New Resources from the National Center for Fatality Review and Prevention
About the National Center for Fatality Review and Prevention

• The National Center for Fatality Review and Prevention (NCFRP) is a resource and data center that supports child death review (CDR) and fetal and infant mortality review (FIMR) programs around the country.

• Supported with funding from the Maternal and Child Health Bureau at the Health Resources and Services Administration, the Center aligns with several MCHB priorities and performance and outcome measures such as:
  – Healthy pregnancy
  – Child and infant mortality
  – Injury prevention
  – Safe sleep
HRSA’s Overall Vision for National Center

• Through delivery of data, training, and technical support, National Center will assist state and community programs in:
  – Understanding how CDR and FIMR reviews can be used to address issues related to adverse maternal, infant, child, and adolescent outcomes
  – Improving the quality and effectiveness of CDR/FIMR processes
  – Increasing the availability and use of data to inform prevention efforts and for national dissemination

• Ultimate Goal:
  – Improving systems of care and outcomes for mothers, infants, children, and families
Acknowledgement

• The National Center is funded in part by Cooperative Agreement Numbers UG7MC28482 and UG7MC31831 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 $1,099,997 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.
Housekeeping Notes

- Webinar is being recorded and will be available within 2 weeks on our website: www.ncfrp.org
- All attendees will be muted and in listen only mode
- Questions can be typed into the “Questions” pane
  - Due to the large number of attendees, we may not be able to get to all questions in the time allotted
  - All unanswered questions will be posted with answers on the NCFRP website
- For video sound, please turn your volume up on your computer speakers
Webinar Goals

• Identify resources available from the National Center.
• Clarify process for requesting technical assistance.
• Learn about new training modules.
Let’s Meet The Team Video
Our Goal

• Learning from death reviews so we can prevent future deaths and help communities celebrate more birthdays
SUID and SDY Case Registry

• Funded by the CDC and NIH
• Builds on child death review programs and uses the NCFRP National Fatality Review Case Reporting System in 22 states/jurisdictions to bring together information about deaths of infants, children and youth to develop strategies to prevent future deaths
  – Expanded SDY Component in 13 jurisdictions
Meet Our Partners

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

citymatch
The National Organization of Urban MCH Leaders

SAFE KIDS WORLDWIDE™

JOHNS HOPKINS BLOOMBERG SCHOOL of PUBLIC HEALTH

The National Center for Fatality Review and Prevention
Meet Our Partners

Teri Covington
Programs Consultant

Heather MacLeod
SUID/SDY Case Registry Consultant

Patti Schnitzer
Data Systems Consultant
Website and Social Media

National Center for Fatality Review & Prevention
Supporting Fetal and Infant Mortality Review and Child Death Review Teams

There are many ways to stay in touch with the National Center for Fatality Review and Prevention:

- twitter.com/NationalCFRP
- facebook.com/NationalCFRP
- www.ncfrp.org
- 800.656.2434
- info@ncfrp.org

The National Center for Fatality Review and Prevention
Technical Assistance—Review Process

- Implementing/enhancing review meetings
- Engaging/revitalizing state/local teams
- Building collaboration between review systems
- Best practices in specific causes of death
Technical Assistance—Best Practices

- Writing effective prevention recommendations
- Reviewing prevention recommendations to identify trends and develop action plans
- Tips for effective advocacy
- Strategic planning
- Self-care/vicarious trauma
Technical Assistance—Written

- CDR listserv
- FIMR listserv
- Best practice guidances
- Informational brochures
Quarterly Newsletters

- Upcoming Events
- Field Notes: Highlights for State and local programs
- Data Matters
- Resources for Prevention
- Kudos Corner
- Opportunity for Fatality Review Partners
Webinars

• Process and best practice webinars specific for fatality review field
• Topics generated from evaluations, regional calls and hot topics
Regional Support

• Purpose:
  – Create a “virtual” learning collaborative around FIMR or CDR, by Region
  – Strengthen support available to state CDR coordinators and local and state FIMR coordinators and team members
  – Exchange Information
  – Share successes
  – Mutual problem solving
CDR Regional Networks

Key: Regions
- West*
- Midwest
- Mid-Atlantic
- Southeast
- Northeast

*Including Guam and Navajo Nations
Puerto Rico – 1 project, in US affiliated Islands FIMR CoIN

175 FIMR Programs in 28 States, DC,
Support for Healthy Start

• Healthy Start Initiative: Eliminating Disparities in Perinatal Health
• 100 grantees in 35 states and DC
• Goals: improve health outcomes before, during, and after pregnancy, and reduce racial/ethnic differences in rates of infant death and adverse perinatal outcomes
• Demonstrate collaboration with FIMR, Maternal Mortality Review, and/or Perinatal Periods of Risk (PPOR)
National Center Data Technical Assistance

- National Fatality Review Case Reporting System
- Data Quality
- Data Dissemination
- Data Products
NFR-CRS by the numbers...

- 45 states - CDR
- 16 states - FIMR
- >2,100 users – CDR
- >235 users - FIMR
- 2,600 variables – CDR
- 3,600 variables - FIMR
- >216,400 cases – CDR
- >3,800 cases - FIMR
So many users, so many variables.....
Common requests for Technical Assistance

• Missing and inconsistent data
• Timeliness of data entry
• Understanding Poor/Absent Supervision, Abuse, Neglect, Exposure to Hazards
• Data entry implications for multiple gestations
• “What if?” scenarios....... 
• Shortcuts/tips in working with your data
Major releases every 2-3 years
Minor releases approx. annually
NFR-CRS enhancements come from the great ideas suggested by our users!!
Your input is always welcome
Data Quality

Patti Schnitzer
Data Systems Consultant
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
NFR-CRS Data Dissemination

- De-identified CDR data available to researchers
  - Interested researchers must complete a detailed application
  - Application reviewed by committee
- FIMR data will be available to approved researchers in two years
Data Products

Keeping Kids Safe In and Around Water
Exploring Misconceptions that Lead to Drowning

July 2016

Paediatric suicide in the USA: analysis of the National Child Death Case Reporting System

Henderson S. Thompson,1,2 Elisa M. Reynolds,1 Sarah W. Peterson,1 Faith E. Styker,2 Richard Lichtenstein1

INTRODUCTION

Suicide is a leading cause of death among young people. The motivations behind child deaths in the USA are not well understood, and the impact of suicide on health and survival are poorly understood. The National Child Death Case Reporting System (NCDCRS) is a large, national surveillance system that provides detailed data on child deaths in the USA. The system is designed to identify child deaths that are preventable, and to improve the understanding of the circumstances and causes of child deaths.

METHODS

The NCDCRS is a population-based surveillance system that collects information from all 50 states and the District of Columbia. The system includes data from all causes of death, including suicide. The data are collected from a variety of sources, including medical examiner offices, coroners, and other public health agencies.

RESULTS

The results of this study are based on data from the NCDCRS. The study included all cases of suicide among children aged 1 to 17 years in the USA from 2001 to 2013. The data were analyzed using statistical methods, including logistic regression and survival analysis.

CONCLUSIONS

The findings of this study suggest that suicide among children is a significant public health concern. The results also highlight the need for more research to better understand the factors that contribute to suicide among children.
Quick-Looks

- Infographics using NFR-CRS data
- Available at ncfrp.org under Data – Quick-Looks
- Send us topics you would like to see featured
Requesting Technical Assistance

• Contact any National Center staff or email info@ncfrp.org

• Helpful to share:
  – Training need
  – Date, time, location
  – Audience

• Remember there is no cost to your state for on-site technical assistance
Video Modules

• 13 video modules to support the work of CDR and FIMR teams
• All under one-hour in length
• All available on our website
Module topics

Process Topics
• Child Death Review 101
• Fetal and Infant Mortality Review 101
• National Fatality Review-Case Reporting System: Overview and Common Features
• Maternal Interviews
• Writing Recommendations
• Translating FIMR Findings into Action

Best Practice Topics
• Best Practices for Improving Data Quality
• Meeting Facilitation
• Effective Review Team Meetings
• Building, Maintaining, and Sustaining FIMR Teams
• Collaborating Across Review Systems
• Partnering for Prevention
• Using Health Equity in Fatality Review
Accessing the modules
Session 1: Child Death Review 101

Session 2: Best Practices for Improving Data Quality

Session 3: Meeting Facilitation

Session 4: Effective Review Team Meetings
Navigating

- Session name
- Speaker
- Length of module

- Session description
- Additional resources
Using the modules: Teams

- For Teams
  - Orientation for new members
  - Annual team training sessions
  - When rolling out a new process (maternal interviews; using the NFR-CRS)
  - When there are no cases ready for review
Using the modules: Leaders and Partners

• For Coordinators
  – Build capacity in coordination and team leadership
  – Onboarding new staff

• For Partners
  – Inform partners about the CDR/FIMR process
  – Recruit new members
• As a reminder:
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  – Due to the large number of attendees, we may not be able to get to all questions in the time allotted
  – All unanswered questions will be posted with answers on the NCFRP website
  – **Recording of webinar and copy of slides will be posted within 2 weeks on the NCFRP website**: [www.ncfrp.org](http://www.ncfrp.org)
National Center is on Social Media: NationalCFRP
What’s Next?

Our next webinar:
Dynamic collaboration with other review processes

May 2019
Registration coming soon...
THANK YOU!

Additional questions can be directed to: info@ncfrp.org