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Enhancing Collaboration Across Maternal and Child Fatality Review Programs

National Center Guidance Report

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Table of Contents

Introduction 6

Programmatic Overview 10

What is MMR? 10

What is FIMR? 10

What is CDR? 11

What is the SUID/SDY Case Registry 12

Opportunities for Collaboration 16

Initial Considerations 19

Legal Authority 19

Institutional Agreements 20

Informant and Family Interviews 21

Collaborating on Essential Functions 22

Recommendation #1: 22

Recommendation #2 24

Recommendation #3: 26

Recommendation #4: 27

Models of Collaboration 28

Alaska 28

Arizona 29

Indiana 30

Ohio 31

Pennsylvania 32

Tennessee 33

Conclusion 34

Resources 35

Endnotes 37

Enhancing Collaboration Across Maternal and Child Fatality Review Programs

Introduction

In 2011, a multidisciplinary group was convened from across the country to discuss enhancing collaboration between fatality reviews. The meeting proceedings resulted in *The Coordination and Integration of Fatality Reviews: Improving Health and Safety Outcomes Across the Life Course*,[1] a report that made recommendations for fatality review programs and national partners. Program expansion and development have further informed what program coordination and alignment can and does look like in jurisdictions. Based on the report and program development, this document will explore the following ways in which different fatality review programs may effectively coordinate efforts to support progress in maternal and child health.

1. Formalize coordination of different review programs within states and/or locales
2. Improve communication throughout the case preparation process
3. Share data collected from different reviews to support planning objectives
4. Jointly disseminate reports, and information in order to amplify shared messages

Over the past decade, some states and jurisdictions aligned and launched new collaborative efforts across fatality review programs. Due to the variety of state and local public health organizational structures, these programs sometimes sit within the same agency, division, or unit in state or local health departments or medical examiners' offices – while in other places, they do not. Though there may be no shared structure between programs, there may be overlapping community partners and stakeholders, and they may identify similar risk factors and prevention recommendations.

> In response to the recommendation to continue efforts at the national level to foster collaborative efforts, this resource is being provided by the organizations that deliver ongoing technical assistance, support, and in some cases funding, to maternal, infant, and child fatality review teams and programs across the country. It was developed to share strategies for collaboration between the similar, but distinct, programs for collective impact. This product is the result of ongoing efforts to understand and support collaboration at the national level, and support states and jurisdictions in their efforts to align programs to achieve collective impact.

When different fatality review programs align or collaborate, it is important to do so in ways that allow fidelity to each of the programmatic models as well as each jurisdictional authority. While this resource will illustrate ways programs may align or collaborate, each is a unique process with specific implementation requirements. The resources below can provide tailored programmatic support to organizations hoping to better align these activities.

Maternal mortality review:

- Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) in CDC's Division of Reproductive Health: www.cdc.gov/erasemm
- Review to Action: https://www.reviewtoaction.org/

Fetal, infant and child death review:

- The National Center for Fatality Review and Prevention: www.ncfrp.org
- The Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry in the CDC's Division of Reproductive Health: https://www.cdc.gov/sids/case-registry.htm

Each year in the United States, about 700 childbearing people die as a result of pregnancy complications, and American Indian/Alaska Native and Black women are 3 times as likely to die from a pregnancy-related cause than white women.[2] The time surrounding pregnancy can be an especially vulnerable time in which women and childbearing people should be surrounded by community and clinical support.

Almost 20,000 infants died in the United States in 2020.[3] A similar number of babies are stillborn, without signs of life.[4] While fetal and infant mortality in the United States has improved overall, racial disparities persist, with Black, Native Hawaiian/Pacific Islander, and American Indian/Alaska Native infants at the highest risk. The leading causes of infant mortality in 2020 were congenital disorders, preterm birth and low birth weight, sudden infant death syndrome (SIDS), injuries (including suffocation), and maternal pregnancy complications.[5]

Of the infant deaths described above, about 3,400 sudden unexpected infant deaths (SUID) take place in the United States each year. These deaths occur among infants less than 1-year-old and have no immediately obvious cause. The three commonly reported types of SUID include sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed, and deaths of unknown cause.[6]

Every year in the United States, over 30,000 children, including infants, die before their 18th birthday. After the first year of life, the most common cause of death for children in 2020 was unintentional injuries, followed by homicide, suicide, and cancer.[7]

In jurisdictions across the country, fatality review teams regularly convene to examine and better understand individual cases of maternal, fetal, infant, child, and/or youth fatalities with the goal of identifying service delivery and systems-level interventions that can prevent future deaths. Fatality review processes enable states and communities to generate a deeper understanding, identify underlying risk and protective factors, and create meaningful change and safer, more just, communities. They also allow communities to conduct essential public health functions of needs assessment, quality assurance, and policy development at state and local levels.

Fatality review teams examining these deaths include:

- Maternal Mortality Review Committees (MMRC)
- Fetal and Infant Mortality Reviews (FIMR)
- Child Death Reviews (CDR)
- Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry Advanced Review teams

Programmatic Overview

What is MMR?

Maternal Mortality Review Committees (MMRCs) are multidisciplinary committees in states and cities that perform comprehensive reviews of deaths among childbearing people during and within a year of the end of pregnancy. They typically include representatives from public health, obstetrics and gynecology, maternal-fetal medicine, nursing, midwifery, forensic pathology, mental and behavioral health, patient advocacy groups, and community-based organizations. They use findings and recommendations to improve service systems for women and advance health equity for childbearing people.

MMRCs provide enhanced surveillance of maternal mortality and seek to categorize deaths as either pregnancy-related or pregnancy-associated but not related. Connect with the MMRC in your jurisdiction (URL: https://reviewtoaction.org/tools/networking-map).

MMR case criteria: Death of a woman or childbearing person during or within one year pregnancy.

What is FIMR?

Fetal and Infant Mortality Review (FIMR) is an evidence-based, prevention focused examination of fetal and infant deaths. It is a community-owned, action-oriented process to improve systems and resources for women, infants, and families. FIMR is conducted in a two-tiered model. The FIMR process brings multidisciplinary community groups together to examine de-identified infant and fetal death cases using a Case Review Team (CRT) to review individual cases and a Community Action Team (CAT) to implement recommendations based on the reviews. The CRT is composed of prenatal care providers, perinatologists, public health, and social service providers and they review de-identified case summaries created from abstracted service delivery records and a family interview. This team uses the abstracted case summary to identify risk factors, collect data, and make recommendations for community change. The CAT is comprised of community leaders representing government, consumers, key institutions, and health and human service organizations. This team acts to implement recommended systems improvements based on findings from reviews.

See if there is a FIMR program in your state or community, or to identify a program coordinator and access the FIMR map (URL: https://www.ncfrp.org/fimr-map/).

FIMR case criteria: Vary between jurisdictions, but cases are selected from stillbirths and cases of infant deaths before the first birthday.

What is CDR?

Child Death Review (CDR) is a comprehensive and multidisciplinary review of child deaths that aim to lead to a better understanding of how and why children die. These findings are used to catalyze action to prevent future deaths, ultimately improving the health and safety of communities, families, and children. CDR teams are comprised of multidisciplinary members including law enforcement, child protective services, prosecutors, medical examiners or coroners, public health professionals, and pediatricians. Teams may choose to add additional members depending on the type of review being conducted, the landscape of the community, or relevant legislation. Team members must be willing to have open, honest, cooperative relationships and dialogue. They must also be willing to advocate for change to prevent future deaths.

There are CDR teams in all 50 states, the District of Columbia, and within some Native American tribes. They are commonly coordinated through maternal child health (MCH) or injury prevention programs in state or local public health, or within child welfare agencies. See if there is a CDR program in your state, or to identify a program coordinator, and access the CDR map (URL: https://ncfrp.org/cdr-map/).

CDR case criteria: Vary between jurisdictions, but they are selected from children from birth to younger than the age of 18 who died of any cause, commonly prioritizing sudden, unexpected deaths or those related to injuries.

What is the SUID/SDY Case Registry

The SUID/SDY Case Registry in the CDC's Division of Reproductive Health, in partnership with the National Institutes of Health, provides technical assistance to funded states and jurisdictions building on existing CDR programs to review and collect standardized data in the National Fatality Review-Case Reporting System (NFR-CRS) (URL: https://ncfrp.org/data/nfr-crs/) on 100% of their SUID and SDY deaths. For more information, visit the SUID/SDY Case Registry (URL: https://www.cdc.gov/sids/case-registry.htm).

Currently, 22 states and jurisdictions are funded for SUID, covering about 1 in 3 SUID cases in the United States. Thirteen of those jurisdictions are also funded for SDY expanded component that includes an Advanced Review by a team of medical specialists. To see if your jurisdiction is funded as part of the SUID/SDY Case Registry, visit the Case Registry website (URL: https://www.cdc.gov/sids/case-registry.htm).

SUID/SDY Case Registry Criteria:

- **SUID cases are selected when the cause of death for an infant is listed as unknown, undetermined, SIDS, SUID, unintentional sleep-related asphyxia/ suffocation/strangulation, unspecified suffocation, cardiac or respiratory arrest without other well-defined causes, or unspecified causes with potentially contributing unsafe sleep factors.**
- **SDY cases are selected when a child is less than 20 years old at the time of death, the death is sudden and unexpected, and an autopsy determined the death was not due to a known external cause, homicide, suicide, intentional overdose, or terminal illness.**

Fatality Review Processes in Maternal and Child Health

	Case Review Criteria	Key Team Members and Partners	Unique Process Goals	Unique Process Features
MMR	Deaths of women or childbearing people during or within one year of pregnancy.	OB-GYNs, maternal fetal medicine; midwives; public health; domestic violence experts; forensic pathologists; patient advocacy groups; substance use experts; mental and behavioral health experts	Categorize deaths as either pregnancy-related or pregnancy-associated, but not related to better understand and prevent maternal mortality.	Informant interviews; Community Vital Sign Dashboards (case – specific social and environmental Indicators).
FIMR	Cases are selected from stillbirths and cases of infant deaths before the first birthday.	Maternal child health public health; OB-GYNs; midwives; maternal fetal medicine; home visiting; social service providers; community advocates; patient advocacy groups	Enhance the health and well-being of women, infants, and families by improving the community resources and service delivery systems available to them.	Parental interviews; 2-tiered system with a Case Review Team (CRT) and a Community Action Team (CAT); de-identified case process
CDR	Cases are selected from children from birth to under the age of 18 who died of any cause, commonly prioritizing sudden, unexpected deaths or deaths due to maltreatment.	Injury prevention programs; child welfare agencies; public health; law enforcement; medical examiners/ coroners; pediatricians	Identify risk factors and prevention strategies to address deaths of infants, children, and youth.	Team members bring identified records to the review meeting to share and discuss the death and make case findings.

Fatality Review Processes in Maternal and Child Health (continued)

	Case Review Criteria	Key Team Members and Partners	Unique Process Goals	Unique Process Features
SUID/ SDY Case Registry	SUID: Deaths listed as unknown, undetermined, SIDS, SUID, unintentional sleep-related asphyxia/ suffocation/ strangulation, unspecified suffocation, cardiac or respiratory arrest without other well-defined causes, or unspecified causes with potentially contributing unsafe sleep factors. SDY: Decedents less than 20 years old at the time of death when the death is sudden and unexpected and autopsy determined the death was not due to a known external cause, homicide, suicide, intentional overdose, or terminal illness.	Injury prevention programs; child welfare agencies; public health; law enforcement; medical examiners/ coroners; social service providers	Categorize sleep related deaths of infants and unexpected deaths for children over age 1 year based on the SUID and SDY categorization algorithms to better understand why children die.	SDY deaths are reviewed by an Advanced Review team comprised of medical experts to determine if there were underlying medical or genetic risks

Fatality Review Processes in Maternal and Child Health (continued)

	Data Collection Tool	Lead Agencies	Federal Leadership and Technical Support
MMR	Maternal Mortality Review Information Application (MMRIA)	State public health, local public health, medical examiner's offices	Centers for Disease Control and Prevention
FIMR	National Fatality Review-Case Reporting System (NFR-CRS)	Local public health; hospitals	Health Resources and Services Administration; National Center for Fatality Review and Prevention
CDR	NFR-CRS	Public health; child welfare; medical examiner/coroner	Health Resources and Services Administration; National Center for Fatality Review and Prevention
SUID/SDY Case Registry	NFR-CRS	Public health; medical examiners offices	Centers for Disease Control and Prevention; SUID and SDY Case Registries Data Coordinating Center

Opportunities for Collaboration

There are many reasons why different fatality review programs may seek enhanced collaboration or alignment, including maximizing resources, reducing redundancy, or learning from the successes of a parallel program. Fatality review programs often have shared processes, partners, and may even select the same cases for review. They also have distinct characteristics, are often led by different agencies, have different funders and resources, and may have distinct legal obligations.

Processes

While different fatality review processes have distinct characteristics, there are shared processes and functions across programs. For instance, all fatality review teams:

- Identify deaths
- Request records to inform case review
- Convene multidisciplinary teams
- Review individual cases
- Make determinations about individual cases
- Make prevention recommendations
- Compile aggregate data
- Share data with additional community collaborators to move data forward to catalyze action

Different fatality reviews are able to share successes across these activities, and in some cases, reduce redundancies by enhancing communication and ensuring that there are not repeat requests for the same records.

Partners

While fatality review programs may be led by different agencies or organizational units within an agency, often they are coordinated by a state or local health department, and frequently in a division or bureau focused on maternal and child health. Even when program leadership is not adjacent within an organization, similar external partners may be asked to participate in fatality case reviews or advance recommendations. Some of these shared partners may include:

- Medical examiners/coroners
- Public health
- Law enforcement/ investigators
- Child welfare
- Prenatal care providers

Cases

Occasionally, a single death or event may meet selection criteria for multiple fatality review programs. Examples may include:

- An infant death in an automobile crash may be reviewed by both a FIMR and CDR team.
- A SUID may be reviewed by a local FIMR, a CDR team, and a SUID Case Registry grantee.
- A teen mother who died within a year of pregnancy and whose death may be reviewed in both CDR and MMR. Depending on the cause of death, the same death may be eligible for review in an SDY Case Registry Advanced Review.

While team composition and expertise may mean the case reviews play out differently, all teams reviewing a case have a shared interest in resulting case findings, recommendations, and prevention activities. The connectedness of some of these examples illustrates why, in some communities, multiple programs come together to triage cases to the appropriate team(s), choose to conduct dual reviews in separate processes, or join in focusing on improving death scene investigations.

Recommendations

While fatality review programs focus on separate populations, these populations are often seen as parts of a whole population of interest to external collaborators. Risks to women in pregnancy are directly related to risks for infant mortality, and fatality reviews often result in similar system or community-level recommendations. Fatality review programs of all types can identify ways in which the social determinants of health drive outcomes, and recommendations across programs are able to focus on these systems-level risks that affect maternal, infant, child, and youth populations.

MMRCs are prompted to develop specific, actionable recommendations for each case during the case review process at each meeting, in the format of "who should do what and when" to prevent future deaths. Using qualitative and quantitative analysis, MMRCs prioritize recommendations from individual case reviews after a set period of time, e.g. a year.

FIMR teams identify issues present in each case that they determine were contributing factors in the death of the infant – not necessarily causative, but factors that played a strong role in determining the outcome. Teams identify gaps or areas for improvement in the quality of service delivery systems. Recommendations may be generated after a single case review, but more commonly several cases will illustrate similar problems or trends over time. When taken together, these data may be a very compelling way to illustrate a problem and the need for action.

CDR teams generate findings in individual case reviews focused on key systems-level risk factors. Findings focus on systems, policies, or program areas, and provide case-specific rationale. Teams can generate reports in the NFR-CRS that summarize findings from their cases and determine which systems, policies, or program areas they want to prioritize for action based on available resources, partnerships, political climate, or other timely factors. From findings, teams can craft actionable recommendations using a SMARTIE framework (strategic, measurable, ambitious, realistic, time-bound, inclusive, and equitable).[8]

Initial Considerations

There are many areas in which teams may be able to align or collaborate their efforts, but there are several significant issues that should be addressed before programs undertake collaboration, including a review of the legal authority in place to empower fatality review processes, agreements and MOUs teams may have with other organizations, team members or families, and the parameters established for sharing interview information, if relevant.

Legal Authority

Before collaborating between fatality review programs, there should be a review of relevant state statutes and agency policies.

- **Which statutes or policies are relevant to all the state's fatality review programs?**
- **Which statutes or policies only apply to specific types of fatality reviews?**
- **What opportunities for information sharing between programs exist in state statute or policy?**
- **What limitations for information sharing are outlined in statute/policy?**

Teams may choose to identify individuals responsible for interpreting or enforcing relevant policy—often the lead agency's general counsel, fatality review program or MCH/Title V coordinators. Asking these partners for their perspective on what is possible will allow teams to identify what areas may be ideal for aligning program efforts, and if there is a need to advocate for policy changes through formal recommendations from the fatality review teams through a single piece of enabling legislation that could apply across programs.

Institutional Agreements

Before considering collaboration across programs, the fatality review program should review the agreements already in place with partner organizations and agencies to determine what opportunities and limitations may exist. It may be necessary to propose changes to agreements with these partners for productive collaboration to take place.

Some relevant agreements fatality review programs should review include:

- Data use agreement
- Vital records agreements
- Interagency agreements
- Memoranda of understanding
- Agreements with health systems for medical records
- Confidentiality agreements
- Interview consent forms
- Institutional Review Board (IRB) approvals

If changes are identified, they should be implemented prior to collaborations that include exchanging information of any kind.

Informant and Family Interviews

Interviews are an important aspect of some fatality review programs, allowing case reviews to include a more well-rounded and equitable perspective on relevant circumstances than records alone could provide. Many MMRCs are now conducting informant interviews;[9] FIMR teams conduct parental interviews[10] as a part of their information-gathering efforts, collecting information on the circumstances of the pregnancy, birth (if relevant), life, and death of the deceased; and for the SDY Case Registry, the family is contacted to discuss family medical history and consent to later research. It is important that key informants and bereaved parents are assured that any information they provide remains anonymous and confidential, and all consent forms, state laws, agency policies, and other relevant documents are reviewed to fully understand if information gathered through interviews can be shared with parallel programs in the jurisdiction.

If sharing of information gained in interviews is allowed within the scope of agreements with interviewees, teams should consider the following questions before sharing details from the interview:

- **What is the purpose of the interview?**
- **How does sharing information from the interview benefit the goal of prevention?**
- **Should interview information be shared verbally, in a case review discussion, or through a protected data transfer?**
- **Can teams coordinate so that the family is contacted once on behalf of multiple programs?**

If all parties agree to share information gathered during interviews, it may be necessary to update relevant agreements.

Collaborating on Essential Functions

Recommendation #1:
Formalize coordination of different review programs within states and/or locales

Leadership

Collaborative leadership across these fatality review programs occurs across the United States. In some states, just two of the programs may be led by similar or collaborative leaders; in others, MMR, FIMR, the SUID/SDY Case Registry, and CDR are administered out of one agency and division. Collaborative leadership can reduce costs and duplication while improving efficiency and potential for the implementation of effective, evidence-based or evidence-informed prevention recommendations.

In some jurisdictions, leaders share record abstractors across programs, providing case summaries for more than one type of fatality review. In others, one individual serves as the interviewer for both FIMR and MMR.

Programmatic collaboration is most successful when it is supported at all levels of program leadership. Programs with unconnected fatality review program leadership may benefit from collaboration by meeting periodically, dividing process tasks, and coordinating prevention activities.

Membership

Membership on diverse case review teams varies, but it is common for some members to participate on multiple fatality review teams.

Common membership across programs may include:

- Public health representatives, including MCH and injury prevention professionals, or home visiting programs
- Medical specialists, including obstetrician-gynecologists and maternal-fetal medicine
- Mental health professionals
- Hospital system representatives
- Medicaid representatives
- Domestic violence prevention professionals
- Substance use experts
- Social workers
- Law enforcement officers
- Human service representatives
- MCH advocates and champions
- Medical examiners, forensic pathologists, and death investigators

In some local communities where these partners serve on more than one fatality review team, meetings are planned to run simultaneously or back-to-back to reduce barriers to team participation.

Funding

As of early 2022, the CDC directly funds the ERASE Maternal Mortality project for 30 states and 22 SUID Case Registry awardees, with 13 of the SUID awardees also funded to participate in the SDY expanded component through a collaboration with the National Institutes of Health. Awardees are funded to conduct fatality reviews, enter data, and work on prevention. HRSA's Title V funds administered by the Maternal Child Health Bureau, The Administration for Children and Families' Child Abuse and Treatment Act (CAPTA) Preventative Health and Health Services Block Grant, and state general funds are common sources of funding to support MMR, FIMR, and CDR programs or augment these programs by ensuring ongoing supportive infrastructure.

Programs can leverage funding to increase program efficiency. Fatality review programs at both state and local levels sometimes leverage funding with multiple programs paying a portion of a full FTE for a shared staff position, such as a fatality review abstractor, epidemiologist, or key informant/parental interviewer. Other examples of collaborative approaches to program funding include:

- **Assigning one agency to coordinate and administer MCH-focused fatality review programs**
- **Consolidating staff resources**
- **Partnering on grant applications**
- **Coordinating training opportunities**

Recommendation #2:
Improve communication throughout the case preparation process

Obtaining Records

Identifying one person or agency to request or subpoena records on behalf of multiple fatality review programs can decrease duplicate requests to partners and increase efficiencies for both the fatality review programs and those providing records. Teams can assist each other in accessing records or provide introductions to those from whom they request records at specific organizations or providers if that is the preference of the organization. Possible partners to consider for consolidating requests may be organizations such as vital records, law enforcement, medical examiners, Medicaid, or WIC. Consolidated requests will require clear and coordinated timelines between programs.

Interviews

Family and informant interviews are important aspects of FIMR programs and have been a growing strategy among MMR programs in recent years. In some jurisdictions, one interviewer may conduct interviews on behalf of multiple programs.

When interviewing families and other informants, it is important to understand what other interviews may have taken place, such as those conducted by law enforcement, medical examiners' offices, child welfare, other investigators, or other fatality review programs. This can decrease the burden on the individuals being interviewed during a very difficult time and ensure they do not need to unnecessarily recall details they have already shared. Fatality review programs can increase efficiency in these processes by communicating about their interview processes with parallel fatality review programs and with other investigating agencies and planning interviews to maximize efficiency.

In some jurisdictions, there are protocols for collaboration between coroner investigators and public health professionals, including family interviewers. In others, several agencies who require information from witnesses or family members attend the investigator's interview together, ensuring that all agencies' questions are addressed at once, decreasing the burden on witnesses and family.

In addition to the possibility of sharing one interviewer, fatality review programs may choose to collaborate on summarizing shared resources to provide to bereaved families in the interview context, including contact information, eligibility criteria, and even bereavement referrals.

However communities and states may choose to address this, it should be done thoughtfully, and with the best interest of interviewees in mind.

Recommendation #3:
Share data collected from different reviews to support planning objectives

Compiling and Entering Data

Data compilation is a key activity across fatality review programs. High-quality data allows programs to identify risk and protective factors and disparities effectively, and ultimately drive prevention activities. Compiling fatality review data requires an understanding of data sources, fatality review processes, data platforms, and data quality.

Although the data platforms or methods may vary between fatality review processes, programs may share a staff member focused on data entry across programs or establish data entry protocols that apply to data for multiple fatality reviews. Currently, FIMR, CDR, and SUID/SDY programs all enter data into the NFR-CRS, so this may be a natural opportunity to consolidate data entry across programs.

Sharing Data for Internal Program Planning

Sharing aggregate data across review programs offers the opportunity to identify shared factors to inform internal planning and prioritization of strategies for MCH populations within jurisdictions. Programs may identify variables of interest and share aggregated data for the purposes of educating parallel programs and identifying leading, shared risk factors and priority recommendations for prevention.

Under certain circumstances, fatality review programs may identify a reason to share case-specific data, particularly if a case is under review by more than one fatality review program. Prior to data sharing, ensure that doing so would not violate state statute, agency policy, or existing agreements. Parallel review programs may publish or simply share relevant summary data with each other to inform the recommendations parallel programs are making.

Recommendation #4:
Jointly disseminate reports and information in order to amplify shared messages

Amplify Aligned Prevention Strategies

Coordinating prevention activities and data dissemination has the potential to support collective impact and may be a powerful collaborative effort.

Fatality review teams may decide to review team recommendations and elevate coordinated recommendations that address shared contributing factors focusing on specific domains such as those to improve system or community level access or social support, to address forms of discrimination, or to address the social determinants of health. Each process has its own methodology for arriving at recommendations,[11,12] but there are several ways that programs may consider coordinating their efforts when it comes to recommendations, reports, and interventions. Opportunities may include shared community listening sessions co-hosted by multiple programs to inform data projects, holding shared summits or other opportunities for information sharing, or planning complementary data analyses.

Models of Collaboration

Alaska

Structure

MMR, CDR, and the SUID Case Registry share staff, case abstractors, and case review facilitators as part of combined program operations as Alaska's Maternal Child Death Review (MCDR) (URL: https://health.alaska.gov/dph/wcfh/Pages/mchepi/mcdr/default.aspx). Through the MCDR, if a maternal/child dyad or a teen mother dies, the maternal subcommittee, made up of members of the larger MCDR, reviews the case (s) in a shared case review with CDR partners.

Collaboration innovations

Alaska has streamlined the work process by creating an administrative database to track all fatality cases across its fatality review programs. This customized Access database is an automated platform to track all data requests to partner agencies and automate pre-populated records request letters to relevant agencies. The programs have also partnered to publish resources focused on cross-cutting issues, including youth suicide risk and Adverse Childhood Experiences, MCDR Issue 3 of 4 primary (URL: https://www.alaskahha.org/_files/ugd/ab2522_308f311defbd42d186e5873c209a2631.pdf).

Lessons learned

The MCDR partnered with additional programs, including Alaska's National Violent Death Reporting System, to reduce redundancy in data requests to law enforcement. In most cases, NVDRS requested records on behalf of both programs. There have been difficulties related to MCDR's distinct statutory authority and a higher level of detail needed from requested records, including scene photos for SUID investigations. These obstacles have resulted in records delays, and the programs are continuing to explore other approaches and solutions.

Arizona

Structure

Effective collaboration between Arizona's Maternal Mortality Review (MMR) (URL: https://www.azdhs.gov/prevention/womens-childrens-health/index.php#maternalmortality-review) and Child Fatality Review (CFR) (URL: https://www.azdhs.gov/prevention/womens-childrens-health/injury-prevention/index.php#child-fatality) is possible because of shared support staff, leadership, and statutory authority. Shared staff execute some administrative duties, including managing paper records when necessary, and shared supervisors for MMR, CDR, and the SUID Case Registry in the Bureau of Assessment and Evaluation support liaising and records management with external partners, including medical examiners, health care, behavioral health, child welfare, and home visiting agencies. This also facilitates effective data sharing between programs.

Collaboration innovations

The Arizona CFR program shares its prevention recommendations for maternal deaths among mothers under the age of 18 with the state's MMR program to ensure that all relevant recommendations in these cases are considered together. The programs collaborate on presentations, data dissemination, and dissemination of fatality review recommendations. They have recently transitioned the Department of Health Services' annual Maternal Mortality Summit to a Maternal and Infant Mortality Summit, highlighting cross-program fatality review data and prevention strategies together.

Lessons learned

Arizona's separate fatality review programs have different prescribed case review timelines. This has made it challenging to report data on similar timeframes between the programs. They also have had to navigate the differences between state-level reviews for MMR and local-level reviews for CFR/SUID cases.

Indiana

Structure

The Indiana Department of Health's Division of Fatality Review and Prevention (URL: https://www.in.gov/health/cfr/) houses its MMR (URL: https://www.in.gov/health/cfr/maternal-mortality-review-committee/), FIMR (URL: https://www.in.gov/health/cfr/fetal-infant-mortality-review/), CFR (URL: https://www.in.gov/health/cfr/local-child-fatality-review-teams/overview/) and SUID Case Registry activities, as well as Overdose Fatality Review, and Suicide Fatality Review programs. The programs share funding, case records, staff, leadership, team members, and case findings. Statutory changes have increased records access and facilitated collaboration.

Collaboration innovations

The fatality review programs in Indiana create joint external reporting for relevant agencies and partners. Borrowing from the two-tiered FIMR model, Indiana's fatality review programs share regional Community Action Teams (CATs) to spearhead prevention activities based on local fatality review findings and recommendations for FIMR and CFR. They are currently exploring how their individual, community, provider, facility, and systems-level MMR recommendations could best fit with this regional prevention model to address risk across the life course.

Lessons learned

Coordinated records requests between programs help local coroners provide records to fatality review teams. Relationships are a pivotal piece of effective fatality review. While having the right people at the table for reviews is vital, members who sit on multiple fatality review teams can become easily overwhelmed. Teams should make efforts to minimize the burden of participating on multiple review teams. Shared resources on trauma and trauma-informed approaches have been helpful to review team members across programs.

Ohio

Structure

Ohio's Pregnancy-Associated Mortality Review (PAMR) (URL: https://odh.ohio.gov/know-our-programs/pregnancy-associated-mortality-review), Child Fatality Review (URL: https://odh.ohio.gov/know-our-programs/child-fatality-review/child-fatality-review), and Fetal and Infant Mortality Review (URL: https://bit.ly/3NSYtbN) sit under the same manager at the Ohio Department of Health. FIMR and CFR share the same program coordinator.

Collaboration innovations

The Ohio PAMR and CFR programs established a data use agreement to ensure they could share records for cases that fit inclusion criteria for both review processes, such as the death of a teen mother.

Lessons learned

Maintaining shared collaborators, team members, and prevention partnerships facilitates richer review meetings, ensures open and continual communication between programs, and supports programmatic collaboration.

Pennsylvania

Structure

The Pennsylvania MMRC (URL: https://www.health.pa.gov/topics/healthy/Pages/MMRC.aspx), CDR (URL: https://www.health.pa.gov/topics/programs/Pages/Child-Death-Review-Team.aspx), and SUID Case Registry activities sit in the Pennsylvania Department of Health's Bureau of Family Health. The programs are managed under different divisions within the larger Bureau organizational structure. CDR and the SUID/SDY Case Registry share programmatic staff. The state subcontracts with Philadelphia's medical examiner's office to conduct SDY reviews in the local jurisdiction.

Collaboration innovations

The Pennsylvania Department of Health is in the process of cross-walking and comparing MMR findings and recommendations with findings in their CDR data to explore how these data may identify similar issues or solutions. The Department of Health created a "Working with Coroners and Medical Examiners Workgroup." The group includes all offices who make records requests to coroners and medical examiners in the state, including CDR, MMR, SUID/SDY Case Registry, National Violent Death Reporting System, Overdose Fatality Review, Prescription Drug Monitoring Program, and Injury Prevention. This group holds quarterly calls to discuss how to streamline and make effective data requests.

Lessons learned

Statutes governing the separate review programs can differ, and legislation can limit the programs' ability to collaborate to share data internally.

Tennessee

Structure and case reviews

The Tennessee FIMR (URL: https://www.tn.gov/health/health-program-areas/fhw/fetal-infant-mortality.html) and CFR (URL: https://www.tn.gov/health/health-program-areas/fhw/child-fatality-review.html) programs have shared staff. The MMR, FIMR, CFR, and SUID and SDY Case Registry Activities each have their own director, but sit under the same section chief in the state health department's Injury Prevention, Infant Mortality Reduction and Death Review Section.

Collaboration highlights

Tennessee's fatality review programs work together to share information, resources, and prevention efforts around shared risk factors, including those related to violent deaths, overdose, suicide, medical maternal deaths, and medical/natural deaths of infants and children. The fatality review programs disseminate information to the same maternal child health collaborators from across programs. They are currently collaborating with a state home visiting program on two projects that would support maternal mental health and infant safe sleep. The state's Perinatal Quality Collaborative responds to both maternal and infant data and findings.

Lessons learned

Creating a strong peer network of state-level fatality review coordinators supports individual program coordinators and makes each of the programs' work more effective.

Conclusion

Effective partnership and collaboration between fatality review programs is allowing jurisdictions across the country to improve processes, better understand community-level risk, and amplify the shared findings and recommendations for collective impact. Enhanced alignment can maximize resources and reduce redundancy and burdens on agencies, fatality review staff, and the bereaved.

Distinct, but parallel, fatality review programs focusing on maternal, infant and child deaths, and SUID/SDY cases have the opportunity to collaborate, using their case findings and recommendations to make communities safer for women and childbearing people, infants, children, and youth across the country.

Resources

Maternal Mortality Review manuals and documents

https://reviewtoaction.org/tools/resource-center

Fetal and Infant Mortality Review program manual

https://ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMRManual.pdf

Child Death Review program manual

https://ncfrp.org/wp-content/uploads/NCRPCD-Docs/ProgramManual.pdf

Review to Action—MMR technical assistance requests

Review to Action (URL: https://reviewtoaction.org/) is a resource supported through a partnership between the Association of Maternal and Child Health Programs (AMCHP) and the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) administered by the CDC. The goal of Review to Action is to promote the state-based maternal mortality review process as the best way to quantify and understand maternal mortality and prioritize interventions to improve maternal health. To contact a team member, email erasemm@cdc.gov.

Review to Action provides resources to enhance the quality and comprehensiveness of maternal mortality reviews. Its objectives include:

- Connect states with an MMRC to national-level support and peer programs to build capacity to conduct maternal mortality review and translate findings into action.
- Assist states without an MMRC in gathering resources, tools, and support to build political and social will to establish a committee.
- Raise awareness of the critical role MMRCs play in supporting the elimination of preventable maternal deaths and promoting the health and wellness of expecting and new mothers and birthing people.

National Center for Fatality Review and Prevention—FIMR and CDR technical assistance requests

The National Center for Fatality Review and Prevention (URL: https://www.ncfrp.org) is the technical support and data center serving Child Death Review (CDR) and Fetal and Infant Mortality Review (FIMR) programs across the country. Funded by the Maternal and Child Health Bureau at the Health Resources and Services Administration, the National Center offers a wide variety of technical assistance services that are available via site visits, virtual meetings, email, and phone. The National Center is funded by the Health Resources and Services Administration to provide technical assistance, training, and assistance with strategic planning to help support teams to develop, implement, and sustain prevention-focused fatality review processes and maintain the National Fatality Review-Case Reporting System (NFR-CRS), a database for fatality review teams to enter data related to the circumstances of the individual infant and child deaths they review.

SUID and SDY Case Registry Data Coordinating Center—SUID/SDY Case Registry technical assistance requests

The SUID and SDY Data Coordinating Center (URL: https://sdyregistry.org/) is funded by the Centers for Disease Control and Prevention to offer training, technical assistance, and data support to CDC's Case Registry awardees. They also contract with the Sudden Death in the Young Biorepository at the University of Michigan Children's Hospital and provide data and support to the recipients of the National Institutes of Health R01 grant examining genetic causes for sudden death in youth. They coordinate data collection and data quality activities for Case Registry awardees and provide information and resources for families who may be contacted by awardees after the death of a child.

Endnotes

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