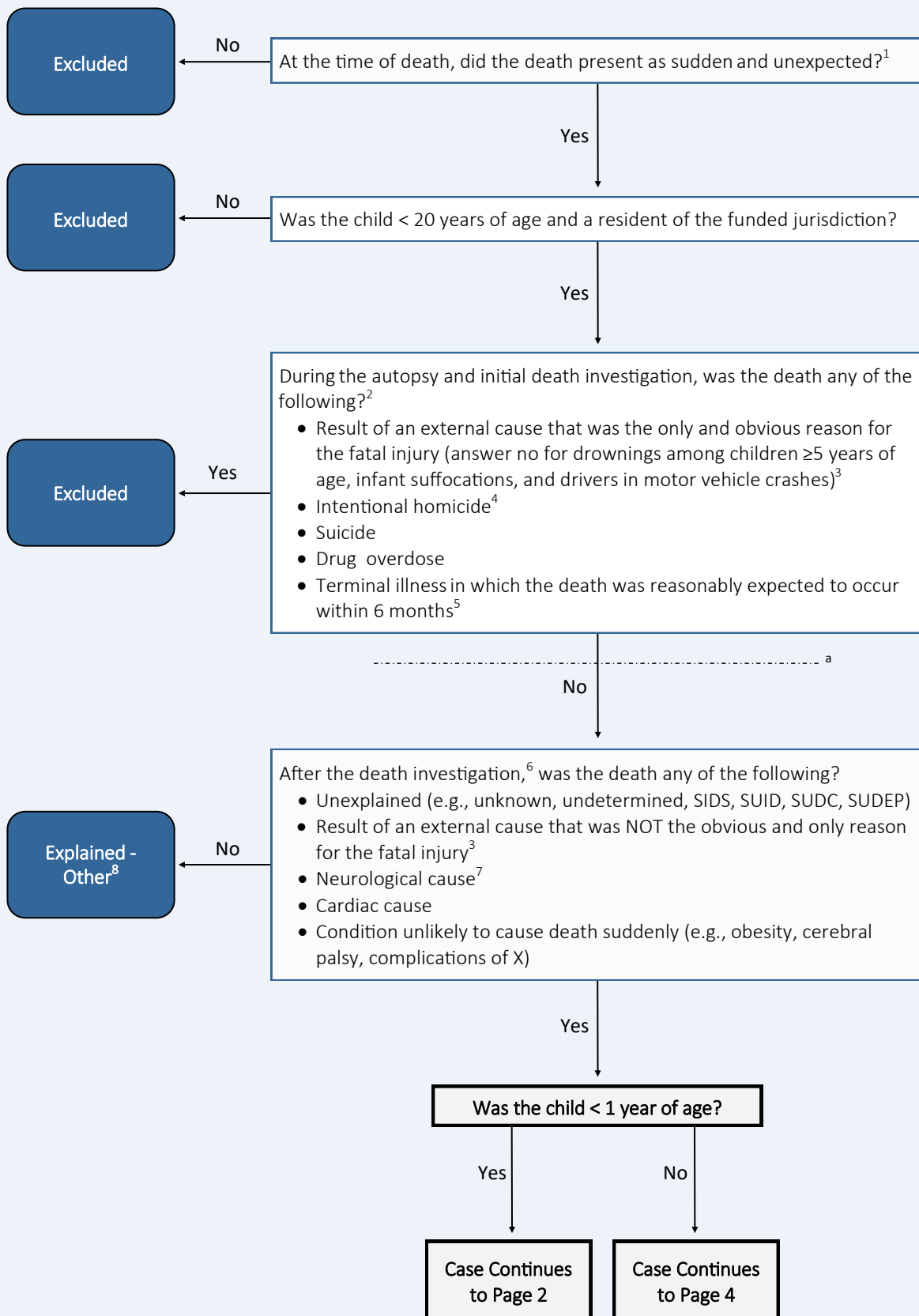


SUID and SDY Case Registry Algorithm

Page 1 - Inclusion Criteria

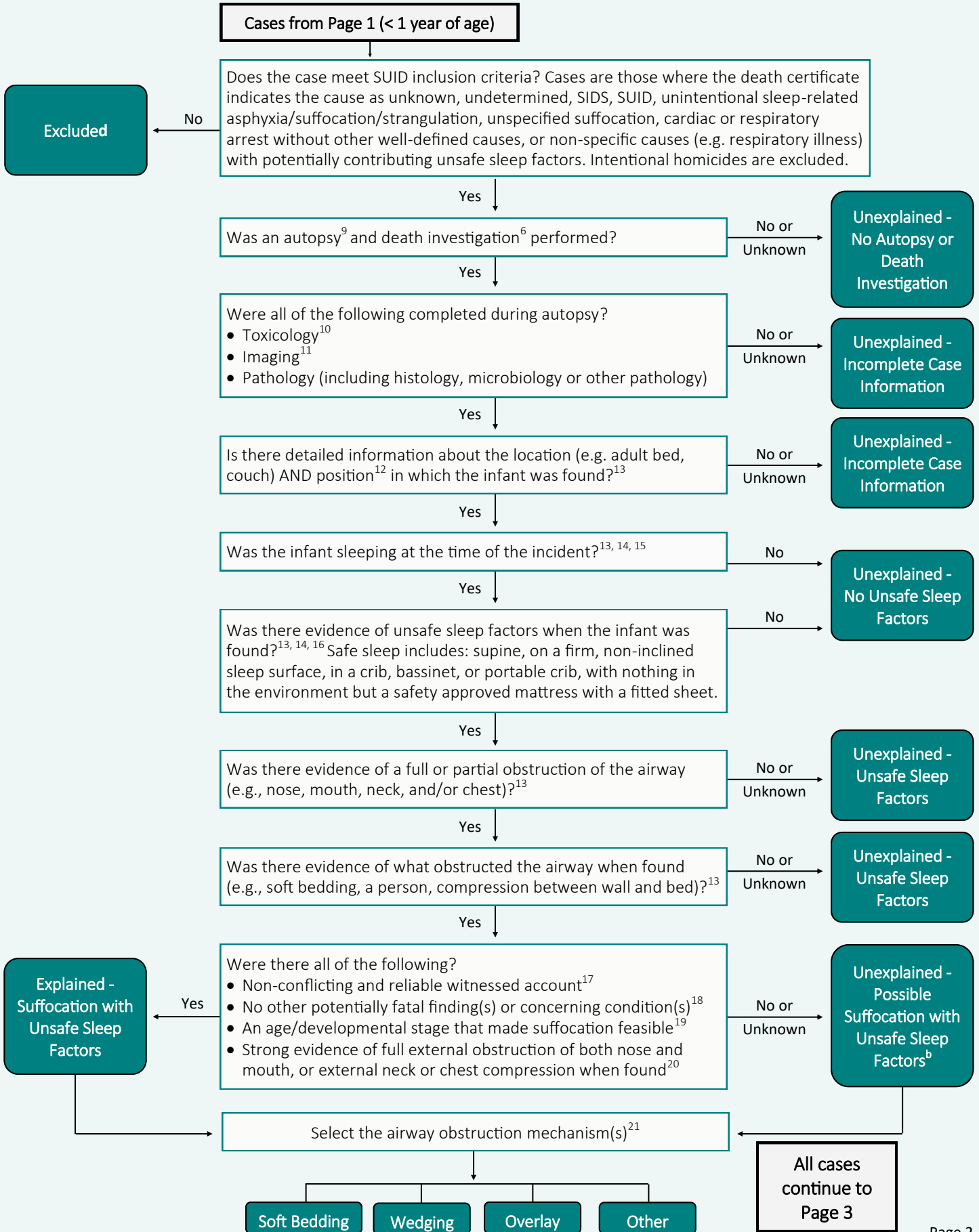
Completed in jurisdictions participating in the SDY Component



SUID and SDY Case Registry Algorithm

Page 2 - SUID Inclusion Criteria and Categorization

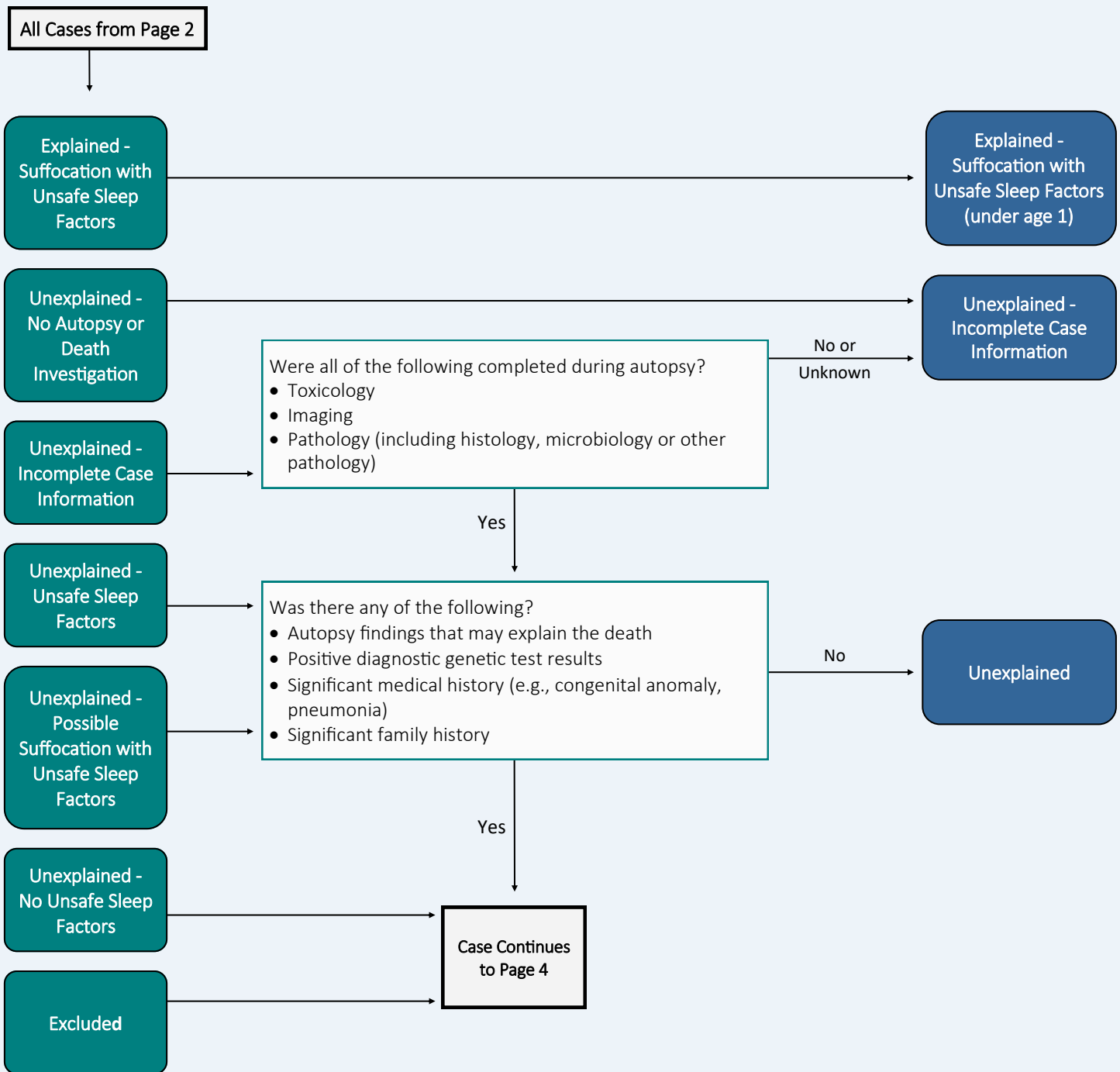
Completed in all participating jurisdictions by a multidisciplinary team



SUID and SDY Case Registry Algorithm

Page 3 - SUID/SDY Categorization

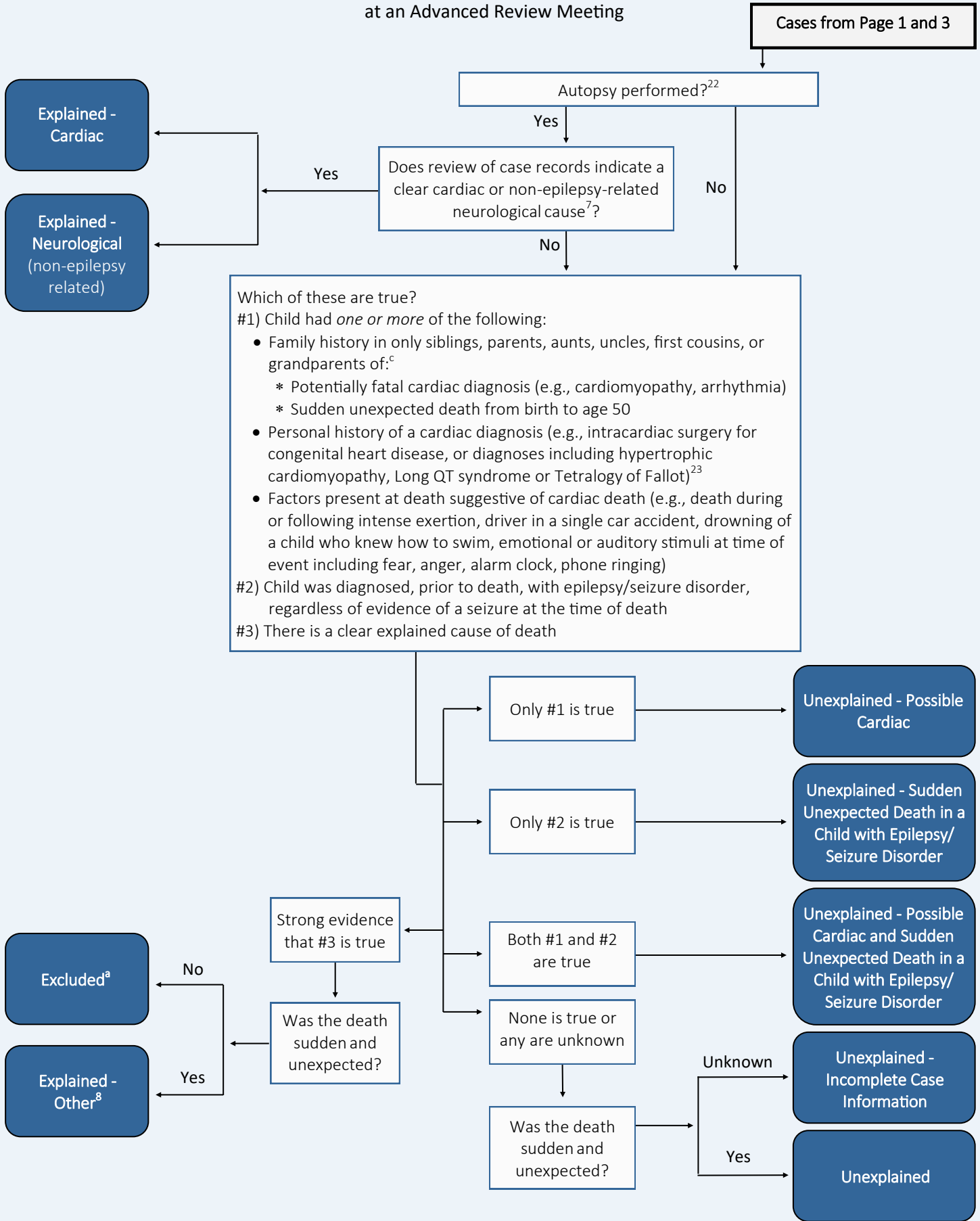
Completed in jurisdictions participating in the SDY Component



SUID and SDY Case Registry Algorithm

Page 4 - SDY Categorization

Completed in jurisdictions participating in the SDY Component at an Advanced Review Meeting



SUID and SDY Case Registry Algorithm Footnotes

Process Instruction Footnotes

- Categories are documented in section N of the Pediatric National Fatality Review-Case Reporting System (NFR-CRS).
 - * All infants (<1 year of age) will be assigned a SUID category (teal boxes).
 - * All cases (0-max age of jurisdiction's Child Death Review) will be assigned an SDY category (blue boxes) in jurisdictions participating in the SDY Component. Therefore, infants in these jurisdictions will be assigned both a SUID and SDY category.
- Submit all consents and consented samples and retain all entered data regardless of the final category.
- **a.** Select 'No' for N1 for cases categorized above this line on page 1. Select 'Yes' for N1 for cases categorized below the line, except when the Advanced Review Team (page 4) determines the case was not sudden or unexpected. In those situations, categorize the case as Excluded and select N1 in accordance with jurisdictional guidance.
- For all cases with 'Yes' to N1 selected, enter at a minimum the data elements of age, cause of death, and category in the NFR-CRS.
- Document (in the NFR-CRS narrative and/or Notes from Advanced Review) the details that led the team to the final categories, especially if it contradicts the algorithm or falls under an algorithm caveat.
- **b.** If the airway was fully obstructed, indicate in the NFR-CRS narrative why Unexplained - Possible Suffocation was selected instead of Explained - Suffocation (e.g., competing cause of death, lack of evidence of a full external airway obstruction, details about why the witness was conflicting or not reliable).
- Cases assigned an SDY category on pages 1-3 do not need to go to Advanced Review.

Advanced Review (page 4)

- The category of Explained - Suffocation with Unsafe Sleep Factors should be assigned according to page 2 of the algorithm. SUID cases that were categorized as Explained - Suffocation by the Child Death Review Team receive the SDY category of Explained Suffocation with Unsafe Sleep Factors (under age 1) and do not proceed to Advanced Review. If the Advanced Review Team determines there is sufficient evidence to categorize a SUID case as Explained - Suffocation per page 2, communicate this decision to the Child Death Review program and, if in accordance with the algorithm, update the category in the NFR-CRS.
- If a case is assigned an Explained SDY category by a full Advanced Review Team (including clinicians and a pathologist) (page 4), the SUID category should be Excluded. Communicate this with the Child Death Review program, update the SUID category in the NFR-CRS, and document the reasons for the change in the Notes from Advanced Review. If no pathologist is present at the Advanced Review meeting, one should be consulted before any changes are made.

SUID and SDY Case Registry Algorithm Footnotes

Process Instruction Footnotes Continued

- Use the following list to guide Advanced Review discussion and detailed documentation in the NFR-CRS variables (sections H and I1) and narrative for drowning cases.
 - * Child's age
 - * Child's swimming ability
 - * Was the drowning witnessed or unwitnessed?
 - Were other children present?
 - What happened to them?
 - * Details of the body of water (i.e., what kind of body of water)
 - * Risks in the water (e.g., deep water, dark water, rushing water)
 - * Family history (specifically in siblings, parents, aunt, uncles, first cousins, or grandparents) of:
 - Sudden death <50 years old
 - Irregular heart rhythms
 - Unexplained fainting
 - Motor vehicle accidents
 - Drowning?
- c. If there is a positive family history, document the diagnosis or type of event, which relative, and relative's age at death in I1f in the NFR-CRS.

Definition Footnotes

1. Sudden is defined as a death within 24 hours of first symptom, or death during the initial hospitalization after resuscitation from a cardiac event or anoxic event in a sleep environment. Unexpected is defined as a 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.
2. This includes the initial autopsy results and death investigation; do not wait for the toxicology results.
3. Cases in which the underlying cause of the fatal event (e.g., drowning among children ≥ 5 years of age, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin and should not be considered the 'result of an external cause that was the obvious and only reason for the fatal injury'.

Drownings

Drownings should be categorized as Excluded if they occurred among children <5 years of age or if more than 1 person drowned due to the same dangerous conditions (e.g., flood, strong undertow). All other drownings should be included.

SUID and SDY Case Registry Algorithm Footnotes

Definition Footnotes Continued

Motor Vehicle Crashes

Crashes not in a car or truck (e.g., ATV) should be categorized as Excluded. Motor vehicle crashes can be categorized as Explained - Other on page 1 only when information is known for the checklist below and the information points to a true accident. Each point must be thoroughly documented in the NFR-CRS narrative:

- Circumstances of the crash including road conditions (e.g., dry, icy), time of day and speed.
 - Condition of the driver including if they were distracted, sleep deprived, intoxicated, upset, an inexperienced at driving, or feeling sick in the day/hours leading up to the event.
 - Medical history of the driver including if they had any history of fainting, seizures, arrhythmia or heart palpitations.
 - Family medical history of the driver including young sudden death (< 50 years old), irregular heart rhythms, unexplained fainting, motor vehicle crashes or drowning.
4. The determination of homicidal intention should not be based solely on the official manner of death or whether charges were filed; accidental unsafe sleep cases where homicide charges were filed against the caregiver should not necessarily be considered intentional.
 5. Terminal Illness is defined as a diagnosis prior to death that is incurable and irreversible.
 6. Death investigation is defined as any agency obtaining information about the circumstances of the death; this does not need to include a visit to the scene or have complete information.
 7. Neurological cause is defined as a neurological condition found on autopsy that could have independently led to death (e.g., large subarachnoid hemorrhage, meningitis, or encephalitis) or that may have caused first seizure at time of death. Status epilepticus should be categorized as Explained - Other.
 8. Explained - Other is assigned when there is one specific cause supported by evidence from the death investigation (e.g., not "Complications of..."). Explained - Other does not include explained infant suffocation and does include status epilepticus.
 9. Autopsy must include an internal exam.
 10. Toxicology needs to have been conducted upon post-incident admission to hospital or during autopsy to reflect the child's status at the time of the incident.
 11. Imaging includes any of the following: X-ray, ultrasound, computed tomography (CT), magnetic resonance imaging (MRI), and other imaging of bones; photographs alone are not sufficient to continue down the algorithm.
 12. Examples of detailed information about the position in which the infant was found include prone, supine, or feet down wedged between wall and mattress. 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.

SUID and SDY Case Registry Algorithm Footnotes

Definition Footnotes Continued

13. Evidence should be based on witness' observation and detailed findings documented during the death investigation not on assumption. When there is conflict within the account:
 - Use the expertise of your multi-disciplinary team to reach consensus and consider ALL of the evidence to determine the most accurate account of events.
 - If there is enough evidence for the team to resolve the conflict, then document the team's decision in the NFR-CRS 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.
14. If unknown, categorize as Incomplete Case Information.
15. If the infant was placed in a sleep environment to sleep, and the death was unwitnessed, the infant can be presumed to be asleep.
16. Unsafe sleep factors as defined by the 2022 Updated Recommendations for a Safe Infant Sleeping Environment to Reduce the Risk of Sleep-Related Infant Deaths (Moon RY, et al.). A car seat is not considered a safe sleep environment, unless the infant was put in the car seat to travel (not sleep) with no soft objects or loose bedding. An infant placed supine and found prone, no matter their age or stage of development, is considered to have unsafe sleep factors.
17. The witness is uncompromised, and the account is consistent and does not conflict with other accounts or physical evidence. See NFR-CRS data dictionary for more detail.
18. Other potentially fatal finding(s) or concerning condition(s) should be severe enough to independently cause death. However, in these cases, their contribution to the death is uncertain, creating doubt that the airway obstruction alone was the cause (e.g. drug toxicity, severe respiratory illness).
19. Example: A premature newborn is unlikely to have the strength to free their airway if obstructed.
20. The following are not considered strong evidence of a full external obstruction of the airway when found:
 - Obstruction by a Consumer Product Safety Commission approved infant mattress (covered by only a tight fitted sheet) in working condition that was used as recommended
 - Obstruction by only a chin to chest position even if the position is forced by something firm (e.g., a nursing pillow)
21. Needs to be assigned at least one mechanism using the following definitions (examples are included but are 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 or loose bedding that are part of the immediate sleep environment.
 - Wedging: when an infant's airway is obstructed as a result of being stuck or trapped between inanimate objects.
 - Overlay: when an infant's airway is obstructed by a person or animal
 - * 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).
 - * Document what part of the person who overlaid was on top of what part of the infant in the NFR-CRS narrative.

SUID and SDY Case Registry Algorithm Footnotes

Definition Footnotes Continued

- 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.
 - * Other should not be selected for unsafe sleep factors like prone positioning or impaired caregivers.
 - Single mechanism examples
 - * Soft Bedding Only
 - Infant supine with blanket covering nose and/or mouth
 - Infant prone with face into the intersection of soft bedding (e.g., where a pillow and mattress meet, where the back and seat of a couch meet)
 - * Wedging Only
 - Infant stuck or trapped with chest and/or neck between wall and bedframe, and nose and mouth unobstructed
 - * Overlay Only
 - Infant supine with torso (chest compressed) under caregiver’s shoulder, nose and mouth unobstructed
 - Infant found face down with nose and mouth into caregiver’s chest
 - Infant found pinned between caregiver and the back of couch, facing caregiver
 - Multiple mechanisms examples
 - * Wedging and Soft Bedding
 - Infant stuck or trapped between mattress and wall with face into soft bedding (mattress, pillow, blankets), nose and mouth obstructed
 - * Overlay and Soft Bedding
 - Infant prone with torso under caregiver’s shoulder, nose and mouth into soft bedding (mattress, pillow, blankets)
 - Infant found pinned between caregiver and the back of couch, facing back of couch
22. 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 should be documented in the NFR-CRS in the Notes from Advanced Review Meeting.
23. Patent foramen ovale (PFO) and patent ductus arteriosus (PDA) are not severe enough to be included a cardiac diagnosis in this case.

SUID and SDY Case Registry Algorithm Footnotes

References

- Parks SE, Erck Lambert AB, Hauck FR, Cottengim CR, Faulkner M, & Shapiro-Mendoza CK. Explaining Sudden Unexpected Infant Deaths, 2011-2017. *Pediatrics*. 2021;147(5): e2020035873.
- Shapiro-Mendoza CK, Camperlengo L, Ludvigsen R, et al. Classification system for the Sudden Unexpected Infant Death Case Registry and its application. *Pediatrics*. 2014;134:e210-e219.
- Burns KM, Bienemann L, Camperlengo L, Cottengim C, Covington TM, Dykstra H, Faulkner M, Kobau R, Erck Lambert AB, MacLeod H, Parks SE, Rosenberg E, Russell MW, Shapiro-Mendoza CK, Shaw E, Tian N, Whittemore V, Kaltman JR; Sudden Death in the Young Case Registry Steering Committee. The Sudden Death in the Young Case Registry: Collaborating to Understand and Reduce Mortality. *Pediatrics*. 2017 Mar;139(3):e20162757. doi: 10.1542/peds.2016-2757. PMID: 28228502; PMCID: PMC5330401.