



Monitoring Data Quality in the National Fatality Review-Case Reporting System:

The First Five Years

National Center Data Report

ACKNOWLEDGMENTS:

Child Death Review (CDR) teams throughout the US contributed data to NFR-CRS, which is featured in this report. Improving NFR-CRS data quality, consistency, and completeness is an essential part of understanding how and why children die. The National Center gratefully acknowledges the effort and dedication of CDR teams in courageously seeking to improve the quality of their NFR-CRS data and the health and safety of their communities.

TABLE OF CONTENTS

Background 4

Data Quality Dimensions 6

Data Quality Summary Report..... 9

NFR-CRS Changes to Support Data Quality12

Impact of the Data Quality Initiative on Data Quality in the NFR-CRS13

State Highlights22

Arkansas 22

Delaware..... 26

Montana 30

Conclusions and Next Steps.....34

Appendix.....34

Monitoring Data Quality in the National Fatality Review-Case Reporting System:

The First Five Years

Background

The National Fatality Review-Case Reporting System (NFR-CRS) was developed in 2005 by the National Center for Fatality Review and Prevention (National Center) to provide states with a standard format for collecting, summarizing, and reporting information shared during the Child Death Review (CDR) process. These data can then be used at the local, state, and national levels to improve child health and safety and prevent future deaths. NFR-CRS is a web-based system containing important details of the circumstances of infant and child deaths, uniquely capturing child, family, risk factor, and death investigation information not available in any other mortality database.

As of July 2021, 47 states use NFR-CRS to record CDR data. The system has more than 2,600 data elements and more than 2,200 individuals registered to enter CDR data. Ensuring data quality across and within jurisdictions is challenging due to the large number of data elements, large number of users, high user turnover, and complexity of the information collected. Nevertheless, high quality data are critical to ensuring the usefulness of the data for informing prevention and system improvements at the local, state, and national levels, as well as for monitoring the effectiveness of prevention strategies system improvements that have been implemented. It is for these reasons that the NFR-CRS CDR Data Quality Initiative was started in September 2015 with the goal of improving the quality of CDR data in the NFR-CRS.



The Data Quality Initiative was comprised of the following components:

- ☐ A Data Quality Workgroup was convened to provide overall guidance for the Data Quality Initiative.
- ☐ Identification of priority variables for monitoring data quality.
- ☐ Development of expanded definitions of priority variables in hopes of improving accuracy, completeness and consistency of data entered for each of the priority variables.
- ☐ Development of a Data Quality Summary Report to provide feedback to each state on the priority variables. The first Data Quality Summary Report was issued in September 2016.
- ☐ Compilation of best practices for monitoring/improving data quality at the state program level. A Guidance for Improving Child Death Review Data Quality was issued in October 2017.
- ☐ Provision of training and technical assistance related to data quality. Numerous webinars have been presented, a Data Quality Training module developed, and technical assistance has been provided in numerous states and delivered via various platforms.

**THE FIRST
FIVE YEARS**

The purpose of this document is to describe the progress made in improving CDR data quality in the NFR-CRS at the conclusion of the first five years of the Data Quality Initiative by evaluating the data to assess where improvements have been made. Ongoing challenges to improving CDR data quality in the NFR-CRS will be discussed.

Data Quality Dimensions

Data quality can be measured in several ways, commonly referred to as dimensions, that define properties of the data. The four dimensions of data quality most relevant for monitoring NFR-CRS data are:

1

Completeness. Completeness refers to the extent to which the expected data elements are answered/data are entered. There are two components of data completeness in the NFR-CRS:

- ☐ All deaths meeting the state's criteria for review are reviewed (this can be monitored at the state-level).
- ☐ All expected information from the reviewed deaths are entered in the NFR-CRS with no missing data and few responses marked "unknown."

2

Consistency. Consistency refers to the uniformity and agreement of data elements across cases. Consistency can be monitored in two ways. First, it can be monitored within the data on each death. For example, for an infant death, are all the infant questions in Section A (Child Information) in NFR-CRS answered? This can be monitored at the national as well as state level. Second, consistency can be monitored across deaths with similar circumstances. For example, is supervision consistently documented for unintentional injury deaths of toddlers (guidance for documenting supervision is provided in the NFR-CRS data dictionary)? This can be monitored at the state level. It can be assessed at the national level but would be a resource and time intensive endeavor.

3

Accuracy. Accuracy refers to the extent to which the entered data reflect the known facts about the child, family, and circumstances surrounding the death. For example, is the child's age accurately recorded in the NFR-CRS? Checking accuracy often requires access to a second source of information. At the state level, the narrative (Section O1) can be used to assess accuracy (and consistency) of data entered in other sections of the NFR-CRS.

4

Timeliness. Timeliness refers to the extent to which the data are up-to-date. Several components of timeliness can be measured in the NFR-CRS, including time from death to review, time from review to data entry, time from death/review/initial data entry to date entry marked complete. Different components of timeliness might be important to different states.





Data Quality Summary Report

The Data Quality Summary Report is a key component of the National Center's Data Quality Initiative, it is how data quality is monitored and was developed to provide annual feedback to each state. The development of the Data Quality Summary Report was guided by a Data Quality Workgroup, first convened in October 2015. The Data Quality Workgroup consists of representatives from seven states with experience using the NFR-CRS. During a process review of all variables in the NFR-CRS, 116 priority variables were identified for monitoring data quality. Due to the large number of priority variables identified, the Data Quality Workgroup also suggested a subset of these be designated CORE variables. See [Appendix – Table A](https://bit.ly/3hL3wNp) (URL: <https://bit.ly/3hL3wNp>). Following initial identification of the priority variables, the Data Quality Workgroup has continued to guide the scope and content of the Data Quality Summary Report as it has evolved over the previous five years.

MODELED AFTER SUID/SDY CASE REGISTRY

The Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry, supported by the CDC's Division of Reproductive Health and the National Institutes of Health's National Heart, Lung and Blood Institute and National Institute of Neurologic Disorders and Stroke, builds on CDR programs and uses the NFR-CRS, bringing together information about the circumstances associated with SUID and SDY cases, as well as information about investigations into these deaths.

The Case Registry began in 2009 with seven awardee states receiving CDC funding to conduct SUID surveillance. With additional funding from the NIH, the SDY component was added in 2015, with some awardees increasing their surveillance activities to include sudden and unexpected deaths up to age twenty. Currently, 22 states and jurisdictions are funded for SUID surveillance, with 13 of those receiving additional funding for SDY surveillance. In addition to funding to compile and enter data, awardees also receive dedicated technical assistance from CDC, NCFRP, and the Case Registry Data Coordinating Center. Part of the technical assistance is quarterly monitoring of data quality for established completeness, timeliness, and case ascertainment metrics. The templates and process for the Case Registry Quarterly Data Quality Summaries were used in the initial planning of the first Data Quality Summary Report by the National Center.

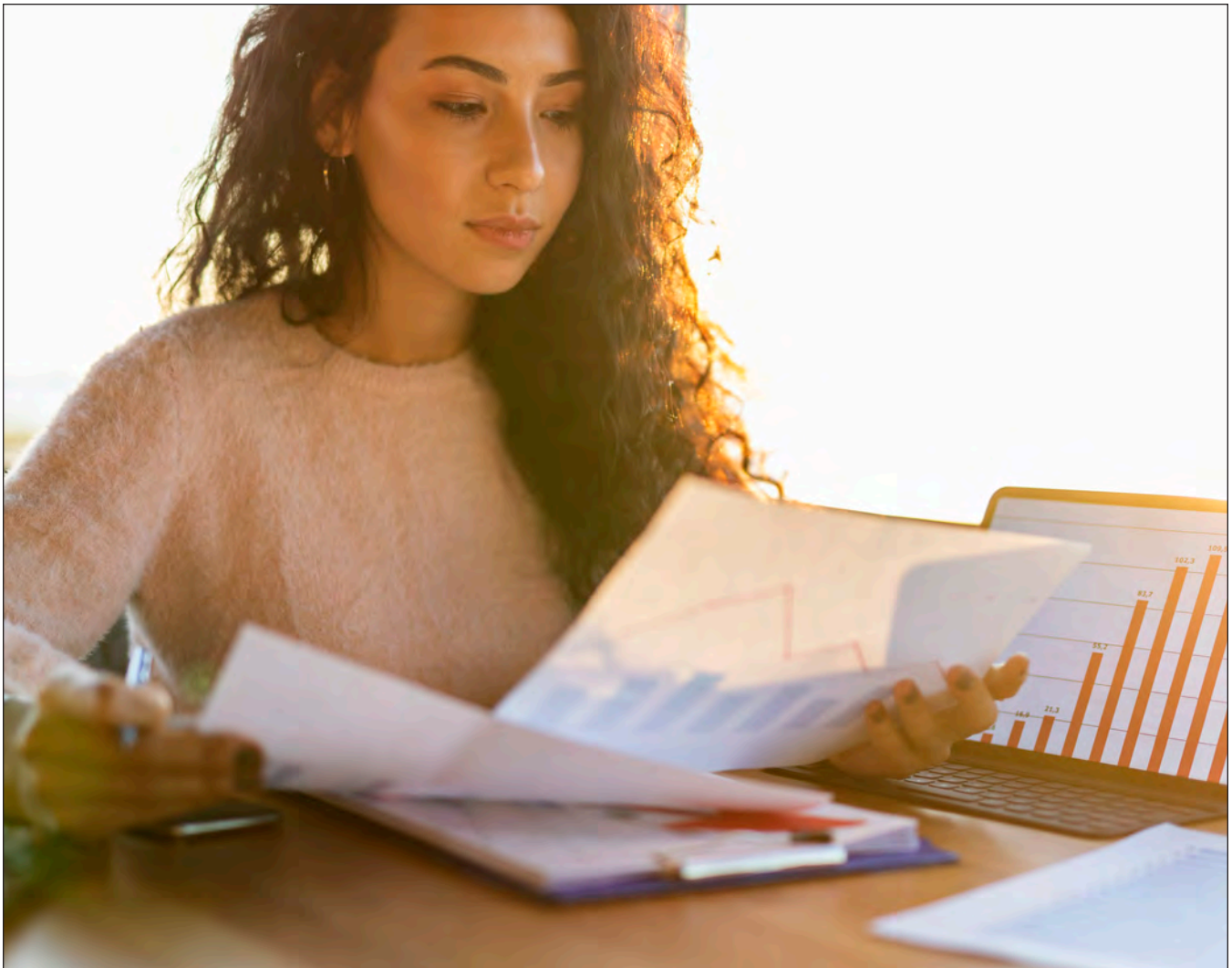
The First Report

The first Data Quality Summary Report, released in October 2016, included all deaths that occurred in 2014 and were entered in the NFR-CRS by June 30, 2016. The report included the number and percent missing and unknown responses for each of the priority variables for the aggregate national data and each individual state with at least 30 deaths entered for the year. The data included in the Data Quality Summary Report account for skip patterns in the NFR-CRS and appropriate denominators are listed. Starting with the second Data Quality Summary Report in 2017, two years of state data are included, the current year, and the prior year. The Data Quality Summary Reports can be used to monitor data quality in the individual states as well as compare the state to national data. They can also be used as a training tool within the state and to guide decisions regarding state data quality efforts. A training video introducing the report and discussing the report's components as well as suggestions for how the data might be used was released with the first reports.

Progress

In the five years since its inception, the Data Quality Summary Report has evolved to include additional data quality dimensions and updates to NFR-CRS. The first three years the Data Quality Summary Reports focused exclusively on completeness, that is, the proportion of priority variables that were missing or unknown in the aggregate national data and in each state. However, to make the Data Quality Summary Report easier for state coordinators to read and interpret, two graphs summarizing key data were added in 2017 (reporting 2015 deaths). One graph highlighted the five priority variables with the highest proportion of missing and unknown national data, and one highlighted the five priority variables with the lowest proportion of missing and unknown national data. Individual state data were included with the national data in each graph for easy visual comparison on how the state was performing compared to all states combined.

In 2019 (2017 data), the Data Quality Summary Report underwent a major redesign. In addition to the original format and graphs, the completeness data were presented in several ways and new data and information were included. These additions included adding a table reporting the percent missing and unknown combined into one proportion for each of the priority variables, as well as two additional tables reporting the combined missing and unknown proportions for the CORE variables and non-CORE variables separately. Timeliness variables and benchmarks for the CORE variables recommended by the Data Quality Workgroup were added in the Data Quality Summary Report. The benchmarks set are a target proportion completeness for states to achieve. In addition, after review by the Data Quality Workgroup, the number of CORE variables was increased by 20 variables for a total of 54. Each of these 20 were priority variables, just not designated CORE. The 2019 report also incorporated changes to variables necessitated by the release of Version 5 of the NFR-CRS.



The most recent addition to the Data Quality Summary Report is the inclusion of consistency checks in 2020 (2018 data). The focus of the consistency checks is to assess the uniformity and agreement of data elements within a death record. Twelve checks of data consistency were chosen for inclusion, based on logic and available data elements. For example, based on instructions in the data dictionary, the response “no, not needed” to question D1. Did the child have supervision at the time of incident leading to death should not be selected for children less than six years of age. When this response is examined by age in the 2018 data it was found that 10% of the deaths with the response “no, not needed” were among children less than 6 years of age. Similarly, if the manner of death is suicide, the person handling the weapon should be “self” for question H5o (6% of suicide deaths did not have “self” marked) and use of weapon at the time should be marked “self-injury” (5% of suicide deaths did not have “self-injury” marked). Due to small numbers, consistency checks are only calculated for the National aggregate data; however, these checks will be run on a state’s data and provided to the state upon request. It is hoped that with increased awareness of the interrelatedness of these variables that consistency will increase with time.



NFR-CRS Changes to Support Data Quality

Progress

Two enhancements focused on data quality have been made to NFR-CRS since the Data Quality Initiative began in 2015. A standardized report focusing on data quality was added in 2018. (The NFR-CRS has over 30 predefined automated reports that enables users to quickly summarize data they have entered). The data quality report facilitates the quick identification of records where data are missing for 18 of the priority variables. This report can be used at the state or local levels to track missing data or flag records for follow-up.

In January 2021, icons identifying each priority variable were added to NFR-CRS. These icons serve as a reminder during data entry of which data elements are priority variables. The hope is that highlighting these variables during data entry will result in fewer missing and unknown entries.

Impact of the Data Quality Initiative on Data Quality in the NFR-CRS

To assess improvements in data quality over the first five years of the Data Quality Initiative, several analyses were conducted. Expecting improvements in data quality to be incremental, change over a five-year time span was assessed, comparing 2018 data, the fifth year report, to 2014 data, the first year.

Analyses Conducted

Missing and unknown responses. The first Data Quality Summary Report included only one data quality dimension: completeness. Documenting the proportion of missing or unknown data for each priority variable has been the primary focus of the Data Quality Summary Report since its inception in 2016. As the report has evolved and additional data quality measures have been added, the proportion of missing and unknown data continues to be a key indicator of data quality. For simplicity, the proportion of missing and the proportion of unknown responses were combined for the purposes of this report. The percent change in missing/unknown between 2014 and 2018, for each priority variable as well as the average percent change for all priority variables, and for the subset of CORE priority variables was evaluated.

Benchmarks. Benchmarks were not established and reported until 2019 (2017 data) and were only applied to the CORE priority variables. The benchmark set was based on the percent missing/unknown in the national aggregate data. If a CORE variable had 25% or more missing/unknown responses, the benchmark for that variable was set at 25%. If a CORE variable had less than 25% missing/unknown responses, the benchmark for that variable was set at 10%. For the purposes of this analysis, the National Center retroactively calculated whether a state would have met the benchmark in the 2014 data. The average number of benchmarks met per state and the average number of states meeting each of the 48 CORE variable benchmarks for 2014 and 2018 was assessed. Due to revision of the suicide section of the NFR-CRS in 2020, six CORE variables related to suicide were not included in the 2020 report, resulting in 48 CORE variables for the benchmark analysis.

Timeliness. Like benchmarks, timeliness was not added until the 2019 report, so the National Center retrospectively calculated timeliness for the 2014 data. For this report, two timeliness variables, the average number of days between the date of death to the date of the review meeting, and the average number of days between the date of death and data entry complete date were examined.

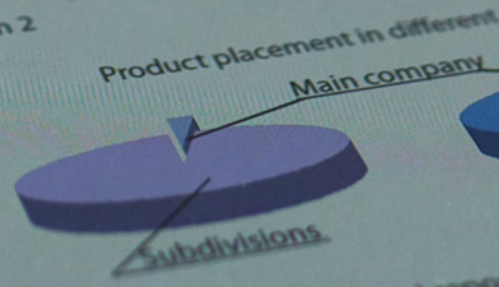
Data included in these analyses. The percent change in missing or unknown data for each priority variable was calculated based on the aggregate national data reported in the 2016 and 2020 Data Quality Summary Reports. This national aggregate data includes all deaths entered in the NFR-CRS for the death year being reported, 2014 deaths reported in 2016 and 2018 deaths in the 2020 report.

Each state with 30 or more deaths entered for the year of death being reported receives their state data on completeness, benchmarks met, and timeliness. In both report years, 35 states had 30 or more deaths entered; 33 of the states had 30 or more deaths in both report years. Two states included in the 2014 data did not have 30 deaths in 2018, and 2 states with 30 or more deaths in 2018 did not meet that threshold in 2014. The benchmark and timeliness analyses included in this report are based only on the 35 states with 30 or more deaths in 2014 or 2018.

Results

Percent change in missing and unknown responses. The percent change for all priority variables are listed in [Appendix – Table A](https://bit.ly/3hL3wNp) (URL: <https://bit.ly/3hL3wNp>). The average proportion of missing or unknown responses for all priority variables declined by 11%, from 24% to 21% over the 5-year period, whereas the decline was 19%, from 25% to 20%, for the 48 CORE priority variables only. That is, improvement, as measured by fewer missing or unknown responses, was demonstrated across the board but was even greater in the subset of CORE priority variables. This finding is consistent with the recommendation that if a state has limited resources that prohibit monitoring data quality for all the priority variables that they would focus first on data quality for the CORE priority variables.

Looking closer at changes in the proportion of missing or unknown responses for the CORE priority variables, one variable, child's age, which is rarely missing, showed no change in percent missing/unknown over the 5-year period. Six of the CORE variables had a net increase in percent missing/unknown while proportion missing/unknown declined in the remaining 41 CORE variables. However, despite this improvement, seven (15%) of the CORE priority variables still have more than 40% missing/unknown responses. The percent change for all CORE variables are listed in [Appendix – Table B](https://bit.ly/3hL3wNp) (URL: <https://bit.ly/3hL3wNp>). Variables with the highest percent decline in missing/unknown responses are shown in [Table 1](#) and variables with greater than 40% missing/unknown are shown in [Table 2](#).



The given analytical report
current situation both in all c
likely it will allow to predict
growth of development of
analysis of analysis data
as a result of some
from other data



Table 1. Core Priority Variables With the Largest Percent Decline in Missing or Unknown Responses Between 2014 and 2018

| Variable | Description | 2014 Missing or Unknown % | 2018 Missing or Unknown % | % Change |
|------------|--|---------------------------|---------------------------|----------|
| I5a | What act caused/contributed (yes/probable) | 2.7% | 0.6% | -77.8% |
| H2b | Type of incident (Fire, Burn, Electrocution) | 6.6% | 1.6% | -75.8% |
| F5 | Autopsy Performed | 18.6% | 7.1% | -61.8% |
| H3d | Drowning location | 8.7% | 3.5% | -59.8% |
| H4a | Type of event (Unintentional Asphyxia) | 4.7% | 1.9% | -59.6% |
| F1 | Was a death scene investigation performed | 33.2% | 13.5% | -59.3% |

Table 2. Core Priority Variables With Greater Than Forty Percent Missing/Unknown Responses

| Variable | Description | 2014 Missing or Unknown % | 2018 Missing or Unknown % | % Change |
|------------|---|---------------------------|---------------------------|----------|
| A15 | Child's health insurance | 60.4% | 54.0% | -10.6% |
| A22 | Child had history of maltreatment as victim | 50.8% | 40.0% | -21.3% |
| D5 | Supervisor age in years | 62.7% | 44.4% | -29.2% |
| D16 | Was supervisor impaired at time of incident | 43.9% | 45.0% | 2.5% |
| H1i | Motor vehicle protective measures | 47.6% | 47.1% | -1.1% |
| H2p | Smoke alarms present (fire deaths only) | 50.0% | 43.2% | -13.6% |
| P | Data Quality Assurance completed by state | 81.0% | 73.3% | -9.5% |

State Summary:

Twenty-four (of 35, 69%) states reduced their proportion of missing/unknown data for the CORE variables between 2014 and 2018; five of these states reduced missing/unknown by more than 50%. Data not shown in [Appendix – Table A](https://bit.ly/3hL3wNp) (URL: <https://bit.ly/3hL3wNp>). The proportion of missing/unknown responses increased during this time period in 9 states.

Benchmarks

The average number of states meeting each benchmark increased by 4, from 20 to 24 states meeting the benchmark. Benchmarks with the greatest improvement (greatest difference in the number of states meeting the benchmark from 2014-2018 are shown in [Table 3](#)).

Table 3. Core Priority Variables With the Greatest Improvement in Number of States Meeting the Benchmark

| Variable | Description | 2014 States Meeting Benchmark | 2018 States Meeting Benchmark | 2018-2014 Difference | Benchmark % Missing/ Unknown |
|------------|--|-------------------------------|-------------------------------|----------------------|------------------------------|
| A15 | Child's health insurance | 5 | 21 | 16 | <25% |
| H2p | Smoke alarms present (fire deaths only) | 19 | 35 | 6 | <25% |
| D6 | Supervisor sex | 14 | 28 | 14 | <25% |
| A22 | Child had history of maltreatment as victim | 11 | 24 | 13 | <25% |
| H8b | Death expected as a result of this condition | 9 | 21 | 12 | <25% |
| F1 | Was a death scene investigation performed | 20 | 30 | 10 | <25% |
| H1a | Child's vehicle type | 17 | 27 | 10 | <10% |

State Summary:

The average number of benchmarks met by each state increased by 6, from an average of 27 benchmarks met to an average of 33 met. In 2014, 2 states met at least 43 of the 48 benchmarks (90%). This increased to 5 states in 2018. Three states ([Table 4](#)) demonstrated considerably more improvement than others, increasing the number of benchmarks met by a low of 28 benchmarks to a high of 38.



Table 4. States With the Most Improvement in Number of Benchmarks Met, 2014-2018*

| State | 2014 Number of Benchmarks Met | 2018 Number of Benchmarks Met | Difference |
|----------|-------------------------------|-------------------------------|------------|
| Montana | 7 | 45 | 38 |
| Delaware | 15 | 46 | 31 |
| Arkansas | 16 | 44 | 28 |

*Data shown with permission by states.



Timeliness

For both timeliness measures, the average number of days for all states declined between 2014 and 2018. The percent change in average number of days for timeliness measures is shown in [Table 5](#).

Table 5. Average Number of Days Between Date of Death and Two Timeliness Measures, 2014 and 2018

| Description | 2014 Average Number of Days | 2018 Average Number of Days | % Change |
|--------------------------------------|-----------------------------|-----------------------------|----------|
| Date of Death to Review Meeting Date | 253 days | 234 days | -7.5% |
| Date of Death to Data Entry Complete | 340 days | 316 days | -7.1% |

State Summary:

The average number of days between date of death and review meeting decreased in 15 states between 2014 and 2018. The average number of days between date of death and data entry complete decreased in 19 states between 2014 and 2018.

Discussion of Results

In the first five years of the Data Quality Initiative improvements have been made in both completeness and timeliness, the two data quality dimensions examined. The proportion of missing or unknown responses for the CORE priority variables decreased by 19% overall and for each of the benchmarks, the average number of states meeting the benchmark increased from 20 to 24. While these improvements are laudable, work remains to be done. Seven (15%) of the CORE priority variables still have more than 40% missing/unknown responses. Large proportions of missing data reduce its usefulness for informing prevention. Improvements in timeliness were also documented but there is still an average of eight months between death and review meeting date and more than 10 months before the data entry is complete.

State Highlights

The three states with the greatest improvements in reducing the proportion of missing/unknown data, meeting benchmarks, and timeliness were Arkansas, Delaware, and Montana. We queried the CDR coordinators in these states to learn what they attributed the improvements in data quality to. The following is a summary from each state:

Arkansas

Program Details

The Arkansas Infant and Child Death Review (ICDR) Program was established through legislation in 2005, however no deaths were reviewed until county-based review teams were established and started conducting reviews in 2011. All unexpected deaths of a child less than 18 years old are eligible for review, an average of 98 deaths per year were reviewed during the 5 years covered in this report. The Arkansas ICDR is housed in the Arkansas Injury Prevention Center within the Arkansas Children's Hospital. Funding for the ICDR Program is provided by the Arkansas Department of Public Health.



Dawn Porter started as the ICDR Program Coordinator in April 2016 and continued in that position through December 2020. Although she has moved to another position within the Injury Prevention Center, she remains involved with ICDR and given that a new ICDR Program Coordinator had not yet been named, Ms. Porter was interviewed for this report. When asked what she attributed the improvements in data quality over the 5-year period covered by this report, she described several initiatives that likely contributed to improved data quality.

Program Components Contributing to Improved Data Quality

Local CDR team members in Arkansas are essentially volunteers, that is they serve on the review team as a representative of the agency or organization where they are employed. In 2016, the 11 county-based review teams were relatively new, and some were still being established. When Ms. Porter started as Coordinator that year, she noted a lack of data reported in the ICDR Annual report and immediately decided to focus on improving the ICDR data.

1

Ms. Porter traveled to and met with each team to help them understand the larger prevention purpose of the reviews, the important role complete and accurate data are in understanding how children die and identifying effective prevention strategies, and to understand their barriers to obtaining and recording information necessary for complete and accurate reviews. It became clear that obtaining all the information pertinent to the death in advance of the review meeting was often a challenge and entering the data into the NFR-CRS was a particular burden for the local team members, resulting in high proportions of missing data and long delays in data entry.

2

Based on these findings Ms. Porter developed a one-page sheet for each agency detailing the information they needed to bring to each review meeting.

3

She attended every meeting of each of the 11 county-based teams and early in her tenure decided to take over responsibility for data entry following the review. Having one person who attends all the review meetings be responsible for data entry facilitates completeness and consistency in data entry, and results in improved data quality.

4

During the review meetings she queries the team if key data components are not available, facilitates acquisition of missing information, and discusses what needs to be done to ensure more complete availability in the future.

5

During initial meetings with the local teams, she helped them build relationships with key organizations; these relationships have resulted in improved data acquisition and quality over time.

6

Ms. Porter actively uses the annual Data Quality Summary Reports to provide feedback to the local teams on areas of improvement over the prior year and areas where improvements are still needed.

7

The Data Quality Summary Reports are also used to identify gaps and weaknesses in the program or resources available at the local level and help focus program priorities and strategic planning.

Ongoing Challenges to Data Quality Improvements

Despite all these program improvements that have resulted in improved data quality, challenges remain in Arkansas. The biggest ongoing challenge is with high turnover in the county review team membership and the resulting need of nearly constant training of new members. An immediate and related, although hopefully temporary, challenge facing the program involves rebuilding the county-level teams after they were crippled by COVID-19 during the pandemic. Many team members were involved in COVID response, reviews were delayed or did not take place, and team members moved on. Re-establishing teams, training team members, and re-establishing relationships with key agencies, organizations, and individuals is the current challenge faced by the Arkansas ICDR.

Table 6. Arkansas Data

| 2014 CORE Average Missing/Unknown % | 2018 CORE Average Missing/Unknown % | % Change |
|-------------------------------------|-------------------------------------|----------|
| 28.4% | 6.1% | -79% |

| 2014 Number of CORE Benchmarks Met | 2018 Number of CORE Benchmarks Met | Difference |
|------------------------------------|------------------------------------|------------|
| 16 | 44 | 28 |

| 2014 Mean DOD* to Data Entry | 2018 Mean DOD* to Data Entry | % Change |
|------------------------------|------------------------------|----------|
| 767.6 days | 608.6 days | -20.7% |

*DOD = Date of death





Delaware

Program Details

The Delaware Child Death Review Commission was established in 1995 by statute. After functioning within several different agencies, the Commission became a state agency with dedicated staff in 2004. The Commission is housed within the Delaware Judiciary, which ensures stability and allows the Commission to advocate for policy change. All deaths among children less than 18 years old are reviewed by one of 2 panels. The Sudden Death in the Young (SDY) panel reviews all Delaware child deaths that meet the SDY criteria, and the Child Death Review Panel reviews all other Delaware child deaths. An average of 57 deaths per year were reviewed during the 5 years covered in this report. The data are collected and entered in the NFR-CRS by one of two staff with final quality checks conducted by the Director. Delaware also conducts fetal and infant mortality reviews (FIMR) and maternal mortality reviews. Funding for the Commission is provided through the state budget, as well as the Centers for Disease Control and Prevention's (CDC) Sudden Unexpected Infant Death (SUID) and SDY case registries, and an Enhancing Reviews and Surveillance to Eliminate (ERASE) Maternal Mortality grant, also from the CDC.

Anne Pedrick has served as a member of the Delaware Child Death Review Commission since 2001 and has been the Director since 2006. When asked what she attributed the improvements in data quality between the 2014 and 2018 recorded deaths documented in these analyses to, Ms. Pedrick mentioned several changes implemented in 2015.

Program Components Contributing to Improved Data Quality

1

Until 2015, the CDR panel included a review of all deaths and near fatalities resulting from child abuse and neglect. Over the prior ten years, the number of deaths identified as due to child abuse or neglect increased, resulting in a dramatically increased workload for the review panels and Commission. In 2015, the responsibility for reviewing these deaths was transferred to another agency, thus reducing the workload and freeing up to Commission to focusing on eliminating the backlog of reviews of other causes of death.

2

The Commission also implemented a policy that reviews occur within 6 months of the death unless the death was pending prosecution. Per statute, deaths pending prosecution could not be reviewed until prosecution was complete, but this requirement had resulted in a backlog of non-reviewed deaths. Some deaths pending prosecution were never prosecuted, for example, unsolved murders. Consequently, these deaths remained in the system indefinitely. To address these languishing cases, the Commission put a cap of two years on the length of time a death pending prosecution could be in the system. After two years, if the prosecution has not occurred, the case is closed.

3

To better monitor the timeliness of reviews and other components of the review process, the Director developed a case management system to track the progress of individual deaths through the review and data entry process.

4

Delaware was awarded a SDY Case Registry grant in 2014, commencing in 2015. This resulted in the addition of one staff member ensuring additional staff time for the review process, data entry, and quality checks.

5

In 2015, collaboration with the Medical Examiner's Office improved, and training on death investigations was completed with law enforcement agencies. Both improvements are thought to contribute to the improved data quality.

Finally, the development and release of the first Data Quality Summary Report in 2016 offered concrete guidance on variables to monitor and focus on for improvement. The later addition of icons identifying the priority variables in the CRS during data entry also helped immensely. Ms. Pedrick also mentioned that having staff that are detail oriented is critical to ensuring data quality.

Ongoing Challenges to Data Quality Improvements

When asked about challenges to data quality improvements in Delaware, Ms. Pedrick discussed the challenge of sharing records and other information across state lines. Delaware is a small state that shares borders Pennsylvania and Maryland. If a child dies after recently moving to Delaware from one of these bordering states, the Commission does not have jurisdiction over requesting records or information necessary for a complete review. Having a data sharing agreement with bordering states would ensure more complete data for review and enhance the overall quality of the Delaware data.

Table 7. Delaware Data

| 2014 CORE Average Missing/Unknown % | 2018 CORE Average Missing/Unknown % | % Change |
|-------------------------------------|-------------------------------------|----------|
| 43.6% | 5.8% | -87% |

| 2014 Number of CORE Benchmarks Met | 2018 Number of CORE Benchmarks Met | Difference |
|------------------------------------|------------------------------------|------------|
| 15 | 46 | 31 |

| 2014 Mean DOD* to Review Meeting | 2018 Mean DOD* to Review Meeting | % Change |
|----------------------------------|----------------------------------|----------|
| 411.8 days | 187.1 days | -54.6% |

| 2014 Mean DOD* to Data Entry | 2018 Mean DOD* to Data Entry | % Change |
|------------------------------|------------------------------|----------|
| 639.4 days | 383.8 days | -40.0% |

*DOD = Date of death





Montana

Program Details

The Montana Fetal, Infant, Child, and Maternal Mortality Review (FICMMR) program was established in 1997 by legislation. FICMMR is housed within the Montana Department of Public Health and Human Services. All fetal, infant, and child deaths (children less than 18 years old) are reviewed by county-based review teams. An average of 115 deaths per year were reviewed during the 5 years covered in this report. The data are collected and entered in the NFR-CRS by the county FICMMR leader with final quality checks conducted by the state FICMMR Coordinator. Montana also conducts maternal mortality reviews. Funding for FICMMR is provided through the state's Maternal and Child Health Title V Block Grant.

Kari Tutwiler has served as state FICMMR Coordinator since 2015. When asked what she attributed the improvements in data quality over the 5-year period covered by this report, she described several key elements to her data quality control efforts that likely contributed to improved data quality.

Program Components Contributing to Improved Data Quality

1

Once data are entered into the NFR-CRS by the county FICMMR leader, the state FICMMR Coordinator reviews the details on each death and documents any inconsistencies or missing data elements. The FICMMR Coordinator summarizes any inconsistencies or missing data in a letter to the county FICMMR leader, with requests for further explanation and modification of the data entered. These letters include praise for the positive aspects of the data entered, as well as an explanation of why the modification request is being made, and an opportunity to discuss.

2

Through these modification letters and follow up telephone calls, the FICMMR Coordinator has established a supportive relationship and provides ongoing technical assistance provided to the county FICMMR leaders.

3

The FICMMR Coordinator also conducts training conference calls for all FICMMR leaders, held quarterly. These training sessions have contributed to improved data quality over time.

Ongoing Challenges to Data Quality Improvements

When asked about challenges to data quality improvements in Montana, Ms. Tutwiler discussed the fact that FICMMR duties: obtaining and reviewing numerous medical and other records, facilitating the mortality reviews, and entering the review data are just a few of the FICMMR leader's key responsibilities at their local county health departments. Staff shortages locally often contribute to the challenge of prioritizing staff time, and frequent turnover among the county FICMMR leaders exacerbates these challenges. Further, several counties have instituted barriers to obtaining information, requiring law enforcement and death scene investigation reports only be released by the county attorney. Accessing death reports and investigation information can also be extremely challenging when the death occurs on Native American tribal lands (Reservations). Montana has eight federally recognized Native American Tribes. Officials on some of the Montana reservations serve as members of the local FICMMR team helping provide critical insights, others decline to do so, providing a unique challenge to ensuring data quality and completeness.

Table 8. *Montana Data*

| 2014 CORE Average Missing/Unknown % | 2018 CORE Average Missing/Unknown % | % Change |
|-------------------------------------|-------------------------------------|----------|
| 9.7% | 4.8% | -51% |

| 2014 Number of CORE Benchmarks Met | 2018 Number of CORE Benchmarks Met | Difference |
|------------------------------------|------------------------------------|------------|
| 7 | 45 | 38 |

| 2014 Mean DOD* to Review Meeting | 2018 Mean DOD* to Review Meeting | % Change |
|----------------------------------|----------------------------------|----------|
| 297.6 days | 251.7 days | -15.4% |

| 2014 Mean DOD* to Data Entry | 2018 Mean DOD* to Data Entry | % Change |
|------------------------------|------------------------------|----------|
| 362.8 days | 344.0 days | -5.2% |

*DOD = Date of death

Remarkably, these three states are dissimilar in important ways, emphasizing that there is not a specific formula for improving data quality at the state level regarding size of the state; number of deaths reviewed; where the program is based; or program details such as type, scope, or funding.



Many of the challenges to improving data quality that existed before the Data Quality Initiative was launched in 2015 continue to be challenges after the first five years, including the large number of registered users and frequent personnel turnover in state and local CDR programs that make training and technical assistance a constant need. Furthermore, the number of data elements and the complexity of the data system continue to present significant challenges to data quality; these issues have the potential to increase with the release of Version 6 in 2022. Although not an issue the Data Quality Initiative was designed to address, limited staff and resources at state CDR program offices inhibit development and implementation of comprehensive data quality monitoring procedures. This may be a significant limitation to improving data quality in the long term. To address this, our goal is to help states develop data quality programs that meet their needs and can be implemented with their existing resources.

Conclusions and Next Steps

The documented improvements in data quality over a relatively short time are to be commended and provide a positive structure for sustained progress. However, the key challenges to data quality – a large number of users and high staff turnover – remain, requiring creative strategies for addressing continued improvements in data quality. This report focused on completeness and timeliness. Improvements in both dimensions were documented, but there is still room for improvement. Some priority variables have over 40-50% missing responses, which limits the usefulness of the data. The average number of days from death to review and data entry is still eight to eleven months, respectively, with some states taking well over a year and one-half to complete the reviews and data entry. Setting benchmarks for timeliness might bring this data quality dimension into sharper focus for states. Several consistency checks were introduced in the Data Quality Summary Report in 2020, too recent to include in this report. However, exploring embedding changes in the NFR-CRS to automatically limit inconsistent entries could greatly improve data quality. The release of version 6 of the NFR-CRS in 2022 will require revision of the priority variables and provide new opportunities to address data quality.

Appendix

Visit the NCFRP website to view the [supporting data for this report](https://bit.ly/3hL3wNp) (URL: <https://bit.ly/3hL3wNp>).

This report was made possible in part by Cooperative Agreement Numbers UG7MC28482 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling \$944,745 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Copyright © September 2021 MPHI



www.ncfrp.org