SDY Case Registry Algorithm-Step One

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?
    - No
      - Excluded\(^3\)
    - Yes
      - During the autopsy and initial investigation\(^7\), was the death any of the following?
        - Accident in which the external cause was the obvious and only reason for the death\(^4\)
        - Homicide
        - Suicide
        - Accidental or intentional overdose of drugs even if this caused cardiac or respiratory arrest with no prior history of other possible chronic disease or autopsy findings suggestive of another cause
        - Terminal illness\(^5\) in which the death was reasonably expected to occur within 6 months
      - No
        - Case Continues to Step 2 (< 1 year of age) or Step 3 (≥ 1 year of age)

- No
  - Excluded\(^3\)

During the death investigation, do the following:
- Obtain triggers, symptoms and child’s and family’s medical history
- Complete an autopsy per the SDY Autopsy Guidance
- Save an EDTA (purple top) tube of blood and liver sample
- Attempt and, if obtained, send consent to the Data Coordinating Center
- Send blood sample to the biorepository

\(^1\) Death within 24 hours of first symptom or death in hospital after resuscitation from a cardiac event.

\(^2\) Death of someone who was believed to be in good health or had a stable chronic condition or had an acute illness that would not be expected to cause death.

\(^3\) No consent necessary, but if consent was obtained, send in sample and consent, and retain all data entered into the Case Reporting System (CRS).

\(^4\) Cases in which the underlying cause of the accident (e.g. drowning, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin should not be considered an ‘accident in which the external cause was the obvious and only reason for the death’ and should continue to Step 2 or 3.

\(^5\) Diagnosis prior to death that is incurable and irreversible.

\(^6\) At a minimum follow state/local Child Death Review protocol; no Advanced Review necessary.

\(^7\) Investigation is defined as any attempt, by any agency, to seek information about the death.
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 with potentially contributing unsafe sleep factors.

Yes

Unexplained, No Autopsy or Death Scene Investigation

No

Autopsy and death scene investigation done?

Yes

No

Unexplained, Incomplete Case Information

Detailed information about where and how the body was found (position, sleep surface, soft bedding), AND toxicology, x-ray, and pathology (including histology, microbiology or other pathology such as genetic testing, but not solely gross examination) were performed and documented.

Yes

No

Unexplained, No Unsafe Sleep Factors¹,*

Any unsafe sleep factors? Examples: soft objects or loose bedding (e.g. pillow, blanket, bumper pads), not in a crib, portable crib or bassinette, shared sleep surface, found non-supine, or other suffocation or strangulation hazards.

Yes

No

Unexplained, Unsafe Sleep Factors¹,*

Factors for suffocation present? Examples: face pressed into or obstructed by soft bedding (e.g., pillow, egg crate, sleeping bag, couch), witnessed overlay, entrapment or wedging.

Yes

No

Unexplained, Possible Suffocation with unsafe sleep Factors¹,*

Explained, Suffocation with unsafe sleep factors

Yes

No

Explained, Exclude*

Was there strong evidence of full, external obstruction of both nose and mouth, or external neck or chest compression WITH a reliable and non-conflicting witnessed account AND no other potentially fatal findings or concerning conditions AND suffocation is probable given the infant age and likely stage of development?

Which primary mechanism explains suffocation or possible suffocation?

- Soft Bedding
- Wedging
- Overlay
- Other

Any unsafe sleep factors? Examples: soft objects or loose bedding (e.g. pillow, blanket, bumper pads), not in a crib, portable crib or bassinette, shared sleep surface, found non-supine, or other suffocation or strangulation hazards.

¹Category includes cases that may or may not have other potentially fatal findings, concerning conditions, or competing cause of death, but how these factors contribute to death is uncertain.

²If consent was obtained, send in sample and consent, and retain all data entered into the Case Reporting System (CRS).

*Excluded, No Unsafe Sleep Factors, Unsafe Sleep Factors, and Possible Suffocation continue to Step 3

Explained Suffocation is the terminal category for both SUID and SDY, should not continue to Step 3 and no consent necessary
SDY Case Registry Algorithm Step Three

Cases from Steps 1 and 2

Autopsy Done?

Yes

Does review of case records indicate a clear cardiac or non-epilepsy-related neurological\(^1\) cause?

No

Explained Cardiac

Explained Neurological (non-epilepsy-related)

Incomplete Case Information

Possible Cardiac

SUDEP

Possible Cardiac & SUDEP

Explained Other\(^2,^3\)

Unexplained Infant Death/ SUID\(^4\)

Unexplained Child Death

Is there enough case information from the investigation continue with categorization? Case information can come from, but is not limited to, the following:

- Autopsy
- Death scene investigation
- Triggers
- Symptoms
- Family’s medical history
- Child’s medical history

No

Yes

Only #1 is true

Only #2 is true

Both #1 and #2 are true

Neither #1 nor #2 is true

Do records indicate a clear explained other cause of death?\(^5\)

Yes

No

Child age 1 or over?

Yes

No

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

- Family history of potentially fatal cardiac conditions (heritable conditions)
- Personal history of cardiac issues
- Factors present at death suggestive of cardiac death (e.g. death following intense exertion)

#2) Child had one of the following:

- Prior history of epilepsy/non-febrile seizures/ convulsions
- First seizure at time of death with non-fatal structural brain lesions identified at autopsy (e.g. benign tumor, cortical dysplasia, etc.)
- First seizure at time of death with a normal brain on autopsy

Only #1 is true

Only #2 is true

Neither #1 nor #2 is true

\(^1\)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).

\(^2\)No consent necessary, but if consent was obtained, send in sample and consent, and retain all data entered into the Case Reporting System (CRS).

\(^3\)Does not include infant suffocation cases.

\(^4\)Include all Sudden Unexpected Infant Death (SUID) cases including those the Advanced Review team deems to be suffocation.

Last updated April 2016
APPENDIX: COMPLETED WHEN IDENTIFYING CASES USING VITAL RECORDS FOR CASE ASCERTAINMENT CHECK

SDY Case Registry Algorithm-Appendix

Was the child < 20 years of age and a resident of the funded state/jurisdiction?  
Yes →  
No → Excluded

Was the death any of the following?  
- Accident in which the external cause was the obvious and only reason for the death
- Homicide
- Suicide
- Accidental or intentional overdose of drugs even if this caused cardiac or respiratory arrest with no prior history of other possible chronic disease or autopsy findings suggestive of another cause
- Terminal illness in which the death was reasonably expected to occur within 6 months

No →  
Yes → Excluded

Was the death any of the following?  
- Unexplained (e.g. unknown, undetermined, SIDS, SUID, SUDC, SUDEP)
- Accident in which the external cause was NOT the obvious and only reason for the death
- Neurological cause
- Cardiac cause
- Condition unlikely to cause death suddenly (e.g. obesity, cerebral palsy)

No →  
Yes → Case Continues to Step 2 (< 1 year of age) or Step 3 (≥ 1 year of age)

Did the death present as sudden and unexpected?  
Yes → Explained Other

No → Excluded

1Death within 24 hours of first symptom or death in hospital after resuscitation from a cardiac event.
2Death of someone who was believed to be in good health or had a stable chronic condition or had an acute illness that would not be expected to cause death.
3No consent necessary, but if consent was obtained, send in sample and consent, and retain all data entered into the Case Reporting System (CRS).
4Cases in which the underlying cause of the accident (e.g. drowning, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin should not be considered an ‘accident in which the external cause was the obvious and only reason for the death’ and should continue to Step 2 or 3.
5Diagnosis prior to death that is incurable and irreversible.
6At a minimum follow state/local Child Death Review protocol; no Advanced Review necessary.