The National Center for the Review and Prevention of Child Deaths

Case Reporting System
Part One
Building the Data System
How States were Using Their Data:

- To develop action plans based on their recommendations
- To keep or increase CFRT grant funding
- To meet legislative mandates.
- To report out fatality data
State of the States in 2003

- CDR in 49 states; 44 states had a case report tool
- 39 states published an annual report with findings and recommendations
  - 18 states had legislation that requires a report on child death
- However, there was no consistency among any state case report tools or state reports
From One Review to Many Reports

- Case Review
- Case Report
- Local Report or DCFS required report
- State Report
- National Reports
Clearing Up the Confusion on the Reporting of Death Investigation and Review Team Findings
Building the System

- Funded by Maternal and Child Health Bureau, HRSA, HHS. Built and managed by MPHI

- A 30 person workgroup of 18 states over two years, analyzed 32 existing state case report forms
  - Developed standard data elements, data dictionary, and 33 standardized reports
    - Piloted in 17 states for 18-24 months


- SUID Version 2009-2011
Purpose of the System

To systematically collect, analyze and report comprehensive CDR data on:

- Child, family, supervisor and perpetrator information
- Investigation actions
- Services needed, provided or referred
- Risk factors by cause of death
- Recommendations and actions taken to prevent deaths
- Factors affecting the quality of your case review
Participating

Enrollment in process

No Plans

National Center for Child Death Review: Case Reporting System
Status of State Enrollment, April 2013
FEATURES

- Web Based
- Real time data
- Easy to track/monitor cases from local to state level
- Comprehensive, Prevention Focused
- Local, State and National Users
- Enter, Search, Print, & Download Data
- 32 standardized Reports
- It’s adaptable
- Can migrate old data into it.
- We provide all training and help desk support.
- It’s free
The Child Death Review Case Reporting System
From Case Review to Data to Action

Step 1: Complete case review of child death.


Step 3: Send Report through Web, to servers at MPHI

Step 4: Servers sort and store data and permit access according to state requirements.

Step 5: State and local teams and national CDR download standardized reports and/or download data to create custom reports.

Step 6: Reports and data are used to advocate for actions to prevent child deaths and to keep children healthy, safe and protected.
With the Internet

- You do not need specialized software
- If you have access to the Internet and Microsoft Internet Explorer 6.0 or Firefox, you can use this system
- System updates are centralized and taken care of routinely for all users at once
- Users are controlled.
- Michigan Public Health Institute designed the software for the web-based application
Security

- Secured login to website
  - Everyone has individual accounts approved by their state administrator
- Data transmission is protected by 128-bit secured sockets layer (SSL)
  - Strongest commercially available
- Multiple firewalls protect the servers where the data is stored
Permissions

- **Local Users** can only enter and view specific case reports for non NYS SSL Section 20 cases.

- **State Users** can enter and view case reports for all NYS SSL Section 20 cases in their region.

- National Center staff can view only de-identified data across all states.
Confidentiality

- Prior to the issuance of NCCDR login and password, all CFRT users must sign a confidentiality/re-disclosure agreement.
- Data is owned by the state and local team.
- All data entered should be in compliance with NYS laws.
- The Receiver of the data, the Michigan Public Health Institute, is not subject to the Freedom of Information Act (FOIA).
Confidentiality

- No state identified data will be released for national-level reports without state approval
  - When released this data will be de-identified
- National Center staff cannot view identifiable data
  - Data are de-identified by HIPAA standards
HIPAA De-Identified

- Case number
  - State of review and year of review are kept
- Birth certificate and death certificate numbers
- Child’s name
- Date of birth
- Date of death (year of death is kept)
- Address
- Date and Time of incident
- Incident county
- Narrative
- Form completed by – name and contact information
Resources

- Paper Forms
- User Manual
- Data Dictionary
- Codebook for data download
- Microsoft Macro for ACCESS database
Part II  The Paper Form

- Appears lengthy at 16 pages
- When to use the form?
When to Use the Form

- Try not to let the form run the review
- Use the form as a guide for discussion
- Fill in questions as you can
- It will be helpful if you can fill out information that is known before the meeting, such as demographics
Don’t be Discouraged

It is normal not to have information on new data elements at first

• It will take time to learn what the new data elements are and where to find the information

• Allow the form to prompt you on what is needed for next time
Answer Options

Multiple Choice
- No
- Yes
- Unknown

Check All That Apply
- White
- Black, African American
- Native Hawaiian
- Pacific Islander
- Asian
- American Indian
- Alaskan Native
- Unknown

Fill in the Blank
46 pounds
Tips on Answering Questions

Don’t check more than one box unless it says “Check all that apply”, circles mean only one answer.

### A. CHILD INFORMATION

<table>
<thead>
<tr>
<th>1. Child’s name:</th>
<th>First:</th>
<th>Middle:</th>
<th>Last:</th>
<th>○ U/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Date of birth:</td>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mm / dd / yyyy</td>
<td>mm / dd / yyyy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Date of death:</td>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Age:</td>
<td>○ Years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Months</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>○ Days</td>
<td></td>
<td></td>
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<tr>
<td>○ Hours</td>
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<td></td>
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<tr>
<td>○ Minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ U/K</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. Race, check all that apply:</td>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ White</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>□ Native Hawaiian</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Black</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Pacific Islander</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Asian, specify:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ American Indian, Tribe:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ Alaskan Native, Tribe:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Hispanic or Latino origin?</td>
<td>○ No</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>○ Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Sex:</td>
<td>○ Male</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Female</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>○ U/K</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>8. Residence address:</td>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Street</td>
<td>Apt.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>State</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>County</td>
<td>Zip</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Type of residence:</td>
<td>○ Parental home</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Licensed group home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Licensed foster home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Relative foster home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Relative home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Living on own</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Shelter</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Homeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Jail/Detention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Other, specify:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. New residence in past 30 days?</td>
<td>○ No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ U/K</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Tips on Answering Questions

- Some questions have additional parts
- Watch for “Other, specify” and “If yes, then”
Tips on Answering Questions

Watch for skip patterns
Tips on Answering Questions

Check “Unknown”

• If you have tried to find the information to answer a question, but could not get a definite answer

Leave Blank

• If you did not try to locate the information to answer the question
Form Overview

Cause of death sections in yellow
  • To help distinguish sections of the form

Case Number
  • Specific to each state

  state number - team or regional office number -year-
case sequence

Example:  35– 0012 – 2009 – 0001
Example:  35– 0093 – 2009 – 0001
Form Overview

Can collect information on:

• two caregivers
• one supervisor, and
• two persons total causing or contributing to the death
Form Overview

Choose only one manner and one cause of death

<table>
<thead>
<tr>
<th>F. OFFICIAL MANNER AND PRIMARY CAUSE OF DEATH</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Official manner of death from the death certificate:</td>
</tr>
<tr>
<td>- Natural</td>
</tr>
<tr>
<td>- Accident</td>
</tr>
<tr>
<td>- Suicide</td>
</tr>
<tr>
<td>- Homicide</td>
</tr>
<tr>
<td>- Undetermined</td>
</tr>
<tr>
<td>- Pending</td>
</tr>
<tr>
<td>- U/K</td>
</tr>
<tr>
<td>2. Primary cause of death: Choose only one of four, then a specific cause. For pending, choose most likely cause.</td>
</tr>
<tr>
<td>- From an injury (external cause), select one:</td>
</tr>
<tr>
<td>- Motor vehicle and other transport, go to G1</td>
</tr>
<tr>
<td>- Fire, burn, or electrocution, go to G2</td>
</tr>
<tr>
<td>- Drowning, go to G3</td>
</tr>
<tr>
<td>- Asphyxia, go to G4</td>
</tr>
<tr>
<td>- Weapon, including body part, go to G6</td>
</tr>
<tr>
<td>- Animal bite or attack, go to G7</td>
</tr>
<tr>
<td>- Fall or crush, go to G8</td>
</tr>
<tr>
<td>- Poisoning, overdose or acute intoxication, go to G9</td>
</tr>
<tr>
<td>- Exposure, go to G10</td>
</tr>
<tr>
<td>- Undetermined, If under age one, go to G5 &amp; G12</td>
</tr>
<tr>
<td>- If over age one, go to G12</td>
</tr>
<tr>
<td>- Other cause, go to G12</td>
</tr>
<tr>
<td>- U/K, go to G12</td>
</tr>
<tr>
<td>- From a medical cause, select one:</td>
</tr>
<tr>
<td>- Asthma, go to G11</td>
</tr>
<tr>
<td>- Cancer, specify and go to G11</td>
</tr>
<tr>
<td>- Cardiovascular, specify and go to G11</td>
</tr>
<tr>
<td>- Congenital anomaly, specify and go to G11</td>
</tr>
<tr>
<td>- HIV/AIDS, go to G11</td>
</tr>
<tr>
<td>- Influenza, go to G11</td>
</tr>
<tr>
<td>- Low birth weight, go to G11</td>
</tr>
<tr>
<td>- Malnutrition/dehydration, go to G11</td>
</tr>
<tr>
<td>- Neurological/seizure disorder, go to G11</td>
</tr>
<tr>
<td>- Pneumonia, specify and go to G11</td>
</tr>
<tr>
<td>- Prematurity, go to G11</td>
</tr>
<tr>
<td>- SIDS, go to G5</td>
</tr>
<tr>
<td>- Other infection, specify and go to G11</td>
</tr>
<tr>
<td>- Other perinatal condition, specify and go to G11</td>
</tr>
<tr>
<td>- Other medical condition, specify and go to G11</td>
</tr>
<tr>
<td>- Undetermined, If under age one, go to G5 and G11, If over age one, go to G11</td>
</tr>
<tr>
<td>- Undetermined if injury or medical cause, go to G12</td>
</tr>
<tr>
<td>- U/K, if under age one, go to G5 and G11, If over age one, go to G11</td>
</tr>
</tbody>
</table>
Form Overview

Fill out a single section of *G. Detailed Information on Cause of Death*

<table>
<thead>
<tr>
<th>5. SIDS AND UNDETERMINED CAUSE UNDER ONE YEAR OF AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ No ☐ Yes ☐ U/K</td>
</tr>
<tr>
<td>If yes, how often?</td>
</tr>
<tr>
<td>☐ Frequently</td>
</tr>
<tr>
<td>☐ Occasionally</td>
</tr>
<tr>
<td>☐ U/K</td>
</tr>
</tbody>
</table>

*5. Fill out Section H, page 11. For undetermined injury cause to infants also complete G12, page 11, then go to Section H. For undetermined or unknown medical cause to infants also complete G11, page 10, then go to Section H.*
Form Overview

Section H is follow up regardless of cause of death: # possible scenarios

### H. OTHER CIRCUMSTANCES OF INCIDENT - ANSWER RELEVANT SECTIONS

<table>
<thead>
<tr>
<th>1. DID DEATH OCCUR WHILE CHILD SLEEPING OR IN A SLEEPING ENVIRONMENT?</th>
<th>○ No, go to H2</th>
<th>○ Yes</th>
<th>○ U/K, go to H2</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Incident sleep place:</td>
<td>○ Crib</td>
<td>○ Playpen</td>
<td>○ Carseat/stroller</td>
</tr>
<tr>
<td></td>
<td>○ Bassinet</td>
<td>○ Couch</td>
<td>○ Other, specify:</td>
</tr>
<tr>
<td></td>
<td>○ Adult bed</td>
<td>○ Chair</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>○ Waterbed</td>
<td>○ Floor</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>If adult bed, what type?</td>
<td>○ Twin</td>
<td>○ King</td>
</tr>
<tr>
<td></td>
<td>○ Full</td>
<td>○ Other, specify:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Queen</td>
<td>○ U/K</td>
<td></td>
</tr>
<tr>
<td>b. Child put to sleep:</td>
<td>○ On back</td>
<td>○ On stomach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ On side</td>
<td>○ U/K</td>
<td></td>
</tr>
<tr>
<td>c. Child found:</td>
<td>○ On back</td>
<td>○ On stomach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ On side</td>
<td>○ U/K</td>
<td></td>
</tr>
<tr>
<td>d. Usual sleep place:</td>
<td>○ Crib</td>
<td>○ Couch</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>○ Bassinet</td>
<td>○ Chair</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>○ Adult bed</td>
<td>○ Floor</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>○ Waterbed</td>
<td>○ Carseat/stroller</td>
<td>○ U/K</td>
</tr>
<tr>
<td></td>
<td>If adult bed, what type?</td>
<td>○ Twin</td>
<td>○ King</td>
</tr>
<tr>
<td></td>
<td>○ Full</td>
<td>○ Other, specify:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Queen</td>
<td>○ U/K</td>
<td></td>
</tr>
<tr>
<td>e. Usual sleep position:</td>
<td>○ On back</td>
<td>○ On stomach</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ On side</td>
<td>○ U/K</td>
<td></td>
</tr>
<tr>
<td>f. Was there a crib, bassinet or port-a-crib in home for child?</td>
<td>○ No</td>
<td>○ Yes</td>
<td>○ U/K</td>
</tr>
<tr>
<td>g. Child in new/different environment?</td>
<td>○ No</td>
<td>○ Yes</td>
<td>○ U/K</td>
</tr>
<tr>
<td>If yes, specify:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section I:
Answer whether an action/inaction directly caused the death or indirectly contributed to the death.

- Poor/absent supervision, go to 11
- Child abuse, go to 4
- Child neglect, go to 9
- Other negligence, go to 10
- Assault, not child abuse, go to 11
- Religious/cultural practices, go to 11
- Suicide, go to 28
- Medical misadventure, specify and go to 12
- Other, specify and go to 11
- U/K, go to 11
Form Overview

Local and State prevention efforts resulting from reviews are tracked throughout the nation

<table>
<thead>
<tr>
<th>Education</th>
<th>Current Action Stage</th>
<th>Type of Action</th>
<th>Level of Action</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recommendation</td>
<td>Planning</td>
<td>Implementation</td>
</tr>
<tr>
<td>Media campaign</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>School program</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Community safety project</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Provider education</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Parent education</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Public forum</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other education</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Part Three:
Entering a Case ~
and Our Never Ending Quest for Data Quality
Why is Data Quality Important?

- Consistency across users from comparisons.
- Makes analysis easier.
- Improves reviews.
- Reduces unknowns and missing.
- Guides prevention initiatives
General Points

- Read the question and response options carefully.
- Consult your Data Dictionary!
- Contact your State Administrator and/or the National Center.
General Points

Data Quality Issues with Report Tool:

• Data Omission (Missing Data)
  - Failure to understand question
  - Information not available

• Data Inconsistency
  - Differences in definitions
General Points

- Confusion about use of “unknown” vs. leaving a question blank
  - Check “unknown” if you tried to find the information to answer the question, but no clear or satisfactory response was obtained.
  - Leave question blank (unanswered) if no attempt was made to find the answer or question is not applicable.

- Limit the use of the “other, specify”

- Be sure to run any definitions or “rules” by your State Coordinator
Quality assurance

- Skip patterns will hide questions not relevant to the case entered
- Cannot enter conflicting data into some questions
- Red asterisks will flag questions where the answer is not recognized - error messages will come up if you try to save the page
For what fatalities do we complete NCCDR data?

“Should we be putting in data on a death not reviewed by our team?”

“Am I supposed to fill out a report for each death in my county?”

“Does each child get his/her own case report/case ID?”
Section A – Child Information

- **A9 & A10, Type of Residence**
  - Residence information is often left blank. Please try to complete this important question.
  - For newborns who never left the hospital, residence is primary caregiver’s.

- **A22, History of Substance Abuse**
  - For tobacco abuse of child, please select “Other, specify” and state “tobacco” in text box.
Tobacco abuse of caregiver should be marked in Section B, Question 10, “Caregiver have substance abuse history” – select “other” and write in “tobacco.”

Teams will need to decide if caregiver smoking in the home should be considered tobacco abuse.

If the cause of death was “SIDS” or “Undetermined Cause Under Age One”, then Section G5a asks “if Child was exposed to 2nd hand smoke.”
“If a child died of prematurity, is that considered a ‘chronic disease’?” (Question A20)

Response: The answer is probably ‘no’ for most cases since prematurity is more of a perinatal condition. If the child was born premature and 18 months later died, and it was felt that prematurity was the cause of the death, then your team might decide to select prematurity as a chronic disease.
Sections A, B and C – Child, Caregiver and Supervisor

- A23, B11,B12, C10, History of Maltreatment
  - For unsubstantiated referrals, please select ‘Yes’ regarding history, unless the referral was found to be completely falsified.

- A23-26, C10, History of Maltreatment & CPS
  - This data is also not getting reported consistently. Your CPS representative should be bringing this information to meetings.
B5, Caregiver(s) Income Level

- Often difficult to obtain but it is a marker for socioeconomic status (SES).

Income level categorized as “high” or “low” is a subjective response based on the local team’s decision. For some individuals, living in a very affluent community, ‘low’ may mean ‘middle’ for many of us. If a family is on public assistance, that would certainly help to identify the family as low income.
Section C (ctd)

- C1, Did Child have Supervision

  - Answer this question carefully. Consider all response options.

  - For example, infant sleeping in room next to parents. Even though child was asleep at time of incident and parents were in the next room, the child was still “supervised.”

  ![Pie chart showing 81% answered, 19% not answered]
Section C (ctd)

- C4, Primary Person Responsible for Supervision
  - You can only select one response.
  - If newborn infant dies in a hospital shortly after birth, in most circumstances, hospital staff should be listed as supervisor.
Section D – Incident Information

- Please answer Section D questions, even if case is a natural death.
  - For natural deaths, consider the ‘incident’ as the acute event leading to the death. For a child with a chronic illness, the incident date may be the same as the date of death with no acute event occurring.

- D1, Date of Incident
  - For newborns that do not leave the hospital, select ‘same as date of death.’
Section D (ctd)

- **D2, Time of day that Incident Occurred**
  - Reminder that this is the time incident occurred, not the time of death (but the incident could be same as death).

- **D4, Place of Incident**
  - Please note that this is a “check that all apply” question.
  - Reminder that question asks for place of incident and not place where child was pronounced dead.
  - For children that die of natural causes, with no acute event leading to the death, the incident place is usually the same as the place of death.
Section D

“Please give an example of ‘incident’ in a natural death.”

Response: If a child dies from a fatal asthmatic episode, the incident date would be the date of the onset of the asthma attack leading to the death. For example, if the child had an acute asthma attack at school, you would have a lot of information about the incident in terms of where the asthma attack occurred.
“What should ‘Child’s activity at time of incident’ be if child died at birth or lived only a few days?” (Question D12)

Response: Per the Data Dictionary, for natural deaths, determine if the child’s activity contributed to the onset of an acute incident leading to death. For children that died at birth or lived only a few days, please leave the question blank.
Section E – Investigation Information

- **E1, Death Referred To**
  - There is a difference between a medical examiner and a coroner. Please be sure you are selecting the correct one.

- **E4, Scene Investigation**
  - Mark the agencies that conducted an investigation at the death scene, not the agencies present or from whom there are records.
Section E (ctd)

- E8, Investigation Find Evidence of Prior Abuse
  - If no investigation was conducted, leave question blank.
- E10, Death in Licensed Setting, Action Taken
  - If infant dies in hospital, leave question blank.
Section F - Manner and Cause of Death

• F1, Manner of Death
  - Choose the manner of death from the death certificate.

• F2, Cause of Death
  - Use the cause of death from the death certificate that will take you to the section in G with the richest picture of the case. This should be a cause that is listed on the death certificate but may not necessarily be the first or last cause listed.

• If the team does not agree with the designations on the death certificate, this can be captured in Section L.
F2, Cause of Death

- For infant deaths in which the ME declared both manner and cause to be undetermined, please check ‘Undetermined if injury or medical cause.’
“If the death certificate says ‘respiratory arrest,’ how does that get us to the SIDS section?” (Question F2)

Response: Because the death certificate can list more than one cause of death, it is up to your team deliberation to choose the cause of death that would take you to Section G (Cause) that would offer the most information in regards to prevention. If the death certificate was marked with both ‘respiratory arrest’ and ‘SIDS,’ then it is the team’s decision to mark the most appropriate cause in Question F2 (medical condition). The System will take users to the SIDS section (Section G5) only when ‘SIDS’ is marked in Question F2.
“What if the death certificate leaves official manner of death blank but manner of death makes it obvious that it is a natural cause? Can you put ‘Natural’ though this isn’t on the death certificate officially? Or do we request to amend the death certificate?” (Question F1)

Response: It is not uncommon for this to be blank on a death certificate. Please ask your State Coordinator for guidance. From the National Center’s perspective, it is not problematic to enter ‘Natural’ for manner if the situation was clear cut. However, if manner was not obvious, then you may want to leave the question blank. You should also ask your medical examiner or coroner for their opinion.
“What category would maternal substance abuse leading to premature birth/death be classified as in Section F?” (Question F1,F2)

Response: For manner, select the official manner of death from the death certificate. For cause, you would probably select ‘prematurity’ or ‘other perinatal conditions’.

Some may have the death listed as accidental due to perinatal intoxication. As with many of the form’s questions, there is no right or wrong answer, and you should use your team’s discretion.
Section G1 - Motor Vehicle

- **G1a, Vehicle**
  - ‘Bicycle’ is an option for vehicles involved in incident. Treat a bicycle as a vehicle for the remainder of this section (d,g,h).
  - If child is a pedestrian, child’s vehicle should be marked ‘None.’

- **G1b, Position of Child**
  - Children boarding or blading are considered ‘pedestrians.’
Section G1 – Motor Vehicle (ctd)

- **G1c-d, Cause of Incident & Collision Type**
  - For single vehicle rollovers, check ‘Rollover’ in G1c. If vehicle rolled and hit a ditch, mark ‘Other event’ in G1d.

- **G1g, Drivers Involved**
  - Please try to answer driver license status for all involved drivers.
  - If age of driver is unknown, you may enter ‘999’ to indicate unknown age.
  - If age of driver is roughly known, you may enter your approximate age estimate.
“Is ‘rolled over’ child in driveway the same as vehicle rolled over and into ditch?” (Question G1c)

Response: If a child is backed over by a vehicle in a driveway, select ‘Back over’ in Question G1c. If a child is in a vehicle accident where a vehicle turns over on its side or roof, then select “Rollover” in Question G1c.
Section G4 – Asphyxia & Section G6 - Weapon

- Suicide by Hanging
  - Choose either cause of death = Asphyxia and Strangulation (Section G4) or cause of death = Weapon and Rope (Section G6), but be consistent within your state.
Section G6 – Weapon Including Person’s Body Part

- Physical Abuse is recorded in Section G6 if it is the cause of death.
  - If Physical Abuse is not the cause of death, use Section I to record the abuse in Question I3.
Section G9 – Poisoning, Overdose or Acute Intoxication

- G9f, What is the difference between Accidental Overdose or Acute Intoxication?
  - Accidental overdose: Unintentionally administering medication above recommended safe dosage levels. Also includes children ingesting/exposed to agents (including nonpharmaceutical agents) without knowledge of adverse consequences.
  - Acute Intoxication: Refers to agents taken as a result of recreational use or addiction. It excludes suicide.
Section G12 – Other, Undetermined or Unknown Cause

- Section G12 is only completed if Cause of Death (F2) is one of the following:
  - External injury is Undetermined, Other or Unknown cause
  - Undetermined if injury or medical cause
  - Unknown cause of death

- Section G12 is not intended to be used for the Narrative (Section M).
Section H – Other Circumstances of Incident

- H1a,d – Incident & Usual Sleep Place
  - Port-a-crib or Pack ‘n Play should be marked as “Crib”.
  - If child was sleeping in a twin bed, select “Adult bed” and then specify “Twin” in the follow up question.
“Does crib count if they are in the NICU at death?” (Question H1)

Response: Yes, if an infant is in an ICU bed then select ‘crib.’
Section I – Acts of Omission and Commission

- This section should be considered for the majority of deaths, excluding natural deaths.

- I1, Act Cause or Contribute to Death
  - An act of homicide or suicide would be a *cause* of death.
  - An act such as failing to supervise a child may *contribute* to the death.
I3, What Act Caused or Contributed to Death

- This question is the one place on the form where you can provide more information for suicides, homicides, child abuse and neglect.
- Check poor absent supervision if you believe it was a factor, but did not rise to the level of abuse or neglect.
- “Suicide” leads you to I28 and I29 (detailed suicide risk factor questions).
- “Other negligence” captures acts such as vehicular homicide from drunk driving, negligent manslaughter, etc.
Caused or Contributed?

Examples:
Caused: Abuse-Mother's boyfriend beat an infant to death.
Contributed: Neglect-Mother knew boyfriend was abusive to child.

Caused: Suicide- Teen shot himself with a firearm
Contributed: Other negligence or supervision-Father knew son was suicidal but kept loaded and unlocked weapons in house.

Caused: Neglect-Mother would not seek medical attention for infant.
Contributed: Religious practices-Mother's religious beliefs opposed traditional medicine.
Section I 11

Chronic with Child

Versus

Pattern in Family
Section I (Acts of Omission or Commission)
“How do you answer Question I1 for a teenager who is riding with a drinking teenager?”

Response: This depends on your team’s deliberation. A team could select that the crash was the direct cause and the drunken driver was the contributing cause. Or if the team felt that the driver was so incapacitated that he/she completely caused the accident to occur, the team could select the drunk driver as the direct cause.
Section J – Services to Family and Community

- 53% of our survey respondents “Always” try to complete this section.

- Respondents indicated they frequently don’t have this information; however, these questions should generate a conversation among the team.

- Only 23% said they had more than 60% of the information needed to complete this section.
“Our team feels itself is a Review team, not an Intervention team. They would not want to put any effort into finding this info, even if it was available.”

Response: Section J is not just about interventions for the actual case but about looking forward and thinking about improving services, which is an important part of prevention as well. Ask your team to think about services that may have been identified as a result of this death that you feel need to be put in place for your community for the future – an opportunity to think through improvements and services in the community to help families in the future.
Section K – Prevention Initiatives Resulting from the Review

- 52% of survey respondents say they ‘Always’ try to complete this section. Only 32% said they had more than 60% of the information they needed to complete this section.

- K1 “Could the death have been prevented” is frequently used in analysis
  - During team review, this question can drive a useful conversation.

- Please do not include recommendations or actions already in place.
Our recommendations rarely result from a specific case, rather, from an aggregate view. And the recommendations are made long after the cases are reviewed.”

Response: The National Center recognizes this difficulty and will continue to think about ways to design a specific module that would better capture the recommendations and prevention initiatives your team has designed in the aggregate.

The System, under Search, does give you the ability to retrieve all cases that have been marked to ‘add prevention actions at a later date.’ This aids your ability to add prevention actions at a later date.
Section L – The Review Meeting Process

- Please try to complete L5 (Factors that Prevented Effective Review) and L6 (Review Meeting Outcomes) in order to evaluate changes needed to your review process.

- L6 is the place to record the team’s disagreement with the official manner or cause of death.
Section M – Narrative

- The responses don’t always tell the complete story. Often, even a short narrative here goes a long way to communicate what happened in the case.

- Do not record identifying information in the narrative (names, addresses).

- Exclude information already provided elsewhere in the form.
Log In

- Log Into training.cdrdata.org
- Enter your User ID and Password

If you get locked out-wait 60 minutes or call us
Welcome Adams County, Pennsylvania

Why do children die in Pennsylvania? Which deaths might have been prevented?

These questions are the motivating force behind the PA Child Death Review Program. A child death review is a multi-agency, multi-disciplinary process that routinely and systematically examines the circumstances surrounding child deaths in a given geographical area and a given age group.

The PA Child Death Review Team is comprised of pediatricians, forensic pathologists, coroners/medical examiners, representatives from PA Deps. of Health, Public Welfare, Community Affairs, the Attorney General’s office, social services and law enforcement. The aggregate information will be shared with legislators and state policy makers in order to concentrate funding and program priorities on appropriate prevention strategies.

The Pennsylvania Child Death Review Program has 44 local teams representing 48 counties reviewing over 90% of child deaths in Pennsylvania (Feb 2002).

For more information contact:
Vick Zittle, Program Director
Yvonne McCalla, Program Assistant
PA Chapter, American Academy of Pediatrics
919 Conestoga Road, Bldg 2, Suite 307
Rosemont, PA 19010

Phone: 800-916-9776
Fax: 610-520-9177
Navigation

- Use side menu bar or bottom and top of save and continue
- Do not use the back button
- You can move anywhere at anytime—but you will lose skip patterns first time through
- Time out after 60 minutes-wait an hour
- Beware of red asterisks
Entering/Editing a Case

The first data entry page is where you define the case number

You can edit Year and Sequence

---

**Case Definition**

State / County / Year of Review / Sequence of Review

Case Type:
- Child death
- Child near-death event
- Not born alive

Death Certificate #: 

Birth Certificate #: 

---

**Case Definition**

A. Child Information
B. Primary Caregiver(s) Information
C. Supervisor Information
D. Incident Information
E. Investigation Information
F. Official Manner and Primary Cause of Death
G. Detailed Information by Cause of Death
H. Other Circumstances of Incident
I. Acts of Omission or Commission
J. Services to Family and Community as a Result of Death
K. Prevention Initiatives Resulting from the Review
A. Child Information

1. Child’s Name:
First: ______________________  □ Unknown
Middle: ____________________
Last: ______________________

2. Date of Birth: ____________  □ Unknown
   (i.e. MM/DD/YYYY)

3. Date of Death: ____________  □ Unknown
   (i.e. MM/DD/YYYY)
Part IV
Using Your Data
In Version 2.1, you can also search for prevention updates.
# View All Cases

23 cases returned.

<table>
<thead>
<tr>
<th>Case Number</th>
<th>Last Name</th>
<th>Date of Death</th>
<th>Edit</th>
<th>Print</th>
<th>Delete</th>
</tr>
</thead>
<tbody>
<tr>
<td>23-01-2004-0001</td>
<td>Williams</td>
<td>10/20/2004</td>
<td>Edit</td>
<td>Print</td>
<td>Delete</td>
</tr>
<tr>
<td>23-01-2006-0001</td>
<td>Jones</td>
<td>12/12/2006</td>
<td>Edit</td>
<td>Print</td>
<td>Delete</td>
</tr>
<tr>
<td>23-01-2007-0001</td>
<td>Smith</td>
<td>8/16/2006</td>
<td>Edit</td>
<td>Print</td>
<td>Delete</td>
</tr>
<tr>
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<td>Swanson</td>
<td>9/15/2006</td>
<td>Edit</td>
<td>Print</td>
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<tr>
<td>23-01-2007-0007</td>
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<td>2/12/2006</td>
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<tr>
<td>23-01-2007-0011</td>
<td>Nelson</td>
<td>5/2/2006</td>
<td>Edit</td>
<td>Print</td>
<td>Delete</td>
</tr>
</tbody>
</table>
**Print Case**

### Detailed Information by Cause of Death: Choose One Section Only

#### 1. Motor Vehicle and Other Transport

<table>
<thead>
<tr>
<th>a. Vehicles involved in incident:</th>
<th>b. Position of child:</th>
<th>c. Causes of incident, check all that apply:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Home</td>
<td>☐ Driver</td>
<td>☐ Speeding over limit</td>
</tr>
<tr>
<td>☐ Car</td>
<td>☐ Passenger</td>
<td>☐ Unsafe speed for conditions</td>
</tr>
<tr>
<td>☐ Van</td>
<td>☐ Front seat</td>
<td>☐ Back over</td>
</tr>
<tr>
<td>☐ Sport utility vehicle</td>
<td>☐ Back seat</td>
<td>☐ Redness</td>
</tr>
<tr>
<td>☐ Truck</td>
<td>☐ Truck bed</td>
<td>☐ Ran into object</td>
</tr>
<tr>
<td>☐ Semi truck</td>
<td>☐ Other, specify</td>
<td>☐ Other driver error</td>
</tr>
<tr>
<td>☐ RV</td>
<td></td>
<td>☐ Animal in road</td>
</tr>
<tr>
<td>☐ School bus</td>
<td></td>
<td>☐ Poor visibility</td>
</tr>
<tr>
<td>☐ Other bus</td>
<td></td>
<td>☐ Poor weather</td>
</tr>
<tr>
<td>☐ Motorcycle</td>
<td></td>
<td>☐ Racing, not authorized</td>
</tr>
<tr>
<td>☐ Tractor</td>
<td></td>
<td>☐ Other, specify</td>
</tr>
<tr>
<td>☐ Other farm vehicle</td>
<td></td>
<td>☐ UK</td>
</tr>
<tr>
<td>☐ All terrain vehicle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Snowmobile</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Bicycle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Train</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Subway</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Inclined</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Other, specify:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ UK</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d. Driving conditions, check all that apply:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Normal</td>
</tr>
<tr>
<td>☐ Loose gravel</td>
</tr>
<tr>
<td>☐ Construction zone</td>
</tr>
<tr>
<td>☐ Murky</td>
</tr>
<tr>
<td>☐ Inadequate lighting</td>
</tr>
<tr>
<td>☐ Ice/snow</td>
</tr>
<tr>
<td>☐ Fog</td>
</tr>
<tr>
<td>☐ UK</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>e. Location of incident, check all that apply:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ City street</td>
</tr>
<tr>
<td>☐ Residential street</td>
</tr>
<tr>
<td>☐ Parking area</td>
</tr>
<tr>
<td>☐ Rural road</td>
</tr>
<tr>
<td>☐ Off road</td>
</tr>
<tr>
<td>☐ Highway</td>
</tr>
<tr>
<td>☐ Railroad crossing/tracks</td>
</tr>
<tr>
<td>☐ Intersection</td>
</tr>
<tr>
<td>☐ Other</td>
</tr>
<tr>
<td>☐ Shoulder</td>
</tr>
<tr>
<td>☐ Sidewalk</td>
</tr>
<tr>
<td>☐ UK</td>
</tr>
</tbody>
</table>

#### 2. Drivers Involved in Incident:

- Child as Driver: 16
- Other primary vehicle: 16

<table>
<thead>
<tr>
<th>Age of Driver</th>
<th>Responsible for causing incident</th>
<th>Violated graduated licensing rules</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 3. Total Number of Occupants in Vehicle:

- In child's vehicle, including child:
  - ☐ N/A, child was not in a vehicle
  - ☐ N/A, incident was a single vehicle crash

- In other primary vehicle involved in incident:
  - ☐ N/A, incident was a single vehicle crash

<table>
<thead>
<tr>
<th>Total number of occupants</th>
<th>Total number of deaths</th>
<th>Total number of teen deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total number of occupants</th>
<th>Total number of deaths</th>
<th>Total number of teen deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Print Case**
Select reports with multiple filters

33 reports are readily available
## Factors Involved in Sleep-Related Deaths

**Review Year Range: 2005 to 2010**  
**Michigan**  
**Child Deaths Reviewed**  
**All Cases**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>0-1 Mts</th>
<th>2-3 Mts</th>
<th>4-5 Mts</th>
<th>6-7 Mts</th>
<th>8-11 Mts</th>
<th>1-4 Yrs</th>
<th>5 Yrs Up</th>
<th>Unk</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths Reviewed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not in a crib or bassinette</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not sleeping on back</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Sleeping with other people</td>
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<td>0</td>
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<td>0</td>
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<td>Adult was alcohol impaired</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Adult was drug impaired</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Caregiver/Supervisor fell asleep while bottle feeding</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Caregiver/Supervisor fell asleep while breast feeding</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**Footnote:** Columns do not add up to total deaths because the factors are not mutually exclusive. If factor is unknown, it is not included in these counts. Portable cribs may inadvertently be counted as not in a crib or bassinette since they are typically coded as "other." Unsafe bedding or toys include pillow, comforter, stuffed toy, and other toy.
“Any plans to have reports that you can create - i.e. all children that drowned in one city or county or zip code?”

Response: You can run any report you want if you download the data for different combinations of jurisdictions. Standardized reports are limited by the 33 types. If additional funding becomes available to support further modification of the System, then additional customization of the Standardized Reports may be available.
Data Download

Download Your Data

Download All Sections

All Tables (zip file)

Download a Section

Table TCase - Case Definition
Table TMF - Section A
Table TGV - Section B
Table TUP - Section C
Table TNC - Section D
Table TNV - Section E
Table TCAL - Section F, G12
Table TVEH - Section G1
Table TFR - Section G2
Table TUR - Section G3
Table TSUE - Section G4
Table TSID - Section G5
Table TWEA - Section G6
Table TBIT - Section G7
Table TIAL - Section G8
Table THG - Section G9
Table TEXP - Section G10
Table TNED - Section G11
Table TCR - Section H
Table TACT - Section I, J, K
Table TACT2 - Section I, J, K
Table TREV - Section L, M, N
When Downloading Data

- Supporting documents
  - Codebook: gives you the values for every item
  - Microsoft Access macro: allows you to import tables into Access
Data Dissemination Policy

- Respond to requests for counts.
- Create reports with states for publication.
- Allow access to aggregated data, using a committee of states and a formal application process, FOR BONA FIDE RESEARCHERS AND FEDERAL AGENCIES ONLY
Accounts Administration

- Add a New User
- Manage Existing Users
- Download Contact Information
- Set Reports Maximum Year
Help

Contact Information for the National MCH Center for Child Death Review:

2440 Woodlake Circle, Suite 150
Okemos, MI 48864

Phone: 1-800-656-2434
Fax: (517) 324-7365
Email: info@childdeathreview.org

Maintaining Your Account:

Change your Password
Edit your Contact Information

Supporting Documents:

Guide for Effective Child Death Reviews .pdf
Child Death Review Case Report Form .pdf
Internet Database User Manual .pdf
Internet Database User Manual for State Administrators .pdf
Internet Database Error Report Form .pdf
Data Dictionary .pdf
Data Codebook for Download .pdf
Macro to Import Data into Microsoft Access .mdf

For Administrators:

Accounts Administration
Help

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For Administrators:

Accounts Administration
Version 3 Enhancements

• All users are offered the expanded SUID Case Registry questions
• Enhanced search features
• Greater flexibility for granting user permissions
• An easier snapshot of select data for download
• Ability of states to add a few custom questions
• Improved navigation between sections
• Multi-jurisdiction logins
Version 3 Enhancements

- Cross-referencing of caregivers, supervisors and people who directly caused or contributed to the event
- Ability to de-select radio dial responses
- Data Dictionary is more easily available with every question
- Ability to upload vital statistics data before a case is created to minimize transposition errors
- Users can upload a scene re-creation photo
- Calendar date-pickers are available for date fields
Thank You

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www.childdeathreview.org

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