

The National Center for the  
**REVIEW &**  
**PREVENTION**  
OF CHILD DEATHS

Understanding HOW  
and Why Children Die  
& Taking Actions to  
Prevent Child Deaths

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*Child Death Review  
Case Reporting System*

*Data Dictionary*

Version 4.0  
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National Center for Review & Prevention of Child Deaths



The data dictionary can help you complete the *Child Death Review Case Report*. The dictionary provides a definition for terms/data elements used in the report and examples for terms that may seem ambiguous or unfamiliar. Whenever possible, this dictionary uses the same definitions found in nationally accepted health surveillance systems.

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## Case Number / Case Definition

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.

### 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 CDRT Notified of Death

The date the case was first identified by the state coordinator or child death review team.

## Section A. Child Information

### 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.

### 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, U/K*: 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 CDR Case Reporting System, American Indian, Alaskan Native, Native Hawaiian and Pacific Islander each have their own category. Select more than one race category if the child is multi-racial.

### A6: Hispanic or Latino origin?

This question refers to the child's ethnicity. Ethnicity is usually listed on the death certificate. Ethnicity is used to differentiate population groups on the basis of shared cultural characteristics or geographic origins.

### 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 this is the case, leave this field blank.

A9: 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.

A10: New residence in past 30 days?

Child's place of residence (stated in A9) was new to child within last 30 days preceding death.

A11: Was the 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.

A12: 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.

A13: 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.

A14: Child's weight

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

A15: Child's height

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

A16: Highest education level

Select the highest level of education that child completed. If child received a GED, code '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. For infants, the response option N/A will automatically be selected for this question in the web based system.

A17: 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. For infants, the response option N/A will automatically be selected for this question in the web based system.

A18: 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. Code as '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 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.
- *U/K*: Select unknown if your team was unable to determine the types of problems the child was experiencing with school.

For infants, the response option N/A will automatically be selected for this question in the web based system.

A19: 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 insurance is defined as family's medical care paid for by private third party payer, such as Blue Cross Blue Shield or under a private HMO or managed care program.
- *Medicaid*: Medicaid is defined as family's medical care paid for by Human Services or other government support, non-managed care or by a managed care program of Human Services or other government support.
- *State plan*: State plan is defined as family's medical care being paid for by any type of state-sponsored plan, except Medicaid.
- *Other, specify*: Family's medical care paid for by any other type of support, excluding self-support.
- *Unknown*: CDR team does not know if the child was insured.

A20: 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.

- *Physical/orthopedic*: Physical 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*: Any mental or psychological disorder, such as emotional or mental illness. Examples include major 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*: Cognitive/intellectual impairment is 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*: Sensory disorders refer to any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include vision and hearing impairment.
- *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 coded as yes.

A21: Child’s mental health

- *Child had received prior mental health services*: 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*: 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:* Specify if 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. Code "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. Describe the nature of the barrier in the narrative section.

For infants, the response option N/A will automatically be selected for this question in the web based system.

A22: 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, it can be coded in the 'Other' category. Code as '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 gas). If the child is mentioned as using illegal drugs even if addiction or abuse is not specifically mentioned code as 'Yes'.

A child who is noted as participating in a drug or alcohol rehabilitation program or treatment including self-help groups and 12-step program should be coded as "yes" even if the child was noted as being currently clean and sober. A child with short-term experimental use that did not cause life problems and/or addictions should be coded "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 coded "yes". Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

For infants, the response option N/A will automatically be selected for this question in the web based system.

A23: Child had history of child maltreatment?

Child has 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 or documentation from autopsy, law enforcement report or medical records. Select 'N/A' if the child was too young to perpetrate child maltreatment. (For infants, the response option N/A will automatically be selected for this question in the web based system.)

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. Terminology regarding referrals and substantiations varies by state.

A24: 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. Code as 'yes' even if abuse or neglect was not substantiated. For example, services were in place such as family preservation/strengthening.

A25: Was child ever placed outside of the home prior to death?

Code as "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.

A26: Were any siblings placed outside of the home prior to child's death?

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

A27: Did child have a 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.

A28: 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.

A29: Child spent time in juvenile detention?

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

A30: Was child acutely ill in the two weeks prior to 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, code as no. Exacerbations of chronic illness may include a severe asthma attack or insulin shock.

A31: Was any parent a first generation immigrant?

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

A32: If child over age 12, what was child's gender identity?

Gender identity is what a person considers their gender to be regardless if this gender is different from the sex that was assigned to them at birth. This should only be answered if you have reliable documentation that the adolescent self-reported their gender identity.

A33: If child over age 12, what was child's sexual orientation?

Sexual orientation is the pattern of a person's emotional, physical, sexual attraction and psychological attraction to someone of a particular sex. This should only be answered if you have reliable documentation that the adolescent self-identified their sexual orientation.

- *Heterosexual*: Someone whose predominant physical or sexual attraction is to the opposite sex ("Straight").
- *Gay*: Preferred term for homosexual. Can apply to men and women, mostly men.
- *Lesbian*: Preferred term for homosexual woman. Can only apply to women.
- *Bisexual*: Someone who has a physical or sexual attraction to both sexes.
- *Questioning*: Questioning refers to questions about whether one is gay or a lesbian. Select questioning if the child is experiencing conflict or is confused regarding their sexual orientation.
- *Unknown*: Select unknown if the team was not able to determine the child's sexual orientation given the information available.

A34: Gestational age

If under one year, gestational age in weeks as stated on birth certificate.

A35: Birth weight

If under one year, birth weight in grams OR pounds and ounces as stated on birth certificate.

A36: Multiple birth?

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

A37: Number of pregnancies (gravida)

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".

A38: Number of live births (para)

Record the number of live births that the mother had previous to and 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 or stillbirths, this number can be different than her number of pregnancies.

A39: Number living (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”.

A40: Prenatal care

Prenatal visit (as stated on birth certificate) 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.

A41: During pregnancy did mother:

Indicate any health risk that mother experienced during pregnancy.

- *Have medical complications/infections?* Mother had documented medical complications (pregnancy-related or non-pregnancy-related) or infections during pregnancy at anytime. These categories are not mutually exclusive. For example, herpes is considered an infectious disease. Code the medical complication/infection that provides the most specificity.
  - *Acute/Chronic Lung Disease:* Disorders affecting the lungs, such as asthma, chronic obstructive pulmonary disease, infections like influenza, pneumonia and tuberculosis, lung cancer and many other breathing problems.
  - *Anemia:* A condition in which a person’s blood has a lower than normal number of red blood cells (RBCs), or the RBCs don’t have enough hemoglobin to carry oxygen from the lungs to the rest of the body.
  - *Cardiac Disease:* A narrowing or blockage of the coronary arteries, the blood vessels that supply blood to the heart. Disorders involving the valves in the heart or the ability of the heart to pump.
  - *Chorioamnionitis:* Infection of the membranes surrounding the fetus.
  - *Chronic Hypertension:* Elevated Blood Pressure documented before pregnancy, B/P greater than 140/90, or greater than 10 mm above patient’s baseline B/P.
  - *Diabetes:* Pre-existing diabetes is a condition in which levels of sugar in the blood are too high. Gestational diabetes arises during pregnancy; it results from the effect of hormones and usually subsides after delivery.
  - *Eclampsia:* Hypertensive states of pregnancy accompanied by seizures.
  - *Genital Herpes:* A sexually transmitted infection that is caused by a herpes simplex virus. Genital herpes affects the genitals, buttocks or anal area. Mothers can also infect their babies during childbirth.

- *Hemoglobinopathy*: A group of rare, inherited disorders involving abnormal structure of the hemoglobin molecule include hemoglobin C disease, hemoglobin S-C disease, sickle cell anemia and various types of thalassemia.
- *High MSAFP*: A screening that examines alpha-fetoprotein in the mother's blood during pregnancy. It is often part of the triple or quad screen test that assesses whether further diagnostic testing may be needed. High levels of AFP may suggest that the developing baby has a neural tube defect such as spina bifida or anencephaly. Low levels of AFP and abnormal levels of hCG and estriol may indicate that the developing baby has Trisomy 21( Down syndrome), Trisomy 18 (Edwards Syndrome) or another type of chromosome abnormality.
- *Hydramnios/Oligohydramnios*:
  - *Hydramnios/Polyhydramnios* – Larger than normal amount of amniotic fluid, often associated with certain congenital anomalies or maternal diabetes.
  - *Oligohydramnios* – Smaller than normal amount of amniotic fluid.
- *Incompetent Cervix*: A weakened cervix that results in rapid and unexpected premature dilatation of the cervix and repeated spontaneous abortions, usually during second trimester.
- *Low MSAFP*: Low levels of AFP and abnormal levels of hCG and estriol may indicate that the developing baby has Trisomy 21( Down syndrome), Trisomy 18 (Edwards Syndrome) or another type of chromosome abnormality.
- *Other Infectious Disease*: Any significant source of maternal infection, including periodontal, UTI, etc. (not classified as STI)
- *Pregnancy-Related Hypertension*: Hypertensive states of pregnancy that have not been preceded by any chronic high blood pressure.  
Classification: 1. Without proteinuria (protein in the urine); 2. With proteinuria (pre-eclampsia); and 3. Accompanied by seizures (eclampsia).
- *Preterm labor*: Onset of Labor before 37 completed weeks gestation.
- *Previous Infant 4000+ Grams*: Previous birth to infant weighing more than 4000 grams at birth
- *Previous Preterm/Small for Gestation*: Previous delivery of an infant before 37 completed weeks gestation. Birth weigh 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.
- *Renal Disease*: Damage to the nephrons resulting in kidney disease. This damage may leave kidneys unable to remove wastes. Commonly associated with diabetes and high blood pressure
- *Rh Sensitization*: Rh incompatibility occurs when a pregnant woman has Rh-negative blood and the fetus has Rh-positive blood. If Rh antibodies cross the placenta to the fetus, they may destroy some of the fetus's red blood cells. Once a woman is sensitized, problems are more likely with each subsequent pregnancy in which the fetus's blood is Rh-positive. If

red blood cells are destroyed faster than the fetus can produce new ones, the fetus can develop anemia. Such destruction is called hemolytic disease of the fetus (erythroblastosis fetalis) or of the newborn.

- *Uterine Bleeding*: Most commonly caused by placental problems in pregnancy such as:
  - *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 os.
- *Other, specify*: Indicate other medical complications/infections that occurred during pregnancy.
- *Experience intimate partner violence?* Mother experienced intimate partner violence at any time during the pregnancy. Intimate partner violence 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.
- *Use illicit drugs?* Mother used illicit drugs at any time during the pregnancy. Illicit drugs are defined as controlled substances that possess a high potential for abuse, have no currently accepted medical use in the United States and demonstrate a lack of accepted safety for use under medical supervision.
- *Infant born drug exposed?* For a child to be born drug exposed, there must be a documented presence of drugs that were taken by the mother in the child's system at time of birth. Documented refers to information from CPS or hospital records.
- *Misuse over-the-counter or prescription drugs?* Mother misused over-the-counter or prescription drugs at any time during pregnancy. Misuse of over-the-counter drugs is defined as a person taking a non-prescribed drug in a way other than recommended in product safety warnings or instructed by a supervising physician. Misuse of prescription drugs is defined as a person taking a medication that was not prescribed for them, taking a prescription drug in a way other than was instructed by the prescribing doctor or a prescription being used in a manner inconsistent with safe prescribing practices.
- *Have heavy alcohol use?* Mother used a heavy amount of alcohol after her pregnancy was confirmed.
- *Infant born with fetal alcohol effects or syndrome?* Child displayed documented effects associated with fetal alcohol syndrome or was diagnosed with fetal alcohol syndrome.

For questionable or suspicious use of drugs or alcohol, add comments in Section N. Narrative.

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

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 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: Maternal smoking – before pregnancy

Maternal smoking 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.”

A44: Maternal smoking – any time during pregnancy

- 1<sup>st</sup> Trimester

Found on the revised 2003 birth certificate, record the average number of cigarettes the mother smoked a day while she was in her first three months of her pregnancy. (20 cigarettes in a pack.) If quantity of cigarettes is unknown, select “unknown quantity.”

- 2<sup>nd</sup> Trimester

Found on the revised 2003 birth certificate, record the average number of cigarettes the mother smoked a day while she was in her second three months of her pregnancy. (20 cigarettes in a pack.) If quantity of cigarettes is unknown, select “unknown quantity.”

- 3<sup>rd</sup> Trimester

Found on the revised 2003 birth certificate, record the average number of cigarettes the mother smoked a day while she was in her last three months of her pregnancy. (20 cigarettes in a pack.) If quantity of cigarettes is unknown, select “unknown quantity.”

A45: Breastfeeding

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. This may be noted in hospital discharge notes, pediatric records or WIC file.

A46: Mother – Injury 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 car accidents, other unintentional injuries as well as intentional injuries as a result of domestic violence.

A47: Inborn errors in metabolism/Fatty acid oxidation error

Found in pediatric medical records and perhaps WIC records, the infant tested positive for a genetic metabolic error. This is often called newborn screening and is conducted with a heel stick while the infant is still in the hospital after delivery. Results are sent to the infant’s doctor and often the infant is placed on special formula. A fatty acid oxidation error, such as MCAD, is an abnormal metabolic newborn screening result. If infant had another abnormality, please describe.

A48: Medical History

Indicate if 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.
- 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.
- Metabolic disorders: Infant had a positive newborn screening result and was confirmed to have a metabolic disorder, usually requiring specialized formula.
- Other (specify): Infant had any other notable medical history that deviated from normal. This includes any hospitalizations or specialist visits after delivery discharge.

*A49: Recent medical complications in last 72 hours*

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: It was noted in a medical record or the caregiver reported that the infant had a temperature over 100 degrees Fahrenheit.
- Excessive sweating: It was noted in a medical record or the caregiver reported that the infant had been notably sweating or their skin was damp.
- Lethargy or sleeping more than usual: It was noted in a medical record or the caregiver reported that the infant had been sleeping more than usual and was difficult to arouse.
- Fussiness or excessive crying: It was noted in a medical record or the caregiver reported that the infant had been more fussy than usual or had been crying more than usual.
- Decrease in appetite: It was noted in a medical record or the caregiver reported that the infant had not been eating as much as usual.
- Vomiting: It was noted in a medical record or the caregiver reported that the infant had been throwing up, not merely spitting up.
- Choking: It was noted in a medical record or the caregiver reported that the infant had choked.
- Diarrhea: It was noted in a medical record or the caregiver reported that the infant had runny stools.
- Stool changes: It was noted in a medical record or the caregiver reported that the 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:** It was noted in a medical record or the caregiver reported that the infant had trouble breathing and may have exhibited ‘grunting’ or gasping noises.
- **Apnea:** It was noted in a medical record or the caregiver reported that the infant had stopped breathing for a short period of time.
- **Cyanosis:** It was noted in a medical record or the caregiver reported that the infant’s skin turned blue due to low oxygen in the blood.
- **Seizures or convulsions:** It was noted in a medical record or the caregiver reported that the infant had a seizure or convulsions.
- **Other (specify):** It was noted in a medical record or the caregiver reported that the infant had a medical complication not listed above.

*A50: Injury in last 72 hours*

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 car accident or fall) or intentionally, such as in the case of abuse.

*A51: Vaccinations in last 72 hours*

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 shot 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.

*A52: Medications in last 72 hours*

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.

*A53: Last Meal*

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

## Section B. Primary Caregiver(s) Information

### B1: Primary caregiver

Primary caregiver is defined as person or persons (up to two) who had responsibility for care, custody and control of 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, code both as primary caregivers. If a parent lives outside of the child's home and does not provide the majority of care for the child, do not code that person as a primary caregiver.

If a newborn infant dies in a hospital shortly after birth, list at least the birth mother as the primary caregiver. Indicate relationship of caregiver to child.

### B2: Age in years

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

### B3: Caregiver(s) sex

Sex of caregiver.

### B4: Caregiver(s) employment status

Caregiver's employment status at time of incident. To be considered unemployed, a person does not work at any time during the week.

### B5: 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.

### B6: Caregiver(s) education

Specify highest level of education which caregiver completed.

### B7: Does caregiver speak English?

Indicate if caregiver speaks and understands English. Code as 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.

### B8: Caregiver(s) on active duty in military?

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.

### B9: Caregiver receiving social services in past 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, 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.

*B10: Caregiver(s) have history of substance abuse?*

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 coded in the 'Other' category. Code as '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 gas). If the person is mentioned as using illegal drugs, even if addition or abuse is not specifically mentioned, code as '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 coded 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 coded "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 coded "yes". Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

*B11: Caregiver(s) have history of child maltreatment as a victim?*

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 caregiver was ever in foster care or adopted.

*B12: Caregiver(s) have history of child maltreatment as a perpetrator?*

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 or Family Preservation services, or had children removed.

*B13: 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*: Physical includes any anatomical loss, physiological disorders, cosmetic impairments and/or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate or cancer.
- *Mental*: Mental disorders are health conditions characterized by alterations in thinking; mood or behavior (or some combination thereof) associated with distress and/or impaired functioning. They include any psychiatric disability, mental illness or mental retardation. Examples may include depression, bi-polar disorders or Downs Syndrome. This includes cognitive/learning disabilities.
  - *If mental illness, was caregiver receiving mental health services?* Indicate if caregiver was currently receiving services.
- *Sensory*: Sensory disorders refer to any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include blindness and deafness.

*B14: Caregiver(s) have prior child deaths?*

Caregiver 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 due to child abuse, child neglect, accidental, suicide, SIDS or other.

*B15: 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.

*B16: Caregiver(s) have delinquent or 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 C. Supervisor(s) Information

Supervision 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, code person with primary responsibility. If responsibility of supervision was divided between two people, code person who was in closest proximity with the child prior to incident as the primary supervisor.

*C1: Did child have supervision at time of incident leading to death?*

Indicate if a person had care and control of the child at the time of incident. If infant was asleep at time of incident in a room next to the caregivers' room and the caregivers were present in the next room, the infant would be considered "supervised."

*C2: How long before incident did supervisor last see child?*

Approximate amount of time that passed between last time 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.

*C3: Is person a primary caregiver as listed in previous section?*

Supervisor is listed as a caregiver in Section B. If yes, go to question 15.

*C4: Primary person responsible for supervision at time of incident?*

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 C4-C14 will be hidden.

*C5: Supervisor's age in years*

Age of the supervisor.

*C6: Supervisor's sex*

Sex of the supervisor.

*C7: Does supervisor speak English?*

Indicate if supervisor speaks and understands English. Code as 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.

*C8: Supervisor on active duty in the military?*

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.

*C9: Supervisor has history of substance abuse?*

Supervisor is perceived by self or others to have a problem with, or to be addicted to,

alcohol or other drugs. If tobacco abuse exists, it can be coded in the 'Other' category. Code as 'yes' if supervisor 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 supervisor is mentioned as using illegal drugs, even if addiction or abuse is not specifically mentioned, code as '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 coded 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 coded "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 coded "yes". Previously attempting suicide via overdose is not sufficient justification for answering "yes" to this question in the absence of other information.

*C10: Supervisor have 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 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 or adopted or had children removed.

*C11: 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*: Physical includes any anatomical loss, physiological disorders, cosmetic impairments and/or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate or cancer.
- *Mental*: Mental disorders are health conditions characterized by alterations in thinking; mood or behavior (or some combination thereof) associated with distress and/or impaired functioning. They include any psychiatric disability, mental illness or mental retardation. Examples may include depression, bi-polar disorders or Downs Syndrome. This includes cognitive/learning disabilities.
  - *If mental illness, was supervisor receiving mental health services?*  
Indicate if supervisor was currently receiving services.
- *Sensory*: Sensory disorders refer to any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include blindness and deafness.

*C12: Supervisor has prior child deaths?*

Supervisor 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 due to child abuse, child neglect, accidental, suicide, SIDS or other.

*C13: 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.

*C14: 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.

*C15: At time of incident was supervisor impaired?*

Indicate supervisor's status at time of incident.

- *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.
- *Asleep:* Supervisor was sleeping at time of incident.
- *Distracted:* Distracted refers to the supervisor's attention being diverted off the child and onto something else.
- *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 D. 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 a fatal 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.

*D1: Date of incident event if different than date of death*

If date of incident was different than date of death, specify date of incident. If dates are identical, check same. For a newborn that did not leave the hospital, select 'Same as date of death'.

*D2: Approximate time of day that incident occurred*

Specify time of day that the incident occurred using a 12 hour clock. "AM" or "PM" can be selected without providing the specific hour.

*D3: Interval between incident and death*

If a date was given for question one, specify amount of time (days, weeks, months or years) that elapsed between incident and date of death. If incident and death occurred on the same date, provide the approximate time (hours or minutes) that elapsed. Deaths that occurred instantaneously or within seconds should be coded as one minute.

*D4: 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 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), code 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.

*D5: 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.

*D6: 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.

D7: Incident county

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

D8. Death state

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

D9. Death county

County in which death occurred as stated on death certificate. If death occurred 'Out of Country,' then this field will be disabled.

D10. Was the incident witnessed?

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

D11: Was 911 or local emergency number called?

911 or local emergency number was documented as being called at time of incident. For newborns that never left the hospital or if the incident occurred in a hospital, select N/A.

D12. 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 rescue breathing (mouth-to-mouth resuscitation).
- *Rescue medications:* Medications used for quick relief or control of symptoms. Examples include epinephrine and atropine.
- *If yes, was a rhythm recorded?* Indicate if the heart's rhythm was documented by a rhythm strip, AED or EKG. Rhythm includes ventricular fibrillation and sinus rhythm.

D13: At time of incident leading to death, had child used alcohol or drugs?

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 levels of drugs the child was taking for known medical conditions.

*D14: 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.

*D15: Total number of deaths at incident event*

Specify total number of deaths, including child, that occurred as a result of incident. For natural deaths, this question may not apply.

## Section E. Investigation Information

### E1: 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.

### E2: Person declaring official cause and manner of death

Specify who certified cause and manner of death as recorded on death certificate. Qualifications for medical examiners and coroners differ by state.

### E3: Autopsy performed?

Autopsy was performed on the child as stated on death certificate, or other source. Specify person who performed the autopsy.

- *Forensic pathologist:* The forensic pathologist is 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:* Pediatric pathology is a subspecialty of pathology concerned with 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 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 or fully completed. If known, describe the reason for the objection, for instance because the parents objected or the medical examiner denied jurisdiction on the case

### *Autopsy conducted – 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.

### E4. Were the following assessed either through the autopsy or through information collected prior to the autopsy:

Report whether the following test results were performed based on the autopsy report or on testing 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 child death review meeting, please contact them for this information.

- *X-ray - single*: The radiograph single view 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*: The radiograph complete skeletal view includes extremities, head, chest, abdomen, etc. One indication for a complete skeletal survey is child abuse.
- *CT scan*: A computerized axial tomography scan (also known as CAT scan) is an x-ray procedure that combines many x-ray images with the aid of a computer to generate cross-sectional views and, if needed, three-dimensional images of the internal organs and structures of the body.
- *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.
- *In situ exam and removal and dissection of*: In situ means to examine the organs in their original position in the body. Record subsequent removal and dissection of the brain, neck structures (including thyroid, major vessels, trachea, esophagus, etc.), and other organs.
- *Weights*: Weights and measures of the brain, heart, lungs, liver, kidneys, thymus, and spleen should be available.
- *Microscopic/histological exam*: This test result includes creating slides of the tissues and conducting a microscopic examination.
- *Microbiology*: The microbiology screen is to rule out infections and other bacterial infections.
- *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 long QT, hypertrophic cardiomyopathy, etc.
- *Toxicology screen*: The toxicology screen is to rule out ethanol and major classes of sedatives and stimulants, including cold medications. 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, code as 'Other'.

E5. Was the child's medical history reviewed as 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.

*If yes, review of the newborn metabolic screen results:*

Indicate if a review of the newborn metabolic screen results was performed as part of the investigation. Select 'Not performed' if a review was not conducted.

*If yes, review of neonatal CCHD screen results:*

Indicate if a review of the Critical Congenital Heart Disease (CCHD) screen results was performed as part of the autopsy. Select 'Not performed' if a review was not conducted.

*E6: Other significant autopsy findings*

Describe any other significant autopsy findings that have not been addressed in the other autopsy investigative questions above.

*E7: Agreement between pathology COD and death certificate*

The pathology 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.

*E8. Was a death scene investigation performed?*

Indicate whether a formal death scene investigation was completed. If yes, select any of the death scene investigation components which were completed and whether the investigation information was shared with the team.

*E9: List all agencies that conducted a scene investigation*

Specify all agencies that conducted an investigation of the incident at the death scene after the death occurred. A scene investigation refers to conducting an investigation at the event place. If the child was killed while working, include child labor enforcement agencies and/or workplace health and safety enforcement agencies under 'Other'.

*E10: Was a CPS record check conducted as a result of the death?*

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

*E11: 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.

*E12: CPS action taken because 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.

*E13: 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 F. Official Manner and Primary Cause of Death

F1. 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.

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

F2. Enter the following information exactly as written on the death certificate. List the Immediate Cause (final disease or condition resulting in death).

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

F3. Enter other significant conditions contributing to death but not an underlying cause(s) listed in F2 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.

F4. 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.

F5: 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. If homicide, indicate whether there was child abuse and/or neglect. If suicide, complete Section I, Acts of Omission or Commission.

F6: Primary cause of death: Choose only 1 of the 4 major categories, then a specific cause. For pending, choose the most likely.

From an injury (external cause). Select one and answer F4.

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 final cause of death may be head trauma. For the purposes of this database, the primary cause of death is coded as "motor vehicle and other transport". If the external cause is undetermined or unknown, go to H1. If external cause is 'Other', go to G11.

From a medical cause

If death was due to a medical condition, indicate category of primary cause of death. This is the cause of death that began the events resulting in the final cause of death. SIDS is considered a medical condition according to the International Classification of Diseases (ICD).

Undetermined if injury or medical cause

Select this option if the death was not classified as an injury or medical cause. For example, in some jurisdictions, medical examiners/coroners are not classifying the sudden unexpected death of an infant in either category. If undetermined, go to H1.

Unknown

Team does not have information on the primary cause of death. If unknown, go to H1.

## Section G1. Motor Vehicle and Other Transport

### G1a: Vehicles involved in 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. Determine which vehicle was the other primary vehicle involved in incident. This is the vehicle that most affected the incident involving the child. Indicate vehicle type for other primary vehicle.

### G1b: Position of child

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

- *Driver*: An occupant who is in actual physical control of a transport vehicle or, for an out-of-control vehicle, an occupant who was in control until control was lost.
- *Passenger*: Any occupant of a road vehicle other than its driver. Indicate seating position of passenger. Also if passenger, please note the relationship of driver to child.
- *On bicycle*: Any person riding on a bicycle or other non-motorized wheeled vehicle with pedals.
- *Pedestrian*: Any person who is not an occupant of a transport vehicle. Specify pedestrian activity at time of incident.
- *Unknown*: CDR team does not know the position of the child involved in the motor vehicle/other transport incident.

### G1c: Causes of incident

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

- *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 ran 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.

### G1d: 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'.

*G1e: 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.

*G1f: 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.

*G1g: 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 section 1a2. as other primary vehicle involved in crash.

*G1h: 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. N/A applies to h1 if the child was not in a vehicle. N/A applies to h2 if the incident was a single vehicle crash.

*G1i: Protective measures for 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.

- *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.
  - *If child seat is selected, indicate type*: A *rear facing* child seat is a type of child restraint system that is specifically meant for use by children from birth up to approximately 20 pounds and used in the rear-facing mode only. A *front facing child seat* is a type of child restraint that is specifically meant for use by children at least age one and at least 20 pounds and up to 40 pounds and used in the forward-facing position only. State regulations for safety seats may vary. The source for the definitions listed here is the National Highway Traffic Safety Administration.

- *Belt positioning booster seat*: A platform that raises the child to provide a taller sitting height so that adult lap and shoulder belts 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.

## Section G2. Fire, Burn or Electrocution

G2a: Ignition, heat or electrical source

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

G2b: Type of incident

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

G2c: 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.

G2d: Material first ignited

Type of material that first lit on fire following ignition.

G2e: Type of building on fire

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

G2f: 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.

G2g: Fire started by person?

Code as "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.

G2h: 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.

G2i: 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, were windows opened or broken out, doors opened, etc., thereby fueling the fire with oxygen and increasing the volume of smoke?

G2j: Did any factors delay fire department arrival?

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

G2k: 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.

G2l: Was building a rental property?

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

G2m: 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 code as “yes”.

G2n: 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 combustible materials (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](http://www.nfpa.org/freecodes/free_access_document.asp)).

G2o: Was sprinkler system present?

A sprinkler system was present in building/structure of fire at time of incident. If yes, indicate if it was working.

G2p: 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.

G2q: Suspected arson?

Cause of fire was documented as a suspected arson incident.

G2r: 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.

G2s: For electrocution, cause

If incident was electrocution, specify cause of electrocution.

G2t: Other, describe

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

## Section G3. Drowning

### G3a: Where was child last seen before drowning?

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

### G3b: 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.

### G3c: 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 code as "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.

### G3d: Drowning location

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

### G3e: For open water, place

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

### G3f: Contributing environmental factors

If any environmental factors contributed to the drowning, specify. If no environmental factors contributed, leave blank.

- *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.

### G3g: For boating, type of boat

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

### G3h: For boating, child piloting boat?

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

G3i: Type of pool

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

G3j: Child found

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

G3k: For pool, ownership

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 residence. A public pool includes municipal, institution, hotel, apartment, mobile home or RV park, private club or YMCA facility pools.

G3l: 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.

G3m: 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.

G3n: 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.

G3o: Fence

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

G3p: Gate

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

G3q: Door

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

G3r: Alarm

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

G3s: Type of cover

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

G3t: 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 they were violated.

G3u: 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.

G3v: 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.

G3w: For bathtub, was 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.

G3x: 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.

G3y: Lifeguard present?

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

G3z: Rescue attempt made?

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

G3aa: Did rescuer(s) also drown?

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

G3bb: 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.

## Section G4. Asphyxia

### G4a: Type of Event

Specify the type of asphyxiation. 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, such as in hanging or manual strangulation using the hands. Choking refers to asphyxiation caused by an object becoming lodged in the airway.

### G4b: If suffocation/asphyxia, action causing event:

For cases of suffocation, specify the circumstances that led to the asphyxial 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 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 G9a.

### G4c: If strangulation, object causing event:

For cases of strangulation, indicate what object caused the compression of the child's neck. If manual strangulation by an assailant be sure to also answer question G6q and Section I.

### G4d: If choking, object causing event:

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

### G4e: Was asphyxia an autoerotic event?

Autoerotic asphyxiation is defined as the practice of inducing cerebral anoxia, usually by means of self-applied ligatures or suffocating devices, while the individual masturbates. The most common practitioners are adolescent and young adult males. Select 'U/K' if the team could not determine if the child was participating in an autoerotic event or intentionally killed him/herself.

### G4f: Was child participating in 'choking game' or 'pass out game'?

Indicate whether asphyxial death was related to play 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 'U/K' if the team could not determine if the child was participating in the 'choking game' or intentionally killed him/herself.

G4g: 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?

G4h: 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?

G4i: 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.

## Section G5. Weapon, Including Person's Body Part

### G5a: Type of weapon

Specify type of weapon used in incident to cause injury to the child. A firearm is 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. A sharp instrument refers not only to knives, but also to razors, machetes, or pointed instruments (e.g., chisel, broken glass). A person's 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. Blunt instrument refers to clubs, bats, etc. Biological weapon is defined as 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.

### G5b: For firearms, type

If firearm was weapon, specify type.

### G5c: Firearm licensed?

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

### G5d: Firearm safety features

If firearm was weapon, specify safety features present on firearm at time of incident. Trigger lock is defined as 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 is defined as a device installed in a firearm that prevents unauthorized users of any age from firing it. External safety or drop safety is defined as 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 is defined as a gauge showing when a gun is loaded. Magazine disconnect is defined as 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 is defined as a gun feature that only enables a gun to fire if a minimum level of force is placed on trigger.

### G5e: Where was firearm stored?

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

### G5f: Firearm stored with ammunition?

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

### G5g: Firearm stored loaded?

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

### G5h: Owner of fatal firearm

Specify documented owner of weapon. 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.

G5i: Sex of owner of fatal firearm

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

G5j: Type of sharp object

If sharp object was weapon, specify type.

G5k: Type of blunt object

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

G5l: 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.

G5m: Did person using weapon have history of similar offense?

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

G5n: 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.

G5o: 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.

G5p: Sex of person(s) handling weapon

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

G5q: Use of weapon at time

Specify intended use of the fatal weapon at time of incident.

## Section G6. Animal Bite or Attack

G6a: Type of animal

Specify type of animal causing fatal injury even if child died from complications rather than actual injury. If insect is selected, only answer remaining section questions if applicable.

G6b: Animal access to child

Indicate how animal gained access to child.

G6c: Child provoke animal?

Code as “yes” if child's actions provoked, angered or startled the animal, causing a bite or other attack.

G6d: Animal has history of biting or attacking?

Animal has a documented or reported history of biting or attacking.

## Section G7. Fall or Crush

G7a: Type of incident

Indicate if incident was fall or crush.

G7b: 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'.

G7c: Child fell from

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

G7d: Surface child fell onto

Type of surface onto which child fell.

G7e: Barriers in place

Type 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 includes metal grates.

G7f: Was child in a baby walker?

Baby walker is defined as a light frame on casters or wheels to help a baby learn to walk.

G7g: Child pushed, dropped or thrown?

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

G7h: For crush, did child

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

G7i: 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.

## Section G8. Poisoning, Overdose or Acute Intoxication

### G8a: 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 drugs should be listed in the prescription drug category even if the prescription drug was obtained “on the street” or was prescribed for another person. Pain killer (opiate) should be selected for all prescribed opiates except methadone. Cardiac medication should be selected for all drugs typically prescribed for heart disease, except for blood pressure medication. Check the class for which the drug is most typically used. In some instances this may not be the reason for which the drug is prescribed. For example, Codeine should be checked as pain killer (opiate) even if it was prescribed as a cough suppressant.

Street drugs include recreational drugs not generally available by prescription such as heroin, cocaine, LSD and methamphetamine. If the child died from a prescription drug that was obtained illicitly, please list the agent in the appropriate prescription drug category.

In order to obtain data on the exact agents involved in poisoning deaths among children and youth, please indicate the actual trade or generic name of each agent contributing to the death in the “other specify” field, for the corresponding category, as well as in the narrative. For example, if codeine was one of the contributors to the death, check pain killer (opiate) and write codeine in the other specify field.

### G8b: 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.

### G8c: Was the product in its original container?

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

### G8d: Did the container contain 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.

### G8e: If prescription, was it for child?

If source of poison was a prescription medication, indicate if the medication was prescribed for the child.

### G8f: Was the incident the result of?

- *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.

- *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.

G8g: Was Poison Control called?

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

G8h: 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.

## Section G9. Exposure

Exposure refers to death resulting from lack of protection over prolonged periods from weather or extreme temperatures.

G9a: Circumstances

Specify circumstances involved in the incident.

G9b: Condition of exposure

Indicate if primary cause of death was hyperthermia or hypothermia. Hyperthermia is defined as an above normal body temperature. Hypothermia is defined as a below normal body temperature. Specify ambient temperature of child when found. Ambient temperature is defined as the temperature of room or place surrounding where child was found.

G9c: Number of hours exposed

Total number of hours child was documented as being exposed to extreme temperature.

G9d: Clothing appropriate?

If child was wearing appropriate clothing for conditions at time of incident, code as “yes”.

## Section G10. Medical Condition

G10a: 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.

G10b: 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.

G10c: Was child receiving health care for the medical condition?

Indicate if child was receiving health care for medical condition resulting in the death. Code as '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.

G10d: 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.

G10e: Was child/family compliant with 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'.

G10f: Was child up to date with American 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/>.

G10g: Was medical condition associated with disease outbreak?

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

G10h: Was environmental tobacco exposure a contributing factor in the death?

Code as 'yes' if the team believes that environmental tobacco exposure contributed to the death. Do not code yes if the child was a smoker but 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)

*G10i: 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. G11h options are defined in section A39.

## Section G11. Other Known Injury Cause

### G11a: Cause

Describe the cause and/or circumstances involved in the child's death. The following causes of death are included in this section.

- Other injury cause

## Section H. Other Circumstances of Incident

### Section H1 – Sudden and Unexpected Death in the Young

H1a. Was this death a homicide, suicide, overdose, injury with the external cause as the only and obvious cause of death or a death which was expected within 6 months due to terminal illness?

If the manner was indicated on the official death certificate as a) homicide, or b) suicide, or c) if the medical examiner / coroner indicated that an external injury was the only and obvious cause of the death, or d) if death was expected within 6 months due to a terminal illness, the questions related to symptoms and diagnoses of medical conditions should not be answered.

H1b. Did the child have a history of any of the following acute conditions or symptoms within 72 hours prior to death?

A symptom noted/reported by a child at any age is valid and should be recorded. If it was noted, it is notable.

- *Palpitations*: Sensations of the heart that include pounding or racing. They can be felt in the chest, throat, or neck.
- *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.
- *Psychiatric symptoms*: Includes depression or anxiety.

H1c. At any time more than 72 hours preceding death did the child have a personal history of any of the following chronic conditions or symptoms?

- *Palpitations*: Sensations of the heart that include pounding or racing. They can be felt in the chest, throat, or neck.
- *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.

H1d. Did the child have any prior serious injuries?

If yes, describe the injuries.

H1e. Had the child ever been diagnosed by a medical professional for the following?

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

- *Sickle cell trait*: Include sickle cell trait if the child was a carrier.
- *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), 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.
- *Commotio cordis*: A blow to chest causing cardiac arrest or death.
- *Anoxic brain injury*: An injury caused by lack of oxygen to the brain.
- *Developmental brain disorder*: Can include such diagnoses as cerebral palsy, intellectual disability (mental retardation) or a structural brain malformation.

- *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.
- *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.
- *Mental 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.
- *Prematurity*: A premature birth is a birth that takes place at less than 37 weeks of pregnancy.

*Hint. 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, 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.

- *Arrhythmia / arrhythmia syndrome*: Can also be called a fast or irregular heart rhythm and 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*: Defined as occurring in utero and present at birth. Includes a vast array of physical and developmental conditions including heart disease, deafness, and Down syndrome.
- *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.
- *Febrile seizures:* Seizures brought on by fever.
- *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.

*H1g. Have any blood relative (siblings, parents, aunts, uncles, cousins, grandparents) had genetic testing?*

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

Genetic testing - A genetic test identifies changes in our genetic information (DNA) that can be related to a health condition.

*If yes, describe what test and/or for what disease and results:*

Include the following information: name of test or gene tested, reason for testing (suspected disease/diagnosis), results of test including negative results. Specify which family member had the testing.

*Was a gene mutation found?*

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

*H1h. In the 72 hours prior to 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.

*H1i. Within 2 weeks prior to death had the child:*

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.

*H1j. Was the child compliant with their prescribed medications?*

If the child was not taking medication as prescribed, indicate '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.

*H1k. Was the child taking any of the following substance(s) within 24 hours of death?*

- *Diet assisting medications:* Can be prescription medications and or OTC compounds.
- *Tobacco:* Includes cigarettes, chewing, electronic/nicotine.
- *Illegal drugs:* Can 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.’

H1l. Did the child experience any of the following stimuli at time of incident or within 24 hours of the 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.
- *Visual stimuli:* Flickering, flashing or strobe lights, television, computer or other visual stimuli that form patterns in time or space.
- *Emotional stimuli:* Strong reaction including anger, sadness, and stress
- *Auditory stimuli/startle:* A sudden startling noise.
- *Physical trauma:* Injury caused to a person by physical forces such as motor vehicle crashes, assault, falls, near drowning.

H1m. Was the child an athlete?

If the child participated in a sport that required moderate to vigorous exercise, indicate ‘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.

H1n. 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.

H1o. For children 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 and safety for a child prior to their participation in an athletic sport. These may be performed by any professional such as general practitioners or specialists including sports medicine physicians. Requirements for sports exams vary by locality.

H1p. 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.

H1q. What were the underlying causes of the child’s seizures?

- *Central nervous system infection:* Infection of the brain, spinal cord and associated membranes. Specific diagnoses can include: encephalitis, meningitis.
- *Cerebrovascular:* Includes stroke, hemorrhage, trauma, CNS infection (congenital or not).
- *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.
- *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.
- *Cryptogenic:* Unknown origin.

H1r. 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 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:* Occur when exposed to strobe lights, video games, or flickering light. Triggers for seizures can include flashing lights or rolling images, sometimes known as photosensitivity. Seizures may or may not include a loss of consciousness.

H1s. Describe the child's epilepsy/seizures.

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 lasting more than 30 minutes or a series of seizures without recovery in between.
- *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):* Triggers for seizures can include flashing lights or rolling images, sometimes known as photosensitivity.

H1t. 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 “4 or 5,” mark 5. A best estimate is preferred over a response of unknown.

H1u. Did treatment for seizures include anti-epileptic drugs?

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

H1v. Was night surveillance used?

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.

**H2. Death Related to Sleeping or the Sleep Environment**

If yes, answer the following questions if the child is under the age of five. If no or unknown, go to question H2s.

H2a: Incident sleep place

Type of place child was sleeping in or on.

- Select crib if an infant has been placed in a NICU or ICU bed.
- Select portable crib if the child has been placed in a Port-a-crib, Pack ‘n Play, or a hotel crib.
- Select adult bed (and then twin bed in the follow up question) if the child has been placed in a twin bed.
- Select futon if the death occurred on a futon and then indicate futon position in the follow up question.
- A playpen is a small “pen” or enclosed structure with an open top, designed to keep babies and small children safe while playing. Playpens are not small, portable bassinets, such as a Pack ‘n Play.
- Select car seat if the child was placed in an infant or toddler car seat that was placed either in the car, stroller or in the home for the child to sleep.
- Select stroller if the stroller does not use the click-in car seat combination. Children are often placed in strollers lying flat.

H2b: Child put to sleep

Position child was put to sleep in.

H2c: Child found

Position child was found unresponsive.

H2d: Usual sleep place

Usual sleep place refers to the place the child slept a majority of the time. The sleep place selected should be the usual place for the time the incident occurred. For example, if the death occurred at a licensed child care home, where did the infant usually sleep while at child care? See 'Incident sleep place' for more information about response options.

H2e: Usual sleep position

Position child slept most times.

H2f: Was there a crib/bassinette/port-a-crib in the home for the child?

Indicate if there was a crib/bassinette or port-a-crib in the home and/or location where the incident occurred. Pack 'n Plays are considered cribs (portable cribs).

H2g: Child in new/different sleep environment?

Child was sleeping in an environment new or different to child up to one week prior to the death. A new or different sleep environment refers to an environment that is not part of the child's normal routine. 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 this would be considered a new sleep environment. Include temporary sleep environments as well such as a hotel stay.

H2h: Pacifier use

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.

H2i: Child swaddled?

Answer yes if the child was intentionally wrapped or swaddled in a blanket prior to putting him/her to sleep. You should not answer yes if the child became tangled or wrapped in the blanket while he/she slept. If yes, include a brief description of the weight and thickness of the blanket the child was wrapped in as well as information about how loose or tight the swaddle/wrap was when found, whether or not the blanket was covering the child's nose or mouth, and/or had gotten underneath the child resulting in a soft bedding sleep environment.

H2j: Child overheated?

Child was overheated at 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.

H2k: Child exposed to second-hand smoke?

Child was exposed to second hand smoke regularly during lifetime. Second hand smoke is defined as smoke which is exhaled by a smoker, or originates from a tobacco product which he/she is using, to which a child is exposed. It includes smoke from a smoldering 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.

H2l: Child's face when found

Child's face 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 was found face straight down on a pillow; select "Up" if the child was lying on a pillow with only the back of the neck 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.

H2m: Child's neck when found

Indicate the position of the child's neck relative to the body. Select "Hyperextended" if the child's neck was arched backwards with the chin far away from the chest. Select "Hypoextended" if the child's neck was bent towards the body with the chin close to the chest. Select "Neutral" if the child's head and neck were in a normal relaxed position.

H2n: Child's airway

Child's airway refers specifically to his/her nose, mouth or chest. Select "Unobstructed" if no objects were interfering with the child's nose or mouth or compressing the child's chest. For example, mark "Unobstructed" if the child was on his/her back, face up, neutral neck, in a crib with no other objects obstructing airway. Select "Fully obstructed" if the child's nose and mouth were completely covered by an object such as face down on a pillow. "Fully obstructed" could also include a full chest compression such as a child found with an adult's thigh over his/her chest. Select "Partial obstruction" if only the nose, only the mouth, or only part of the face including nose/mouth were covered by an object. "Partial obstruction" could also include a child that was found with only a portion of his/her chest compressed by a caregiver or object. If airway was fully or partially obstructed, indicate what parts of the airway were partially or fully obstructed (nose, mouth, chest compressed).

H2o: Objects in sleep environment in 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:

- Present – Inventory of objects present in the child's sleep environment. This should include an inventory of the child's sleep surface (crib, adult bed, couch, etc).
- If present, describe position of object – Identify the listed object(s)' position as it directly related to the child. For example, if a pillow was present, was the pillow next to the child or under the child? You may select more than one option.

- If present, did object obstruct airway – For each object present in the sleep environment, indicate if any of the listed object(s) obstructed the child’s nose and mouth or resulted in a chest compression.

Example: Child was in crib, found under a thick blanket with nose and mouth obstructed by blanket. Teddy bear in crib, at base of crib. Child dressed in onesie.

<b>Object Present (Yes)</b>	<b>Describe Position</b>	<b>Object Obstruct Airway</b>
Mattress	Under child	No
Comforter	On top of child	Yes
Crib railing	Next to child	No
Clothing	On top of; Under child	No
Toy	Next to child	No

H2p: Caregiver/supervisor fell asleep while feeding child?

If caregiver/supervisor fell asleep while feeding child, specify type of feeding.

H2q: Room sharing

Room sharing is defined as a child and caregiver(s) sleeping in the same room. The child may or may not be on the same sleep surface as caregiver(s).

H2r: Child sleeping on same surface with person(s) or animal(s)?

If child was sleeping with a person or animal, specify number of adults sleeping with child and if they were obese, number of other children sleeping with child and their ages and number of animals sleeping with child and type of animal(s). If age of children or type of animal(s) is unknown, write in unknown. Select ‘yes’ regarding obesity if there was clear evidence that the adult(s) sharing a sleep surface with the child was in fact obese from photos, police reports or other documentation.

H2s: Scene re-creation photo available for upload?

Scene re-creation photo should ideally be a doll re-enactment photo depicting where the child was found specifically showing 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. Only one photo (.jpg format) less than 6MB in size may be attached. Blur or crop any facial images contained in the photo to preserve confidentiality of any individuals depicted.

**H3. Death a Consequence of a Problem with a Consumer Product**

If yes, answer the following questions.

H3a: Describe product and circumstances

If 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.

H3b: Was product used properly?

If 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.

H3c: Recall in place?

If death was the 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 return the product.

H3d: Did product have safety label?

Indicate if product had 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.

H3e: Was Consumer Product Safety Commission notified?

If the Consumer Product Safety Commission was notified of the incident, code as “yes”.

**H4. Death Occurred During Commission of a Another Crime**

If yes, answer the following question.

H4a: Type of crime

If 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 coded 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.

## Section I. Acts of Omission or Commission including Poor Supervision, Child Abuse & Neglect, Assaults and Suicide

Completion of this Section is especially important because it provides information about any human behaviors that may be involved in a child's death. For example, it addresses intentional (e.g., homicides, child abuse and neglect, suicides), unintentional injuries, and medical misadventures (e.g., errors). Not only can this information serve critical data tracking functions, it may be critical to the prevention of both intentional and unintentional injury deaths. **Section I should be considered for the majority of deaths, excluding most natural deaths.**

### *II: Did any act(s) of omission or commission cause and/or contribute to the death?*

Acts of omission or commission are defined as any act or failure to act which causes (i.e., directly) and/or substantially contributes to (i.e., indirectly) the death of the child. Communities may have different standards that apply, but they should be based on evidence and professional judgments. Legal definitions may serve as a baseline, although they need not be used as a strict criterion.

Because this question serves a gatekeeper role, please pay particular attention to the broad definition of act(s) of commission and omission. This is not a determination of blame, but rather just an identification of whether there were specific human behaviors involved that caused or contributed to the child's death. If one or more acts of commission or omission potentially related to the child's death are not identified and coded here, you will not be able to complete any other parts of the Section. In the past this has led to some important data being omitted.

A new category of "Probable" has been added to allow coders to include cases where there may not be sufficient evidence for the team to be certain that any particular act(s) of commission or omission related to the death occurred, but there is some reasonable evidence indicating such a link. Case in which the "Probable" category is selected will be treated separately than the cases categorized as "Yes". For example, this "Probable" category allows the team to check "child abuse" or "child neglect" in those situations where they only have reasonable suspicions, but are not certain enough to classify the case as child maltreatment (Section I 3).

Although this is not intended to be exhaustive, examples of acts of commission that would count as direct causes of a child's death include: 1) someone shooting the child with a gun and the bullet wound causing the death; 2) a teen driver falling asleep and crashing his car into a tree causing death due to blunt force trauma; 3) a caregiver shaking an infant so hard to cause severe head trauma and death; 4) a drunk driver hitting another car causing severe trauma and death to a young child passenger in the other car; 5) a young girl taking an overdose of prescription medicines causing her death; and 6) even an institutional breakdown in the enforcement of DUI laws.

Although this is not intended to be exhaustive, examples of acts of omission that served as contributing or indirect causes of a child's death include: 1) an unsupervised toddler falling into an open residential pool and drowning; 2) a child left in a closed car on a hot day who dies from hyperthermia; 3) a caregiver failing to get necessary medical attention

for an ill child who died of the untreated illness; 4) hospital personnel failing to provide the correct medicine in a timely manner that leads to patient death; 5) a caregiver who unintentionally rolls onto an infant in an adult bed and the infant suffocates.

*Direct or Contributing Cause of Death:* The second part of the question simply asks whether the cause(s) are considered direct or contributory. Both choices can be selected if more than one act of commission or omission is present.

The direct cause of death refers to an act that was the primary event leading directly to the death. It describes a specific act of commission or omission that, in and of itself, led to the physiological processes precipitating the child's death. Generally, the act in question was both *necessary and sufficient* to kill the child. The death may have occurred instantaneously or substantially after the act.

The contributing cause of death refers to an act that plays a role, but not the primary role, in the death. The contributing (or indirect) cause of death describes a *necessary but not sufficient* act of commission or omission that contributed in a substantial manner to the death of the child. The act did not, in and of itself, precipitate or lead inevitably to the physiological processes leading to death. However, it is understood to have been a necessary element in the child's death. The death may have occurred instantaneously or substantially after the act.

*I2: What act(s) caused or contributed to the death?*

Acts of omission or commission that caused or contributed to the death of child should be identified by category. Only one can be selected for caused and one for contributed, if applicable. In addition, this is the single question that will be used to track child maltreatment cases. For the CDR purposes, child abuse and child neglect are defined, at a minimum, as an act or failure to act on the part of a *parent or caregiver* which results in death, or presents an imminent risk of serious harm. States may have their own definitions based on these minimum standards. CDRTs also have different standards they apply, but they should be based on evidence and professional judgments. Legal definitions may serve as a baseline, although they need not be used as a strict criterion. Both a direct cause and a contributed cause of maltreatment can be checked (e.g., direct cause of abuse by shaking a baby and contributing cause of neglect by failure to protect from a known hazard).

If the team judges that the caregiver behavior caused or contributed to the death but did not reach the level of maltreatment, they should check the poor or absent supervision category. Also as mentioned in Section I1, if the team is not certain whether to classify a child death as child maltreatment, they can also use the initial question (I1) to check "Probable" and then check child abuse or neglect. For example, if the team can't determine whether an abandoned baby was born alive or stillborn, they could check the I1. Act(s) of Commission/Omission item as "Probable" and the I3. Cause item as "child abuse" or "child neglect" to capture the information about the circumstances surrounding the death without having to classify the case as a child maltreatment death (given the question of whether it was a live birth).

- *Other negligence*: Refers to acts or failures to act that are neglectful including criminal negligence, vehicular manslaughter, voluntary intoxication, but not restricted to the level of criminal culpability. See Item I.1. for definition of caused and contributed.
- *Assault, not child abuse*: Refers to those cases where the alleged perpetrator is not in an explicit or implicit caregiver role.
- *Religious or cultural practices*: Refer to potential mitigating factors that teams might consider in determining that the act(s) of commission or omission that lead to the child's death should not be classified as maltreatment. CDRTs should be free to consider these potential exceptions or not, although some states specifically allow for such religious or cultural exceptions. But primary consideration should be given to the best interests of the child and the level of risk of harm to the child.
- *Suicide*: Please select "Caused" and "Suicide" in I3 for any cases where manner of death has been marked "Suicide" in Section F1. Once "Caused" and "Suicide" have been selected in I3, the more detailed suicide risk factor questions in I27 and I28 will appear in the web based Case Reporting System.
- *Medical misadventure*: 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.

I3: Child abuse, type

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. Physical abuse is any non-accidental act that results in physical injury or the imminent risk of harm. Emotional abuse refers to such acts as verbal assault, belittling, threats and blaming. Sexual abuse is a single or series of sexual assault(s) or sexual exploitation(s).

I4: Type of physical abuse

Check category(ies) and provide brief details. Abusive head trauma is a broader term for any child abuse case involving head injury, including shaken baby syndrome. Chronic battered child syndrome refers to children who have undergone physical abuse multiple times that has left them with both physical and psychological trauma. Munchausen's Syndrome by Proxy (MSP) is a parenting disorder where parents fabricate symptoms in their children, thus subjecting the child to unnecessary medical tests and/or surgical procedures, or inflict injury of children in the process.

I5: For abusive head trauma, were there retinal hemorrhages?

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. Formal medical documentation of retinal hemorrhages is needed to code as "yes".

I6: 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 and/or medical records.

*I7: Event triggering physical abuse*

If death occurred as a result of abuse, specify "trigger" for abusive behavior. Trigger is defined as an environmental circumstance or action of the child, person committing act or another person that led person to cause abuse.

*I8: Child neglect*

If death occurred as a result of neglect or neglect contributed to the death based on evidence available to the team, specify type of neglect. Check all that apply.

*I9: Other negligence*

If other type of negligence was documented as a contributing factor in death, specify. Does not include child neglect.

*I10: Was act(s) of omission/commission?*

Chronic with child refers to a pattern of ongoing acts of abuse or negligence inflicted specifically on this child. A pattern in family or with perpetrator refers to a pattern of ongoing acts of abuse or negligence inflicted on one or more members of a family or household. An isolated incident refers to a single event with no documentation of similar prior incidents. See Item I.1. for definition of caused and contributed.

*I11: Is person the caregiver/supervisor listed in previous section?*

Indicate if person causing act is same person specified as caretaker or supervisor in Section 2 and/or 3. See Item I.1. for definition of caused and contributed.

*I12: Primary person responsible for action(s) that caused or contributed to the death*

Relationship of person causing act on child. See Item I.1. for definition of caused and contributed.

*I13: Person's age in years*

Age of person causing act. See Item I.1. for definition of caused and contributed

*I14: Person's sex*

Sex of person causing act. See Item I.1. for definition of caused and contributed.

*I15: Does person speak English?*

Indicate if person speaks and understands English. Code as "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.

*I16: Person on active duty in the military?*

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. See Item I.1. for definition of caused and contributed.

*I17: Person has history of substance abuse?*

Person is perceived by self or others to have a problem with, or to be addicted to, alcohol or other drugs. If tobacco abuse exists, it can be coded in the ‘Other’ category. Code as ‘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 gas). If the person is mentioned as using illegal drugs even if addiction or abuse is not specifically mentioned code as ‘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 coded 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 coded “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 coded “yes”. Previously attempting suicide via overdose is not sufficient justification for answering “yes” to this question in the absence of other information.

*I18: Person has history as a victim of child maltreatment?*

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. See Item I.1. for definition of caused and contributed. 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. Terminology regarding referrals and substantiations varies by state.

*I19: Person has history as a perpetrator of child maltreatment?*

Person has documented history of being the perpetrator of child maltreatment (child abuse or neglect). Documented 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 which type of maltreatment was substantiated. See Item I.1. for definition of caused and contributed. If child welfare referral or substantiations are documented, indicate total number of CPS referrals and substantiations. Indicate if person received

CPS prevention or Family Preservation services. Indicate if person ever had children removed. Terminology regarding referrals and substantiations varies by state.

I20: Person has disability or chronic illness?

Person 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*: Physical includes any anatomical loss, physiological disorders, cosmetic impairments and/or diseases. Examples may include paraplegia, cerebral palsy, cystic fibrosis, diabetes, cleft palate or cancer.
- *Mental*: Mental disorders are health conditions characterized by alterations in thinking; mood or behavior (or some combination thereof) associated with distress and/or impaired functioning. They include any psychiatric disability, mental illness or mental retardation. Examples may include depression, bi-polar disorders or Downs Syndrome. This includes cognitive/learning disabilities.
  - *If mental illness, was perpetrator receiving mental health services?*  
Indicate if perpetrator was currently receiving services.
- *Sensory*: Sensory disorders refer to any disability or chronic disease that impairs the senses, including visual, auditory and olfactory. Examples include blindness and deafness.

I21: Person has prior child deaths?

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 due to child abuse, child neglect, accidental, suicide, SIDS or other. See Item I.1. for definition of caused and contributed.

I22: Person has history of intimate partner violence?

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. See Item I.1. for definition of caused and contributed.

I23: Person has delinquent or criminal history?

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. See Item I.1. for definition of caused and contributed.

I24: At time of incident was person?

Indicate person's status at time of incident for items a-h. See Item I.1. for definition of caused and contributed.

- *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 function or 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 function or supervise a child.
- *Asleep:* Person was sleeping at time of incident.
- *Distracted:* Distracted refers to person's attention being diverted off the child and onto something else.
- *Absent:* Person 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 function or 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.

I25: Does person have

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.

I26: 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.

I27: For suicide, check all that apply and describe answers in narrative

- *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 coded 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.

*I28: For suicide, was there a history of acute or cumulative personal crisis or events that may have contributed to the child's despondency?*

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).
- *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*: Sexual orientation is the pattern of a person's emotional, physical, sexual attraction and psychological attraction to someone of a particular sex.
- *Religious/cultural crisis*: Child was experiencing a personal conflict with their religion or culture, for example child was not allowed to date person or engage in certain activities due to religions prohibitions; child was questioning personal belief system as it related to family's cultural practices or religion.
- *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.
- *Gambling problems*: Child was involved in gambling, to the extent that the child had debts, was suspected of illegal gambling, was betting for sports while participating on a team, or had a gambling addiction.
- *Involvement in cult activities*: A cult is a religion regarded as unorthodox or spurious. Members of a cult feel a great devotion to a person, idea, object or movement.
- *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. Services to Family and Community as a Result of the Death

### *J1: Services*

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.

## Section K. 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.

### K1: 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.

K2: What specific recommendations and/or initiatives resulted from the review? Note: If you need to make changes to data entered for question K2 on the web version, reset your answers by checking and unchecking the “No recommendations were made” check box at the beginning.

Indicate specific prevention strategies developed during the review process. 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. An action means that the team or others are taking steps to implement the recommendation.

- *Nothing:* 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.
- *Agency (New policy(ies), revised policy(ies), new program, new services, expanded services):* An institutional change could be made in an agency's formal or informal policies, practices and/or procedures that affect the way the agency does its business.
- *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.

*K2a: Current action stage*

Identify whether the proposed action is currently at the recommendation stage only, or action planning is underway or some form of action to implement the prevention strategy has already begun.

*K2b: Type of action*

Indicate if the proposed preventive action is an immediate short term solution (e.g., drafting a letter, holding a public meeting or writing a newspaper article) or involves a longer term, and/or more complex intervention, such as development of a home visitation program, implementation of a school health curricula or development of a community wide injury prevention plan.

*K2c: Level of action*

Indicate if the proposed action involves local, state and/or national level activities.

*K3: Who took responsibility for championing the prevention initiatives?*

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.

## Section L. The Review Meeting Process

### L1. Date of first CDR meeting

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

### L2. Number of CDR meetings for this case

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

### L3: Is review complete?

The review is complete if the team has determined that there will be no further meetings on this case. For more information on determining if the review is complete, check with your state CDR coordinator.

### L4. Agencies at CDR meeting

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

### L5. Were the following data sources available at the CDR meeting?

Record which of the listed data sources were available for the child death review team.

### L6. Factors that prevented an effective CDR meeting

Issues that arose during the review process that impacted the CDR 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 CDR 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 CDR 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.

#### L7. CDR meeting outcomes

Indicate the outcomes of the CDR 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 child death 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.

#### L8: Describe the factor(s) that directly contributed to this death:

This is a subjective question and asks which factors the team feels directly and more immediately contributed to this child's death. For example, it is more important to note in this question that the infant was sleeping on soft pillows at the time of death rather than listing previous history of substance abuse by the caregiver or inadequate prenatal care, both of which were risk factors that were less immediate (more distal) to the death.

Only include factors that are relevant to the infant death. If the mother was bedsharing with the infant and the mother was obese, obesity may be a contributing factor. However, if the mother was obese and infant was not sleeping with mother at the time of death, obesity did not contribute to this death. Other examples may include: prone sleep

position, bed sharing, heavy blanket obstructing nose and mouth, prematurity, respiratory infection, using alcohol while operating a motor vehicle, lack of supervision at family pool.

*L9: Which of the factors that directly contributed to this death are modifiable?*

This is a subjective question and asks the team what factors listed in L8 were able to be changed. Removing pillows from the infant's sleep environment or changing the infant sleep position from prone to supine are examples of modifiable risk factors that could be listed here. Other modifiable examples may include: bedsharing, not putting baby to sleep in crib/bassinette, sleep position, propping a bottle, noncompliance with medications, not wearing a seat belt in motor vehicle.

*L10: List any recommendations to prevent deaths from similar causes or circumstances in the future.*

Record the recommendations the team developed in order to prevent similar deaths. Work hard with your team to develop recommendations that are feasible and specific. Recommendations should include changes to practices, policies, and procedures, as well as maintenance of current prevention activities. Suggesting all parents should be educated is neither feasible nor specific. Rather, suggesting targeted safe sleep messages through home visiting or during the hospital stay following delivery is a better recommendation. Other examples include: Train 100% of ABC Daycare staff on Safe to Sleep campaign; create a Safe to Sleep checklist for home visitors; initiate a car safety seat inspection at Kids Elementary School.

*L11: What additional information would the team like to know 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.

*L12: What additional information would the team like to know 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 or genetic testing, long QT test on surviving siblings, additional funding for contrast/staffing of MRI/CT utilization.

## Section M. SUID and SDY Registry

M1: Is this an SDY or SUID case?

Indicate whether this case should be included as a case for the SDY or SUID Case Registry.

M2: Did the case go to Advance Review for the SDY Case Registry?

Indicate whether or not the case went to Advance Review. If 'Yes' indicate the date of the first Advance Review meeting.

M3: Notes from Advance Review meeting:

Use this space for notes specific to the Advance Review team.

M4: If autopsy performed, did the ME/coroner/pathologist use the SDY Autopsy Guidance Summary?

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

M5: Was a specimen sent to the SDY biorepository?

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

M6: Did the family consent to the SDY Case registry?

This question refers only to the written, signed form worded specifically for the SDY Case Registry.

M7: Categorization for SDY Case Registry

These categorization options are defined for the jurisdictions which are funded to participate in the NIH/CDC Sudden Death in the Young Case Registry (SDY-R). If your jurisdiction is not funded for the SDY-R project, you do not need to complete this question. If your jurisdiction is funded, any questions should be directed to the SDY-R coordinator in your state. Grantees with funding for only the CDC SUID Case Registry DO NOT need to complete M7, only M8.

M8: Categorization for SUID Case Registry

These categorization options are defined for the jurisdictions which are funded to participate in the CDC SUID Case Registry (SUID-CR) and/or NIH/CDC Sudden Death in the Young Case Registry (SDY-R), infants only. If your jurisdiction is not funded for the SUID-CR or SDY-R project, you do not need to complete this question. If your jurisdiction is funded, any questions should be directed to the SUID-CR or SDY-R coordinator in your state. This question only applies to infants.

## Section N The 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, 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 CDR-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.

The names of public or private agencies involved in the case may be included.

## Section O. Form Completed By:

*Person:* Enter name of person completing the case report form.

*Title:* Enter title of person completing the case report form.

*Agency:* Enter agency of person completing the case report form.

*Phone:* Enter phone number of person completing the case report form.

*Email:* Enter email address of person completing the case report form.

*Signature:* Person completing case report form should sign if using paper copy.

*Data entry finished for this case:* Code as “yes” once data entry is finished for this case. For more information on determining if data entry is complete, contact your state CDR coordinator.

*Date completed:* Enter date the case report form was completed.

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

*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. It will be used to identify cases which are finished for data entry and quality assurance.

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**www.childdeathreview.org**  
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**1-800-656-2434**

**National Center for the Review and Prevention of Child Deaths**