# Understanding three approaches to reporting sudden unexpected infant death in the USA

**Alexa B Erck Lambert**[1], **Sharyn Parks**[1], **Kristin Bergman**[2], **Carri Cottengim**[1], **Andrew Woster**[3], **Esther Shaw**[4], **Hongyan Ma**[5], **Rachel Heitmann**[6], **Tiffany Riehle-Colarusso**[1], **Carrie Shapiro-Mendoza**[1]

[1]Division of Reproductive Health, Centers for Disease Control and Prevention, Atlanta, Georgia, USA

[2]Department of Maternal and Child Health, Gillings School of Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

[3]Violence and Injury Prevention, Colorado Department of Public Health and Environment, Denver, Colorado, USA

[4]Center for Child and Family Health, Michigan Public Health Institute, Okemos, Michigan, USA

[5]Division of Family Health and Wellness, Tennessee Department of Health, Nashville, Tennessee, USA

[6]Injury Prevention and Detection, Tennessee Department of Health, Nashville, Tennessee, USA

## Abstract

**Introduction—**In the USA each year, there are approximately 3400 sudden unexpected infant (<1 year of age) deaths (SUID) which occur without an obvious cause before an investigation. SUID includes the causes of death (COD) undetermined/unknown, sleep-related suffocation/ asphyxia and sudden infant death syndrome (SIDS); these are often called SUID subtypes. Three common ways SUID subtypes are grouped (SUID subtype groups) include International Classification of Diseases (ICD) Codes, SUID Case Registry Categories or Child Death Review

(CDR)-Assigned Causes. These groups are often used to monitor SUID trends and characteristics at the local, state and national levels. We describe and compare the characteristics of these three SUID subtype groups.

**Discussion**—SUID subtype groups are distinct and not directly interchangeable. They vary in purpose, strengths, limitations, uses, history, data years available, population coverage, assigning entity, guidance documentation and information available to assign subtypes.

**Conclusion**—Making informed decisions about which SUID subtype group to use is important for reporting statistics, increasing knowledge of SUID epidemiology and informing prevention strategies.

## INTRODUCTION

Each year in the USA, approximately 3400 sudden unexpected infant (<1 year of age) deaths (SUID) occur without an obvious cause before an investigation.[1][2] SUID includes infant deaths with cause-of-death (COD) determinations reflecting unknown causes, sleep-related suffocation/asphyxia and sudden infant death syndrome (SIDS). We will refer to these causes as SUID subtypes. In the USA, three ways SUID subtypes are grouped (hereafter called SUID subtype groups) include International Classification of Diseases (ICD) Codes, Centers for Disease Control and Prevention's (CDC) SUID Case Registry Categories or Child Death Review (CDR)-Assigned Causes. These SUID subtype groups have different purposes and definitions and are used to monitor SUID trends and characteristics at the local, state and national levels. For example, many state CDR programmes use one or more of the three SUID subtype groups to report annual SUID rates and characteristics of deaths. The reports are used to educate decision-makers, public health agency staff and the public about SUID rates, the prevalence of risk factors and opportunities for prevention.[3–5]

While there are similarities between SUID subtype groups, they are not interchangeable. For example, due to different definitions, the ICD-10-coded subtype of Accidental Suffocation and Strangulation in Bed (ASSB) is distinct from the SUID Case Registry category Explained-Suffocation with Unsafe Sleep Factors, and each generates different population rates. In comparable data from SUID Case Registry states and jurisdictions for 2011–2017, the rate of ASSB was 27.3 per 100 000 live births while the rate of Explained-Suffocation with Unsafe Sleep Factors was 17.7 per 100 000 live births.[6] Because of these differences, it is important to have a comprehensive understanding of how data for SUID subtype groups are collected and defined when interpreting statistical data based on these groups.

To inform reporting and interpretation of SUID statistics, we describe the three SUID subtype groups: ICD Codes, SUID Case Registry Category and CDR-Assigned Cause. For each SUID subtype group, we describe the data source, availability, SUID subtypes, purpose, uses, history, data years available, population coverage, assigning entity, guidance documentation, information for assignment and other variables available (eg, death certificate and death investigation information) in the data source. Based on these descriptions, we summarise each SUID subtype group's strengths and limitations.

## DISCUSSION

Online supplemental table 1 describes each SUID subtype group and can be used as a resource to understand the distinct characteristics, uses, strengths and limitations of each group. This is key when determining which SUID subtype group to use for analysing and reporting SUID data as well as when interpreting SUID statistics. When reporting SUID statistics, it is important to describe the SUID subtype group used to facilitate improved interpretability of findings across reports.

### ICD Code Group

ICD codes were developed in 1893 and have been managed by the World Health Organisation (WHO) since 1948.[7] The codes allow for the systematic recording, analysis, interpretation and comparison of mortality data globally. Underlying COD ICD codes, assigned by the National Center for Health Statistics (NCHS) based on the COD recorded on the death certificate,[8 9] are available in national and state mortality files, including linked birth-infant death files. These files are derived from the death certificate and include all codable information from the COD section, as well as demographic data. These files are publicly accessible through NCHS (eg, downloadable files available at https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm and interactive web-based system at https://wonder.cdc.gov/).

ICD Code Group subtypes include:

- Accidental Suffocation and Strangulation in Bed (ASSB, ICD-10 code: W75)—infant deaths where the manner of death is accidental, and COD is reported as asphyxia/suffocation/strangulation with mention of terminology indicating the death occurred in bed or while sleeping.

- Other Ill-defined and Unspecified Causes of Mortality (unknown cause, ICD-10 code: R99)—infant deaths where the manner of death is natural or could not be determined, and COD is reported as unknown, undetermined or unexplained.

- Sudden Infant Death Syndrome (SIDS, ICD-10 code: R95)—infant deaths where the manner of death is natural or could not be determined, and COD is reported using terms that indicate a sudden unexpected or unexplained infant death including SIDS.

The ICD Code Group is useful when reporting aggregate SUID statistics including historical trends, especially at the national level.[10–12] However, reporting trends in SUID by ICD Code Group subtypes can be misleading due to diagnostic shifting caused by a variety of reasons; for example, a lack of criteria and definitions that are agreed on by death certifiers.[10 12–14] The ICD Code Group can also be used to report and compare overall SUID rates by jurisdiction (eg, county, state and country).[14 15]

### SUID Case Registry Category Group

Another SUID subtype grouping is available as a part of the CDC SUID Case Registry which is a multi-jurisdictional, population-based SUID surveillance system built on existing

CDR programmes.[16–18] CDC designed an algorithm to standardise the categorisation of cases in the SUID Case Registry into subtypes for epidemiological purposes.[19] SUID Case Registry Category subtypes are assigned, using the algorithm,[6 19] to each case twice. Once, by CDR programmes participating in the SUID Case Registry and those which opt to select a category; their selection is recorded in the National Fatality Review-Case Reporting System (NFR-CRS). And a second time, independently, by CDC staff who record their selection in an internal CDC database. The NFR-CRS is a web-based, standardised data collection tool to report case information available to local and state CDR programmes.[20] It is managed by the National Center for Fatality Review and Prevention (National Center) and used by the SUID Case Registry and CDR programmes to compile case information from primary data sources including, but not limited to, birth and death certificates, scene investigation reports, autopsy findings, child protective services, social services, law enforcement and medical records. The SUID Case Registry data are a subset of the larger NFR-CRS dataset. Requests can be made for NFR-CRS data and the Internal CDC Database through a National Center data application at https://www.ncfrp.org/resources/data-dissemination/.

The variable for SUID Case Registry Category Group subtype was added to the NFR-CRS in 2015.[21] As a result, all CDR teams (including jurisdictions not participating in the SUID Case Registry) have been able to select a SUID Case Registry Category Group subtype and document it in the NFR-CRS since 2015. Jurisdictions participating in the SUID Case Registry began categorising cases and recording the assigned SUID Case Registry Category Group subtype in the NFR-CRS for deaths that occurred in 2016 and onward. CDC staff began categorising cases and recording the assigned SUID Case Registry Category Group subtype in an internal CDC database for deaths that occurred in 2011 and onward. CDC regularly trains staff in participating jurisdictions on data quality and completes quality assurance checks to improve internal consistency in applying the SUID Case Registry algorithm between CDC and participating jurisdictions. As a result, agreement between the internal database and the NFR-CRS among participating jurisdictions increased from 51% in 2015 to 73% in 2018 (unpublished analysis). Because the SUID Case Registry Category Group in the NFR-CRS historically has been more broadly available than the internal CDC database, it is used more often by SUID researchers, state public health programmes and CDR programmes in reporting SUID statistics.

SUID Case Registry Category Group subtypes include[6 16]:

- Unexplained-No Death Scene Investigation (DSI) or Autopsy—SUID case with no DSI or post-mortem examination information reported.

- Unexplained-Incomplete Case Information—SUID case with DSI and autopsy information reported, and a lack of detailed information about where and how the body was found, or lack of toxicology, X-ray/imaging or pathology (eg, histology, microbiology, genetic testing).

- Unexplained-No Unsafe Sleep Factors—SUID case with a complete investigation, and the death occurred either while the infant was awake or sleeping with no unsafe factors in the sleep environment.

- Unexplained-Unsafe Sleep Factors—SUID case with a complete investigation, and the death occurred in an unsafe sleep environment but the role of the unsafe sleep environment in causing or contributing to death is uncertain; no factors that might indicate suffocation were presented (eg, airway obstruction).

- Unexplained-Possible Suffocation with Unsafe Sleep Factors—SUID case with a complete investigation, the death occurred in an unsafe sleep environment and there was evidence of at least a partial external airway obstruction; however, there was not a reliable, non-conflicting witness account, there were potentially fatal findings or concerning medical conditions present, or suffocation did not seem probable given the infant's age and likely stage of development.

- Explained-Suffocation with Unsafe Sleep Factors—SUID case with a complete investigation, the death occurred in an unsafe sleep environment, there was strong evidence of a full external airway obstruction, there was a reliable, non-conflicting witness account, there were no potentially fatal findings or concerning medical conditions present and suffocation was probable given the infant's age and likely stage of development.

For the purpose of classifying cases for inclusion in the SUID Case Registry, SUID is defined as an infant death with any of the following causes written on the death certificate: unknown, undetermined, SIDS, SUID, unintentional sleep-related asphyxia/suffocation/strangulation, unspecified suffocation, cardiac or respiratory arrest without other well-defined causes or ill-defined causes with potentially contributing unsafe sleep factors.[19] Intentional homicides are excluded. A DSI is defined as the process by which any agency obtains information about the circumstances of death. A safe sleep environment is defined as one where the infant is found supine on a firm sleep surface, including a crib, bassinet or portable crib, and the sleep surface is free of other people or animals, soft objects, loose bedding or any object that could increase the risk for suffocation or SIDS.[22]

The SUID Case Registry Category Group subtypes were developed to address inconsistent reporting practices by death certifiers and a diagnostic shift in SUID subtypes.[23] The SUID Case Registry Category is a complement to and does not replace official COD reporting. This group is useful when monitoring its specific subtypes (eg, Unexplained-Incomplete Case Information, Unexplained-Unsafe Sleep Factors, Explained-Suffocation) over time and, for cases categorised as Explained-Suffocation or Unexplained-Possible Suffocation, the mechanism to which the airway obstruction was attributed (ie, soft bedding, wedging, overlay or other) in participating jurisdictions.[6] It is important to note fluctuation in consistency between the SUID Case Registry Category Group in the NFR-CRS and those in the internal CDC database during the first 4 years of its use. As such, caution should be taken in the use and interpretation of the NFR-CRS SUID Case Registry Category data for any longitudinal analyses of data from 2015 to 2018. Because the SUID Case Registry has more detailed data about case investigation findings than death certificates alone, the SUID Case Registry Category Group is useful for examining the role of the medical, environmental and social factors, such as sleep environment, in SUID cases.[16] This additional detail is valuable for informing prevention strategies. Also, the SUID Case Registry Category Group subtypes of Unexplained-No Death Scene Investigation

or Autopsy and Unexplained-Incomplete Case Information are useful for examining and improving the completeness of death scene investigation and autopsy data, which are critical for understanding SUID aetiology.

### CDR-Assigned Cause Group

The CDR process and protocols equips communities to better understand how and why children die and inform prevention through multidisciplinary, in-depth case review.[24] The CDR-Assigned Cause is also available in the NFR-CRS.[20] It is assigned by CDR programmes after reviewing multiple data sources (eg, birth and death certificates, scene investigation reports, autopsy findings, child protective services, social services, law enforcement and medical records) for each death. Access can be requested to CDR-Assigned Cause in NFR-CRS data by applying to National Center (https://www.ncfrp.org/resources/data-dissemination/).

CDR-Assigned Cause Group subtypes include:

- Unintentional asphyxia

- SIDS

- Undetermined/unknown

Although some guidance is given, the NFR-CRS data dictionary[25] does not specifically define the CDR-Assigned Cause Group subtypes. In the NFR-CRS, when a COD is selected, a specific section of questions opens to capture the details of the death. The data dictionary instructs users to select the COD based on the section that most comprehensively captures the details of the death. For example, if the cause of death selected was 'Unintentional Asphyxia', more detailed information is captured such as if the death was sleep related, due to being confined in a tight space, or due to gas asphyxiation. As such, a variety of causes of death are selected for SUID cases, including 'Unintentional Asphyxia' for sleep-related suffocation, 'Medical Cause' for SIDS and 'Undetermined if Injury or Medical Cause', 'Injury/Undetermined' or 'Unknown' for undetermined/unknown.

Like the SUID Case Registry Category Group, there is more detailed information available (eg, about the sleep environment at the time of death) in the NFR-CRS with the CDR-Assigned Cause Group than in death certificate data alone. As a result, the CDR-Assigned Cause Group is also useful when examining the role of the medical, environmental and social factors, such as sleep environment, in SUID cases including those from states or jurisdictions not participating in the SUID Case Registry.[26 27] Strengths of the CDR-Assigned Cause Group include availability for 48 states and for data years 2004 onward. Also, because the categories focus on risk factors, the data can facilitate prevention recommendations. A limitation of the CDR-Assigned Cause Group is that the NFR-CRS data dictionary lacks specificity in distinguishing between Unintentional Asphyxia versus SIDS versus Undetermined/Unknown.

## CONCLUSIONS

This paper summarises descriptions and characteristics of three common ways SUID subtypes are grouped in the USA including ICD Code, SUID Case Registry and CDR-Assigned Cause. Having multiple systems of SUID subtype classification complicates SUID monitoring and surveillance, especially when comparing rates derived from different SUID subtype groups. We show that the three groups have distinct characteristics, purposes, strengths and limitations, highlighting the need for careful understanding of SUID subtype groups when analysing, reporting and interpreting SUID data. While similar, these groups are not interchangeable. Using them without a detailed understanding of each group may affect the interpretation of SUID statistics. This summary and accompanying online supplemental table can be used to guide decisions about reporting and interpreting SUID statistical data.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgements

## Data availability statement

Data sharing not applicable as no datasets generated and/or analysed for this study.

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**WHAT IS ALREADY KNOWN ON THIS TOPIC**

Sudden unexpected infant death (SUID) subtype groups, including International Classification of Diseases (ICD) Codes, SUID Case Registry Categories and Child Death Review (CDR)-Assigned Causes, are often used to monitor SUID trends and characteristics at the local, state and national levels.

**WHAT THIS STUDY ADDS**

SUID subtype groups vary in purpose, strengths, limitations, uses, history, data years available, population coverage, assigning entity, guidance documentation and information available to assign subtypes.

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

When reporting SUID statistics, increasing knowledge of SUID epidemiology and informing prevention strategies, it is important to understand the strengths of each SUID subtype group and which group might be best for each study and audience.