

Enhancing Sudden Unexpected Infant Death Surveillance in Illinois



Understanding SUID in Illinois: A Critical Public Health Challenge

Sudden Unexpected Infant Death (SUID) remains a leading cause of infant mortality in the United States, with approximately 3,400 infants dying suddenly and unexpectedly before their first birthday each year. SUID encompasses three main categories: sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed, and deaths from unknown or undetermined causes.

In Illinois, SUID rates have remained relatively steady in recent years, with a rate of 0.8 per 1,000 live births reported in 2022. However, this stability masks significant disparities across different populations. Notably, there is a persistent and stark racial disparity in SUID rates, with non-Hispanic Black infants being disproportionately affected. Multiple risk factors contribute to SUID, including poverty, limited education, inadequate prenatal care, maternal smoking, and unsafe sleep practices.

To address this critical issue, Illinois enacted a law (20 ILCS/2310-236) effective January 1st, 2020, mandating that all coroners and medical examiners in the state submit supplementary information to the Illinois Department of Public Health (IDPH) within 72 hours for all potentially sleep-related infant deaths. This law aimed to establish a more comprehensive SUID surveillance system.

Importance of Effective SUID Surveillance:

- 1. Comprehensive Monitoring and Prevention:** Robust SUID surveillance is critical for accurately tracking trends, identifying high-risk populations, and guiding evidence-based prevention strategies. An effective system enables strategic allocation of resources and interventions to reduce SUID burden among disproportionately affected communities. By improving our understanding of SUID cases and patterns, enhanced surveillance can significantly contribute to addressing the stagnation in infant mortality rates and improving outcomes for all infants in Illinois.
- 2. Enhancing Data Quality and Completeness:** The current surveillance system aims to capture information beyond what's available on death certificates alone, providing a more complete picture of each SUID case. However, existing data quality issues and underreporting limit the depth of analysis possible. Improving the system can lead to more comprehensive and reliable data, which is crucial for effective policymaking and intervention design.
- 3. Addressing Health Equity:** Given the significant racial disparities in SUID rates, a more robust surveillance system is essential for understanding and addressing these inequities. Comprehensive data can drive policy changes aimed at reducing infant mortality and eliminating racial disparities, playing a crucial role in working towards health equity in Illinois. By ensuring more representative data collection and analysis, the system can better inform targeted interventions to support vulnerable populations and reduce disparities in SUID outcomes.

Evaluating Illinois' SUID Surveillance System: Need for Evaluation

Due to the incomplete nature of the current SUID surveillance system in Illinois, it is crucial to conduct a thorough evaluation before sharing data or drawing conclusions. A comprehensive evaluation is necessary to guide improvements in our SUID surveillance efforts.

Evaluation Methodology:

The evaluation was conducted in two phases: Phase 1: 2016-2019 and Phase 2: 2020-2023.

We compared SUID coroner reports to death certificate data, using the latter as the "gold standard" for identifying true SUID cases. Our analysis utilized an integrated dataset of SUID coroner report forms and death certificates, linked through probabilistic matching with a 96% success rate.

We assessed five key surveillance system attributes: (1) sensitivity, (2) positive predictive value (PPV), (3) data quality, (4) representativeness, and (5) timeliness.

Enhancing Sudden Unexpected Infant Death Surveillance in Illinois

Key Findings:

- **Low sensitivity:** Only about 1 in 4 true SUID cases were reported, with over 80% of cases going unreported based on death certificate data.
- **Data quality issues:** High proportions of missing values were found in key fields. For example, Hispanic ethnicity was missing in up to 89% of cases in Phase 1, improving only slightly to 31% in Phase 2.
- **Poor representativeness:** Sensitivity varied across subgroups, with lower reporting for non-Hispanic White infants and cases occurring in rural counties.
- **Low PPV:** The system's PPV ranged between 65% and 70%, indicating that nearly a third of reported SUID cases did not meet the state's case definition per death certificate codes.
- **Acceptable timeliness:** In Phase 2, coroners took an average of 4 days to submit completed SUID coroner report forms to IDPH, which is close to the legal mandate of 3 days after the infant's death. However, timeliness data was unavailable for Phase 1.

Next Steps:



1. Transition to Active Surveillance

- Switch from passive coroner reporting to active death certificate case identification
- Improve case capture and consistency in applying SUID definition



2. Create Electronic Data System

- Continue refining REDCap for standardized SUID case data collection
- Implement data validation rules and automated quality checks



3. Enhance Quality Assurance Measures

- Develop robust quality assurance procedures for all phases of data flow
- Conduct regular audits and monitor data quality metrics



4. Standardize Training and Tools

- Create comprehensive curricula and protocols for reporting
- Provide ongoing training for coroners/medical examiners



5. Strengthen Stakeholder Collaboration

- Improve coordination between IDPH and key partners
- Integrate efforts with hospitals, law enforcement, review committees, etc.



6. Establish Routine Evaluation Process

- Conduct thorough annual or biennial surveillance system assessments
- Regularly monitor key performance indicators to drive improvements

Looking Ahead:

With the implementation of our new active surveillance system, we anticipate significant improvements in data quality and completeness. In subsequent annual reports, we will be able to provide more accurate and comprehensive SUID data for Illinois. This enhanced system will allow for:

- More precise tracking of SUID trends over time
- Better identification of high-risk populations and geographic areas
- Improved ability to evaluate the effectiveness of prevention strategies
- More reliable data to inform policy decisions and resource allocation

Resources:

For more information on SUID prevention and safe sleep practices, please visit the following resources:

1. Illinois Safe Sleep Support:

[\[Insert link to Illinois-specific safe sleep support page\]](#)

2. Centers for Disease Control and Prevention (CDC) - SUID and SIDS:

<https://www.cdc.gov/sids/index.htm>

3. National Institute of Child Health and Human Development (NICHD) - Safe to Sleep® Campaign:

<https://safetosleep.nichd.nih.gov/>

4. American Academy of Pediatrics (AAP) - Safe Sleep Recommendations:

<https://www.aap.org/en/patient-care/safe-sleep/>

5. Cribs for Kids® - National Infant Safe Sleep Initiative:

<https://cribsforkids.org/>