

Outcome Measure Worksheet

Sudden Unexpected Infant Death Prevention

Instructions

Complete the first page of this worksheet. Then, using the other pages of the worksheet, identify which datasets are used in your state/jurisdiction and who is the individual responsible for reporting to that system. Contact that individual to explore options for getting real time data on a monthly basis.

Why We Need Data and How It Will Be Used

We are looking for real-time data for the purposes of Quality Improvement and determining the impact our work is having on rates of sudden unexpected infant deaths. The data can be used to:

- Assess progress made towards the achievement of aim statements
- Compare trends in fatality to test small changes

Description of the Data

In an ideal world, these data will:

- Be collected and reported on a monthly basis
- Relate to this geographic region: _____

- Relate to this age group: _____

- Relate to populations with these characteristics: _____

- Reflect the following International Classification of Diseases (ICD) codes:

Table 1: Sudden Unexpected Infant Death ICD Codes

	Deaths
ICD system	ICD-10
Sudden Unexpected Infant Death	Accidental suffocation and strangulation in bed (ASSB): W75 Sudden Infant Death Syndrome (SIDS): R95 Unknown cause: R99



These data do not need to be cleaned to the same extent that they are cleaned for federal data systems. From the Quality Improvement standpoint, some data is better than no data. We encourage you to explore your options.

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Who Manages Datasets?

The following individuals or organizations may be able to provide you with more information about data collected and reported in your state/jurisdiction:

Table 2: Individuals with Access to Data

State Epidemiologist	Name:	Phone Number:
	Email:	
Medical Examiners or Coroners	Name:	Phone Number:
	Email:	
Child Death Review Coordinator	Name:	Phone Number:
	Email:	
SUID Case Registry Coordinator	Name:	Phone Number:
	Email:	
State Administrator	Name:	Phone Number:
	Email:	
Hospital Epidemiologist(s)	Name:	Phone Number:
	Email:	
Other:	Name:	Phone Number:
	Email:	
Other:	Name:	Phone Number:
	Email:	
Other:	Name:	Phone Number:
	Email:	

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Datasets

The following datasets contain the relevant data we are seeking on a state/jurisdiction (S/J) level. You may need help from individuals in the table above to answer questions about these systems.

Table 3: Data Reporting Systems

Data System	Does your S/J, or hospitals in your S/J have or report to this system?	Who is responsible for this system in your state/jurisdiction?	Does the system contain the data you are looking for?
Death Data Systems			
Child Death Review			
SUID Case Registry			
Vital-Statistics Office			
Other:			
Other:			
Other:			

Guiding Questions

Once you find the data you are looking for in your state or jurisdiction, choose one dataset (or one dataset per outcome measure) and explore the following questions with the point person for that dataset:

- How is the data collected? For example: Where specifically does it come from? Who is it reported to? How frequently is the data collected?
- Is it possible to generate monthly reports that contain the data described on the first page of this worksheet?
- If I can't get data on a monthly basis, how often can I get data?
- If I can't get the specific data I am looking for, what data can I get related to deaths?
- Do we need a data sharing agreement or memorandum of understanding to access the data?

If your state/jurisdiction does not have or report to any of these systems, ask the individuals listed in the second table (page 2) if they can think of other data systems or ways to collect the data described on page one of this worksheet. Surveys that include safe sleep behaviors may be relevant. Safe sleep behaviors are reported in the [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#) and the [National Survey of Children's Health \(NSCH\)](#).