



Improving the Consistency and Accuracy of Sudden Unexpected Infant Death Reporting



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Sudden Unexpected Infant Death

In 2004, approximately 4,600 U.S. infants died suddenly of no immediately obvious cause. Nearly half of these sudden unexpected infant deaths (SUID) were attributed to sudden infant death syndrome (SIDS). SIDS is the 3rd leading cause of infant death in the United States and the 1st leading cause of death among infants aged 1–12 months.

The SIDS rate has been declining significantly since the early 1990s. However, CDC research has found that the decline in SIDS since 1999 can be explained by increasing SUID rates (e.g. deaths attributed to overlaying, suffocation, and wedging). This change in reporting or classification of SUID can be explained by changes in how investigations are conducted and by how diagnoses of SUID are made; that is whether to assign SIDS as a cause of death or say accidental suffocation.

Inaccurate Reporting

Many SUID cases are not investigated and, when they are, cause-of-death data are not collected and reported consistently. Inaccurate classification of cause and manner of death hampers prevention efforts and researchers are unable to adequately monitor national trends, identify risk factors, or evaluate intervention programs. We need valid and reliable data to support research and prevention efforts if we want to reduce these infant deaths.

SUID Initiative

In 2003, CDC began leading the effort to revise the 1996 SUID Reporting Form and guidelines, as well as actively educate and disseminate training materials on infant death scene investigations to improve inaccurate classification of SUID in the US. In 2004, the Division of Reproductive Health at the CDC and its partners implemented additional activities aimed at improving the accuracy and consistency of the reporting and classification of SUID deaths. These activities included the

development of a new standard investigation reporting form, training curriculum, materials for conducting a thorough SUID death scene investigation, a planned effort to disseminate and promote the use of these SUID investigations tools and materials, and the development of a SUID case registry.

SUID Initiative Goals

The goals of the SUID initiative are to develop tools and protocols to:

- Standardize and improve data collected at infant death scenes
- Promote consistent diagnosis and reporting of cause and manner of death for SUID cases
- Prevent SUID by using improved data to monitor trends and identify those at risk

SUID Investigation Reporting Form

In March 2006, a revised reporting form known as the Sudden, Unexplained Infant Death Investigation Reporting Form (SUIDI Reporting Form) was released and is important for several reasons. The form:

- Contains 25 questions medical examiners/coroners should ask before autopsy
- Guides the investigator through SUID investigation steps
- Allows the investigator to document information easily and consistently
- Produces information that assists the death certifier in accurately classifying SIDS and other SUID.
- Yields information that researchers can use to recognize new risk factors for infant death

SUID Investigation Training Academy

As a means of disseminating the training curriculum and materials, CDC began conducting train-the-trainer academies in five U.S. regions in 2006. Five-member multidisciplinary teams from each

state and three Indian Nations were trained on how to conduct comprehensive infant death scene investigations. These teams of train-the-trainers have gone on to train more than 15,000 additional medico-legal professionals.

Topics Covered at the training academy

- Completing the SUID Investigation Reporting Form
- Family interviewing techniques
- Death scene reenactments or re-creations; how was the infant discovered and what was the sleeping environment
- Using a web-based electronic reporting system allowing rapid communication between the death scene investigator to the forensic pathologist

These SUID investigation materials are available for download at: www.cdc.gov/sids.

SUID Surveillance System Feasibility Study

In 2007, CDC conducted a SUID surveillance feasibility study with seven states in collaboration with CDC's National Violent Death Reporting System (NVDRS). NVDRS is a state-based surveillance system that links data from law enforcement, coroners and medical examiners, vital statistics, etc. Building upon their system, participating states collected data for SUID deaths that occurred in 2005 and 2006. The feasibility study indicated that the most efficient way to develop a surveillance system would be to utilize the Child Death Review (CDR) system already in place. States agreed that the SUID surveillance system would be a useful tool and would allow state health departments to improve partnerships with child death review teams, law enforcement, medical examiner, and coroner offices that routinely collect SUID data. CDC partners suggested calling a future surveillance system the SUID Case Registry.

SUID Case Registry Planning and Development Information Gathering Sessions.

In March and July 2008, public and private partners came together to discuss the logistics of the SUID Case Registry. Support to build upon and enhance the Child Death Review (CDR) system was voiced as it would strengthen multidisciplinary team reviews already in place and avoid duplication of

efforts. Discussion also focused around creating a program model, delineating objectives and questions that a SUID Case Registry could answer, and defining a limited set of variables.

SUID Case Registry Pilot Project

A new funding announcement was released March 11, 2009. State health departments are eligible to submit their proposals for a new SUID Case Registry Pilot. Proposals must be submitted electronically by May 11, 2009. The announcement (CDC-RFA-DP09-904) may be accessed below.

Department of Health and Human Services,
Centers for Disease Control and Prevention
National Sudden Unexpected Infant Death Case Registry: A Pilot Study Grant

<http://www07.grants.gov/search/search.do?&mode=VIEW&flag2006=false&oppId=45952>

SUID Initiative Impact

To date the SUIDI Reporting Form and training curriculum have been endorsed by several national organizations representing law enforcement and medical examiners and coroners. Nearly 15,000 individuals have been trained, and many jurisdictions have reported that they are using the new SUID Investigation Reporting Form.

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