

Novel Use of a National Case Reporting System for Data Delivery and Case Notification

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Office of Health Informatics

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Outline

- **Background**
 - Definitions
 - Wisconsin statistics
- **Methods**
 - Local health department interviews
 - Identify data needs
 - Identify common data barriers
- **Results**
 - Goals
 - Technical solutions
 - Use of case reporting system
- **Limitations**

Definitions

- In Wisconsin, a fetal death is defined as one of the following:
 - 350 grams or more
 - 20 completed weeks gestation or more, calculated from the date the last normal menstrual period began to the date of delivery

Definitions

- Infant death: death occurring before a child's first birthday if the child was born alive, without regard to gestational age or weight
- Infant mortality rate (IMR): number of infant deaths per 1,000 live births during the given time period

Definitions

- Child: “A child means every human being below the age of 18 years.” (WHO, United Nations’ Convention on the Rights of the Child, 2015).
- Child death: death of a child from birth until 18 years.

Fetal and Infant Mortality Review (FIMR) and Child Death Review (CDR)

FIMR

- Community led teams
- Stillborn and Infant (up to one year) deaths
- De-identified data presentation
- Includes maternal health factors
- Local action

CDR

- Community led teams
- Review deaths of all children 0-18 years (may extended up to 20 or 25)
- May include Infant Death Review
- Identified cases
- Leads to local action

FIMR and CDR

	Child death review (CDR)	Fetal infant mortality review (FIMR)
Cases reviewed	At a minimum, CDR teams review all deaths to children younger than age 18. However, many Wisconsin teams review deaths to children and adults younger than age 25.	FIMR teams review all stillbirths weighing more than 350 grams or 20 weeks gestation and all infant deaths occurring in the first year of life.
Purpose	CDR teams are comprised of professionals from a variety of agencies who identify risk factors and circumstances surrounding the death in order to prevent future deaths.	FIMR teams are comprised of professionals and community members from a variety of backgrounds who seek to improve maternal and fetal (stillbirth) health.

Wisconsin Statistics

- Population: 5,730,937 (2013)
- 72 counties
- 99 local health departments
- Approximately 350 fetal deaths and 425 infant deaths annually



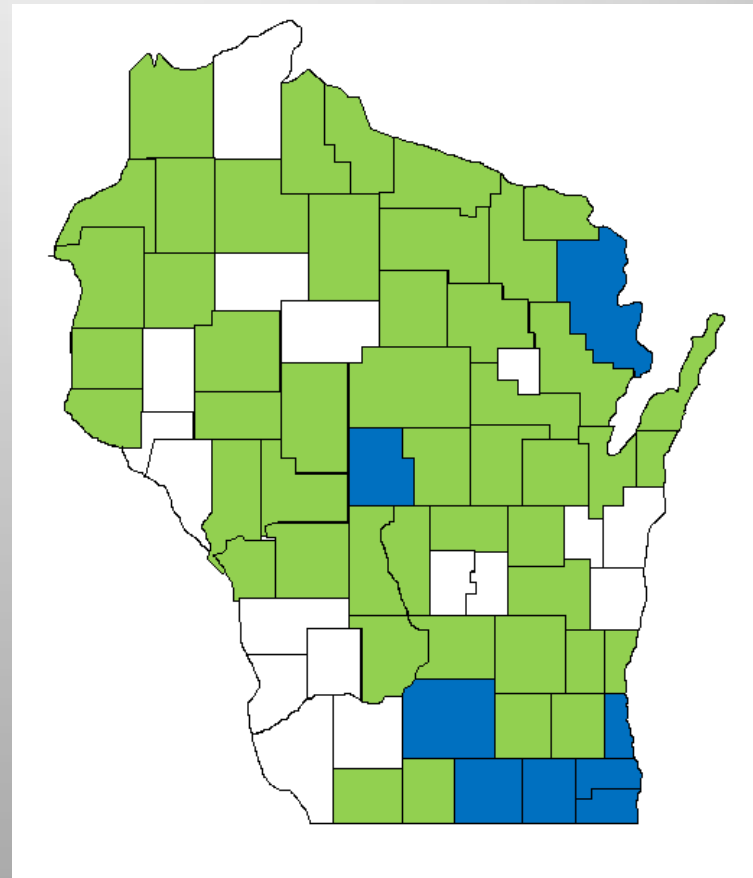
Strengthening Health Systems through Interprofessional Education



Health Systems Integration Program

Wisconsin FIMR and CDR

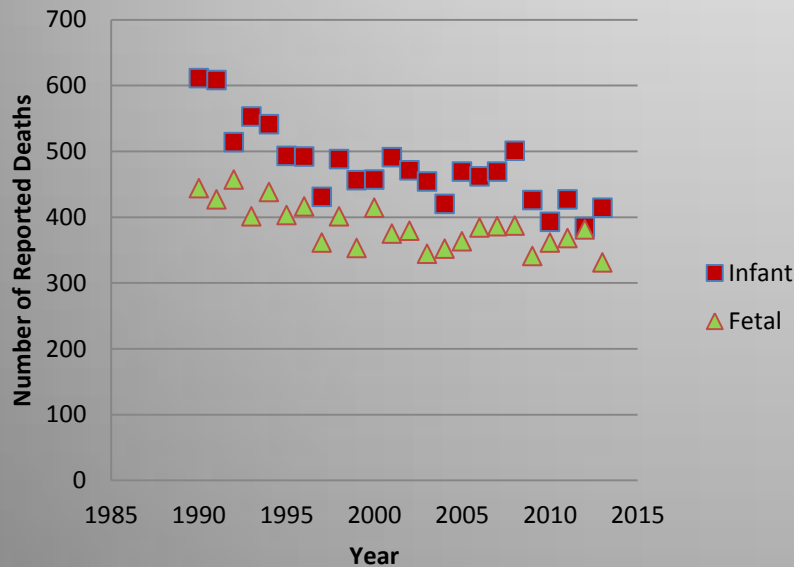
- Wisconsin has:
 - 8 active FIMR teams
 - Covering 2.2 million people (38% of the population)
 - Represents 48% of infant deaths
- Wisconsin has:
 - 48 CDR teams
 - Covering 51 counties and 90% of the population



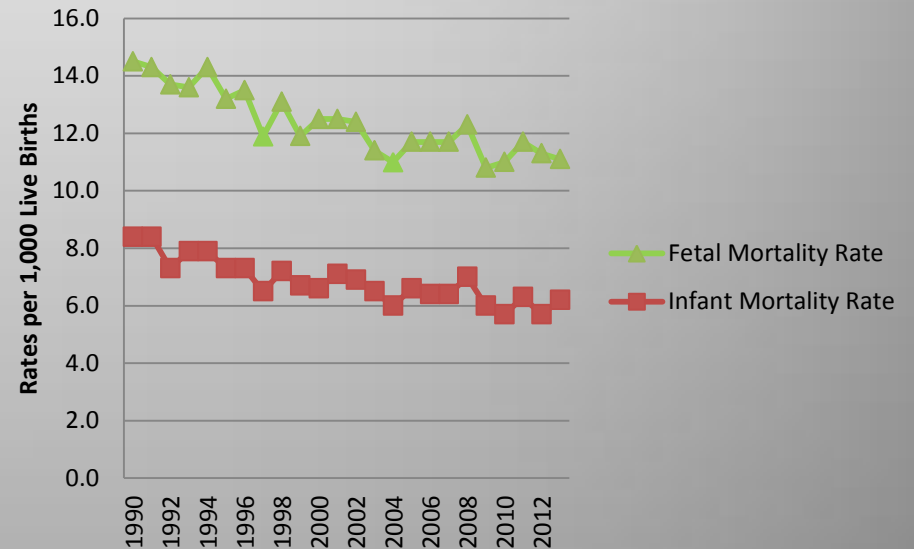
FIMR 
CDR 

Infant and Fetal Death Trends

Wisconsin Fetal and Infant Deaths



Wisconsin Fetal and Infant Mortality Rates



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Local Health Department Outreach

- Children's Health Alliance of Wisconsin
- Met with each of the eight local health departments to discuss data access for purpose of FIMR
- Aggregated common data sources and data barriers

Data Needs

- How do FIMR teams get their information?

Obituary

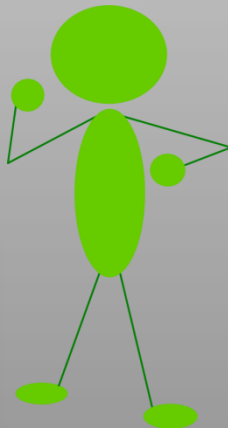
Word of Mouth

Voluntary Reporting

Social Media
(such as Facebook)

Support Groups

Newspaper



Data Sources for FIMR

- Vital records: death certificate and birth certificate data
- Autopsy report
- Family or maternal interview
- Maternal and pediatric medical records
- Law enforcement
- Child Protective Services

Data Barriers

- Absence of mandated collection and reporting of specific data
- Varied interpretation at hospital level
- Varied access to electronic medical records
- Timely access to data
- Multiple LHD jurisdiction example

Vital Records Data Needs

Fetal Death	Fetal Death Record
Infant Death	Death Certificate Birth Certificate
Child Death	Death Certificate



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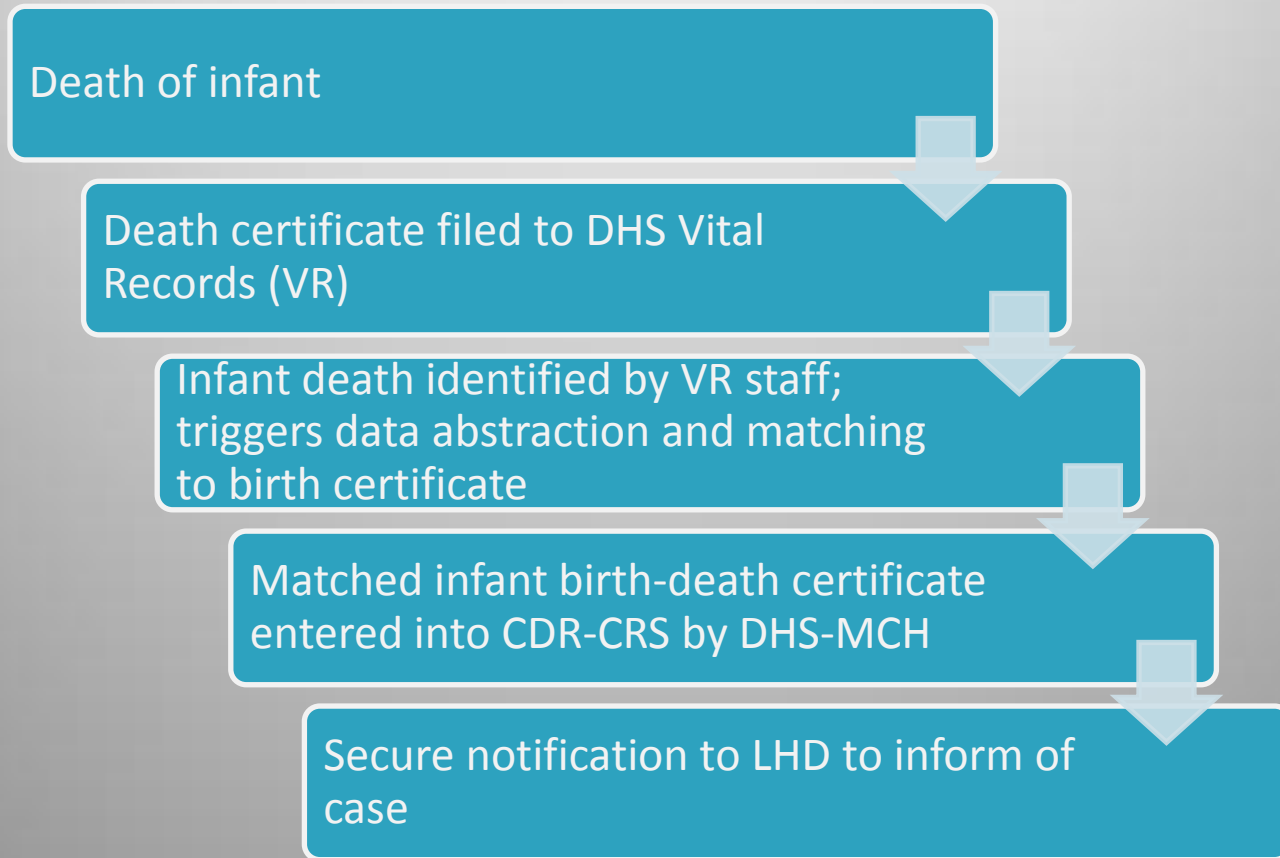
Goals of Project

- Timely notification
- Matched birth-death information
- Maternal data access
- Standardized format
- Reduce errors in data entry
- Secure format
- Initiate process for FIMR or CDR
- Reduce data requests
- Reduce access to unnecessary data fields

Technical Solutions

- Provide data file from Vital Records to LHD.
- Use Child Death Review Case Reporting System to securely deliver data.
- Inform LHD via case notification to initiate download and review.

Process of Case Entry



Process of Case Entry (Continued)

LHD searches CDR-CRS using PII and “pulls” case into jurisdiction.

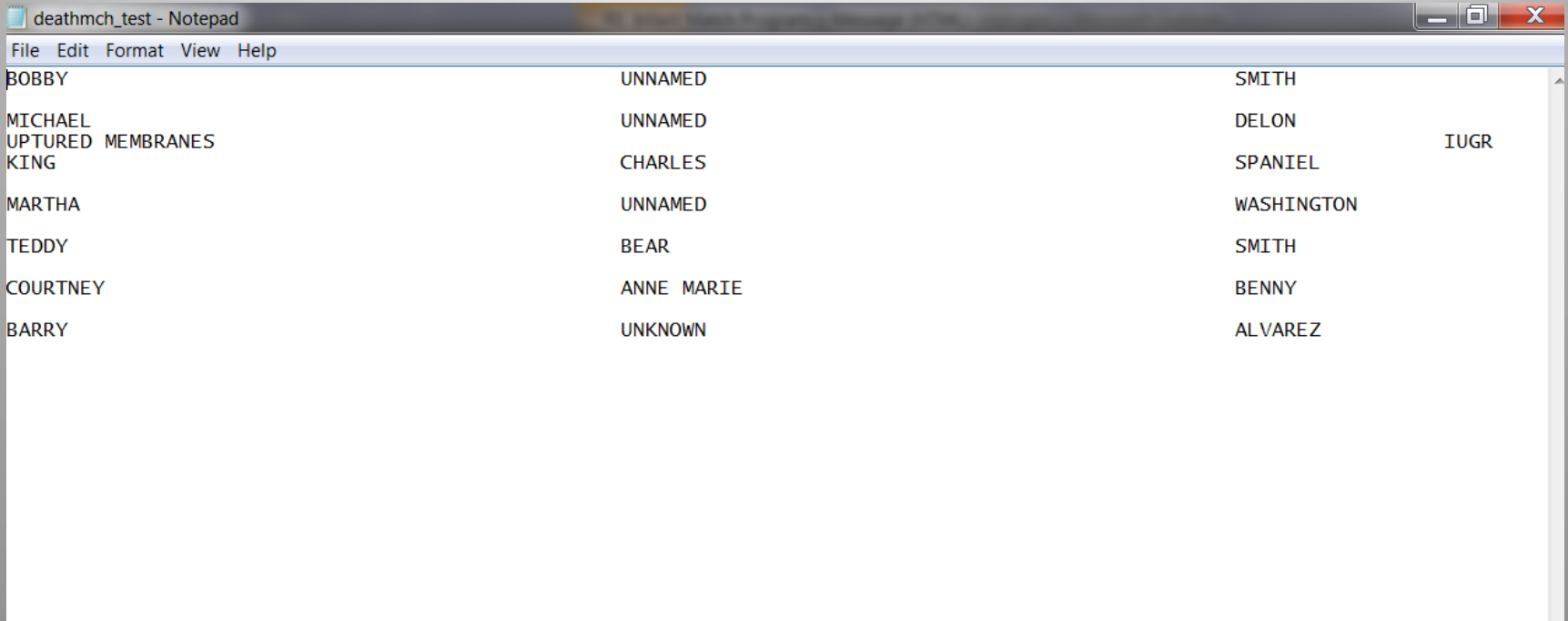
Local FIMR decides whether to review or report without review.

Local FIMR team may continue with investigation.

Local FIMR team can amend CDR-CRS.

FIMR team meeting: de-identified presentation.

Vital Records Infant Death File



The screenshot shows a Notepad window with the following text:

BOBBY	UNNAMED	SMITH	
MICHAEL UPTURED MEMBRANES KING	UNNAMED	DELON	IUGR
	CHARLES	SPANIEL	
MARTHA	UNNAMED	WASHINGTON	
TEDDY	BEAR	SMITH	
COURTNEY	ANNE MARIE	BENNY	
BARRY	UNKNOWN	ALVAREZ	

Vital Records Infant Birth File

```
birthmch_test - Notepad
File Edit Format View Help
201306170612062013ALVAREZ          BARRY          03042014008552    WI383856018802Y11081975MARRY          UNN, ^
201400047201062014SMITH           BOBBY          01062014000533    WI210422018801Y01011988BETH          BETI
201400144101042014DELON           MICHAEL        01042014001885    WI180142020201Y04271991BRITTANY      LIE:
201400338101152014SPANIEL         KING           01152014003156    WI210380018804Y01251982RITA          UNN,
201400668602102014BENNY           COURTNEY       02102014010901    WI230615018800Y05171992MEGHAN        UNN,
201306635808132013WASHINGTON      MARTHA         020820142014005428WI402750018800Y01011990KATHERINE UNN,
```

Vital Records Linked Data File

	A	B	C	D
1	birth record			
2	Birth state file number	1-10		
3	date of birth	11-18		
4	last name	19-40		
5	first name	41-61		
6	date of death	62-69		
7	death state file number	70-79	This field is 10 characters and some records have the six digit number preceded by the year and others don't	
8	death state	80-81		
9	gestation weeks	82-83		
10	weight in grams	84-87		
11	plurality	88-89		
12	births born alive this delivery if plural	90-91		
13	live births now living	92-93		
14	prenatal care	94-94		
15	mother's date of birth	95-102		
16	mother's first name	103-122		
17	mother's middle name	123-142		
18	mother's current last name	143-162		
19	mother's birth last name	163-182		
20	birth id	182-191		
21				
22				
23				
24				
25				

Case Reporting System



Logged in as **Wisconsin Training1. (Wisconsin - Vernon)** Logout

- [Main](#)
- [Your Account](#)
- [Enter New Case](#)
- [Manage Cases](#)
- [Standardized Reports](#)
- [My CDR Outcomes](#)
- [Data Download](#)
- [Help](#)
- [Logout](#)

Welcome, Wisconsin

Nothing compares to the death of a child, in the sadness, the sense of loss, the unfulfilled promise. It reverses the natural order, and challenges our belief in a universal good.

- Dr. William Perloff, Chair, Wisconsin Child Fatality Review Team

Thank you for your efforts to prevent future injuries and deaths of children in your community. Entering your data into this system allows you to monitor the deaths that occur in your community and identify key prevention efforts that will protect your community's children.

For more information, please contact:

Abby Collier
Project Manager, Children's Health Alliance of Wisconsin
ajcollier@chw.org
414-292-4016

If you need assistance using the data system, please contact Abby Collier or the National MCH Center for Child Death Review at 800-656-2434.

Understanding How
And Why Children Die



& Taking Action to
Prevent Child Deaths



Strengthening Health Systems through Interprofessional Education



Health Systems Integration Program

Administrator Case Entry

Microsoft Word - InjuryCau... x CDR Case Reporting System... x

https://cdrdata.org/case/record/import

Google

The National Center for the
REVIEW & PREVENTION
OF CHILD DEATHS

Logged in as **Andrea Gromoske, (Wisconsin)** Logout

Main
Administration
Your Account
Enter New Case
Manage Cases
Standardized Reports
My CDR Outcomes
Data Download
Help
Logout

Powered By
Vantage

Manage Cases > Import

Import Data for Potential Case Creation For State ID 49

- How to Import Vital Stats
- Download External Source Linkage Template
- Download Previously Imported Vital Stats For State ID 49

External Source Linkage No file selected.

File*

Suppress Notices

Hide Duplicate Warnings

Update Existing

Email me the Message log

← Back

LHD Case Retrieval

- Main
- Your Account
- Enter New Case
- Manage Cases
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- Data Download
- Help
- Logout



Create New Case From Import

Last Name	First Name	Death Cert #	Birth Cert #	Death Date	Manner of Death	Actions	Status
No results.							

Search Imports:

Date of Death

First Name

Last Name

Search Imports

[← Back](#)

Data Elements






Logged in as **Wisconsin Training1. (Wisconsin - Vernon)** Logout

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Data Download

-  [View Codebook](#)
-  [View Pared Down Flat File Codebook](#)
-  [Macro to Import Data into Microsoft Access](#)

Download All Sections

All	Every Section	All Data	zip
Flatfile	Most Sections	Selected Data	txt

Download By Section

tCase	Section Case	Case Information	txt
tINF	Section A	Child Information	txt
tINF2	Section A	Child Information, Part II	txt
tGIV	Section B	Primary Caregiver(s)	txt
tSUP	Section C	Supervisor Information	txt
tINC	Section D	Incident Information	txt
tINV	Section E	Investigation Information	txt
tCAU	Section F	Official Manner and Primary Cause of Death	txt
	Section G12	Other cause, undetermined cause or unknown cause	txt


Case Modification

Case Sections

- # - Case Definition
- A - Child Information
- B - Primary Caregivers
- C - Supervisor
- D - Incident
- E - Investigation
- F - Cause of Death
- H - Circumstances
- I - Acts
- J - Services
- K - Prevention
- L - Review
- M - Narrative
- N - Form Completion
- Save and Exit

Manage Cases > Section F

Enter Case Information [49-63-2015-00003]

 Print this section

Section F: Official Manner and Primary Cause of Death

1. Official manner of death from the death certificate

- Natural
- Accident
- Suicide
- Homicide
- Undetermined
- Pending
- Unknown

2. Primary cause of death.

Choose only 1 of the 4 major categories, then a specific cause.
For pending, choose most likely cause.

- From an external cause of injury
- From a medical condition
- Undetermined if injury or medical cause
- Unknown

Powered By



Benefit of the CDR-CRS

- Rapid notification of cases
- Reduced work and data entry from LHD
- Consistent format of birth and death data
- Compliance with reporting
- Reporting reviewed and non-reviewed cases
- Improved data access from Vital Records

Future Use of the CDR-CRS

- Phase I: infant death case notification
 - Most difficult; matched death-birth record
- Phase II: child death case notification
- Phase III: fetal death case notification

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Limitations of the CDR

- LHD needs to register for access to CDR-CRS.
- Unclaimed cases need jurisdictional assignment.
- Duplicate case reviews.
- Out-of-state birth or death restrictions.

The Big Picture



Acknowledgements

Wisconsin Department of Health Services

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Wisconsin
Department of Health Services



Health Systems Integration Program

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Strengthening Health Systems through Interprofessional Education



Health Systems Integration Program

Strengthening Health Systems through Interprofessional Education

A collaboration between the Association of State and Territorial Health Officials, Centers for Disease Control and Prevention, the Council of State and Territorial Epidemiologists, the National Association of County and City Health Officials, and the Public Health Informatics Institute

Vision statement: Illuminate pathways for professionals, organizations, and communities to achieve a collective, transformative, and sustainable impact on population health.



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Health Systems Integration Program

Questions?

Julie Lench, D.V.M., M.P.H.
Health System Integration Program
CDC/CSTE Fellowship
Julianna.lench@wisconsin.gov

To learn more about Project SHINE, check out our website:
<http://shinefellows.org>.

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Additional Slides

FIMR and CDR team members

- Local public health
- Coroner
- Law enforcement
- Child Protective Services
- District attorney
- Pediatrician/OB-Gyn/health care
- Ems
- Hospital
- Tribal council
- Domestic violence
- Mental health
- School district
- Child care facility
- Neonatology
- SIDS SME



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Criteria for FIMR Review

Reviewed

- SIDS
- Low birth weight
- Premature
- Homicide
- Suicide
- Unintentional injury
- Undetermined causes

Not reviewed

- Cancer
- Congenital

Partners

- Wisconsin Department of Health Services
 - Office of Health Informatics
 - Maternal and Child Health (MCH)
- Children's Health Alliance of Wisconsin (CHAW)



Strengthening Health Systems through Interprofessional Education



Health Systems Integration Program

Partners

- Local health departments
- National Center for the Review and Prevention of Child Deaths
 - Child Death Review Case Reporting System