At the time of death, did the death present as sudden\(^1\) and unexpected\(^2\) ?

- **Yes**
  - Was the child < 20 years of age and a resident of the funded state/jurisdiction?
    - **Yes**
      - During\(^6\) the autopsy and initial death investigation\(^7\), was the death any of the following?
        - Result of an external cause that was the only and obvious reason for the fatal injury (however include drownings among children ≥5 years of age, infant suffocations and drivers in motor vehicle crashes)\(^8\)
        - Homicide\(^9\)
        - Suicide
        - Intentional overdose of drugs\(^10\)
        - Terminal illness\(^11\) in which the death was reasonably expected to occur within 6 months
      - **No**
    - **No**
  - **No**

- **No**
  - Explained, Excluded\(^3, 4, 5\)

After the death investigation\(^7\), was the death any of the following?

- **Yes**
  - Explained, Excluded\(^3, 4, 5\)
- **No**
  - Explained, Other\(^3, 5, 13-17\)

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**Case Continues to Step 2 (< 1 year of age) or Step 3 (≥ 1 year of age)**

*If at any point it is determined that these cases are homicide, suicide or intentional overdose then categorize as Excluded\(^3, 4, 5, 13-17\)*
**SDY Case Registry Algorithm - Step Two**

**Cases from Step 1 (< 1 year of age)**

**Does the infant death meet the criteria for SUID Case Registry categorization?** Cases are those where the death certificate indicates the cause as unknown, undetermined, SIDS, SUID, unintentional sleep-related asphyxia/suffocation/strangulation, unspecified suffocation, cardiac or respiratory arrest without other well-defined causes, or unspecified causes (e.g. pneumonia) with potentially contributing unsafe sleep factors.

**SDY Category: Incomplete Case Information**

- **Unexplained, No Autopsy or Death Investigation**
  - **Was an autopsy and death investigation done?**
    - **No/Unknown**
      - **Unexplained, Incomplete Case Information**
    - **Yes**
      - **Unexplained, Possible Suffocation with Unsafe Sleep Factors**

**Hypertext Reference:**
- SDY Category: Incomplete Case Information: 3, 5, 13, 14, 17
- Unexplained, No Autopsy or Death Investigation: 14
- Unexplained, Incomplete Case Information: 18
- Unexplained, Possible Suffocation with Unsafe Sleep Factors: 23
- Unexplained, Unsuffocation: 24, 25
- Explained, Suffocation with Unsafe Sleep Factors: 3, 14, 25, 26
- Explained, Suffocation: 18

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**SDY Category: Incomplete Case Information**

- **Unexplained, Incomplete Case Information**
  - **Were all of the following completed during autopsy: toxicology, any imaging, and pathology (including histology, microbiology or other pathology)?**
    - **No/Unknown**
      - **Unexplained, Incomplete Case Information**
    - **Yes**
      - **Unexplained, Unsuffocation**

**Hypertext Reference:**
- Was there evidence of unsafe sleep factors when the infant was found? 19, 21, 22
- Safe sleep includes: supine, in crib, bassinet, or portable crib, with nothing in the crib but a safety approved mattress with fitted sheet. An infant placed supine and found prone, no matter his/her age or stage of development should continue down the algorithm.

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**SDY Category: Incomplete Case Information**

- **Unexplained, Incomplete Case Information**
  - **Is there detailed information about the location (e.g. adult bed, couch, etc.) AND position (e.g. prone, supine, side) in which the infant was found?**
    - **No/Unknown**
      - **Unexplained, Incomplete Case Information**
    - **Yes**
      - **Unexplained, Unsuffocation**

**Hypertext Reference:**
- Was there evidence of a full or partial obstruction of the airway (nose, mouth, neck and/or chest)? 19
- The team does not have to know the singular item that obstructed the airway. The following are acceptable examples: infant prone in bassinet on top of an adult sized pillow, infant face down on an adult bed, multiple/layered items identified (e.g., a mattress, sheet and blanket), and supine infant with blanket overhead even with unknown blanket weight.

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**SDY Category: Incomplete Case Information**

- **Unexplained, Incomplete Case Information**
  - **Was there evidence of what obstructed the airway when found (e.g., blanket, pillow and blanket, adult bed)?** 19
  - The team does not have to know the singular item that obstructed the airway. The following are acceptable examples: infant prone in bassinet on top of an adult sized pillow, infant face down on an adult bed, multiple/layered items identified (e.g., a mattress, sheet and blanket), and supine infant with blanket overhead even with unknown blanket weight.

**Hypertext Reference:**
- Were there all of the following?
  - Non-conflicting and reliable witnessed account — Can come from a description like “Father reported…” or “Mother saw…”, doll reenactment, or very clear complete detailed description
  - No other potentially fatal findings or concerning conditions
  - An age/developmental stage that made suffocation feasible (e.g., a mobile 11 month old unlikely to suffocate due to position alone)
  - Strong evidence of full external obstruction when found (e.g., report of full obstruction of nose and mouth, and/or external compression of the neck or chest)

**SDY Category: Explained Suffocation**

- **Explained, Suffocation with Unsafe Sleep Factors**
  - **Which mechanism(s) explains suffocation or possible suffocation?**
    - **Soft Bedding**
    - **Wedging**
    - **Overlay**
    - **Other**

**Hypertext Reference:**
- Explained, Suffocation with Unsafe Sleep Factors: 3, 14, 25, 26
- Explained, Suffocation: 18
- Explained, Possible Suffocation: 24, 25
SDY Case Registry Algorithm - Step Three

**Cases from Steps 1 and 2**

Autopsy Done?\(^{28}\)

- Yes
  - Does review of case records indicate a clear cardiac or non-epilepsy-related neurological\(^{29}\) cause?
    - Yes
      - **Explained, Cardiac**
    - No
      - **Explained, Neurological (non-epilepsy related)**
  - No
    - **Unexplained, Possible Cardiac**
    - **Unexplained, SUDEP**
    - **Unexplained, Possible Cardiac and SUDEP**
    - **Explained, Other 3, 5, 15-17**

- No
  - **Unexplained, Incomplete Case Information 3, 5, 13, 17**

#1) Child had *one or more* of the following:

- Family history in only siblings, parents, aunts, uncles, first cousins, or grandparents of:
  - Potentially fatal cardiac conditions (e.g., cardiomyopathy, arrhythmia)
  - Sudden unexpected death from birth to age 50
- Personal history of a cardiac diagnosis (e.g., intracardiac surgery for congenital heart disease, or diagnoses including hypertrophic cardiomyopathy, Long QT syndrome or Tetralogy of Fallot)
- Factors present at death suggestive of cardiac death (e.g., death during or following intense exertion, driver in a single car accident, drowning of a child who knew how to swim, emotional or auditory stimuli at time of event including fear, anger, alarm clock, phone ringing)

#2) Child had a history of epilepsy/seizure disorder with or without evidence of a seizure\(^{12}\) at the time of death

#3) There is a clear explained cause of death\(^{15}\)

- Only #1 is true
- Only #2 is true
- Both #1 and #2 are true
- Strong evidence that #3 is true\(^{30}\)
- None are true or any are unknown

Was the death sudden\(^1\) and unexpected\(^2\)?

- Yes
  - **Unexplained Death**\(^{31}\)
- No
  - **Explained, Excluded 3, 5, 13, 17, 32**
- Unknown
  - **Unexplained, Incomplete Case Information 3, 5, 13, 17**
SDY Case Registry Algorithm - Appendix

Was the child < 20 years of age and a resident of the funded state/jurisdiction?  
Yes  
No  
Explained, Excluded3, 4, 5

During6 the autopsy and initial death investigation7, was the death any of the following?  
• Result of an external cause that was the only and obvious reason for the fatal injury8  
• Homicide9  
• Suicide  
• Intentional overdose of drugs10  
• Terminal illness11 in which the death was reasonably expected to occur within 6 months  
Yes  
No  
Explained, Excluded3, 4, 5

Was the death any of the following?  
• Unexplained (e.g., unknown, undetermined, SIDS, SUID, SUDC, SUDEP)  
• Result of an external cause was NOT the obvious and only reason for the fatal injury (include drownings among children ≥5 years of age, infant suffocations and drivers in motor vehicle crashes)8  
• Neurological cause12  
• Cardiac cause  
• Condition unlikely to cause death suddenly (e.g., obesity, cerebral palsy, complications of X)  
Yes  
No

Did the death present as sudden1 and unexpected2?  
Yes  
Case Continues to Step 2 (< 1 year of age) or Step 3 (≥ 1 year of age)  
No  
Explained, Other3, 5, 13-17  
Explained, Excluded3, 4, 5
Footnotes
1. Sudden = Death within 24 hours of first symptom, or death in the initial hospitalization after resuscitation from a cardiac event.
2. Unexpected = Death of someone who was believed to be in good health, or have a stable chronic condition or acute illness that would not be expected to cause death.
3. No consent necessary, but if consent was obtained send it and the sample in.
4. Answer no to N1.
5. Retain all data entered.
6. This includes the initial autopsy results and death investigation; do not wait for the toxicology results.
7. Death investigation = Any agency obtaining information about the circumstances of the death; this does not need to include a visit to the scene.
8. Cases in which the underlying cause of the fatal event (e.g., drowning among children ≥5 years, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin should not be considered the ‘result of an external cause that was the obvious and only reason for the fatal injury’ and should continue to Step 2 or 3. Drownings among children <5 years should be excluded.
9. Homicide = Intention to kill, not by official manner of death or if charges were filed (e.g., this excludes accidental unsafe sleep cases where charges were filed against the parents).
10. Include cases of accidental overdoses, medical treatment mishaps and adverse medication effects.
11. Terminal Illness = Diagnosis prior to death that is incurable and irreversible.
12. Exclude status epilepticus - categorize status epilepticus as Explained Other, no Advanced Review necessary.
14. No Advanced Review necessary.
15. Excludes infant suffocation cases; includes status epilepticus at the time of death.
16. Explained Other needs to be one definable cause, not “Complications of…” . If the cause cannot be identified specifically and supported by autopsy evidence then it is not an explained cause of death and should be categorized as Unexplained Infant Death/SUID or Unexplained Child Death.
17. Enter at a minimum the data elements of age, sex, cause of death and category in the Case Reporting System.
18. Autopsy must include an internal exam.
19. When there is conflict:
   • Use the expertise of your multi-disciplinary team and ALL of the evidence to figure out what really happened.
   • If there is enough evidence for the team to resolve the conflict, then document the team’s decision in the narrative and continue down the algorithm.
   • If the evidence does not reveal a clear resolution, then document the sustaining conflict and treat it as an unknown.
20. Consideration of lividity may be useful in verifying position, but lack of information on lividity does not make the case incomplete. Lividity that indicates supine positioning could be from flipping the infant after death and should be considered cautiously.
21. Answer no, if the infant was not sleeping.
22. Infant put in car seat...
   • To sleep, should continue down the algorithm
   • To travel, not sleep, with soft objects or loose bedding, should continue down the algorithm
   • To travel, not sleep, with no soft objects or loose bedding, should be categorized as Unexplained, No Unsafe Sleep Factors
Footnotes

23. Includes infants who were witnessed going unresponsive.

24. Includes infants whose airways were obstructed by a Consumer Product Safety Commission approved mattress used as recommended in a crib, portable crib, or bassinet.

25. Needs to be assigned at least one mechanism using the following definitions (the following are examples, not a comprehensive list):

- **Soft bedding:** when an infant’s airway is obstructed by a blanket, sheet, pillow, couch or recliner cushions, or other soft objects of loose bedding that are part of the immediate sleep environment.
  ➞ Nose and/or mouth obstructed at the intersection of soft bedding (e.g., where a pillow and mattress meet, where the back and seat of a couch meet)

- **Wedging:** when an infant’s airway is obstructed as a result of being stuck or trapped between inanimate objects.
  ➞ Wedged with face clear (e.g., in gap, face above mattress), chest/neck obstruction only

- **Overlay:** when a person rolls on top of or against an infant obstructing the infant’s airway.
  ➞ Overlay with face clear (obstructed chest/neck only)
  ➞ Face into person with or without chest/neck obstruction
  ➞ Infant pinned between person and couch, facing person
  ➞ Note: Surface sharing only is not enough evidence for overlay. An overlay needs to be witnessed (e.g., someone waking up on top of an infant, or someone seeing someone else on top of an infant).

- **Other:** when an infant’s airway is obstructed by something in the sleep environment other than soft bedding, overlay or wedging like a plastic bag.
  ➞ Note: Other should not be selected for unsafe sleep factors like prone positioning or impaired caregivers.

- **Multiple mechanisms:**
  ➞ Wedging and Soft Bedding
    * Wedged with face into soft bedding (mattress, pillow, blankets), nose and mouth obstructed
    * Wrapped/entangled in blankets and wedged
  ➞ Overlay and Soft Bedding
    * Overlay with nose/mouth obstructed by soft bedding (mattress, pillow, blankets)
    * Infant pinned between person and couch, facing couch

26. Examples include:

- A 1-month-old infant found face down in a pillow with her nose and mouth fully obstructed.
- A 2-month-old infant found with her head and face wedged between the cushions at the back of the sofa.
- A 4-month-old infant found lifeless in a twin bed with his head and body underneath his mother.


28. If extensive testing was performed during the same hospitalization as the death and identifies a cause of death, the Advanced Review Team can decide to answer “yes” to this question, even if an autopsy was not performed. Justification and explanation of why the Advanced Review Team made their decision needs to be documented in the Case Reporting System in the Notes from Advanced Review Meeting.

29. Includes first seizure at time of death with neurological process that could have independently led to death found on autopsy (e.g., large subarachnoid hemorrhage, meningitis, or encephalitis).

30. If Explained Other is selected, and #1 or #2 are also present, please document, in the Case Reporting System in the Notes from Advanced Review Meeting, the evidence supporting your choice of Explained Other over the other categories.

31. Includes all Sudden Unexpected Infant Death (SUID) cases including those the Advanced Review Team deems to be suffocation.

32. The combination of yes to N1 and the category of Excluded should only be used when a case looked like it was sudden and unexpected until the experts at the Advanced Review Team uncovered that it was not.