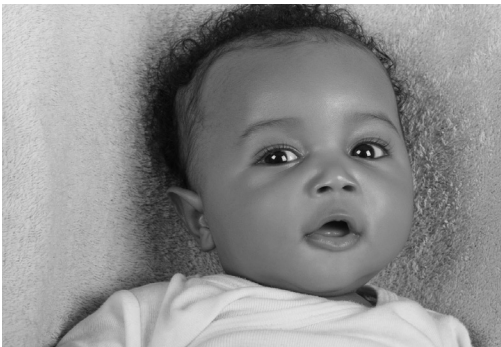


KEEPING KIDS ALIVE *in Wisconsin*



DEATH REVIEW TEAM GUIDELINES



Keeping
Kids Alive
IN WISCONSIN

★ Children's Health
Alliance of Wisconsin

WELCOME LETTER



I am the mother of Brian Jacob Paulus. He was a silly happy three year old who loved soccer, Skittles candy, McDonald's play land, and to run around with little on, but his boots. He was his dad's little buddy, his sister Sara's best - friend and my little snuggler. An officer showed up at my door to tell me Brian wandered out of grandpa's cottage in the middle of the night and fell into the nearby pond. *He died of an unintentional, but preventable injury from a near drowning.*

This should not have happened. The loss from the death of one child is far reaching. After Brian died, myself and other family members have experienced extreme emotional pain and other mental

health challenges. Brian's sister, Alyssa, born after he died, struggles with the sadness and anger of never having the chance to know her brother. The loss of my son extended to my co-workers who struggled with how to help me, and carried the burden of my work when I just didn't have the strength to do it. Friends and community members wanted to help, but were at a loss. They would say, "if there is anything I can do, let me know."

Child death review (CDR) is the answer to "if there is anything I can do, let me know". It recognizes and honors each child that has died. It remembers them all which lets us then see why our children are dying and what we as a community can

do to prevent our children from dying. ***CDR ultimately prevents other families and communities from going through the devastation I experienced.*** It keeps our children safe and alive.

All of the expert medical care could not save my son. In the words of Dr. Perloff, my child's doctor and former chair of the state CDR Council, "A measure of a society's worth is how well it cares for its most vulnerable members. How then can we not treat the loss of even one child as an event to be prevented if at all possible? To do this we must study each child death to learn the lessons contained in the events leading to the death, and find ways to translate these lessons

into actions that will prevent future deaths." This is the purpose of the CDR Team.

I want to thank you for your commitment to Keeping Kids Alive. ***Know that your dedication definitely makes a difference.*** It warms my heart to know there are people like you that take the time to keep our children safe and alive.

With gratitude,

Teresa Paulus

Teresa Paulus, Brian's Mom
Winnebago County Child
Death Review Team

ACKNOWLEDGMENTS



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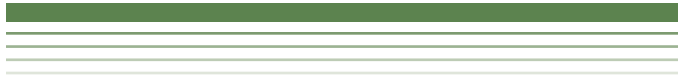


TABLE OF CONTENTS

- Introduction..... 6
- Background 7
 - State CDR Council 8
- Child Death Review 10
 - Purpose of local team 10
 - Team membership 12
 - Criteria for review by team 15
 - Team operating procedures..... 16
 - CDR process 18
- Fetal Infant Mortality Review (FIMR)..... 20
 - Purpose of local team 20
 - Team membership 21
 - Criteria for review by team 23
 - Team operating procedures..... 24
 - FIMR process 25
- Collaboration between CDR & FIMR 30
 - Structure for CDR & FIMR collaboration 31
- Data 36
 - Incident vs. resident death reviews 36
 - Counties with CDR & FIMR..... 40
 - Data sources 41
 - Using the CDR-CRS 42
 - Data quality..... 45
 - Using data 47
 - Data assistance..... 48
- Prevention..... 50
- Self-Care 51
- Resources for CDR & FIMR Coordinators 53
 - Establishing CDR & FIMR teams 53
 - Team operating procedures 56
 - Conducting an effective review team meeting 57
 - Team member roles 60
 - Maintaining an effective review team..... 63



INTRODUCTION

Children are not supposed to die. The death of a child is a tragic event. Especially tragic is a child death that could and should have been prevented. From 2005 to 2012, an average of 820 Wisconsin children (ages 0 to 19) died each year; almost half of these were infants (younger than age 1) (Wisconsin Vital Statistics). Most of these deaths are preventable, but require a better understanding of risk factors in order for effective prevention initiatives to be developed and implemented. In response to a national movement, Wisconsin established a child death review (CDR) and fetal infant mortality review (FIMR) program, called Keeping Kids Alive in Wisconsin.

Keeping Kids Alive in Wisconsin establishes local CDR and FIMR teams who work to understand the risk factors and circumstances surrounding a child death. The ultimate goal of Keeping Kids Alive in Wisconsin is to prevent future deaths by applying a public health approach to prevention. The public health approach promotes better understanding of all causes of potentially preventable child deaths.

Local CDR and FIMR teams do not place blame or find fault. Instead, they focus on identifying opportunities to improve the health and safety of their community.

In 2014, 55 of 72 Wisconsin counties have some form of CDR team. These are multidisciplinary teams that work to improve interagency communication and cooperation. CDR teams strive to improve their understanding of how and why children have died, investigation methods and delivery of services to families that have lost a child.

In 2014, 7 of 72 Wisconsin counties have some form of FIMR team. Similar to CDR, FIMR teams are comprised of a diverse group of professionals and community members who seek to understand the risk factors associated with stillbirth and infant deaths. FIMR teams provide communities with an opportunity to monitor health care delivery, enhance public health, implement continuous quality improvement processes and unite key stakeholders around a common prevention message.

*The **ultimate goal** of FIMR and CDR is to prevent future deaths.*

BACKGROUND

The need for local review teams

Death certificate records from the Wisconsin Department of Health Services (DHS) provide statistics on the number of Wisconsin child deaths and causes. However, we know very little about the specific circumstances, such as *“who, what, when, where, why and how.”* Statistics do not reveal how a community responded to the death of a child. Many questions remain unanswered, such as: How was the death investigated? What services were provided to the family and community? Did state and local agencies review their policies, programs and actions as they related to the death, or take action to prevent similar deaths? CDR and FIMR teams can help answer these questions and identify other preventable risk factors contributing to a death.

In May 1998, Wisconsin Department of Justice (DOJ) created a state Child Facility Review Team. Now called the Child Death Review Council (CDRC). The CDRC was formed under the federal Child Justice Act grant. At that

time, Wisconsin was 1 of 12 states without a statewide CDR program. Unlike most other states, the Wisconsin CDR program (now known as Keeping Kids Alive in Wisconsin) was challenged by the lack of enabling or mandating legislation. As a result, local CDR teams were established at the discretion of local leaders.

The first Wisconsin-based FIMR team was implemented in the City of Milwaukee in 1993. The need for FIMR was identified by concerned and committed families, social service professionals and health care providers. Similar to other FIMR programs, it was challenging to identify sustainable funding for FIMR.

From 2008 to 2014, 55 local CDR teams were created, maintained or enhanced. During the same time period, Wisconsin’s FIMR program grew from one FIMR team to seven. This growth demonstrates the strong commitment at the local and state level to death review. The goal of Keeping Kids Alive in Wisconsin is to establish death review teams to cover each of Wisconsin’s 72 counties.




STATEWIDE CHILD DEATH REVIEW COUNCIL

The CDRC was housed in DOJ until 2010 when it transitioned to DHS. The membership of the CDRC was broadened to reflect professionals with a vested interest in maternal, fetal and infant health. The mission of the CDRC is to prevent fetal, infant, child and adolescent injury and death by supporting local death review team case reviews. The CDRC partners with local teams to promote effective local and statewide advocacy, policy and prevention. The CDRC accomplishes this by:

- Advising the legislature and state agencies on the need for modifications to law, policy or practice
- Educating the public regarding the incidence of fetal, infant and child deaths as well as specific steps the public can take to prevent future deaths
- Identifying training needs and making resources available to statewide professional organizations, advocacy groups and others

- Facilitating the development of local/ regional teams

CDRC members are appointed by the secretary of DHS and include the following:

- Secretary of the Department of Health Services or designee
 - Secretary of the Department of Children and Families or designee
 - Attorney general or designee
 - Superintendent of the Department of Public Instruction or designee
 - Secretary of the Department of Transportation or designee
 - Secretary of the Department of Natural Resources or designee
 - Law enforcement representative
 - Representative from a prosecutor's office
 - Child protective services (CPS) representative recommended by the Wisconsin County Human Services Association Technical Advisory Committee on CPS
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- Pediatrician who is board certified in pediatrics through the American Board of Pediatrics and a current member of the Wisconsin Chapter of the American Academy of Pediatrics
 - Pediatrician who is board certified in child abuse pediatrics through the American Board of Pediatrics and a current member of the Wisconsin Chapter of the American Academy of Pediatrics
 - Pediatrician who is board certified in neonatology through the American Board of Pediatrics and a current member of the Wisconsin Chapter of the American Academy of Pediatrics
 - Epidemiologist
 - Forensic pathologist who is board certified in forensics through the American Board of Pathology
 - Medical examiner/coroner
 - Statewide child advocacy representative
 - Children's Trust Fund representative
 - Consumer product safety representative
 - Injury prevention professional
 - Public representative (e.g., caregiver, faith-based community, health)
 - Tribal member
 - Obstetrician/gynecologist who is board certified by the American College of Obstetrics and Gynecology
 - Program director for Emergency Medical Services for Children

CHILD DEATH REVIEW (CDR)

PURPOSE OF LOCAL TEAM

Operating principle

The death of a child should invoke a community response. The circumstances involved in most child deaths are multidimensional with many factors. Responsibility should not rest in any one place.

Goals

- Improve our understanding of risk factors and circumstances surrounding each child death
- Identify opportunities to influence policy and programs
- Improve child health, safety and protection
- Prevent other child deaths

Objectives

1. *Accurate identification and uniform reporting into the National Center for the Review and Prevention of Child Deaths Case Reporting System (CDR-CRS) of cause, manner and relevant circumstances of every child death with special emphasis on prevention*

2. *Improved communication and coordination of agency responses to child deaths in the investigation and delivery of services*
3. *Design and implementation of cooperative, standardized guidelines for the investigation of certain categories of child death*
4. *Identification of changes needed in legislation as well as policy and practices that expand efforts in child health and safety*

Achieving objectives

1. *Accurate identification and uniform reporting of cause, manner and relevant circumstances of every child death with special emphasis on prevention*

CDR teams provide a forum that ensures relevant information is shared and available to determine why a child has died and better understand all contributing factors. A team's multidisciplinary membership facilitates more accurate reporting. When CDR teams identify a lack of sufficient information to accurately determine how a child has died, the systematic



collection of more information is agreed upon. For example, a county began tracking cell phone use in motor vehicle crashes after questions repeatedly came up during team meetings.

The CDR-CRS serves as the state-level database for CDR and FIMR in Wisconsin. More information about data collection can be found on page 36.

2. Improved communication and coordination of agency responses to child deaths in the investigation and delivery of services

Meeting regularly to talk about child deaths can significantly improve interagency cooperation and coordination. The benefits of sharing information and clearly understanding agency responsibilities can make the process worthwhile even if new information does not surface at a review. Team meetings help identify problems regarding the coordination of investigations or the investigative responsibilities of different agencies. Reviews identify ways to conduct and coordinate

investigations to maximize available resources.

Reviews can improve the delivery of services to families and others in a community following a child death. For example, one Wisconsin county created a directory of grief and bereavement services available for first responders, law enforcement, medical examiners/coroners and others to share with families.

3. Design and implementation of cooperative, standardized guidelines for the investigation of certain categories of child death

Child death investigations vary greatly across the state, depending on available resources. The review process can assist agencies in developing standardized guidelines for investigation and delivery of services. A consistent approach within and among counties can clearly define roles and procedures, resulting in more accurate reporting of child deaths. For example, the Sudden Unexpected Infant Death (SUID) Reporting Form designed by the Centers

for Disease Control and Prevention is one tool that is promoted by the Keeping Kids Alive in Wisconsin program to standardize investigation of SUIDs.

4. Identification of changes needed in legislation as well as policy and practices that expand efforts in child health and safety

The ultimate purpose of CDR is prevention. The review of each child death concludes with a discussion of how to prevent another death.

*Teams are not expected to design and implement recommendations; **reviews** are intended to **catalyze** community **actions**. Teams should identify the best way to translate prevention recommendations, based on data and an **analysis** of existing gaps and resources in the community into action. Individuals, agencies or team members can assume responsibility and work with existing prevention partners or **establish** new connections.*

For example, one team wrote a letter of recommendation to an existing community board calling for improved safety measures at a local beach.

The CDRC will develop recommendations for legislation, administrative agency policy and practice, and public education based on comprehensive data collected by local teams.

TEAM MEMBERSHIP

A CDR team enables various disciplines to share their knowledge on a regular basis. The authority, responsibility and activities of participating agencies does not change. See page 60 for more information on team member roles.

Team members

At a minimum, it is recommended that CDR teams include a core membership from:

- County medical examiner/coroner
- Local law enforcement
- Child protective services

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- District attorney's office
 - Local public health department
 - A pediatrician or health care provider who specializes in pediatrics
 - Emergency medical services
 - Women, Infants and Children (WIC) program
 - Hospital(s)
 - Mental health providers
 - Juvenile division of probate or family court
 - School district

Teams generally average 10-15 members depending on resources and needs.

Additional team members

Teams may include other members as appropriate for case reviews and meeting community needs. Examples include: Child advocacy centers; tribal representatives; domestic violence coalitions; suicide awareness coalitions; lesbian, gay, bisexual and transgender resource centers; Infant Death Center; and U.S. Consumer Product Safety

Commission, etc. Team members should always email the team coordinator for permission to bring a guest.

Ad hoc members

Ad hoc members are not permanent and do not receive team notices. They attend meetings only when they have been directly involved in a case. Ad hoc members provide valuable information without increasing the number of core team members. They may include a specific social worker, law enforcement officers who responded to the scene or a child advocate who worked with the family.

Regional review teams: An alternative to a county team

Regional teams consist of representatives from more than one county. Regional teams are a useful alternative to individual county teams where the annual number of child deaths is small, making it difficult for the local team to maintain continuity and efficiency. Such teams are recommended for counties where current relationships, natural boundaries and resource sharing exist.

When building regional teams, organizers should consider natural partners such as existing inter-county collaboratives or facilities that cross county jurisdictions (e.g., health department regions or emergency medical service regions).

Every county covered by a review team should be represented on the team. An agency regional director or other professional whose jurisdiction or responsibilities include all of the counties can fulfill this requirement.

To ensure that the concept of community involvement is met, reviews should be attended by at least one representative from a core member agency in the county where the child death occurred. This allows regional teams to receive information from professionals directly involved with a death while strengthening team relationships with various local agencies. Establishing and maintaining such relationships is critical if team objectives for prevention, training and education are to be reached.

The role of team members

The role of team members can be flexible to meet the needs of particular communities. The individual abilities of members should be utilized to enhance team effectiveness. The role of team members is to:

- Contribute information from his or her records.
- Serve as a liaison to their respective professional counterparts.
- Provide definitions of professional terminology.
- Interpret agency procedures and policies.
- Explain the legal responsibilities or limitations of his or her profession.
- Contribute to discussions on prevention and system change.

See page 60 for more in-depth information on individual team member roles.

CRITERIA FOR REVIEW BY TEAM

Scheduling reviews

Meetings are scheduled during a designated time period to discuss all deaths that meet review team criteria. Reviews of such deaths usually occur after completion of the investigation and information gathering. Reviews are scheduled monthly, bimonthly or quarterly, based on the size and needs of the county or region. The average time for a case review is 20-30 minutes, depending on the circumstances. Review findings and proceedings are used primarily for identifying potential prevention measures, but also may influence systems and procedures for future death investigations.

Reviewable deaths

The team should review as broad a category of deaths as possible to improve their ability to identify trends enhancing prevention and policy development. There are three major criteria for selecting cases for review by a team:

1. Age
2. Cause of death
3. Residence

1. Age

Teams should review all deaths to children younger than age 19. However, teams can focus reviews on specific age groups or other criteria based on interest and resources. It is not uncommon to review deaths to persons younger than age 21 or 25. The decision may depend upon the workload and interests of a review team.

2. Cause of death

Review teams can choose to review deaths in all categories. If this is not possible, teams should review the following:

- Homicides
- Unintentional injury
- Suicides
- Undetermined causes

- Unexplained infant and child deaths, including Sudden Infant Death Syndrome (SIDS) and SUID
- All cases reported to medical examiner/coroner offices
- All cases with previous CPS involvement and/or under law enforcement investigation

It is important to focus on **all cases**, not just those involving abuse, neglect, injury or homicide.

3. Residence

CDR teams should review all deaths that occur in their counties as well as deaths of children residing in their communities, but dying elsewhere. In Wisconsin, death certificates are filed in the county where a death occurs. When a child dies in a county other than that of residence, the death is known as a non-resident occurrence. For more information on issues of residence and non-residence, see page 36.

TEAM OPERATING PROCEDURES

Confidentiality

Safeguards for the confidential exchange of information must be in place. At a review team meeting all data and information regarding the death must be kept confidential. Team members should sign a confidentiality agreement at each meeting.

At this time (2014), Wisconsin does not have comprehensive death review legislation. However, many current local, state and federal laws allow for participation and disclosure of case-related information during CDR and FIMR. Visit the Alliance Web page for a list of statutes, which facilitate the work of CDR and FIMR teams.

Media inquiries

In no case, will any team member disclose any information regarding team discussion outside of the meeting other than pursuant to the mandated agency responsibilities of that individual. Public statements about the general

purpose of the CDR process may be made, as long as they are not identified with any specific case.

Conflict of interest

A conflict of interest may arise for a team member. A conflict is defined as any “vested interest” in a specific case. It is the responsibility of the team member to excuse him/herself from the case discussion.

Member designees and meeting attendance

Team members can designate another agency representative to replace them at a meeting if they are unable to attend. However, the team coordinator must be notified. Additionally, team members should recognize the importance of regular attendance. Team members who consistently miss meetings should be replaced. See page 14 for more information on team member roles.

Record keeping

Each case reviewed by a CDR team should be entered into the CDR-CRS by the designated

team data entry specialist. It is Wisconsin’s goal to have all local teams utilize the database to capture fetal, infant and child deaths. For more information about data collection, please see page 36.

Team members should **not** take notes of the review meeting. However, notes on prevention or follow-up activities are encouraged.

Participate and be prepared for meetings

Reviews require regular attendance and participation by all team members. Members should become acquainted with the discussion questions and come prepared to discuss the case. Prior to each meeting, team members should gather relevant information on each case on the agenda. Sample guidelines of information by discipline (e.g., law enforcement, medical examiner/coroner) are available at www.chawisconsin.org.

Team members should remember:

- Confidentiality is **essential** to the function of a death review team.

- Specific case reviews are closed to the public.
- All participants agree to keep the discussions of specific case information confidential.
- The team keeps no case-specific written record of the meeting.
- Individuals come and leave with only their records.
- The purpose of the team is to identify ways to prevent other deaths and to improve how systems work together.

CDR PROCESS

The CDR process contains five key steps.

1. Case identification

The first step in the CDR process is to identify cases that meet team criteria. **When possible, a death certificate should initiate the case.** A local CDR team may access death certificates by implementing a memorandum of understanding with their local registrar of deeds or they may purchase death certificate information from DHS. A number of complementary sources also may be used to identify deaths including:

1. Medical examiner/coroner reports
2. Secure Public Health Electronic Record Environment (SPHERE)
3. Funeral homes
4. Newspapers
5. Hospitals

2. Team coordinator prepares list for meeting

The second step in the process is compiling a list of cases for review. The team coordinator will use the criteria developed by the team.

This list should be shared with critical partners (e.g., the medical examiner/coroner, district attorney) to ensure the case is ready for review. Whenever possible, team members should receive the list of cases approximately two weeks before the meeting.

3. Begin data collection

The third step in the CDR process begins with the collection of data. Once the data entry specialist has the list of cases to review, he or she will begin to gather information to enter into the CDR-CRS. The goal is to enter as much information as possible into the CDR-CRS prior to the meeting. The data collection and

entry process continues through the review team meeting and concludes when all possible information has been collected. See page 36 for more information on data collection.

4. Review team meeting

The fourth step in the CDR process is to hold the review team meeting. It is recommended that CDR teams meet at least quarterly for a period of 2 to 4 hours. Developing a team meeting schedule for an entire calendar year is advised in order to ensure key members are available for review team meetings. For communities with a FIMR and CDR team, it may be beneficial to coordinate the meetings. For more information on collaboration of FIMR and CDR, see page 30. As part of the review team meeting, recommendations and prevention opportunities should be discussed.

*Teams are not peer reviews. They are designed to **examine** system issues, not performance of individuals. The team review is a professional process **aimed** at improving system response to deaths.*

5. Recommendations

The fifth step in the CDR process is to identify opportunities for prevention. CDR teams should review data as part of the development

of recommendations. Recommendations can be focused on specific action items and also include broad, population-level approaches, including, education, the modification or enactment of new policies or changing physical environments. Recommendations should be specific, utilize a variety of strategies to impact change and be evaluated.

For more information on prevention, see page 50.

FETAL INFANT MORTALITY REVIEW (FIMR)

PURPOSE OF LOCAL TEAM

Operating principle

A stillbirth or an infant death is a sentinel event in the life of a community. It speaks to how a community cares for its families. FIMR puts a face to the problem of infant mortality. The circumstances involved in most fetal and infant deaths are multidimensional with many factors.

FIMR includes the following four public health program elements:

1. Assessment of fetal and infant deaths in local communities via data collection and analysis.
2. Program planning by organizing community members to develop recommendations and a plan of action addressing identified medical, social, environmental and other factors.
3. Implementation of primary, secondary and tertiary prevention interventions through system changes and the institutionalization of long-term policies.

4. Evaluation and monitoring of program outcomes.

Goals

- Understand the underlying factors contributing to fetal and infant loss.
- Develop collaborative approaches to prevention of these losses.
- Reduce the racial/ethnic disparities in birth outcomes.
- Improve maternal health.

Objectives

1. *Obtain unique information not typically available solely from vital statistics.*
2. *Monitor the communitywide effects of a changeable health care system.*
3. *Enhance the performance of core public health functions.*

Achieving objectives

1. *Obtain unique information not typically available from vital statistics.*

Information collected for a FIMR team complements local fetal and infant mortality



data. Multiple data sources are gathered and a core set of information is entered into the CDR-CRS for state surveillance purposes. Local databases built for FIMR also can be used. More information on data collection can be found on page 36.

2. Monitor the communitywide effects of health care systems to improve access to care and service utilization.

FIMR provides invaluable information that helps communities understand how changing conditions influence services and resources, and affect families throughout the community trying to access or utilize services. Additionally, the FIMR process actively seeks the voice of the family. This provides a unique perspective on service delivery.

3. Enhance the performance of core public health functions.

Communities with active FIMR teams are more likely to engage in many of the 10 essential public health functions. These may include data assessment and analysis,

quality assurance and improvement activities, community partnerships and mobilization, policy development, and increasing the skill of professionals within the community.

TEAM MEMBERSHIP

A FIMR team enables various disciplines to share their knowledge on a regular basis. The authority, responsibility and activities of participating agencies does not change.

Team members

At a minimum, it is recommended that FIMR teams include membership from:

- Local public health department
- Physicians (e.g., obstetricians, pediatricians, neonatologists, perinatologists, family practice, internal medicine, hospital pathologist)
- Nurses (e.g., certified nurse midwives, prenatal care coordinators, nurse-family partnership)
- Social workers (e.g., hospital, human services and community-based)

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- WIC program staff
 - Medical examiner/coroner office
 - Child protective services
 - Parents who have had an infant loss/stillbirth
 - Hospital pastoral care
 - Faith community
 - School district
 - Health insurance companies (e.g., maternal health program managers, outreach staff)
 - Nursing, medical school, public health and other educators
 - Child advocacy
 - EMS, fire and law enforcement representatives
 - Community members
 - Other programs working to address fetal and infant mortality, such as the Wisconsin Lifecourse for Healthy Families project.

Ad hoc members

Ad hoc members are not permanent and do not receive team notices. Ad hoc members provide valuable information without increasing the number of core team members. Ad hoc members attend based on the request of the team coordinator and provide specific information to the FIMR team.

The role of team members

The role of team members can be flexible to meet the needs of particular communities. The individual abilities of members should be utilized to enhance team effectiveness. The role of team members is to:

- Actively contribute to the discussion.
- Serve as a liaison to respective professional counterparts.
- Provide definitions of professional terminology.
- Explain the legal responsibilities or limitations of his or her profession.

- Contribute to discussions on prevention and system change

See page 60 for more information on team member roles.

CRITERIA FOR REVIEW

Scheduling reviews

Meetings are scheduled during a designated time period to discuss all deaths that meet review team criteria. Reviews are scheduled monthly, bimonthly or quarterly, based on the size and needs of the county. The average time for a case review is 20-30 minutes, depending on the circumstances. Review findings are used for identifying potential prevention measures. The findings also are used to drive changes in health care systems and procedures.

Reviewable deaths

The team should review as broad a category of deaths as possible to improve their ability to identify trends enhancing prevention and policy development. At a minimum, teams should review:

1. Stillbirths
2. Infant deaths
3. Resident deaths

1. Stillbirths

Teams should review all stillbirths occurring at or after 20 weeks gestation. However, teams can focus reviews on specific risk factors or circumstances. The decision may depend upon the workload and interests of a review team.

2. Infant deaths

Teams should review all infant deaths. This includes any infant who shows any sign of life (breath, pulse in the umbilical cord or heart beat) at birth up to his or her first birthday.

3. Residence

FIMR teams should review all deaths that occur in their counties as well as residents of their communities, but dying elsewhere. In Wisconsin, death certificates are filed in the county where a death occurs. When a child dies in a county other than that of residence, the death is known as a non-resident occurrence. For more information on issues of residence and non-residence, see page 36.

TEAM OPERATING PROCEDURES

Confidentiality

While FIMR cases generally are deidentified, safeguards for the confidential exchange of information must be in place. At a review team meeting all data and information regarding the death must be kept confidential. Team members should sign a confidentiality agreement at each meeting.

Media inquiries

In no case, will any team member disclose any information regarding team discussion outside of the meeting other than pursuant to the mandated agency responsibilities of that individual. Public statements about the general purpose of the FIMR process may be made, as long as they are not identified with any specific case.

Conflict of interest

A conflict of interest may arise for a team member. A conflict is defined as any “vested interest” in a specific case. It is the

responsibility of the team member to excuse him/herself from the case discussion.

Member designees and meeting attendance

Team members can designate another agency representative to replace them at a meeting if they are unable to attend. However, the team coordinator must be notified. Additionally, team members should recognize the importance of regular attendance. Team members who consistently miss meetings should be replaced. See page 22 for more information on team member roles.

Record keeping

Each case reviewed by a FIMR team should be entered into the CDR-CRS by the designated team data abstractor. It is Wisconsin’s goal to have all local teams utilize the database to capture fetal, infant and child deaths.

For more information about data collection, please see page 36.

Team members should *not* take notes of the review meeting. However, notes on prevention or follow-up activities are encouraged.

Participate and be prepared for meetings

Reviews require regular attendance and participation by all team members.

Team members should remember:

- Confidentiality is essential to the function of a death review team.
- Specific case reviews are closed to the public.
- All participants agree to keep the discussions of specific case information confidential.
- The team keeps no case-specific written record of the meeting.
- The purpose of the team is to identify ways to prevent other deaths and to improve how systems work together.

FIMR PROCESS

The FIMR process contains seven key steps.

1. Notification

The first step in the FIMR process is to identify cases that meet team criteria. *When possible, a death certificate or stillbirth death report should initiate the case.* A local FIMR team may access death certificates by implementing a memorandum of understanding with their local registrar of deeds or they may purchase death certificate information from DHS. A number of complementary sources also may be used to identify deaths including:

1. Medical examiner/coroner reports
2. SPHERE
3. Funeral homes
4. Newspapers

2. Abstraction

The second step in the FIMR process is to complete case abstraction. FIMR abstraction requires the comprehensive investigation and

review of all medical and social service records of all stillbirths and infant deaths that occur in a given locality. These investigational items can include autopsy reports; police records; maternal and infant hospital records including social service and bereavement; outpatient records; physician office records; and standardized interviews with parents and other caregivers. They also may include city planning information, crime data, hospital and life-birth comparison data. All cases are abstracted and entered into the CDR-CRS database.

The abstractor can utilize a variety of methods for accessing medical records, including:

- Onsite review
- Printed copies
- Electronic copies
- Electronic access to electronic health records

It is recommended the FIMR team coordinator meet with the primary hospitals they will be requesting records from in order to identify a process for requesting records. This process

could be different for each hospital within a community.

FIMR teams can utilize a similar process for requesting records from other agencies. Visit the Alliance website for template letters, memorandums of understanding and other forms.

Once all records have been compiled, the person completing the abstraction should read the records and begin to complete the CDR-CRS. Once the case review is complete, the records should be destroyed. See the page 36 for more information on data.

One key element of FIMR is the de-identified nature of the data. ***Unlike CDR, case information that is shared with the team does not contain identifiers.*** Identifiers include any names, including the deceased, parents, providers, hospital, birthdates or addresses. It is critical that the case summary and any documents prepared for meetings have the identifiers removed. At a minimum, the following information should be redacted from

case summary reports presented at FIMR team meetings:

- Names: All names of the child, mother, medical and social service providers.
- Dates: All dates of service, birth or death. The year can be maintained.
- Location: All address information, except zip codes, should be redacted. If the population is small, zip codes may be withheld.
- Contact information: All telephone and fax numbers, email addresses and physical addresses.
- Certificate/license numbers: All birth, death, marriage and other license or certificate numbers.

During the abstraction process, each case should be assigned a unique identifier. This ensures the case remains de-identified. It is recommended that team coordinators consult agency, local, state and federal policies and laws. See page 56 for more information on confidentiality.

3. Maternal interview

The third step in the FIMR process is to conduct a maternal interview. This can include both parents, if they are available. This interview is vital to the story of the life and death of the infant. All interviewers should be trained in interviewing techniques, the stages of grief, cultural competence, confidentiality, community resources and the maternal interview template. It is recommended that maternal interviewers practice interviewing before conducting their first interview.

Information gathered during a maternal interview should never be shared in an identified format.

Maternal interviews can be accomplished in several ways.

- Send a letter to the family that introduces the FIMR program, the interviewer and explains the interview process. This letter is generally followed by a phone call to schedule the interview.

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- Directly approach the family via phone or in-person. The interviewer would introduce themselves, the FIMR program and ask the family to participate.

Prior to beginning the maternal interview, the interviewee must sign a consent form. This clearly defines how the data gathered will be used and stored. Some programs offer stipends or gifts of appreciation to mothers and families who complete a maternal interview. Most often these gifts are in the form of a gift card to a local store.

For maternal interview templates, visit the Alliance Web page.

4. Selecting cases for review

The fourth step in the FIMR process is selecting cases for the review meeting. Although all cases are abstracted, interviewed and entered into the CDR-CRS, not all cases may be reviewed. Some FIMR teams may decide to discuss every case, while others may discuss only a subset of the total cases due to high volume. There are many methods to base

the selection of cases for review, such as risk factors (e.g., smoke exposure, previous poor pregnancy outcome), cause of death (e.g., all sleep-related, prematurity), or other criteria. FIMR teams should determine a process for selecting which cases will be discussed as part of the start-up process.

Some FIMR teams may choose to have a case selection team that reviews all cases and selects a subset for the full review team. This provides an opportunity for all cases to be reviewed. Additionally, a case selection team ensures that a variety of relevant cases are brought to the full team.

5. Case summary

The fifth step in the FIMR process is completing the case summary. This summary is used during the case review team meeting to provide information on the case. For more information on producing the case summary, visit www.chawisconsin.org

6. Review team meeting

The sixth step of the FIMR process is to conduct a review team meeting. It is recommended that FIMR teams meet at least quarterly for a period of 2 to 4 hours. Developing a FIMR team meeting schedule for an entire calendar year is advised in order to ensure key players are available for review team meetings. For communities with a FIMR and CDR team, it may be beneficial to coordinate the meetings. For more information on collaboration between FIMR and CDR, see page 30. As part of the review team meeting, recommendations and prevention opportunities should be discussed.

*Teams are **not** peer reviews. They are designed to examine system issues, not performance of individuals. The team **review** is a professional process **aimed** at improving system responses to deaths.*

7. Recommendations

FIMR teams should review data as part of the development of recommendations.

Recommendations may be focused on specific action items and/or broad population-level approaches, such as education, the modification or enactment of new policies, or changing physical environments. Recommendations should be specific, utilize a variety of strategies to impact change and be evaluated.

For more information on prevention, see page 50.

COLLABORATION BETWEEN CDR & FIMR

Some communities may have both a CDR and FIMR team. In these communities collaboration between CDR and FIMR is imperative for maximizing prevention activities and resources. There are a few key differences between CDR and FIMR, including:

CDR	FIMR
Cases are identified	Cases are de-identified (see page 25)
Team members bring records to meeting for discussion	Case summary prepared by abstractor is used during review team meeting
Families are not contacted	Maternal interviews may be conducted (see page 27)

Although there are differences, there are many similarities between CDR and FIMR, including:

- Focus on prevention
- Focus on system change
- Reviews conducted by local, multidisciplinary teams
- Teams seek the risk factors associated with the death
- Data is collected, entered and analyzed in order to drive prevention

Communities who develop collaboration between these two review processes are able to maximize resources and broaden the impact of their prevention. In order to build a collaborative process, these steps should be followed:

1. Team coordinator meeting

The CDR and FIMR team coordinators should meet and develop a plan for collaboration. During this meeting the coordinators should determine:



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- A process for identifying cases
 - What cases each team should review
 - Who should enter data into the CDR-CRS
 - What opportunities for collaboration exist throughout the CDR and FIMR process

It is important to consider the expertise of each partner when identifying cases for the CDR and FIMR team to review. Additionally, local policies should be considered during the development of collaboration. As a result of this meeting, both coordinators should have a clear understanding of how the teams will operate and collaborate to improve the health and safety of their community.

2. Hold review team meetings

Once a timeline for review meetings and a plan for reviewing cases is developed, it should be implemented. When scheduling CDR and FIMR meetings, overlap in membership should be considered and scheduled to ensure maximum participation. Ongoing communication around case identification and meetings is essential.

3. Enter data into the CDR-CRS

Once data is collected, records should be entered into the CDR-CRS. ***It is recommended that each case be entered into the CDR-CRS once.*** For more information on data collection, entry and analysis, see page 36.

4. Collaborate on prevention recommendations and activities

CDR and FIMR teams should work together on prevention recommendations and activities, when appropriate. This collaboration may come in the form of joint reports, education, policy changes or other activities. A collective voice for prevention activities magnifies the likelihood of positive change.

STRUCTURE FOR CDR AND FIMR COLLABORATION

There are several ways CDR and FIMR teams can collaborate. Given Wisconsin's strong history of local control, each county will develop a plan for collaboration that meets their needs. At this time (2014), technical assistance is available from the Alliance and DHS.



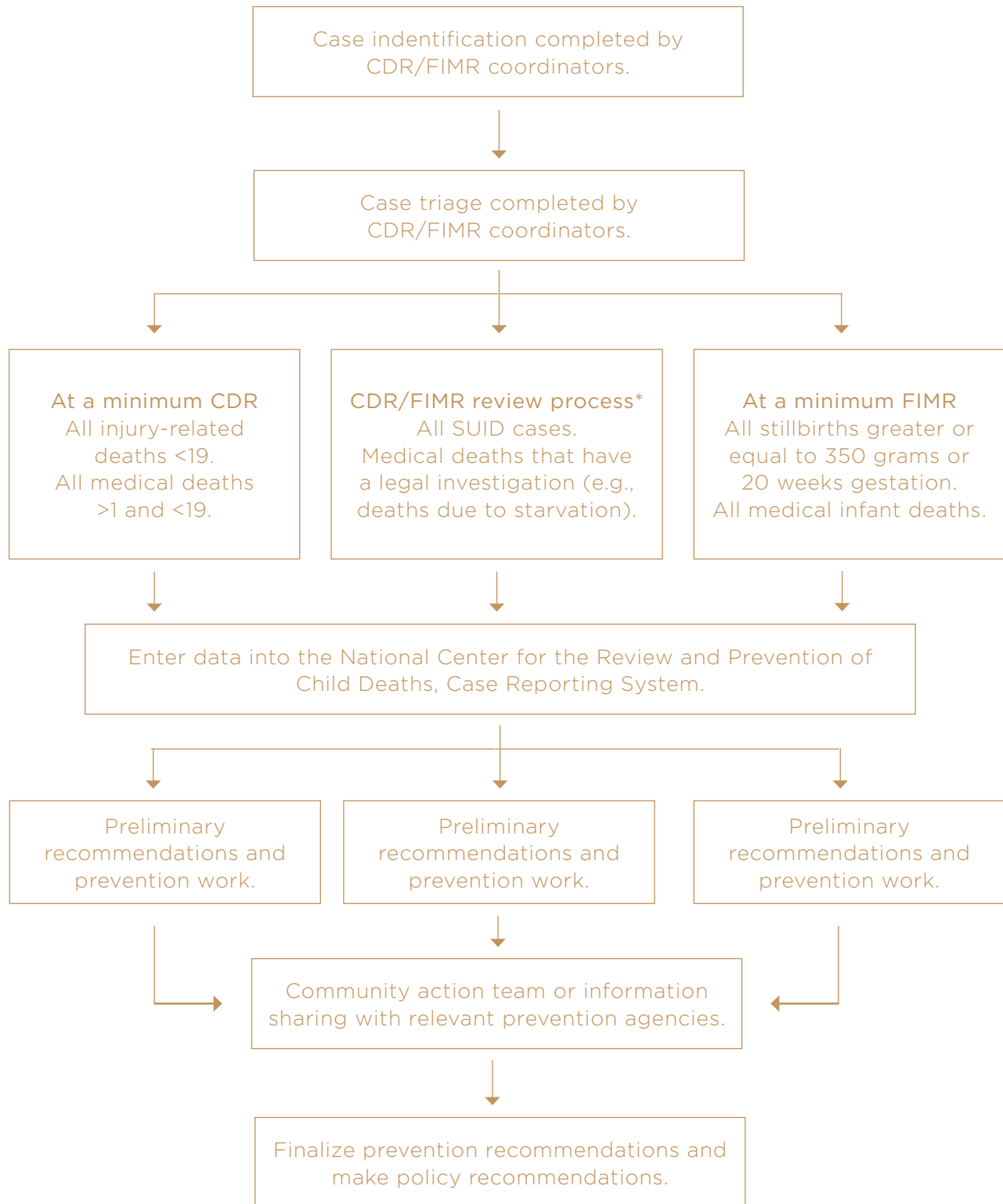
OPTION 1: TRIAGE CASES FOR REVIEW

CDR and FIMR teams may choose to triage cases and direct them into the appropriate review system. In this process, the CDR and FIMR coordinators would meet to determine which team will review which case. If the case is going to be reviewed by both the CDR and FIMR team, the coordinators should identify the process that will be used. The teams could decide to jointly review the case at one meeting or review the case

separately and collaborate in other aspects of the review process. It is important to honor local team agreements developed during the implementation of the CDR and FIMR teams.

Triaging cases into CDR and/or FIMR allows the local community to utilize local expertise. This format reduces duplication of reviews and ensures that data is only entered into the CDR-CRS once. Also, this format of collaboration may work best if one agency is leading both the CDR and FIMR teams.

OPTION 1: TRIAGE CASES FOR REVIEW



* This review can be completed jointly at one team meeting or individually by each CDR and FIMR team.



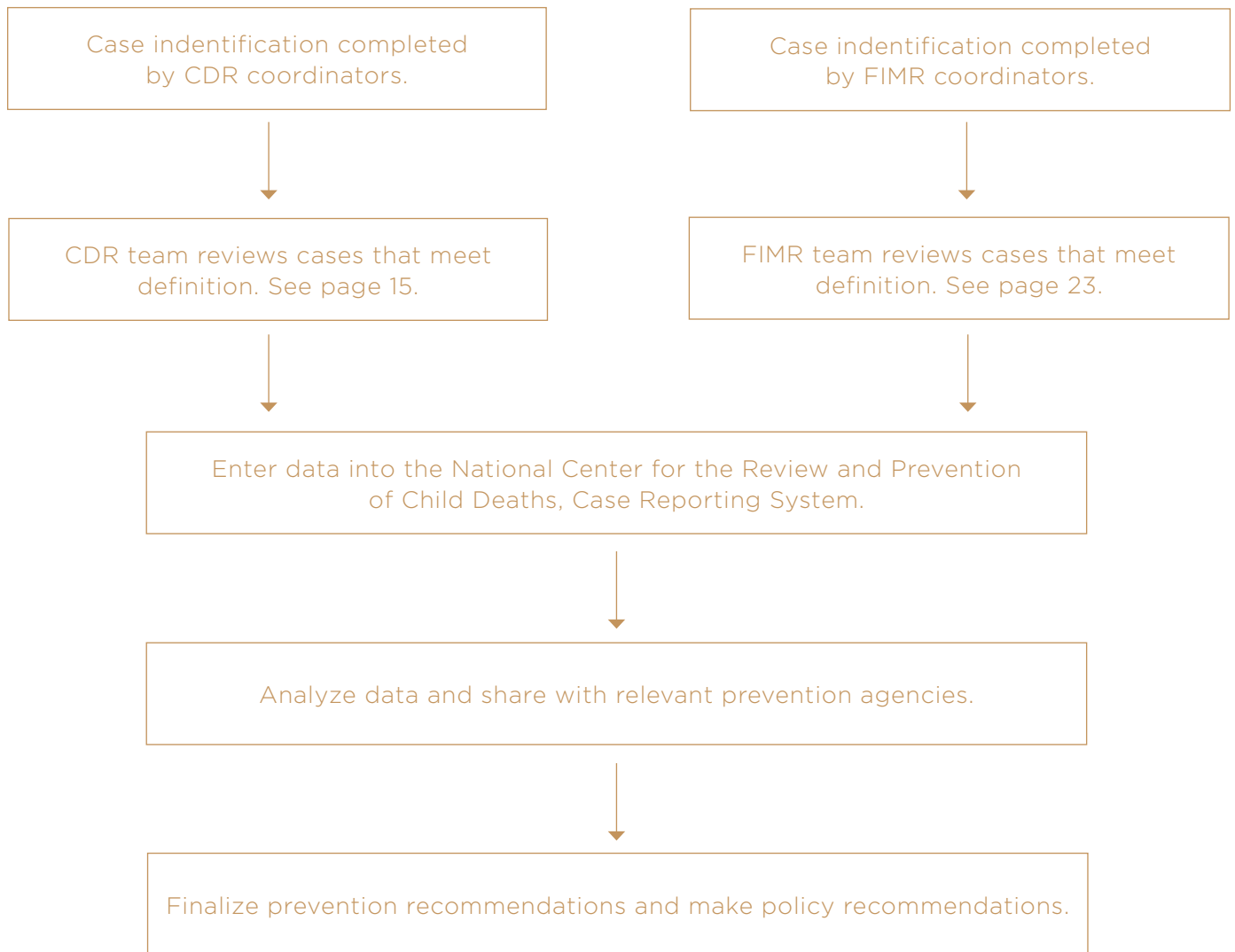
OPTION 2: SEPARATE CDR AND FIMR TEAM REVIEWS

Some CDR and FIMR teams may choose to conduct reviews separately, meaning that cases could be reviewed more than once. In these communities, it is recommended that data is only entered into the CDR-CRS once. Data collected can be analyzed and joint prevention recommendations can be made, when appropriate. *It is imperative that opportunities for collaboration be identified*

OPTION 3: ONE HYBRID TEAM FOR REVIEWS

Some communities may choose to use one review team to serve as both the CDR and FIMR team. In these communities team membership is broadened to reflect both CDR and FIMR. These communities may choose to adopt components of the CDR and FIMR model, creating a hybrid team. *It is critical these teams work with the Alliance or DHS to implement a team that meets local needs and adheres to state standards.*

OPTION 2: SEPERATE CDR & FIMR REVIEW TEAMS



DATA

Keeping Kids Alive in Wisconsin uses the CDR-CRS. The CDR-CRS is a national Web-based system for the capture of important variables relating to each infant and child death case. It is available at www.cdrdata.org (requires login information). The CDR-CRS is the surveillance database for use by both FIMR and CDR teams within Wisconsin. Teams also can develop local tools to complement the CDR-CRS in the event that its variables do not accommodate the needs of the team. A paper form of the variables included in the system can be found on the Alliance website.

Access

Access for Wisconsin teams to the CDR-CRS is maintained through DHS. To obtain access, each team selects a person responsible for data entry, the data entry specialist or data abstractor. This person will go through a one-hour Web-based data system training and sign required confidentiality and access

request forms. Trainings on the CDR-CRS are available multiple times throughout the year and invitations for the training are sent via email. Upon DHS receiving the confidentiality and access request forms, users will be given a user name and password to log into the CDR-CRS. Each user is given team-level access. In other words, the user is only allowed to enter and view cases from their respective county. In the case of regional teams, access will be given to the data entry person for all counties participating in the regional team.

INCIDENT VS. RESIDENT DEATH REVIEWS

There are several instances where teams may have to collaborate with other teams in reviewing a death including when the resident county and incident county differ, or when a county has both a CDR and FIMR team, see page 30.



Collaboration between resident and incident counties, including out-of-state

At a minimum, teams should review resident deaths. A resident death refers to a death of a child whose permanent address was in the county. However, some teams may opt to review incident and/or occurrent deaths as well. An incident or occurrent death is a death which occurs at a location within the county to any child, regardless if they are a resident of that same county. If your team decides to review incident deaths of non-resident children, there are some issues to consider:

1. Is the resident county in Wisconsin?

a. No: If the incident county wishes to review the case, please contact the Alliance to facilitate contacting the out-of-state team for additional information.

b. If yes, proceed to step 2.

2. Does the resident county have a CDR/FIMR team?

a. No: If the resident county does not have a CDR/FIMR team and the incident county wishes to review the case, the incident county should contact the local health department in the resident county to obtain necessary information.

b. Yes: If the resident county has a CDR/FIMR team, they may be reviewing the case. If your team, as the incident county, wants to review the case, it is recommended the team coordinators from both counties discuss a plan for reviewing and entering the case. The recommended process is:

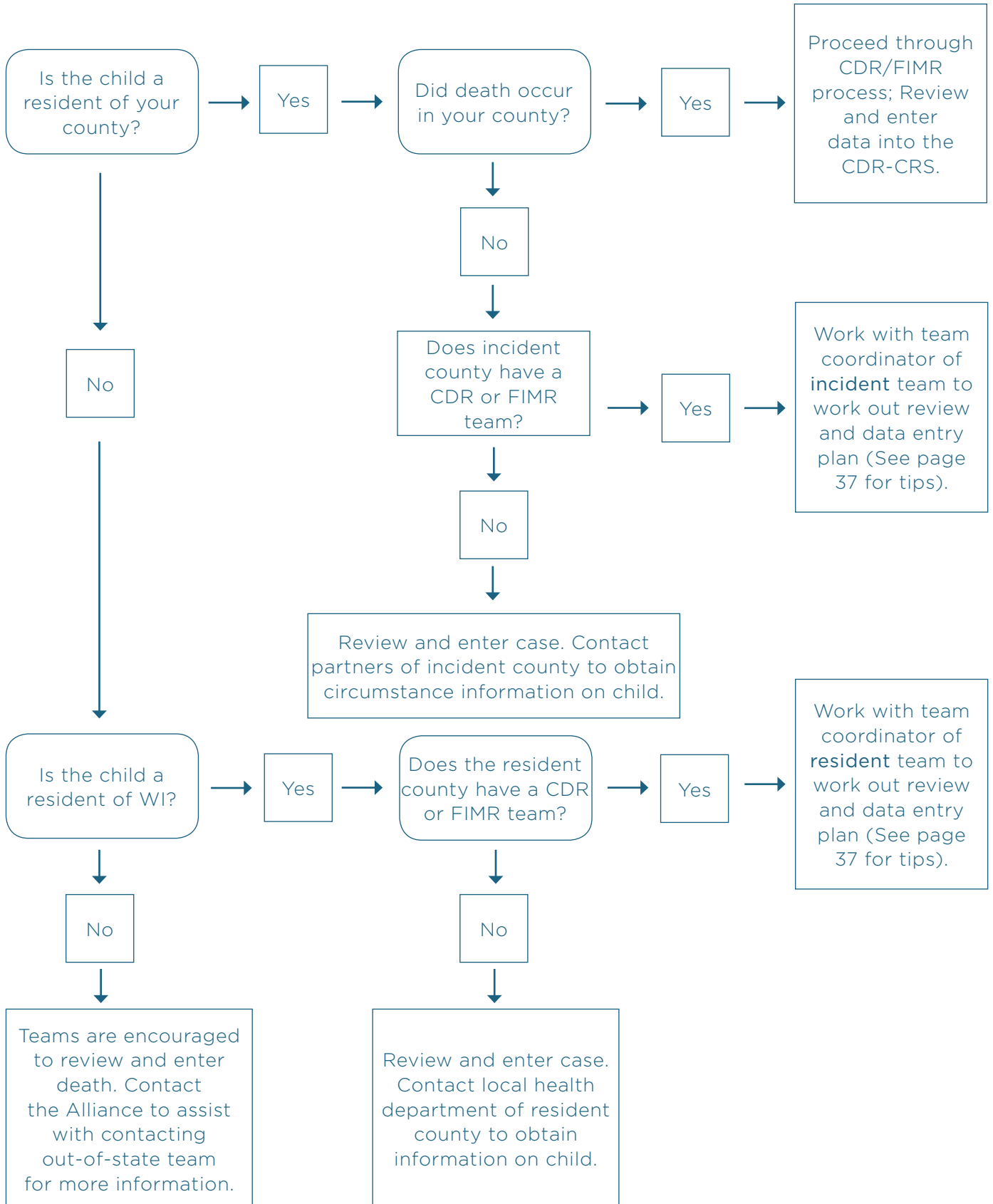
- Resident county and incident county each identify death. Coordinators from each team communicate with each other.
- Resident county reviews case and incident county participates in review. *One* paper CDR-CRS form is completed.

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- ***Resident county enters data into the CDR-CRS for this case. Incident County does not enter data.***
 - Resident county can access data for this case. Incident county cannot access data. ***One record exists in the CDR-CRS.***

If the recommended process cannot be implemented, the following process allows for collaboration between the review teams:

- Resident county and incident county both identify death. Coordinators from each team communicate with each other.

- Resident county reviews case and incident county participates in review. ***One*** paper CDR-CRS form is completed. Both counties receive a copy of the form.
- Incident county and resident county enters data for this case.
- Incident county and resident county can access data for this case. ***Two*** records exist in the CDR-CRS.



COUNTIES WITH CDR AND FIMR

As chapter 3 recommends, CDR and FIMR team coordinators should meet to develop a protocol for reviewing and entering cases. The following data entry scenarios match the options presented beginning on page 31.

Scenario 1: Triage cases for review

1. CDR and FIMR teams have met and developed a local protocol whereby cases are triaged to the CDR and/or FIMR team at identification based on agreed upon criteria.
2. Each team reviews cases that fall within their team guidelines.
3. Each team enters the cases they review into the CDR-CRS. FIMR teams may choose to enter additional information into a local FIMR database.
4. In cases of overlap, the protocol needs to identify which team will have responsibility for entering the case into the CDR-CRS.

Scenario 2: Separate CDR and FIMR reviews - option A

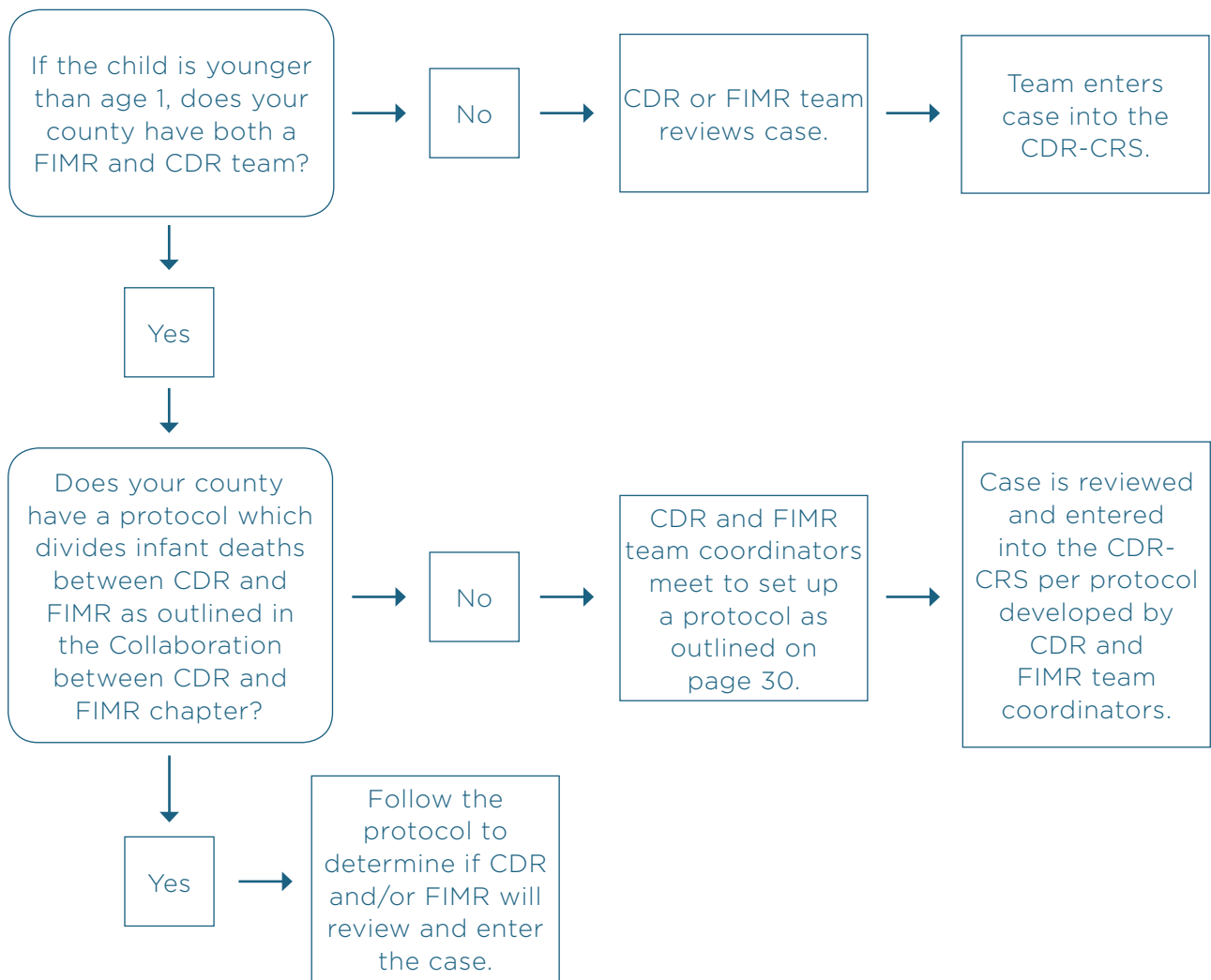
1. CDR and FIMR teams each identify death. Coordinators from each team communicate with each other.
2. Each team reviews the case independently and completes the paper CDR-CRS form. The case has two forms.

3. CDR and FIMR teams provide copies of their paper CDR-CRS form to each other to ensure complete information is provided to both teams.
4. Team coordinators determine who will enter the case into the CDR-CRS. If a local FIMR database exists, the FIMR team will enter the case into that database.

Scenario 2: Separate CDR and FIMR reviews - option B

1. CDR and FIMR teams each identify death. Coordinators from each team communicate with each other.
2. FIMR team reviews the case and a representative(s) from the CDR team participates in the review. One paper CDR-CRS form is completed.
3. FIMR team enters data for this case into the CDR-CRS. FIMR team may choose to enter additional information into a local FIMR database. CDR team does not enter data.

This process works with the CDR team reviewing the case with representation from the FIMR team. A flow chart of this process is as follows:



DATA SOURCES

The following table provides a list of data sources necessary for conducting a productive review and answering all questions about a case in the CDR-CRS. Teams with members from a variety of disciplines may have an easier time obtaining records by going through the representative on the team. It is important to note that a given data source may or may

not have the information requested by the CDR-CRS. In this instance, it may be beneficial to discuss adding items to the original data sources to ensure the information is captured in a systematic way. Additionally, placing the data collected for each case in the context of other information about local communities including social determinants of health is essential.

Table 1: Data sources for CDR and FIMR

Data source	How to access	CDR team	FIMR team
Death certificate or statistical abstract	Request through local register or public health	X	X
Birth certificate or statistical abstract	Request through local register or public health through SPHERE	X	X
Fetal birth and death records	Request through Office of Health Informatics (Vital Records) at Wisconsin Department of Health Services or directly through birthing hospital		X
Law enforcement investigation records, including standardized death scene investigation forms (e.g., SUIDIRF)	Request through law enforcement	X	X
Medical examiner/coroner report	Request through medical examiner/coroner	X	X
School records	Request through guidance counselor or principal of child's school	X	
Medical records, including clinic and/or hospital	Request through hospital, clinic or involved physician	X	X
Maternal medical records if infant case	Request through hospital, clinic or involved physician	X	X
WIC	Request through WIC office in public health	X	X
Social services	Request through human services department or public health	X	X
Other applicable public health records (e.g. immunizations, screening)	Request through appropriate public health office	X	X
Home visiting records	Request through public health	X	X

USING CDR-CRS

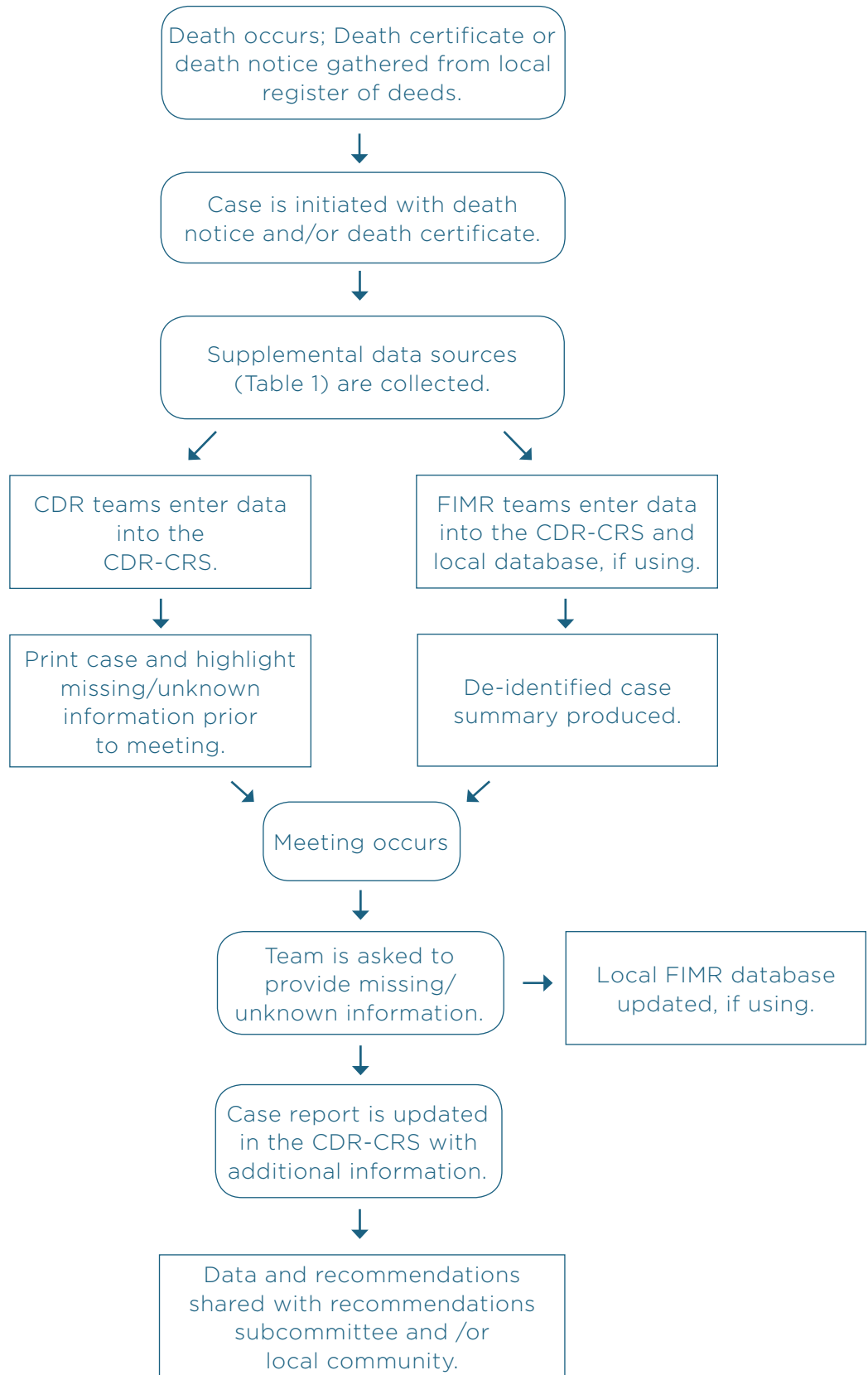
Process for gathering data

*The death certificate or death notice is the **preferred** method of case identification for both CDR and FIMR teams.*

Once a death has occurred in the local jurisdiction, supplemental data sources (Table 1) are collected. The data entry specialist or data abstractor for each team will enter data into the CDR-CRS. For CDR reviews, identified information is shared during the team meeting. For FIMR reviews, a de-identified case summary is produced to share during team meetings. (See Figure on the following page). At this time (2014), the development of a case

summary function is underway with the CDR-CRS. Sample case summary templates are available at www.chawisconsin.org for teams to use in the meantime.

It is important that teams collect information for each case in the same way and include the same data sources for each case to appropriately answer variables in the CDR-CRS. Ensuring as much standardization as possible will allow your local team and the state to be confident in the data that is collected and shared through the recommendation process.



How to enter a case

1. Log into the CDR-CRS at www.cdrdata.org
2. On the left side of the screen is a menu bar (select “Enter a Case”)
3. Select your “Team/County” from the drop down menu (local-level users will have this field populated and will not be able to edit it)
4. Select the appropriate “Year of Review”
5. Enter a sequence of review

(Note the system will automatically assign your cases in numerical order. You can use this default numbering system, or create your own)

6. Proceed through the data fields, clicking “Save and Continue” to move through each section of the form

(Note: The system will automatically skip variables that do not apply to the type of case you are entering based on the information you input into the system)

DATA QUALITY ISSUES

High quality data is essential to drive successful prevention efforts. ***Data that is obtained from the CDR-CRS is only as good as the data entered.*** Several things affect data quality:

Missing or unknown data

High amounts of missing and unknown data are one sign of poor quality data. “Missing” data is reflected by questions in the CDR-CRS that are left unanswered or blank. It is recommended that questions be left blank (i.e., no answer choice selected) when a team has made no attempt to locate the answer. Most questions in the CDR-CRS have an option to select “U/K” or “unknown.” It is recommended that “unknown” be selected when a team has made attempts to locate the answer to the question, but is unable to find the answer. Decreasing the amount of missing and unknown responses is one way to increase data quality. Gathering additional data sources may be necessary in order to locate answers

to questions that were initially answered “unknown” or left blank. Printing out a case report via the “Manage Cases” function within the CDR-CRS and highlighting questions that are missing or unknown is a recommended practice for teams to assist in decreasing poor quality data.

Incorrect data

The CDR-CRS has several ways to protect against data errors. The system has built in skip patterns to hide questions that would not pertain to the case you are entering. For example, if you enter the birthdate of a child that indicates the child is older than one year, you will not be asked questions specific to infants. Additionally, the system will prohibit you from entering conflicting data into some questions. Errors will be flagged with yellow triangles with an exclamation point and the system will not allow the user to save the page until the error is corrected. For example, the date of death cannot come before the date of birth.

Inconsistent data

It is important that questions be answered consistently across all users of the system and across all cases entered by the same team. At times, it may be unclear what is meant by a question in the CDR-CRS. All users are encouraged to download a copy of the data dictionary and have a copy available to consult. The data dictionary provides additional context and direction for every question in the CDR-CRS. The data dictionary is accessible by clicking the question mark next to each question in the CDR-CRS. If you are still unclear how to answer a question, please consult your technical assistance person at the Alliance. The data dictionary can be downloaded at

www.cdrdata.org > HELP menu >
Data Dictionary

Timeliness

Teams are asked to enter data for cases within 30 days of a review. All deaths occurring during a calendar year need to be entered into

the CDR-CRS by Dec. 31 of the following year. For example, all 2014 cases need to be entered by 12/31/2015.

USING DATA

Users of the CDR-CRS can download data in four ways: “Manage Cases”, “Standardized Reports”, an Excel “flat file” of 250 most-used variables or the “raw data tables.”

Manage Cases

The “Manage” option allows the user to see all of the information entered for a given set of cases or an individual case. Users can search for a case based on the following criteria:

- Last name
- Case number
- Team
- Manner of death
- Cause of death
- Date of death

With the exception of last name and case number, users may search with multiple parameters, such as cause and manner of death.

Standardized reports

Standardized reports can be created in the CDR-CRS. After logging into the system, select “Standardized Reports” from the menu bar. Select from the case types, year of death, year of review and 1 of 31 reports the system creates. These reports are not modifiable and are programmed to populate pre-made data tables. More information and assistance in working with standardized reports can be found on the Alliance website.

Flat file

An Excel file of data can be accessed from the “Data Download” menu within the CDR-CRS. Users can select the “Flat file” .txt document and import this .txt file into Excel to work with 250 of the most commonly used variables in the dataset. A codebook for this file also is available at the same Web page. The variables included in this flat file are set by the National Center for the Review and Prevention of Child Death and are not modifiable.

All data tables

Users also can download the raw data for all data tables that comprise the system. Each section of the system corresponds to a data table located in the “Data Download” menu. Users can download only those sections they need. The National Center for the Review and Prevention of Child Death offers a macro to import this raw data into Microsoft Access for teams to work with the data using this software.

DATA ASSISTANCE

Teams can receive assistance from Keeping Kids Alive staff members on working with their data. All users who wish to make a data request should fill out the request form available at www.chawisconsin.org. Requests will be processed in the order received.

Teams should make their data requests at least 30 days in advance of when the data is needed, when possible.

Limitations of data

Many teams exist in small population counties. These counties often report small numbers of fetal, infant and child deaths. These small numbers may be misleading due to instability of rates. It may be more useful to look at regional data, multiple aggregated years of data and additional data sources to inform your prevention efforts.

Other complementary data sources

Teams are encouraged to use complementary data sources when making prevention decisions. Data complementary to the child, fetal and infant death review include:

- Wisconsin Interactive Statistics on Health (WISH)
 - o Injury Mortality, Injury Hospitalizations, Injury Emergency Department Visits, Infant Mortality, Births, Mortality and Population modules
 - o www.dhs.wisconsin.gov/wish
- County Health Rankings
 - o www.countyhealthrankings.org/

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- Youth Risk Behavior Survey (YRBS)
 - o sspw.dpi.wi.gov/sspw_yrbsindx or at www.cdc.gov/HealthyYouth/yrbs/index.htm
 - Pregnancy Risk Assessment Monitoring System (PRAMS)
 - o www.dhs.wisconsin.gov/births/prams/ or www.cdc.gov/prams/cponder.htm
 - Wisconsin Violent Death Reporting System Fact Sheets
 - o www.dhs.wisconsin.gov/health/injuryprevention/Data.htm
 - The Burden of Suicide in Wisconsin Report
 - o www.dhs.wisconsin.gov/health/injuryprevention/
 - The Burden of Injury in Wisconsin Report
 - o www.dhs.wisconsin.gov/health/injuryprevention/
 - Wisconsin Birth and Infant Death Reports
 - o www.dhs.wisconsin.gov/births/

- Community mapping resources available in your jurisdiction
- Local law enforcement statistics
- Other data specific to your locale, including census and city data

Often local data may be very informative and timelier than statewide data. Teams are encouraged to work with local partners to investigate uses of local data.

PREVENTION

The ultimate purpose of CDR and FIMR is to **Keep Kids Alive**. By understanding how and why deaths occur, our communities can take action to prevent similar deaths. Teams are encouraged to review their local data on a regular basis in order to develop informed recommendations. Teams should make sure their recommendations are put into action.

*Again, teams are not expected to design and implement prevention recommendations; **reviews** are intended to **catalyze** community **actions**. Individual agencies or team members can assume responsibility to work with existing or new coalitions to enact **changes** based on the recommendations set forth by the team. Connect your review team findings with these community groups to ensure **results**.*

Local, state and national programs are available to assist communities with implementation of recommendations. Such programs address specific prevention needs for the health, safety and well-being of children and families. Additionally, the Centers

for Disease Control and Prevention funded the Alliance and the Injury Research Center at the Medical College of Wisconsin to develop a **Web-based prevention planning tool and clearinghouse of local examples**. The planning tool provides step-by-step guidance through the process of reviewing data, developing a recommendation and implementing it in the community. Completed tools are housed in the Web-based clearinghouse to help others learn from local teams that have already implemented the prevention activity. The benefits of using these templates include:

- Planning tool for moving from data to prevention.
- Standardized approach to prevention planning.
- Evidence-based clearinghouse of prevention activities and outcomes for replication.

These templates can be viewed by clicking on the community prevention link at www.chawisconsin.org.



SELF-CARE

Participating in a local death review process is hard work that can leave you drained and burned out. While we cannot eliminate stress from the review process, we can take steps to ensure we practice good self-care.

Below are a few suggestions for individual and team activities that support self-care.

Deep breathing

One of the simplest things we can do to manage emotions and ground ourselves is to breathe. Deep breathing is a perfect exercise because it can be done anywhere and does not take long.

1. Sit up straight and place your feet on the floor.
2. Take a long, slow deep breath through your nose.
3. As you inhale, feel the air go into your lungs.
4. Exhale fully through your mouth.
5. Repeat for at least two minutes.

To check your breathing place a hand on your abdomen or chest to feel it expand and contract with each breath.

Stretch or go for a walk

Take a few minutes to stretch or go for a brief walk. Sometimes a brief change of scenery can reduce your stress level and re-energize you.

Focus on the positive

Teams often get stuck on the negative aspects of the review team meeting. Taking a few minutes to acknowledge the positive can mitigate the effects on team members. Some ideas include incorporating a prevention activity, monitoring a change in how professionals work together, or acknowledging one of your personal achievements that came out of the review process.

Play video games

In a study published by the University of Oxford (2009), participants who played a video game (Tetris) soon after viewing traumatic material were able to reduce the



number of flashbacks they experienced. It may be helpful to download this game on a mobile phone or computer for quick access.

Use the power of suggestion

There are many ways to “trick” our brains into dealing with traumatic images.

- Develop a mantra for managing death review team participation. This can be as simple as “today I will focus on prevention.”
- Develop a ritual that signals the end of the review meeting or work day. Examples include, removing your work identification badge, listening to calming music on the return drive to the office and/or identifying a physical marker (e.g., road sign) that once passed means you will no longer think of the team meeting.

Take a self-assessment

Sometimes we do not realize we are feeling stressed, traumatized or burned out until we reach our preverbal breaking points. Self-assessment tools can be useful in providing concrete insight into our thoughts and feelings. These assessments can be conducted on an ongoing basis and serve as a method for tracking stress and trauma over time.

Ending the team meeting

It is recommended that team meetings end on a positive note. This can include discussing prevention, utilizing the strategies described above or an open discussion about how team members are feeling.

For more resources on self-care, visit www.chawisconsin.org.

RESOURCES FOR CDR AND FIMR COORDINATORS

ESTABLISHING CDR AND FIMR TEAMS

The steps below are a general guide for establishing CDR and FIMR teams. This process can be tailored to meet the needs of each team.

1. Designate a team coordinator

Review teams are created through individual efforts and voluntary cooperation among agencies and professionals involved with child death. To establish a multi-agency, multidisciplinary CDR/FIMR team in your community, one (or two) person(s) must be willing to commit to the time and effort required to lead a team. Individuals interested in organizing review teams can come from any profession.

2. Designate a member or members to fulfill specialized roles: Data entry specialist, case abstractor (FIMR), maternal interviewer (FIMR)

Each CDR and FIMR team should identify at least two individuals who will serve as data entry specialists. The role of the data entry specialist is to collect and enter data into the CDR-CRS. These members should be trained prior to the first review team meeting. See page 36 for more information on data collection.

For communities implementing a FIMR team, an abstractor and maternal interviewer should be identified and trained. See page 25 for more information on abstraction and maternal interviewing.

3. Contact CDRC

The team coordinator should contact the CDRC for team information and membership recruiting materials. A community's local political climate and relationships among core agencies can impact the approach to creating a review team. Each community should adapt an approach that best suits its unique characteristics.



4. Study team materials

The team coordinator should become thoroughly familiar with the operation of a review team by studying the informational materials supplied by the state program and attending trainings. Supplemental information regarding other professions involved in CDR and FIMR and how they function also should be studied. Visit www.chawisconsin.org for additional resources.

5. Contact an existing review team

Observing an existing review team will answer many questions regarding how teams operate and also may provide direction for recruiting potential members. A team coordinator must receive permission to observe prior to the meeting. A list of team coordinators can be found on the Alliance website.

6. Contact the local member agencies

The team coordinator should contact the directors of local member agencies to discuss establishing a team. Before meeting with various agencies, team coordinators need to

become familiar with agency rules and the value they bring to the team. In recruiting team members, request that the highest level of agency staff join the team, because they will have the authority to implement changes and commit their agency to cooperative projects. When an agency director is not available, a staff member authorized to make agency decisions should be recruited. Designate an individual who is knowledgeable and experienced with child deaths to represent the agency.

7. Schedule an organizational meeting

All organizational issues should be addressed prior to implementing a team. After all agencies have been contacted, the team coordinator schedules a meeting by offering a choice of dates and times with a 3 to 4 week notice. Meetings should only be held if most invitees are able to attend. Request that a state program representative attend your first meeting to provide guidance and child mortality data for your county or region.

8. Conduct an organizational meeting

The organizational meeting is intended to:

- Introduce potential members.
- Provide an overview of Keeping Kids Alive in Wisconsin.
- Describe how a review team operates.
- Present child mortality statistics.
- Discuss current agency responses to a child death. A review of current procedures helps everyone understand how local systems interact. Many attending an initial meeting may be unfamiliar with the procedures followed when a child dies.
- Discuss the benefits of team involvement for participating agencies.
- Determine types of cases to review.
- Establish a meeting schedule.
- Identify core and ad hoc members.
- Discuss, revise and agree on an Inter-agency Agreement to Participate, and Confidentiality Agreement that meets the legal requirements of all team members and agencies.

These documents must be signed prior to conducting team reviews.

- Agree on materials to distribute at the first review meeting.
- Identify roles, including designating a team member (or several team members) to enter data into the CDR-CRS.

9. Obtain acknowledgment of team

The team coordinator must submit a letter to the CDRC indicating the establishment of the team, membership and potential meeting dates. The CDRC program staff, in collaboration with DHS, will acknowledge the local team and maintain contact through the team coordinator.

The team coordinator should contact the county register of deeds and medical examiner/coroner to establish a procedure for identifying all fetal and child deaths, and for obtaining death certificate information. This may include setting up a memorandum of understanding with the local register to access vital statistics information.

TEAM OPERATING PROCEDURES

Confidentiality

Safeguards for the confidential exchange of information must be in place. At a review team meeting, all data and information regarding the death must be kept confidential. Team members should sign a confidentiality agreement at each meeting.

At this time (2014), Wisconsin does not have comprehensive death review legislation. However, many current local, state and federal laws allow for participation and disclosure during CDR and FIMR. Visit the Alliance Web page for a list of statutes which facilitate the work of CDR and FIMR teams.

Conflict of interest

A conflict of interest may arise for a team member. A conflict is defined as any “vested interest” in a specific case. It is the responsibility of the team member to excuse him/herself from the case discussion.

Member designees and meeting attendance

Team members can designate another agency representative to replace them at a meeting they are unable to attend. However, the team coordinator must be notified. Additionally, team members should recognize the importance of regular attendance. Team members who consistently miss meetings should be replaced. See page 14 for more information on team member roles.

Record keeping

Each case reviewed by a CDR/FIMR team should be entered into the CDR-CRS. It is Wisconsin’s goal to have all local teams utilize the database to capture fetal, infant and child deaths. For more information about data collection, please see page 36.

Team members *should not* take notes of the review meeting. However, notes on prevention or follow-up activities are encouraged.

CONDUCTING AN EFFECTIVE REVIEW TEAM MEETING

Team coordinators play a vital role in maintaining an effective review team.

Six steps to effective reviews

1. Share, question and clarify all case information
2. Discuss the investigation, if appropriate
3. Discuss the delivery of services
4. Identify risk factors
5. Recommend systems improvements
6. Identify and be a catalyst for action to implement prevention recommendations

Beginning the meeting

The team coordinator should remind team members:

- Confidentiality is essential to the function of a death review team.
- Specific case reviews are closed to the public.

- All participants agree to keep the discussions of specific case information confidential.
- The team keeps no case-specific written record of the meeting.
- The purpose of the team is to identify ways to prevent other deaths and to improve how systems work together.
- For CDR, individuals come and leave with only their records.

The coordinator should address any logistical issues prior to conducting review meetings.

Sharing information

Reviews are conducted by discussing each death individually. Each case review averages 20-30 minutes depending on the circumstances.

For CDR teams

Reviews begin with individual agency presentations. Participants provide information from their agency's records. Information should be shared in the following order:

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1. The medical examiner/coroner presents a summary of the death including: the circumstances surrounding the death; resuscitative attempts by family and/or medical personnel; autopsy results; past medical history; and final determination of cause and manner of death.
 2. The EMS provider presents the run report and any other data. The physician can interpret the medical records present.
 3. The law enforcement officer presents information on the scene and investigation.
 4. CPS reports on any information it has on the family, child and circumstances.
 5. Public health reports on any information it has on the family, child or circumstances.
 6. Other team members report on any information they can share with the team.
 7. The prosecutor reports on the status of the investigation and any legal action.

It may be helpful for the coordinator to call on each member to encourage information sharing.

For FIMR teams

Reviews begin with the case summary. This summary may be provided in a written or verbal format. Once the summary has been provided, team members should be given a few minutes to review any materials.

Clarification

Ask for clarification or raise questions about the information. Prior to moving on with a review, all team members should feel confident they understand all information as presented or ask for further clarification.

Discussion

The team coordinator should ask the following questions, each of which should be answered thoroughly before proceeding. When all the questions have been answered to the team's satisfaction, the team should move to the next case.

- Does the team have enough information to proceed with the review? If not, identify missing pieces of information and team members responsible for gathering the information.

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- Are there services that should be provided to the family, community or professionals as a result of this death?
 - Has CPS determined that other children are at risk of harm? If so, what arrangements have been made for the children?
 - Should we recommend any changes to agency practices or policies based on what we know about the circumstances, cause and manner of this death?
 - What does this case tell us about how families are able to access existing local services and resources?
 - What risk factors were involved in this death?
 - Could this death have been prevented?
 - What do we recommend should be done to prevent another similar death?
 - Who should take the lead in implementing our recommendations?
 - Is our review of this case complete or do we need to discuss it at our next meeting?

- Are there questions asked on the data form that have not been answered? If so, where can that information be found?

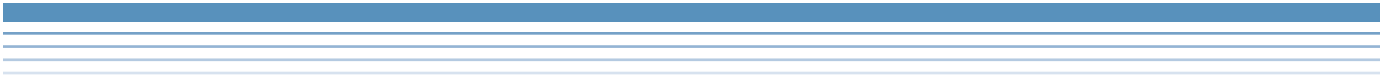
Holdover reviews

Cases may need to be discussed at more than one meeting. Team members may wish to obtain additional information from their agencies or need to wait for investigation results. A team or ad hoc member with significant information may be absent. A case may continue to progress and need to be updated.

Referrals: If a team identified the need for services, referrals should be made by the team member professional associated with the family. Teams should discuss how referrals will be made and who will be responsible.

Agency conflict resolution

Participating agencies may have individuals with concerns or disagreements regarding specific cases. Reviews are not opportunities to criticize or second-guess agency decisions in child death cases. Team members are



responsible for taking further action related to agency policies or procedures.

Teams are not peer reviews. They are designed to examine system issues, not performance of individuals. The team review is a professional process aimed at improving system response to deaths.

When conflict among team members interrupts a review, the team coordinator should intervene. The team coordinator can contact the team members outside the meeting to discuss and help resolve conflicts. Sometimes disagreement is both productive and appropriate, but disruption of the review is not acceptable. Reviews are to be conducted in a professional manner.

Media inquiries

In no case, will any team member disclose any information regarding team discussion outside of the meeting other than pursuant to the mandated agency responsibilities of that individual. Public statements about the general purpose of CDR/FIMR processes may be made,

as long as they are not identified with any specific case.

*Team coordinators are **encouraged** to contact the Alliance **prior** to working with the **media**.*

TEAM MEMBER ROLES

All team members must have a clear understanding of their own and other professional and agency roles in the community's response to child deaths. In addition, team members need to be aware and respect the expertise offered by each profession and agency. The integration of these roles is key to well coordinated community systems.

Medical examiner/coroner

Medical examiners/coroners are central to child death investigations. State law requires all unexpected infant and child deaths to be reported and investigated by the county medical examiner/coroner. In Wisconsin, medical examiners/coroners have the responsibility and right to determine cause

and manner of death. They lay the groundwork for discussion by presenting basic information about cause and manner of death, including findings from the scene investigation, autopsy and medical history.

Law enforcement

Law enforcement team members provide information on investigations of infant and child deaths. They also check histories of children, family members and suspects in intentional child death cases. To ensure sufficient representation, both the sheriff and police departments with the largest jurisdictions should have members on the team. Law enforcement team members serve as liaisons between the team and other local law enforcement departments. Law enforcement professionals are usually the team members best trained in scene investigation and essential skills for determining how a child died. Such expertise provides useful information and training to other members.

Child protective services (CPS)

CPS has the legal authority to investigate child deaths and provide protection for at risk siblings. As team members, CPS representatives provide detailed information on families and child death investigations. CPS may have prior agency contact information including reports of neglect or abuse on a child or siblings as well as services provided to a family. They may provide information of a family's history and sociological factors that influence family dynamics, such as unemployment, divorce, previous deaths, history of domestic violence or drug addiction, and previous child abuse. If the child's death is due to maltreatment, CPS workers can refer family members for appropriate services. Their knowledge on issues related to child abuse and neglect cases is essential to team effectiveness.

Prosecuting attorney

Prosecutors educate death review teams on criminal law and provide information about

criminal and civil actions taken against those involved. They also can explain when a case can or cannot be pursued, and provide information on previous contact or criminal prosecutions of family members or suspects.

Public health

Public health agencies facilitate and coordinate preventive health services and community health education programs. Public health members provide vital records and epidemiological risk profiles of families for early detection and prevention of child deaths, as well as information on local public health services. If a child was treated in a local public health facility or received home visits, they can provide medical histories and explain previous treatments, especially helpful in the review of infant deaths. Many public health agencies can provide information on risk factors and services available to high-risk pregnant woman and their families.

Physician

Physicians provide death review teams with medical explanations and information about development. They access medical records from hospitals and other doctors. The team may have several physicians, including obstetricians, pediatricians, neonatologists, perinatologists, family practice, internal medicine or hospital pathologists.

Emergency medical services

Emergency medical services (EMS) is frequently first at the scene and observes critical information regarding the circumstances, including the behavior of witnesses. The EMS run report also is useful in determining body position at death and identification of other evidence that may have been moved before an investigator's arrival at a scene.

Hospitals

Local hospital representatives on teams can be emergency department staff, quality assurance officers, social workers or key administrators.

Their participation facilitates the sharing of medical records with a team. When an infant or child is transported to an emergency department, hospital representatives can provide a review team with pertinent information. They also obtain valuable information from reviews to help improve hospital practice.

Additionally, hospitals may serve as an identification source for fetal, infant and child deaths.

Community mental health

The mental health representative on a team provides information and insight regarding psychological issues related to events that caused or contributed to a death. The participation of community mental health at the review can provide valuable insight into the behavior of the child and family. Additionally, mental health professionals are well positioned to assist the team with self-care.

Probate or family court

Juvenile judges or probation officers provide teams with information on crimes and delinquencies involving older children. A large number of teenagers die as a result of suicide and homicide. Records from juvenile probation workers can assist in reviews. The courts provide information related to child abuse and neglect. The courts learn from reviews and improve child protection and juvenile court proceedings.

Educators

Educators provide teams with perspective on child health, growth and development. The schools provide leadership in identifying interventions and implementing prevention recommendations.

MAINTAINING AN EFFECTIVE REVIEW TEAM

A death review team follows three stages of development to achieve its goal of reducing the number of deaths in the community:

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- Organization
 - Operation
 - Initiation of prevention efforts and strategies developed from team findings

Once a team has been established and its operating procedures are thoroughly understood, maintenance of the team is essential.

Respect team agreements

To operate effectively, it is essential that team agreements be recognized and followed by all team members. Team coordinators have a lot of information to manage. Below is a suggested list for updating team materials.

Once a year

- Confidentiality forms
- Memorandum of understanding with register of deeds
- Review list of users (e.g., data entry specialists) for the CDR-CRS
- Team member contact information

Every three-years

- Recognition from the state CDRC
- Inter-agency agreements
- Team training
- Review purpose and objectives of the team

Participate and be prepared for meetings

Reviews require regular attendance and participation by all team members. Members should become acquainted with the discussion questions and come prepared to discuss the case. Prior to each meeting, team members should gather relevant information on each case on the agenda. Sample guidelines of information by discipline (e.g., law enforcement, medical examiner/coroner) are available at www.chawisconsin.org.

Keep regular meeting schedules

Regularly scheduled meetings allow team members to make long-term plans and increase attendance. Canceling scheduled meetings diminishes a team's ability to gather

information and hinders the cooperative networking among members. A team can only achieve its objectives by meeting routinely.

Provide an educational element at team meetings

Keep team members informed of team-related trainings, changes in laws regarding their professions and new programs. Ongoing education should be an integral part of every review team's operation. Periodic presentations and informative handouts enhance a team's ability to accomplish its objectives.

Use the Wisconsin network of review teams

When a team needs information on a case or identifies trends, be sure to contact other teams for problem-solving suggestions or to obtain input on innovative efforts. Staff at the Alliance can assist with contacting other teams.

Use professional associations represented on teams

Professional associations can answer questions on many aspects of the responsibilities and statutes that govern a profession.

Use available support services

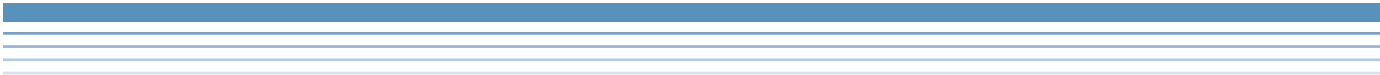
At the present time (2014), the Alliance is under contract with DHS to provide technical assistance to local CDR and FIMR teams.

Complete your case report in a timely manner

This report becomes your county's database on deaths. By completing it accurately, you will be developing a rich source of information for your county. See page 36 for more information on data collection, entry and analysis.

Provide other members with support

Each profession brings to the review team its perspective, professional knowledge and expertise. It is support, not criticism, which will encourage change and foster improvements.



Do not lose sight of the team’s purpose and objectives

A periodic review of a team’s stated purpose, goals and objectives will provide direction to the team and remind members why the team was originally formed. It is recommended that all teams schedule a re-training every three years.

Team membership is a long-term commitment

A review team is not an ad hoc committee that collects data on deaths for a designated period. It is a panel of professionals dedicated to establishing a better understanding of the causes of child deaths in their community. Discovering the patterns that cause or

contribute to deaths is an ongoing process. Patterns change over time and aggregate knowledge acquired by team members provides structure for achieving effective results.

A team is both a message to and from the community.

By participating in a local death review team, professionals pledge to better understand deaths and improve the health and safety of their community. Participation represents their commitment to eliminating obstacles, integrating community responses and creating opportunities for prevention.



www.chawisconsin.org