Enhancing Collaboration Between Child Death Review and Fetal and Infant Mortality Review

National Center Guidance Report
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Enhancing Collaboration Between Child Death Review and Fetal and Infant Mortality Review

Introduction

States and communities across the country benefit from both child death review (CDR) and fetal and infant mortality review (FIMR) programs.

Collaboration between these review processes at the state or community level can enrich both reviews, increase efficiency, and achieve collective impact while decreasing costs and reducing redundancy.

Collaboration between CDR and FIMR teams occurs differently in each state and local team. There is no right or wrong way for the two programs to align their efforts if state laws and policies are followed. Collaboration between CDR and FIMR has many positive effects at both the state and local level. Communities and states whose programs are actively collaborating reduce duplication, increase potential for implementing prevention activities, and identify broad system gaps.

Fatality review has been a national priority for more than 20 years. In 2011, a multidisciplinary group was convened by the National Center of Fatality Review and Prevention, formerly known as the National Center for Review and Prevention of Child Deaths, to discuss collaboration across fatality reviews.

The proceedings of the aforementioned meeting were published as Coordination and Integration of Fatality Reviews: Improving Health and Safety Outcomes Across the Life Course (https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/CoordinatedReviews.pdf).
The report of the proceedings contains the following recommendations for fatality review programs:

1. **Consolidate management and administration of different review programs within states and/or locales.**

2. **Improve communication during the case review process.**

3. **Standardize and/or link data collected from different reviews.**

4. **Coordinate recommendations, reports, and interventions among review teams of different types.**

5. **Continue efforts at the national level to foster collaboration.**

**This guidance highlights broad considerations that affect collaboration.** It is designed as a tool to help communities and states consider how best to align two similar, parallel processes in meaningful ways to benefit both programs and the communities they serve.
Initial Considerations

When enhancing collaboration at the state or local level, the following items should be considered:

**Legal Authority**

Before enhancing collaboration between CDR and FIMR, it is critical to review any relevant state laws.

**Important questions to ask include:**

- What opportunities for information sharing between CDR and FIMR are in state statute or policy?
- What limitations for information sharing between CDR and FIMR are in state statute or policy?

What do state (e.g., CDR, FIMR, or maternal child health coordinators) and local (e.g., corporation counsel, district attorney) partners think about collaboration between CDR and FIMR? These partners are often charged with enforcing and implementing state laws. The support from these partners is critical for successful collaboration. If legal authority for review teams is lacking and appears to be needed, teams may need to work together for the passage of relevant legislation. Formal recommendations from the review teams can help accomplish this goal. A single piece of enabling legislation is preferable to authorization contained in several statutes.

**Agreements**

CDR and/or FIMR teams have agreements in place with partners/agencies for a variety of reasons. It is critical to identify and review these agreements before enhancing collaboration to determine if changes are needed in order for productive collaboration to occur.
EXAMPLES OF AGREEMENTS USED FOR FATALITY REVIEW

- Institutional Review Board (IRB) approvals
- Confidentiality agreements
- Vital records agreements
- Interagency agreements
- Memoranda of understanding
- Hospital agreements for medical records
- Interview consent forms
- Data use agreements

If needed changes are identified, they should be implemented prior to the exchange of information.
Interviews

Historically, CDR teams have not contacted families to seek their input during the review process. Many FIMR teams conduct maternal or family interviews to hear the story of the pregnancy, birth, and death. Prior to sharing information gathered during family interviews, consent forms, state laws, and other appropriate documents should be reviewed to ensure information sharing is allowed. It is critical to ensure that families have the opportunity to participate in the interview with their information remaining anonymous and confidential.

If information sharing is allowed, consider the following before proceeding to share interview information:

- **What is the purpose of the interview?**
- **How does sharing the interview information benefit the goal of prevention?**
- **Should interview information be shared verbally or just for data purposes?**
- **Should interview information be shared on specific cases or in aggregate?**

If all parties agree to share information gathered during family interviews, be sure to update any relevant agreements. It is important for community partners to have a clear understanding of why separate interviews, such as an investigative interview and a FIMR maternal interview, are necessary.

Collaborating on Essential Functions

There are many opportunities to coordinate CDR and FIMR work. Collaboration strategies may include joint reviews and/or merging teams. There are many ways to collaborate while maintaining separate review teams and review processes. The following are suggestions and examples of collaboration on the essential functions of CDR and FIMR, highlighting effective implementation of the collaboration recommendations from the report *Coordination and Integration of Fatality Reviews: Improving Health and Safety Outcomes Across the Life Course.*
Consolidate management and administration of different review programs within states and/or locales

Leadership

Collaborative leadership in CDR and FIMR occurs throughout the United States. Collaborative leadership can reduce cost and duplication while improving efficiency and potential for the implementation of effective, evidence-based or informed prevention recommendations. Collaboration is most successful when it is supported at all leadership levels. Communities with separate CDR and FIMR team leadership can benefit from collaboration by meeting regularly, dividing process tasks, and coordinating prevention activities.

Several states have a fatality prevention system focused on infants, children, and youth that uses a FIMR and CDR process within that system. Other states use the same agency to lead both CDR and FIMR at the local level as well.

Leaders from CDR and FIMR hold joint trainings and attend review meetings for the partner program. In some states, one staff member leads CDR, FIMR, and maternal mortality review programs. Additionally, local teams may share an abstractor between programs to access and summarize records for CDR and FIMR.

Membership

Membership of review teams varies, but great potential exists for some shared membership between CDRs and FIMRs. Despite the variations in CDR and FIMR team membership, some common members could be shared between teams to provide continuity, share information and perspectives, and reduce work overloads. Both CDR and FIMR review teams should include members who reflect the community’s diversity, including differences in culture, socioeconomic status, and urban or rural concerns.
“A combined FICCMR team allows Montana the opportunity to maximize resources while gaining deep insight into our community. We are then able to use that data to help inform other programs, such as Title V.”

Kari Tutwiler, MA, Montana State FICMMR Coordinator
Fetal, Infant, Child and Maternal Mortality Review and Prevention

Case Study: One Review System

In Montana, there is one team that reviews all fetal, infant, child and maternal deaths. These teams, known as FICMMR, are charged with reducing preventable deaths. FICMMR teams review all causes of death of children under 18 years of age and maternal deaths are reviewed by local teams. Some fetal deaths are also reviewed by the county teams. Local review teams are led by a designated county health employee and offer a variety of prevention services.

Montana has 31 county mortality review teams, which are defined in state statute. Due to the state’s rural population, 23 other counties utilize a neighboring county’s FICMMR team to help review their county deaths and generate evidence-based and best practice prevention recommendations. The recipient county is responsible for implementing evidence-based or best practice prevention initiatives in their county. This model of cooperation is effective and efficient as reviews are conducted for 54 counties and six of the seven American Indian tribes.

At the state level, one staff person supports all FICMMR teams. The FICMMR program closely collaborates with other key public health functions, such as the Maternal Child Health Program which leads the Title V program.
In some instances, an agency is a vital partner in both case review contexts. Examples include law enforcement, public health professionals, and child protective services professionals. Some teams plan their CDR and FIMR meetings back-to-back to make it easier for these professionals to attend both reviews.

**Funding**

Sharing funding between CDR and FIMR can assist in sustaining both programs. Funding can be shared at the state and/or local level. Opportunities to share funding while enhancing current activities should be explored.

**Examples include:**

- Assigning one agency to coordinate/administer CDR and FIMR
- Consolidating staff resources
- Partnering on grant applications
- Coordinating trainings
- Establishing a dedicated staff member who participates in both CDR and FIMR

Title V funding is often used to support CDR and FIMR across the country. In some states, Title V funds can be used to support either program, or to support staff who work on both programs. Several states have staff who are funded to work on both programs, commonly in data collection or analysis capacities.

2. **Improve communication during the case review process**

**Case Identification**

Fatality review programs can coordinate the identification of cases for review, maximizing staff time. One person may review all death certificates and separate them into cases for each review team, or may review newspapers and other sources to identify cases. The coordinators from both programs may meet to review death certificates together, deciding which cases each team will review.

One state has a shared electronic death registration system whose staff distribute death certificates to local CDR and FIMR programs statewide.
**Obtaining Records**

Identifying one person or agency to request records that are used by both CDR and FIMR can decrease duplication and increase efficiency. Additionally, it can be easier for community partners if records are not requested multiple times. The CDR team can assist the FIMR team in accessing records and vice versa. In some states, one records technician may request or subpoena all records for various fatality review programs.

**Interviews**

Maternal or family interviews are a key feature of the FIMR process. In certain types of infant deaths, it is critical that a FIMR maternal interview and an investigative interview, including a doll reenactment, be conducted. In these instances, CDR and FIMR can facilitate mutual understanding of when investigations may be conducted, and what community agencies may be interviewing families and when. This allows FIMR staff to be aware of what other professionals may have already interacted with families, or which may still need to do so. Family interviews may occur in person, over phone, or via email/mail. Additional information on family interviews can be found at the National Center website.

In one state, the protocol requires collaboration between the coroner investigator and the public health professional, and in many counties the FIMR maternal interviewer as well. Understanding each other’s role and sharing resources and information allows the public health professional and coroner to have a better understanding of the nature of the home visit and its powerful value. Creating a team approach benefits the coroner’s investigator as well as the families, allowing the FIMR interviewer to be more effective in support of the families and to better address their individual needs. It also helps families by reducing their burden of repeatedly answering the same questions and describing the details of their baby’s death over and over again. The FIMR interviewer has more time for answering the family’s questions and helping the family through the grieving process.

**Standardize and/or link data collected from different reviews**

**Collecting and Entering Data**

Collecting and entering data are core components of CDR and FIMR reviews. However, this can be time intensive, especially for communities with both CDR and FIMR. Streamlining data collection and entry can maximize resources. In some states, one person has entered data for CDR and FIMR into separate data collection systems.
The ultimate goal of child fatality review and fetal and infant mortality review is to prevent child and infant deaths. The collaboration of these two programs in Tennessee has allowed us to expand our infant mortality reduction efforts to save babies’ lives.

Rachel Heitmann, MS, Section Chief, Injury Prevention and Detection
Tennessee Department of Health

Case Study: Separate Review Teams

In Tennessee, both CDR and FIMR are housed within the section of Injury Prevention, Infant Mortality Reduction and Death Review, within the Division of Family Health and Wellness at the Tennessee Department of Health. This allows for full collaboration between CDR and FIMR at the state level. Although there are separate FIMR and CDR coordinators, both programs benefit from joint resources and leadership.

The goal for all fatality review in Tennessee is to prevent future deaths. At the local level, Tennessee has 31 of CDR teams that review all deaths to children younger than age 18. There are five local FIMR teams who review fetal and infant deaths. In communities where there are both CDR and FIMR teams, the Department of Health provides significant leadership and guidance about collaboration.
“In past years, Louisiana’s Bureau of Family Health has housed both FIMR and CDR under one mortality surveillance team, operationalized through nine regional abstractor/coordinators. By operationalizing our program in this way, recommendations from both systems have led to more integrated and collaborative local efforts that have allowed our Community Action and Advisory Teams (CAATs) to move recommendations to action and help shape prevention efforts at both the local and state level.”

Rosaria Trichilo, Statewide Surveillance Manager
Louisiana Office of Public Health, Bureau of Family Health

Case Study: Triage Cases

In Louisiana, FIMR and CDR are led by State Department of Health, Maternal Child Health Coordinator. Much like in Tennessee, there are significant benefits from shared leadership. In all 9 of Louisiana’s parishes, there is a process of triaging deaths into either a CDR review, FIMR review or Maternal Mortality Review. This process allows for easy collaboration as well as clear guidelines around what team is reviewing what cases.

See page 23 for a visual example of Louisiana’s system triaging cases.
Since the launch of the version 5 of National Fatality Review-Case Reporting System [https://data.nckfrp.org](https://data.nckfrp.org) (NFR-CRS) in 2018, jurisdictions have the option of using one system to collect both CDR and FIMR case data. Additionally, to reduce data entry, cases can be copied from CDR to FIMR accounts, and vice versa when both teams will be reviewing a case. In some communities, CDR provides the FIMR team with a completed copy of the NFR-CRS data collection form or some similar form ahead of their review, or vice versa.

**EXPLORING NEW OPTIONS**

Although the information-gathering methods of CDR and FIMR review teams are distinct, programs should explore ways to move beyond their historical practices to identify what information can be shared legally and ethically without compromising their respective purposes. The development of standard protocols for gathering information and developing minimum data sets should be encouraged.

**Sharing Data**

Sharing CDR and FIMR data can be a powerful tool for creating a comprehensive picture of the risk factors and circumstances surrounding fetal, infant and child deaths. Data can be shared on an aggregate or case-specific level. Prior to data sharing, make sure to review state laws and existing agreements.

**Coordinate recommendations, reports, and interventions among review teams of different types**

**Prevention Recommendations**

Collaborating on prevention can be accomplished by all CDR and FIMR teams. Teams can create a prevention team that reviews both FIMR and CDR data to identify and implement prevention programs. Partnering to address specific recommendations around infant mortality in a coordinated way can maximize the impact of both teams' prevention efforts. Teams can coordinate training and education opportunities for their staff related to best or evidence-based practice to consider when creating recommendations. Programs can coordinate to host a meeting to share findings and recommendations jointly.
Reports

Many state and local teams are required to issue reports. Collaborating on reports can maximize staff time as well as provide a clear and comprehensive picture of fetal, infant, and child deaths. Data can be analyzed jointly or include separate sections for CDR and FIMR in the same report. CDRs and FIMRs should develop a minimum circulation list of individuals, agencies, and organizations with whom they routinely share their reports of findings and recommendations. These recipients may be the same entities that will be responsible for implementing review team recommendations.

In several states, a state-wide body analyzes both CDR and FIMR data for an annual report, drawing broad conclusions for key prevention recommendations and initiatives. In other states, independent annual reports include a section highlighting the work and findings of the other fatality review process.

Continue efforts at the national level to foster collaboration

Since 2015, HRSA has supported technical assistance that demonstrates increased and systematic collaboration between FIMR and CDR programs. The National Center continues to provide training opportunities, shared resources and publications, and data support to fatality review programs across the country. These resources can be accessed at the National Center website. National Center staff can provide consultation on more effective integration and collaboration strategies to state and local teams.

Models of Collaboration

Common models of collaboration between CDR and FIMR have the following components:

- Conducting joint reviews
- Merging the CDR and FIMR teams into one new mortality review team
- Setting case criteria for FIMR or CDR so cases are only reviewed by one team
- Sharing prevention recommendations

The following section contains three examples of collaboration models. However, as long as state laws and policies are followed, there is no right or wrong way for a team to collaborate. These models are meant to serve as a starting place to consider collaboration within jurisdictions.
CDR and FIMR teams may decide to review certain cases jointly. Below is an example of how a community may decide to structure its review processes and meetings. In this model, cases are identified by different program coordinators. A joint review meeting would see the larger fatality review team break into a CDR team and a FIMR team, with each reviewing cases most appropriate for their sub-group. Finally, all of the partners would reconvene to discuss prevention recommendations. The larger joint team could function as the FIMR community action team, or simply to make recommendations to a different prevention-focused team. Data collection and entry may take place anywhere throughout the process.
**Separate Review Teams**

Some communities keep separate CDR and FIMR review teams. In this system, cases are only reviewed once. Below is an example of how a community may decide to structure its review processes and meetings.

Not all communities utilize a prevention team. If your team does not use a prevention team, FIMR team reviews can bypass that step, linking directly to finalizing and implementing prevention recommendations in the process model. Data collection and entry may take place anywhere throughout the process.

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**Case identification completed by CDR coordinator**

CDR team reviews cases that meet definition

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**Case identification completed by FIMR coordinator**

FIMR team reviews cases that meet definition

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Community action team reviews data and makes recommendations

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Finalize and implement prevention recommendations
Triaging Cases

Some communities may decide to keep separate CDR and FIMR teams. However, there may be a certain subset of cases that are reviewed by CDR and FIMR each individually. Communities with both FIMR and CDR team may also choose to do dual review. For example, cases of Sudden Unexpected Infant Deaths (SUIDs) may be reviewed in both CDR and FIMR. CDR may focus on completion of the death scene investigation and mobilizing the community to develop improved safe sleep activities. FIMR, with its access to medical records and maternal interviews, may reveal that there were missed opportunities for education to families and may elect to work with the provider networks on how and when to educate new parents on safe sleep. Collaboration between the teams to strategically select cases can ensure comprehensive findings and recommendations.

CDR and FIMR team reviews can link to finalizing and implementing prevention recommendations in this model. Below is an example of how a community may decide to structure its review processes and meetings to effectively triage cases between review programs. Data collection and entry may take place anywhere throughout the process.
Louisiana’s Bureau for Family Health Case Triage Algorithm:

**All Deaths**
- All Maternal, Fetal, Infant, and Child Deaths

**Categories**
- Maternal death
- Fetal death
- Infant death
- Child death

**Definition/Age**
- All women during or within one year of pregnancy
- Stillborn (no breath taken)
- Live birth (died before the age of one)
- 1-14 years of age
- >14 years of age

**Cause**
- All causes
- Expected/medical
- Unexpected and SUID (SIDS, accidental suffocation or strangulation in bed and unknown causes)
- Unexpected (accidental injury, homicide, and suicide)
- Expected/medical

**Gestation**
- Anytime during or within one year of pregnancy
- <28 weeks
- ≥28 weeks
- 24-26 6/7 weeks
- <24 and >36 6/7 weeks
- All gestational ages
- All gestational ages

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PAMR | FIMR | CDR
Conclusion

As more communities launch fatality review programs, the need to think creatively about effective collaboration will increase. States are innovating ways for CDR and FIMR programs to strategically coordinate their efforts. As the processes are similar, and often examining the same types of cases, collaboration between the programs can enrich the work of each. Effective coordination between CDR and FIMR will affect greater impact on the systems both processes seek to improve through case reviews and recommendations for prevention.
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