inappropriate level of care: Infant delivered or childbearing parent treated in facility without level of care designation needed for the childbearing parent or infant conditions. For example, a 24-week gestation infant being delivered at a facility without a NICU.
- Positive drug test: Infant had a positive toxicology screen post-delivery.

7. Pediatric Care

- Standard of care not met: Infant assessment of treatment did not meet commonly accepted pediatric practice standards.
- Inadequate assessment: Pediatric provider did not appropriately assess for certain conditions or circumstances.
- No pediatric care: The infant was not seen for routine well baby visits, immunizations or other non-emergency care.
- Lack of referrals: Conditions or circumstances were identified in assessment, but no referral(s) made to existing appropriate services.
- Missed appointments/immunizations: Missed pediatric appointments resulted in ineffective pediatric care or Missed one or more of standard immunizations recommended for age.
- Multiple providers/cites: Infant received pediatric care from more than one provider, resulting in sporadic and fragmented care.
- Inappropriate use of ER: Multiple visits to ER to treat conditions that could be handled by attending physician, either general practitioner or primary care pediatric doctor.

8. Environment

- Unsafe neighborhood: Childbearing parent or family discloses that there is general fear for safety in the neighborhood where they resided during pregnancy and while the infant was alive.

Neighborhood known to local law enforcement or public health to have a high incidence of violence, crime, and neglect.

- Substandard housing: Any housing that does not meet local housing codes; evidence of unreliable heat, poor water quality, infestations, structural insufficiencies.
- Overcrowding: More people living in the housing space than the space was designed to accommodate.
- Second-hand smoke: Regular ongoing smoke inhaled by a pregnant person or the infant from tobacco, MJ and crack cocaine.
- Little/no breastfeeding: Infant was not breastfed or did not receive pumped breast milk for significant amount of time as determined by the team's subjective deliberation.
- Improper formula prep/feeding: Guidelines for sanitation of bottles, and water, mixing, dilution, safe handling and storage of formula was not followed. Evidence of un-safe feeding practices, such as bottle propping, over or underfeeding, frequency and amount of feeding not within AAP guidelines.
- Improper/no car seat use: While in a moving vehicle, infant was not restrained or was restrained incorrectly in a child passenger safety seat at the time of injury leading to death. Includes using the car seat for infant sleep or leaving the car seat on a table or other furniture where the infant and/or car seat can fall.
- Unsafe sleep location: Infant was placed in near proximity to one or more persons, on the same sleep surface, when found unresponsive. Infant was sleeping on a surface other than one specifically designed for safe infant sleep* when found unresponsive. Infant was found unresponsive on bedding softer than a firm crib mattress and/or near pillow, blankets, comforter, waterbed, sheepskin, etc. (*CPSC approved).
- Objects in the sleep environment: Indicate if there was anything in the sleep space with the baby. For more information, refer to question I2o, *Objects in child's sleep environment and relation to airway obstruction*.
- Infant overheating: When found unresponsive, infant was overheated by over dressing with too many clothes or blankets, the room or area was overly warm from a furnace, space heater, fireplace, oven, or there was a lack of ventilation allowing heat to build up.
- Not back sleeping position: Infant put to bed or found in any position other than on their back.
- Apnea monitor, misuse: Infant was on prescribed apnea monitor following discharge from hospital. This includes a monitor was prescribed, but not in use, as well as a monitor that was in use, but malfunctioned or was not used properly.
- Lack of adult supervision: An event in which parent or caretaker did not provide adequate and reasonable supervision of infant due to absence or impairment. Also see section P14—Child Neglect.

9. Injuries

- Suffocation/strangulation: Accidental suffocation or strangulation in bed, or ASSB, occurs when something limit's a baby's breathing such as soft bedding, entrapment between two objects, such as a mattress and wall, or overlay by another person. Suffocation occurs when something presses on or wraps around the infant's head and neck blocking the airway.
- Abusive head trauma: Infant died due to injuries or conditions resulting from Abusive Head Trauma, including being intentionally shaken by another.
- General trauma: Any injury that has the potential to cause prolonged disability or death, accidental or intentional.

10. Social Support

- Lack of family support: The childbearing parent had few or no friends or family members providing emotional, financial, or physical support during or after their pregnancy.
- Lack of neighbors/community support: The childbearing parent did not feel that they could rely on neighbors or nearby community members for help or support if they needed it.
- Lack of partner support: The biological non-childbearing parent of the baby did not contribute in a significant emotional, financial, or physical fashion.
- Single parent: A parent who has a dependent child or dependent children and who is widowed, divorced, unmarried, or otherwise raising a child or children alone, without the support of a partner.
- Living alone: Childbearing parent is living on their own or alone with their dependent children.
- < 12th grade education: Last grade of school completed by the childbearing parent is less than 12th grade.
- Special education/disability: Childbearing parent has documented learning disability or condition resulting in impaired understanding or use of knowledge.
- Physical or cognitive disability: Childbearing parent had documented physical or cognitive disability

11. Partner/ Caregivers

Partner/biological non-childbearing parent/caregiver is indicative of another person, besides the childbearing parent, who has shared care for the infant on a regular basis or other individual in the role of parent

- Employed: Was employment an issue that was a present or contributing factor in the death? If present or contributing, mark “yes” if the partner/biological non-childbearing parent was employed or “no” to indicate the partner/biological non-childbearing parent was not employed.
- History of mental illness: Documented history of mental illness.
- Substance or tobacco use/abuse – Current: Any use by the partner/biological non-childbearing parent/caregiver of any alcohol, illicit drugs or tobacco product during or after pregnancy up to the time of the infant’s death. Specify the type(s) of drug, including tobacco if known. (*Note: Second-hand smoke from any source in the home is noted in section P8, Environment.*)
- Substance or tobacco use/abuse – History: Any use by the partner/biological non-childbearing parent/caregiver of any alcohol, illicit drugs or tobacco product prior to pregnancy up to the time of the infant’s conception. Specify the type(s) of drug, including tobacco if known. (*Note: second hand smoke from any source in the home is noted in section P8, Environment.*)

12. Family Transition

- Frequent/recent moves: Living situation is unstable and childbearing parent has moved frequently before, during, or after the pregnancy.
- Living in shelter/homeless: The childbearing parent and baby were homeless, living on the street, living in a shelter, or making frequent moves among friends and family members immediately before, during, or after the pregnancy, or while the infant was alive.
- Concern re: citizenship: The childbearing parent or other principal caretaker exhibited concerns that their documentation or citizen status may compromise their ability to seek or receive services.
- Divorce/separation: The childbearing parent separated or divorced from their spouse or intimate partner immediately before, during, or after the pregnancy or while the infant was alive.

- Multiple partners: The childbearing parent had more than one sexual partner in a 12-month period.
- Childbearing parent in prison/parole or probation: Childbearing parent was incarcerated, paroled, or on probation immediately before, during or after the pregnancy or while the infant was alive.
- Non-childbearing parent in prison/parole or probation: Either biological non-childbearing parent or other individual in the role of parent was incarcerated, paroled, or on probation immediately before, during or after the pregnancy or while the infant was alive.
- Major illness/death in family: A major illness or death of a family member, causing stress or anxiety or having an impact on the family's socioeconomic status or essential functions immediately before, during, or after the pregnancy, or while the infant was alive.

13. Mental Health/Stress

- Childbearing parent history of mental illness: Just prior to conception, childbearing parent has a history of documented mental illness, suicide attempts or gestures, hospitalizations, supervised medication, or other indicators of mental illness.
- Depression/mental illness during pregnancy: The childbearing parent of the baby displays clinical symptoms of depression, makes suicidal attempts or gestures, is hospitalized or under supervised medication, or otherwise is experiencing other indicators of mental illness during pregnancy.
- Depression/anxiety/mental illness in postpartum period: The childbearing parent of the baby displays clinical symptoms of depression, makes suicidal attempts or gestures, is hospitalized or under supervised medication, or otherwise is experiencing other indicators of mental illness. Anxiety disorders share features of excessive fear and anxiety and related behavioral disturbances. These disorders include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, panic disorder, agoraphobia, generalized anxiety disorder, substance/medication-induced anxiety disorder, and anxiety disorder due to another medical condition.
- Multiple stresses: The childbearing parent experiences three or more family, economic, environmental, or other stresses during pregnancy or while the infant is alive.
- Social chaos: The childbearing parent's history suggests social interactions and social support systems are destructive and/or disruptive of functional stability making it difficult for them to function in life.
- Employed: Was employment an issue that was a present or contributing factor in the death? If present or contributing, mark "yes" if the childbearing parent was employed or "no" if not employed.
- Concern about enough money: The childbearing parent or other principal caretaker expressed concerns about having enough money on a month to month basis to meet basic needs of the family during pregnancy or while the infant is alive.
- Work/employment problems: An aspect of the childbearing parent's employment or work situation caused worry or stress during pregnancy or during the time the infant is alive. (examples: insufficient or no parental leave, large amounts of time without rests, etc.)
- Child/Children with special needs: Other dependent child(ren) of the childbearing parent or partner experiencing health or behavioral problems.
- Problems with family/relatives: The childbearing parent's friends, partner, biological non-childbearing parent, and/or family members were a negative influence or contributed to the childbearing parent acting in a manner detrimental to their health or their baby's health.

- Lack of grief support: Family did not receive appropriate and culturally relevant services related to bereavement and grief support following the death of the infant. These are examples of lack of grief support:
 - No referral for grief services made.
 - No appropriate bereavement services available in this community.
 - Referral was made and services were reasonably available, however family did not access services.

14. Family Violence/Neglect

- History of abuse (Childbearing parent): Disclosure or evidence of past physical, emotional, or sexual abuse of childbearing parent, not with current partner or biological non-childbearing parent, not during the pregnancy or while infant is alive. Specify the type of abuse.
- Current abuse (Childbearing parent): Disclosure or evidence of physical, emotional, or sexual maltreatment of the childbearing parent by spouse, current or former dating partner, or any other family member, friend, or relative. Current abuse includes events taking place in the three months prior to conception, during the pregnancy, and while the infant is alive. Specify the type of abuse.
 - *Physical Abuse*: Hitting, slapping, pushing, throwing objects, or any other act, which results in non-accidental physical injury to the childbearing parent.
 - *Emotional abuse*: Name-calling, threats, intimidation, coercive behavior, controlling or preventing childbearing parent from seeking and engaging in services.
 - *Sexual Abuse*: Forced or hurtful sex, non-protected sex, or otherwise engaging the childbearing parent in sexual acts they do not want to do.
- History of abuse (Biological non-childbearing parent): Disclosure or evidence of past physical, emotional, or sexual abuse of biological non-childbearing parent, not during the childbearing parent's pregnancy or while infant is alive. *Specify type of abuse.*
- Current abuse (Biological non-childbearing parent): Disclosure or evidence of physical, emotional, or sexual maltreatment of the biological non-childbearing parent by spouse, current or former dating partner, or any other family member, friend, or relative. Current abuse includes events taking place in the three months prior to conception, during the pregnancy, and while the infant is alive. Specify the type of abuse.
 - *Physical Abuse*: Hitting, slapping, pushing, throwing objects, or any other act, which results in non-accidental physical injury to the childbearing parent.
 - *Emotional abuse*: Name-calling, threats, intimidation, coercive behavior, controlling or preventing childbearing parent from seeking and engaging in services.
 - *Sexual Abuse*: Forced or hurtful sex, non-protected sex, or otherwise engaging the childbearing parent in sexual acts they do not want to do.
- History child abuse, this infant: Evidence of past physical, emotional, or sexual abuse of this child by the parent or caretaker. May be disclosed in home interview, suspected or confirmed reports to child protective services, law enforcement records, and/or medical records.
- History child abuse, other child: Evidence of past physical, emotional, or sexual abuse of any other child(ren) in the household by the parent or caretaker. May be disclosed in home interview, suspected or confirmed reports to child protective services, law enforcement records, and/or medical records. Include children in other homes, for example a biological non-childbearing parent's previous relationship, and non-custodial children.
- Current child abuse, this infant: Evidence of past physical, emotional, or sexual abuse of this child by the parent or caretaker. May be disclosed in home interview, suspected or confirmed

reports to child protective services, law enforcement records, and/or medical records. Current abuse includes events taking place in the while the infant is alive.

- Current child abuse, other child: Evidence of past physical, emotional, or sexual abuse of any other child(ren) in the household by the parent or caretaker. May be disclosed in home interview, suspected or confirmed reports to child protective services, law enforcement records, and/or medical records. Include children in other homes, for example a biological non-childbearing parent's previous relationship and non-custodial children.
- History child neglect, this infant: The negligent treatment or maltreatment of **this child** by the parent or caretaker under circumstances indicating harm or threatened harm to the child's health or welfare. Neglect includes willfully permitting the child to be placed in a situation such that their personal health is endangered (failure to provide adequate food, clothing, shelter, medical care, competent supervision).
- History child neglect, other child: The negligent treatment or maltreatment of **any other child(ren) in the household** by the parent or caretaker under circumstances indicating harm or threatened harm to the children's health or welfare. Neglect includes willfully permitting the child to be placed in a situation such that their personal health is endangered (failure to provide adequate food, clothing, shelter, medical care, competent supervision).
- Current child neglect, this infant: The negligent treatment or maltreatment of **this child** by the parent or caretaker under circumstances indicating harm or threatened harm to the child's health or welfare. Neglect includes willfully permitting the child to be placed in a situation such that their personal health is endangered (failure to provide adequate food, clothing, shelter, medical care, competent supervision).
- Current child neglect, other child: The negligent treatment or maltreatment of **any other child(ren) in the household** by the parent or caretaker under circumstances indicating harm or threatened harm to the children's health or welfare. Neglect includes willfully permitting the child to be placed in a situation such that their personal health is endangered (failure to provide adequate food, clothing, shelter, medical care, competent supervision).
- CPS referrals: Any CPS referrals, substantiated or not.
- Police reports: More than one occurrence where either parents or caretakers of the infant are involved in police reported incidents as victim, perpetrator, or witness to violent or potentially criminal event.

15. Culture

- Language barrier: The childbearing parent and/or other principal caretakers for the infant were not able to communicate expediently with providers because of language differences. Includes use of interpreters.
- Beliefs re: pregnancy/health: The childbearing parent or principal caretakers for the infant exhibited health beliefs inconsistent with standard medical practice.

16. Payment for Care

- Private: Private health insurance refers to health insurance plans marketed by the private health insurance industry, as opposed to government-run insurance programs. Examples of private health insurance companies may be Aetna, Humana, or Blue Cross Blue Shield (BCBS). Common types of private health insurance plans include:
 - *Health Maintenance Organizations (HMOs)*
 - *Participating Provider Options (PPOs)*
 - *Point-of-Service (POS)*
 - *Fee for Service Plans*

- *Health Savings Accounts*
- Medicare: Family's medical care was paid for by Medicare.
- Medicaid: Medicaid is a health care program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is a joint program, funded primarily by the federal government and run at the state level, where coverage may vary.
- Self-Pay/medically indigent: Patient/family did not have insurance or other means for paying for prenatal care, delivery, and/or pediatric care.

17. Services Provided

- Inadequate Information: The family/childbearing parent did not receive prevention education and information that would have helped to prevent the infant death. Specify the education topic area in the space provided, e.g. signs and symptoms of preterm labor or infant safe sleep environment.
- Lack of WIC (eligible): Lack of participation in the Women, Infants, Children's program despite eligibility.
- Lack of Home Visiting (eligible): Lack of evidence-based home visiting despite eligibility. This could apply when there are no services in the area or the childbearing parent declined home visiting.
- Parent/child not eligible: The childbearing parent, principal caretaker, and/or child are not eligible for a needed service.
- Poor provider-to-provider communication: The service providers in the case were not known to each other or did not share with each other potentially important information about the case. This is provider-to-provider communication.
- Poor provider-to-patient communication: Health information was not effectively communicated to the patient. This could be due to several factors including no, poor or inappropriate communication, or low health literacy.
- Client dissatisfaction: The family's dissatisfaction with a pediatric care provider, hospital, prenatal care provider or other medical health professional was a factor in their not using a service in a timely or effective manner.
- Dissatisfaction, support services: The family had fear of, distrust, or dissatisfaction with services such as WIC, Healthy Start, etc.
- Lack of child care: Parent or principal care giver did not have access to quality, affordable child care by relatives, support persons, or licensed day care during pregnancy, delivery, or while infant was alive.

18. Transportation

- No public transportation: No existing or readily accessible public transportation during pregnancy, time of delivery, postpartum, and while infant was alive.
- Inadequate/unreliable transportation: Childbearing parent or principal caretaker of infant did not have reliable private transportation to needed services, or lack of transportation caused childbearing parent or caretaker to miss appointments or services.

19. Documentation

- Inconsistent or unclear information: Abstractor or review team members felt some part of the record was ambiguous, unclear or data from different sources is found to be conflicting, e.g. the prenatal record shows 5 OB/GYN visits, but the birth certificate shows 10.
- Missing data: Data that was documented as ordered or assessed, but results were not found, e.g. placental pathology was ordered but could not be found in the childbearing parent's chart.

- No death scene investigation: No death scene investigation was performed if the incident that precipitated the infant's death occurred outside of the hospital.
- No doll re-enactment: No doll re-enactment was done during the death scene investigation and the incident that precipitated the infant's death occurred outside of the hospital.

20. Other

Document any other issues pertinent to this case which have not already been captured in prior category.