



Data Dictionary
National Fatality Review
Case Reporting System

Version 5.0



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SAVING LIVES TOGETHER

Contents

| | |
|---|----|
| Case Number..... | 4 |
| Section A. Child Information..... | 6 |
| A1. Child Information (Complete for all ages) | 6 |
| A2. Complete for Children Over One Year Old | 9 |
| A3. Complete for All Infants Under One Year | 11 |
| A4. Expanded Infant/Maternal Questions..... | 21 |
| A5. Maternal Interview | 34 |
| Section B. Biological Parent Information | 38 |
| Section C. Primary Caregiver(s) Information | 42 |
| Section D. Supervisor Information..... | 46 |
| Section E. Incident Information | 50 |
| Section F. Investigation Information..... | 53 |
| Section G. Official Manner and Primary Cause of Death | 56 |
| Section H. Detailed Information by <i>Cause</i> of Death | 58 |
| H1. Motor Vehicle and other Transport | 58 |
| H2. Fire, Burn, or Electrocution | 60 |
| H3. Drowning | 62 |
| H4. Unintentional Asphyxia | 65 |
| H5. Assault, Weapon, or Person’s Body Part | 66 |
| H6. Fall or Crush..... | 68 |
| H7. Poisoning, Overdose, or Acute Intoxication | 69 |
| H8. Medical Condition | 70 |
| H9. Other Known Injury Cause..... | 71 |
| Section I. Other Circumstances of Incident | 73 |
| I1: Sudden and Unexpected Death in the Young (SDY) | 73 |
| I2. Death Related to Sleeping or the Sleeping Environment | 83 |
| I3. Was Death a Consequence of a Problem with a Consumer Product..... | 87 |
| I4. Did Death Occur During Commission of Another Crime..... | 87 |
| I5. Child Abuse, Neglect, Poor Supervision, and Exposure to Hazards | 88 |
| I6. Suicide | 93 |

| | |
|---|-----|
| Section J. Person Responsible (Other than Decedent) | 96 |
| Section K. Services to Family and Community as a Result of the Death..... | 101 |
| Section L. Prevention Initiatives Resulting from the Review | 102 |
| Section M. The Review Meeting Process | 105 |
| Section N. SUID and SDY Case Registry..... | 107 |
| Section O. Narrative..... | 110 |
| O1. Narrative..... | 110 |
| O2. Issues Summary (present and contributing factors) | 110 |
| 1. Pre-, Inter-, and Post-conception Care | 110 |
| 2. Medical: Mother | 111 |
| 3. Family Planning | 112 |
| 4. Substance Use..... | 113 |
| 5. Prenatal Care/Delivery | 113 |
| 6. Medical: Fetal/Infant..... | 114 |
| 7. Pediatric Care | 114 |
| 8. Environment..... | 115 |
| 9. Injuries..... | 116 |
| 10. Social Support | 116 |
| 11. Partner/FOB/Caregivers..... | 116 |
| 12. Family Transition..... | 116 |
| 13. Mental Health/Stress | 117 |
| 14. Family Violence/Neglect | 118 |
| 15. Culture..... | 119 |
| 16. Payment for Care | 119 |
| 17. Services Provided | 120 |
| 18. Transportation | 120 |
| 19. Documentation | 120 |
| 20. Other | 121 |
| Section P: Form Completed By | 121 |

Description of Integrated CDR/FIMR Case Reporting System

The National Fatality Review Case Reporting System (NFR-CRS), Version 5.0 integrates Child Death Review (CDR) reporting and Fetal and Infant Mortality Review (FIMR) reporting into one data system. Depending on the age of the child or the cause of the death being reviewed, some sections of the database and data dictionary will be relevant to the case you are reviewing and some will not. The table below outlines which sections are CDR-specific, which ones are FIMR-specific, and which sections are shared by both fatality review forms.

Overview of the CDR and FIMR Case Reporting System

| Section | Description | CDR | FIMR |
|-----------|--|-----|------|
| A1 | Child information (age, race, etc.) | √ | √ |
| A2 | Children over 1 year old | √ | |
| A3 | Infants | √ | √ |
| A4 | Expanded infant/maternal questions (expanded medical complications, education topics, referrals, etc.) | | √ |
| A5 | Maternal interview | | √ |
| B | Biological parents | √ | √ |
| C | Caregiver | √ | √ |
| D | Supervisor | √ | √ |
| E | Incident | √ | √ |
| F | Investigation | √ | √ |
| G | Cause of Death | √ | √ |
| H | Detailed causes (motor vehicle, fall/crush, drowning, etc.) | √ | √ |
| I1 | Sudden Death in the Young (SDY) | √ | |
| I2 | Sleep-related environment | √ | √ |
| I3 | Problem with a consumer product | √ | √ |
| I4 | Commission of a crime | √ | √ |
| I5 | Child abuse, neglect, poor supervision, exposure to hazards | √ | √ |
| I6 | Suicide (displayed if manner = suicide) | √ | |
| J | Person(s) responsible | √ | √ |
| K | Services provided | √ | √ |
| L | Prevention initiatives | √ | √ |
| M | Review meeting | √ | √ |
| N | SUID/SDY categorization | √ | |
| O1 | Narrative | √ | √ |
| O2 | Issues (present and contributing factors) | | √ |
| P | Form completion | √ | √ |

Case Number

The first data entry page that appears on your screen is the Case Definition Page, which corresponds to the “Case Number” section of the paper form. This is where you create the unique identifier for the case you are entering. The paper form allows for five levels of information to define a case: State, County or Team Number, Year of Review, and Sequence of Review. However, depending on the profile that your state has established with the National Center, you may not see all of these options.

State

This identifier is automatically filled in for you, and you cannot edit this field. Every state has a unique identifier.

County or Team Number

This identifier indicates the local team. For states with County teams, this will be a county. For states with non-county teams, this will be the team name. Local-level users will have this identifier filled in automatically and will not be able to edit this field. State-level users will be able to select from among the counties or teams in their state to fill in this field.

Year of Review

This identifier is automatically filled in to the current year. You can edit this field in order to enter cases from past years.

Sequence of Review

This identifier is automatically filled in to the next highest sequence number for the current year. For example, if the last sequence number you entered in the current year was “00021” then the next new case you enter will come up as sequence “00022”, regardless of whether sequences “00019” or “00020” exist. You can edit this field to any sequence number. Number must be numeric only – no letters or characters allowed.

Case Type

Indicator if review occurred for death, near death/serious injury, or not born alive (fetal death/stillborn). For CDR users, the case type will always default to “death”; however, CDR users may select one of the other case types from the drop-down menu if appropriate. There is no default case type for FIMR users: FIMR users will need to select one of the three case types in the drop-down box in order to proceed with data entry/saving.

Fetal death/stillborn is the spontaneous intrauterine death of a fetus at any time during pregnancy. Fetal deaths are also sometimes referred as stillbirths. States vary on fetal death reporting requirements, please check your state code for specific requirements.

Death Certificate

Death certificate number as stated on death certificate.

Birth Certificate

Birth certificate number as stated on birth certificate.

Medical Examiner/Coroner

Medical examiner or coroner case number (if applicable). This is not the medical examiner or coroner's license number.

Date Team Notified of Death

The date the case was first identified by the state or local coordinator, fetal infant mortality review team, or child death review team. This can be when the team was made known of the death through vital records, newspaper clippings, agency alerts, etc.

Child Never Left Hospital Following Birth

Use this question to note if the child never left the hospital following birth. The main purpose of this question is to hide other questions in the NFR-CRS that are not applicable to this case (for example, if the child never left hospital following birth, then the user will not be asked to complete question A17 (Type of residence) as that question is not relevant to the child.) If the child was not born alive, please also check this question.

Section A. Child Information

A1. Child Information (Complete for all ages)

A1: Child's name

Legal name of child as stated on death certificate. Some reporting sites may find that an individual data source will require that unique identifiers such as name or social security number be stored in hard copy only, not in the electronic database. If this is the case, it is acceptable to leave these fields blank.

A2: Date of birth

Date of child's birth as stated on birth or death certificate.

A3: Date of death

Exact date of child's death as stated on death certificate. Exact date of death is sometimes unknown, as in an unwitnessed suicide or homicide. If this is the case, select unknown. If the child was not born alive (fetal death/stillborn), the date of delivery should also be used for the date of death, even if there is reason to believe the fetus expired prior to the delivery date.

A4: Age

Numerical age of child as stated on death certificate. In some cases, the child's exact age will not be known. If age is provided within a five-year age range or less, choose the midpoint of the range; round to the lower year if the midpoint calculation results in a half year. If an age range of greater than five years is provided, leave this field blank.

- *Years, Months, Days, Hours, Minutes, Unknown:* Type of unit used to report child's numerical age as stated on death certificate.

A5: Race

Race of child as stated on death certificate. These categories were issued by the Office of Management and Budget in order to promote comparability of data among federal data systems. The standards for 1997 have five racial groups: American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or other Pacific Islander and White. For the NFR-CRS, American Indian, Alaskan Native, Native Hawaiian and Pacific Islander each have their own category. If child is Arab, select "White."

A6: Hispanic or Latino origin

Specify whether the child is of Hispanic or Latino origin.

A7: Sex

Sex of child as stated on death certificate.

A8: Residence address

Residential address of child as stated on death certificate. If a person is currently residing in a short-term facility for less than six months, use his or her home address as their residential address. If a person is residing in a long-term facility for over six months, such as a college dormitory, prison or residential nursing home, use the institution's address. If they are living in a short-term facility and no residential address is noted, use the address of the short-term facility.

If child was not a resident of the United States, select “out of country” in the drop down list of states and enter the country of residence in the text box.

Some reporting sites may find that an individual data source will require that unique identifiers, such as a specific street address, be stored in hard copy only, not in the electronic database. If possible, enter resident state at a minimum, as it can be used to confirm state residency.

A9: Child's weight at death

Child's weight at time of death (in pounds/ounces, grams, or kilograms).

A10: Child's height at death

Child's height at time of death (in feet/ inches or centimeters).

A11 State of death

Indicate the state in which the child died.

A12: County of death

Indicate the county in which the child died.

A13: Child had disability or chronic illness

Child had a disability or chronic illness prior to the time of incident. Chronic implies an impairment or illness that has a substantial long-term effect on the child's day-to-day function or health. For fetal deaths/stillborn, please leave the question blank.

- *Physical/orthopedic*: Includes any anatomical loss, mobility loss, physiological disorders, cosmetic impairments and/or chronic illnesses or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate epilepsy/seizure disorder/convulsions or cancer.
- *Mental health/substance use disorders*: Includes any mental or psychological disorder, such as emotional or mental illness. Examples include depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, schizophrenia, and personality disorders. A mental disorder is a disability only if it substantially limits one or more major life activities. A substance use (abuse or dependence) disorder is a maladaptive pattern of recurrent substance use leading to clinically significant impairment or distress.
- *Cognitive/intellectual*: Includes when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. Cognitive deficits may be congenital or caused by environmental factors. Examples may include deficits from brain injury, Down syndrome, or any of a number of congenital conditions that cause cognitive impairment. This definition includes cognitive/learning disabilities. Cognitive deficits may be congenital or caused by environmental factor or other diseases” (such as Alzheimer’s disease, etc.)
- *Sensory*: Includes any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.

If yes, Receiving Children's Special Health Care Needs Services: Children's Special Health Care Needs Services are provided by states through their Federal Title V Block Grant, and

may include medical care, family support services, counseling and special therapeutic services. Each state may name these types of services differently; however, if the child is receiving any services paid for through the Title V CSHCS, this question should be marked as yes.

A14: Were any siblings placed outside of the home prior to this child's death

If yes, indicate number of child's siblings who had been placed in foster care or adopted before date of death. If no other siblings were present in the child's home, select "N/A."

A15: Child's health insurance

Indicate type of health insurance child was covered under at time of incident.

- *None*: Family/child had no medical insurance at time of incident.
- *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*
- *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.
- *State plan*: State plan is defined as family's medical care being paid for by any type of state-sponsored plan, except Medicaid.
- *Indian Health Service*: Indian Health Service is an agency within the Department of Health and Human Services and is responsible for providing federal health services to American Indians and Alaskan Natives.
- *Other, specify*: Family's medical care paid for by any other type of support, excluding self-support. Tricare should be noted in Other.
- *Unknown*: FR team does not know if the child was insured.

A16: Was the child up to date with Academy of Pediatrics Immunization schedule

According to documentation, indicate if child was up to date with recommended immunization schedule based on child's age and the immunization series required. These are available at <http://www.cispimmunize.org/>.

A17: Type of residence

Place where child lived a majority of the time. If a newborn infant dies in a hospital shortly after birth, residence is still primary caregiver's.

A18: New residence in past 30 days

Child's place of residence (stated in question A8) was new to child within last 30 days preceding death.

A19: Residence overcrowded

This is a subjective determination to be made by the team based on the number of rooms and the number of persons living in the residence. The answer to this question may indicate a risk factor for specific causes of deaths, including fires, suffocation and violence-related deaths.

A20: Child ever homeless

Homeless is defined as having no fixed address and living in a shelter, on the street, in a car or in makeshift quarters in an outdoor setting. A person who has no home of their own but is staying indefinitely with friends or family is not considered homeless here.

A21: Number of other children living with child

Number of other children under 18 (siblings and non-siblings) living in child's household at time of incident.

A22: Child had history of child maltreatment

Indicate whether the child has history of being the victim of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from autopsy, law enforcement report or medical records. If referrals were made but not substantiated, still select "yes" regarding history unless the referral was found to be completely falsified.

A23: Was there an open CPS case with child at time of death

A Child Protective Services (CPS) case was currently open with the child that occurred prior to the incident causing the child's death. Select "yes" even if abuse or neglect was not substantiated. For example, services were in place such as family preservation/strengthening.

A24: Was child ever placed outside of the home prior to the death

Select "yes" if child ever had foster parents whether through the death of the biological parents; through voluntary or forced adoption; or through forced removal from a biological or adoptive home. Foster care includes licensed and relative/kinship foster homes.

A2. Complete for Children Over One Year Old

Section A2 is only completed by CDR users.

A25: Child's highest education level

Select the highest level of education completed by the child. If child received a GED, select "high school graduate" as highest education level. Select "N/A" for specific circumstances such as a child being too young to attend school or an inability to attend due to severe disabilities.

A26: Child's work status

Indicate if child held a job of any type within the past four weeks. This includes formal jobs for pay or other compensation, informal jobs such as paper delivery, child and lawn care (if done outside one's family setting), volunteer activities for an organized group only (e.g. excluding helping neighbors if not for production), working on the family farm or ranch if it is production related (e.g. milking a cow on a dairy farm). Employment also includes working in a family business regardless of pay if the work contributes to the profitability of the business. Sporadic

jobs should be considered part time employment. Select “N/A” for specific circumstances such as if the child was severely disabled.

A27: Did child have problems in school

Problems in school include those from a documented history from school, social services, juvenile court or law enforcement records. Select “yes” if no documented history exists but the child perceived that he or she was experiencing problems. Problems in school include:

- *Academic*: This category should be selected if a student’s academic performance was poor or declining.
- *Truancy*: A chronic failure to attend school.
- *Suspensions*: Includes all suspensions received for any reason.
- *Behavioral*: This is a broad category and can include acting out in class, disobedience, being disruptive, bullying or being bullied.
- *Expulsion*: Refers to the removal of a student from a school for violating rules.
- *Other*: Select this category if the school problem your team has identified doesn’t fit into any other category. Please specify the problem in the text field.
- *Unknown*: Select unknown if your team was unable to determine the types of problems the child was experiencing with school.

A28: Child had history of intimate partner violence

Child had a documented history of intimate partner violence (IPV) as either victim or perpetrator. Documented refers to evidence from law enforcement, medical or human services. IPV is defined as actual or threatened physical or sexual violence or psychological and emotional abuse directed toward a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner. Intimate partners may be heterosexual or of the same sex. This may also include domestic disturbance complaints to which law enforcement responded.

A29: Child’s mental health

- *Child had received prior mental health services*: Indicate whether the child had ever received professional treatment for a mental health problem, either near the time of death or in the past.
- *Child was receiving mental health services*: Indicate whether the child was in current treatment (that is, had a current prescription for a psychiatric medication or saw a mental health professional within the past two months). Treatment includes seeing a psychiatrist, psychologist, medical doctor, therapist or other counselor for a mental health or substance abuse problem; receiving a prescription for an antidepressant or other psychiatric medication; or residing in an inpatient or halfway house facility for mental health problems. If the child died of an overdose, the existence of an antidepressant or other psychiatric medication in the child’s bloodstream is not sufficient evidence of mental health treatment because the medication may not have belonged to the child.
- *Child was on medications for mental illness*: Indicate whether the child had an active prescription for psychiatric medication at time of death. They need not have actually been taking the medication.
- *Issues prevented child from receiving mental health services*: Evidence exists in the records to indicate the child experienced barriers to accessing mental health care, applicable only to children noted as having a mental health problem and not being in treatment. Select “yes” if there were obstacles such as lack of insurance coverage,

transportation problems or long waiting lists or if it is known that treatment was either recommended by a health professional and/or identified by the family and care was not received.

A30: Child had history of substance abuse

Child was perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse occurred, select "other." Select "yes" if child was noted as using illegal drugs (such as heroin or cocaine), abusing prescription medications (such as pain relievers or Valium), or regularly using inhalants (e.g., sniffing or huffing gas). If the child is mentioned as using illegal drugs even if addiction or abuse is not specifically mentioned, select "yes."

Select "yes" for a child who is noted as participating in a drug or alcohol rehabilitation program or treatment including self-help groups and 12-step program, even if the child was noted as being currently clean and sober. Select "no" for a child with short-term experimental use that did not cause life problems and/or addictions.

Select "yes" for a problem from the past (e.g. five years or more ago) that has resolved and no longer appears to apply. Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

A31: Child had delinquent or criminal history

Child had a documented history of delinquent or criminal behaviors or actions. This includes any history with the juvenile justice system or the criminal justice system. If yes, specify type of delinquent or criminal history that is documented. Delinquent behavior may include school disciplinary actions, charges or convictions for misdemeanor offenses. Criminal behavior includes charges or convictions for felony charges.

A32: Child spent time in juvenile detention

Child had documented history of time spent in a juvenile detention center.

A33: Child acutely ill in the two weeks before death

Child was reported to have been sick in the two weeks before the death, including an exacerbation of a chronic illness. A reported illness refers to documentation from a school district, a school referral, a pediatrician, emergency room, hospital, first responder, police report or autopsy. Examples include any acute illness such as an upper respiratory infection, strep throat, diarrhea and pneumonia. For a child with a chronic illness but without any acute symptoms in the two weeks prior to death, select "no." Exacerbations of chronic illness may include a severe asthma attack or insulin shock.

A3. Complete for All Infants Under One Year

A34: Was this case reviewed by both a Fetal and Infant Mortality Review (FIMR) and a Child Death Review (CDR) team

Indicate whether this case was reviewed by multiple fatality review programs.

A35: Gestational age

Indicate gestational age in weeks as stated on birth certificate or medical records.

A36: Birth weight

Indicate birth weight in grams OR pounds/ounces as stated on birth certificate or medical records.

A37: Multiple gestation

Pregnancy with more than one fetus at conception as stated on birth certificate or medical records.

A38: Including the deceased infant, how many pregnancies did the birth mother have

Record the number of pregnancies that the mother had previous to and including the deceased infant. Often abbreviated in medical records as “G” for *gravida*, this number may appear as a subscript after “G”.

A39: Including the deceased infant, how many live births did the birth mother have

Record the number of live births that the mother had, including the deceased infant. Often abbreviated in medical records as “P” for *para*, this number may appear as a subscript after “P.” Because some women have miscarriages, abortions, or stillbirths, this number can be different from her number of pregnancies.

A40: Not including the deceased infant, number of children birth mother still has living

Record the number of the biological mother’s living children, even if the mother does not have custody. Often abbreviated in medical records as “L” for *living*, this number may appear as a subscript after “L”.

A41: Prenatal care provided during pregnancy of deceased infant

Prenatal visit (as stated on birth certificate or medical records) is defined as pregnancy-related medical care delivered by a doctor, nurse or other health professional with the goal of monitoring the pregnancy, providing education and increasing the likelihood of a positive maternal/fetal outcome. Document the number of prenatal visits child's mother made to doctor during pregnancy and month of first prenatal visit as stated on birth certificate or medical records.

A42: Were there access or compliance issues related to prenatal care

Indicate if there were compliance with care issues on the part of the mother, family or health care providers related to the death. Specify issues if appropriate. Compliance with care is defined as recommended ways of caring for a pregnant mother or child as prescribed by a physician.

- *Lack of money for care:* Mother or family did not have insurance or other means for paying for prenatal care, delivery and/or pediatric care.
- *Limitations of health insurance coverage:* Delay, loss or inaccessibility of medical services due to problems with health insurance coverage.
- *Multiple health insurance, not coordinated:* Mother had multiple health insurance coverage policies, resulting in delay or loss of medical care coverage, authorizations for treatment, etc.

- *Lack of transportation*: Mother did not have reliable public or private transportation to needed services, or lack of transportation caused mother to miss appointments or services.
- *No phone*: Home, workplace or dwelling where mother resided did not have a working phone nor was a cell phone available.
- *Cultural differences*: Mother exhibited health beliefs inconsistent with standard medical practices in the U.S.
- *Religious objections to care*: Mother had religious objections to care. Parents sometimes deny their children the benefits of medical care because of religious beliefs. In some jurisdictions, exemptions to child abuse and neglect laws can restrict government action to protect children or seek legal redress when the alleged abuse or neglect has occurred in the name of religion.
- *Language barriers*: The mother and provider(s) were not able to communicate effectively because of language differences. For example, the mother spoke a different language than the provider and an interpreter was not available.
- *Referrals not made*: Conditions or circumstances warranting a referral were identified in an assessment, but no referral(s) made to appropriate services.
- *Specialist needed, not available*: A needed or required specialist was not located reasonably nearby mother's residence.
- *Multiple providers, not coordinated*: Mother received care from more than one provider, resulting in sporadic and fragmented care.
- *Lack of child care*: Mother did not have access to quality, affordable child care by either relatives, support persons or licensed day care during pregnancy.
- *Lack of family/social support*: Mother had few or no friends or family members providing emotional, financial or physical support during pregnancy.
- *Services not available*: A needed or required clinical service was not located reasonably nearby mother's residence.
- *Distrust of health care system*: The mother's or family's fear or distrust of or dissatisfaction with a provider(s) was a factor in their not using a service in a timely or effective manner.
- *Unwilling to obtain care*: Mother unwilling to seek prenatal care regardless of provider encouragement or referrals.
- *Intimate partner would not allow care*: The mother's intimate partner, who could be her husband, boyfriend or female partner, used violence or threats of violence or termination of the relationship to prevent her from seeking prenatal care.
- *Other, specify*: Indicate other access or compliance issues related to care.

A43: During pregnancy, did mother have any medical conditions/complications:

Specify any medical complications (pregnancy-related or non-pregnancy-related) experienced during this pregnancy. This question will not appear in the NFR-CRS if you are entering a FIMR case. See question A83.

- Cardiovascular
 - *Hypertension-gestational*: High blood pressure that occurs during the second half of pregnancy and disappears soon after the baby is born.
 - *Hypertension-chronic*: A long-term condition in which blood pressure is higher than normal.

- *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 severe manifestation of the disease.
- *Clotting disorder*: Certain abnormalities of blood coagulation that can threaten the health of pregnancies. Some of these conditions include Antithrombin Deficiency, Antiphospholipid Syndrome, Factor V. Leiden Thrombophilia, Prothrombin Thrombophilia, Prothrombin Thrombophilia and Protein S Deficiency.
- Hematologic
 - *Folic acid deficiency*: A lack of folate—or vitamin B9—that can lead to anemia. Can be caused by not eating enough foods that contain folic acid, excessive alcohol intake, or conditions that inhibit absorption of folic acid, such as celiac disease or cancers of the digestive tract.
 - *Sickle cell disease*: There was a known diagnosed of sickle cell disease and/or the mother of the deceased infant had two abnormal hemoglobin genes.
 - *Anemia*: Abnormally low levels of blood or red blood cells in the bloodstream.
- Respiratory
 - *Asthma*: A chronic lung disease that inflames and narrows the airways, and can cause recurring periods of wheezing, chest tightness, shortness of breath, and coughing.
 - *Pulmonary embolism*: A sudden blockage in the lung artery, usually caused by a blood clot that travels to the lung from a vein in the leg.
- Endocrine/Metabolic
 - *Diabetes, type 1 chronic*: A chronic condition in which the pancreas does not produce enough insulin, resulting in elevated blood sugar. Previously called insulin-dependent or juvenile diabetes, as it is commonly diagnosed in children, teens, or young adults.
 - *Diabetes, type 2 chronic*: The most common form of diabetes, type 2 diabetes occurs when the body either resists the effects of insulin or resists the effects of insulin, resulting in elevated blood sugar. Unlike type 1, can often be managed by diet and exercise.
 - *Diabetes, gestational*: Diabetes that arises during pregnancy.
 - *Thyroid*: Disorders of the thyroid, including hypothyroidism, Hashimoto's Thyroiditis, hyperthyroidism, goiter, thyroid nodules, and thyroid cancer.
 - *Polycystic ovarian disease*: A condition of the female reproductive system characterized by enlarged ovaries that can contain follicles surrounding the eggs, irregular or very heavy periods, and excess male hormone (androgen) levels. This high levels of androgen may result in physical signs such as excess facial and body hair, and occasionally severe acne and male-pattern baldness.
- Neurologic/Psychiatric
 - *Addiction disorder*: Substance abuse and dependence, typically characterized by the overuse of drugs or alcohol.
 - *Eating disorder*: Mother experienced inappropriate relationships with food, such as anorexia, bulimia, or binge eating disorder. Include extreme emotions, attitudes, and behaviors surround weight and food issues.

- *Depression*: Mother displayed clinical symptoms of depression, was hospitalized, or under supervised medication, or otherwise experienced other indicators of depression during any of her pregnancies.
- *Seizure disorder*: Defined by any of the following conditions: At least two unprovoked (e.g., not febrile) seizures occurring more than 24 hours apart
 - One unprovoked seizure and a probability of further seizures occurring over the next 10 years.
 - Diagnosis of an epilepsy syndrome.
- *Sexually Transmitted Infections (STI)*
 - *Bacterial vaginosis (BV)*: An imbalance of the bacterial vaginal flora, detected prenatally or at delivery. Requires documented diagnosis in medical records.
 - *Chlamydia*: Documented positive chlamydia screening.
 - *Gonorrhea*: Documented positive gonorrhea screening.
 - *Herpes*: Documented positive herpes screening.
 - *HPV*: Documented positive HPV screening.
 - *Syphilis*: Documented positive syphilis screening.
 - *Group B strep*: Documented positive vaginal group beta strep culture.
 - *HIV/AIDS*: Documented diagnosis of human immunodeficiency virus, or acquired immunodeficiency syndrome.
 - *Other STI*: Documented diagnosis of any sexually transmitted infection not identified above.
- *Gynecologic*
 - *Uterine/vaginal bleeding*: Indicate if the mother had vaginal bleeding at any point in any of her pregnancies, other than light spotting in early pregnancy, which is common and typically benign. There are many causes of maternal vaginal bleeding in pregnancy. Some are quite serious, while others are not. Bleeding in early pregnancy is common, and in many cases it does not indicate a serious problem. Bleeding later in pregnancy can be much more serious. Vaginal bleeding can often originate in the uterus.
 - *Chorioamnionitis*: Infection of the membranes surrounding the fetus.
 - *Oligohydramnios*: Smaller than normal amount of amniotic fluid.
 - *Polyhydramnios*: Larger than normal amount of amniotic fluid, often associated with certain congenital anomalies or maternal diabetes.
 - *Intrauterine growth restriction (IUGR)*: Birth weight of the fetus is below the 10th percentile of mean weight for gestational age.
 - *Premature rupture of membranes (PROM)*: Spontaneous rupture of the bag of waters any time before the onset of labor.
 - *Preterm premature rupture of membranes (PPROM)*: Bag of waters ruptured before onset of labor and before 37 completed weeks of gestation.
 - *Incompetent cervix*: An incompetent cervix, also called a cervical insufficiency, is a condition that occurs when weak cervical tissue causes or contributes to premature birth or the loss of an otherwise healthy pregnancy.
 - *Umbilical cord complications*
 - *Prolapse*: A serious complication that occurs prior to or during the delivery of a baby where the umbilical cord drops (prolapses) through the vaginal opening ahead of the baby. The cord can then become trapped against the mother's cervical opening and the presenting part of the baby, compressing the cord. This compression can pinch the vein

in the cord, causing the baby's blood to fill with carbon monoxide. The baby may also experience variable decelerations in its heart rate, changes in blood pressure, and lack of oxygen to the brain.

- *Nuchal cord*: A nuchal cord occurs when a baby's umbilical cord is wrapped completely around its neck in utero. It is not uncommon, and nuchal cords often resolve themselves before delivery or are easily remedied at delivery. Nuchal cord can cause serious complications, however, if the cord is tightly wound around the baby's neck.
- *Other cord, specify*: Please identify any other umbilical cord complications not identified above. Some examples include *velamentous insertion, vasa previa, and true and false knots in the cord.*
- *Placental problems*:
 - *Abruption*: A condition in which the placenta separates from the inner wall of the uterus before the baby is born.
 - *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.
 - *Other placental*: Any other documented placental abnormality or placenta-related problem.
- *Other Complications/Conditions*
 - *UTI*: A urinary tract infection (UTI) can occur anywhere in the urinary system, including the kidneys, ureters, bladder, or urethra. Identify if there was a positive UTI diagnosis.
 - *Decreased fetal movement*: Identify if the mother or a healthcare provider observed a decrease in fetal movement.
 - *HELLP syndrome*: A rare but serious condition of pregnancy characterized by: *hemolysis* (the breakdown of red blood cells); *elevated liver enzymes*; and *low platelet count*. While around 1 in 1000 pregnant women develop HELLP Syndrome, about 2 in 10 pregnant women with preeclampsia develop it. It can be treated pharmaceutically in some cases. In others, even if the baby is premature, it requires immediate delivery of the baby to protect both the mother and infant.
 - *Maternal developmental delay*: Mother falls below the norm in any one of these five areas: gross motor control, fine motor control, social interaction, language, or self-help.
 - *Dental or gum infection*: Identify if there was any known periodontal infection including gingivitis or abscesses.
 - *Gastrointestinal*: Identify any conditions or complications of the stomach or digestive tract, including gallstones, abdominal pain, constipation, diarrhea, or ulcers.
 - *Maternal genetic disorder*: Indicate whether the mother had any known gene variants.
 - *Abnormal MSAFP*: The Maternal Serum Alfa-Fetoprotein screening is given to women in pregnancy for early identification of possible genetic disorders. It is often part of the triple-screen test to determine if further diagnostic testing of the fetus is needed. Indicate if the results of this screen were abnormal.
 - *Preterm labor*: Onset of labor before 37 completed weeks gestation.
 - *Other*: Identify any other complication or condition not mentioned above.

A44: Did the mother experience any medical complications in previous pregnancies

Indicate if the mother had any of the following complications with any pregnancy prior to the deceased child.

- *Previous preterm birth:* Any child born to this mother before the deceased infant was born prior to 37 completed weeks of gestation.
- *Previous low birth weight birth:* Any child born to this mother prior to the deceased infant weighted less than 2500 grams, or 5lb. 5 oz. at birth.
- *Previous small for gestational age:* Any child born to this mother prior to the deceased infant that had a birth weight and length below the 10th percentile of all babies of the same gestational age. See <https://www.aap.org/en-us/Documents/GrowthCurves.pdf>
- *Previous large for gestational age:* Any child born to this mother prior to the deceased infant that had a birth weight greater than the 90th percentile of all babies of the same gestational age. See <https://www.aap.org/en-us/Documents/GrowthCurves.pdf>

A45: Did the mother use any medications, drugs, or other substances during pregnancy

Indicate if the mother took any over-the-counter medications, prescription drugs, illicit drugs, mood-altering substances, homeopathic remedies, or supplements that were not prenatal vitamins during her pregnancy with the deceased child.

A46: Was the infant born drug exposed

Identification of whether infant was born drug exposed should be determined by maternal history; clinical presentation of the newborn; and laboratory testing of biological maternal matrices (ie, urine, blood, oral fluid, sweat, hair, and breast milk), neonatal matrices (ie, urine, meconium, hair, and umbilical cord blood and tissue), and/or matrices from both the mother and neonate (ie, placenta and amniotic fluid).

A47: Did the infant have neonatal abstinence syndrome (NAS)

Indicate if the infant exhibited a drug withdrawal syndrome, most commonly occurring in infants after in utero exposure to opioids, though other substances have been associated with the syndrome. The clinical symptoms usually appear within 48-72 hours after birth, accompanied a constellation of clinical signs, including central nervous system irritability (tremors), gastrointestinal dysfunction (feeding difficulties), and temperature instability.

A48: Level of birth hospital:

Birthing hospitals have different levels of capacity to treat laboring mothers, birth outcomes, and newborns.

- *Level 1/Basic Care:* A facility capable of peripartum care of low-risk women with uncomplicated singleton term pregnancies with a vertex presentation who are expected to have an uncomplicated birth.
- *Level 2/Specialty Care:* Has all of the capability of a Level 1 facility, as well as capability to provide appropriate care for high-risk antepartum, intrapartum, or postpartum conditions, both directly admitted and transferred from another facility.
- *Level 3/Subspecialty Care:* Has all of the capability of a Level 2 facility, as well as the ability to care for more complex maternal medical conditions obstetric complications, and fetal conditions. **Note if the birth hospital was a Level 4 facility, please select Level 3.** Level 4 will be added as a response option in Version 5.1. A Level 4/Regional

Perinatal Health Care Center has as all of the capability of a Level 3 facility, as well as on-site medical and surgical care of the most complex maternal conditions and critically ill pregnant women and fetuses throughout antepartum, intrapartum, and postpartum care.

- *Free standing birth center:* Is a health facility that is not a hospital (and is not attached to a hospital) where childbirth is planned to occur away from the pregnant woman's residence. A free standing birth center is licensed or approved to provide prenatal labor and delivery or postpartum care and other ambulatory services.
- *Home birth:* A planned homebirth is a birth that intentionally takes place in a residence rather than in a hospital or birth center. It may be attended by a midwife or a lay attendant with experience in managing home births. It may also be intentionally unattended. If the baby was born at home due to a precipitous labor, but a homebirth was not planned, please select "other" and indicate that the birth was an unintentional home birth.
- *Other:* Includes unexpected delivery of newborns at home or in a vehicle or other unplanned site.

A49: At discharge from the birth hospital, was a case manager assigned to the mother

Case management is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality, cost-effective outcomes. A case manager may be employed by a health plan, individual provider, or health care institution.

A50: Did the mother attend a postpartum visit

Indicate whether the mother kept her 4- 6 week postpartum check.

A51: Did the infant have a NICU stay for more than one day

Indicate whether the infant was cared for in the neonatal intensive care unit for more than 24 hours.

A52: Did mother smoke in the 3 months before pregnancy

Indicate if there was maternal smoking, including e-cigarettes, in the three months prior to becoming pregnant. If yes, record the average number of cigarettes smoked per day. (20 cigarettes in a pack.) If quantity of cigarettes is unknown, select "unknown quantity." If the mother primarily used e-cigarettes, select "unknown quantity," and please make a note regarding the frequency of use in the narrative section if known.

A53: Did the mother smoke at any time during pregnancy

Indicate if there was maternal smoking, including e-cigarettes, during the pregnancy with the deceased infant. If so, indicate which trimester(s) there was smoking, and the average number of cigarettes smoked per day, if known. If the mother primarily used e-cigarettes, select "unknown quantity," and please make a note regarding the frequency of use in the narrative section if known.

- *1st Trimester:* Found on the birth certificate or any other documented source, record the average number of cigarettes the mother smoked a day while she was in her first three months of her pregnancy. There are 20 cigarettes in a pack. If quantity of cigarettes is unknown, select "unknown quantity."

- *2nd Trimester:* Found on the birth certificate or any other documented source, record the average number of cigarettes the mother smoked a day while she was in her second three months of her pregnancy. There are 20 cigarettes in a pack. If quantity of cigarettes is unknown, select “unknown quantity.”
- *3rd Trimester:* Found on the birth certificate or any other documented source, record the average number of cigarettes the mother smoked a day while she was in her last three months of her pregnancy. There are 20 cigarettes in a pack. If quantity of cigarettes is unknown, select “unknown quantity.”

A54: Was mother injured during pregnancy

Found in medical or hospital records, any incident where the mother was injured to the extent that she sought medical care or reported it to a medical professional. Can include motor vehicle crashes, other unintentional injuries, as well as intentional injuries as a result of domestic violence.

A55: Did the mother have postpartum depression

Indicate if the mother had feelings of sadness, anxiety, or despair after childbirth that interfered with her ability to function and that lasted longer than two weeks.

A56: Infant ever breastfed

Record if the infant was ever breastfed. This can be for any duration, just as long as there is some reported indication that the infant received breast milk, either expressed or at the breast. This may be noted on the birth certificate, in hospital discharge notes, pediatric records or in the WIC file.

A57: Did infant have abnormal metabolic newborn screening results

Indicate if the infant tested positive for any genetic metabolic error such as a fatty oxidation error like MCAD. This can typically be found in pediatric medical records, often in newborn screening results, and perhaps WIC records. If infant had any abnormality, please describe. Select N/A if no newborn screening was conducted, including when the parents declined the screening.

A58: At any time prior to the infant’s last 72 hours, did the infant have a history of

Indicate if the infant experienced (as noted in a medical record or by a caregiver report) any of the following prior to the infant’s last 72 hours:

- *Infection:* Infant had an infection, such as a virus or bacteria like strep.
- *Allergies:* Infant had a food, environmental or medication allergy.
- *Abnormal growth or weight gain/loss:* Most infants lose weight after delivery, but abnormal weight loss or gain is noted in medical or WIC records and deviates from infant growth curves.
- *Apnea:* Infant stopped breathing for a short period of time. Can occur in the delivery room or any time afterwards.
- *Cyanosis:* Infant had a reported bluish color of the skin or mucous membranes due to low oxygen in the blood. Can occur in the delivery room or any time afterwards.
- *Seizure or convulsions:* Infant had an observed and documented seizure or convulsions. Could be a febrile seizure.

- *Cardiac abnormalities:* Infant had experienced reported abnormalities of the heart including a murmur which may not require any medical intervention, or more serious cardiac abnormalities that may require specialists' care.
- *Other:* Infant had any other notable medical history that deviated from normal. This includes any hospitalizations or specialist visits after delivery discharge.

A59: In the 72 hours prior to death, did the infant have any of the following

Indicate if infant experienced (as noted in a medical record or by caregiver report) any of the following in the 72 hours prior to death:

- *Fever:* Infant had a temperature over 100 degrees Fahrenheit.
- *Excessive sweating:* Infant had been notably sweating or their skin was damp.
- *Lethargy or sleeping more than usual:* Infant had been sleeping more than usual and was difficult to arouse.
- *Fussiness or excessive crying:* Infant had been more fussy than usual or had been crying more than usual.
- *Decrease in appetite:* Infant had not been eating as much as usual.
- *Vomiting:* Infant had been throwing up, not merely spitting up.
- *Choking:* Infant had choked.
- *Diarrhea:* Infant had runny stools.
- *Stool changes:* Infant had changes in their usual bowel movements. This can be constipation or excessively runny stools, as well as any noted changes in smell or color.
- *Difficulty breathing:* Infant had trouble breathing and may have exhibited 'grunting' or gasping noises.
- *Apnea:* Infant had stopped breathing for a short period of time.
- *Cyanosis:* Infant's skin turned blue due to low oxygen in the blood.
- *Seizures or convulsions:* Infant had a seizure or convulsions.
- *Other:* Infant had a medical complication not listed above.

A60: In the 72 hours prior to death, was the infant injured

In the 3 days before the infant died, it was noted in a medical record or the caregiver reported that the infant had been injured either unintentionally, such as a motor vehicle crash or fall, or intentionally, such as due to abuse/neglect.

A61: In the 72 hours prior to death, was the infant given any vaccines

In the 3 days before the infant died, it was noted in a medical record or the caregiver reported that the infant had received immunizations. If yes, please list the type of vaccine the infant received. Common vaccines in the first year include: Hepatitis B, rotavirus, DPT, HiB, pneumonia, flu, polio, MMR, chicken pox (varicella), Hepatitis A and meningitis.

A62: In the 72 hours prior to death, was the infant given any medications or remedies

In the 3 days before the infant died, it was noted in a medical record or the caregiver reported that the infant was given medication (over-the-counter or prescription) or was given a home remedy, using food or herbs. A home remedy is a food, herb or other treatment not considered a usual store bought medication. Please note the medication or remedy and last dose given.

A63: What did the infant have for his/her last meal

By caregiver report, record the last thing the infant had to eat. This could be liquid (breast milk or formula) and/or solid foods (baby food, cereal or adult food).

A4. Expanded Infant/Maternal Questions

Section A4 is only completed by FIMR users.

A64: Mother's name

Legal name of the biological mother as stated on the infant's birth certificate. If a maternal interview is completed and it conflicts, defer to her preferred name.

A65: Father's name

Legal name of the biological father as stated on the birth certificate.

A66: Mother's country of birth

Name of the country where biological mother was born.

A67: Father's country of birth

Name of the country where the biological father was born.

A68: Mother's residence address

Residential address of mother at the time of the infant's death. If the mother is currently residing in a short-term facility for less than six months, use his or her home address as their residential address. If the mother is residing in a long-term facility for over six months, such as a college dormitory, prison or residential nursing home, use the institution's address. If they are living in a short-term facility and no residential address is noted, use the address of the short-term facility.

If mother was not a resident of the United States, select 'out of country' in the drop down list of states and enter the country of residence in the text box.

Some reporting sites may find that an individual data source will require that unique identifiers, such as a specific street address, be stored in hard copy only, not in the electronic database. If possible, enter resident state at a minimum, as it can be used to confirm state residency.

A69: Mother's marital status during pregnancy

Specify if the biological mother was single, married, divorced, separated or widowed during the pregnancy. If her marital status changes during her pregnancy, use the marital status at the time of birth.

A70: Number of months between prior pregnancy and this one

The number of months between the outcome of the previous pregnancy and the conception of the most recent pregnancy.

A71: Was the mother taking folic acid or a multivitamin prior to this pregnancy

Specify if the mother took folic acid or multivitamins at any time just prior to or during her pregnancy.

A72: Mother's employment during pregnancy

Select the employment status of the mother during her pregnancy. If it changed during the course of the pregnancy, choose the option that describes the most time (number of months or weeks) of the pregnancy.

If the mother was employed or a student, indicate how long after the delivery the mother returned to her job or classes. If both apply, choose the number of weeks closest to delivery. Indicate who watched the infant while she was at work or class.

A73: Mother’s pre-pregnancy weight, height, BMI

The weight, height, and body mass index of the mother before pregnancy. If both height and weight are entered, the system will automatically calculate the BMI. If either height or weight is unknown but BMI is known, enter the BMI but don’t enter either height or weight. Categories to be used for summarizing BMI in analysis by the National Center will be as follows:

- *Underweight:* (BMI < 18.5)
- *Normal weight:* (BMI 18.5 to 24.9)
- *Overweight:* (BMI 25 to 29.9)
- *Obese:* (BMI 30 or higher)

The formula for calculating BMI is taken from

https://www.cdc.gov/nccdphp/dnpao/growthcharts/training/bmiage/page5_2.html

$$BMI = \left(\frac{\text{Weight in Pounds}}{(\text{Height in inches}) \times (\text{Height in inches})} \right) \times 703$$

A74: Mother’s pregnancy weight gain or loss in pounds

The amount of weight gained or lost in pounds after the pre-pregnancy weight is subtracted from the pregnancy weight. Weight loss should be entered as a negative number.

A75: Did mother achieve the recommended weight gain

Recommended weight gain varies according to pre-pregnancy body mass index. Recommended growth charts for mothers who were underweight, normal weight, overweight, and obese at the start of pregnancy are located in the FIMR glossary, and can also be found at:

<https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-weight-gain.htm#tracking>.

General recommendations for second and third trimester are:

| | |
|---------------|-----------------|
| Underweight | 1 – 1.3 lb/wk |
| Normal Weight | 0.8 – 1 lb/wk |
| Overweight | 0.5 – 0.7 lb/wk |
| Obese | 0.4 – 0.6 lb/wk |

Data Source: <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-weight-gain.htm#tracking>

A76: Mother’s age at first pregnancy

Provide the age of the mother at the time of conception of her first pregnancy, regardless of the outcome of that pregnancy.

A77: For each previous pregnancy

For each of the mother's previous pregnancies, indicate the year of the delivery, the mother's age at time of delivery; the gestational age of the infant; the birth weight in grams; the type of delivery (types defined below); number of fetuses in each pregnancy; and the outcome code, also outlined below.

- Delivery types:
 - NSVD: Natural spontaneous vaginal delivery
 - C-Sec: Cesarean Section, a surgical delivery
 - VBAC: Vaginal birth after Cesarean
- Outcome Codes:
 - Full-term, live birth: An infant born alive after 37 completed weeks of gestation.
 - Premature live birth: an infant born live before 37 completed weeks of gestation.
 - Stillbirth ≥ 20 weeks: Delivery of a baby that shows no signs of life from 20 weeks gestational age or after.
 - Spontaneous abortion/miscarriage/stillbirth <20 weeks:
 - Therapeutic abortion: The interruption of a pregnancy because of risks to maternal health or because of fetal disease.
 - Voluntary abortion: A voluntary, or elective, abortion is the interruption of a pregnancy at the woman's request for reasons other than maternal health or fetal disease.
 - Ectopic: A pregnancy in which the fertilized egg begins to grow in a place other than inside the uterus, usually in the fallopian tubes.
 - Unknown: Select unknown if the outcome of the pregnancy is unavailable in the case abstraction process.

A78: Was mother using birth control in the 3 months prior to this pregnancy

Specify what type/method of birth control the mother was using three months before the pregnancy. If she changed birth control methods within the three months before pregnancy, specify that multiple types/methods were used. If no birth control was used, specify if pregnancy was unintended, intended or mistimed if no birth control was used in the three months prior to the pregnancy.

A79: Where was prenatal care most frequently provided for this pregnancy

A place where the mother received pregnancy and health care information most of the time during this pregnancy, e.g. private provider's office, county or city health department, managed care organization, community/neighborhood health center, clinic, etc.

- Private provider: A location, other than a hospital, community health center, state of local public health clinic, or intermediate care facility where health professionals routinely provide health examinations, diagnosis, and treatment of illness injury, or conditions on an ambulatory basis.
- County or city health department: A health department is a part of government which focuses on issues related to the general health of the citizenry.
- Clinic: An establishment or hospital department, other than a private provider, county or city health department, community/neighborhood health center, or managed care

organization, where outpatients are given medical treatment or advice, especially of a specialist nature.

- *Managed care organization:* A managed care organization (MCO) is a health care provider or a group or organization of medical service providers who offers managed care health plans. It is a health organization that contracts with insurers or self-insured employers and finances and delivers health care using a specific provider network and specific services and products.
- *Community/neighborhood health center:* A private, nonprofit organizations that directly or indirectly (through contracts and cooperative agreements) provide primary health services and related services to residents of a defined geographic area that is medically underserved. Federally Qualified Health Centers (FQHCs) are examples of community/neighborhood health centers.

A80: Which type of provider most frequently provided prenatal care for this pregnancy

Indicate the type of health specialist who mostly provided the mother with prenatal care services/information for the pregnancy, e.g. nurse practitioner, nurse midwife, obstetrician, Maternal Fetal Medicine specialist, family physician, etc.

A81: Was this pregnancy a result of assisted reproductive technology

Specify whether or not any of the assisted reproductive technology such as fertility drugs, artificial insemination, in vitro fertilization, etc., was used to conceive the pregnancy.

A82: Which of the following tests were performed during the pregnancy

Specify the test performed by the mother's healthcare provider during the pregnancy period. Identify whether the results were normal, abnormal, or unknown.

- *CBC-Complete Blood Count:* This test typically includes white blood cell count (leukocytes), red blood cell count (erythrocytes), hematocrit, hemoglobin, platelets and several other values of the cellular, formed elements of blood.
- *GTT-Glucose Tolerance Test:* A diagnostic test of diabetes mellitus and assessment of patients with fasting blood glucose levels just above the normal range.
- *HCT- Hematocrit:* The ratio of the volume of red cells to the volume of whole blood.
- *HGB-Hemoglobin:* Hemoglobin is the iron-containing protein found in all red blood cells that enables RBCs to bind to oxygen in the lungs and carry it to tissues and organs throughout the body. The hemoglobin test is often used to check for anemia, usually along with a hematocrit or as part of a complete blood count (CBC). The test may be used to screen for, diagnose, or monitor a number of conditions and diseases that affect red blood cells (RBCs).
- *Quad screen:* The quad screen — also known as the quadruple marker test, the second trimester screen or simply the quad test — is a prenatal test that measures levels of four substances in a pregnant woman's blood:
 - *Alpha-fetoprotein (AFP),* a protein made by the developing baby
 - *Human chorionic gonadotropin (HCG),* a hormone made by the placenta
 - *Estriol,* a hormone made by the placenta and the baby's liver
 - *Inhibin A,* another hormone made by the placenta

Ideally, the quad screen is done between weeks 15 and 18 of pregnancy — the second trimester. However, the procedure can be done up to week 20. The quad screen is used to evaluate whether a pregnancy has an increased chance of being affected by certain

genetic or chromosomal conditions, such as Down syndrome. The alpha-fetoprotein part of the test can help evaluate the chance for neural tube defects, such as spina bifida, and abdominal wall defects, such as omphalocele.

- *Fetal movement assessment (kick counts)*: The fetal kick count is the count of any movements that the unborn baby makes such as jabs, punches, rolls, twists and turns. Kick counts are a specific intervention strategy that a provider might recommend that encourages a mother to count her baby's movements once a day, at the same time each day, generally starting in the third trimester. The American College of Obstetricians and Gynecologists (ACOG) describes the perception of 10 distinct movements in a period of up to 2 hours as reassuring.
- *Contraction stress test*: The contraction stress test (also called a stress test or an oxytocin challenge test) may be done during pregnancy to measure the baby's heart rate during uterine contractions. The CST is used to determine fetal reserve prior to labor by evaluating the response of the fetal heart rate to spontaneous or induced uterine contractions.
- *Nonstress test*: A non-stress test (NST), also known as fetal heart rate monitoring, is a common prenatal test used to check on a baby's health. During a non-stress test a baby's heart rate is monitored to see how it responds to the baby's movements.
- *Biophysical profile*: A noninvasive test that predicts the presence or absence of fetal asphyxia and, ultimately, the risk of fetal death in the antenatal period. BPP is done with a combination of ultrasound and fetal heart rate monitoring, and measures 5 parameters:
 - Fetal heart rate
 - Fetal breathing
 - Fetal movement
 - Fetal tone
 - Amniotic fluid volume
- *Maturity (L/S) ratio*: lecithin–sphingomyelin ratio is a test of fetal amniotic fluid to assess for fetal lung maturity.
- *Pap smear*: The Papanicolaou test (abbreviated as Pap test, known earlier as Pap smear, cervical smear, or smear test) is a method of cervical screening used to detect potentially pre-cancerous and cancerous processes in the cervix (opening of the uterus or womb).
- *Sickle prep or equivalent*: A screening test done on blood to find if sickle cell trait or sickle cell disease is present.
- *Ultrasound*: sonography or diagnostic medical sonography, is an imaging method that uses high-frequency sound waves to produce images of structures within the body. Ultrasound exams are commonly used in pregnancy to scan a woman's abdomen and pelvic cavity, creating a picture (sonogram) of the baby and the placenta.
- *TORCH*: A blood test that detects several different infections in a newborn. TORCH refers to toxoplasmosis, rubella, cytomegalovirus, herpes simplex, and HIV.
- *Urine culture*: A *urine culture* is used to diagnose a urinary tract infection (UTI) and to identify the bacteria or yeast causing the infection so it can be treated.
- *Rubella titer*: The rubella (German measles) titer is a blood test that is used to detect antibodies in the blood that develop in response to a rubella infection or immunization.

- *Antibody screen*: An RBC antibody screen is used to screen an individual's blood for antibodies directed against red blood cell (RBC) antigens other than the A and B antigens. In pregnancy, antibody screening is used to determine if a mother and her fetus have blood groups or types that could be incompatible.
- *STI culture or test*: A culture is a test in which a laboratory attempts to grow and identify a microorganism causing an infection. Common sexually transmitted infections may include gonorrhea, syphilis, chlamydia, chancroid, herpes, human papillomavirus, and human immunodeficiency virus (HIV). A sample of material is taken from the infection site, places in a sterile container, and sent to the laboratory.
- *Urine toxicology*: Sometimes referred to as “tox” screen, a urine toxicology test checks the urine for the presence of drugs or other chemicals, including prescription medicines and nonprescription medicines.
- *Blood type and Rh factor*: A test to determine the blood type (either A, B, AB, and O) and Rh factor (negative or positive).
- *Other*: Identify any other notable tests that were administered.

A83: Did the mother have any medical conditions/complications during this pregnancy and including any previous pregnancies

Specify any medical complications during this pregnancy or in past pregnancies, including the timeframe of the occurrence, and any referrals that helped manage the complication. If there is documentation of the mother receiving a referral, but no appointment resulted, select “Referral made, no follow through by mother.”

- *Cardiovascular*
 - *Hypertension-gestational*: High blood pressure that occurs during the second half of pregnancy and disappears soon after the baby is born.
 - *Hypertension-chronic*: A long-term condition in which blood pressure is higher than normal.
 - *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 severe manifestation of the disease.
 - *Clotting disorder*: Certain abnormalities of blood coagulation that can threaten the health of mothers or pregnancies. Some of these conditions include Antithrombin Deficiency, Antiphospholipid Syndrome, Factor V. Leiden Thrombophilia, Prothrombin Thrombophilia, Prothrombin Thrombophilia and Protein S Deficiency.
- *Hematologic*
 - *Folic acid deficiency*: A lack of folate—or vitamin B9—that can lead to anemia. Can be caused by not eating enough foods that contain folic acid, excessive alcohol intake, or conditions that inhibit absorption of folic acid, such as celiac disease or cancers of the digestive tract.
 - *Sickle cell disease*: There was a known diagnosed of sickle cell disease and/or the mother of the deceased infant had two abnormal hemoglobin genes.
 - *Anemia*: Abnormally low levels of blood or red blood cells in the bloodstream.
- *Respiratory*

- *Asthma*: A chronic lung disease that inflames and narrows the airways, and can cause recurring periods of wheezing, chest tightness, shortness of breath, and coughing.
- *Pulmonary embolism*: A sudden blockage in the lung artery, usually caused by a blood clot that travels to the lung from a vein in the leg.
- *Endocrine/Metabolic*
 - *Diabetes, type 1 chronic*: A chronic condition in which the pancreas does not produce enough insulin, resulting in elevated blood sugar. Previously called insulin-dependent or juvenile diabetes, as it is commonly diagnosed in children, teens, or young adults.
 - *Diabetes, type 2 chronic*: The most common form of diabetes, type 2 diabetes occurs when the body either resists the effects of insulin or resists the effects of insulin, resulting in elevated blood sugar. Unlike type 1, can often be managed by diet and exercise.
 - *Diabetes, gestational*: Diabetes that arises during pregnancy.
 - *Thyroid*: Disorders of the thyroid, including hypothyroidism, Hashimoto's Thyroiditis, hyperthyroidism, goiter, thyroid nodules, and thyroid cancer.
 - *Polycystic ovarian disease*: A condition of the female reproductive system characterized by enlarged ovaries that can contain follicles surrounding the eggs, irregular or very heavy periods, and excess male hormone (androgen) levels. This high levels of androgen may result in physical signs such as excess facial and body hair, and occasionally severe acne and male-pattern baldness.
- *Neurologic/Psychiatric*
 - *Addiction disorder*: Substance abuse and dependence, typically characterized by the overuse of drugs or alcohol.
 - *Eating disorder*: Mother experienced inappropriate relationships with food, such as anorexia, bulimia, or binge eating disorder. Include extreme emotions, attitudes, and behaviors surround weight and food issues.
 - *Depression*: Mother displayed clinical symptoms of depression, was hospitalized, or under supervised medication, or otherwise experienced other indicators of depression during any of her pregnancies.
 - *Seizure disorder*: : Defined by any of the following conditions: At least two unprovoked (e.g., not febrile) seizures occurring more than 24 hours apart
 - One unprovoked seizure and a probability of further seizures occurring over the next 10 years.
 - Diagnosis of an epilepsy syndrome.
- *Sexually Transmitted Infections (STI)*
 - *Bacterial vaginosis (BV)*: An imbalance of the bacterial vaginal flora, detected prenatally or at delivery. Requires documented diagnosis in medical records.
 - *Chlamydia*: Documented positive chlamydia screening.
 - *Gonorrhea*: Documented positive gonorrhea screening.
 - *Herpes*: Documented positive herpes screening.
 - *HPV*: Documented positive HPV screening.
 - *Syphilis*: Documented positive syphilis screening.
 - *Group B strep*: Documented positive vaginal group beta strep culture.
 - *HIV/AIDS*: Documented diagnosis of human immunodeficiency virus, or acquired immunodeficiency syndrome.

- *Other STI*: Documented diagnosis of any sexually transmitted infection not identified above.
- Gynecologic
 - *Uterine/vaginal bleeding*: Indicate if the mother had vaginal bleeding at any point in any of her pregnancies, other than light spotting in early pregnancy, which is common and typically benign. There are many causes of maternal vaginal bleeding in pregnancy. Some are quite serious, while others are not. Bleeding in early pregnancy is common, and in many cases it does not indicate a serious problem. Bleeding later in pregnancy can be much more serious.
 - *Chorioamnionitis*: Infection of the membranes surrounding the fetus.
 - *Oligohydramnios*: Smaller than normal amount of amniotic fluid.
 - *Polyhydramnios*: Larger than normal amount of amniotic fluid, often associated with certain congenital anomalies or maternal diabetes.
 - *Intrauterine growth restriction (IUGR)*: Birth weight of the fetus is below the 10th percentile of mean weight for gestational age.
 - *Premature rupture of membranes (PROM)*: Spontaneous rupture of the bag of waters any time before the onset of labor.
 - *Preterm premature rupture of membranes (PPROM)*: Bag of waters ruptured before onset of labor and before 37 completed weeks of gestation.
 - *Incompetent cervix*: Also referred to as cervical insufficiency, incompetent cervix is diagnosed when weakened cervical muscles result in premature delivery or infant/fetal loss in an otherwise healthy pregnancy.
 - *Umbilical cord complications*
 - *Prolapse*: A serious complication that occurs prior to or during the delivery of a baby where the umbilical cord drops (prolapses) through the vaginal opening ahead of the baby. The cord can then become trapped against the mother's cervical opening and the presenting part of the baby, compressing the cord. This compression can pinch the vein in the cord, causing the baby's blood to fill with carbon monoxide. The baby may also experience variable decelerations in its heart rate, changes in blood pressure, and lack of oxygen to the brain.
 - *Nuchal cord*: A nuchal cord occurs when a baby's umbilical cord is wrapped completely around its neck in utero. It is not uncommon, and nuchal cords often resolve themselves before delivery or are easily remedied at delivery. Nuchal cord can cause serious complications, however, if the cord is tightly wound around the baby's neck.
 - *Other cord, specify*: Please identify any other umbilical cord complications not identified above, such as velamentous insertion, vasa previa, or true and false knots in the cord.
 - *Placental problems*:
 - *Abruption*: A condition in which the placenta separates from the inner wall of the uterus before the baby is born.
 - *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.
 - *Other placental*: Any other documented placental abnormality or placenta-related problem.
- Other Complications/Conditions

- *UTI*: A urinary tract infection (UTI) can occur anywhere in the urinary system, including the kidneys, ureters, bladder, or urethra. Identify if there was a positive UTI diagnosis.
- *Decreased fetal movement*: Identify if the mother or a healthcare provider observed a decrease in fetal movement.
- *HELLP syndrome*: A rare but serious condition of pregnancy characterized by: *hemolysis* (the breakdown of red blood cells); *elevated liver enzymes*; and *low platelet count*. While around 1 in 1000 pregnant women develop HELLP Syndrome, about 2 in 10 pregnant women with preeclampsia develop it. It can be treated pharmaceutically in some cases. In others, even if the baby is premature, it requires immediate delivery of the baby to protect both the mother and infant.
- *Maternal developmental delay*: Mother falls below the norm in any one of these five areas: gross motor control, fine motor control, social interaction, language, or self-help.
- *Dental or gum infection*: Identify if there was any known periodontal infection including gingivitis or abscesses.
- *Gastrointestinal*: Identify any conditions or complications of the stomach or digestive tract, including gallstones, abdominal pain, constipation, diarrhea, or ulcers.
- *Maternal genetic disorder*: Indicate whether the mother had any known gene variants.
- *Abnormal MSAFP*: The Maternal Serum Alfa-Fetoprotein screening is given to women in pregnancy for early identification of possible genetic disorders. It is often part of the triple-screen test to determine if further diagnostic testing of the fetus is needed. Indicate if the results of this screen were abnormal.
- *Preterm labor*: Onset of labor before 37 completed weeks gestation.
- *Other*: Identify any other complication or condition not mentioned above.

A84: Did the care provider recommend precautions to prevent premature labor or early labor

Indicate whether there is any mention of precautions received from health care provider to prevent early labor. Indicate which precautions were recommended by the provider.

A85: Type of delivery

Indicate how the baby was delivered. Please note, if it was a spontaneous labor, and a vaginal delivery, but included an intervention such as forceps or vacuum extraction, select the appropriate interventional delivery method. If it was a C-Section delivery, please indicate the reason the C-Section was performed, as noted in the medical record.

A86: Were there any signs of fetal distress

Fetal distress includes unhealthy condition of the fetus before the birth process or during the birth process that puts the baby or the mother at risk. Compromise of a fetus during the antepartum period (before labor) or intrapartum period (during the birth process). The term fetal distress is commonly used to describe fetal hypoxia (low oxygen levels in the fetus), which can result in fetal damage or death if it is not reversed or if the fetus is not promptly delivered. Fetal distress can be detected via abnormal slowing of labor, changes in fetal heart rate, the presence of meconium (dark green fecal material from the fetus) or other abnormal substances in the amniotic fluid, or fetal monitoring with an electronic device that shows a fetal scalp pH of less than 7.2.

A87: Were there any birth defects noted

Any defect present in a baby at birth, irrespective of whether the defect is caused by a genetic factor or by prenatal events that are not genetic. Minor or severe abnormality in appearance, organ function, physical and mental development.

A88: Date of mother's discharge from the birth hospital

The day, month, and year of mother's discharge. For home births, indicate "not applicable."

A89: Was there evidence of injury at death

Indicate any sign of physical damage to any part of the body e.g. scratches, marks, fractures, bruises, burns etc.

A90: Was a placental pathology performed

Placental Pathology includes a microscopic examination of the umbilical cord and its vessels, the placental membranes (amnion, chorion) and the placental disk or fetal surface. If yes, describe the test and findings of the pathology.

A91: Payer source for mother's care for the timeframe (pre-pregnancy, pregnancy, labor and delivery, post-pregnancy)

Indicate the type of individual or health care plan that made the payment for the cost of mother's care before her pregnancy, during her pregnancy, after her pregnancy as well as the cost of her labor and delivery.

A92: Did the mother have stable housing during her pregnancy

Indicate if the mother had stable housing throughout her pregnancy. Some examples of unstable housing include mother and baby were homeless, living on the street, living in a shelter, or making frequent moves among friends and family members, or mother was incarcerated immediately before, during, or after the pregnancy, or while the infant was alive. If housing was unstable, select the appropriate type of instability.

A93: Did the mother have phone service during her the pregnancy

Indicate how often mother had reliable phone service.

A94: Did the mother have any high risk prenatal/antepartum encounter

Indicate if the mother received inpatient or outpatient care provided to pregnant patients with serious and acute complications requiring intensive care and surveillance by an obstetrician-gynecologist or a specialist in maternal fetal medicine. Such conditions may include diabetes, high blood pressure and pulmonary problems. These women require specialized prenatal care during pregnancy and the High Risk Antepartum unit often provides this specialized care.

A95: Did the mother have any hospitalization greater than 24 hours prior to labor and delivery excluding the birth

Specify if the mother has previously been hospitalized for over twenty-four hours because of any injury or medical condition before her labor and delivery.

A96: Health education topics discussed at any time between the first prenatal care and delivery

Indicate pregnancy/health care-related education that a care provider discussed with the mother during the period between the first prenatal care and labor and delivery.

- *Maternal Nutrition:* General information on recommended nutrient intake, and dietary planning that is undertaken before, during and after pregnancy to achieve an optimum outcome.
- *Weight gain counseling:* Specific guidelines the provider discusses with the mother that varies according to pre-pregnancy body mass index. Weight gain counseling could include avoidance of excessive weight gain and/or avoidance of inadequate weight gain.
- *Eating disorders:* Disorders such as anorexia, bulimia, and binge eating disorder – include extreme emotions, attitudes, and behaviors surrounding weight and food issues.
- *Fetal movement monitoring:* General knowledge about normal fetal movement, monitoring techniques, and response to decreased fetal movement.
- *Kick counts:* The fetal kick count is the count of any movements that the unborn baby makes such as jabs, punches, rolls, twists and turns. Kick counts are a specific intervention strategy that a provider might recommend that encourages a mother to count her baby's movements once a day, at the same time each day, generally starting in the third trimester. The American College of Obstetricians and Gynecologists (ACOG) describes the perception of 10 distinct movements in a period of up to 2 hours as reassuring.
- *Family planning:* The practice of controlling the number of children in a family and the intervals between their births, particularly by means of artificial contraception or voluntary sterilization. Comprehensive family planning services, (according to the CDC), include:
 - Contraceptive services
 - Pregnancy testing and counseling
 - Pregnancy-achieving services including preconception health services
 - Basic infertility services
 - Sexually transmitted disease services
 - Broader reproductive health services, including patient education and counseling
 - Breast and pelvic examinations
 - Breast and cervical cancer screening
 - Sexually transmitted infection (STI) and human immunodeficiency virus (HIV) prevention education, counseling, testing, and referral

A97: Hospital education topics discussed at any time between mother's admission and discharge from birth hospital

Mention any or all kinds of maternal/post-pregnancy health care related topics that a care provider discussed with the mother between the period when she was admitted for delivery and when she was discharged after delivery. This includes health education topics discussed by care providers at home births such as doulas and mid-wives.

A98: Infant safety topics discussed between first prenatal care visit and mother's discharge from birth hospital

Indicate topics/messages related to infant health safety that the mother had received from the prenatal care provider between the period of her first visit to the provider and the time she was discharged from the hospital after birth.

A99: Mother's experience of stressors during her pregnancy

Stressors are life events that impact and individual's emotional, physical, and psychological wellbeing. Select the stressors the mother experienced during her pregnancy.

A100: Was the mother a victim of intimate partner violence

Indicate whether the mother experienced any sort of verbal, emotional physical, economic, or sexual abuse prior to conception, during the pregnancy, or in the postpartum period. If the mother experienced intimate partner violence, indicate if a referral was made. If the mother scheduled a follow up to a referral but didn't attend, or if there is documentation of a referral but no documentation of a subsequent appointment, select "referral made, no follow up by mother."

A101: Referral to health or human service program during or after the pregnancy

Specify if mother was referred to any human service program such as case management, legal aid, child protection services, infant health program, mental health services, family planning etc. and specify if mother utilized programs to which she was referred. Infant mental health services may include promotion, prevention, and/or treatment programs to promote and infant's social, emotional, behavioral, and cognitive development and parent-infant attachment. If there is documentation of a referral, but no documentation of a subsequent appointment, select, "referral made, no follow up by mother."

A102: At any time before or during pregnancy or until the infant's death, did the family experience any difficulty in obtaining, communicating, processing, or understanding basic health information

Indicate if the infant's family exhibited an inability assess, understand, or send feedback and questions about health information, limiting their ability to make appropriate health and/or health care decisions. This is an indicator of health literacy.

A103: Apgar scores for child at the first minute and fifth minute after delivery

APGAR scores range from 1 to 10. If one is known and the other unknown, or the infant didn't live 5 minutes, mark the one that you know. Check unknown only if both are unknown.

A104: Were neonatal resuscitation measures required or attempted in the delivery room

Resuscitation measures are actions taken to ensure the safety of child or during a high risk delivery e.g. physical stimulation, intubation, respiratory or cardiac meds for resuscitation, oxygen etc.

A105: Disposition from delivery room, did the infant go to

Specify the newborn care facility within the hospital that the child was moved into following his/her delivery.

A106: Were there morbidities noted during the nursery stay

Indicate any case of diagnosed illness, disease or injury during the period between post-delivery and discharge from the hospital. If there was no nursery stay, select "not applicable."

A107: Was a urine or meconium toxicology done on the infant

Indicate whether a urine or meconium toxicology was conducted, and if it was positive for identified substances. If positive, please indicate which substances were identified.

Note: The following 8 questions are only answered if the child left the hospital after birth, including home births.

A108: Date of infant's last discharge from any hospital

This includes any hospitalization, addressing only those inpatient hospitalizations that occurred after discharge from the birth hospital. If the child died while in the hospital, enter the date of death.

A109: Total number of days infant hospitalized

Provide the number of days infant stayed in the hospital including the number of days at the birth hospital and any inpatient hospitalizations that occurred after discharge from the birth hospital. If applicable, include the hospital stay in which the death occurred while the infant was hospitalized.

A110: Infant's disposition (after birth, from any hospital)

When the child left the birth hospital, did they go home with the parents or to another place, such as foster care? If this was a home birth, select "home with parents."

A111: Did the infant have a primary care provider

Primary care providers include doctors, physician assistants or nurse practitioners if that was the health care provider who regularly saw the infant for routine health care. This question does not refer to healthcare providers who may have participated in prenatal care or delivery

A112: Were any medications prescribed for the infant at any discharge

Specify any type of medication recommended for the infant at the point of any discharge and who administered the prescription.

A113: Was the infant technologically dependent on discharge from any hospital visit

Indicate if the infant was placed on any kind of technological medical support when leaving the hospital. This could include a mechanical pump for feeding, a mechanical ventilator, an apnea monitor, etc. If so, specify the type.

A114: After the infant came home from the hospital after delivery, did s/he have to go back into the hospital overnight for any reason

If the child was hospitalized for any reason after discharge from the birth hospital, indicate how many nights hospitalized. This number does not include hospitalizations at birth, only those hospitalizations in which the child went home for any length of time. If there were multiple hospitalizations after discharge from the birth hospital, add the number of nights together. If yes, indicate the child's age in weeks when admitted for the last time. Less than 7 days is 0 weeks.

A115: Number of outpatient/ambulatory infant encounters

Ambulatory encounters are medical observation, consulting, diagnosis, intervention and treatment services done outside of the hospital. These are actual encounters, not just those recommended but not received. The number of lines displayed in data entry will equal the number entered into the number of encounters up to a maximum of 12 lines. Enter the full number of encounters even if it is over 12 and fill in the encounters starting with the one most recent to the death and working backward. In the "why" column, put in the reason for the visit.

A5. Maternal Interview

Section A5 is only completed by FIMR users.

A116: Was a home interview conducted

This can include interviews with other family members even if the mother was not interviewed.

A117: Does the mother expect to have any more children

Indicate whether the mother intends to have more children, and if known, how many she expects to have.

A118: Was the mother currently pregnant at time of maternal interview

Indicate if the mother was pregnant at the time of the last maternal interview, and if not, if she was using birth control at that time.

A119: How does the mother remember feeling about becoming pregnant

Indicate how the mother reacted to the news of being pregnant. Specify feelings of disappointment, anxiety, sadness, anger, happiness, etc. and reasons why she had those feelings, e.g. she wanted the pregnancy sooner, later, or never.

A120: How does the mother describe the time just before her pregnancy

Indicate generally the mother's life context prior to conception. Specify notable states, such as peaceful or chaotic, in a happy or unhappy relationship, or having or lacking adequate resources.

A121: Did the mother feel she had family or friends who could help with the infant at home

Indicate if the mother felt she had anyone on whom she could rely on to help with the infant if necessary.

A122: In the months prior to the infant's death, how often did the mother feel that daily activities were overwhelming

Indicate if the mother felt she was unable to complete necessary tasks of living, meet normal expectations, or was she easily overwhelmed by her normal responsibilities.

A123: In the months prior to the infant's death, how often did the mother say that she felt very sad

Indicate how frequently the mother said she felt sad, choosing from *never*, *almost never*, *sometimes*, *fairly often*, *very often*, or *unknown*.

A124: According to the mother, was the infant in the same room with someone who was smoking

Indicate if the mother reported the infant was often in the same room with someone who was smoking. If so, indicate the average number of hours per day the infant was in the same room with someone who was smoking.

A125: According to the mother, did she have a crib, Pack 'n Play, bassinet, bed side sleeper, or baby box for the infant

Indicate if the mother identified a safe sleep space she had for the infant. If she had one of the identified safe sleep spaces, indicate how often the infant slept in the space from among the answers *always, usually, half the time, occasionally, never, or unknown*. If the response is anything other than always, describe where else the infant slept.

A126: Did the mother feel that her infant was ever treated differently or unfairly in getting services

Did the mother express a disparity in access to care or treatment based on race, cultural background, the infant's citizenship status, the mother's marital status, the type of insurance to cover the infant's care, the family's ability to pay for treatment or some other type of bias?

A127: How supportive was the father toward the mother during the pregnancy

Indicate if the father was: *not involved; supportive; unsupportive; or unknown*.

A128: How satisfied was the mother with the father's contribution(s) toward her or the infant's financial support

Indicate whether the mother felt satisfied by the father's financial contributions.

A129: Were any of the following identified as psychosocial or lifestyle problems experienced by the mother AT ANY TIME in her life, as a child herself, before or during pregnancy, or while the infant was still alive

The "mother as child" variables assess adverse events a mother may have been exposed to as a child. Indicate the mother's experience as a child and the mother's experience during her pregnancy or after birth. If the mother was a minor throughout the pregnancy, answer both "mother as child" and "current" questions.

- *Mother as child:*

- *Housing inadequate, homeless:* Indicate whether the occupied housing unit had moderate to severe physical problems, including lack of functioning plumbing, lack of a complete kitchen, unvented heating, lack of hot or cold water, or if the housing was overcrowded. Determining whether housing inadequacy is present is at the discretion of the review team. Homelessness includes "couch surfing," or staying with someone(s) in a transient manner.
- *Food insecurity:* Indicate any lack of consistent access to enough food to sustain an active, healthy life.
- *Mother treated violently:* Indicate whether the mother was treated violently by any adults or caregivers when she was a child.
- *Parents or caregiver with substance abuse problem:* Indicate if there is evidence of any caregiving adults in the mother's life having a substance use problem or addiction disorder.
- *Parents or caregiver problem drinkers:* Indicate if the mother's parents or caregiver used alcohol in ways that negatively affected their life or health in the absence of physical dependence on alcohol.
- *Parents or caregiver with mental health problems:* Indicate if there is reason to believe that any caregiving adults in the mother's life had challenged mental health, including depression or anxiety disorders. This will be subjective based

- on the maternal interview, and the mother's memory of her parents and caregivers and their behavior.
- Parental separation or divorce: Indicate if the mother's parents were separated or divorced when she was a child.
 - Incarcerated household member: Indicate if anyone in the mother's family or household was in prison while she was a child.
 - Current (during pregnancy or after birth)
 - Disturbed mother/infant relationship: A normally developing child will develop an attachment relationship with any caregiver who provides regular physical and/or emotional care, regardless of the quality of that care. A disturbed mother/infant relationship is characterized by an inability to make the child feel safe, secure, and protected.
 - Mother or Husband/Partner developmental disability
 - Physical Disability: A limitation on a person's physical functioning, mobility, dexterity or stamina. Physical disabilities may include impairments which limit other facets of daily living, such as respiratory disorders, blindness, epilepsy and sleep disorders.
 - Developmental Disability: A condition or group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.
 - Mother-employment/education needs: Any aspect of the mother/father's employment or education that might be a cause of stress or anxiety, such as underemployed, discrimination or harassment on the job, unsafe workplace, unfair/unjust compensation, wrongful termination, insufficient or no maternity/paternity leave, large amounts of time without rests, etc.
 - Inadequate support system: Indicate if the mother lacked adequate physical, emotional, or financial support when she was a child. This is determined at the discretion of the review team.
 - Mother or husband/partner felt "stereotyped" or profiled due to race, gender, class, etc.: Indicate whether the mother or father/partner felt that they were treated differently than other people based on a difference such as race, age, socioeconomic status, religion, sexual orientation, or physical ability.

A130: Did the mother feel that she was ever treated differently or unfairly in getting services

Indicate if the mother expressed a disparity in access to care or treatment based on race, cultural background, the infant's citizenship status, the mother's marital status, the type of insurance to cover the infant's care, the family's ability to pay for treatment or some other type of bias.

A131: During the mother's recent pregnancy, did the mother have others who would have helped her if a problem had come up

Were there people in the mother's life on whom she could rely for support and assistance during her pregnancy.

A132: Did the father experience any stressors during mother's pregnancy

When answering, consider events during the pregnancy that impacted the physical, social, emotional, and psychological wellbeing of the father as reported in a family interview.

A133: Did the infant ever have an illness for which they weren't seen or treated

Indicate whether the infant had an illness that went untreated, and if so, identify the barriers the family encountered.

Section B. Biological Parent Information

If available, please provide information for both biological parents. If information is only available for one of the biological parents, leave the responses blank for the parent for whom there is no information.

B1: Parents' race

Race of parent(s). These categories were issued by the Office of Management and Budget in order to promote comparability of data among federal data systems and they include five racial groups: American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or other Pacific Islander; and White. For the NFR-CRS, American Indian, Alaskan Native, Native Hawaiian and Pacific Islander each have their own category. If the parent is Arab, select White.

B2: Parent of Hispanic or Latino origin

Specify whether the parents are of Hispanic or Latino origin.

B3: Parents' age in years

Age of parents at the time of child's death.

B4: Parents' employment status

Parents' employment status at time of incident or at time of death if newborn never left hospital following birth. To be considered unemployed, a person does not work at any time during the week. If the parent is incarcerated, select "unemployed."

B5: Parents' income

Income level is an estimate based on the local context and costs of living in the community. Economic indicators such as education, social service enrollment, and health insurance type can assist in determining a parents' income level. If no concrete evidence exists regarding income, select unknown.

B6: Parents' education

Specify highest level of education which parents completed. "High school" includes a high school equivalency diploma, such as a GED.

B7: Parents speak and understand English

Indicate if parents speak and understand English. Select "Yes" if parents were able to respond to questions surrounding the circumstances of the child's death. If parents do not speak English, specify language spoken.

B8: Parents first generation immigrant

The child's parents were born in a country other than the United States and were citizens of another country at the time they moved to the United States.

B9: Parents on active military duty

Parents are documented as being active in the military at time of incident. "Active in the military" includes all people performing active duty in the United States Armed Forces. This includes those in reserve forces and National Guard performing temporary duties at the time of incident. If yes, specify branch of military.

B10: Parents receiving social services in past 12 months

Parents have had contact with social services within the past 12 months. Social services are defined as contact with the health and human service systems, as in receiving home visits from a health educator, receiving assistance through WIC or TANF, etc. WIC, the Women, Infants and Children is a nutrition program that helps pregnant women, new mothers and young children eat well and stay healthy. WIC receives federal funding from the U.S. Department of Agriculture. TANF is the Temporary Assistance for Needy Families Program. TANF became effective July 1, 1997, and replaced what was then commonly known as welfare: Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. TANF provides assistance and work opportunities to needy families by granting states the federal funds and wide flexibility to develop and implement their own welfare programs. SNAP is the Supplemental Nutrition Assistance Program that provides benefits to low-income individuals and families to help purchase food. Formerly "food stamps," these benefits are typically provided in the form of a debit-style card. EBT, or Electronic Benefit Transfer, is a program that provides either welfare cash or food benefits on a debit-style card to cover living and nutrition expenses.

B11: Parents have substance abuse history

Parents are perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse occurred, it can be marked in the 'Other' category. Select "yes" if person was noted as using illegal drugs (such as heroin or cocaine), abusing prescription medications (such as pain relievers or Valium), or regularly using inhalants (e.g., sniffing or huffing gas). If the person is mentioned as using illegal drugs, even if addition or abuse is not specifically mentioned, select "yes." A person who is noted as participating in a drug or alcohol rehabilitation program or treatment including self-help groups and 12-step program should be selected as "yes" even if the person was noted as being currently clean and sober. A person with short-term experimental use that did not cause life problems and/or addictions should be marked "no".

A problem from the past (e.g. five years or more ago) that has resolved and no longer appears to apply should still be marked "yes". Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

B12: Parents ever victim of child maltreatment

Parents have documented history of being the victim of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from law enforcement report or medical records. If referrals were made but not substantiated, still select "yes" regarding history unless the referral was found to be completely falsified.

If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if parents were ever in foster care or adopted.

B13: Parents ever perpetrator of maltreatment

Parents have documented history of being the perpetrator of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from law enforcement report or medical records. If referrals were made but not

substantiated, still select “yes” regarding history unless the referral was found to be completely falsified.

If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if caregiver ever received CPS prevention or Family Preservation services, or had children removed.

B14: Parents have disability or chronic illness

Parents have a disability or chronic illness prior to the time of incident. Chronic implies an impairment or illness that has a substantial long-term effect on day-to-day functioning or health.

- *Physical/orthopedic*: Includes any anatomical loss, mobility loss, physiological disorders, cosmetic impairments and/or chronic illnesses or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate epilepsy/seizure disorder/convulsions or cancer.
- *Mental health/substance use disorders*: Includes any mental or psychological disorder, such as emotional or mental illness. Examples include depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, schizophrenia, and personality disorders. A mental disorder is a disability only if it substantially limits one or more major life activities. A substance use (abuse or dependence) disorder is a maladaptive pattern of recurrent substance use leading to clinically significant impairment or distress. If yes, indicate if parent was receiving services.
- *Cognitive/intellectual*: Includes when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. Cognitive deficits may be congenital or caused by environmental factors. Examples may include deficits from brain injury, Down syndrome, or any of a number of congenital conditions that cause cognitive impairment. This definition includes cognitive/learning disabilities. Cognitive deficits may be congenital or caused by environmental factor or other diseases” (such as Alzheimer’s disease, etc.)
- *Sensory*: Includes any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.

B15: Parents have prior child deaths

Parents have a documented history of having a child (anyone 17 years of under) die while in his/her care, custody, or control. If yes, indicate number of prior child deaths, and the cause of death from among the identified causes. If the cause of death is not listed, choose “Other,” and specify the cause.

B16: Parents have history of intimate partner violence

Parents have a documented history of intimate partner violence (IPV) as either victim or perpetrator.

- Documented refers to evidence from law enforcement, medical, or human services.
- IPV is defined as actual or threatened physical or sexual violence or psychological and emotional abuse directed toward a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner.

- Intimate partners may be heterosexual or of the same sex. This may also include domestic disturbance complaints to which law enforcement responded.

B17: Parents have delinquent/criminal history

Parent have a documented history of delinquent or criminal behaviors or actions. This includes any history with the juvenile justice system or the criminal justice system. If yes, specify type of delinquent or criminal history that is documented. Delinquent behavior may include school disciplinary actions, charges or convictions for misdemeanor offenses. Criminal behavior includes charges or convictions for felony charges.

Section C. Primary Caregiver(s) Information

C1: Primary Caregiver(s)

Indicate relationship of caregiver(s) to child. Primary caregiver is defined as the person or persons (up to two) who had responsibility for care, custody, and control of the child a majority of the time. If primary caregiver at time of death was different from primary caregiver at time of incident, answer regarding primary caregiver at time of incident. If the child was living with his/her biological or adoptive parents, assume that they were the primary caregivers and had legal custody of the child unless otherwise specified in the records. **If the biological mother and father of the child have joint custody and the child spent equal time with each, select the mother as primary caregiver 1 and the father as primary caregiver 2.** If a parent lives outside of the child's home and does not provide the majority of care for the child, do not indicate that person was a primary caregiver.

If a newborn dies in a hospital shortly after birth, list at least the birth mother as the primary caregiver.

C2: Age in years

Age of caregiver(s) at the time of child's death.

C3: Caregiver(s) sex

Sex of caregiver(s).

C4: Caregiver(s) race

Race of caregiver(s). These categories were issued by the Office of Management and Budget in order to promote comparability of data among federal data systems and they include five racial groups: American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or other Pacific Islander; and White. For the NFR-CRS, American Indian, Alaskan Native, Native Hawaiian and Pacific Islander each have their own category. If the caregiver is Arab, select White.

C5: Caregiver(s) Hispanic or Latino origin

Specify whether the caregiver(s) is of Hispanic or Latino origin.

C6: Caregiver(s) employment status

Caregiver's employment status at time of incident or at time of death if newborn never left hospital following birth. To be considered unemployed, a person does not work at any time during the week. If the parent is incarcerated, select "unemployed."

C7: Caregiver(s) income

Income level is an estimate based on the local context and costs of living in the community. Economic indicators such as education, social service enrollment and health insurance type can assist in determining a caregiver's income level. If no concrete evidence exists regarding income, select unknown.

C8: Caregiver(s) education

Specify highest level of education caregiver completed. This information is available on the birth certificate if the caregiver is a birth parent. "High school" includes a high school equivalency diploma, such as a GED.

C9: Do caregiver(s) speak and understand English

Indicate if caregiver(s) speak and understand English. Select "Yes" if caregiver was able to respond to questions surrounding the circumstances of the child's death. If caregiver does not speak English, specify language spoken.

C10: Caregiver(s) first generation immigrant

The child's caregiver was born in a country other than the U.S. and were citizens of another country at the time they moved to the United States.

C11: Caregiver(s) on active military duty

Caregiver is documented as being active in the military at time of incident. "Active in the military" includes all people performing active duty in the United States Armed Forces. This includes those in reserve forces and National Guard performing temporary duties at the time of incident. If yes, specify branch of military.

C12: Caregiver(s) receive social services in the last 12 months

Caregiver has had contact with social services within the past 12 months. Social services are defined as contact with the health and human service systems, as in receiving home visits from a health educator, receiving assistance through WIC or TANF, SNAP, EBT, etc. WIC, the Women, Infants and Children is a nutrition program that helps pregnant women, new mothers and young children eat well and stay healthy. WIC receives federal funding from the U.S. Department of Agriculture. TANF is the Temporary Assistance for Needy Families Program. TANF became effective July 1, 1997, and replaced what was then commonly known as welfare: Aid to Families with Dependent Children (AFDC) and the Job Opportunities and Basic Skills Training (JOBS) programs. TANF provides assistance and work opportunities to needy families by granting states the federal funds and wide flexibility to develop and implement their own welfare programs. SNAP is the Supplemental Nutrition Assistance Program that provides benefits to low-income individuals and families to help purchase food. Formerly "food stamps," these benefits are typically provided in the form of a debit-style card. EBT, or Electronic Benefit Transfer, is a program that provides either welfare cash or food benefits on a debit-style card to cover living and nutrition expenses.

C13: Caregiver(s) have substance abuse history

Caregiver is perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse occurred, it can be indicated in the "other" category. Select "yes" if person was noted as using illegal drugs (such as heroin or cocaine), abusing prescription medications (such as methadone, pain relievers or Valium), or regularly using inhalants (e.g., sniffing or huffing gas). If the person is mentioned as using illegal drugs, even if addition or abuse is not specifically mentioned, select "yes." A person who is noted as participating in a drug or alcohol rehabilitation program or treatment, including self-help groups and 12-step programs, should be selected as "yes" even if the person was noted as being currently clean and sober. A person with short-term experimental use that did not cause life problems and/or addictions would not qualify as substance abuse history.

A problem from the past (e.g. five years or more ago) that has resolved and no longer appears to apply should still be “yes,” as having a substance abuse history. Previously attempting suicide via overdose is not sufficient justification for answering “yes” to this question in the absence of other information.

C14: Caregiver(s) ever victim of child maltreatment

Caregiver has documented history of being the victim of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from law enforcement report or medical records. If referrals were made but not substantiated, still select “yes” regarding history unless the referral was found to be completely falsified. If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if parents were ever in foster care or adopted.

C15: Caregiver(s) ever perpetrator of maltreatment

Caregiver has documented history of being the perpetrator of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from law enforcement report or medical records. If referrals were made but not substantiated, still select “yes” regarding history unless the referral was found to be completely falsified. If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if caregiver ever received CPS prevention, Family Preservation services, or had children removed.

C16: Caregiver(s) have disability or chronic illness

Caregiver has a disability or chronic illness. Chronic implies an impairment or illness that has a substantial long-term effect on day-to-day functioning or health.

- *Physical/orthopedic*: Includes any anatomical loss, mobility loss, physiological disorders, cosmetic impairments and/or chronic illnesses or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate epilepsy/seizure disorder/convulsions or cancer.
- *Mental health/substance use disorders*: Includes any mental or psychological disorder, such as emotional or mental illness. Examples include depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, schizophrenia, and personality disorders. A mental disorder is a disability only if it substantially limits one or more major life activities. A substance use (abuse or dependence) disorder is a maladaptive pattern of recurrent substance use leading to clinically significant impairment or distress. If yes, indicate if caregiver was receiving services.
- *Cognitive/intellectual*: Includes when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. Cognitive deficits may be congenital or caused by environmental factors. Examples may include deficits from brain injury, Down syndrome, or any of a number of congenital conditions that cause cognitive impairment. This definition includes cognitive/learning disabilities. Cognitive deficits may be

congenital or caused by environmental factor or other diseases” (such as Alzheimer’s disease, etc.)

- *Sensory:* Includes any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.

C17: Caregiver(s) have prior child deaths

Caregiver has a documented history of having a child (anyone 17 years of under) die while in his/her care, custody, or control. If yes, indicate number of prior child deaths and the cause of death from among the identified causes. If the cause of death is not listed, choose “Other,” and specify the cause.

C18: Caregiver(s) have history of intimate partner violence

Caregiver has a documented history of intimate partner violence (IPV) as either victim or perpetrator.

- Documented refers to evidence from law enforcement, medical, or human services.
- IPV is defined as actual or threatened physical or sexual violence or psychological and emotional abuse directed toward a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner.
- Intimate partners may be heterosexual or of the same sex. This may also include domestic disturbance complaints to which law enforcement responded.

C19: Caregiver(s) have delinquent/criminal history

Caregiver has a documented history of delinquent or criminal behaviors or actions. This includes any history with the juvenile justice system or the criminal justice system. If yes, specify type of delinquent or criminal history that is documented. Delinquent behavior may include school disciplinary actions, charges or convictions for misdemeanor offenses. Criminal behavior includes charges or convictions for felony charges.

Section D. Supervisor Information

Supervision is defined as the action or process of watching and directing what someone does. With respect to supervision of a child, supervision can be measured by the proximity of the supervisor to the child and the attention (visual and auditory) to the child (i.e., how close was the supervisor to the child). If not close (i.e., is separate rooms of a house), determine whether the supervisor could see and/or hear the child.

A supervisor is defined as a person who has responsibility for care and control of child at time of incident. If there were two supervisors at time of incident, but one clearly had primary responsibility, answer these questions based on the person with primary responsibility. If responsibility of supervision was divided between two people, answer based on the person who was in closest proximity with the child prior to incident as the primary supervisor.

D1: Did child have supervision at time of incident leading to death

Children less than 6 years of age require constant or close supervision most of the time. If the supervisor of a child less than age 6 was out of visual or auditory proximity, that is, they could not see or hear the child at the time of the incident, mark supervision as “No, but needed.”

For children of any age, if the supervising adult is not within close enough proximity to see or hear the child, consider the child not supervised. There are 2 possible responses for not supervised: “No, but needed” and “No, not needed given developmental age or circumstances.” Infants should always be supervised.

If the adult is within proximity that would permit them to see or hear the child, but was attending to other tasks (e.g., talking on the phone, making dinner,) consider the child supervised, but document that the supervisor was impaired in D16 by indicating “yes,” then selecting “distracted.”

If the supervisor was asleep at the time of the incident, and the child was also asleep, and if the incident occurred during the night (when you would expect families to be sleeping), the child would be considered “supervised.” However, if the supervisor is sleeping during the day or evening hours when they should be supervising the child, no other alternative supervisor is assigned, and the child is awake, the child is not considered supervised; check no here. Document supervisor sleep status in D16.

D2: How long before incident did supervisor last see child

Approximate amount of time that passed between the last time the supervisor physically saw child and the incident. If time of incident is unknown, indicate amount of time that passed between last time supervisor physically saw child and time child was found.

D3: Is supervisor listed in a previous section

Supervisor is listed as a parent or caregiver in Section B or C. If yes, go to question D15.

D4: Primary person responsible for supervision

Relationship of supervisor to child. If a newborn infant dies in a hospital shortly after birth, in most circumstances, hospital staff should be listed as the supervisor. If hospital staff or institutional staff is selected, questions D5-D14 will be hidden.

D5: Supervisor's age in years

Age of the supervisor.

D6: Supervisor's sex

Sex of the supervisor.

D7: Does the supervisor speak and understand English

Indicate if supervisor speaks and understands English. Select "Yes" if supervisor was able to respond to questions surrounding the circumstances of the child's death. If supervisor does not speak English, specify language spoken.

D8: Supervisor on active military duty

Supervisor is documented as being active in military at time of incident. "Active in the military" includes all people performing active duty in the United States Armed Forces. This includes those in reserve forces and National Guard performing temporary duties at the time of incident. If yes, specify branch of military.

D9: Supervisor has substance abuse history

Supervisor is perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse occurred, it can be indicated in the "other" category. Respond "yes" if person was noted as using illegal drugs (such as heroin or cocaine), abusing prescription medications (such as methadone, pain relievers or Valium), or regularly using inhalants (e.g., sniffing or huffing gas). If the person is mentioned as using illegal drugs, even if addition or abuse is not specifically mentioned, select "yes." A person who is noted as participating in a drug or alcohol rehabilitation program or treatment, including self-help groups and 12-step programs, should be selected as "yes" even if the person was noted as being currently clean and sober. A person with short-term experimental use that did not cause life problems and/or addictions would not qualify as substance abuse history.

A problem from the past (e.g. five years or more ago) that has resolved and no longer appears to apply should still be "yes," as having a substance abuse history. Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

D10: Supervisor has history of child maltreatment

Supervisor has documented history of being the victim or the perpetrator of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services (CPS) or documentation from law enforcement report or medical records. If referrals were made but not substantiated, still select "yes" regarding history unless the referral was found to be completely falsified.

If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if supervisor ever received CPS prevention or Family Preservation services, was ever in foster care, adopted, or had children removed.

D11: Supervisor has disability or chronic illness

Supervisor has a disability or chronic illness. Chronic implies an impairment or illness that has a substantial long-term effect on day-to-day functioning or health.

- *Physical/orthopedic*: Includes any anatomical loss, mobility loss, physiological disorders, cosmetic impairments and/or chronic illnesses or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate epilepsy/seizure disorder/convulsions or cancer.
- *Mental health/substance use disorders*: Includes any mental or psychological disorder, such as emotional or mental illness. Examples include depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, schizophrenia, and personality disorders. A mental disorder is a disability only if it substantially limits one or more major life activities. A substance use (abuse or dependence) disorder is a maladaptive pattern of recurrent substance use leading to clinically significant impairment or distress. If yes, indicate if supervisor was receiving services.
- *Cognitive/intellectual*: Includes when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. Cognitive deficits may be congenital or caused by environmental factors. Examples may include deficits from brain injury, Down syndrome, or any of a number of congenital conditions that cause cognitive impairment. This definition includes cognitive/learning disabilities. Cognitive deficits may be congenital or caused by environmental factor or other diseases” (such as Alzheimer’s disease, etc.)
- *Sensory*: Includes any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.

D12: Supervisor has prior child deaths

Supervisor has a documented history of having a child (anyone 17 years of under) die while in his/her care, custody, or control. If yes, indicate number of prior child deaths, and the cause of death from among the identified causes. If the cause of death is not listed, choose “Other,” and specify the cause.

D13: Supervisor has history of intimate partner violence

Supervisor has a documented history of intimate partner violence (IPV) as either victim or perpetrator. Documented refers to evidence from law enforcement, medical or human services. IPV is defined as actual or threatened physical or sexual violence or psychological and emotional abuse directed toward a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner. Intimate partners may be heterosexual or of the same sex. This may also include domestic disturbance complaints to which law enforcement responded.

D14: Supervisor has delinquent or criminal history

Supervisor has a documented history of delinquent or criminal behaviors or actions. This includes any history with the juvenile justice system or the criminal justice system. If yes, specify type of delinquent or criminal history that is documented. Delinquent behavior may include school disciplinary actions, charges or convictions for misdemeanor offenses. Criminal behavior includes charges or convictions for felony charges.

D15: At the time of the incident, was the supervisor asleep

Indicate if the supervisor was sleeping at the time of the incident. If yes, select the most accurate description of the supervisor's sleeping period. If the sleep period is not accurately described by the response options, select "Other," and describe the type of sleep period the supervisor was experiencing.

D16: At time of incident was supervisor impaired

Indicate supervisor's status at time of incident. For this question, impairment is interpreted broadly and includes being distracted or absent.

- *Drug impaired:* Drug impaired refers to being under the influence of any intoxicating compound or combination of intoxicating compounds to a degree that impairs a person's ability to supervise a child.
- *Alcohol impaired:* Alcohol impaired refers to being under the influence of alcohol to a degree that impairs a person's ability to supervise a child.
- *Distracted:* Distracted refers to the supervisor's attention being diverted off the child and onto something else; talking on the telephone, watching TV, cooking, doing laundry, for example.
- *Absent:* Supervisor was not present at time of incident.
- *Impaired by illness, specify:* Impaired by illness refers to a physical illness that renders a person incapable of effectively supervising a child. This includes any acute or chronic medical condition that may limit the person's ability to care for a child. Impaired by mental illness may include conditions such as depression, PTSD, bi-polar disorder or other diagnosed mental health condition.
- *Impaired by disability, specify:* Impaired by disability refers to a condition that renders a person incapable of effectively supervising a child. Impaired by disability may include developmental delays. Blindness is an example of a disability that may limit a person's ability to care for a child.
- *Other:* Specify all other factors that contributed to poor quality of supervision.

Section E. Incident Information

Incident refers to the place where the event occurred. For injury deaths, incident refers to the injury event. For natural deaths, consider the incident as the acute event leading to the death. This may be the same as the date of death. For example, if a child dies from an asthmatic episode, the incident date would be the date of the onset of the asthma attack leading to the death. For a child with a chronic illness such as cancer, the incident date may be the same as the date of death, with no acute event occurring. **Section E should only be answered if the child left the hospital following birth.**

E1: Was the date of the incident the same as the date of death

If the date of incident was different than the date of death, select “No” and then specify the date of incident. If dates are identical, select “Yes, same as date of death.”

E2: Approximate time of day that incident occurred

Specify the approximate time of day that the incident occurred using a 12 hour clock; “AM” or “PM” can be selected without providing the specific hour. If the specific time of death is unknown, but the window of time in which the child died is a small amount of time (less than 3 hours), choosing a midpoint as the time of death is acceptable. If the window of time is large, the team should select “unknown.”

E3: Place of incident

Specify where incident leading to death occurred, e.g., where the child was first injured. For designations of specific buildings (such as "child's home" or "school"), include both the building itself and area directly outside, such as side walk. If a child was injured in a variety of locations (for example, a teen was shot and was pursued by the attacker into a store and shot a second time), select the location at which the child was first injured. For children that died of natural causes, with no acute event leading to the death, the incident place is usually the same as the place of death.

E4: Type of area

Specify type of area where incident occurred. Urban is defined as a large city or densely populated area. Suburban is defined as a residential district located on the outskirts of a city. A rural area is a community with low population densities and can include agricultural and recreational land. Frontier is a very sparsely populated region in which there are less than three persons per square mile.

E5: Incident state

State in which incident occurred as stated on death certificate. If incident occurred out of the United States, select ‘Out of Country’ and type in the country where incident occurred.

E6: Incident county

County in which incident occurred as stated on death certificate. If incident occurred ‘Out of Country’ this field will be disabled.

E7: Did the death occur due to a natural disaster or mass fatality

Indicate whether the death was caused by a natural disaster such as a tornado, hurricane, flood or earthquake. A mass fatality is any event where medical resources were inadequate for the

number and severity of injuries incurred. Examples include building or bridge collapses, train and bus collisions, or terrorist attacks.

E8: Was the incident witnessed

Indicate if a person or persons physically observed the incident leading to the death.

E9: Was 911 or local emergency called

Indicate if there is documentation of 911 or local emergency services being called at the time of the incident.

E10: Was resuscitation attempted

Indicate whether any person, medically trained or not, attempted to resuscitate the child.

Resuscitation is attempting to revive someone back to conscious or active state who is unconscious, not breathing, or close to death. Even if resuscitation was not successful, indicate if attempted.

- *If yes, by whom:* If the resuscitation occurred in a hospital setting and medical personnel attempted resuscitation, indicate “Health care professional, if death occurred in a hospital setting.” If Emergency Medical Services (EMS) personnel such as an EMT attempted resuscitation in a non-hospital setting, indicate “EMS.”
- *If yes, type of resuscitation:*
 - *CPR:* Cardiopulmonary resuscitation (CPR) is a combination of chest compressions and/or rescue breathing (mouth-to-mouth resuscitation).
 - *AED:* An automated external defibrillator (AED) is a portable device that checks the heart rhythm and can send an electric shock to the heart to try to restore a normal rhythm. AEDs are used to treat sudden cardiac arrest. Please indicate if one was available and accessible, and if shock was administered by the AED.
 - *Rescue medications:* Please indicate if rescue medications (medications used for quick relief or control of symptoms) were administered, and specify the type of medication. Examples include albuterol, epinephrine, atropine, naloxone, and anti-epileptic drugs to control seizures.
- *If yes, was a rhythm recorded:* Indicate if the heart’s rhythm was documented by a rhythm strip, automated external defibrillator (AED) or electrocardiogram (ECG or EKG). Rhythm includes ventricular fibrillation and sinus rhythm. Please record the observed rhythm.

E11: At time of incident leading to death, had child used drugs or alcohol

Indicate if there was documentation by toxicology or reports by witnesses or others, including statements that the child was using or had alcohol or other drugs in their system, in the events leading up to or at the time of death. This would not include appropriate levels of prescribed or over-the-counter drugs the child was taking for known medical conditions. For infants, if toxicology results were positive for drugs or alcohol, please select “Not Applicable.”

E12: Child’s activity at time of incident

Specify activity child was engaged in at time of incident. For natural deaths, determine if the child’s activity contributed to the onset of an acute incident leading to death, for example, playing may have precipitated an asthma attack. If yes, answer this question. If no, leave blank. For infants that died at birth or lived only a few days, please leave the question blank.

E13: Total number of deaths at incident event, including child

Specify total number of deaths, including child, which occurred as a result of incident.

Section F. Investigation Information

F1: Was a death investigation conducted

Indicate whether a death investigation was completed. “Yes” may be selected even if the investigation was not conducted at the place where the child died. For example, an interview of caregivers by law enforcement at the hospital, in absence of a death scene investigation, is sufficient to select “yes” for this question. If “yes”, indicate which professionals contributed to the death investigation.

F2: Death referred to

Specify if the death was referred to the medical examiner or coroner. If medical examiner or coroner were not made aware of the death, select not referred.

F3: Person declaring official cause and manner of death

Specify who certified cause and manner of death as recorded on death certificate.

F4: Autopsy performed

Autopsy was performed on the child as stated on death certificate or other source. If “yes,” specify person who performed the autopsy.

- *Forensic pathologist:* A pathologist with a subspecialty in the examination of persons who die sudden, unexpected or violent deaths. The forensic pathologist is an expert in determining cause and manner of death. The forensic pathologist is specially trained: to perform autopsies to determine the presence or absence of disease, injury or poisoning; to evaluate historical and law-enforcement investigative information relating to manner of death; to collect medical evidence, such as trace evidence and secretions, to document sexual assault; and to reconstruct how a person received injuries.
- *Pediatric pathologist:* A pathologist with a subspecialty in the study and diagnosis of disease from conception through adolescence, recognizing that diseases of early life are distinct from those of adulthood. It is often at the forefront of advances in understanding and treatment of disorders of the fetus, the newborn infant, and the child.
- *General pathologist:* A pathologist who is a physician trained in the medical specialty of pathology. Pathology is the branch of medicine that deals with the diagnosis of disease and causes of death by means of laboratory examination of body fluids (clinical pathology) cell samples, (cytology) and tissues (pathologic anatomy).

Autopsy conducted—If no, why not: Record whether the autopsy was not performed. If known, describe the reason for the objection, for instance because the parents objected due to religious beliefs or the medical examiner denied jurisdiction on the case

Autopsy conducted—If yes, specialist consulted: Indicate whether someone other than the person conducting the autopsy provided specialty consultation. If yes, indicate the specialty of the person(s) consulted. Examples could include seeking advice from a cardiac pathologist, neuropathologist, pediatric cardiologist, or radiologist.

F5: Were the following assessed either through the autopsy or through information collected prior to the autopsy

Report whether the following tests were performed either during the autopsy or done after the incident leading to death up to the time of death. For example, if a child is injured and an MRI or

toxicology was performed after the injury but before death, include the test results. If the autopsy report is not available or the medical examiner, coroner, or pathologist who performed the autopsy is not present at the fatality review meeting, please contact them for this information.

- *X-ray - single*: The will at least provide a radiographic record of gross findings. For infants this might be described as a baby gram.
- *X-ray – multiple views*: This includes x-rays taken from multiple views but not a complete skeletal survey.
- *X-ray - complete skeletal*: This includes extremities, head, chest, abdomen, etc. One indication for a complete skeletal survey is child abuse.
- *Other imaging*: This includes but is not limited to MRI, CT scans, or photography taken.
- *Exam of general appearance*: This is a visual examination of the child to note the shape of the head and body, evidence of trauma, resuscitation, and other scars/marks that are notable.
- *Head circumference*: Indicate if head circumference was measured.
- *Was a gross examination of organs done*: This is a visual survey without the use of a microscope. Gross examination occurred if the autopsy report includes descriptions of the physical appearance of organs. This is a standard part of a complete autopsy.
- *Were weights of any organs taken*: This occurred if the autopsy report includes weights of major organs.

F6: Were any of these additional tests performed at or prior to the autopsy

- *Cultures for infectious disease*: Also known as microbiology, this screen is to rule out infections and other bacterial infections.
- *Microscopic/histological exam*: This test includes creating slides of the tissues and conducting a microscopic examination.
- *Postmortem metabolic screening*: The metabolic screen is to test blood, blood spot card, urine, or hair specimens for metabolic disorders such as MCAD. This is not the same as newborn screening done in the hospital at birth.
- *Vitreous test*: The vitreous test is used as an adjunct to toxicology testing, or if metabolic or hydration status is an issue.
- *Genetic testing*: Genetic testing is a process looking at an individual’s DNA for changes that may be disease-causing. Diseases may include syndromes (e.g., DiGeorge syndrome), inherited irregular heart rhythms (e.g., long QT syndrome), diseases of the heart muscle (e.g., hypertrophic cardiomyopathy), and many other diseases.

F7: Was any toxicology testing performed

The toxicology screen is to rule out the role of ethanol and major classes of sedatives and stimulants, including cold medications, in the death. If performed, specify results and substances found. If toxicology found that therapeutic levels of prescription or over the counter drugs were too low or too high, select as “other” and specify.

F8: Was the child’s medical history reviewed as a part of the autopsy

Indicate if the pathologist/physician or other professional conducting the autopsy or scene investigation reviewed the child’s medical history as part of the autopsy.

F9: Describe any abnormalities or other significant findings noted in the autopsy

Describe any other significant autopsy findings that have not been addressed in the other autopsy investigative questions above. List all abnormalities/significant findings from the tests indicated as assessed in F5.

F10: What additional information would the team like to have known about the autopsy

Record the team's questions pertaining to the autopsy which were not answered during the review. If resources were not limited, what tests would the team like to have ordered at autopsy. For example, full x-ray, genetic testing, long QT test on surviving siblings, or additional funding for contrast/staffing of MRI/CT utilization.

F11: Was there agreement between the cause of death listed on the pathology report and on the death certificate

The pathology report (autopsy report) often lists a suggested cause of death which may or may not be the same as the official cause of death on the death certificate. Record whether these two causes were the same for this case. If the two causes were different, please describe.

F12: Was a death scene investigation conducted at the place of the incident

Indicate whether an investigation was conducted at the location where the child died. **NOTE for CDC SUID/SDY Case Registry awardees: if an in-depth interview with witnesses of the incident occurred in a different location, but obtained information on the circumstances of the incident, you may select yes.** If yes, select any of the death scene investigation components which were completed and whether the investigation information was shared with the team. For infants, on scene investigation may or may not include a doll re-enactment. If the decedent was not an infant, select "no" to "CDC's SUIDI Reporting Form or jurisdictional equivalent."

F13: What additional information would the team like to have known about the death scene investigation

Record the team's questions pertaining to the death scene investigation which were not answered during the review. If resources were not limited, what information would the team like to have at the table? For example, photos from doll re-enactment or scene recreation, information about airway obstruction, second-hand smoke.

F14: Was a CPS record check conducted as a result of the death?

Indicate if CPS records on child were checked by investigating agencies.

F15: Did any investigation find evidence of prior abuse?

If evidence of abuse prior to incident was found during the course of the investigation, indicate from what source the evidence was found. If no investigation was conducted, please select N/A.

F16: CPS action taken because of death?

Indicate whether CPS action was taken as a result of death. If CPS action was taken as a result of death, select report screen out/not investigated, unsubstantiated, inconclusive or substantiated. Indicate services or actions that occurred. These terms may vary by state.

F17: If death occurred in licensed setting, indicate action taken

Specify action taken if death occurred in a licensed setting, such as child care. This question will

only appear in the CDR-CRS if question D4 (Place of Incident) has been marked as licensed foster care home, licensed group home, licensed child care center, or licensed child care home.

Section G. Official Manner and Primary Cause of Death

G1: Enter the cause of death code (ICD-10) assigned to this case by Vital Records using a capital letter and corresponding number (e.g., W75 or V94.4) and include up to one decimal place if applicable

If available from Vital Records, enter the exact ICD-10 code assigned to this case. Do not indicate an ICD-10 code unless it is on the death file from Vital Records.

G2: Enter the following information exactly as written on the death certificate. List the immediate cause (final disease or condition resulting in death)

Death certificates vary from state to state. However, at the bottom of most official death certificates, there is a section which has spaces for **Immediate** and **Underlying Causes** which are lettered "a" through "d." Copy the exact information from the death certificate, being careful to follow the "a" through "d" spaces.

Sequentially list any conditions leading to immediate cause of death. In other words, list underlying disease or injury that initiated events resulting in death.

G3: Enter other significant conditions contributing to death but not the underlying cause(s) listed in G2 exactly as written on the death certificate

Death certificates vary from state to state. However, at the bottom of most official death certificates, there is a space to write **other significant conditions contributing to the death**. Copy the exact information from the death certificate.

G4: If injury, describe how injury occurred exactly as written on the death certificate

Death certificates vary from state to state. However, at the bottom of most official death certificates, there is a section to describe **how the injury occurred**. Copy the exact information from the death certificate.

G5: Official manner of death from the death certificate

Official manner of death as stated on death certificate or if unavailable, as stated in medical examiner/coroner report. If pending, update when official manner is available. The official manner of death is rarely documented on a fetal birth certificate; in these instances, skip this question.

G6: Primary cause of death: Choose only 1 of the 4 major categories, then a specific cause. For pending, choose the most likely

Use this field is to identify whether the death resulted from an injury or illness (medical cause) for the purpose of completing the most appropriate risk factor details in Section H. This risk factor information is important for guiding possible prevention strategies. Consequently, the primary cause of death marked here may not be the same as the immediate cause of death listed on the death certificate.

From an injury (external cause). Select one and answer G4: If death was due to an injury, indicate primary injury category causing death. Injury refers to any unintentional or

intentional damage to the body resulting from acute exposure to thermal, mechanical, electrical or chemical energy that exceeds a threshold of tolerance in the body or from the absence of such essentials as heat or oxygen. For example, if a person is involved in a motor vehicle crash and dies from head trauma received during the crash, the primary cause of death would be motor vehicle crash and the death should be marked as from an external cause, and "motor vehicle and other transport". If the external cause is undetermined or unknown, go to I1. If external cause is "Other," go to H9. If the infant died during sleep or in the sleep environment, risk factors related to the infant sleep environment should also be answered in Section I2.

From a medical cause: If death was due to a medical condition, indicate the medical cause category of primary cause of death and then select one of the specific medical causes from the list. SIDS is considered a medical condition according to the International Classification of Diseases (ICD). However, if the infant died during sleep or in the sleep environment, risk factors related to the infant sleep environment should also be answered in Section I2. For medical conditions including hypoxia/asphyxia, hypoxic-ischemic encephalopathy (HIE), placental problems, necrotizing enterocolitis (NEC), respiratory distress syndrome (RDS), and pulmonary hypoplasia, select "other medical condition," and specify the condition, before skipping to H8.

Undetermined if injury or medical cause: Select this option if it is not possible to classify the death as due to an injury or medical cause, for example, sudden unexpected infant death. If the cause of death is undetermined, go to I1. If the child was under age five and died during sleep or in the sleep environment, risk factors related to the infant sleep environment should also be answered in Section I2.

Unknown: Team does not have information on primary cause of death. If unknown, go to H1. If the child was under age five and died during sleep or in the sleep environment, risk factors related to the infant sleep environment should also be answered in Section I2.

Section H. Detailed Information by *Cause of Death*

Choose the one section that is the same as the cause selected above.

H1. Motor Vehicle and other Transport

H1a: Vehicles involved in the incident

Write in the total number of vehicles involved in the incident. Indicate the type of vehicle the child was in. If child was not in a vehicle check none. For example, if the child was crossing a street and hit by a car, check vehicle “none” for child’s vehicle and select “pedestrian” on question H1b. If the vehicle was a utility terrain vehicle (UTV), select “ATV.”

H1b: Position of child

Position of child in relation to motor vehicle at time of incident as recorded on motor vehicle crash report.

- *Driver*: Child was in actual physical control of a transport vehicle or, for an out-of-control vehicle, child was in control until control was lost.
- *Passenger*: Child was an occupant of a road vehicle, not the vehicle driver.
- *On bicycle*: Child was riding on a bicycle or other non-motorized wheeled vehicle with pedals.
- *Pedestrian*: Child was not an occupant of a transport vehicle. Specify pedestrian activity at time of incident. If child was playing in a driveway and run over by a car backing out, mark this as “pedestrian” and specify activity as “other, playing in driveway.”
- *Unknown*: CDR team does not know the position of the child involved in the motor vehicle/other transport incident.

H1c: Causes of incident

Causes of incident as determined by reporting law enforcement officer on motor vehicle crash report. Check all that apply.

- *Recklessness*: Level of intent of driver to operate vehicle in an unsafe manner not conducive to road, weather and other traffic conditions.
- *Driver distraction*: When a driver engages in a secondary task that is not necessary to perform the primary driving task, i.e. talking to a passenger, eating. This includes distractions that occur outside of the vehicle as well. If a cell phone was the distraction, select ‘Cell phone in use while driving’.
- *Driver inexperience*: Use the information available to the team to make this decision. For example, if the crash occurred during winter conditions, was this the first time the child had driven on icy roads?
- *Drugs or alcohol use*: This includes use by the driver of any vehicle, pedestrian, bicyclist or passenger that contributed to the incident.
- *Back/Front over*: When a child is run over by the front or back of a vehicle in a roadway or driveway.
- *Flipover*: When a child is in a vehicle accident where the vehicle turns over on its side or roof.

H1d: Collision type

Indicate circumstances existing at time of incident causing injury of child. Vehicle rollovers in which another vehicle or objects was not struck should be categorized in "other event."

H1e: Driving conditions

Environmental conditions affecting road surface conditions and driver's ability to drive vehicle safely, as specified on law enforcement's motor vehicle crash report.

H1f: Location of incident

Type of place where incident occurred as specified on law enforcement's motor vehicle crash report. City streets typically consist of commercial areas whereas residential streets are predominantly housing. Highway includes *interstates*.

H1g: Drivers involved in incident

Specify details relating to drivers involved in incident. If child was driving, fill out "child as driver" column. If child was passenger, fill out "child's driver" column. Specify driver of other vehicle involved in crash. If more than two vehicles were involved in crash, report on the vehicle identified in H1a as other primary vehicle involved in crash.

H1h: Total number of occupants in vehicles

An occupant is any person who is part of a transport vehicle. Specify total number of occupants, number of teens ages 14-21, total number of deaths and total number of teen deaths (including child) in each vehicle involved in crash.

H1i: Protective measures for the child

Specify types of protective measures used by child. Protective measures are defined as steps taken by child or supervisor to ensure child's safety in the event of a crash. Use your own state laws to determine if the use was appropriate. Something should be checked **for each protective measure**. If the measure is not applicable, check "not needed." For example, for a child pedestrian hit by a car when crossing a street, check "not needed" for all measures listed.

- *Airbag*: A passive (idle) restraint system that automatically deploys during a crash to act as a cushion for the occupant. It creates a broad surface on which to spread the forces of the crash, to reduce head and chest injury. It is considered "supplementary" to the lap/shoulder belts because it enhances the protection the belt system offers in frontal crashes.
- *Lap belt*: A safety belt anchored at two points, for use across the occupant's thighs/hips.
- *Shoulder belt*: A safety belt anchored at two points, for use across the occupant's shoulder.
- *Child seat*: A crash tested device that is specially designed to provide infant/child crash protection.
- *Belt positioning booster seat*: A platform that raises the child to provide a taller sitting height so that adult lap and shoulder fit better. Some have high backs as well.
- *Helmet*: Activity appropriate protective head gear designed to reduce or prevent injuries from occurring while bicycling, skateboarding, rollerblading, riding a motorcycle, snowmobile or ATV.
- *Other, specify*: Indicate if other protective measures were used.

H2. Fire, Burn, or Electrocution

H2a: Ignition, heat, or electrocution source

Source from which fire or burn originated. Source is the direct cause or start of the fire.

H2b: Type of incident

Indicate type of incident child was involved in (e.g. fire, scald, other burn, electrocution, other or unknown).

H2c: For fire, child died from

For child who died during fire, ultimate cause of death to child as specified on death certificate. A child may have been burned in a house fire, but many times the ultimate cause of death was smoke inhalation.

H2d: Material first ignited

Type of material that first lit on fire following ignition.

H2e: Type of building on fire

Type of building/structure that was on fire at time of incident.

H2f: Building's primary construction material

Type of material of which building/structure was constructed. Specify type of material that made up majority of structure/building.

H2g: Fire started by a person

Select "yes" if any person's actions ignited the fire, regardless of whether the person intentionally set the fire. A person with a history of setting fires should have a documented or reported history of setting fires. Indicate age of person that started fire.

H2h: Did anyone attempt to put out fire

Any person, including victim, caregiver, supervisor or first responders that were reported to have tried to extinguish the fire.

H2i: Did escape or rescue efforts worsen fire

Indicate if attempts by child or family members to escape or anyone's attempts to rescue victims worsened the situation. For example, windows may have been opened or broken out, doors opened, etc., thereby fueling the fire with oxygen and increasing the volume of smoke.

H2j: Did any factors delay the fire department arrival

If factors delayed fire department arrival such as lack of communication, environmental conditions, etc., specify factors.

H2k: Were barriers preventing safe exit

List any barriers that prevented the safe exit of child, thus resulting in child's death, such as objects blocking child's path of exit, etc.

H2l: Was building a rental property

Building/structure that was on fire was a rental property, not owned by occupants.

H2m: Were building/rental codes violated

Existing state or local building/rental codes were violated. Answer if specific code violations were related to the fire incident. For example, if barriers were improperly installed, select "Yes."

H2n: Were proper working fire extinguishers present

A proper extinguisher refers to having a type of fire extinguisher appropriate to the type of fire. Fire extinguishers are classified for use on specific types of fires. For example, an extinguisher classified for Type A, B, or C fires can be used for ordinary combustibles (Type A), flammable liquids (Type B), and electrical equipment (Type C). A Class D extinguisher would be used for flammable metals. Many fire extinguishers sold today can be used for more than one type of fire (A-B-C). See the National Fire Protection Association Code 10: Portable Fire Extinguishers, Chapter 5 which describes appropriate fire extinguishers (http://www.nfpa.org/freecodes/free_access_document.asp).

H2o: Was a sprinkler system present

Indicate whether or not a sprinkler system was present in building/structure of fire at time of incident. If yes, indicate if it was working.

H2p: Were smoke detectors present

If smoke detectors were present in building/structure at time of incident, specify type (with removable batteries, with non-removable batteries or hardwired). For each type, indicate if detectors were functioning properly. If any were not functioning, select "No."

If not functioning properly, select the reason they were not working (missing batteries or another reason). Indicate if there were an adequate number of detectors for the space. Suggested guidelines for judging adequate coverage are based on codes from the National Fire Protection Association (NFPA code 72: National Fire Alarm Code, Chapter 11):

- There should be a smoke alarm on every level of the home, including the basement.
- There should be an alarm in all sleeping rooms and guest rooms and outside every sleeping area.
- All hard-wired smoke alarms must be interconnected.
- In addition, if house > 1000 sq feet (excluding garage), smoke alarms shall be installed to the equivalent of 1 per every 500 square feet.

It is important to note that these are national guidelines. The actual recommendations and code may vary by state, so please consult your state codes or Fire Marshal.

H2q: Suspected arson

Cause of fire was documented as a suspected arson incident.

H2r: For scald, was hot water heater set too high

The standard setting for a water heater is under 120 degrees Fahrenheit. Specify temperature setting of hot water heater if known.

H2s: For electrocution, cause

If incident was electrocution, specify cause of electrocution.

H2t: Other

If incident type was other or unknown (not already indicated), describe incident and cause of death.

H3. Drowning

H3a: Where was child last seen before drowning

Place where child was last seen before incident leading to drowning. Please check all that apply.

H3b: What was child last seen doing before drowning

The last known or observed activity of child before incident leading to drowning. Please note that boating includes jet skis or personal water crafts.

H3c: Was child forcibly submerged

Force was used to intentionally hold the child under water. This would include persons intending to drown the child as well as persons holding a child under water during play, without the intent of drowning. Do not select "yes" if a child was held under water by an object, such as being caught by an anchor or raft rope or submerged under debris or hit by a surfboard.

H3d: Drowning location

Type of location in which drowning occurred. Bath tub includes in home bath tubs with water jets.

H3e: For open water, place

For open water deaths, indicate type of place where incident occurred.

H3f: For open water, contributing environmental factors

If any environmental factors contributed to the drowning, specify. If no environmental factors contributed, leave blank. If more than one environmental factor was present, select the factor that was most salient to the fatality.

- *Weather:* Wind, heavy rains, or snowmelt can create dangerous water conditions. Additionally, poor weather conditions may have limited visibility or access to the decedent. For example, severe wind or rain may have made the water unnavigable, impeding rescue efforts.
- *Current:* A current can include an ocean current or a river current. For example, in the ocean, a long shore current is located in the surf zone, moving generally parallel to the shoreline, generated by waves breaking at an angle with the shoreline. Rip currents should be included here. Rip currents are powerful, channeled currents of water flowing away from shore. They typically extend from the shoreline, through the surf zone, and past the line of breaking waves. Rip currents can occur at any beach with breaking waves, including the Great Lakes.
- *Riptide/undertow:* A riptide includes both ebb and flood tidal currents that are caused by egress and ingress of the tide through inlets and the mouths of estuaries, embayment's and harbors. An undertow occurs after a wave breaks and runs up the beach. Most of the water flows seaward; this "backwash" of water can trip waders,

move them seaward, and make them susceptible to immersion from the next incoming wave.

- *Drop off:* A sharp drop in the ground beneath a body of water can make an area much deeper than the surrounding water. This difference can be indiscernible from the surface, while making the water more dangerous for those in the water.
- *Rough waves:* Choppy conditions can make boating more dangerous, watersports more difficult, and swimming more dangerous.
- *Other:* Identify any other environmental factors or conditions that may have contributed to the drowning.

H3g: If boating, type of boat

If boating-related death, specify type of boat child was riding in/on at time of incident.

H3h: For boating, was the child piloting the boat

If boating-related death, specify if child was piloting boat at time of incident.

H3i: For pool, type of pool

If pool death, specify type of pool. This includes hot tubs and spas.

H3j: For pool, child found

If pool death, specify if child was found in pool/hot tub/spa or under cover. If neither, leave blank.

H3k: For pool, ownership is

Definitions of public and private pools can vary by state and locality. Consult your state guidelines for more information. In general, a private pool includes a swimming pool, spa, wading pool or portable above ground pool at a single or two-family family residence. A public pool includes municipal, institution, hotel, apartment, mobile home or RV park, private club or YMCA facility pools.

H3l: Length of time owners had pool/hot tub/spa

If residential pool/spa/hot tub death, specify length of time person owned pool/spa/hot tub.

H3m: Flotation device used

Indicate if child was wearing a personal flotation device at time of incident. If yes, specify if it was Coast Guard approved and type of device. If flotation device was not Coast Guard approved, specify type of device used.

H3n: What barriers/layers of protection existed to prevent access to water

Specify type of barrier(s) and layer(s) of protection that were in place to prevent access to water or alert persons that access to water had occurred. Check all that apply.

H3o: Fence

If fence was present at time of incident as barrier/layer of protection, specify type, height and sides of water it surrounded.

H3p: Gate

If gate was present at time of incident as barrier/layer of protection, check all that apply.

H3q: Door

If door was present at time of incident as barrier/layer of protection, specify type. Check all that apply.

H3r: Alarm

If alarm was present at time of incident as barrier/layer of protection, specify type. Check all that apply.

H3s: Type of cover

If cover was present at time of incident as barrier/layer of protection, specify type.

H3t: Local ordinance(s) regulating access to water

Indicate if local ordinance(s) related to pools/hot tubs barriers was/were in place at time of incident. If yes, indicate if regulations were violated. If this is not applicable to the situation, select "no."

H3u: How were layers of protection breached

If barriers/layers of protection were breached during incident, indicate how they were breached. Breached is defined as opened, not functioning or not well placed.

H3v: Child able to swim

For incidents occurring in pool, hot tub, spa or open body of water, indicate if child had ability to swim. This is subjective, based on investigative reports and relative to child's developmental ability.

H3w: For bathtub, child in a bathing aid

Child was left unattended in a bathtub seat or ring at time of incident. Bath tub seat or ring is defined as a plastic ringed chair with three or four attached legs that is placed inside a bathtub. The infant sits up inside the bathtub seat, leaving the caregiver's hands free to wash the child.

H3x: Warning sign or label posted

Warning signs or labels were posted at the place of incident or on the object that the child drowned in, indicating potentially hazardous conditions. Examples could include warning signs at rivers to indicate dangerous currents, warning signs at beaches, labels on five gallon buckets of water, or signs posted at swimming pools indicating that lifeguards were not present.

H3y: Lifeguard present

For pool and open body of water deaths, indicate if a lifeguard was present at time of incident.

H3z: Rescue attempt made

If rescue was attempted, indicate who attempted to rescue the child.

H3aa: Did rescuer(s) also drown

If rescue was attempted, indicate if person/people attempting rescue also drowned. Specify number of persons that drowned.

H3bb: Appropriate rescue equipment present

For pool and open body of water deaths, indicate if appropriate rescue equipment was present and available at time of incident. Appropriate is relative to the place of drowning. For example, a swimming pool or public beach should have rescue equipment easily accessible.

H4. Unintentional Asphyxia

H4a: Type of event

Specify the type of unintentional asphyxiation. **Note effective in Version 5.0, intentional asphyxia should now be noted in Section H5 (Assault, Weapon or Person's Body Part).** For example, if the child died by suicide via means of rope, then cause of death should be marked as "Assault, Weapon, or Person's Body Part." If the child died by homicide via means of strangulation by another person's hands, then the cause of death should be marked as "Assault, Weapon, or Person's Body Part."

- Suffocation is a broad term that refers to death or serious injury by deprivation of oxygen; can involve a variety of mechanisms.
- Strangulation is more narrowly defined as death by asphyxiation caused by some sort of compression of the neck.
- Choking refers to asphyxiation caused by an object becoming lodged in the airway.

H4b: If suffocation/asphyxia, action causing event

For cases of suffocation, specify the circumstances that led to the asphyxia event. Overlay refers to death, usually of an infant, due to asphyxiation caused inadvertently by another person with whom they are sharing a sleep surface. This could be caused by the person or animal rolling over onto the infant or against if their body in any other way inhibits the infant's ability to breathe. Wedging is when a child, usually and infant, becomes trapped between objects, often a mattress and a wall, such that it limits their ability to breathe. Asphyxia by gas could include carbon monoxide poisoning, or death by "huffing" or inhalant abuse; be sure to also answer question H7g.

H4c: If strangulation, object causing event

For cases of strangulation, indicate what object caused the compression of the child's neck. Intentional strangulation should not be noted in Section H4 (Unintentional asphyxia). If the child died by suicide via means of rope, then cause of death should be marked as "Assault, Weapon, or Person's Body Part" (Section H5). If the child died by homicide via means of strangulation by another person's hands, then the cause of death should be marked as "Assault, Weapon, or Person's Body Part" (Section H5))

H4d: If choking, object causing choking

For cases of choking, indicate what type of object blocked the child's airway.

H4e: Was asphyxia an autoerotic event

Autoerotic asphyxiation is defined as the practice of inducing cerebral anoxia, usually by means of ligatures or suffocating devices for the purposes of sexual arousal. The most common practitioners are adolescent and young adult males. Select "Unknown" if the team could not determine if the child was participating in an autoerotic event or intentionally killed him/herself.

H4f: Was child participating in 'choking game' or 'pass out game'

Indicate whether asphyxia death was related to playing a game known by many names, most commonly as 'choking game' or 'pass out game'. The goal of this game, most often played by younger adolescents (9-14 year-olds) is to achieve a brief high or euphoric state by stopping the flow of oxygen-containing blood to the brain. Sometimes children choke each other until the person being choked passes out. The pressure on the arteries is then released and blood flow to the brain resumes, causing a "rush" as consciousness returns. There are variations of this activity, which could involve purposefully induced hyper-ventilation or the use of ligatures. It may be most dangerous when played alone, as the child may lose consciousness before being able to release the mechanism of asphyxiation, thereby causing death. Select "Unknown" if the team could not determine if the child was participating in the "choking game."

H4g: History of seizures

Indicate whether child had a documented history of seizures. A seizure is an involuntary muscular contraction and relaxation originating from the "short circuit" of the central nervous system. Seizures vary in pattern, length and intensity. Causes include fever, tumors, injuries or epilepsy. If yes, were the seizures ever witnessed?

H4h: History of apnea

Indicate whether child had a documented history of apnea. Apnea is defined as an interruption in the normal breathing patterns of a child. If yes, was the apnea ever witnessed?

H4i: Was Heimlich Maneuver attempted

If child was choking, indicate whether the Heimlich maneuver was attempted to try to dislodge the item child was choking on. Heimlich Maneuver is defined as abdominal thrusts applied manually to dislodge an object blocking the airway.

H5. Assault, Weapon, or Person's Body Part

Assault, Weapon, or Person's Body Part should be selected for causes of death involving firearms, sharp instruments, or when a person's body part has been used as a primary means of the assault or injury. Intentional strangulation, either by suicide or homicide, should also be noted in this section.

H5a: Type of weapon

Specify type of weapon used in incident to cause injury to the child.

- *Firearm:* A weapon consisting of a metal tube that fires a projectile at high velocity using an explosive charge as a propellant. This definition includes handguns, rifles, and shotguns.
- *Sharp instrument:* These include knives, razors, machetes, or pointed instruments (e.g., chisel, broken glass).
- *Person's body part:* Any part of a person used as the primary instrument of the assault or injury. For example, fists for punching, feet for kicking. Body part should not be checked if the person was using hands to hold another weapon.
- *Blunt instrument:* Items that can cause harm, but are not sharp, such as clubs, bats, sticks, hammers, rocks, household items, etc.
- *Biological weapon:* Any infectious agent such as a bacteria or virus used intentionally to inflict harm upon others. This definition is often expanded to include biologically derived toxins and poisons.

H5b: For firearms, type

If firearm was weapon, specify type.

H5c: Firearm licensed

If firearm was weapon, indicate if it was licensed to owner.

H5d: Firearm safety features

If firearm was weapon, specify safety features present on firearm at time of incident.

- *Trigger lock*: An external device that is attached to the handgun with a key or combination and is designed to prevent a handgun from being discharged unless the device has been deactivated.
- *Personalization device*: A device installed in a firearm that prevents unauthorized users of any age from firing it.
- *External safety/drop safety*: A device that blocks the trigger or the hammer from striking the firing pin, will sometimes de-cock the pistol's hammer, and can disengage the trigger mechanism.
- *Loaded chamber indicator*: A gauge showing when a gun is loaded.
- *Magazine disconnect*: A device that prevents the gun from firing if the ammunition magazine (or part of gun that hold the bullets prior to chambering) is removed.
- *Minimum trigger pull*: A gun feature that only enables a gun to fire if a minimum level of force is placed on trigger.
- *Other*: Indicate any other safety feature that was present on the firearm, not included above.

H5e: Where was firearm stored

If firearm was weapon, indicate where firearm was stored at time of incident.

H5f: Firearm stored with ammunition

If firearm was weapon, indicate if it was stored/kept in same place as ammunition.

H5g: Firearm stored loaded

If firearm was weapon, indicate if it was stored/kept loaded with ammunition.

H5h: Owner of fatal firearm

Specify documented owner of weapon.

H5i: Sex of fatal firearm owner

Sex of person who owned the weapon that killed the child.

H5j: Type of sharp object

If sharp object was weapon, specify type.

H5k Type of blunt object:

If blunt object was weapon, specify type of blunt object.

H5l: What did person's body part do

Body part includes any part of a person used as the primary instrument of the assault or injury. For example, fists for punching, feet for kicking. Body part should not be checked if the person was using hands to hold another weapon. If body part was weapon, how was body part used to create injuries that killed the child? This includes child abuse and other assaults. Only select "Other, specify," if body part action does not fit into any other category.

H5m: Did person using weapon have history of weapon-related offenses

Person using weapon has a documented history of weapon-related offense.

H5n: Does anyone in child's family have a history of weapon offenses or die of weapons-related causes

Member of child's family has a documented history of weapon offenses or died of causes due to a weapon-related injury.

H5o: Persons handling weapons at time of incident

Relationship of person/people handling weapon(s) at time of incident that killed child. Partner is defined as a person who lives with and is sexually involved with (but is not married to) the child's mother or father. Select "other, specify" for person/people handling weapon(s) at time of incident only if those person(s) do not fit into any other category. Fatal weapon is the weapon that injured the child. Other weapon includes any weapon involved in the incident that did not injure the child.

H5p: Sex of person(s) handling weapon

Sex of person who handled fatal and/or other weapon being used at the time of incident.

H5q: Use of weapon at time

Specify intended use of the fatal weapon at time of incident. Check apply that apply.

H6. Fall or Crush

H6a. Type

Indicate if the incident was a fall or crush.

H6b: Height of fall

Estimate the number of feet and inches child fell from. This is measured from the lowest point of the child to the surface they fell to. The number of feet in one story varies by building architecture. If unable to estimate, then select "unknown."

H6c: Child fell from

Indicate the type of place where child fell from. An example of a natural elevation would be a cliff; an example of a man-made elevation would be a scaffolding, balcony, porch, or other structure not otherwise listed.

H6d: Surface child fell onto

Indicate type of surface onto which child fell.

H6e: Barrier in place

Indicate type(s) of barriers that were in place at time of incident to prevent fall. Barriers are defined as obstacles or objects placed in the child's way to prevent them from accessing a certain place. "Other window guard" does not include screen, but does include metal grates.

H6f: Child in baby walker

Baby walker is defined as a light frame on casters or wheels to help a baby learn to walk. Some have seats for younger babies, and some are more like a push toy.

H6g: Was child pushed, dropped, or thrown

Specify if child was either pushed, dropped or thrown. If none of these apply, leave blank.

H6h: For crush, did child

If crush was primary cause of death, specify child's position in relationship to object at time of incident.

H6i: For crush, object causing crush

If crush was primary cause of death, specify object that crushed child. If crush caused by person, indicate activity at time of incident in H5q.

H7. Poisoning, Overdose, or Acute Intoxication

H7a: Type of substance involved

Indicate type of substance involved in incident. List all types of substances contributing to the death, not just the substance causing death. Do not list substances unless they contributed to the death as documented on death certificate or autopsy report.

- *Prescription drug:* Prescription drug is a pharmaceutical drug that legally requires a medical prescription to be dispensed. Select prescription drug if the medication was prescribed for the child or another member of the child's family/household. Prescription drugs that were obtained illegally should be noted as illicit drugs. Pain medication (opiate) should be selected for all prescribed opiates except methadone, which has its own reporting category. In addition to noting the type of prescription drug, please indicate if the prescription was for the child.
- *Over-the-counter drug:* Over-the-counter drug is a medication that can be obtained without a prescription from a health care professional and is sold directly to the consumer.
- *Illicit drug:* Illicit drug is the non-medical use of a variety of drugs prohibited by law. Illicit drugs are illegal to make, sell or use. These include cocaine, methamphetamine, amphetamines, heroin, and MDMA (ecstasy). Illicit drugs also include using prescribed medications illegally.
- *Other substance:* Includes the use of alcohol, carbon monoxide, other fumes, and other substances.

H7b: Where was the substance stored

Specify place substance was stored at time of incident. This may not be applicable in all cases such as recreation drug use. In these situations, leave the item blank.

H7c: Was the product in its original container

Select as yes, if poison was in the container that the manufacturer originally packaged it in or in its original prescription dispensing format.

H7d: Did container have a child safety cap

The container the poison was in at time of incident was equipped with a child safety cap that was securely on. Child safety cap is defined as a lid to a container that requires the level of developmental ability to open it to be equal to that of an eight-year-old child.

H7e: Was the incident a result of

Indicate if the incident occurred due to one of the following:

- *Accidental overdose*: Unintentionally administering medication above recommended safe dosage levels. Also includes children ingesting/exposed to agents (including nonpharmaceutical agents) without knowledge of adverse consequences. An example would include a caregiver accidentally giving a child a dangerous dose of cold medicine. Unintended alcohol poisoning is NOT an accidental overdose but rather should be noted as acute intoxication (see below).
- *Medical treatment mishap*: Includes medication incorrectly prescribed or incorrectly administered by medical personnel.
- *Adverse effect but not overdose*: Includes prescribed or over-the-counter medication administered and prescribed correctly but child had adverse reaction.
- *Deliberate poisoning*: Refers to intentionally administering medication with the intent to harm the child. This includes both suicidal and homicidal poisonings.
- *Acute Intoxication*: Refers to agents taken as a result of recreational use or addiction. It excludes suicide. Examples include unintended alcohol poisoning or drug overdose while using recreational drugs.

H7f: Was Poison Control called:

If Poison Control was called as a result of incident, specify relationship of caller to child.

H7g: For CO poisoning, was a CO detector present

If carbon monoxide (CO) poisoning was primary cause of death, indicate if CO detector was present. If detector was present, indicate if it was functioning properly at time of incident.

H8. Medical Condition

H8a: How long did the child have the medical condition

Specify general length of time child had medical condition. This is often stated on the death certificate.

H8b. Was death expected as a result of the medical condition

If childhood death was expected as a result of the medical condition, indicate if death was expected to happen at a later time.

H8c. Was child receiving healthcare for the medical condition

Indicate if child was receiving health care for medical condition resulting in the death. Select “yes” even if the child was not diagnosed correctly. Indicate if care was provided within 48 hours of the death.

If the team concludes that the child was receiving care but there was a delay in the diagnosis or the child was misdiagnosed and the delay/misdiagnosis contributed to the death, this should be included in the narrative section.

H8d: Were the prescribed care plans appropriate for the medical condition

Indicate if care plans prescribed by physician were appropriate for the medical condition. If no, specify why inappropriate.

H8e: Was child/family compliant with the prescribed care plans

Indicate if child/family was in compliance with care plans prescribed by physician. If not, specify part of the plan that child/family was out of compliance with. If no care plan was in place, select 'N/A'.

H8f: Was the medical condition associated with an outbreak

Indicate if medical condition child suffered from was associated with a disease outbreak (e.g. flu, virus, etc.).

H8g: Was environmental tobacco exposure a contributing factor in death

Select "yes" if the team believes that environmental tobacco exposure contributed to the death. Do not choose "yes" if the child was a smoker and secondhand smoke was not known to be a contributor. Secondhand smoke, also known as environmental tobacco smoke, is a complex mixture of gases and particles that includes smoke from the burning cigarette, cigar, or pipe tip (sidestream smoke) and exhaled mainstream smoke. Secondhand smoke contains at least 250 chemicals known to be toxic, including more than 50 that can cause cancer (National Toxicology Program. [11th Report on Carcinogens, 2005](#)).

Secondhand smoke exposure causes respiratory symptoms in children and slows their lung growth. Secondhand smoke causes acute respiratory infections, ear problems, and more frequent and severe asthma attacks in children. There is no risk-free level of secondhand smoke exposure. Even brief exposure can be dangerous (U.S. Department of Health and Human Services. [The Health Consequences of Involuntary Exposure to Tobacco Smoke: A Report of the Surgeon General, 2006](#)).

H8h: Were there access or compliance issues related to the death

If there were compliance with care issues on part of child, family or health care providers related to death, specify issues. Compliance with care is defined as recommended ways of caring for child as prescribed by a physician. H8h options are defined in section A42.

H8i: Was death caused by a medical misadventure

Medical misadventure is a broad term that encompasses the recognition that unintentional events or errors may occur in medical institutions or by medical practitioners. This does not refer to individual's intentional or unintentional misuse of medicines or medical procedures carried out without medical supervision.

H9. Other Known Injury Cause

H9. Other known injury cause

Describe the cause and/or circumstances involved in the child's death.

Section I. Other Circumstances of Incident

I1: Sudden and Unexpected Death in the Young (SDY)

This section is designed for the jurisdictions funded to participate in the Centers for Disease Control and Prevention Sudden Death in the Young (SDY) and Sudden Unexpected Infant Death (SUID) Case Registries. If your jurisdiction is funded, complete this section. If your jurisdiction is not funded, you do not need to complete these questions (Section I1 may not display for your State, depending upon State Fatality Review Coordinator). If your jurisdiction is not funded but your state would like to complete these questions, please contact the National Center for more information. **Section I1 will not display for FIMR teams.**

I1a: Was this death

During the initial investigation was the death any of the following:

- Homicide – select if death was caused intentionally by another person
- Suicide – select if death was caused intentionally by the decedent
- Overdose – select if death was caused by accidental or intentional overdose of drug killed decedent even if this caused cardiac or respiratory arrest with no prior history of other possible chronic disease or autopsy findings suggestive of another cause
- External injury – select if death was caused by an external injury which was the only and obvious reason for the death (do not select if the underlying cause of the accident may have been cardiac or neurological in origin including drownings, infant suffocations, drivers in motor vehicle crashes, etc.)
- Terminal illness – select if the death was reasonably expected to occur within 6 months due to an incurable and irreversible illness that was diagnosed prior to death

If any of preceding categories apply, this case is NOT AN SDY CASE. If the response is “none of the above” or “unknown,” then proceed to I1b. THIS IS AN SDY CASE.

I1b: Did the child have a history of any of the following acute conditions or symptoms within 72 hours prior to death

Please note if any of the identified symptoms in I1b were noted or reported by the child, caregiver, or family member. Some but not all of the symptoms are described further below.

- *Chest pain*: Discomfort or pain felt anywhere along the front of the body between the neck and upper abdomen.
- *Dizziness/lightheadedness*: A variety of conditions including a spinning sensation, unsteadiness, or a sensation of losing one’s balance.
- *Fainting*: A temporary loss of consciousness.
- *Palpitations*: Sensations of the heart that include skipped or stopped beats, pounding or racing. They can be felt in the chest, throat, or neck.
- *Convulsions/seizure*: An episode or history of an episode(s) that could be seizure(s), even in the absence of a definitive diagnosis of epilepsy. Terms commonly used by families to indicate seizure-like activity include:
 - *History of seizure*
 - *Fit*
 - *Episode*
 - *Attack or spell*
 - *Falling out spell*
 - *Drop attack*

- *Staring spell*
- *Out-of-touch*
- *Psychiatric symptoms*: Includes depression or anxiety.

11c: At any time more than 72 hours preceding death did the child have personal history of any of the following chronic conditions or symptoms

Please note if any of the identified symptoms in 11c were noted or reported by the child, caregiver, or family member. Some but not all of the symptoms are described further below.

- *Chest pain*: Discomfort or pain felt anywhere along the front of the body between the neck and upper abdomen.
- *Dizziness/lightheadedness*: A variety of conditions including a spinning sensation, unsteadiness, or a sensation of losing one's balance.
- *Fainting*: A temporary loss of consciousness.
- *Palpitations*: Sensations of the heart that include pounding or racing. They can be felt in the chest, throat, or neck.
- *Convulsions/seizure*: An episode or history of an episode(s) that could be seizure(s), but without a definitive diagnosis of epilepsy. Terms used to indicate seizure-like activity include:
 - *History of seizure*
 - *Fit*
 - *Episode*
 - *Attack or spell*
 - *Falling out spell*
 - *Drop attack*
 - *Staring spell*
 - *Out-of-touch*

11d: Did the child have any prior serious injuries

If yes, please describe the injuries.

11e: Had the child ever been diagnosed by a medical professional for the following

Diagnoses should be reported only if found in the medical records.

- *Blood Disease*
 - *Sickle cell disease*: Child was diagnosed with sickle cell disease and/or had two abnormal hemoglobin genes.
 - *Sickle cell trait/carrier*: Child has one abnormal hemoglobin gene, also known as sickle cell trait.
 - *Thrombophilia*: An increased tendency to form abnormal blood clots in blood vessels. People with thrombophilia are at great risk for deep vein thrombosis and pulmonary embolism. Genetic forms include Factor V Leiden and prothrombin thrombophilia.
- *Cardiac*

If any of the following cardiac symptoms are selected, please indicate in the follow up question in 11e what cardiac treatments the child received.

- *Abnormal electrocardiogram (EKG or ECG)*: An EKG or ECG measures the heart's electrical activity.

- *Aneurysm/aortic dilatation/aortic rupture*: Abnormal dilation of the wall of the aorta, usually 50% greater than its normal diameter/tear in the intima (inner layer) creating a false lumen. This includes aortic rupture. Some examples of at risk youth include but is not limited to those with collagen vascular diseases (e.g., Marfan syndrome, Ehlers-Danlos) or bicuspid aortic valve, Turner Syndrome, or hypertension.
- *Arrhythmia/arrhythmia syndrome*: Can also be called a fast or irregular heart rhythm and palpitations and includes diagnoses such as: long QT, Brugada, Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT), Wolff Parkinson White (WPW), and Short QT syndrome.
- *Cardiomyopathy*: A disease of the heart muscle. Specific diagnoses can include hypertrophic, dilated, arrhythmogenic right ventricular or left ventricular non-compaction.
- *Comotio cordis*: A blow to chest causing cardiac arrest or death.
- *Congenital heart disease*: Structural heart disease present at birth. There are many varieties. Some forms of congenital heart disease have been associated with sudden cardiac death (e.g., tetralogy of Fallot, double outlet right ventricle, transposition of the great arteries, and single ventricle lesions such as double inlet left ventricle, hypoplastic left heart syndrome, and tricuspid atresia).
- *Coronary artery abnormality*: Considered causative when specific anomalies known to be associated with sudden death were noted on autopsy, or a coronary anomaly was the only finding (e.g., anomalous left main coronary with take-off from the right coronary cusp and an intramural course between the pulmonary artery and aorta, anomalous right coronary artery with oblique take-off, and regional acute or chronic corresponding regional perfusion defect, single coronary artery, and anomalous left coronary artery from the pulmonary artery (ALCAPA). Separate coronary ostia, cloacal left main coronary artery and anomalous circumflex off the right coronary cusp are not commonly considered to be causative of sudden death.
- *Coronary artery disease (atherosclerosis)*: Gross pathologic and/or histopathologic findings of an acute myocardial infarction or occlusive atherosclerotic coronary artery disease.
- *Endocarditis*: Bacterial infection of the heart valves with findings of vegetation that may result in septic emboli (to the brain, lungs, eyes, skin, digits).
- *Heart failure*: A chronic condition in which the heart doesn't pump blood as well as it should.
- *Heart murmur*: A heart murmur is an unusual sound heard between heartbeats. Murmurs sometimes sound like a whooshing or swishing noise. Murmurs may be harmless, also called innocent, or abnormal.
- *High cholesterol*: Build up of fatty deposits in blood vessels.
- *Hypertension: Abnormally high blood pressure.*
- *Myocarditis (heart infection)*: Histopathologic diagnosis of inflammatory infiltrates of the heart muscle with necrosis and/or degeneration of adjacent myocytes not typical of ischemic damage associated with coronary artery disease, leading to heart failure, arrhythmias, and sudden death.
- *Pulmonary hypertension*: Elevated pulmonary artery pressure leading to vasculopathy/muscularization of the small muscular pulmonary arterioles (medial hypertrophy, intimal hyperplasia, and plexiform lesions). May be idiopathic

(primary) or secondary to other diseases (e.g., connective tissue diseases or unrepaired/palliated congenital heart disease).

- *Sudden cardiac arrest*: Sudden cardiac arrest (SCA) is a condition in which the heart suddenly and unexpectedly stops beating. If this happens, blood stops flowing to the brain and other vital organs. SCA usually causes death if it's not treated within minutes.

- Neurologic

- *Anoxic brain injury*: An injury caused by lack of oxygen to the brain.
- *Traumatic brain injury*: Disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury. Most often an acute event. Symptoms may appear right away or may not be present for days or weeks after the injury.
- *Brain tumor*: Brain tumors may arise primarily from the brain tissues or may result from tumors in other organs (lung, breast, GI tract, skin, etc.) spreading (metastasizing) to the brain. There are two main types of tumors: malignant or cancerous tumors and benign tumors.
- *Brain aneurysm*: A brain aneurysm is a balloon or bulge in a blood vessel in the brain. This can cause a weak area in the artery that supplies blood to the brain, which can eventually cause leaking or rupture.
- *Brain hemorrhage*: A type of stroke that is caused when a blood vessel in the brain bursts causing localized bleeding in the surrounding tissues. This bleeding kills brain cells.
- *Developmental brain disorder*: Can include such diagnoses as cerebral palsy, intellectual disability (mental retardation) or a structural brain malformation.
- *Epilepsy/seizure disorder*: Defined by any of the following conditions: At least two unprovoked (e.g., not febrile) seizures occurring more than 24 hours apart; one unprovoked seizure and a probability of further seizures occurring over the next 10 years; or diagnosis of an epilepsy syndrome.
- *Febrile seizure*: Febrile seizures are seizures or convulsions that occur in young children and are triggered by fever
- *Mesial temporal sclerosis*: Mesial temporal sclerosis is closely related to temporal lobe epilepsy, a type of focal (partial) epilepsy in which the seizure initiation point can be identified within the temporal lobe of the brain. Mesial temporal sclerosis is the loss of neurons and scarring of the temporal lobe associated with certain brain injuries.
- *Neurodegenerative disease*: A process in which the function or structure of the affected brain area will increasingly deteriorate over time.
- *Stroke/mini stroke*: The loss of brain function due to a disturbance in the blood supply to the brain. This disturbance is due to either ischemia (lack of blood flow) or hemorrhage.
- *Central nervous system infection (meningitis or encephalitis)*:
 - *Encephalitis*: An inflammation of the brain. Usually the cause is a viral infection, but bacteria can also cause it. It can be mild or severe.
 - *Meningitis*: Inflammation of the thin tissue that surrounds the brain and spinal cord, called the meninges. The most common type is viral meningitis, which you get when a virus enters the body through the nose or mouth and travels to the brain. Bacterial meningitis is rare, but can be deadly. It usually starts with

bacteria that cause a cold-like infection. It can block blood vessels in the brain and lead to stroke and brain damage. It can also harm other organs.

- Respiratory
 - *Apnea*: A suspension of breathing.
 - *Asthma*: A condition in which a person's airways become inflamed, narrow and swell, and produce extra mucus, which makes it difficult to breathe.
 - *Pulmonary embolism*: Obstruction of the pulmonary artery or one of its branches by thrombus, tumor, air or fat that originated elsewhere in the body. If severe, it may result in acute right ventricular heart failure and death.
 - *Pulmonary hemorrhage*: An acute bleeding from the lung, from the upper respiratory tract and the trachea, and the alveoli.
 - *Respiratory arrest*: Respiratory arrest is the interruption of pulmonary gas exchange- or breathing- for five minutes or more.
- Other
 - *Connective tissue disease*: Connective tissue disease refers to a group of disorders involving the protein-rich tissue that supports organs and other parts of the body. Examples of connective tissue are fat, bone, and cartilage. These disorders often involve the joints, muscles, and skin, but they can also involve other organs and organ systems including the eyes, heart, lungs, kidneys, gastrointestinal tract, and blood vessels. Specific diagnoses include Ehlers Danlos, Marfan syndrome, bicuspid aortic valve with aortic root dilation and/or cystic medial necrosis.
 - *Diabetes*: Indicate if the child had ever been diagnosed with any type of diabetes.
 - *Endocrine disorder, other*: Indicate if the child had been diagnosed with any other disorder of the endocrine system. If it was a disorder of the thyroid, adrenal, or pituitary gland, specify the gland associated with the disorder.
 - *Hearing problems or deafness*: Indicate if the child had any degree of hearing impairment.
 - *Kidney disease*: Indicate if the child had decreased/limited kidney function.
 - *ental illness/psychiatric disease*: Includes depression or mood disorder including bipolar disorder, anxiety disorder, autism spectrum disorder, attention deficit hyperactivity disorder (ADHD), conduct disorder, oppositional defiant disorder, schizophrenia, alcohol or substance abuse.
 - *Metabolic disease*: Identify if the child had any known metabolic dysfunction.
 - *Muscle disorder or muscular dystrophy*: Identify if the child was diagnosed with a muscular disorder—often manifesting as weakness—or was diagnosed with genetic muscular dystrophy.
 - *Oncologic disease treated by chemotherapy or radiation*: Identify if the child had a cancer or tumor diagnosis that required either of these therapies.
 - *Prematurity*: A premature birth is a birth that takes place at less than 37 weeks of pregnancy.
 - *Congenital disorder/genetic syndrome*: A medical condition that is present at or before birth. These conditions are also referred to as birth defects. Genetic disorder is a genetic problem caused by one or more abnormalities in the genome, usually a condition that is present from birth but may not be diagnosed until later in life.
 - *Other*: Please identify any other disease or condition not identified in this section.

1f: Did the child have any blood relatives (brothers, sisters, parents, aunts, uncles, cousins, grandparents, or other more distant relatives) with the following diseases, conditions, or symptoms

Include blood relatives only. Do not include relatives married into the family (step-relatives), in-laws or adopted family members.

- Sudden Unexpected Death before age 50:
 - *Sudden*: Implies death within 24 hours of first symptom or in hospital after resuscitation from cardiac arrest.
 - *Unexpected*: The death of someone who was believed to be in good health or who had a stable chronic condition (e.g. hypertrophic or dilated cardiomyopathy, congenital heart disease, a neurological condition such as epilepsy, or a respiratory condition such as asthma) or had an acute illness which would not be expected to cause death.
 - Examples of a sudden, unexpected death would include SIDS, drowning, a relative who died in a single and/or unexplained motor vehicle accident if they were the driver of the car.
- Heart Disease
 - *Heart condition/heart attack or stroke before age 50*: Indicate, if before the age of 50, any of the child's blood relatives had diseased cardiac vessels, structural problems, an arterial blockage, or a heart attack.
 - *Aortic aneurysm or aortic rupture*: Abnormal dilation of the wall of the aorta, usually 50% greater than its normal diameter/ tear in the intima (inner layer) creating a false lumen. The worst outcome is aortic rupture. At risk young individuals include those with collagen vascular diseases (e.g., Marfan syndrome, Ehlers-Danlos) or bicuspid aortic valve, Turner Syndrome, or hypertension.
 - *Arrhythmia (Fast or irregular heart rhythm)*: Can also be called palpitations and includes long QT, Brugada, Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT), and Wolff Parkinson White (WPW).
 - *Cardiomyopathy*: A disease of the heart muscle. Specific diagnoses can include hypertrophic, dilated, arrhythmogenic right ventricular or left ventricular non-compaction.
 - *Congenital heart disease*: Structural heart disease present at birth. There are many varieties. Some forms of congenital heart disease have been associated with sudden cardiac death (e.g., tetralogy of Fallot, double outlet right ventricle, transposition of the great arteries, and single ventricle lesions such as double inlet left ventricle, hypoplastic left heart syndrome, and tricuspid atresia).
- Neurologic Disease
 - *Epilepsy or convulsions/seizure*: Include those that may be described as: fit, episode, attack or spell, falling out spell or drop attack, staring spell, or out-of-touch.
 - *Other neurologic diseases*: Diseases of the nervous system. Specific diagnoses include stroke, brain tumor, brain aneurysm, dementia, Parkinson's disease, Alzheimer's disease, headache disorders, multiple sclerosis, cerebral palsy, and cerebral hypoplasia.
- Symptoms
 - *Febrile seizures*: Seizures or convulsions that occur in young children and are triggered by fever.

- *Unexplained fainting*: A temporary loss of consciousness.
- *Other Diagnoses*
 - *Congenital deafness*: Indicate if any of the child's relatives were ever born deaf.
 - *Connective tissue disease*: Connective tissue disease refers to a group of disorders involving the protein-rich tissue that supports organs and other parts of the body. Examples of connective tissue are fat, bone, and cartilage. These disorders often involve the joints, muscles, and, but they can also involve other organs and organ systems including the eyes, heart, lungs, kidneys, gastrointestinal tract, and blood vessels. Specific diagnoses include Ehlers Danlos, Marfan syndrome, bicuspid aortic valve with aortic root dilation and/or cystic medial necrosis.
 - *Mitochondrial disease*: Mitochondria are present in every human cell except for red blood cells, and they are responsible for creating 90% of the energy needed to sustain life. Mitochondrial disease causes mitochondria to fail. Indicate if any of the child's relatives were ever diagnosed with mitochondrial disease.
 - *Muscle disorder or muscular dystrophy*: Identify if any of the child's relative were diagnosed with a muscular disorder—often manifesting as weakness—or was diagnosed with genetic muscular dystrophy.
 - *Thrombophilia (clotting disorder)*: Thrombophilia is an increased tendency to form abnormal blood clots in blood vessels. People with thrombophilia are at great risk for deep vein thrombosis and pulmonary embolism. Genetic forms include Factor V Leiden and prothrombin thrombophilia. Indicate if any of the child's relatives were ever diagnosed with thrombophilia.
 - *Other*: Please identify any other conditions not outlined in this section.

11g: Has any blood relative (siblings, parents, aunts, uncles, cousins, grandparents) had genetic testing

Include blood relatives only. Do not include relatives married into the family (step-relatives), in-laws or adopted family members. If testing was conducted, please provide the following information: which family member was tested; name of test or gene tested; reason for the testing (suspected disease/diagnosis); results of test, including negative results.

A gene mutation, or variant, is a change to DNA. Indicate if any mutation(s) or variants were noted. Be as specific as possible, for example: Patient's mother had genetic testing for suspected long QU syndrome. She was found to have an A178P mutation and/or variant in her KCNQ1 gene.

11h: In the 72 hours prior to the death was the child taking any prescribed medications

Include any medications, related to any condition, prescribed by a medical professional for the child, or prescribed for someone else and taken by the child.

11i: Within 2 weeks prior to death had the child

Indicate notable changes in medication usage, including taking extra doses, missing doses, or changing medications. Include any medications, related to any condition, prescribed by a medical professional for the child, or prescribed for someone else and taken by the child.

11j: Was the child compliant with their prescribed medications

If the child was not taking medication as prescribed, select “no” and describe why child was not compliant with medications. Examples include adverse side effects or caregivers unwilling or unable to administer medications prescribed for the child.

11k: Was the child taking any of the following substance(s) within 24 hours of death

- *Diet assisting medications:* Include prescription medications and or over-the-counter compounds.
- *Tobacco:* Includes cigarettes, chewing, and electronic/vaping nicotine.
- *Illegal drugs:* Include street drugs such as heroin; cocaine; or prescription drugs, such as Adderall taken w/o a prescription for the child. If the child is legally allowed to use marijuana, check the box for “legalized marijuana.”

If yes to any substance above, please note the name of the substance, quantity, and when the substance was last taken.

11l: Did the child experience any of the following stimuli at time of incident or within 24 hours of the incident

Please indicate if the child experienced any of the following stimuli at time of incident and within 24 hours of incident.

- *Physical activity:* Any exercise or movement of the body of moderate or vigorous intensity. Playing a sport such as soccer or dancing are two such examples.
- *Sleep deprivation:* When an individual fails to get enough sleep. While more or less sleep may be appropriate for any given child, recommended sleep for children is as follows (per 24 hour period):
 - ages 1-2 is 11-14 hours
 - for preschoolers ages 3-5 is 10-14 hours
 - for children ages 6-13 is 9-11 hours
 - for teens ages 14-17 is 8-10 hours
- *Driving:* Indicate if the child was driving a motor vehicle within 24 hours of the incident.
- *Visual stimuli:* Flickering, flashing or strobe lights, television, computer or other visual stimuli that form patterns in time or space.
- *Video game stimuli:* Indicate if the child had been playing video games in the 24-hour period prior to the incident.
- *Emotional stimuli:* Strong reaction including happiness, anger, sadness, and stress.
- *Auditory stimuli/startle:* A sudden startling noise (alarm clock, phone ringing, etc).
- *Physical trauma:* Injury caused to a person by physical forces such as a motor vehicle crash, assault, fall, or near drowning.
- *Other:* Indicate any other stimuli the child may have experienced at the time of the incident that is not identified above.

11m: Was the child an athlete

If the child participated in a sport that required moderate to vigorous exercise, select “yes,” then indicate whether they were a competitive or recreational athlete.

The *competitive athlete* has been described as one who participates in an organized team or individual sport requiring systematic training and regular competition against others while placing a high premium on athletic excellence and achievement. Athletes may be regarded as competitive regardless of age or level of participation. An important component of competitive

sports activity concerns whether athletes are able to properly judge when it is prudent to terminate physical exertion. Conversely, individuals participating in a variety of informal *recreational sports* and circumstances engage in a range of exercise levels from modest to vigorous on either a regular or an inconsistent basis, which do not require systematic training or the pursuit of excellence and are without the same pressure to excel against others that characterizes competitive sports. The lack of systematic athletic conditioning in the definition of recreational sports is expected to decrease the risk of cardiovascular events. If yes, also indicate whether or not the child participated in the 6 months prior to their death.

I1n: Did the child ever have any of the following *uncharacteristic* symptoms during or within 24 hours after physical activity

An *uncharacteristic* symptom means that the child did not usually experience these symptoms after participating in physical activity.

- *Convulsions/seizure*: Include those that may be described as: fit, episode, attack or spell, falling out spell or drop attack, staring spell, or out-of-touch.
- *Palpitations*: Sensations of the heart that include pounding or racing. They can be felt in the chest, throat, or neck.

I1o: For child age 12 or older, did the child receive a pre-participation exam for a sport

Include any pre-participation sports exam designed to evaluate the health of a child prior to their participation in an athletic sport to determine if participation is safe. These may be performed by any professional such as general practitioners or specialists including sports medicine physicians. Requirements for sports exams vary by locality.

Note: Questions I1p-I1v only appear if in I1e (Diagnosed by medical professional) was answered as "Epilepsy/seizure disorder."

I1p: How old was the child when diagnosed with epilepsy/seizure disorder

Infants are given an age of 0 years. If a range is given, use the mid-point or round up. For example, if the response is "13 or 14 years old," mark 14 years. A best estimate is preferred over a response of unknown.

I1q: What were the underlying cause(s) of the child's seizures

- *Brain injury/trauma*: A blow or jolt to the head or a penetrating head injury that disrupts the function of the brain.
- *Brain tumor*: A mass or growth of abnormal cells in the brain.
- *Cerebrovascular*: Includes stroke, hemorrhage, trauma, CNS infection (congenital or not).
- *Central nervous system infection*: Infection of the brain, spinal cord and associated membranes. Specific diagnoses can include: encephalitis, meningitis.
- *Degenerative process*: A disease in which the function or structure of the affected brain area will increasingly deteriorate over time.
- *Developmental brain disorder*: Can include such diagnoses as cerebral palsy, intellectual disability (mental retardation), or a structural brain malformation.
- *Inborn error of metabolism*: Inborn errors of metabolism form a large class of genetic diseases. In most of the disorders, problems arise due to an accumulation of substances

which are toxic or interfere with normal function, or to the effects of reduced ability to synthesize essential compounds.

- *Genetic/chromosomal*: Conditions involving or relating to changes in genes or chromosomes.
- *Mesial temporal sclerosis*: Mesial temporal sclerosis is closely related to temporal lobe epilepsy, a type of partial (focal) epilepsy in which the seizure initiation point can be identified within the temporal lobe of the brain. Mesial temporal sclerosis is the loss of neurons and scarring of the temporal lobe associated with certain brain injuries.
- *Idiopathic or cryptogenic*: Unknown origin.
- *Other acute illness or injury other than epilepsy*: Indicate and specify any acute illness or injuries, besides epilepsy, that are not identified above.
- *Other*: Indicate if there was a different underlying cause of the child's seizures than those listed above.
- *Unknown*: Indicate if the cause of the child's seizures was unknown.

11r: What type(s) of seizures did the child have

Indicate all types of seizures the child experienced during life, not including the seizure which led to the child's death.

- *Non-convulsive*: A seizure during which a person's body does not shake rapidly and uncontrollably. Seizures may or may not include a loss of consciousness.
- *Convulsive (grand mal seizure or generalized tonic-clonic seizure)*: A seizure during which a person's body shakes rapidly and uncontrollably. Seizures may or may not include a loss of consciousness.
- *Reflex seizures*: A seizure triggered by flashing lights or rolling images, sometimes known as photosensitivity. Seizures may or may not include a loss of consciousness.

11s: Describe the child's epilepsy/seizures (not including the seizure at time of death)

Indicate applicable description(s) for any seizures the child experienced in life, not including the seizure which led to the child's death.

- *Last less than 30 minutes*: A seizure lasting a short duration of less than 30 minutes.
- *Last more than 30 minutes (status epilepticus)*: A prolonged seizure or a series of seizures without recover lasting more than 30 minutes.
- *Occur in the presence of fever (febrile seizure)*: Seizures in the presence of fever.
- *Occur in the absence of fever*: Seizures which occur with no associated fever.
- *Occur when exposed to strobe lights, video game, or flickering light (reflex seizure)*: A seizure triggered by flashing lights or rolling images, sometimes known as photosensitivity.

11t: How many seizures did the child have in the year preceding death

If a range is given, use the mid-point or round up. For example, if the response is "2" or "3" select "3." A best estimate is preferred over a response of unknown.

11u: Did treatment for seizures include anti-epileptic drugs

If yes, indicate how many anti-epilepsy drugs the child was taking at the time of death.

11v: Was night surveillance used

Night surveillance can include any device that would alert another person that a child is in distress through the night including baby monitors, video cameras, or apnea monitors.

12. Death Related to Sleeping or the Sleeping Environment

12: Was death related to sleeping or the sleep environment

Answer this question for every death of a child who was less than 5 years old, regardless of the primary cause of death. If “yes” or “unknown,” proceed to 12a. If “no,” go to 12s.

12a: Incident sleep space:

Type of place child was sleeping in or on when found unresponsive. If the child was laying on or in the arms of another person, select the location of the person holding the infant unless the child died on another person who was standing at the time. In that case, select “other” and specify. For infants who were witnessed unresponsive (observed by another person at the time they became unresponsive), select the location of the baby at the time they became unresponsive.

- *Crib*: Include full-size crib or a NICU or ICU bed. Portable cribs, such as Pack ‘n Plays, are considered cribs.
- *Bassinet*: A product designed to function as an infant sleep surface. It is smaller than a crib and often oblong or basket-like. If the child is in the bassinet portion of a portable crib, select bassinet.
- *Bed side sleeper*: a bassinet or crib that has one side which is designed to attach to the parents’ bed allowing the infant’s surface to connect to an adult bed (usually three-sided or has one side that is lower than the other three). Also referred to as a sidecar sleeper or bedside bassinet.
- *Baby box*: a cardboard box that includes a mattress and is marketed specifically for purposes of infant sleep.
- *Adult bed*: any adult sized mattress (excluding water beds) regardless if the mattress is on the floor or in bedframe. Adult bed includes air mattresses. Indicate the size of the mattress in the follow up question.
- *Water bed*: a bed with a water-filled rubber or plastic mattress
- *Futon*: usually a cotton-filled mattress used on the floor or in a frame as a bed, couch or chair. Indicate the futon position in the follow up question.
- *Playpen*: a small “pen” or enclosed structure with an open top, designed to keep babies and small children safe while playing. Do not include small, portable bassinets, such as a Pack ‘n Play.
- *Car seat*: infant or toddler car seat that was placed either in the car, stroller or in the home. Indicate if the car seat was secured in the seat of a vehicle at the time of the incident.
- *Rock ‘n Play*: a freestanding, sling shaped baby holder fitted on a metal frame that can rock back and forth.
- *Stroller*: strollers that do not use the click-in car seat combination. If using the car seat part of a stroller, choose car seat.
- *Bouncy chair*: a freestanding product intended to support an infant in a reclined position to facilitate bouncing or vibrating.

- *Other*: all other products marketed for infant sleep or play that are not otherwise specified above (e.g., baby carriers, slings).

12b: Child put to sleep

Indicate the position in which child was put to sleep.

12c: Child found

Indicate the body position in which the child was found unresponsive. If the body was wedged and the position found does not fit into one of these options, select the option that best describes the position found and describe the position found in detail in the narrative section (O1).

12d: Usual sleep space

Identify the place the child slept the majority of the time. The sleep place selected should be the usual place for the location at which the incident occurred. For example, if the death occurred at a licensed child care home, indicate where the infant usually slept while at the child care home. See 'incident sleep place' for more information about response options.

12e: Usual sleep position

Indicate the position in which the child slept most of the time.

12f: Was there any type of crib, Pack 'n Play, bassinet, bed side sleeper, or baby box in home for the child

Indicate whether any of these infant sleep options were available in the home and/or location where the incident occurred.

12g: Child in a new or different environment than usual

At the time of incident, indicate if the child was sleeping in a new or different environment. A new or different sleep environment refers to an environment that is not part of the child's normal routine. For example, if the child went to Grandma's house every Tuesday, this is considered part of the usual routine. If the child had started attending a new child care center/home this would be considered a new sleep environment. Also, include temporary sleep environments such as a hotel stay, moving, traveling, displacement by a disaster, visiting family or friends, and infant more fussy than normal so moved from normal sleep place.

12h: Child last placed to sleep with a pacifier

Indicate if the child was last placed to sleep with a pacifier. A pacifier is sometimes called a 'dummy' or a brand name, such as 'Binky'. It does not matter if the pacifier fell out during sleep, record if the child was **placed** to sleep with a pacifier in his/her mouth.

12i: Child wrapped or swaddled in blanket

Answer yes if the child was intentionally wrapped or swaddled in a blanket prior to placing him/her to sleep. Do not answer yes if the child became tangled or wrapped in a blanket or other soft bedding while he/she slept. If yes, include a brief description of the weight and thickness of the material used to swaddle the baby, and whether it was a product designed for swaddling. Also include information about how loose or tight the swaddle/wrap was when found, whether arms were in or out, whether or not the swaddle was covering the child's nose

or mouth, and/or had gotten underneath the child resulting in a soft bedding sleep environment.

12j: Child overheated

Indicate if child was overheated at the time of death. If yes, specify reason for overheating. Overheated is defined as a body temperature not caused by a fever that is more than one degree above 98.7 degrees Fahrenheit.

12k: Child exposed to second hand smoke

Indicate whether child was regularly exposed to second hand smoke. Second hand smoke is defined as smoke that is exhaled by a smoker or originates from a tobacco product to which a child is exposed. It includes smoke from a smoldering cigarette, e-cigarette, cigar, pipe or other tobacco material. If yes, indicate frequency. Frequent exposure refers to several times a week. Occasional exposure refers to several times a month. This can come from medical records, scene investigation, or witness interviews.

12l: Child's face when found

Child's face (nose and mouth) when found should identify the child's face position relative to the surface the child was sleeping on. For example, select "Down" if the child's face was found straight down on a pillow; select "Up" if the child was lying on a pillow with only the back of the neck and head touching the pillow; select "To the left or right side" if the child's face was turned to the left or right side so that only one side of the child's face was touching the pillow.

12m: Child's neck when found

Indicate the position of the child's neck relative to the body when found. Select "Hyperextended" if the child's head was arched backwards with the chin far away from the chest. Select "Hypoextended" if the child's head was bent towards the body with the chin close to the chest. Select "Turned" if the child's head was turned to the left or the right. Select "Neutral" if the child's head and neck were in a relaxed, neutral position.

12n: Child's airway (includes nose, mouth, neck and/or chest) when found

- *Unobstructed*: If nothing was obstructing the child's nose or mouth or compressing the child's neck or chest when the child was found. For example, select "unobstructed" if the child was found on his/her back, face up, neutral neck, in a crib with no objects obstruction the airway.
- *Fully obstructed*: If, when the child was found, his/her nose and mouth were completely covered by an object (such as a blanket or pillow), or there was a full compression of the neck or chest preventing the lungs from expanding (such as a child found with an adult's thigh over his/her chest, or neck is caught between slats of a crib)
- *Partial obstruction*: When only part of the nose/mouth were covered by an object when the child was found. "Partial obstruction" also includes a child found with only a portion of his/her chest or neck compressed by a caregiver or object or instances where the infant's position (e.g. slumped in a stroller or other sitting device) compressed the airway.

If airway was fully or partially obstructed when the child was found, indicate what parts of the airway were partially or fully obstructed, e.g.: nose, mouth, neck, or chest compressed. If the

team selects either “fully obstructed” or “partially obstructed,” it is important to note the objects/people/positioning responsible for the obstruction in I2o.

I2o: Objects in child’s sleep environment and relation to airway obstruction

This question presents a list of potential objects in the child’s sleep environment. There are three parts to this question:

1. **Present?** –Select all items that are part of the child’s sleep environment no matter their relationship to the child. It is not necessary to indicate clothing for the clothes the infant was wearing at time of death.
2. **If present, describe position of object** – For every item marked as present, identify the position of each of the selected object(s) in relation to the child when found. For example, if a pillow was present, indicate whether the pillow was next to the child or under the child. You may select more than one option. Tangled in/around should be used only when describing something the infant became tangled in during sleep, not something intentionally wrapped around the infant like a swaddle.
3. **If present, did the object obstruct the child’s airway?** – For every item marked as present, indicate whether or not each an object(s) was obstructing the child’s nose or mouth or compressing the neck or chest when the child was found.

Example scenario: Child was in crib, found on back, face up, under comforter with nose and mouth obstructed by comforter. Teddy bear in crib, at base of crib.

| Object Present (Yes) | Describe Position | Object Obstruct Airway |
|-----------------------------|--------------------------|-------------------------------|
| Mattress | Under child | No |
| Comforter | On top of child | Yes |
| Crib railing | Next to child | No |
| Toy | Next to child | No |

I2p: Caregiver/supervisor fell asleep while feeding child

Indicate if caregiver/supervisor fell asleep while feeding child. If “yes,” indicate whether the child was being fed by a bottle or being breastfed.

I2q: Child sleeping in the same room as caregiver/supervisor at time of death

Indicate if the child and supervisor(s)/caregiver(s) were sleeping in the same room at the time of the incident. The child may or may not have been on the same sleep surface as caregiver(s).

I2r: Child sleeping on same surface with person(s) or animal(s)

Indicate if the child was sleeping on the same sleep surface with a person or animal. If so, specify:

- The number of adults sleeping with the child and if they were obese. Select “yes” for obesity if there was clear evidence that the adult(s) sharing a sleep surface with the child was obese from photos, police reports, or other documentation.
- The number of other children sleeping with child and their ages (make sure to indicate if the age is in days, months or years).
- The number of animals sleeping with child and type of animal(s).

12s: Is there a scene re-creation photo available for upload

Scene re-creation photo should ideally include a doll re-enactment depicting where the child was found. It should show the position of the airway in relation to the sleeping environment. If a doll re-enactment was not done or the photo is not available, provide a scene photo of the location where the baby was found. For example, include a picture of an adult bed and its entire contents. If a scene photo is the only option, consider marking the picture to indicate the location of the infant. If only a photo of position placed (not found) is available, please upload and specify in the narrative (section O). Only one photo (.jpg format) less than 6MB in size may be attached. Blur or crop any faces or dates to preserve confidentiality of any individuals depicted.

13. Was Death a Consequence of a Problem with a Consumer Product

If the child's death was a consequence of a problem with a consumer product of some kind, answer the following questions. This includes deaths related to products that were being used in a way that was against manufacturer recommendations, such as an infant who dies while in a swing that was not properly buckled.

13a: Describe product and circumstances

If the death was the consequence of a problem with a consumer product, describe product. Examples of consumer products include toys, cribs, power tools, cigarette lighters and household chemicals.

13b: Was product used properly

If the death was the consequence of a problem with a consumer product, indicate if product was being used properly (all recommended instructions were being followed and warnings observed) at time of incident.

13c: Is a recall in place

If the death was a consequence of a problem with a consumer product, specify if a recall was in place for the product. Recall is defined as a request by the manufacturer of a defective product to repair or replace that product.

13d: Did product have safety label

Indicate if product had a safety label at time of incident that described any known hazards of the product or instructions for safe use. Labels on hairdryers warning consumers to avoid water immersion is an example.

13e: Was Consumer Product Safety Commission (CPSC) notified

Indicate if the Consumer Product Safety Commission was notified of the incident.

14. Did Death Occur During Commission of Another Crime

If the death occurred during the commission of another crime, answer the following questions.

14a: Type of crime

If the death was the consequence of a crime, indicate type of crime committed at time of incident. A crime is a serious offense against the public law. Definitions vary by state.

- *Robbery/burglary*: A robbery is the taking, or attempting to take, anything of value from another person or persons by force or threat of force or violence. If money or goods are stolen without force or threat of force (e.g., a bookkeeper stealing money from a company, thieves stealing equipment from a loading dock), the theft is not a robbery, but larceny, and should be selected as “Other.” A burglary is the unlawful entry into a building or other structure without the owner’s consent with the intent to commit a felony or a theft.
- *Interpersonal violence*: The intentional use of physical force or power, threatened or actual, against another person, or against a group, that either results in or has a high likelihood of resulting in injury, death, psychological harm, or deprivation.
- *Sexual assault*: Sexual contact without consent. Includes sex with a minor with or without consent. Ranges from the non-consensual touching of an intimate part of the body to forced, manipulated, or coerced penetration. It can involve verbal coercion and threats, physical restraint, intimidation, and/or violence.
- *Other assault*: An unlawful fatal or nonfatal attack by one person upon another. To qualify as a serious crime, the assault should be an aggravated assault (one that involves bodily injury or threat with a deadly weapon).
- *Gang conflict*: Gang members are persons who are members of the same association or organization which has as one of its purposes the commission of crime. Gangs include both youth gangs and organized crime organizations.
- *Drug trade*: The buying, selling or passing of drugs from one person to another in exchange for goods or money.
- *Arson*: To unlawfully and intentionally damage, or attempt to damage any building, real estate, or personal property by fire or incendiary device.
- *Prostitution*: Performing sexual acts in exchange for money or its equivalent.
- *Witness intimidation*: To intentionally say or do something that would cause a witness of a crime to be fearful of harm to them if they provide information to authorities about the crime or to kill a witness to prevent him/her from providing information.
- *Illegal border crossing*: To arrive or in or cross the borders into the country in violation of immigration law.
- *Auto theft*: To steal or attempt to steal any motor vehicle.
- *Other*: indicate other crimes (not listed above) was being committed at the time of the incident.

15. Child Abuse, Neglect, Poor Supervision, and Exposure to Hazards

Completion of this section is especially important because it provides information about child maltreatment (abuse, neglect, poor/absent supervision), as well as other behaviors on the part of a parent/caregiver/supervisor that expose the child to hazardous circumstances that cause or contribute to a child’s death (e.g., sleep environment hazards, unsecured firearms or poisons, etc.). **Do not include child’s own behavior**, such as a teen driver engaging in risky behavior that results in crash and death (document in section H1) or suicide (document in section I6).

However, it is important to remember that the purpose of this section and of fatality review more generally is to document circumstances and identify risk factors for use in developing prevention strategies, NOT to determine legal culpability or substantiate child maltreatment. Consequently, although legal definitions for some of these categories (e.g., child abuse, neglect)

may be available, they should not be used as criteria for completing this section. **Section 15 should be considered for all deaths.**

Most natural deaths will not be related to child abuse, neglect, poor supervision or exposure to hazardous circumstances, but occasionally one will. For example, the potential for a failure to seek or provide medical care to contribute to a death should be considered and documented here when appropriate.

Even when the specific cause of a child's death is undetermined or unknown, acts of child abuse, neglect, poor/absent supervision, or exposure to hazards that cause or contribute to the death might be identified, and when they are, they should be documented.

15a: Did child abuse, neglect, poor or absent supervision, or exposure to hazards cause or contribute to the child's death

Indicate if any behavior on the part of a parent/caregiver/supervisor caused or contributed to the death of the child. The purpose of this question is to identify whether there were specific behaviors by a parent/caregiver/supervisor that caused or contributed to the child's death. It is NOT intended to determine blame or legal culpability.

A behavior that causes death is defined as a behavior that in and of itself led to the child's death. Generally, the behavior in question was both necessary and sufficient to kill the child. A behavior that contributes to death is defined as a behavior that plays a role in the child's death. Generally, the behavior in question was necessary but not sufficient to result in death. Examples include (but are not limited to):

- A caregiver shaking an infant so hard to cause severe head trauma and death.
- A caregiver that withholds lifesaving medical care or prescribed treatment.
- An unsupervised toddler falling into an open residential pool and drowning.
- A child left in a closed car on a hot day who dies from hyperthermia.
- A caregiver who unintentionally rolls onto an infant in an adult bed and the infant suffocates.
- An infant suffocates due to thick blankets in the sleep environment.
- A pregnant woman who abuses drugs or alcohol, with deleterious consequences to the newborn infant.

Select "Yes/probable" if the team determines that any behavior on the part of a parent, caregiver, or supervisor caused or contributed to the child's death; or if there is not sufficient evidence for the team to be certain that parent/caregiver/supervisor behavior caused or contributed to the child's death, but there is evidence indicating such a link (i.e., probable). This may be particularly relevant to deaths due to unknown or undetermined causes such as sudden unexpected infant deaths in the sleep environment, particularly if hazards in the sleep environment are noted (e.g., bed-sharing, soft bedding, sleeping on surface not intended for infant sleep).

Select "No" if the team determines that no behavior on the part of a parent/caregiver/supervisor caused or contributed to the child's death.

Select “Unknown” if there is not sufficient evidence for the team to determine whether any parent/caregiver/supervisor behavior caused or contributed to the death.

If yes/probable, choose primary reason. Indicate which behavior caused or contributed to the child’s death. Select ONLY ONE.

Descriptions of each category are included below.

- *Child abuse*: Child abuse is any injury inflicted on a child by a parent or caregiver. The parent or caretaker may not have intended to hurt the child, rather the injury may have resulted from over-discipline or physical punishment. Physical abuse can be the result of punching, beating, kicking, biting, burning, shaking, or otherwise harming a child.
- *Child neglect*: A failure on the part of a parent/caregiver/supervisor to provide for the shelter, safety, supervision and nutritional needs of the child that results in harm to the child. Child neglect includes physical, medical, supervisory, and emotional neglect.
- *Poor/absent supervision*: Parent/caregiver/supervisor’s failure to supervise, provide alternative appropriate supervision, or engage in other behavior that causes or contributes to the child’s death. This category is typically used when poor or absent supervision causes or contributes to injury death in a young child and the team does not feel that the lapse in supervision meets criteria to be classified as child neglect. For example, a single mother with a toddler is home from work, sick. Since she is home she does not take her child to child care, or arrange alternative supervision. She is taking medication for her illness that makes her sleepy. While sleeping during the day, her toddler leaves the house and is struck by a car in the street.
- *Exposure to hazards*: Refers to behavior by a parent/caregiver/supervisor that expose a child to hazard(s) that pose a threat of harm to the child, but team does not feel that the circumstances meet the criteria to be classified as child neglect. This includes hazards in the sleep environment, fire/burn, poisoning, firearm, water/drowning, and motor vehicle hazards. Maternal substance abuse during pregnancy should be checked only if an infant died from a medical cause of death and maternal substance use during pregnancy was documented and felt to cause or contribute to the death.

15b: Type of child abuse

If death occurred as a result of child abuse, specify type of abuse as documented by law enforcement, CPS or other evidence reviewed by the team. Child abuse is any non-accidental act by a parent or caregiver that results in physical injury or death.

Category descriptions below, check all that apply.

- *Abusive head trauma*: Abusive head trauma is any injury to the head that was inflicted on the child. Types of abuse included here are shaken baby syndrome with or without impact, and any other injuries inflicted to the child's head during an assault.
- *Chronic battered child syndrome*: Refers to children who have undergone physical abuse multiple times. Old healed or healing injuries are likely to be present in addition to the new/acute injuries leading to death.

- *Beating/kicking*: Physical injury inflicted by punching, beating, kicking, biting the child; includes shooting or stabbing the child.
- *Scalding or burning*: Physical injury inflicted by scalding with hot liquid, or burning with liquids, solids, cigarettes, etc.
- *Munchausen's Syndrome by Proxy*: Is a disorder in which a caregiver makes up or causes an illness or injury in their child. Victims are most often small children. They may get painful medical tests they don't need. They may even become seriously ill or injured or may die because of the actions of the caregiver.
- *Sexual assault*: Includes sexual abuse such as fondling a child's genitals, intercourse, incest, rape, sodomy, exhibitionism, as well as sexual exploitation through prostitution or the production of pornographic materials.
- *Other, specify*: If another type of child abuse was documented that does not fit into any of the above categories, select this box and specify the type of abuse.
- *Unknown*: If the type of physical abuse cannot be determined, select this box.

15c: For abuse head trauma, were there retinal hemorrhages

Formal medical documentation of retinal hemorrhages is needed to select "yes." Types of abuse included here are shaken baby syndrome with or without impact, and any other injuries inflicted to the child's head during an assault.

15d: For abusive head trauma, was the child shaken

If abusive head trauma, indicate if child was shaken based on formal medical, forensic pathology, or law enforcement documentation. If child was shaken, indicate if there was or was not impact of the child's head on a surface. Impact should be documented by investigators, medical record, or by autopsy.

15e: Event(s) triggering child abuse

A trigger is a circumstance or action that might prompt parent or caregiver's anger or frustration, resulting in physical child abuse. Some of the most common triggers for child abuse include crying, discipline issues and toilet training. If a trigger(s) for the child abuse is identified during the review, mark it here. If no trigger is identified, select none.

15f: Child neglect

If neglect caused or contributed to the death based on information available to the team, specify type of neglect.

Category descriptions below, check all that apply.

- *Failure to provide necessities*: Parent/caregiver/supervisor's failure to provide adequate food, shelter, or other necessities that causes or contributes to the child's death should be indicated here.
- *Failure to provide supervision*: Parent/caregiver/supervisor's failure to supervise, provide alternative appropriate supervision, or is unable or unwilling to supervise (e.g., the caregiver is under the influence of alcohol or drugs, is depressed, sleeps during the day, or has inadequate parenting knowledge or skills), resulting in the child's death.
- *Emotional neglect*: Parent/caregiver/supervisor's failure to provide adequate nurturing and affection to a child. This includes actions such as marked inattention to the child's

needs for affection, refusal of or failure to provide needed psychological care, spouse abuse in the child's presence, and permission of drug or alcohol use by the child.

- *Abandonment, specify:* Child abandonment occurs when a parent/caregiver/supervisor deserts a child without any regard for the child's physical health, safety or welfare and with the intention of abandoning the child.
- *Failure to seek/follow treatment, specify:* The failure of a parent/caregiver/supervisor to seek timely and appropriate medical care for a serious health problem which any reasonable layperson would have recognized as needing professional medical attention. In addition, parents/caregivers/supervisors are responsible to follow up on the medical professional's directives. Failure to provide or allow care prescribed/recommended by a competent health care professional for a physical injury, illness, medical condition, or impairment. Indicate whether the failure to seek/follow care was due to stated religious or cultural practices of the parent/caregiver/supervisor.
- *Exposure to hazards:* Behavior on the part of a parent/caregiver/supervisor that exposes a child to hazard(s) that causes or contributes to the child's death. Select one from the list of hazards.
 - *Hazards in the sleep environment:* In addition to placing the child in a sleep environment that contains soft bedding, pillows, bumper pads, or stuffed animals, sleep environment hazards include, but are not limited to: infants placed on a surface not intended for infant sleep (e.g., adult bed, sofa, car seat), sharing a sleep surface with an adult/children or animals, or placing an infant in a hazardous sleep position (e.g., on stomach).
 - *Fire hazard:* Fire hazards include but are not limited to: child access to fire sources (e.g., matches, lighters), unattended cooking, candles, cigarettes, using oven for heat source, and lack of working smoke detector.
 - *Unsecured medication/poison:* Failure to adequately secure and keep medications and poisons out of reach of children.
 - *Firearm hazard:* Failure to adequately secure firearms, including keeping unlocked, loaded firearms in house with child. Also includes permitting a child or adult to use or handle firearms resulting in discharge and unintended death of a child.
 - *Water hazard:* includes any drowning hazard, e.g., swimming pools without isolating fencing and locking gate, leaving small children unattended in bathtub, failure to use mandated floatation devices.
 - *Motor vehicle hazards:* Includes failure to properly restrain child passenger in a motor vehicle, and leaving child in parked vehicle (knowingly or unknowingly).
 - *Unknown:* Check this if details on the specific type of neglect are not known.

15g: Exposure to hazards

If exposure to hazards is checked in 15a, document the type of hazard here. Do not include child's own behavior, such as a teen driver engaging in risky behavior that results in crash and death (document in section H1) or suicide (document in section I6). Rather, this refers to behavior on the part of a parent/caregiver/supervisor that expose a child to hazard(s) that pose a threat of harm to the child, but team does not feel that the circumstances meet the criteria to be classified as child neglect. If child neglect, check child neglect in 15a and complete 15f.

Each hazard is described below, examples are provided but these examples are not all inclusive. Consider the hazard categories broadly, circumstances not listed may fit. Avoid use of the “Other” category if one of the listed categories is appropriate.

- *Hazards in the sleep environment*: In addition to placing the child in a sleep environment that contains soft bedding, pillows, bumper pads, or stuffed animals, sleep environment hazards include, but are not limited to: infants placed on a surface not intended for infant sleep (e.g., adult bed, sofa, car seat), sharing a sleep surface with an adult/children or animals, or placing an infant in a hazardous sleep position (e.g., on stomach).
- *Fire hazard*: Fire hazards include but are not limited to: child access to fire sources (e.g., matches, lighters), unattended cooking, candles, cigarettes; using oven for heat source; lack of working smoke detector.
- *Unsecured medication/poison*: Failure to adequately secure and keep medications and poisons out of reach of children.
- *Firearm hazard*: Unlocked, loaded firearms in house with child. Also includes permitting a child or adult to use or handle firearms resulting in discharge and unintended death of a child.
- *Water hazard*: includes any drowning hazard, e.g., swimming pools without isolating fencing and locking gate, leaving small children unattended in bathtub, failure to use mandated floatation devices.
- *Motor vehicle hazards*: Includes failure to properly restrain child passenger in a motor vehicle, and leaving child in parked vehicle (knowingly or unknowingly).
- *Maternal substance use during pregnancy*: If infant died from a medical cause of death and maternal substance use during pregnancy was documented and felt to cause or contribute to the infant’s death, check this hazard.
- *Other hazard*: If a hazard not listed above and specify the hazard.

15h: Was poverty a factor

Poverty and child maltreatment are highly correlated. Indicate whether poverty played a role in the child abuse, neglect, poor/absent supervision or exposure to hazards that caused or contributed to the child’s death. For example, a single mother with four children has a new job. If she loses her job, she cannot pay the rent and will be evicted from her apartment. If she misses another day of work, she will be fired. She works nights and one night her sister does not show up to stay with the children while she goes to work. Mom goes to work and leaves the children unattended for several hours before an alternative caregiver can arrive. While unattended, one of the children accidentally shoots a sibling while playing with a firearm. If yes, please explain in the Narrative (Section O).

16. Suicide

This section will only display if manner of death was suicide.

16a: For suicide, select yes, no, or unknown for each question

In addition to selecting the appropriate items in the list, please provide more detail about these items in the narrative portion of the report tool.

- *A note was left:* The child left a note, email, audio tape, video or other communication that they intended to kill him/herself. The existence of a will or folder of financial papers near the child's body does not constitute a suicide note.
- *Child talked about suicide:* Child had expressed that he or she thought about suicide, but child made no mention of or described a plan for suicide. Expressions such as "I think everyone would be better off without me" or "I hate my life and want to end it" would be considered suicide expressions to friends, teachers, parents, etc.
- *Prior suicide threats were made:* The child had previously expressed their intent to kill themselves, "I'm going to kill myself, or "I have made a plan to die" are examples of verbal expressions of intent.
- *Prior attempts were made:* There were reports or documentation that the child had made previous suicide attempts, regardless of the severity of those attempts.
- *Suicide was completely unexpected:* There was no indication from any source that the child was considering suicide.
- *Child had a history of running away:* The child had a documented history of running away from primary residence.
- *Child had a history of self-mutilation:* The child had a documented history of self-infliction of wounds such as cuts, scratches or bruises, or evidence of self-mutilation was found at time of autopsy.
- *There is a family history of suicide:* A member of the child's family (either immediate family or extended family) had completed suicide prior to the child's death.
- *The suicide was part of a murder-suicide:* The child committed a murder(s), as part of a series of actions that also led to his or her suicide. Do not answer "yes" if the child committed suicide at a time much later than the murder event, for example, while incarcerated for the murder.
- *The suicide was part of a suicide pact:* The child victim killed him/herself as part of a mutual agreement(s) to die by suicide made among people the victim knew. The other suicides did not need to be completed as part of the pact for this response to be marked as "yes". There should be documentation or reports of the pact, not rumors of a pact.
- *The suicide was part of a suicide cluster:* A suicide cluster is a group of three or more suicides that occur closer together in time and space than would be expected in a given community, with suicides occurring later in the cluster being motivated by earlier suicides or having a common exposure that may be associated with increased risk of suicides. A community can consist of a geographic area or a social network such as a youth group. The perception of the child fatality review team that a cluster exists is sufficient to endorse this variable.

16b. For suicide, was there a history of acute or cumulative personal crises that may have contributed to the child's despondency

Indicate if the victim experienced a personal crisis leading up to the suicide, in which it is believed the crisis was significant enough to the child to have contributed to their despondency and suicide.

- *None known:* No known personal crisis at time of incident.
- *Family discord:* Problems with a family member, friend or associate (other than an intimate partner).
- *Parent's divorce/separation:* Parents were recently separated or divorced, or the victim was still experiencing the divorce or separation as an on-going problem, as documented in records.

- *Argument with parents/caregivers*: The child had had a major argument with his/her parents/caregivers.
- *Argument with boyfriend/girlfriend*: The child had had a major argument with his/her girlfriend/boyfriend.
- *Breakup with boyfriend/girlfriend*: The child had broken up with his/her girlfriend/boyfriend.
- *Argument with other friends*: The child had a major argument with other friend(s).
- *Emotional neglect/abuse*: The child was not given adequate nurturing and affection. Also includes refusal or delay of needed treatment for emotional or behavior problems. Includes exposure to chronic or extreme domestic violence.
- *Rumor mongering*: The child was the victim or perpetrator of rumors that created a personal or social crisis for the child or for others.
- *Suicide by friend or relative*: The child was distraught over, or reacting to, a suicide of a friend or family member.
- *Other death of friend or relative*: The child was distraught over, or reacting to, a death (other than suicide) of a friend or family member.
- *Bullying as victim*: The child had been experiencing bullying as a victim. Bullying among children and adolescents is aggressive behavior that is intentional and usually persistent. It involves an imbalance of power or strength. Bullying can take many forms, including physical violence, teasing and name calling, intimidation and social exclusion. Bullying can be related to other forms of harassment and social isolation and/or intimidation, including hostile acts perpetrated against racial and ethnic minorities and gay and lesbian youth. Bullying also includes hazing.
- *Bullying as perpetrator*: The child had been perpetrating bullying. Bullying among children and adolescents is aggressive behavior that is intentional and usually persistent. It involves an imbalance of power or strength. Bullying can take many forms, including physical violence, teasing and name calling, intimidation and social exclusion. Bullying can be related to other forms of harassment and social isolation and/or intimidation, including hostile acts perpetrated against racial and ethnic minorities and gay and lesbian youth. Bullying also includes hazing.
- *School failure*: The child had experienced a failure at school. Examples include receiving a failing or low grade (as perceived by the child, parent or teacher), not making a sports team, not winning an election or failing an important test.
- *Move/new school*: Child moved or transferred to a new school within the past year.
- *Other serious school problems*: The child had experienced other major problems in school. This includes suspension or expulsion.
- *Pregnancy*: If female, child was pregnant at the time of death or had been pregnant within the past year. If male, child's girlfriend was pregnant at the time of death or had been pregnant within the past year.
- *Physical abuse/assault*: Child was the victim or perpetrator of any physical abuse or assault at any time prior to the death. Assault refers to an unlawful fatal or nonfatal attack by one person upon another.
- *Rape/sexual abuse*: Child was the victim or perpetrator of any rape, sexual assault or sexual abuse at any time prior to the death. This refers to sexual contact without consent. Includes sex with a minor with or without consent. Ranges from the non-consensual touching of an intimate part of the body to forced, manipulated, or coerced penetration. It can involve verbal coercion and threats, physical restraint, intimidation, and/or violence.

- *Problems with the law*: Child was arrested for or charged with a misdemeanor or felony crime.
- *Drugs/alcohol*: There was documented use of drugs or alcohol.
- *Sexual orientation/gender identity*: Sexual orientation is the pattern of a person's emotional, physical, sexual attraction and psychological attraction to someone of a particular sex.
- *Job problems*: Child had experienced problems with his or her or family's employment, including firing, disciplinary action, difficulty obtaining work, or other stresses related to employment.
- *Money problems*: Child had experienced problems with his or her or family's money, including debts, stolen money and lack of money for activities.
- *Involvement in computer and video games*: There was evidence of the child's involvement with video or computer games that the team has evidence of contributing to child's mental health status and/or suicide ideation.
- *Involvement with the internet*: There was evidence that the child routinely accessed internet chat rooms or sites that were either age inappropriate (e.g., sites with pornographic or excessively violent material) or that may have contributed to the child's suicidal ideations.
- *Other, specify*: Specify other events or personal crisis that may have contributed to the victim's suicide.

Section J. Person Responsible (Other than Decedent)

The purpose of this section is to document information about the person or persons (up to 2 people) that did something to cause or contribute to the child's death.

This section should be completed for every death where it is indicated that child abuse, neglect, poor or absent supervision or exposure to hazards caused or contributed to the child's death (Section I5a checked yes/probable). It should also be completed for every death due to assault (Section G5, Injury death; assault, weapon, or person's body part checked and Section H5 completed).

This section might also be applicable for other causes of death in which a person other than the child cause or contributed to the death (e.g., fires due to arson).

This section should not be completed for suicide deaths.

J1: Did a person or persons other than the child do something that caused or contributed to the death

Indicate if a person or persons did something that caused or contributed to the death. Check yes/probable if child abuse, neglect, poor or absent supervision or exposure to hazards caused or contributed to the child's death (Section I5a is checked yes/probable), or the injury death was caused by assault. Do not complete this section if the deceased child did something that caused or contributed to their death (e.g., suicide, reckless driving resulting in motor vehicle crash).

J2: What act(s)

Indicate what the person did that caused or contributed to the child's death. Typically only one person will be responsible for doing or failing to do something that results in the child's death. If

the team determines that more than one person is responsible, information may be entered on 2 people. Check only one act that caused or contributed to the child's death per person.

If Section I5a is marked yes/probable, then the item selected here should be consistent with the reason stated in I5a. That is, if child abuse is selected in I5a, then child abuse should be selected here as well. Similarly, for child neglect, poor/absent supervision and exposure to hazards. The information in I5a should be consistent with the act selected here.

For assault deaths, select assault, not child abuse. For other deaths where a person did something that caused or contributed to the child's death (e.g., arson), select other and specify the act.

J3: Did the team have information about the person(s)

If the team has information about the person responsible, check yes. If the team does not have information about the person responsible, as might happen with an assault where the assailant has not been caught or in the case of arson where the arsonist is not known, check no (the rest of this section will be skipped).

J4: Is person listed in a previous section

Indicate if person that caused or contributed to the death is the biological parent, caregiver or supervisor listed in Section B, C, or D. If yes, indicate appropriate relationship from choices provided. If no, check no.

J5: Primary person(s) responsible for the action(s)

Select the relationship of person responsible to the decedent child. Select one relationship for each person responsible, up to two people.

J6: Person's age in years

Age of person(s) that caused or contributed to the child's death.

J7: Person's sex

Sex of person(s) that caused or contributed to the child's death.

J8: Person speaks and understands English

Indicate if person speaks and understands English. Select "yes" if person was able to respond to questions surrounding the circumstances of the child's death. If person does not speak English, specify language spoken.

J9: Person on active military duty

Indicate if the responsible person is documented as being active in the military at time of incident. "Active in the military" includes all people performing active duty in the United States Armed Forces. This includes those in reserve forces and the National Guard performing temporary duties at the time of incident. If yes, specify the branch of military.

J10: Person have history of substance abuse

Indicate if the responsible person(s) is perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse exists, select "other." Select "yes" if the person was noted as using illegal drugs (such as heroin or cocaine), abusing prescription medications (such as pain relievers or Valium), or regularly using inhalants (e.g., sniffing gas). If

the person is mentioned as using illegal drugs, even if addiction or abuse is not specifically mentioned, select "yes."

A person who is noted as participating in a drug or alcohol rehabilitation program or treatment including self-help groups and 12-step program should be selected as "yes" even if the person was noted as being currently clean and sober. Select "no" for a person with short-term experimental use that did not cause life problems and/or addictions.

Select "yes" for a problem from the past (e.g. five years or more ago) that has resolved and no longer appears to apply. Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

J11: Person have history of child maltreatment as victim

Responsible person has documented history of being the victim of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from autopsy, law enforcement report or medical records. If referrals were made but not substantiated, still select "yes" regarding history unless the referral was found to be completely falsified.

If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if person was ever in foster care or adopted.

J12: Person have history of child maltreatment as perpetrator

Person(s) has documented history of being the perpetrator of child maltreatment (child abuse or neglect). History means a referral or substantiation from Child Protective Services or documentation from autopsy, law enforcement report or medical records. If referrals were made but not substantiated, still select "yes" regarding history unless the referral was found to be completely falsified.

If yes, specify type(s) of maltreatment substantiated. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if person was ever in foster care or adopted.

J13: Person have disability or chronic illness

Person(s) has a disability or chronic illness prior to the time of incident. Chronic implies an impairment or illness that has a substantial long-term effect on day-to-day functioning or health.

- *Physical/orthopedic*: Includes any anatomical loss, mobility loss, physiological disorders, cosmetic impairments and/or chronic illnesses or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate epilepsy/seizure disorder/convulsions or cancer.
- *Mental health/substance use disorders*: Includes any mental or psychological disorder, such as emotional or mental illness. Examples include depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, post-traumatic stress disorder, schizophrenia, and personality disorders. A mental disorder is a disability only if it substantially limits one or more major life activities. A substance use (abuse or dependence) disorder is a maladaptive pattern of recurrent substance use

leading to clinically significant impairment or distress. If yes, indicate if person was receiving services.

- *Cognitive/intellectual*: Includes when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. Cognitive deficits may be congenital or caused by environmental factors. Examples may include deficits from brain injury, Down syndrome, or any of a number of congenital conditions that cause cognitive impairment. This definition includes cognitive/learning disabilities. Cognitive deficits may be congenital or caused by environmental factor or other diseases” (such as Alzheimer’s disease, etc.)
- *Sensory*: Includes any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.

J14: Person have prior child deaths

Indicate if the responsible person has a documented history of having a child (anyone 17 years or under) die while in his/her care, custody, or control. If yes, indicate number of prior child deaths, and the cause of death from among the identified causes. If the cause of death is not listed, choose “Other,” and specify the cause.

J15: Person have history of intimate partner violence

Indicate if the responsible person has a documented history of intimate partner violence (IPV) as either victim or perpetrator.

- *Documented* refers to evidence from law enforcement, medical, or human services.
- *IPV* is defined as actual or threatened physical or sexual violence or psychological and emotional abuse directed toward a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner.
- *Intimate partners* may be heterosexual or of the same sex. This may also include domestic disturbance complaints to which law enforcement responded.

J16: Person have delinquent/criminal history

Indicate if the responsible person has a documented history of delinquent or criminal behaviors or actions. This includes any history with the juvenile justice system or the criminal justice system. If yes, specify type of delinquent or criminal history that is documented. Delinquent behavior may include school disciplinary actions, charges or convictions for misdemeanor offenses. Criminal behavior includes charges or convictions for felony charges.

J17: At the time of the incident, was the person asleep

Indicate if the responsible person was sleeping at the time of the incident. If yes, select the most accurate description of the person’s sleeping period. If the sleep period is not accurately described by the response options, select “other,” and describe the type of sleep period the supervisor was experiencing.

J18: At time of incident was person impaired

Indicate if the person responsible was impaired at the time of incident.

- *Drug impaired:* Supervisor was impaired by the use of illicit or prescription drugs or a drug-like substance. Please specify the type of drug or substance that impaired the supervisor.
- *Alcohol impaired:* Supervisor was under the influence of alcohol to a degree that limited his/her ability to effectively supervise a child.
- *Distracted:* The supervisor's attention was diverted from attending to the child and onto something else.
- *Absent:* Supervisor was not present at time of incident.
- *Impaired by illness:* Supervisor is rendered incapable of effectively supervising a child by an illness or disease. This includes any acute or chronic medical condition that may limit the person's ability to care for a child. Impaired by mental illness may include conditions such as post-traumatic depressions, chronic depression, post-traumatic stress disorder, bi-polar, or other diagnosed mental health condition. Please specify the type of illness that impaired the supervisor.
- *Impaired by disability:* Supervisor is rendered incapable of effectively supervising a child by a condition of disability, including developmental delays. Blindness is an example of a disability that may limit a person's ability to care for a child. Please specify the type of disability that impaired the supervisor.
- *Other:* Specify all other factors that contributed to poor or ineffective supervision.

J19: Does person have

Indicate if the responsible person has a prior history of similar acts, prior arrests, or convictions. A prior history of a similar act would be based on a documented history of acts of omission or commission. Prior arrests or convictions would be documented.

J20: Legal outcomes in this death

Evidence of documented report of legal outcomes (e.g., guilty verdict on specific charges, sentence given) from law enforcement, district attorney, newspaper, etc.

Section K. Services to Family and Community as a Result of the Death

K1: Were new or revised services recommended or implemented as a result of the death

Indicate if any new or revised services that were provided to the family or community were recommended or implemented as a result of the child's death. Services are any type of supportive resource that the family and community were offered and/or utilized as a direct result of a child's death. In order to accommodate all types of services, the categories listed are general. Health services include any provision of health care, including family planning. To note a specific service, select "other" and write the service in the "specify" text box. Select "not applicable" if services were not needed.

Section L. Prevention Initiatives Resulting from the Review

Mark this case to edit/add prevention actions at a later date

Select this option if you would like to complete this section later after you have more information. To identify these cases, use the 'Search for Prevention Updates' under 'Search for Case' on the navigation menu of your state welcome page.

L1: Were new or revised agency services, policies, or practices recommended or implemented as a result of the review

As a result of the fatality review, indicate if any new or revised agency services, policies, or practices were recommended or implemented. This can include state, local, or non-government agencies, as well as fatality review committee policies and practices. Example: death investigators use doll reenactments for infant death investigations. Select the relevant agency.

L2: Describe the risk factors in the death that team feels need to be addressed

As a result of the fatality review discussion, indicate what risk factors surrounding this death the team feels needs to be addressed. The risk factors that are identified that need to be addressed do not have to necessarily result in team actionable recommendations.

L3: What recommendations and/or initiatives resulted from the review

Indicate if any recommendations regarding education, law, or environment were made as a result of the fatality review. Specific recommendations will be noted in L4 and L5. Changes to agency policies or practices should be recorded in L3, L4 and L5.

- *No recommendations:* Team could not identify any prevention strategies.
- *Education (Media campaign, school program, community safety project, provider education, parent education, public forum, other education):* Education is any combination of learning experiences designed to facilitate voluntary adaptations of behavior conducive to health. Public forum is an educational and/or advocacy event for the broader community to address an issue of concern. A community safety project is a prevention project that involves community or neighborhood in the planning, design, reach/scope, and/or implementation.
- *Law (New law/ordinance, amended law/ordinance, enforcement of law/ordinance):* A proposal to enact a new or amend a current local, state or national regulation, ordinance or law by the appropriate governmental body or action taken to enforce an existing local, state or national regulation, ordinance or law by the appropriate enforcement body.
- *Environment (Modify a consumer product, recall a consumer product, modify a public space, modify a private space):* A change could be made to a product or physical environment. Physical environment refers to physical surroundings (such as highway layout and construction) and specific mechanisms for injury (such as automobile design features). Actions include adding isolation fence around pool, reengineering a roadway intersection or notification of a local, state or national Consumer Product Safety organization of a product related problem.
- *Other, specify:* Indicate other type(s) of strategy(ies) to prevent more deaths.

L4: List the recommendation(s) and/or initiatives that could be implemented

Indicate the specific prevention strategies developed during the review process that **could be implemented** to prevent deaths from similar causes or circumstances in the future. In making

these judgments, the team should consider the feasibility of the proposed solutions, and how they compare with other possible suggestions in terms of priority and likely impact. 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: Briefly describe the recommendations and/or initiatives that will be or have been implemented

Indicate the specific prevention strategies that **will 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.

L6: Who was given the recommendation(s) and/or initiatives to implement

Identify who volunteered or was assigned to take leadership to complete each recommendation, or work on the planning or implementation of each proposed strategy/activity, and to follow up to monitor and report back on what happened.

L7: Could the death have been prevented

Team's conclusions regarding the preventability of the death. A child's death is considered to be 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

Section M. The Review Meeting Process

M1: Date of first review meeting

Enter the date of the fatality review team meeting in which this case was first discussed.

M2: Number of review meetings for this case

Indicate the number of fatality review meetings that were held to discuss this specific case.

M3: Is review complete

Select one of the following responses:

- N/A – Your fatality review team did NOT review this case.
- Yes – Your fatality review team has completed its review of this case. There will be no further meetings to discuss this case. For more information on determining if a review is complete, check with your fatality review coordinator.
- No – Your fatality review team will revisit this case in a future meeting. If “no” is initially selected, the case should be updated in the NFR-CRS (change “no” to “yes”) once the review is complete and there are no plans to discuss this case in any future meetings. For more information on determining if a review is complete, check with your fatality review coordinator.

M4: Agencies and individuals at review meeting

Indicate all agencies/organizations and individuals that participated in the case review.

M5: Were the following data sources available at the review meeting

Record which of the listed data sources were available for the review team. If the data source or its contents were available prior to the meeting, select that they were available for the review meeting.

M6: Did any of the following factors reduce meeting effectiveness

Issues that arose during the review process that impacted the fatality review team from effectively reviewing the case.

- *Confidentiality issues among members prevented full exchange of information.* Confidentiality restraints prevented team members from sharing information.
- *HIPAA regulations prevented access to or exchange of information.* The Health Insurance Portability and Accountability Act of 1996 was cited by a team member or an agency as a reason for not providing or sharing the information needed for an effective review.
- *Inadequate investigation precluded having enough information for review.* The investigation into this child's death was incomplete. The full circumstances surrounding the death were not known to the team because an investigating agency did not collect all crucial pieces of information.
- *Team members did not bring adequate information to the meeting.* Not enough information was brought to the meeting to answer the team's questions.
- *Necessary team members were absent.* Team members with information critical to the review process were unable to attend the meeting.
- *Meeting was held too soon after death.* The fatality review meeting was held too soon after the death, so that investigative reports, autopsy results, etc., were not complete.
- *Meeting was held too long after death.* The fatality review meeting was held too long after the death. Team members may have forgotten relevant details to the case or

since so much time has passed, the team feels uncomfortable making recommendations for services or interventions for the family that were needed but not provided as a result of the death.

- *Records or information needed from another locality in-state.* The team was unable to collect information for the review process from other localities within their state.
- *Records or information needed from another state.* The team was unable to collect information for the review process from another state.
- *Team disagreement on circumstances.* Team members were unable to arrive at a consensus on the actual events surrounding this child's death
- *Other factors, specify:* Specify any other factors that prevented the team from conducting an effective review.

M7: Review meeting outcomes

Indicate the outcomes of the fatality review process.

- *Review led to additional investigation:* As a result of the review, an agency will be conducting further investigation(s) into this death.
- *Team disagreed with official manner of death:* After the review was completed, the team disagreed with the official manner of death from the death certificate. Specify team's decision regarding manner of death based on their review.
- *Team disagreed with official cause of death:* After the review was completed, the team disagreed with the official cause of death from the death certificate. Specify team's decision regarding cause of death based on their review.
- *Because of the review, was the official cause or manner changed:* The team disagreed with the official manner or cause of death as a result of the review process. The team shared their concerns with the medical examiner, coroner or physician who ultimately amended the death certificate.
- *Review led to the delivery of services:* As a result of the review, an agency will be providing services to the family of the child. These services may include bereavement, public health, social services, funeral arrangements, mental health, etc.
- *Review led to changes in agency policies or practices:* As a result of the review, an agency will be amending their internal policies and/or practices. This can include state, local, or non-government agencies, as well as fatality review committee policies and practices. Example: death investigators use doll reenactments for infant death investigations.
- *Review led to prevention initiatives being implemented:* The review led to implementing prevention initiatives, beyond recommendations or plans for prevention activities. This reflects the actual prevention activities and not plans for activities.

Section N. SUID and SDY Case Registry

This section is designed for the jurisdictions funded to participate in the Centers for Disease Control and Prevention Sudden Death in the Young (SDY) and Sudden Unexpected Infant Death (SUID) Case Registry. If your jurisdiction is not funded, you do not need to complete these questions (Section N may not display for your State, depending upon your State Fatality Review Coordinator). If your jurisdiction is not funded but your state would like to complete these questions, please contact NCFRP for more information. Section N will not display for FIMR users.

N1: Is this an SDY or SUID case

Indicate whether this case should be included as a case for the SDY or SUID case per the definitions below:

SDY Case Definition - child's death was:

- Not one of the following:
 - Intentional homicide
 - Suicide
 - Cause as accident in which the external cause was the only and obvious reason for the fatal injury
 - Cases in which the underlying cause of the accident (e.g., drowning, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin should not be considered an 'accident in which the external cause was the only and obvious reason.'
 - Cause of death was expected within 6 months due to a terminal illness (diagnosis prior to death that is incurable and irreversible)
- One of the following:
 - Unexplained (e.g., unknown, undetermined, SIDS, SUID, SUDC, SUDEP)
 - Accident in which the external cause is NOT the obvious and only reason for the death
 - Neurological cause
 - Cardiac cause
 - Condition unlikely to cause death suddenly (e.g., obesity, cerebral palsy)

SUID Case Definition – child's death was any one of the following:

- Unexplained (e.g., unknown, undetermined, SIDS, SUID)
- Unintentional sleep-related asphyxia/suffocation/strangulation
- Unspecified suffocation
- Cardiac or respiratory arrest without other well-defined causes
- Unspecified causes with potentially contributing unsafe sleep factors

N2: Did this case go to Advanced Review for the SDY Case Registry

Indicate whether or not the case went to Advanced Review. If "yes" indicate the date of the first Advanced Review meeting.

N3: Notes from Advanced Review meeting, including case details that helped determine SDY categorization and any ways to improve the review

Use this space for notes specific to the Advanced Review team. Include information about how the team decided the SDY category (if Explained Other was selected, include the cause of death)

and any ways the review could have been improved, for instance, having the child's newborn screening results at the review.

N4: Professionals at the Advanced Review meeting

Identify which professional types were present at the Advanced Review. Please make sure to include professionals not identified in the provided list in the "other" category.

N5: Did the Advanced Review team believe the autopsy was comprehensive

Indicate if the Advanced Review team felt the autopsy was comprehensive to accurately complete a categorization for this case (N9). If the Advanced Review identified additional components that may have not been completed because of resource limitations (e.g., financial, staffing, technological, etc.) or because the need could have only been identified in hindsight, please indicate suggestions in F10.

N6: If autopsy performed, did the ME/coroner/pathologist use the SDY Autopsy Guidance or Summary

Indicate whether or not the SDY Autopsy Guidance or SDY Autopsy Summary was used.

N7: Was a specimen sent to the SDY Case Registry biorepository

Indicate whether a "purple-top tube," fresh frozen (liver, heart, spleen) sample, or other specimen was sent as part of the SDY Case Registry to the biorepository at the University of Michigan.

N8: Did the family consent to have DNA saved as part of the SDY Case Registry

Only select "yes" if the family agreed to at least one part of the SDY consent and signed and returned the SDY Case Registry form.

- *Consent was not attempted* – no one reached out to the family in any way to attempt to obtain consent.
- *Consent was attempted but follow up was unsuccessful* – someone reached out to the family (email, text, call, or letter) at least once to attempt to obtain consent but the family either could not be reached, or they were reached and expressed interest in participating, but did not follow through with returning a consent booklet.
- *Consent was attempted but family declined* – someone spoke to the family but they said no to all parts of the SDY Case Registry consent form.
- *Other, specify* - For example, someone spoke to the family and received a verbal consent but didn't receive a signed consent form before the family was lost to follow up.

N9: Categorization for SDY Case Registry

The response to this question is the primary responsibility of the SDY Case Registry Advanced Review team (only jurisdictions funded to participate in the SDY Case Registry must complete this question). Advanced Review teams in funded jurisdictions should use Step 3 of the SDY algorithm to determine the correct category. Grantees with funding for only the SUID Case Registry DO NOT need to complete N9, only N10.

N10: Categorization for SUID Case Registry

The response to this question is the responsibility of the child death review team and should be completed during the child death review meeting using the SUID algorithm (jurisdictions funded to participate in the SUID and SDY Case Registry must complete this question). Per the SUID

Case Registry Algorithm, each case should be assigned a category. If the most appropriate category is either Explained: Suffocation or Unexplained: Possible suffocation, at least one mechanism should also be assigned.

Section O. Narrative

O1. Narrative

Use this space to provide more detail so that a full picture of the circumstances and the team's review is apparent to a reader. **DO NOT INCLUDE IDENTIFIERS IN THE NARRATIVE such as names, addresses, dates, and specific service providers. Consider the following questions: What was the child doing? Where did it happen? How did it happen? What went wrong? What was the quality of the supervision? What was the injury cause of death?**

Often times, the circumstances of a death are not entirely evident from the case report tool alone. Providing a description of the incident involving the child is helpful in understanding how a death occurred. Include information on past history involving CPS, law enforcement, public health and others. If you would like to add text to the narrative from another document, such as a Microsoft Word file, you may copy the text and paste it into the NFR-CRS.

However, be sure **not** to include any of the following:

- name(s) of any person;
- street or apartment numbers;
- address of any residential program for victims of domestic violence;
- identifying information regarding the source or person making the report of suspected child abuse or maltreatment, including the person's gender or the agency, institution, organization or program to which the person is associated;
- dates;
- telephone numbers;
- social security numbers;
- or other personal identifying information.

The narrative should not reference any information relating to confidential HIV related information, sexually transmitted diseases or reproductive health services provided to the family.

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 mother received postpartum care within the first three weeks after delivery.
- Pregnancy planning/birth control education: The mother received any pregnancy planning or birth control education at any time before this pregnancy.
- Dental/oral care: The mother had a dental care provider and had been seen by a dental care provider in the year prior to this pregnancy.
- Chronic disease control education: Had the mother received education about controlling any of her chronic diseases at any time prior to this pregnancy with appropriate referrals made for control of chronic disease?
- Weight management/Dietician: Had the mother received education about controlling any weight issues, whether under- or over-weight, at any time prior to this pregnancy with appropriate referrals made to a dietician.
- Bereavement referral: Referral to any bereavement program, hospital, pastoral care or local program given at any time

2. Medical: Mother

- Early teen: Maternal age 17 years or less at time of conception.
- Late teen: Maternal age 18 or 19 at time of conception.
- Pregnancy > 35 years: Maternal 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.
- Incompetent cervix: 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.
- Infection, BV: Bacterial Vaginosis, an imbalance of the bacterial vaginal flora, detected prenatally or at delivery.
- 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 maternal infection, including periodontal, UTI, etc. Please specify on line provided.
- Multiple gestation: Pregnancy with more than one fetus at conception: twins, triplets, etc.
- Mother's weight: includes both Underweight – BMI (Body Mass Index) < 19.8 pre-pregnancy and Overweight – BMI 26.1 – 29 and obese pre-pregnancy.
- Insufficient/excess weight gain: Weight loss, little or not enough gain using the mother'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 mother'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 mother 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 severe 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: Mother 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 anomalies or maternal diabetes.
- Previous SAB or miscarriages or therapeutic or voluntary abortions: Previous pregnancy ending in a spontaneous miscarriage (abortion), not live born or therapeutic or voluntary abortions.
- 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 his/her 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.
- Previous C-Section: Delivery of a previous pregnancy by C-section
- Previous ectopic pregnancy: Any pregnancy implanted outside of the uterine cavity
- First Pregnancy < 18 years old: Maternal age less than 18 at conception of first pregnancy.
- 4 Live births: Four 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: Mother wanted to be pregnant at the time of conception.
- Unintended pregnancy: Mother did not want to be pregnant at this time.
- Unwanted pregnancy: Mother did not want to be pregnant then or at any time in the future.
- No birth control: Neither the mother nor her partner used a family planning method prior to this pregnancy.

- Failed contraceptive: The mother and her partner used a family planning method but she became pregnant anyway.
- Lack of knowledge, methods: The mother did not have knowledge or correct understanding of how to use family planning methods.
- Lack of resources: The mother did not know how to access resources for family planning methods, or some barrier existed that prevented her or her partner from obtaining services for family planning.

4. Substance Use

- Positive drug test: The mother had any positive toxicology screen for substances during pregnancy or at delivery.
- No drug test: The mother 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 mother of any tobacco product prior to pregnancy up to the time of 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 mother 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 mother prior to pregnancy up to the time of the infant's conception.
- Alcohol use: current: Any use by the mother 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 mother of any illegal substance during or after the pregnancy, up until the time of the infant's death.
- Illicit drugs, current: Any use by the mother 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 mother of any prescription drug not prescribed for her 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 mother of over the counter or prescription drugs prescribed for the mother 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: Mother 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 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: Mother 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 born 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 mother treated in facility without level of care designation needed for maternal 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: Mother 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 woman 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).
- 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 his/her 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 mother had few or no friends or family members providing emotional, financial, or physical support during or after her pregnancy.
- Lack of neighbors/community support: The mother did not feel that she could rely on neighbors or nearby community members for help or support if she needed it.
- Lack of partner/FOB support: The father 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: Mother is living on her own or alone with her dependent children.
- < 12th grade education: Last grade of school completed by mother is less than 12th grade.
- Special education/disability: Mother has documented learning disability or condition resulting in impaired understanding or use of knowledge.
- Physical or cognitive disability: Mother had documented physical or cognitive disability

11. Partner/FOB/Caregivers

Partner/Father of Baby (FOB)/Caregiver is indicative of another person, besides the mother, 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/father was employed or "no" to indicate the partner/father was not employed.
- History of mental illness: Documented history of mental illness.
- Substance or tobacco use/abuse – Current: Any use by the partner/FOB/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/FOB/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 mother has moved frequently before, during, or after the pregnancy.

- Living in shelter/homeless: The mother 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 mother or other principal caretaker exhibited concerns that their documentation or citizen status may compromise their ability to seek or receive services.
- Divorce/separation: The mother separated or divorced from her spouse or intimate partner immediately before, during, or after the pregnancy or while the infant was alive.
- Multiple partners: The mother had more than one sexual partner in a 12-month period.
- Mom in prison/parole or probation: Biological mom was incarcerated, paroled, or on probation immediately before, during or after the pregnancy or while the infant was alive.
- FOB in prison/parole or probation: Either biological father 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

- Maternal history of mental illness (Mom): Just prior to conception, mother of the baby 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 mother 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/mental illness in postpartum period: The mother 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 while the infant is alive.
- Multiple stresses: The mother experiences three or more family, economic, environmental, or other stresses during pregnancy or while the infant is alive.
- Social chaos: The mother's history suggests social interactions and social support systems are destructive and/or disruptive of functional stability making it difficult for her 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 mother was employed or "no" if the mother was not employed.
- Concern about enough money: The mother 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 mother's employment or work situation caused worry or stress during pregnancy or during the time the infant is alive. (examples: insufficient or no maternity leave, large amounts of time without rests, etc.)
- Child/Children with special needs: Other dependent child(ren) of the mother or partner experiencing health or behavioral problems.
- Problems with family/relatives: The mother's friends, partner, FOB, and/or family members were a negative influence or contributed to the mother acting in a manner detrimental to her health or her 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 (Mom): Disclosure or evidence of past physical, emotional, or sexual abuse of mother, not with current partner or FOB, not during the pregnancy or while infant is alive. Specify the type of abuse.
- Current abuse (Mom): Disclosure or evidence of physical, emotional, or sexual maltreatment of the mother 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 mother.
 - *Emotional abuse*: Name-calling, threats, intimidation, coercive behavior, controlling or preventing mother from seeking and engaging in services.
 - *Sexual Abuse*: Forced or hurtful sex, non-protected sex, or otherwise engaging the mother in sexual acts she does not want to do.
- History of abuse (FOB): Disclosure or evidence of past physical, emotional, or sexual abuse of FOB, not during the mother's pregnancy or while infant is alive. *Specify type of abuse.*
- Current abuse (FOB): Disclosure or evidence of physical, emotional, or sexual maltreatment of the FOB 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 mother.
 - *Emotional abuse*: Name-calling, threats, intimidation, coercive behavior, controlling or preventing mother from seeking and engaging in services.
 - *Sexual Abuse*: Forced or hurtful sex, non-protected sex, or otherwise engaging the mother in sexual acts she does 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 father'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 father'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 his/her 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 his/her 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 his/her 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 his/her 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 mother 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 mother 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/mother 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.
- Mother/child not eligible: The mother, 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: Mother or principal caretaker of infant did not have reliable private transportation to needed services, or lack of transportation caused mother 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 mother'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.

Section P: Form Completed By

Person, Title, Agency, Phone and Email will auto populate with the information contained in the user's contact information upon initial record creation of the case. User may edit the fields at any time.

Person: Provide the name of the individual completing the Report Form.

Title: Provide the position title of the individual completing the Report Form.

Agency: Identify the person's employing or affiliated agency.

Phone: Provide the best phone number to contact the individual completing the form.

Email: Provide the best email to use to contact the individual completing the form.

Date completed: Provide the date that this form was completed.

Data entry completed for this case: Indicate if the data entry for this case is complete.

For State Program Use Only: DATA QUALITY ASSURANCE COMPLETED BY STATE: This checkbox is used by state program staff in charge of cleaning and completing cases and should be checked only when the case is completely entered and reviewed and all data quality assurance protocols are complete.