Version 5 & Data Quality – Good, Bad or Ugly

Your Friendly and Geeky Data Team:
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May 9, 2018
2018 National CDR Conference
Agenda

• Da Good
  – Version 5 NFR-CRS Update
  – NFR-CRS Features You Should be Using but Probably Aren’t

• Da Bad
  – Problem Areas

• Da Ugly
  – Data Quality
CDR Teams by State Using NFR-CRS, May 2018
n=44

Key: Use NFR-CRS
- Yes (n=44)
- No
FIMR Teams by State Using NFR-CRS, May 2018

n=15

Key: Use NFR-CRS
- Green: Yes (n=15)
- Yellow: No
Version 5 launched on 4/23/2018!!!!

- **CDR**
  - Over 202,500 CDR Cases
  - Nearly 2,200 CDR Users

- **FIMR**
  - 2,347 Cases (1,502 from FIMR Data System at MPHI and 845 IEM/CDR cases)
  - 140 FIMR Users
Version 5 Update

• A few items not quite ready at launch
  – Flat file
  – Standardized Reports 23, 24, 28, 30
  – Two new Standardized Reports for FIMR

• Problems
  – Data Download Processing Time
New NFR-CRS Features Under Consideration

Available now:

• **CDR can opt out** of Section I1 (Sudden Death in the Young) and Section N (SUID/SDY Case Registry) if not CDC awardee

Coming soon:

• **Copy Cases** for CDR

• **Data Output** – exploring creation of **SPSS/SAS Master flat file output** of all variables

• **Training video** on NFR-CRS (nuts and bolts of data entry)
Version 5.1 Suggestions – Keep them coming!

✓ Date parameters on Data Download

✓ Add County of Death, Maternal age and Maternal Education to Import Vital Stats template

✓ Add Marital Status to Biological Parent section

The National Center for Fatality Review and Prevention
5 Features You Should Be Using But Probably Aren’t

• Import Vital Stats
• Standardized Reports
• Flat File
• Custom Questions
• My Fatality Review Outcomes
Import Vital Stats: Why Should I Be Using It?

Saves data entry time

Fewer data entry errors

Provides info to teams who may not have access

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Import Vital Stats: Easy as 1 – 2 – 3

**Step 1:**
User with Admin rights in NFR-CRS completes the Import Template.

Required fields: State, State ID, Child’s Name, DOD, and Age.

**Step 2:**
Admin user uploads the template into the ‘holding tank’.

**Step 3:**
Local user finds case in ‘holding tank.’ Must know Child’s name and DOD. Case is created. Fields from template will be filled in the NFR-CRS. User continues with data entry.
Standardized Reports: Why should I be using them?

• 33 easy-to-generate reports available, largely broken out by cause of death

• Filters available to make selection easier
  – Case Type
  – Only Data Entry Complete
  – Only QA Complete
  – Only SUID or SDY Cases (new!!)
  – Year of Review
  – Date of Death (new!!)

• Real time data

• Easy to export to PDF or Excel
Standardized Reports:
What are these reports you speak of?
Flat File: Why should I use it?

- Easy way to look at your data! No linking of tables!
- Data is on a case by case basis (individual)
- Contains over 220 frequently analyzed fields with some re-coding
- Real time data
- Can be exported into Excel
# The Flat File

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<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
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<td>1</td>
<td>N</td>
<td>F</td>
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</table>

**Notes:**
- 1 = Death
- 3 = Stillborn
- 0 = infant
- 1 = Infant
- 2 = 1-4 y
- 3 = 5-9 y
- 4 = 10-14 y
- 5 = 15 - 17 y
- 6 = 18 y +
- 9 = unknown

**Race:**
- 1 = White
- 2 = Black/AA
- 3 = Native Hawaiian
- 4 = Pacific Island
- 5 = Asian
- 6 = Amer Indian
- 9 = unknown

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Custom Questions: Why should I be using them?

• State customization
  – Got a burning question that your state needs to track?
• Easy to add questions via the NCFRP staff
Custom Questions: example

Example for missed prenatal care visits.

Section A3. Children Under 1 Year: Extended Questions

64. Did the mother miss more than 3 of her scheduled prenatal care visits?

Use Not Applicable if the mother had no prenatal care.
Custom Questions: example

Example for missed prenatal care visits.

Section A3. Children Under 1 Year: Extended Questions

64. Did the mother miss more than 3 of her scheduled prenatal care visits? ☭

- N/A
- Yes
- No
- Unknown
Custom Questions

- Can be put at the end of any section or in its own section at the end of data entry
- A limited number of questions (5 – 15) that you would like to capture from your teams
- A check-all-that-apply question counts for 1 question per item
- There are a few limitations, such as asking for HIPAA sensitive data
Custom Questions

• Currently being used by Georgia, Oregon and Montana for such questions as the mother’s marital status during pregnancy and state agencies involved with the child

You can be next!
My Fatality Review Outcomes: Why I should be using them?

- A different way to keep track of prevention initiatives
- Not tied to one particular case
- “One stop shopping” for outcome recommendations
- Important data to document, particularly for NCFRP (pretty please)

Please continue to enter initiatives in the Prevention Section
My Fatality Review Outcomes: example

1. Approximately when this Outcome was implemented:
   - Quarter: Spring
   - Year: 2018

2. A short description of the Outcome implemented (less than 255 characters):
   - Safe sleep packets delivered to birthing hospitals

3. Lead person to contact for more information:
   - First Name: Jane
   - Last Name: D
   - Contact Phone or Email: janed@nowhere.com

4. One cause of death for this initiative (if it applies across multiple causes, select 'no response'):
   - Cause of Death: no response
Da Bad - Persistent problem areas

- Missing data
- Inconsistent data
- Timeliness of data entry
- Overuse of the “Other” specify field
- Entering identifying information into text fields (e.g., Narrative section)
- Understanding Poor/absent supervision, Abuse, Neglect, Exposure to Hazards
- Lack of detail (if there is any) about prevention recommendations
Moving from Ugly to Sweet...
Overview: Moving from Ugly to Sweet!

- Data Quality Initiative Review & Update –
  - Data quality monitoring
  - Data Quality Summary Report
  - New Standardized report
- Center Assistance
- Open dialogue
Why are we collecting these data?

Purpose:

• Provide CDR teams with simple way to systematically collect comprehensive information on every death reviewed
• Enable local/state CDR teams to easily analyze and report findings
• Enable child health and safety advocates access to aggregate data to inform prevention policy and practice
Data Projects

- 14 peer reviewed papers published using CRS data
- De-identified data available to researchers for analysis

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**Cambria County’s Yellow Ribbon Suicide Prevention Program**

During the late 1990s, Cambria County identified an increase in youth suicides. After much collaboration and planning among the Cambria County Child Death Review Team membership, the county adopted the Yellow Ribbon Suicide Prevention Program in 2003. This national suicide prevention model was founded in 1994 by the parents and friends of Mike Emme, a young man who took his life when he could not express his pain nor understand how to let someone know that he was in trouble and needed help.

Starting in 2004, the Cambria County program sponsored informational outreach to schools and civic groups, targeting youth and focusing on suicide prevention. Through this outreach, presenters spoke, and continue to speak directly to youth about the impact of suicide. A surviving parent accompanies the presenters and speaks directly about the personal impact of losing a child to suicide. Informational brochures and cards are disseminated, and crisis hotline telephone numbers are provided to those at risk.

**SCFRT Committee Recommendations**

**Recommendations to the Governor and Legislature**

1. **Pass distracted driver legislation to address the risks of using wireless communication devices while driving.**

A study by Virginia Tech Driving Institute revealed that those who resort to texting while driving are 23 times more likely to crash. According to the 2014 Texas crash statistics compiled by TxDOT³, 51 fatalities and 654 serious injuries were attributed to the use of a wireless device while driving. There were a total of 3,423 motor vehicle crashes in which mobile phone use was a contributing factor.
CHILD DEATH REVIEW SUCCESS STORY

The Ravalli County Fetal Infant Child Maternal Mortality Review (FICMMR) Team in Montana partnered with a variety of government and community organizations to reduce the number of drowning and near-fatal drowning incidents on the Bitterroot River, particularly at one dangerous section near a dam. One partner organization, Montana Fish, Wildlife & Parks (FWP), decided to close the dangerous section of the river during peak times of the year.

Although the closing was not popular in the community, it was necessary to improve the safety of the river. FICMMR members supported the effort to close the river section by writing letters and speaking at open meetings. FICMMR also purchased signs to be placed at strategic locations to...
NFR-CRS by the numbers...

- 44 states using the System
- Over 2,200 authorized users
- Over 1,350 CDR teams have recorded a death in the System
- More than 202,500 deaths have been entered
  - 99% deaths
  - 54% infants
  - 65% cases from 2005-2014
  - 58% males
  - 49% natural deaths; 24% accidents
Data Quality Initiative

Goal:
Improve the quality and consistency of the data entered into the CRS in an effort to improve usefulness of the data at the state and national level for identifying prevention strategies and monitoring the effectiveness of prevention measures that have been implemented.
Components of the Data Quality Initiative

- Convene workgroup
- Identify priority variables for monitoring data quality
- Develop written guidance for priority variables
- Develop a data quality summary
- Training
- Guidance for Improving CDR Data Quality
- Technical Assistance to select states
Data Quality Initiative

The National Center for Fatality Review and Prevention began a Data Quality Initiative under the leadership of Patricia Schnitzer, Ph.D. Its goal is to improve the quality and consistency of the data entered into the Case Reporting System in an effort to improve usefulness of the data at the state and national level for identifying prevention strategies and monitoring the effectiveness of prevention measures that have been implemented.

The initiative, which began in the Fall of 2015, has the following six components:

A Data Quality Initiative Webinar (Access code “Quality” - Firefox or Chrome suggested) was presented on June 23, 2016 to all users of the CDR Case Reporting System. This webinar introduced the Data Quality Initiative and presented some case scenarios in an interactive format using the Guidance. The slides are also available.

A volunteer workgroup identified PRIORITY variables for monitoring data quality. A subset of CORE variables were also identified. These priority and core variables were used as the basis for a Data Quality Guidance and Data Quality Summary.

A Data Quality Guidance for the Case Reporting System was developed to help users understand some of the trickier sections of the report tool and provide additional detail for the priority variables. The Guidance has been incorporated into the Data Dictionary as well. A Frequently Asked Questions document was also created.

A Data Quality Summary was developed for states with at least 30 deaths in the calendar year; 2014 data was used for the first (baseline) annual report. This Summary presents the percent of missing and unknown responses for the priority variables using the national data along-side state-specific numbers. The 2014 Summary was sent to CDR state coordinators with their state’s data. A pre-recorded webinar (access code ‘Quality’ - Firefox or Chrome suggested) more fully explains how to read the Summary and its potential uses; slides of the webinar are also available. In October 2017, the second annual Data Quality Summary was sent to states. This report included the states’ 2014 and 2015 data, as well as national data from 2015. The National Data Quality Summary shows the template and the data from 2014 and 2015.

A Guidance for Improving Child Death Review Data Quality was compiled and published in October 2017 as a resource to state Child Death Review programs for
Guidance for Improving Child Death Review Data Quality
# Data Quality Summary Report

## CDR_CRS Data Quality Summary

**Variables highlighted in **Pink** are designated CORE variables**

<table>
<thead>
<tr>
<th>CDR_CRS DQ Priority Variables</th>
<th>How data* from all states looks right now</th>
<th>How your state's data looks right now</th>
<th>How your state's data looked at the same time last year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Missing (%)</td>
<td>Unknown (%)</td>
<td>Missing (%)</td>
</tr>
<tr>
<td>A4 Child's age</td>
<td>11 (0.1%)</td>
<td>0 (%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>A5 Child's race</td>
<td>630 (4.8%)</td>
<td>252 (1.9%)</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>A6 Hispanic origin</td>
<td>1195 (9.2%)</td>
<td>587 (4.5%)</td>
<td>6 (0.4%)</td>
</tr>
<tr>
<td>A7 Child's sex</td>
<td>436 (3.3%)</td>
<td>20 (0.2%)</td>
<td>2 (0.1%)</td>
</tr>
<tr>
<td>A19 Child's health insurance</td>
<td>3240 (24.9%)</td>
<td>4181 (32.1%)</td>
<td>101 (7.0%)</td>
</tr>
<tr>
<td>A20 Child had disability or chronic illness</td>
<td>3522 (27.0%)</td>
<td>1640 (12.6%)</td>
<td>131 (9.1%)</td>
</tr>
<tr>
<td>A21 Child's mental health: Had received services</td>
<td>1672 (12.8%)</td>
<td>1467 (11.3%)</td>
<td>46 (3.2%)</td>
</tr>
<tr>
<td>A21 Child's mental health: Was receiving services</td>
<td>1720 (13.2%)</td>
<td>1523 (11.7%)</td>
<td>48 (3.3%)</td>
</tr>
<tr>
<td>A21 Child's mental health: On meds for MH issue</td>
<td>1738 (13.3%)</td>
<td>1565 (12.0%)</td>
<td>51 (3.5%)</td>
</tr>
<tr>
<td>A21 Child's mental health: Issues prevented from receiving services</td>
<td>1780 (13.7%)</td>
<td>1709 (13.1%)</td>
<td>53 (3.7%)</td>
</tr>
<tr>
<td>A23 Child had history of maltreatment as victim</td>
<td>5036 (38.6%)</td>
<td>1205 (9.2%)</td>
<td>490 (3.7%)</td>
</tr>
<tr>
<td>A24 Open CPS case with child at time of death</td>
<td>3320 (25.5%)</td>
<td>1407 (10.8%)</td>
<td>114 (0.9%)</td>
</tr>
<tr>
<td>A34 Gestational age (Infants only; n=963)</td>
<td>946 (13.2%)</td>
<td>417 (5.8%)</td>
<td>11 (1.1%)</td>
</tr>
<tr>
<td>A35 Birth weight (Infants only)</td>
<td>938 (13.0%)</td>
<td>678 (9.4%)</td>
<td>11 (1.1%)</td>
</tr>
<tr>
<td>A36 Multiple birth? (Infants only)</td>
<td>1323 (18.4%)</td>
<td>210 (2.9%)</td>
<td>14 (1.5%)</td>
</tr>
<tr>
<td>A40 Prenatal care provided during pregnancy of deceased infant</td>
<td>1402 (10.5%)</td>
<td>888 (12.3%)</td>
<td>18 (1.9%)</td>
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<tr>
<td>A44 Did mother smoke at any time during pregnancy (Infants only)</td>
<td>1536 (21.4%)</td>
<td>1256 (17.5%)</td>
<td>16 (1.7%)</td>
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<tr>
<td>B1 Primary Caregiver (CG) 1 (relationship to decedent)</td>
<td>2530 (19.4%)</td>
<td>144 (1.1%)</td>
<td>26 (1.8%)</td>
</tr>
<tr>
<td>B2 CG1 age in years</td>
<td>3000 (23.0%)</td>
<td>1899 (14.6%)</td>
<td>42 (2.9%)</td>
</tr>
<tr>
<td>B3 CG1 sex</td>
<td>217 (2.1%)</td>
<td>252 (1.9%)</td>
<td>42 (2.9%)</td>
</tr>
<tr>
<td>C1 Did child have supervision at time of incident</td>
<td>2712 (20.8%)</td>
<td>450 (3.5%)</td>
<td>27 (1.9%)</td>
</tr>
<tr>
<td>C4 Person responsible for supervision (relationship= n=1291)</td>
<td>3214 (29.8%)</td>
<td>31 (0.3%)</td>
<td>81 (6.3%)</td>
</tr>
</tbody>
</table>

**The National Center for Fatality Review and Prevention**
How to use DQ Summary Report

- Training tool
- Monitor data quality; compare to national
- Set goals/targets for minimum % missing/unk
- Evaluate state data quality program
- Run reports more frequently (e.g., quarterly)
- Stratify by county or region to see how individual teams are doing
- Technical Assistance available from NCFRP
**Data Quality - Case Numbers with Missing Data on Priority Variables**

State: Vermont  
Local Team: ALL  
Cases Selected By: Review Year  
Review Year From: 1995  
Review Year To: 2016  
For Case Type: Child Death  
Review Type: CDR  

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<thead>
<tr>
<th>Case Number</th>
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<th>Age (A4)</th>
<th>Race (A5)</th>
<th>Sex (A7)</th>
<th>Disable / III (A13)</th>
<th>Maltreat (A22)</th>
<th>Open CPS (A23)</th>
<th>CG1 Type (C1)</th>
<th>Supervise (D1)</th>
<th>Sup Impair (D16)</th>
<th>Autopsy (F4)</th>
<th>DSI (F12)</th>
<th>CPS (F16)</th>
<th>Manner (G5)</th>
<th>Cause (G6)</th>
<th>Sleep Env (I2)</th>
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</tr>
</tbody>
</table>

**Footnote:** Includes only those Case Numbers where data are missing (blank) for select variables. This report does not include those Case Numbers where the data have been marked “unknown.”

Report completed in 14.2270176 Seconds
Assistance from the National Center

- Onsite or by telephone
- Training local and state staff
- Presentations at state/regional meetings
- Assistance establishing/improving state data quality monitoring program.
- Just contact us!
THANK YOU!

Contact us if you have questions or comments:
info@ncfrp.org