



Fetal and Infant Mortality Review Manual

A Guide for Communities

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Chapter One: Fetal and Infant Mortality Review (FIMR)

An Introduction for Team Members

FIMR: A Brief History

The death of an infant is a profound loss to a family and community. Every year in the United States, over 21,000 infants die before reaching their first birthday. Infant Mortality is widely used as a measure of a communities' overall health and wellbeing. The United States Children's Bureau, established in 1912, was the first federal agency to focus exclusively on improving the lives of children and families. The Bureau recognized infant mortality as one of the nation's most pressing issues.

In addition to the burden of infant mortality, an almost equal number of pregnancies in the United States end in a stillbirth or fetal death, an infant born without signs of life, generally after 20 weeks of gestation. Profound and persistent disparities exist for both fetal and infant deaths. According to the U.S. fetal death report, non-Hispanic Black women have more than twice the fetal mortality rate compared with non-Hispanic White and Hispanic women.¹ Infants born to non-Hispanic Black women die at a rate 2.3 times greater than infants born to non-Hispanic White women.² In addition to racial disparities, economic and geographic disparities continue to plague the U.S. Behind these statistics are the stories of individuals and families.




Often the causes of infant deaths leave families and communities with few answers, asking: **"Can anything be done to make a difference in the future?"** Fetal and Infant Mortality Review (FIMR) is one answer to that pressing question.






With its in-depth exploration of the contributors to infant mortality and the systems issues that impact infant deaths, FIMR has helped communities have a clearer understanding of underlying risk factors and inequities that they may not identify otherwise.



Julia C. Lathrop, when leading investigations into infant mortality for the Children's Bureau in the early 1900's, said, "...there is no infant death rate which can be viewed with complacency...The interest shown by the citizens of every town studied, the hearty good will of the mothers whose interviews are the indispensable basis of the work, encourage the bureau's hope that the [infant mortality] inquiry will prove increasingly valuable as a stimulus to more active protections of the youngest and tenderest lives throughout the Nation."



Today there are over 160 FIMR programs in 27 states, the District of Columbia, and two U.S. territories. To read the most recent report on the Status of FIMR in the United States, and for snapshots of lessons learned, feel free to read, [More First Birthdays: A Report on the Status of Fetal & Infant Mortality Review in the United States, 2020](https://bit.ly/3II3rfu) (URL: <https://bit.ly/3II3rfu>).

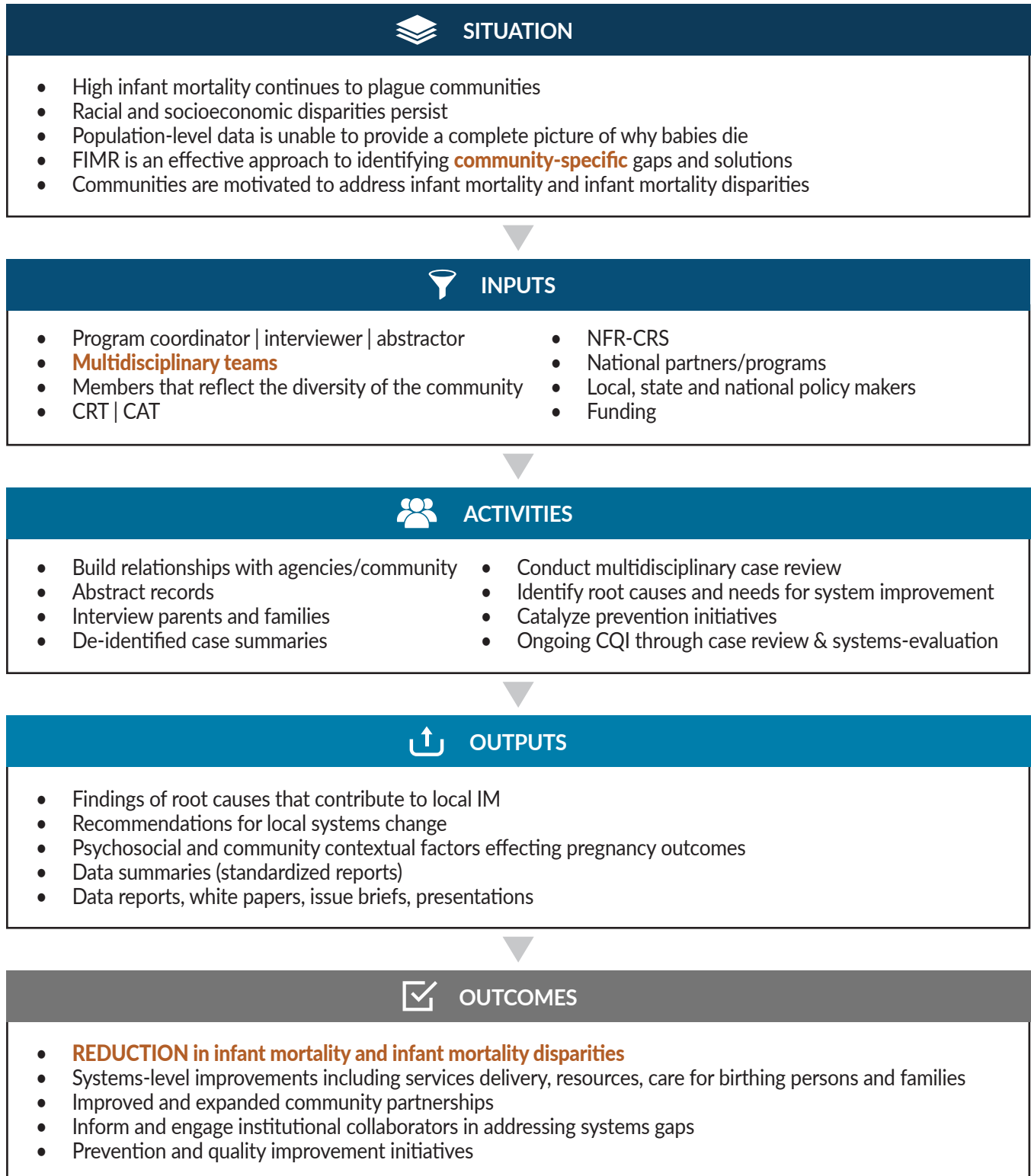
FIMR's Purpose

This section outlines the foundational elements that underlie the FIMR process— its purpose, principles and objectives, core functions, and the qualities of successful FIMR programs.

The purpose of FIMR is to conduct comprehensive multidisciplinary review of fetal and infant deaths to understand how a wide array of local social, economic, public health, educational, environmental, and safety issues relate to the tragedy of fetal and infant loss. Additionally, FIMR teams use the findings to take action that can prevent future infant deaths and improve the systems of care and resources for women, infants, and families.

Figure 1. FIMR Logic Model

Goal: Decrease infant mortality and disparities through records abstraction, family interviews, case review, findings that relate to the root causes and recommendations and initiatives to improve systems of care.



Follow this link for an editable version of the [FIMR logic model](https://bit.ly/3uJrCMZ) (URL: <https://bit.ly/3uJrCMZ>).

Key Operating Principles

There are several key operating principles of FIMR that aid in identifying and addressing risk factors for infant mortality and advancing racial equity. These principles should govern the structure, purpose, and goals of FIMR programs.

- Fetal and Infant deaths are a community problem and too multidimensional for responsibility to rest in any one place or system
- Fetal and infant deaths are sentinel events that illustrate need for investigation and action
- FIMR focuses on systems issues and avoids blaming or placing responsibility on individual behavior
- FIMR's two-tiered process, having separate and distinct teams to carry out an **analytic function** and a subsequent **action function** centered on the lived experience of the impacted families, collectively enhances program effectiveness
- The parental/family interview includes the voices of those who have lost an infant and offers information not available through routine quantitative methods
- Reviews lead to identification of systems factors contributing to fetal and infant mortality
- Reviews focus on prevention and findings should lead to effective recommendations, informed by the voices of those who have lost an infant, that improve the systems of care and resources for women, infants, and families

Objectives of Fetal Infant Mortality Review

The FIMR process provides the review and action teams with the context on the life of the parents, family, and the death of the infant. Social factors such as geography, limited access to education, experience with discrimination, trauma (including historical trauma), and limited access to physical and behavioral healthcare can contribute to poor pregnancy outcomes and fetal and infant mortality. Residential, educational, and occupational segregation impacts access to high-quality education, employment opportunities, healthy foods, and physical and behavioral health care. Combined, these structural inequities have long-lasting health impacts, including adverse birth outcomes, and fetal and infant mortality.

The following are objectives that, if followed, will provide structure and clarity of expectations for the FIMR process:

1

Examine and identify the significant health, social, economic, cultural, safety, and education systems' factors and inequities associated with fetal and infant mortality through review of individual cases.

- For each case of fetal or infant death to be reviewed, information is collected from a variety of sources, which may include physician and hospital records along with those from home visits and relevant community program records.
 - Information is obtained in an interview with the family, usually the parents.
 - All identifying information, names of families, providers, and agencies are removed, and an anonymous summary of the case is presented to the Case Review Team (CRT).
-

2

Improve communication and linkages among local and state agencies to enhance coordination of investigation and prevention efforts.

- Bringing together multiple disciplines and agencies to focus on common barriers affecting health care, quality of care, and delivery of care helps to reduce interagency conflicts by putting aside issues of competition or turf.
 - Multidisciplinary and multi-sector involvement promotes participation of a broad range of community partners, engaging those who represent the systems that affect outcomes.
-

3

Plan a series of interventions and policies that address these factors to improve the service systems and community resources.

- Data and findings from reviews drive community and system interventions.
- FIMR mobilizes community action to effect needed changes through the strength of collective advocacy as well as through actions of organizational leaders.

4

Participate in the implementation of community-based interventions and policies.

- FIMR achieves enhanced visibility and credibility for family issues with policymakers, funders, the media, and the broader community.
 - FIMR can decrease costs by avoiding duplication of services and conserving resources by identifying asset saving opportunities.
 - FIMR can create an opportunity for improving the quality of care provided by medical and service providers.
-

5

Assess the progress of state-level and community-based interventions.

- FIMR is an integral component of an ongoing structural and individual needs assessment, program planning, implementation, and evaluation—essential functions in public health practice.
 - FIMR provides a feedback mechanism to assess whether recommendations and actions are implemented, and problems are resolved.
 - FIMR offers invaluable information that helps communities and systems understand how changing social, environmental, and political conditions impact services and resources and affect the ability of families to thrive throughout the community.
-

6

Identify barriers to care and trends in service delivery and suggests ideas to improve policies, practices, and services that affect families.

- Reviews can identify services the community, family, and/or professionals need following a fetal or infant death.
- Reviews can facilitate interagency referral protocols to ensure timely service delivery.
- Reviews can identify ways agencies can improve policies and practices that serve women, infants, and families.
- Reviews can improve the quality of care delivered by health systems and providers.



The Cycle of Improvement

Continuous Quality Improvement, or CQI, is a management philosophy and method that has its origins in business and industry. Used in health care, it is a process of progressive incremental improvement of processes, safety, and patient care. The CQI approach is positive and encourages trust, respect, communication, collaboration, responsibility, accountability, empowerment, and recognition between leaders and participants. Like FIMR, CQI discourages shame and blame. Carrying out the program objectives in a continuing fashion creates a cycle of improvement for health providers, systems and the community.

Cycle of Improvement

FIMR is Continuous Quality Improvement

Data Gathering

Information is collected from a variety of sources, including family/parental interview, medical records, prenatal care, home visits, WIC, and other social services.

Changes in Community Systems

As the physical, health care, and social environment for childbearing families improves, outcomes, over time, will be better.



Case Review

The multidisciplinary Case Review Team reviews the case to identify barriers to care and trends in service delivery and ideas to improve policies and services that affect families.

Community Action

The Community Action Team receives the recommendations from the review team and is charged with developing and implementing plans leading to positive change within the community.



It is critical to center the voices of affected families for team members to come to a full understanding of the circumstances of the death.

During the review process, the members of the review team will deliberate on strengths and assets illustrated in each case, as well as asking questions about challenges, such as:

- Did the family receive the services or community resources they needed, and were they acceptable? If not, why not?
- Were the service systems and resources culturally and linguistically appropriate and acceptable? If not, why not?
- Are there gaps or flaws in the system that need to be addressed?
- What does this case tell us about how families are able to access existing services and resources?
- What does this case tell us about the quality of care and services being provided and accessed?

As a result, FIMR teams identify family resilience, barriers to care, and trends in service delivery, and propose ideas to improve policies, practices, and services that affect families.



FIMR Process

The following three components of the FIMR process are considered to be the foundation of the program and will be described in greater detail in subsequent chapters:

1

FIMR program staff manages and supports FIMR teams by:

- Selecting cases for review.
- Abstracting medical, public health, and service records.
- Conducting the parental/family interview.
- Creating the de-identified case summary.
- Developing and sustaining, diverse, equitable and inclusive local FIMR teams.
- Providing training and technical assistance to FIMR teams driven by the findings in local data.
- Supporting data collection to inform action.
- Linking FIMR teams to evidence-based prevention resources.
- Collaborating with key community collaborators to identify and resolve barriers FIMR teams encounter.

2

The FIMR Case Review Team (CRT) conducts individual case reviews of fetal and infant deaths by:

- Reviewing deaths from a broad, multidisciplinary, multisectoral or multi-systems perspective.
 - Identifying findings and unpacking the structural components.
 - Making recommendations for prevention policies and practices.
-

3

A FIMR Community Action Team (CAT) receives the review team findings, reviews other mortality and population data and trends to make and act on prevention recommendations by:

- Prioritizing recommendations.
- Developing an action plan that includes policies and practices warranting action.
- Setting a time frame.
- Monitoring progress of implementing actions.
- Informing the larger community, including systems, about the need for action and FIMR successes.
- Keeping track of successful ongoing FIMR systems changes to see that they are sustained.
- Determining if the community's needs are changing over time and deciding how to meet them.
- Ensuring that community voices are centered in the assessment of community needs.



Qualities of Successful FIMR Programs

Hallmarks of successful FIMR programs include both process and community/systems impact qualities.

Process

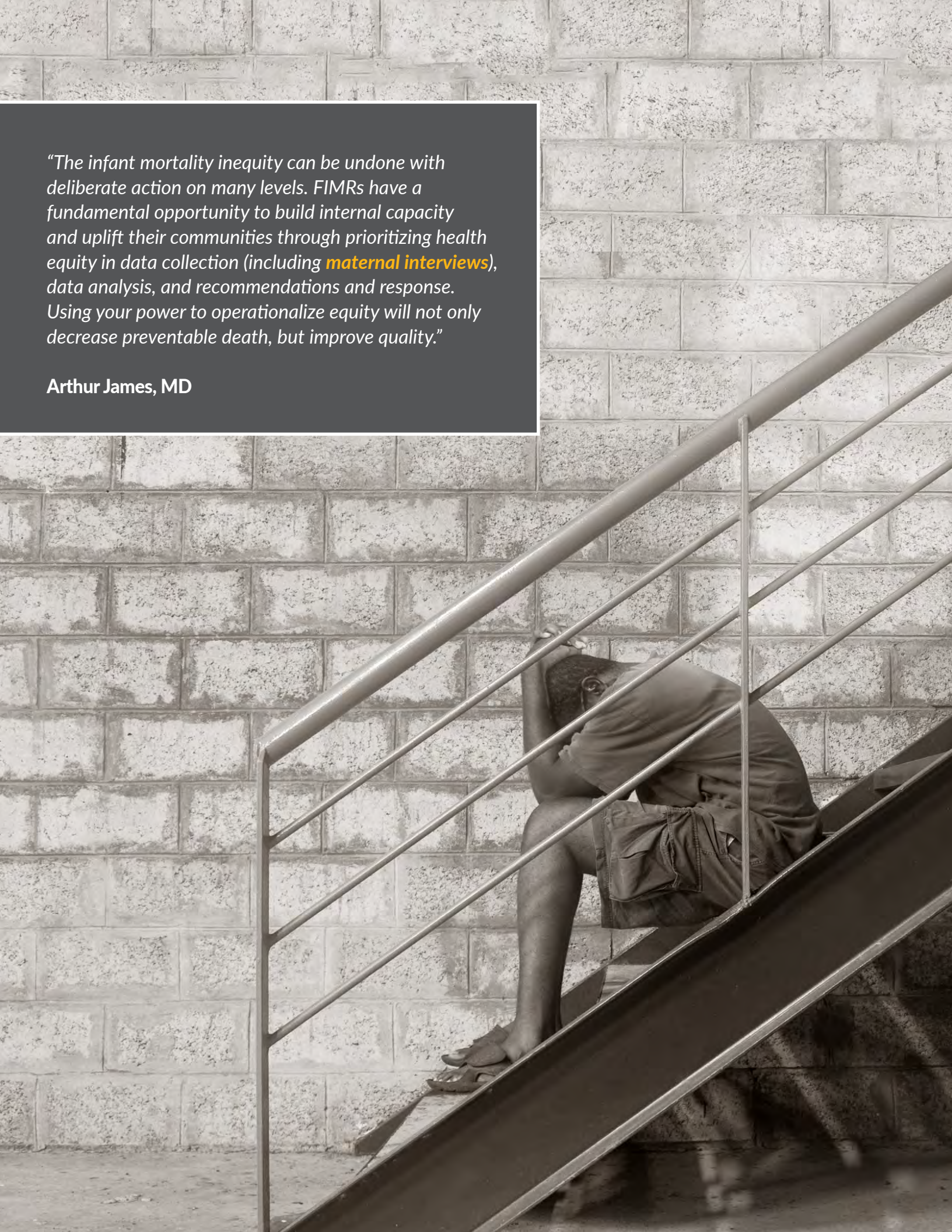
Successful FIMR programs contribute to the community's capacity for assessment. FIMR maintains a strictly anonymous and confidential process, with a racially and culturally diverse membership that includes persons with lived experience and those who have used the services within the community. FIMR deliberations maintain a good balance between medical, public health, and community viewpoints, and the team finds great value in the parental/family interview. There is effective communication between the Case Review Team and the Community Action Team, facilitating the handoff and implementation of effective community and systemic interventions. People in the larger community know what FIMR stands for and are proud of the process, and agencies that participate find that communication with other institutions is improved. Finally, human and fiscal resources support the program.

Community Impact

Successful FIMRs document multiple solutions, including policies and practices, and changes that have been implemented, resulting in positive impacts on local issues. The community takes ownership of perinatal health problems and the FIMR process in the most successful instances. Policymakers participate in or are accessible to successful FIMR programs, effectively connecting the FIMR team to the community's power structure. Finally, an institutional and fiscal base of support sustains the community's FIMR process.

*“The infant mortality inequity can be undone with deliberate action on many levels. FIMRs have a fundamental opportunity to build internal capacity and uplift their communities through prioritizing health equity in data collection (including **maternal interviews**), data analysis, and recommendations and response. Using your power to operationalize equity will not only decrease preventable death, but improve quality.”*

Arthur James, MD



What FIMR Adds

Information obtained through the FIMR process goes far beyond what can be learned from vital statistics or other population-level data and complements it by centering the narratives of families. Communities have identified multiple ways FIMR has added value to their existing infant mortality reduction efforts.

1

FIMR focuses on systems. Each FIMR case review provides an opportunity to improve communication and service delivery among medical, public health, and human service providers and to develop strategies to improve the quality of services and resources for women, infants, and families.

2

Multiple sources of data are utilized in the process. In many cases, Case Review Team members are the only individuals ever to see all the pieces aggregated together and thus are privy to the most comprehensive information about provision of services, community resources, and institutional policies.

3

FIMR includes and centers the voices of the parents and families who have experienced the loss of an infant. These qualitative data are not available anywhere else, and they profoundly impact the context in which the quantitative data are situated. The FIMR interview actively seeks out and includes the families' perspective on the problems faced, how well the systems served them, and their knowledge, attitudes, and beliefs about health.

4

FIMR, with its many diverse partners, promotes broad community ownership and participation. FIMR builds a community coalition that represents the diverse ethnic and cultural experiences and perspectives in the community.

5

FIMR is action-oriented. Long-lasting FIMR programs do not just document the problems but take action to improve the quality and acceptability of care, services, and resources for women, infants, and families.

6

FIMR information reveals whether quality services and community resources are available, accessible, culturally appropriate, and responsive to the community. It also offers insights into why services and resources may not be effective or if certain groups in the community face greater challenges in accessing services than others.

7

FIMR provides unique insights and significant information about health equity and the disparities among diverse populations in the community. More than simply identifying disparities, FIMR provides a framework for determining root causes of persistent disparities in access to and the delivery of care and in infant mortality rates.

What FIMR Is Not

As new FIMR programs develop and as existing programs evolve, it is vital to remind communities and local health professionals not to expect FIMR outcomes or results that FIMR was not designed to accomplish. Keeping these concepts in mind may help existing and developing programs avoid these common misconceptions.

1

The FIMR process is not about fault-finding or assigning blame for the death.

Blame cannot be determined with the subsets of medical information that FIMR abstracts, nor should it be attempted. Rather, FIMR is about improvement in system issues. FIMR is not about individual behavior or assigning blame to the family. Fetal and infant mortality is a multidimensional problem. The goal of the process is to help build safer, more equitable communities and systems that support healthy pregnancies, allowing all babies to be born, grow, and thrive.

2

FIMR is not peer review or a medical institutional review process. Peer review is the process whereby doctors evaluate the quality of their colleagues' work to ensure that prevailing standards of care are being met. Information from the FIMR review should never be used to identify a specific provider, clinic, or institution. If patterns of need emerge, FIMR encourages global solutions aimed at all providers.

3

FIMR is not research into the causes of fetal and infant death. A great deal of population-based literature already exists on infant mortality. Case reviews may be conducted on a smaller subset of all deaths in a community, and not all communities or jurisdictions have a FIMR program.

4

FIMR does not emphasize whether or not a death was preventable. There is much to be learned about the quality of care and services to families even in cases thought to be "not preventable." For example, the death of an infant with a severe congenital anomaly may not be considered preventable. However, issues about cultural dissonance, access to quality care, and lack of insurance could arise in the review of the case. These are issues that a review team would not want to overlook just because the death itself may not have been considered preventable.

5

FIMR is not individual case management. FIMR uses information from individual cases as a springboard for overall, community-wide assessment and improvement of health and human service systems, as well as community resources for women, infants, and families. FIMR teams do not manage individual cases that they review but apply solutions globally to the entire health care community and systems.



Conclusion

The concepts outlined in this chapter, FIMRs purpose, principles and objectives, core functions, qualities of successful FIMR programs, and benefits to the community aim to provide a foundation on which to build a dynamic and effective FIMR program that becomes an invaluable community asset and reckons with health equity. Distinct in its ability to engage diverse collaborators for the purpose of preventing fetal and infant deaths, FIMR equips the community and its partner agencies with a proven process to respond to and improve pregnancy and infant outcomes.



Endnotes

- 1 Pruit, S. et al. Racial and Ethnic Disparities in Fetal Deaths – United States, 2015-2017. Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report/Vol.69/No.37.
- 2 Ely DM, Driscoll AK. Infant mortality in the United States, 2018: Data from the period linked birth/infant death file. National Vital Statistics Reports, vol 69 no 7. Hyattsville, MD: National Center for Health Statistics. 2020.

Chapter Two: Laying the Groundwork

Implementing an Effective FIMR Program

Introduction

To implement an effective FIMR program, leaders should be confident of the community's readiness to participate in and contribute to effective case reviews and meaningful community action to address infant mortality within the context of health and racial equity.

This chapter focuses on essential aspects of FIMR program planning, development, and implementation to garner community buy-in and effective collaboration.

FIMR community collaborators can determine this by assessing:

- Local consensus about how the social determinants of health, including racism, contribute to health inequities such as fetal and infant mortality through a root cause analysis.
- Local consensus about the need to address fetal and infant mortality and maternal and infant health within a racial and health equity framework.
- Local consensus about the need to examine service systems, including medical care and community resources that serve maternal and infant populations.
- Support from relevant professionals or coalitions.
- Commitment from community partners who are willing to work as a planning and implementation group.



Planning Overview

The intention to implement FIMR often arises at the local level: a community will be looking for effective ways to address infant mortality or infant mortality disparities. Early stakeholders are often part of an infant mortality reduction coalition, local health department initiatives, or other similar task forces.

In order to lay adequate groundwork to implement FIMR, a planning team will need to spend time preparing to implement the program. It is common for this planning period to take 6-12 months.

While there is no set order in which different steps need to occur, the planning team should address all the following steps in preparation for implementing FIMR case reviews within the context of advancing racial and health equity.

- 1 Identify a lead agency for FIMR
- 2 Identify the specific geographic catchment area
- 3 Identify community resources/assets
- 4 Determine the type and number of cases for FIMR to review
- 5 Identify and address legal and institutional issues related to case review
- 6 Determine statutory requirements related to confidentiality and records access
- 7 Identify program costs and funding sources
- 8 Select and assure non-biased data collection and processing methods
- 9 Determine if there are other reviews in the area and what FIMR's relationship will be to those processes
- 10 Determine how cases will be identified for case review
- 11 Designate a program director and coordinator with an understanding of and commitment to advancing racial and health equity
- 12 Identify a record abstractor to collect and summarize case information for reviews within a racial and health equity framework
- 13 Formalize policies and procedures that are grounded in advancing health and racial equity
- 14 Build in opportunities of initial and ongoing training, including professional development in root cause analyses to uncover the contributions of structural racism and social determinants of health
- 15 Design a program evaluation plan including metrics for competence in applying a root cause analysis

Identify the Lead Agency for FIMR

One of the first steps is for the community to decide on an agency, organization, or institution to take the lead for implementing FIMR. Over the years, a variety of agencies, such as local or state health departments, local maternal and child health coalitions, federally qualified health centers, local hospitals, or regional perinatal centers, have all been successful as FIMR leaders. Each has its advantages and limitations, however most essential is that there is consistency and commitment to unpacking how structural racism is operationalized in the multiple systems that directly and indirectly affect fetal and infant mortality. Local health departments are often considered an ideal agency to lead FIMR. Local health departments may have the respect and authority in the community that can open doors, attract the attention of other agencies, and gain the endorsement of elected officials. Access to records useful in the FIMR process, especially vital records, can be facilitated within the health agency.



Additionally, as a governmental agency, the local health department may have the mandate to advance racial and health equity in its public health role. Many FIMRs are implemented by local coalitions such as those associated with the federally funded Healthy Start projects, Healthy Mothers/Healthy Babies, or regional perinatal consortia representing several perinatal and maternal and child health advocates and service delivery agencies. Such coalitions may have the advantages of diversity, enthusiasm, community backing, knowledge of community values, and a commitment to health and racial equity. On the other hand, they may have trouble gaining access to institutional records and need to spend time building alliances with large public agencies or medical centers.

FIMR may be implemented across local hospitals and regional perinatal medical centers, bringing expertise and access to relevant medical personnel and in-patient records at various facilities. FIMR programs implemented by a hospital or medical center may need to pay attention to the issues relevant to the broader community, including structural racism, and ensure that reviews are not too medically focused or fixated on issues only of importance to that institution. Coordination and collaboration with all likely local community partners is critical for the success of the program, regardless of which organization or agency implements the FIMR program.

Identify the Catchment Area for FIMR

When choosing a geographic area to implement FIMR, it is important to have a clear understanding of the finer points of maternal and infant health in the community. This information can be determined through analyses of community characteristics, including inequities and vital statistics data. The local county or city health department is the best source for vital statistics information. They often have epidemiologists or infant mortality reduction coalitions already examining these issues.

The planning team should seek relevant data from the following organizations:



The local health department



The state health department



Schools of public health



Reports from maternal child health or perinatal coalitions/task forces



Insight from local community-based organizations and service providers, including doulas, focused on advancing racial and health equity



Child Death Review programs

In addition to data about the number, rate, and type of infant deaths, the planning team may also consider other broad indicators of community well-being from other community agencies, including social services, schools, childcare agencies, employment levels, insurance coverage, state of housing and transportation in the community, and any other areas that may indicate the state of the community.

For a broader list of indicators and information that can help communities better understand the status of local families, please see the [Planning Tool: Planning for a New FIMR Team](https://bit.ly/3ccG0Gm) (URL: <https://bit.ly/3ccG0Gm>).

After a thorough review of the data, the planning team should establish the geographic area or boundaries of the FIMR review catchment area. Communities across the country do this in different ways. Some teams take the outer boundary of a county as the catchment area; others use a service delivery radius from a healthcare system or NICU. Others will choose very specific city or census tract boundaries within a county to investigate deaths in the areas hardest hit by infant mortality. It is important to note that people in communities may have their own defined boundaries, albeit informal, which may or may not align with the formal ones. For example, they might use railroad tracks, a river, or a particular road that may be beyond their access due to historical dynamics. For example, in Detroit, Michigan, it was well known that area residents wouldn't cross 8 Mile Road to get services that were less than half a mile away. Hence, accessibility, acceptability, and affordability must be collectively considered when choosing the catchment area for FIMR.

A final and important issue for the planning team to address is how they will determine if a death falls within the catchment area. Will the address be the one from the death certificate, and if so, will it be selected if the infant was a resident of the catchment area or simply if they die within it? This decision can be influenced by things such as the extent of non-resident deaths or the presence of a subspecialty perinatal center in the community. Almost all FIMR programs choose to review only deaths of residents of the community selected for FIMR because these cases best reflect the functioning of their entire local service system, including utilization patterns.

Why Do We Look at Rates and Not Just Overall Counts of Deaths?

Regardless of the data source, the analysis should highlight observable differences by age, race, ethnicity, parity, sexual orientation, gender identity, and education or income. It should also highlight the areas of the community hardest hit by poor infant outcomes. This information will equip FIMRs to identify disparities and inequities and which members of the community are the most impacted by poor outcomes.



Identify Community Assets and Deficits

It is helpful for the planning team to understand the community resources and identify potential partners for either the case review or community action aspects of FIMR. Keep in mind that resources and services must be accessible, acceptable, and affordable to the intended community for optimal utilization. Planning teams can examine their community to determine capacities, assets, and skills associated with advancing health equity, public and private institutions, community associations, coalitions, organizations, and individuals. Information about community assets will help the Case Review and Community Action Teams understand the strengths upon which future action can be built, as well as better appreciate how to engage the community to unpack and address problems or gaps. Taking the time to compile a directory of current health or social service resources grounded in health equity for FIMR teams will be very beneficial as they begin their reviews and conduct home interviews with bereaved families. These lists are often already available through local health departments. It is important to note that including eligibility criteria for the resources will further clarify who could have or can receive delivered services.

Additional understanding of the community can be provided through a community needs assessment conducted within a racial equity framework. Many communities conduct these assessments through local health departments or hospital systems. It highlights vital statistics, health outcomes, as well as other indicators such as the percent of substandard housing in the community, high school graduation rates, and other indices of the social determinants of health equity along with the related systems that are strongly correlated to poor infant outcomes. This will further illuminate the populations and areas of the community that disproportionately experience negative outcomes and further inform case reviews.

Determine the Type and Number of Cases for FIMR to Review

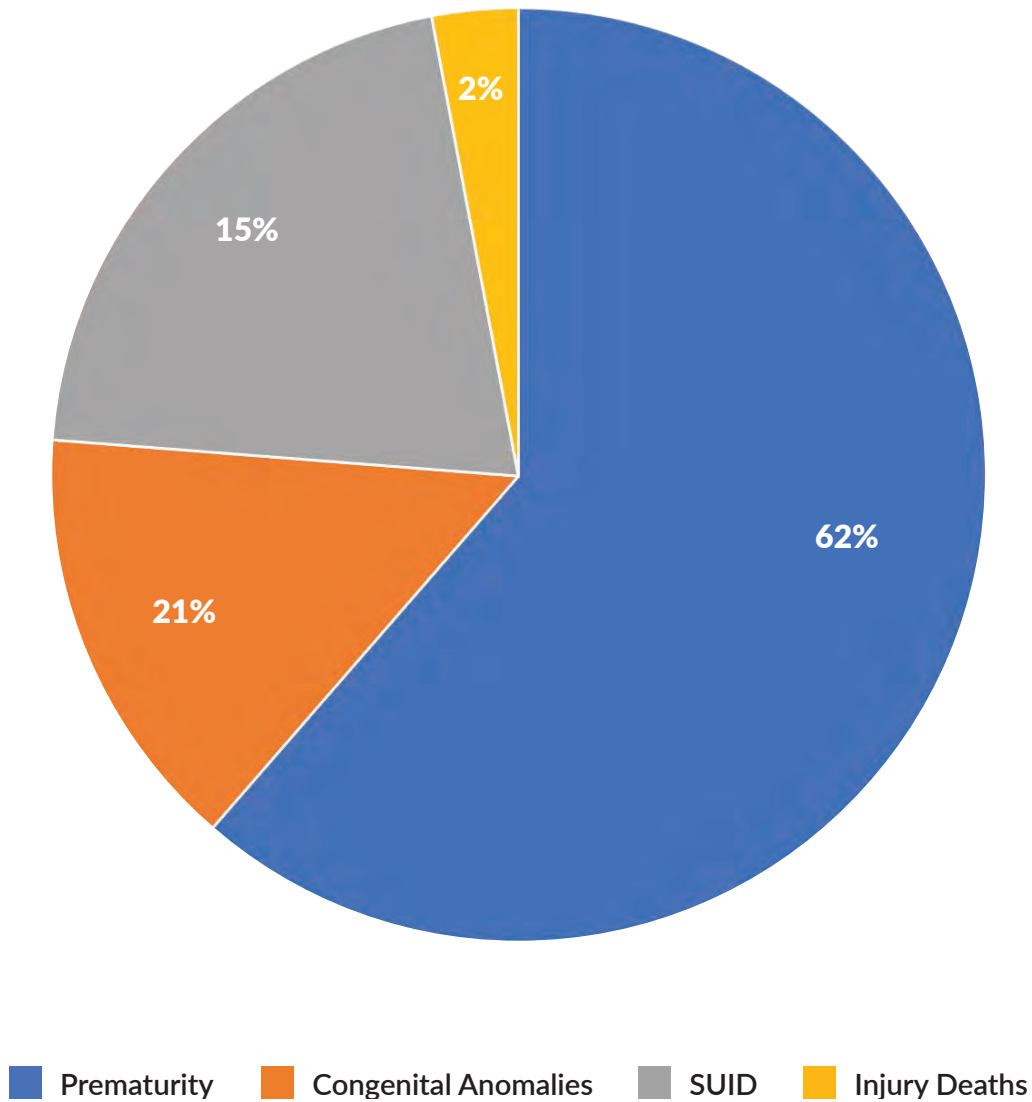
Ideally, FIMR would review all the fetal and infant deaths in the community. Reviewing all deaths will give an excellent picture overall of the community and its services, resources, and inequities. For example, if there were 60 fetal and infant deaths in the catchment area during the year, FIMR would review all 60 deaths in order to describe the fetal and infant mortality problem and its root causes in detail, including the structural contributors. If the annual burden of deaths is too large to review or there is interest in limiting the focus, the FIMR program may want to decide on a subset of cases, including the number and types of cases.

Communities approach this differently; however, advancing racial and health equity should always determine the most illuminating approach.

- Some FIMR teams randomly sample cases for review
- Some review only fetal, only neonatal, or only post-neonatal deaths, or deaths due to specific causes of death
- Some review a combination of the fetal, neonatal, or post-neonatal deaths
- Communities have also chosen to sample cases by specific zip codes, areas or jurisdictions with known high infant mortality rates and/or disparities
- Some use sophisticated analytics that describe causes of excess infant mortality, such as the PPOR analysis; to learn more, visit [CityMatCH](https://bit.ly/3BckQDi) (URL: <https://bit.ly/3BckQDi>)
- Some communities use random sampling of cases based on known cause of death rather than the time period during which the infant expired; using vital statistics to examine all infant deaths in a jurisdiction will guide this process

If this is the method used, consider the following graphic:

Figure 2. Infant Deaths by Cause



If this community chooses to sample by cause of death, then 62% or approximately 2/3 of the cases selected for review would be infant death due to prematurity, 21% of cases for review would be those with congenital anomalies, 15% would be SUID cases, and 2% would be death due to other injuries.

Whatever the approach, it is important to remember that the goal of FIMR is not to review hundreds of cases per year but to take the time to review each abstracted case carefully, completely, and from the broader perspective of the adequacy of community resources and systems of quality care for women, infants, and families that is grounded in health equity. FIMR teams make meaningful change by aiming for health equity, identifying systems-level actionable risk and protective factors to inform prevention, and community and structural actions to reduce infant mortality.

It is important to consider the number of cases that a FIMR team can review at a time and over the course of a program year. A well-run Case Review Team can generally review 3-5 cases in a 2-hour meeting, but this may vary depending on the complexity of the cases. Case Review Team meetings are typically held monthly or as often as needed to review a target number of cases. Larger FIMR teams can review approximately 36-60 cases a year; teams in smaller communities with fewer infant deaths may find 12-20 cases an appropriate and equitable representation of their fetal and infant deaths. In order to be most effective, even teams with very few cases to review should plan to meet at least four times per year. Whether teams plan to have a quarterly review meeting or a monthly meeting, they should put out the meeting dates for the entire year as a standing appointment.

DISCLAIMER:

The guidance in the next section of this document does not include a review of specific state regulations or laws. The information and examples provided in this manual do not constitute legal advice and do not necessarily meet the requirements of your state's laws.

You are advised to consult a state health official, such as your state Title V (MCH) Director, to determine which regulations protect your FIMR program and the need to revise the content of any FIMR form or agreement currently in place.

Legal and Institutional Issues

Statutes that govern the process of FIMR, including records access and use, are primarily found in state laws and public health code. States have laws and rules that provide immunity to those participating in certain types of reviews, particularly for public health surveillance purposes. These laws and rules vary significantly by state, so it is important to be very familiar with relevant state laws as part of the FIMR planning process. If the lead agency has general counsel who works in this area, it will be important to have them review relevant legislation and weigh in on proposed protocols. Privacy Officers or attorneys supporting state or local public health organizations may be helpful resources, as well as your state's Title V Director.

Freedom of Information Act and Immunity from Subpoena

Ideally, FIMR records related to cases, as well as the minutes of case review meetings and any other written records of the case review cannot be subpoenaed or brought to court. It is important that FIMR understands its state's laws/rules regarding immunity from subpoena (Discovery) and the Freedom of Information Act (FOIA). FIMR may be specifically named in state laws/rules, but more commonly, it is included under general terms like **professional review, peer review, or public health surveillance or research**.

Information about individual FIMR cases is not discoverable through state laws or the federal Freedom of Information Act (FOIA). These laws enable private citizens or organizations the right to request all written information on a specific topic from a local, state, or federal government agency.

While situations requiring such protections are rare, FIMR teams must seek protection as a necessary precaution and reassurance for the professionals serving on the Case Review Team. As an added precaution, FIMR should also consider avoiding cases in which litigation is expected to take place or in which families may be complicit in the death of the infant.

Records Access

Laws that provide immunity for reviewers and materials may also allow access to medical records. Many states have other rules or enabling language in their public health code that permits access to medical and vital statistics records for “investigations for the benefit of the health of the public” or similar purposes. Vital statistics data are housed in local, city, county, and state health departments, making access easier for teams situated in health departments.

AVAILABLE LAWS

It is important to make sure all available laws related to accessing medical records and vital statistics certificates are found and interpreted by state or local health department privacy officers or attorneys.

Some FIMRs access medical records under the Health Insurance Portability and Accountability Act (HIPAA) exception, which permits a covered entity, such as a hospital, to disclose protected health information to a “public health authority” for certain activities. According to HIPAA, a public health authority is “an agency or authority of the United States, a state, a territory, a political subdivision of a state or territory, or Indian tribe, or a person or entity acting **under a grant of authority from or contract with such public agency**, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.

A covered entity may disclose protected health information without authorization from the individual to “...a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including but not limited to the reporting of disease, injury, or vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions.”

Many of the activities related to FIMR programs fall within the purview of the HIPAA public health disclosures, and disclosures to FIMR programs that are acting under the auspices of a public health agency will be permissible under the federal privacy rule. A public health authority that is a covered entity may use protected health information for these same purposes. If it is not possible to access medical records under the auspices of some state law or the federal HIPAA regulations, records usually can be obtained if the mother signs a consent form releasing her records and those of her infant.

To more fully understand the FIMR process, view [The HIPAA Privacy Regulations](https://bit.ly/3fRRwt7) (URL: <https://bit.ly/3fRRwt7>).



Consent for Home Interviews

A legally valid consent form is required for the family member who agrees to participate in the home interview. FIMR staff should seek legal advice about the state statutes governing informed consent to be sure the form covers all the statutory provisions.

It is important that, prior to the interview, participants understand:



The purposes for which the information is being collected



The potential risks and benefits of participating in the interview



Steps that are taken to protect their confidentiality



Conditions under which mandatory reporting is obligatory

This information should be explained to the family in clear language, preferably the family's language of origin, and should be included in the consent form. The FIMR interviewer should witness and co-sign the document that the mother has been informed of these issues and understands them. This will be more fully explored in **Chapter 5: Parental/Family Interviews**.

Mandatory Reporting Laws

Most states have mandatory reporting laws requiring physicians, nurses, social workers, teachers, and other health and human services professionals to report suspected child abuse and neglect. Mandatory reporters are granted immunity from civil and criminal prosecution by these statutes. FIMR programs are bound by these requirements.

This is relevant for FIMR teams, as an interviewer may observe neglect or abuse when in a home, or the Case Review Team may suspect or identify abuse or neglect in the process of a case review. Home interviewers who suspect abuse or neglect of the deceased infant or surviving children in the home are obligated to report it. If suspected abuse or neglect is revealed in case review, it is the program director's responsibility to report it to the appropriate agency. It is extremely rare that FIMR programs have had to make these reports, but care should be taken to clarify when such reports must be made. Because of this and other ethical concerns, FIMR programs suggest that no home interview be conducted in suspected or known homicide cases. These types of cases, as well as all cases of sudden unexpected infant death, immediately become coroner or medical examiner cases and have usually been thoroughly investigated before the case review.

Institutional Review Boards

Depending on which agency sponsors or participates in FIMR, it may be necessary to seek Institutional Review Board (IRB) approval for the case review activities and parental interviews. FIMR is generally classified as "public health surveillance" or a continuous quality improvement process and not a research program. However, some hospitals, universities, and other agencies may have IRBs to review all activities generated by the institution. Their role is to ensure that the questions and design of the project are valid and that all who participate in the study ("human subjects") are not harmed. About one-quarter of all programs have had to go through the IRB process. **Consult with your sponsoring agency and be prepared to follow their guidance on designating FIMR as "research" or "non-research".**

Confidentiality

A unique confidentiality issue FIMRs face is the fact that many pieces of confidential information from multiple sources about patient/client care are put together to form one anonymous case summary. Case Review Team members and FIMR staff are the only people who see all the pieces of the case together, privy to the most comprehensive information about the quality of service and care delivery, community resources, institutional policies and practices, and community members' lives.

Preserving the privacy of all the involved parties is of paramount importance to any FIMR program. Local providers and institutions will be reluctant to participate in the FIMR process or provide records for reviews without assurance that all information will be kept strictly confidential. Once cases have been abstracted and summarized, they should contain no identifying information. They should be kept in locked filing cabinets or saved in secure servers with secure access protocols, and they should be destroyed or deleted when they are no longer of use, following agency records retention policies.

The planning group should be aware of what information about families or deceased infants must be kept confidential, including:

- Names, addresses, phone numbers, email, and other identifying contact information.
- Any document that contains both a name and medical record number.
- Completed interview questionnaires.
- Tracking forms or cards linking a FIMR case number to a family name.
- All other forms and papers with individual case information.
- Hospital or clinic names, including names of providers or individual staff from agencies.
- Case summaries, even once they have been de-identified for case review.
- Any description of a case containing enough facts to identify the family, including actual dates of birth or death.



All of these documents should be clearly marked as confidential. After the case review, and after the case has been entered into the National Fatality Review-Case Reporting System (NFR-CRS), or the database being used by the team, all paper records of the case should be shredded. Any records, including reviewer notes that link the FIMR case number to a family name, should also be destroyed. Computer records should not contain information linking program case numbers to names. Computer records should have strict access protocols, emails should be encrypted, and databases should be assigned users with secure passwords.

Team members' knowledge of the case and its details are also confidential. Only discuss cases behind closed doors, and then only for the purposes of developing deeper insight into the problems presented in a case. A formal confidentiality form should be developed for CRT members to sign annually. Some teams incorporate the confidentiality pledge into the routine sign-in sheet for each meeting. Many teams also begin meetings with a verbal reminder that if review team members recognize a case being discussed, that they will not disclose information not already abstracted and presented in the case summary. They are also reminded of one's own bias about certain communities and how that is integrated or not in their role as a CRT member. There is great potential for harm to program participants and activities if confidential information is not contained properly. If staff are unsure of how to treat a certain document, always err on the side of caution. Being overly cautious about confidentiality will ensure integrity in your confidentiality commitments to both participants and organizations providing records.



Confidentiality checklist:

- All abstracted records, including medical, social services, and the home interview, are stored securely with limited access and/or passwords.
- All identifiers are deleted from abstracted records and the interview.
- The case summary is anonymous with no specific names—including participants or local service providers.
- CRT meetings are closed to the public, meetings are confidential, and minutes are secured.
- All CRT members should sign a confidentiality agreement prohibiting them from discussing the case outside the review meeting.
- The confidentiality of the review is guaranteed by the FIMR methodology protocol. Teams will want to explore if the process is also protected by relevant state statute, rules, or grant of authority.

As the groundwork for FIMR is laid and records are requested, programs must be prepared to respond to professional or institutional concerns. The FIMR planning group should stress the strict confidentiality of the FIMR model and review all the steps that are taken to de-identify a case, never identifying specific patients, institutions, or providers. It is also helpful to stress the purpose of FIMR—to improve systems and quality of care and not to find fault.

Systems for Case Identification

All FIMR programs need to develop a timely system to identify where and when infant deaths occur prior to launching case reviews and family interviews. Ideally, FIMR staff should be informed of deaths no longer than two to three weeks from the date of death. Early identification ensures that the family can be found and asked to participate in the interview, records can begin to be accessed and abstracted, and additional sources of information can be identified. While early **identification** of cases is encouraged, **contact** with families must always be guided by the cultural practices and beliefs surrounding fetal and infant deaths. Cases will not adequately reflect the current service delivery system or community resources if they are two or three years old by the time they are reviewed.

Finding cases may be very easy in some communities, especially if the health department leads FIMR. The local vital statistics registrar often agrees to forward all fetal and infant death certificates to the FIMR program within a week or two of death. This is the ideal way to identify cases, as it is the most thorough.

Other methods FIMR staff have used to identify cases include:

- Arranging to review hospital/birthing center admission and discharge logs within the catchment area, including emergency departments, labor and delivery, neonatal and pediatric intensive care units, and the morgue, as well as hospital/birthing center death logs
- Arranging referrals from and maintaining contact with hospital/birthing center bereavement nurses or counselors, local doula providers, funeral directors, hospital medical records staff, medical examiner or coroners' offices, emergency medical transport service teams, and community health workers
- Communicating with agencies and programs such as WIC, Medicaid, home visiting programs, and departments of social services
- Coordinating with existing local programs, such as a local infant safe sleep program, and pregnancy/birth-related community-based organizations
- Reviewing obituary columns in local newspapers, including ethnic-specific publications

Program Costs and Funding Sources

The primary costs associated with FIMR are dedicated staff time for coordinators, case abstractors and home interviewers, clerical services, space, copying, printing, and mailing materials. It is helpful to determine the percent of FTE staff salary required for the mid-level coordinator position, usually ranging from .5-1.0 FTE. The salary is typically comparable to a senior local health department nursing position, though this varies by state and jurisdictional scales. The [FIMR training module \(FIMR\) 101](https://bit.ly/3pnIZkQ) (URL: <https://bit.ly/3pnIZkQ>) describes essential staffing for a typical FIMR program.



Another approach is to estimate project costs based on the number of cases the team will review by an estimated cost per case and multiply that by the number of cases planned at each meeting by the number of annual meetings. While this may be helpful, the program should determine which reimbursement mechanism best serves its purposes. These estimates are only of baseline costs and do not include the in-kind contributions of the agency sponsoring FIMR or the contributions of volunteer time from FIMR team members. They also do not account for the costs associated with implementing FIMR's prevention recommendations or professional development for applying a racial and health equity framework.

Funding sources for FIMR vary. Some programs receive seed money from federal, state, or private sources to get the program started. The planning group must consider the long-term financial sustainability of the program. FIMR is most commonly funded with Title V Maternal and Child Health Services Block Grant funds, making it an important part of the MCH needs assessment process. Local public health departments can also incorporate the FIMR process into existing efforts to implement core public health functions.

Common sources that provide resources include:

- Non-profit organizations such as March of Dimes or Healthy Start may provide space, equipment, staff support, professional development for health and racial equity or cover equipment and printing costs.
 - Businesses may provide direct support, space, equipment, or cover printing.
 - Private foundations may be willing to support salaries or provide start-up funds and funding for professional development to advance health and racial equity.
 - Local public health or related agencies may provide staff, space, or funding.
 - Donations of free food from local restaurants for the Case Review Team meeting or Community Action Team meetings.
-

Private local foundations may be willing to provide start-up funds for staff salaries. Local community public health and related service agencies may provide staff, space, and funding. Local hospice staff or existing home visiting programs may volunteer to conduct maternal interviews free of charge. Some local health departments dedicate a portion of a public health nurse line item for abstractors or home interviews. In one creative FIMR program, a county birth certificate surcharge supports the entire program. Whether in-kind, volunteer, or staff hired under the auspices of the sponsoring agency, attention must be paid to the training and orientation of all FIMR personnel to ensure that they do not contribute to systemic oppression.

Data Collection and Processing Methods

For FIMR to be effective, it is critical to collect standardized information in a standardized way across all cases. The main uses for FIMR information are to create an expansive narrative summary of what happened in each case and to develop a repository of standardized case information that can be used for both an aggregate analysis of the team's cases and to improve the quality of the systems of care and resource delivery.

For most teams, the easiest part of determining what information to collect is to think in terms of sources. Though not each of these will be relevant in every case, FIMR information is typically collected from:



Family interviews



Birth and death certificates



Autopsy reports



Birth and postpartum doulas



Hospitals, including obstetrical, labor and delivery, newborn, neonatal, pediatric care, birthing centers, and emergency rooms



Child welfare agencies



Public health programs, including WIC and home visiting



Outpatient care, including prenatal, pediatric well-baby, and sick baby visits



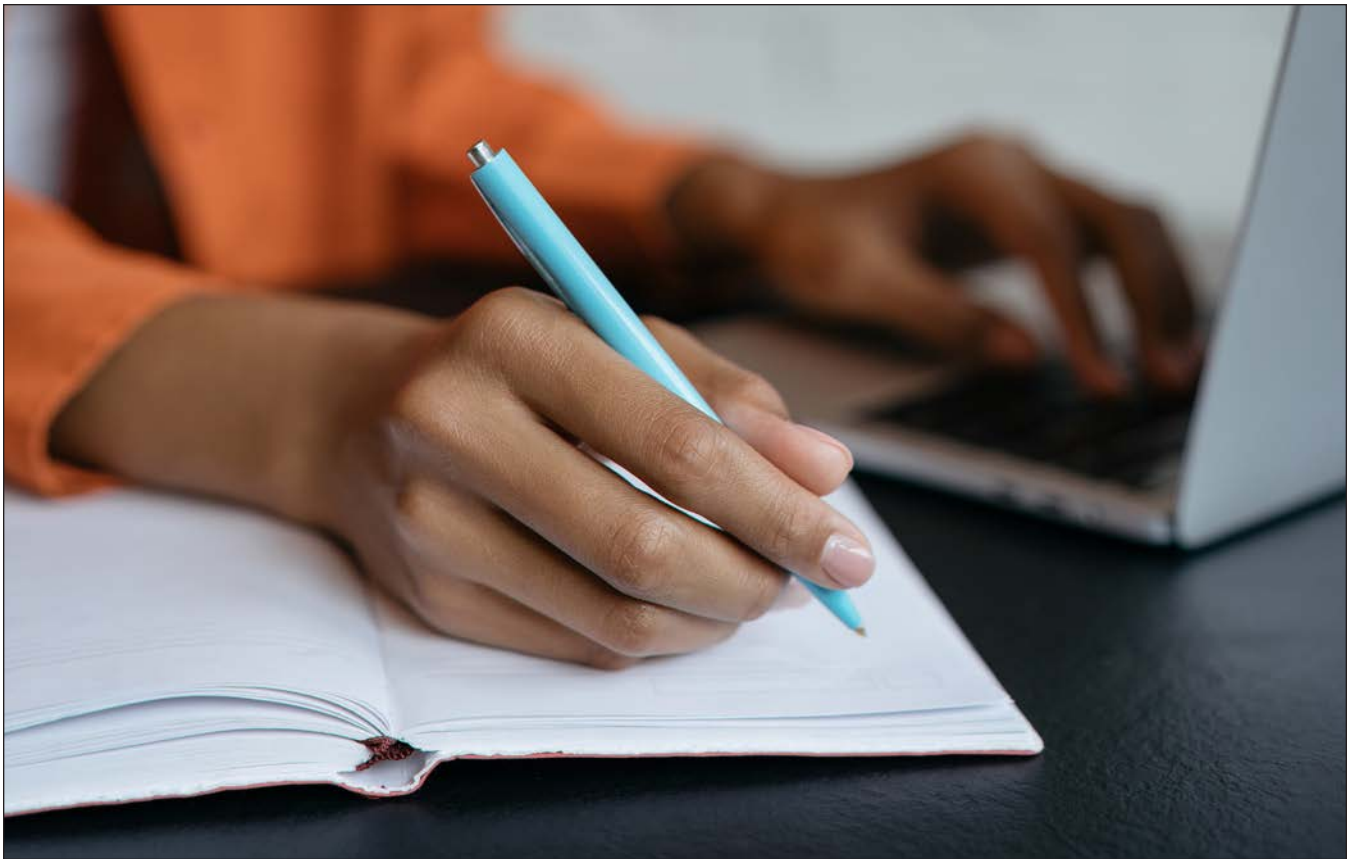
Law enforcement



The more challenging question is not to determine which records to access but to determine how much information is needed to complete a thorough case summary, particularly if the case involves a long illness or hospitalization with many medical interventions throughout. Every FIMR needs to collect information that will relate the story of each case from a systems and quality-of-care perspective, including but not limited to factors such as access, barriers, patient education, psychosocial assessment, lifestyle options and choices, coordination of services, provider and hospital/birthing centers quality of care, and discharge planning.

Three important principles can guide this determination. First, the case summary will need enough detail to tell the overall, unique story of the family, the baby, and the death. Second, when determining what to include or not include, focus on issues related to access to care, quality of care, and health equity and how information could be used to make eventual systems-level prevention recommendations. Third, focus on the details needed to complete standardized unbiased data in every case.

To facilitate effective data standardization, the National Center has developed the FIMR Case Report Form as part of the National Fatality Review Case-Reporting System (NFR-CRS) through a cooperative agreement with the federal Health Resources and Services Administration (HRSA). Participation in and use of the web-based system is free to FIMR teams, and it was developed to meet the confidentiality demands of FIMR programs. To inquire about implementing the NFR-CRS, reach out to info@ncfrp.org. To see the categories of information and the data collected in the NFR-CRS, please review the [FIMR Report Form](https://bit.ly/3fRgwk3) (URL: <https://bit.ly/3fRgwk3>). The paper form is an analog version of the data collected in the NFR-CRS online portal. This can be used to help determine what information should be collected in case abstracts.



Other Reviews, Processes, and Opportunities for Collaboration

Many communities may already have a child death review (CDR) team or a maternal mortality review (MMR) team in place. These are natural partners to a FIMR program, as many of the needs and processes are similar between these teams. They may even have overlaps in membership, as the agencies involved in the reviews are often similar. A representative from the planning group may determine that setting up a meeting for the sake of information gathering and outreach is a helpful step. If communicating with a CDR or MMR team, determine if their methods for case identification may also work for FIMR and if there is a way to minimize redundancy of those processes for entities like coroners or medical examiner's offices.

- View the [National Center Guidance Report on enhancing collaboration between CDR and FIMR teams](https://bit.ly/3gdL52e) (URL: <https://bit.ly/3gdL52e>)
- To identify local CDR teams, reach out to your state's coordinator by accessing the [CDR Map](https://bit.ly/3vTfvh3) (URL: <https://bit.ly/3vTfvh3>)
- To identify if your state conducts MMR, visit the [CDC's webpage on enhancing reviews and surveillance to eliminate maternal mortality](https://bit.ly/3pnGcaY) (URL: <https://bit.ly/3pnGcaY>)

Identifying FIMR Program Personnel

Program Director and Coordinator

Almost all agencies who take the lead in implementing FIMR provide a major in-kind contribution, often in a portion of the dedicated salary/FTE of the FIMR program director. This person may already be involved in the planning group. The director assumes overall responsibility for the planning process and for the critical work of building and maintaining community support for FIMR and good working relationships with other agency leaders. The director should have a deep understanding of how racism operationalizes in the historical and contemporary realities of families and communities of color on a daily basis. Moreover, how structural racism creates and perpetuates health inequities, including maternal, fetal and infant mortality and morbidities, is essential to identifying the root causes and facilitating systemic changes to improve the quality of medical care and community resources available in communities.

The director will also review case summaries before each CRT meeting to ensure they are complete, and in most instances, serves as the team leader for both the CRT deliberations and the Community Action Team meetings. The director hires FIMR staff, including abstractors and interviewers, and typically serves in a supervisory role that includes determining training needs in topic areas such as racial and health equity. Directors are typically responsible for publishing and disseminating annual reports that are drafted in cooperation with the CRT and CAT with the help of the FIMR coordinator.

The lead agency typically designates a FIMR coordinator as well, which is a commonly .4-.5 FTE position. When planning for program implementation, this mid-level position is usually assigned to an individual already working in a complementary position in the agency, such as a SIDS coordinator or a Pregnancy Risk Assessment Monitoring System (PRAMS) coordinator. They help lay the groundwork, do the outreach to community partners, and undertake the tasks of preparing for implementation in a grounded racial equity frame. Once the program is implemented, the coordinator assumes the day-to-day management of FIMR, reporting to the program director. Coordinators communicate with team members, prepare case summaries for the case review meetings, schedule all CRT and CAT meetings, and draft minutes for those meetings. They also ensure that CRT recommendations are provided to the CAT, recording both recommendations and what prevention actions are implemented to advance racial and health equity.

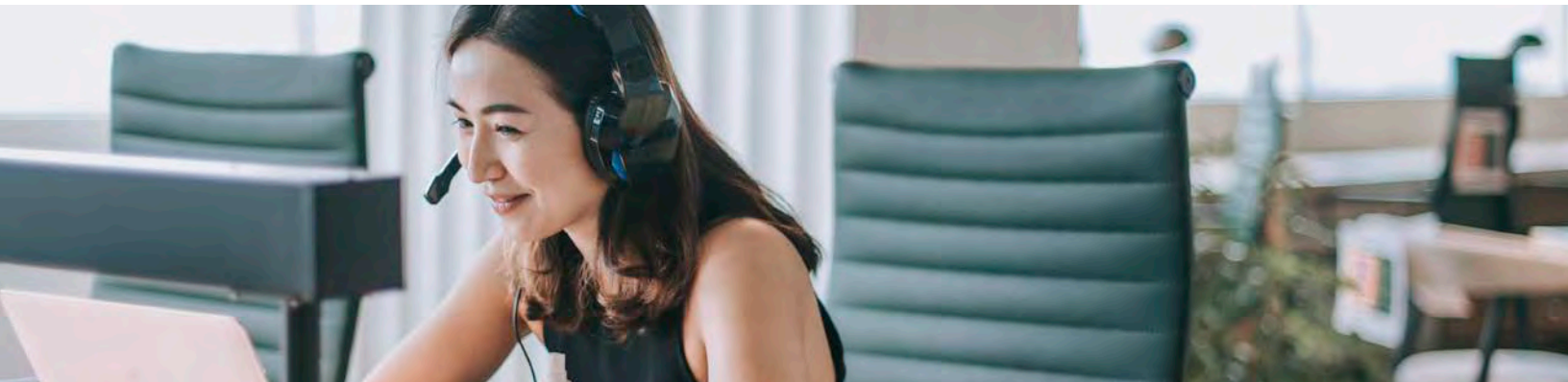
The coordinator typically supervises FIMR staff who abstract case information and interview families, keeping an eye on the timeline. In some communities, the coordinator also serves as an abstractor or interviewer. Most importantly, this work must be rooted in health equity.

Record Abstractor

The record abstractor is a vital contributor to the FIMR process and should also have some understanding of the root causes of health inequities and a commitment to advancing equity. Abstractors communicate with partners to access records, maintain confidentiality protocols, and select and record vital information to inform a comprehensive case summary for the CRT. The amount of time the abstractor will spend on records depends on the number of cases teams will review. It is common for an abstractor to be a .25-.5 FTE employee or contractor.

It is helpful for the abstractor to have a working knowledge of medical terminology and medical records ahead of time, so it is common for the abstractor role to be filled by a nurse or someone with a medical background and commitment to advancing health equity. Regardless, the abstractor should be able to establish and maintain good relationships with diverse outside partners, particularly medical practices and hospitals/birth centers and exhibit keen attention to non-biased detail.

Many teams include the abstractor in the CRT meeting to clarify any issues that may arise through the case review process.



The Interviewer

Program leadership should think carefully about who the interviewer will be. The ideal candidate will have a kind, welcoming demeanor and not be afraid of sad or challenging stories. In addition to being comfortable with stories of fetal and infant death, the interviewer should be comfortable and familiar with the communities that bear the disproportionate burden of infant mortality within the catchment area for the FIMR team. Ideally, the interviewer is a member of this community or reflects the demographics of the community as well.

Examples of position descriptions for core FIMR team members can be found in the template package, [Appendix A](#).

Formalize Policies and Procedures

While planning, keep a written record of emerging policies and procedures for conducting FIMR in the community. These details will be the program's detailed description and roadmap and should be grounded in advancing racial and health equity. They will evolve and expand as the program grows, and they should be reviewed and revised on an annual basis, adding items to reflect the most current policy and practice.

To be considered complete, they should include the following:

- Program mission statement, goals, and objectives
- Job descriptions for all staff, e.g., director, coordinator, interviewer, abstractor, including expectations for professional development related to health equity
- Case Review Team and Community Action Team role and responsibilities, including expectations for professional development
- CRT and CAT rosters
- Methods for maintaining confidentiality
- Methods for conducting an annual or bi-annual review of vital statistics data and reviewing of case selection criteria if necessary
- Methods of identifying cases
- Process for case selection
- Methods for finding and contacting mothers/parents/families with cultural humility
- Methods for conducting culturally-informed home interviews
- Methods for unbiased medical records abstraction
- Community resource library
- FIMR program data abstraction forms
- Data collection and retention methods
- Approaches for reporting to the community

To review an example of FIMR policies and procedures, view the [Template for FIMR Policy and Procedure Operating Guide](https://bit.ly/2TKd16r) (URL: <https://bit.ly/2TKd16r>).

Build in Opportunities for Initial and Ongoing Training

When FIMR team members have received training, they were likelier to adopt a broader understanding of their role in making improvements in perinatal health systems and their role in serving as a forum for community concerns about perinatal health. Training has also proven to increase the average number of FIMR recommendations that were put into practice.¹

If a state has a network of multiple FIMR teams, it is ideal to arrange training opportunities that include multiple teams to maximize resources and shared problem-solving. If a local FIMR team meets monthly, it is appropriate to offer training at one of the monthly meetings annually.

Training can focus on the state or local program's specific policies and procedures, social and structural determinants of health and health equity, emerging research findings, evidence-based prevention programs, or other relevant topics. It is always helpful to revisit the mission, goals, and objectives of the programs. The National Center has created online [training modules that can also be used to facilitate learning](https://bit.ly/2Tza08Q) (URL: <https://bit.ly/2Tza08Q>).

Program Evaluation Plan

Monitoring the ongoing success of your program will assure funders, leaders, and stakeholders of the program's integrity. What FIMR teams may be required to report to lead agencies or government bodies differs. Some teams may only be required to provide an annual report of findings and recommendations; others may have more significant evaluation needs. The planning group should determine what level of information will be most valuable and build evaluation processes into the program from the beginning.

Even if public health is not the lead agency, they are often a helpful resource for considering how best to evaluate FIMR. The team may decide to simply monitor metrics reflecting the number of meetings, participants, recommendation, and implementation on a regular basis and conduct larger, more comprehensive evaluations every few years. It is important to determine ahead of time what information will need to be monitored and to whom it will be given. Click here to view more information on [how to design an effective, comprehensive program evaluation](https://bit.ly/3wYmipL) (URL: <https://bit.ly/3wYmipL>).

Endnotes

- 1 Donnell KA, Allston AA. The nationwide evaluation of Fetal and Infant Mortality Review (FIMR) programs: Development and implementation of recommendations and conduct of essential maternal and child health services by FIMR programs. *Maternal Child Health J* 2004;8(4):225.

Chapter Three: Building Community Support and Collaboration

Introduction

The FIMR planning group must intentionally recruit a wide variety of diverse members to support the program and serve on the Case Review Team (CRT) and the Community Action Team (CAT).

This chapter describes important aspects of building community support and collaboration for FIMR, vital to planning groups.

Supporters and team members should include diverse care providers, agency representatives, policymakers, representatives of community organizations and professional groups, as well as family representatives and consumer advocacy groups. Successful FIMR programs involve both persons with lived experience and community advocates. Community support and collaboration should happen simultaneously to the programmatic planning outlined in chapter 2 and typically takes 6-12 months.



Selecting the Right People to Get the Job Done

Choosing the right mix of people to serve on both the CRT and the CAT is crucial to the success of the FIMR process and requires intentional planning to advance racial and health equity. FIMR membership should include individuals who bring diversity, influence, and commitment to racial and health equity in the FIMR process. Equally important is incorporating and supporting the participation of those with lived experience in the process.

Diversity and Inclusion

Diverse and inclusive FIMR membership is one of the best ways to ensure that the process focuses on advancing health equity.

Both the CRT and the CAT membership should represent a wide array of personal and professional knowledge, expertise, experience, the racial, ethnic, and cultural diversity of the community, and a broad, creative range of organizations. Consider including members not typically included in traditional maternal and child health consortia. Membership should exemplify partnership between public health and healthcare providers, service agencies and people to whom they provide services and community members who represent those most impacted by poor fetal and infant outcomes. Leaders in the faith-based community, business leaders and unions, including those representing employees of childbearing age, should be included.

The strength and the challenge of a diverse group is the breadth of diverse opinions, influence, and expertise they bring to the table. This may make for lively and even divisive team meeting discussions, especially during the first year of the program. However, FIMR programs indicate this type of group interaction is a positive sign because it paves the way for establishing the common ground of understanding critical to FIMR review and action and aids team sensitivity to the many cultural values, attitudes, and beliefs in the community. Finally, diverse membership sets a standard of community cooperation and mutual respect. Refocusing challenging conversations to focus on prevention often diffuses conflicts, as team members share the goal of making the community a safer place for babies to be born, grow, and thrive.

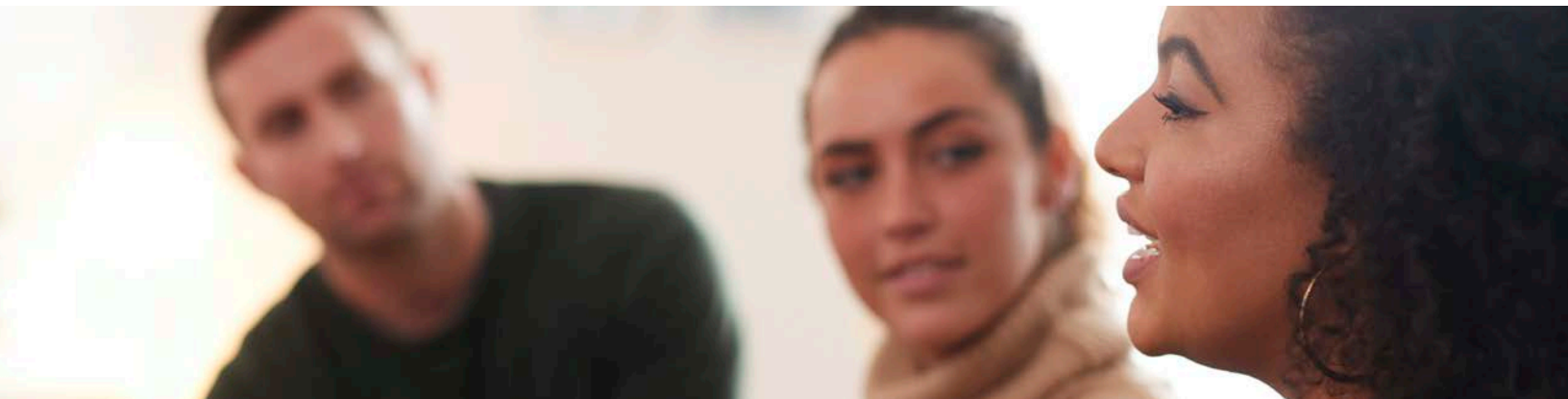
For more information on effective fatality review meeting facilitation, view the [Fatality Review Facilitation Guide](https://bit.ly/3jPxVMv) (URL: <https://bit.ly/3jPxVMv>).

Influence

Including policymakers, institutional and professional leaders, and those with power to make policy and practice decisions and mobilize fiscal and programmatic resources on behalf of communities, agencies, and organizations ensures that FIMR recommendations will have a champion and will be implemented. Team members with influence will often be agency leaders, high-level medical care administrators, elected officials, or high-level staff members with decision-making power to affect structural changes in support of health equity. Influencers are often placed on the CAT because of their ability to effect meaningful systems-level changes that will integrate and advance health equity as a priority.

Commitment

When possible, FIMR should engage new members with a proven track record of advancing health, health equity, and the wellbeing of women, infants, and families. Similarly appealing are potential members who have advocated for systems improvements in favor of equity or implemented significant policy change that will advance health and health equity. While not every potential member will come to the table as a proven community advocate, mobilizing this spirit of commitment—especially among new or younger community members—is one of the overall benefits of active participation in the FIMR process.



Participation of Individuals with Lived Experience

The inclusion of various persons who live, work, worship, and play in the community should be an integral part of the FIMR process from the beginning and throughout the process. Individuals who live in the FIMR community and use its medical and other services and resources are vital to the planning process as well as case review and community action. A special component for all FIMRs is to ensure the inclusion of family members who have suffered a fetal or infant loss on both the CRT and CAT teams.

Bringing the perspective of those with lived experience into the FIMR process is essential to broadening the knowledge base and creativity of the teams and greatly enhancing the character and impact of the recommendations and actions they develop and implement. Because FIMR team membership requires active participation in divergent and occasionally intense group meetings, individuals who already have some experience in community advocacy groups seem best equipped to navigate those dynamics and actively join discussions. To ensure broadly diverse community representation, the planning group should make a special effort to identify and address any barriers that may make it difficult for community members to participate, including transportation and childcare. Equally crucial to equitable participation is the provision of an honorarium for community members' involvement.



Choosing Case Review and Community Action Team Members

Case Review Team

Some community partners will be more appropriate participants on the CRT. These organizations include, but are not limited to, the local health department, including perinatal data experts; primary and tertiary medical care institutions; obstetric and pediatric providers, including doulas; mental health providers; hospital administrators; Medicaid supervisors; WIC program nutritionists; family planning providers; health educators; community health workers; and representatives from substance use treatment centers. Other representatives might include pastoral counselors, bereavement care providers, human rights advocates such as those representing Black and Indigenous people of color, the LGBTQ+ community, a Chamber of Commerce health committee member, or members from the local SIDS-prevention or loss community.



Professionals and agencies on the Case Review Team should represent consumers as well as professionals and agencies that provide medical services or community resources for families.

Sample CRT Team Membership:

- 1 Local health department
- 2 University medical school department of OB/GYN
- 3 State associations of birthing providers such as nurse-midwives and doulas
- 4 Healthy Start program representative
- 5 Medical examiner's office
- 6 Maternal Fetal Medicine specialist
- 7 Maternal health and perinatal nurses
- 8 SIDS center coordinator or bereavement provider
- 9 Health-related coalitions that reflect the racial and ethnic demographic and cultural makeup of the state/community
- 10 State MCH public health
- 11 Managed care representative
- 12 WIC staff
- 13 Social service provider
- 14 Maternal mental health provider or state association
- 15 A family member who experienced an infant death
- 16 Prenatal care coordinator/provider
- 17 Family planning provider
- 18 Community health workers
- 19 Substance use treatment service director



Community Action Team

Other individuals and agencies will collaborate on prevention, intervention, and policy development through the CAT.



The CAT is composed of two types of members: those with the political will and fiscal resources to create large-scale system change and members who can define a community perspective on how best to make the desired change that will advance health equity in the community.

Many communities already have a functioning infant mortality reduction workgroup, task force, or perinatal initiative that could successfully function as a CAT. This includes prenatal/perinatal regional consortia, community advisory boards, mayor or county executives' blue ribbon panel on infant mortality, Healthy Mothers, Healthy Babies Coalitions, perinatal quality collaboratives, Nurse Family Partnership Community Action Boards, or Community Action Networks for federal Healthy Start programs.

Given the close working relationship of the CRT and CAT, some CRT members may serve on the CAT as well. Alternately, some members of the CRT may rotate onto the CAT after several years of service and vice versa.

Sample CAT Team Membership:

- 1 Health-related coalitions that reflect the racial and ethnic demographic and cultural makeup of the state/community
- 2 Mayor
- 3 Members of the city council
- 4 President of the local hospital
- 5 Director of the local medical, nurse midwifery, doula society
- 6 Directors of several local government agencies (housing, social services, and schools)
- 7 Local commissioner of health
- 8 CEO of managed care organization
- 9 Chamber of Commerce representative
- 10 State maternal child health program
- 11 Consumers of community programs
- 12 Perinatal epidemiologist
- 13 Military parenting program representative
- 14 Child abuse prevention services
- 15 Local bereavement support representative
- 16 Urban League
- 17 Local March of Dimes chapter
- 18 Kiwanis Club
- 19 Community Health Advisory board
- 20 Community advocates

More Team Planning Considerations

To determine if the membership is inclusive and appropriate for the vision of health equity, ask the following questions while building the team:

- Does the list include a broad-based, multi-partner array of diverse agencies and individuals who are concerned about and committed to health equity?
 - Does the list include families and consumer advocates representing the diverse racial, ethnic, and cultural groups in the community?
 - Have specific members of the CRT and CAT been identified at sponsor agencies?
 - Are there enough members with the desired level of influence included on both teams?
-

Consider referencing the [Community Participation: A FIMR Member Checklist](#) that can be found in the template package, [Appendix A](#).

After potential CRT and CAT members have been identified, the planning group should set up meetings with these individuals and groups with relevant interests to recruit specific team members and gain the community's commitment to advancing health equity. This will take time, patience, and planning. As team members come on board, ask if they have ideas of others who would be helpful to include and if they would be willing to reach out on FIMR's behalf. At this stage of teambuilding and building community support for FIMR, do not overlook the informal power of personal relationships among agency and institutional leaders.

To keep the team membership at a manageable size, it may be helpful to identify team members who can check more than one box in the list of desired representatives—such as the head of a local medical society who is also an OB/GYN, a police chief who volunteers in a local bereavement program, or a director of a community health worker program who also lives and works in the community with the highest rates of adverse outcomes.





When reaching out to potential members, the planning group should:

- Understand the organization's purpose or mission and any current issues they are addressing
- Describe the general purpose and objectives of the FIMR process in simple terms, and share any relevant program literature
- Consider specific ways the organization might assist FIMR to move recommendations to action and on which team the member should serve
- Explain the reasons why the community would benefit from the FIMR process, benefits to the potential team member's organization, including ways FIMR may help achieve their purpose or mission
- Reinforce the rigorous confidentiality of the FIMR process, the steadfast commitment to advancing health equity, and address any issues that may be of concern to that organization
- Facilitate a frank discussion of the potential member's view of health equity and the FIMR process and address their concerns



Keep in mind that some of the most vital team members see their service on a FIMR team as both a benefit to health equity in the community and a benefit to their own professional growth.

Convening a Community Meeting

After laying the groundwork, building support, and recruiting new members, many communities convene a community meeting to bring together all the individuals and agency representatives who are willing to support the program, as well as those who have agreed to serve on the CRT and CAT. This initial meeting of service providers, community agencies, advocates, and families can synthesize the dynamics of what FIMR is in achieving health equity, how it will function, and coalesce community ownership and enthusiasm.

Choose a convenient time that accommodates most schedules. Choose a neutral site for the meeting. Serving refreshments is always welcome if budgets allow, as it allows team members to have informal time to get comfortable. The meeting facilitator may be the FIMR director or coordinator. A team chair may be chosen at this meeting for one or both of the FIMR teams. The team chair should be skilled in facilitation, well-respected by all as a community leader, and an individual who believes in the power of the FIMR process. Consider the flexibility of having co-chairs to ensure power dynamics and equity.

Invite participants with a formal letter of invitation and a tentative agenda from the head of the agency sponsoring FIMR about six weeks before the meeting. Samples of both are found in the template package, [Appendix A](#).

Chapter Four: Abstracting Medical and Service Records

Introduction

Abstraction of medical records and records of all services received by the childbearing family for FIMR review is critical to building the story, revealing structural inequities; the records abstract is used as the foundation of the case summary.

Abstractors are responsible for obtaining comprehensive case information to help the Case Review Team (CRT) determine if gaps in assessment, quality of care, or services existed. It is important for the abstractor to bring at least a minimum data set of case information to the review team. The review team needs to evaluate the series of social and medical care events in order to make valid recommendations for action to change systems of care. Medical records can be a few pages or thousands of pages long, often consisting of multiple provider encounters and multiple care locations. All of this can challenge the abstractor to find information that will be meaningful for the CRT.

Choosing a FIMR Abstractor

The role of the FIMR program abstractor is to create the de-identified case summary of the fetal or infant death that will be reviewed by the CRT. Experienced FIMR sites have shared that a variety of disciplines may be appropriate for a medical records abstractor. Nurses, physicians, physician assistants, medical students and residents, social workers, and health educators are among the most common personnel that may be best equipped to abstract cases.

THE FIMR ABSTRACTOR

The abstractor should have adequate clinical experience with obstetric, neonatal, and pediatric care to be able to understand the information and to be able to recognize red flags, irregularities or inequities in the standard of care.

In addition, it is highly recommended that the abstractor has or receive **Unconscious Bias** training.

Even more important than the discipline is the following set of core characteristics desired for an abstractor:

- Flexible and creative
- Self-motivated
- Genuinely interested in the FIMR program and improving maternal, infant, and family health outcomes and equity
- Experience working in maternal and child health or the public sector
- A sound understanding of health equity and appreciation for cultural diversity
- Respect for diversity in community values
- Knowledge of the assets and strengths of families and communities
- Unbiased and equity grounded storyteller
- Not judgmental

The template package, [Appendix A](#) has an outline of the duties of the case abstractor.

Initially, it may be helpful to pair a new abstractor with a more seasoned and experienced abstractor, either from the same FIMR program or a nearby mentor site. Teams may find it helpful for beginning abstractors to have a reliability check by comparing the results of two abstractors on the same case. The National Center can assist you if you would like to be connected to experienced sites for this purpose. Contact info@ncfrp.org. Click on the following link to view a [training module covering chart abstraction](https://bit.ly/36l6xxK) (URL: <https://bit.ly/36l6xxK>). The FIMR 101 module focuses on the basics of FIMR methodology, project staffing, case selection, obtaining access to records, abstracting medical records and creating the case summary, and how FIMR benefits health equity and the community.



Records Needed

The FIMR program leadership will make decisions on the type and amount of record abstraction to include when creating case summaries. This section is meant to give programs an overview of the available records and provide options. Abstraction of one record may uncover another source of information for the mother or infant not previously identified. Initial abstraction involves the death and birth certificates, hospital/birth center records for delivery, newborn assessment or newborn intensive care, prenatal records and any additional hospitalizations in those institutions. For complete prenatal and pediatric information, additional data may need to be obtained from private providers, including doulas, as well as public health clinics and community-based case management providers. The abstraction process is time consuming, but essential to getting all the pieces of the story of the family's experience.



The following can be used as a comprehensive check list of the most common components of records abstraction:

- | | |
|--|---|
| <input type="checkbox"/> Birth and Death Certificates | <input type="checkbox"/> Local Law Enforcement Records |
| <input type="checkbox"/> Provider Records: <ul style="list-style-type: none"> • <i>Preconception Care (if available)</i> • <i>Prenatal Care</i> • <i>Postpartum Care</i> • <i>Pediatric Records (Well Child/Sick Child Visits)</i> | <input type="checkbox"/> Department of Human Services Records: <ul style="list-style-type: none"> • <i>Relevant Child Welfare Information</i> • <i>Assistance and Service Provision</i> |
| <input type="checkbox"/> Hospital/Birthing Center Records: <ul style="list-style-type: none"> • <i>Antepartum Hospitalizations</i> • <i>Labor and Delivery</i> • <i>Newborn Care</i> • <i>Neonatal Intensive Care</i> | <input type="checkbox"/> Local Public Health Records: <ul style="list-style-type: none"> • <i>WIC</i> • <i>Home Visiting</i> • <i>Family Planning</i> • <i>Children's Special Health Care</i> |
| <input type="checkbox"/> Medical Examiner Records | <input type="checkbox"/> Mental Health (Before, During, and After Pregnancy) Records |
| <input type="checkbox"/> Emergency Medical Services (EMS) Run Sheets (if applicable) | <input type="checkbox"/> Substance Abuse Treatment Records |



Every FIMR program needs to collect information to be able to relate the story of each case from a systems perspective, including but not limited to factors such as:



Access and acceptability to services



Barriers to services



Quality of care



Patient education



Psychological assessment



Factors influencing lifestyle choices



Family strengths



Discharge planning



Respectful provider communication

Records Considerations

Infant mortality is not merely a medical issue, but social and systems issues with medical implications.

Case summaries must have enough clinical information to be medically credible and enough social context information to understand the whole picture of the pregnancy, life, and death. Information is needed to also examine the systemic issues preceding or surrounding the event. This means the medical professionals on the team need to be able to understand the case and its implications from the perspective of adequate care, quality of care, and service delivery. Abstractors will discover that individual CRT members often have expectations on the minimum amount of information they would like to see in the cases that come to the table. Teams may also find the type of information that is collected and judged to be most useful by the review team may change over time. For example, information about the systems' strengths and weaknesses as it pertains to quality and health equity is a more recent need. The need for detailed medical information must be balanced with attention to community-wide systems issues.

Another factor to consider in deciding what information should be collected is how the information will be used. The main use for FIMR information is to create an expansive narrative summary of what happened in each case for the purpose of using the findings to improve health equity, care quality, and resources for women, infants, and families. Many teams also prioritize comprehensive data collection and data entry into the National Fatality Review Case Reporting System (NFR-CRS) for the purpose of aggregate analysis of cases that complements and supports the qualitative case review required to understand how inequities contributed to the event. Click here to view the [complete print copy of the FIMR NFR-CRS Form](https://bit.ly/3fRgwk3) (URL: <https://bit.ly/3fRgwk3>).

In choosing which information to abstract, teams should consider how realistic it is for the local program to access and collect it. A suggested process for assessing the relative importance of individual information elements is to review the collected variables in the NCR-CRS to identify which ones are of interest to the review team and the FIMR leadership.

- Assess the match between which items are important and which are likely to be available.
- Assess the match between the accuracy of the wanted information and the accuracy of the available information.
- Build in some redundancy to make sure important items are accurate and can be captured for every case (birth weight, race and age of mother, etc.).
- Assess the professional and institutional support for use of each source; choose items that are important, but also feasible to collect.

Obtaining Access to Records

In general, vital statistics data at the county or city level are obtained with the assistance of the local health department. Hospital/birth center-based records are usually more easily obtained than private provider office-based records. The FIMR planning group will need to establish the method for obtaining access to medical and social service records.

Many states have regulations or language in public health code or statute that permits access to medical and vital statistics records for “investigations for the benefit of the health of the public” or comparable purposes. Vital statistics data are often housed in local city and county health departments. Therefore, a FIMR program sponsored by the local health department would probably have an easier time accessing records. A Grant of Authority letter or document from the state, county, or local health department that explains the FIMR program and purpose greatly facilitates the abstracting process. Samples are included in the template package, [Appendix A](#). Some programs have executed simple data use agreements (DUAs) between the agency sponsoring FIMR and the hospitals’/birth centers’ and providers’, including doulas’, offices to allow for record abstraction.

AVAILABLE LAWS

It is important to make sure all available laws related to accessing medical records and vital statistics certificates are found and interpreted by state or local health department privacy officers or attorneys.

Some FIMR programs access medical records under the federal Health Insurance Portability and Accountability Act (HIPAA) exception, section 164.512(b) – Public Health Disclosures. HIPAA permits a covered entity, such as a hospital, to disclose protected health information to a “public health authority” for certain public health activities. A “public health authority” is “an agency or authority of the United States, a State, a territory, a political subdivision of a State or Territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.”¹

For greater detail on HIPAA as it relates to local FIMR programs, specifically their ability to obtain access to pertinent medical records, refer to [The Fetal and Infant Mortality Review Process: The HIPAA Privacy Regulations](#).²

FIMR abstractors find an important strategy for success is to establish working relationships with the medical records staff of each institution, agency, and office where records will be abstracted. The medical records staff from all of the institutions where records will be reviewed will want to know the purpose of the program, who will be examining the records, how many records are expected to be





involved, and how often the abstractor will be coming to the hospital, agency, or office. It may be helpful to provide the abstraction forms to the appropriate staff and any accompanying literature on the program, such as an annual report, newsletter, and policies and procedures the FIMR staff will follow regarding confidentiality.

Many institutions, agencies, and private practitioners are subscribed to electronic health records (EHRs). EHRs contain patient health information such as patient demographics, progress notes, vital signs, medical histories, diagnoses, medications, allergies, lab and test results, and immunization dates. EHR systems are built to share information with other health care providers and organizations, such as laboratories, specialists, medical imaging facilities, pharmacies, emergency facilities, and school and workplace clinics. They may contain information from all clinicians involved in a patient's care, but only if the providers are in the same health care system. FIMR programs may be able to get permission to access EHRs and thereby avoid having to go on site to do time consuming in-person record abstractions. To request direct access to EHRs, programs may need to enter into a memorandum of understanding (MOU) with the healthcare system. MOUs communicate the mutually accepted expectations of the people, agencies, or organizations involved. The content of a typical MOU between a FIMR program and a hospital/birth center or health care system might include the names of the parties, description of the project on which they are agreeing, definition of the scope of the project, and details each party's roles and responsibilities.

Some FIMRs report that they can view records electronically with their hospital systems utilizing an encrypted email system. The hospital system provided each FIMR medical record abstractor an encrypted password and a Health Information Management (HIM) contact person to whom the abstractor can send medical records requests. A similar process may be available for birth centers. Sites may consider developing a FIMR abstraction medical records request form that lists the specific information that is needed. A sample of such a form can be found in the template package, [Appendix A](#). Another creative strategy for accessing electronic medical records is to use a commercial online fax service that allows an agency to send and receive faxes directly via email or a secure online portal. There may be fees associated with these commercial services.

In summary, local FIMR programs can greatly enhance credibility and access to information by making sure that hospitals/birth centers and providers, including doulas:

- Know about the benefits of the local FIMR including how it may contribute to health equity
- Understand that confidentiality and accurate information/data are key to the FIMR process
- Are included in the FIMR Case Review Team or Community Action Team when possible
- Receive explanatory information such as the Sample Health Officer Letter and or Grant of Authority to conduct FIMR (see the template package, [Appendix A](#)) when records are requested

Procedures and Tips for Abstracting Records

When doing on site abstraction at a hospital, birth center, agency, or clinic, these are a few tips and strategies that may be useful to the abstractor.

1

If accessing records onsite, call ahead to arrange for review of records. Agree upon a mutually convenient time to examine the records. In most institutions, 24-72 hours of advance notice is adequate for staff to pull the requested records.

2

If accessing EHRs, share with the institution a specific list of the information that is being requested.

3

Assemble packets for each case containing case identification information (mother's name(s) and date of birth; infant's name(s) and date(s) of birth and death) and appropriate forms. Race and ethnicity of mother and infant are essential for understanding health inequities. For example, fetal losses would include prenatal, labor (where applicable) and delivery forms; infant losses would include additional forms, such as the newborn intensive care or out-patient pediatric record abstraction forms. Click here to view [Data Abstraction Forms](https://bit.ly/36sJVeJ)³ (URL: <https://bit.ly/36sJVeJ>).

4

If abstracting directly to a laptop computer or other electronic device, consider uploading information to a secured cloud or other protected storage site. If stored on the electronic device itself, it is recommended that the device is password protected. Many health care organizations already have software that provides such protections. If carrying paper copies of abstractions, information should be stored in a locked file and/or carried in a locked vehicle to and from the institution. Forms should have only the case number on it. No identifying information should be written on abstracting forms.

5

Follow the protocols of the institution, only reviewing records in a designated area and making photo copies if allowed.

- 6 Document laboratory results pertinent to the diagnosis. For example, if cause of death is anemia, the CRT will want to know the hemoglobin values. Or if infection is noted, check to see if cultures were done and, if positive, record any treatment provided.
- 7 Keep track of any discrepancies in information – these may signal issues with the structures and systems as well as communication and patient and provider understanding.
- 8 Record dates and times for important events, such as presentation at hospital admission, estimated date of confinement, rupture of membranes, delivery, transfer, and discharge.
- 9 Record any supportive information that will help with writing the case summary such as repeat hospital visits prior to delivery, recommended treatments, and follow-up.
- 10 Document when a complicated process went well, when the strengths of a provider, institution, or parent were apparent, or when outcomes were improved.
- 11 Determine if additional records should be requested from providers' (physicians, midwives, doulas) private offices or other facilities such as birth centers.
- 12 Pace yourself! Abstracting these records can be emotionally exhausting.

Maintaining Confidentiality

FIMR program staff must remember the importance of protecting both paper and electronic copies of all information. Staff should never write family, provider, or institutional identifiers on the abstraction forms, but only the number assigned to the case. In the field, staff should be careful not to leave completed forms out in a car where they could be seen and to keep them secured in a locked vehicle until they can be transferred to secure, locked files in the office.



Once there, when the case is being summarized or entered into a computer database and the transcriber must leave, even briefly, the record must be locked up and the computer screen should be closed. Computer systems for entering or summarizing case information should be secured with a password. At the end of the case review meeting, the de-identified case summaries should be collected from all team members and shredded. After the team reviews the case, all tracking forms that might link the family, the provider and institutions to the case summary, including abstraction and home interview forms, should be deleted and/or shredded. If the meetings are being held virtually, share files for review via a secure sharing service, and stick to protocol for securely sharing files in advance of meetings. Do not upload review materials directly to the meeting hosting service. Consider using secure cloud storage such as OneDrive or Google Docs for sharing or saving necessary case information. Follow this link for [more detailed information on planning for and conducting remote fatality reviews](https://bit.ly/3yHNWbE) (URL: <https://bit.ly/3yHNWbE>).

Finally, when keeping minutes of the case review meeting, many FIMR programs already find it prudent to develop minutes that summarize general discussions such as trends, especially as it pertains to health inequities and sentinel events rather than individual case notes, even though these are de-identified.

Creating the De-identified Case Summary

For each case of fetal or infant death to be reviewed, information is collected from a variety of sources, which may include provider and hospital/birth center records along with those from home visits and relevant community program records. Information is also obtained in an interview with the family. Information from all these sources is blended together to paint a complete picture of the death and the time leading to it. All identifying information (i.e., names of families, providers, institutions) should be removed and an anonymous summary of the case is presented to the CRT. Only the case abstractor and the maternal interviewer will know the identities of the families and providers. As much as possible, the goal is to remove all identifiers from the case narrative summary so that those involved in the review will not recognize the case.

When creating the FIMR case summary, it is critical to present the information to the Case Review Team in a way that will not perpetuate systemic oppression.

PRESENTING THE INFORMATION

The staff abstracting the records and/or interviewing families must not present the information they gather through a lens that reflects conscious or unconscious bias or judgment, such as racist, ableist, or heteronormative.

The case summary should describe the family's situation during the pregnancy and at the time of the loss. **The reader should be able to understand what happened from the family's perspective.** If an interview is conducted, it should also be clear whether the family situation was stressful or stable; the living conditions were adequate; the family seemed strong or overwhelmed; whether referrals were made and followed up on; and whether barriers prevented the family from receiving services. Include both challenges and strengths of the family and the systems with which they interacted. Finally, any events since the death that are relevant to the case, such as subsequent pregnancies, family transitions, or resolutions of problems identified in the case should be included in the summary.

All FIMR programs need to collect and summarize enough information to be able to relate the story of each case from a systems perspective, including but not limited to factors such as access, barriers, quality of care, provider biases, patient education, psychosocial assessment, lifestyle choices, coordination of services, and discharge planning. Presenting this information to the CRT in a de-identified way can be challenging.

A New Strategy

A strategy that some fatality review teams are beginning to adopt is to leave off the client demographic information or reorder the demographics to the end of the case summary. Rather than leading the summary with information on race, socioeconomic status, education, and marital status, details that could bias team members' deliberations, demographics are either omitted or left to the end of the case narrative.

The HIPAA Privacy Rule defines “individually identifiable health information” as information, including demographic data, that relates to:

- The individual's past, present, or future physical or mental health or condition.
- The provision of health care to the individual.
- The past, present, or future payment for the provision of health care to the individual and that identifies the individual, or for which there is a reasonable basis to believe it can be used to identify the individual. Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, Social Security Number).

At a minimum, the following information should be redacted from the case summary reports presented at FIMR team meetings:

- Names:** All names of the child, parents, 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.
- Case Numbers:** All insurance numbers, file numbers and other numbers used to identify the child or family.

A few tips and examples of strategies can be seen in the table below:

Figure 3. Fatality Review Team Tips and Strategies

Identified	De-identified
Jane Smith entered prenatal care on 6/15/2019 at the Covenant Family Care Clinic and saw Dr. Jones for 12 visits.	The client was a 25-year old G1 P0 mom who entered prenatal care at 8 weeks gestation. Her care was provided by an OB/GYN physician at a large federally qualified health center and she completed 12 visits.
Mary Jones had an ultrasound on 6/10/19 that confirmed the baby was between 15- and 16-weeks gestation.	Client had an ultrasound appointment at 16 weeks gestation to confirm dating.
Susan White had 4 visits with Dr. Johnson on 1/8/19, 2/10,19, 4/6/29, and 6/8/19.	Client was seen in consultation by a maternal fetal medicine specialist for four visits, at 32, 33, 35, and 37 weeks gestation.

When it will not compromise the flow and chronology of events, leave the specific dates out. Dates and times for important events, such as presentation at hospital admission, estimated date of confinement, rupture of membranes, delivery, transfer, and discharge can all be presented by using the month, year, and gestation.

For example, when presenting previous pregnancy outcomes:

- **November 2019:** Pregnancy under review, infant born at 28 weeks gestation
- **August 2017:** Live born term infant, 39 weeks gestation
- **March 2015:** 12-week miscarriage



Many programs present the case information as a chronology of events. In order to keep the case succinct, use key points and summarizations. For example, a systems review (respiratory, cardiac, neurologic, gastrointestinal, etc.) may be helpful in a case of an infant with a lengthy NICU stay. While styles may vary according to team preference, a third-party narrative is generally used. **Objectivity is key; stick to the known details of the case leaving out opinions and conjecture.** Finally, noting when information is not available may also illuminate systems or documentation issues.

In summary, it is recommended that in all aspects of case abstraction and creating the case summary, keep prevention as the focus. Identify and call out protective factors, including systemic issues, that keep families from having a poor outcome versus defaulting to finding problems. Consider the community's major assets, including the gifts of **individuals, associations, and institutions**. They may not be just the usual suspects!

Detailed information on creating the de-identified case summary can be found in the [FIMR 101 Module](https://bit.ly/36l6xxk) (URL: <https://bit.ly/36l6xxk>) found on the NCFRP website.

FIMR Case Summary in the NFR-CRS

While not all FIMR teams participate in the National Fatality Review-Case Reporting System (NFR-CRS), it is designed to support comprehensive case summaries. The NFR-CRS has a FIMR Case Summary that can be generated after case data are entered into the system. The summary is customizable, and will include selected variables. There are 12 domains of data, and all of them but the Narrative have multiple data points within them.

The summary domains include:

- Infant and childbearing biological parent demographics
- Background/social and medical history
- Preconception care
- Prenatal care
- Maternal labor, delivery, and postpartum care
- Newborn intensive care
- Newborn assessment and hospital course
- Ambulatory infant course and pediatric care
- Investigation
- Life stressors
- Home interview
- Narrative

The Case Summary is generated as an editable Microsoft Word document, allowing abstractors or interviewers to add relevant information to the case summary.

For more information about the FIMR Case Summary, contact the National Center at info@ncfrp.org.

ADDITIONAL RESOURCES

US Department of Health and Human Services, [Guidance Regarding Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act \(HIPAA\) Privacy Rule](https://bit.ly/3yFrdN5) (URL: <https://bit.ly/3yFrdN5>).



Endnotes

- 1 <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/administrative/combined/hipaa-simplification-201303.pdf>.
- 2 <https://www.ncfrp.org/wp-content/uploads/NCRPCD-Docs/FIMRProcessAndHIPAA.pdf>.
- 3 Developed by ACOG's FIMR support, during a collaborative effort between the American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA).

Chapter Five: Parental/Family Interviews

Introduction

Many important and informative data points are provided by relevant case records from health care providers and institutions, public health, vital records, child welfare, social services, emergency response professionals, and other community agencies. However, these records are limited in their ability to fully reflect the experience of the family both in the personal details that impact physical, mental, and emotional health and wellbeing and the family's experiences with and within these community and hospital/provider systems.

To fully understand the factors surrounding preconception, pregnancy, labor, birth, and infant health and wellbeing, it is essential to understand the relationships, stressors, experiences of discrimination, levels of access to vital quality resources and services, and other experiences and social-emotional issues that are often poorly captured and in many cases unavailable in abstracted records. Family strengths and resilience identified through the interview are also valuable information for the review teams' deliberations.

One of the FIMR process goals is to operate as continuous quality improvement (CQI) for community and provider/hospital systems that serve pregnant and birthing parents, infants, and their families. This cannot be done without the perspective of those who have lived through the various experiences that may impact birth outcomes. Lived experience is defined as "Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people. It may also refer to knowledge of people gained from direct face-to-face interaction rather than through a technological medium."¹ The parental/family interview is the opportunity to listen to and understand these experiences.





The parental or family interview is an essential feature that sets FIMR apart from similar review processes, playing an important role in allowing parents to tell their baby's story. Many families have indicated that the interview allowed them the opportunity to pay tribute to their infant's life and validate their personal loss. Interviews are typically conducted with the childbearing parent, but there are times when only a partner or other caregiver is available or even times when both parents may participate.



The purpose of this section is to outline key elements of the FIMR parental interview process, highlight critical considerations in interviews and case reviews, and provide resources for FIMR interviewers.

The FIMR Parental Interview

Locating Families, Initial Contact, and Letters of Consent

When a FIMR team becomes aware of a fetal or infant death for the purposes of case review, the childbearing parent is typically identified from the birth or death record. FIMR teams are often coordinated out of local health departments with easy access to a local vital records office. Sometimes other records, including hospital records or social service records, are used to find contact information to reach out to the parent/family. This process is not always straightforward, as mothers may have moved, be transient, or even staying with a friend or family member for support during the mourning period.

Other ways teams have identified mothers include:



Family members



Online searches



Friends or neighbors



Social media searches



Utility companies



Post offices (asking for forwarding address)



Medical and/or social service providers (WIC or home visiting)

Respecting Each Family's Needs

The best strategy for reaching families is the one that works for the individual program and prioritizes the communication needs of the bereaved parent(s). It is recommended that the differential cultural practices related to fetal and infant death be understood and observed so that the appropriate length of time for contacting families is respected.

When FIMR staff initially contact families, they share condolences, introduce the FIMR process, and ultimately request an interview. In some jurisdictions, this is done all at once, through a phone call. In others, an initial letter of introduction is sent, informing the family that program staff will be reaching out to them to request the interview. These letters should include a phone number or email address for the program, allowing a family to opt-in to the interview process. As cell phones have become ubiquitous, some teams find parents likelier to respond to text messages than phone calls. There is no one “right” way to contact families.

Regardless of how teams decide to operationalize contacting families, FIMR staff need to create a process for obtaining informed consent from the family member(s) who will be interviewed. A letter of consent is typically presented at the time of the interview once a parent has agreed to participate.

It is the interviewer's responsibility to ensure that the entire letter of consent is reviewed and that the participants understand what they agree to before it is signed.

This can be done by examining individual sections one at a time and asking the participant if they have any questions or concerns before moving on to the next. It is most helpful to have the letter of consent translated into the language of origin for families or have an interpreter, other than a family member, explain the process and gain informed consent verbally.



A letter of consent should:

- Identify the agency and program that will conduct the interview, including the name and contact information for the appropriate point of contact.
- Cite relevant legislation, policy, or grants of authority under which FIMR operates.
- State the objectives of the interview and the intended use of the information obtained from it.
- Outline the agency's confidentiality standards for the interview process, highlighting that the information from the interview will be secure and de-identified at all stages of the FIMR process.
- Clarify that the parent/family may stop the interview at any time should they decide they no longer want to participate.

Examples of letters in consent are found in the template package, [Appendix A](#).

Once the family member(s) has agreed to participate in the interview, the interviewer arranges when and where the interview will take place. Interviews are commonly held face-to-face in parents' homes. Occasionally they are held in a more neutral location, such as a provider's office, park, or a coffee shop. Regardless of where the interview will be conducted, confidentiality must be secured and assured.

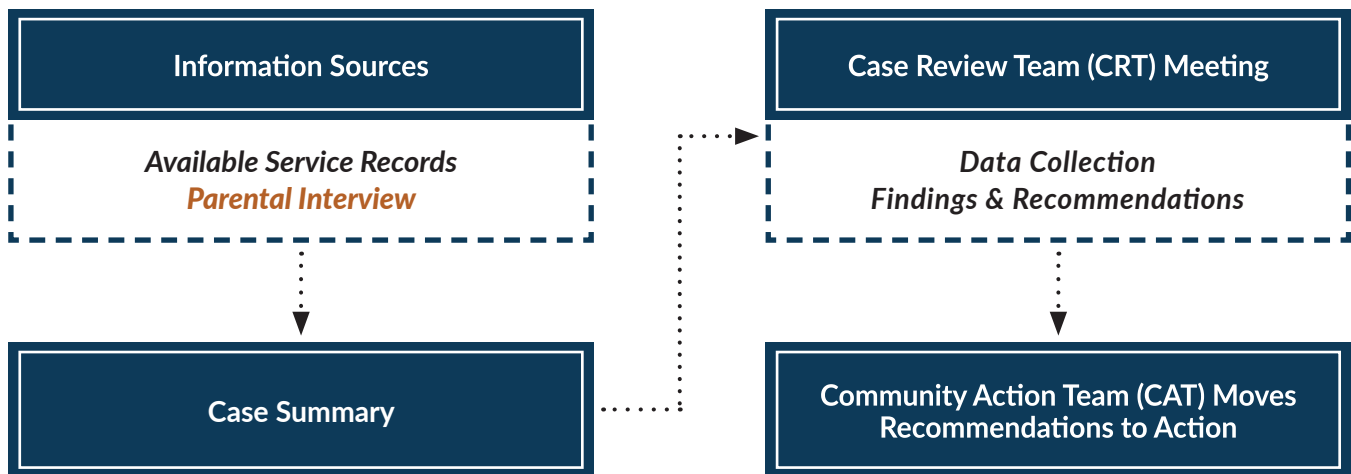
The Interview Process

For an effective case summary, abstracted records are only one of two categories of information needed to provide a comprehensive picture of the risk factors, protective factors, the death, and the response to the death.

Without the interview, all the information provided to the Case Review Team (CRT) is filtered through the lens of health care providers, social services professionals, or other professionals. The interview provides an opportunity for the team to fill in gaps in the available records, confirm and provide context for all the available data, and hear a first-hand account of the family's experience with medical, hospital, and community systems. Further, it ensures the FIMR team does not move forward with findings and recommendations from case reviews that have not been informed by the family's lived experiences. This helps ensure that services and care are held accountable to quality, equity, and excellence standards.

The following process flow chart demonstrates how these two unique sources of information contribute to the review:

Figure 4. *FIMR Process Flow Chart*



On the day of the interview, the interviewer should take time, in the beginning, to express their sympathy for the family member's loss and reassure them that there are no wrong answers to the interview questions and confidentiality will be upheld. Instead, the intention of the interview is to paint a clear and complete picture of the highs and lows of the family's experience.

The interview should focus on the parent’s experience leading up to the fetal or infant death, including the time of conception, the pregnancy, and birthing experience. A simple way to begin the interview is to ask the parent or family member about the pregnancy and when they first found out the baby was on the way. Once a caring and comfortable atmosphere has been created, the interviewer may ask the parent to describe the events leading up to the death in their own words. Once the parent has shared their story, the interviewer can ask clarifying and follow-up questions to understand the family experience better and ensure they can provide a comprehensive summary of the interview to the FIMR team. To do this, the interviewer needs to understand what data the Case Review Team needs to conduct their review and complete data collection.

At a minimum, interviewers should ask mothers to tell them about:

The time leading up to conception

Labor

Pregnancy

Birth

Prenatal care

Postpartum

Important relationships with family, roommates, or significant others

NICU or pediatric care throughout the child’s life

Other support services, including WIC or home visiting

Events precipitating the death and the death itself

Other community supports, including religious or non-profit organizations the family interacted with

Organizations family interacted with at the time of and after the death, including any bereavement care provided

Challenges faced due to insurance coverage, provider attitudes, limited resources, employment challenges, discrimination, transportation, and other barriers

Some jurisdictions create an interview script or outline to guide the discussion, **but it is best to keep the interview as flexible and comfortable as possible and without judgement.** It should not feel like the interviewer is completing a checklist of questions, reading or filling out a form, or interrogating the family. To avoid this, it is important for the interviewer to be intimately familiar with the outline or script, so they won't rely on it to guide the discussion.

FOLLOW UP QUESTIONS

While the parent(s) or person being interviewed describes the events related to the pregnancy, birth, labor, and death of the infant or the fetal death, follow up questions should focus on systems-level issues, inquiring about challenges and barriers the family may have encountered.

This will allow FIMR teams to meet the goal of addressing community systems, including medical providers and hospital systems, that impact maternal, infant and child health.

Interviews typically last between one and three hours. Some interviewers schedule two sessions to build trust with the family and complete thorough interviews. Many successful interviewers seek participant permission to record the interview for accuracy, while others take notes during the interview.

Once the interview is complete, the interviewer should thank the participant(s). Some programs offer family members a memento of some kind to honor their child and as a thank you for participating in the interview. It is important that the item not be so valuable as to seem coercive.

Some commemorative items have included:



Candles



Framed prints



Stuffed animals



Modest gift cards to a local grocery store or retailer

Finally, provide a way for the family to give feedback on their experience in the interview. A link to an anonymous evaluation survey is an easy way to solicit input on the interview process and improve it.



Example of focused follow up to parent/guardian interview questions:

If a prenatal record indicates or a bereaved mother shares that she missed several prenatal visits, ask if something made it difficult for her to make it to the appointments or discouraged her from it. While the record may indicate that she simply skipped appointments or was non-compliant, there may have been significant barriers (like loss of pay or potential job loss) that made going difficult. Common reasons women miss appointments include lack of trust for their provider, poor treatment by the provider, fear of disclosure of domestic violence in the home, lack of affordable transportation, or lack of childcare for other children. These are all things that can be addressed at the systems level through effective recommendations.



Data from Parental/Family Interviews

The parental interview contextualizes all the other data that has been abstracted from various records that the FMR teams will examine. While records may have rich information about the family's experience, the parental interview is the primary source for several data collection priorities for FIMR. Information from the parental interview can inform specific questions throughout the [FIMR Report Form \(https://bit.ly/3e6DUIS\)](https://bit.ly/3e6DUIS).



It is helpful for **as much of the case report to be filled out** from available records before to the interview so that interviewers can go in knowing what information is missing and ask these questions in the interview.

Communities that create an interview outline or script may use the FIMR Report Form as a starting place to craft these documents to ensure that the important questions its poses are effectively addressed in the interview.

The following sections rely either solely or significantly on information from the interview:

Section A5: FIMR Parental Interview

This section collects information on the parent's state of mind before and during the pregnancy; their perceptions of the support around them; whether the family had a safe sleep space available; whether the parent or baby ever experienced discrimination in the healthcare context; as well as adverse experiences the parent may have encountered as a child.

Section I7: Life Stressors

The *Life Stressors* section seeks to identify social and economic experiences that the baby or the family may have experienced, including racism, employment or job problems, food or housing insecurity, another pregnancy or pregnancy scare, and witnessed violence.

Section O2: FIMR Issues Summary—Present and Contributing Factors

The *FIMR Issues Summary* provides a discussion and deliberation tool to help teams with case findings, pulling out items that contributed to individual cases or things that were present in cases that may have affected the level of risk or opportunity. When an item is present across multiple aggregated cases, it can be an important intervention point, even if it did not directly contribute to a specific death.

Many of the items in this section can be determined from available case records, but some are best addressed in the interview context. Examples of these types of data points include whether the pregnancy was intended, unintended, or wanted; whether the parent felt supported by family and the community; insight into the provider/patient experience; whether either parent had spent time in prison, or on parole or probation; whether the family had other children with special needs; and whether the family received grief support after the death.

Key Considerations for Interviewers

The Interviewer

The most important aspect of the interviewer's job is to use active listening skills and to respond to the parent's story compassionately, without judgment.

Program leadership should think carefully about who the interviewer will be. The ideal candidate will have a kind, welcoming demeanor and not be afraid of sad or challenging stories. In addition to being comfortable with stories of fetal and infant death, the interviewer should be comfortable and familiar with the communities that bear the disproportionate burden of infant mortality within the catchment area for the FIMR team. Ideally, the interviewer is a member of this community or reflects the community's demographics as well.

Even if the interviewer does not have experience with fatality review or personal interviews related to somber topics, a background in motivational interviewing would be very valuable in an interviewer.

Common professionals who conduct interviews include:

- Public health nurses
- Community health workers
- Social workers
- Home visitors
- Doulas

Often, programs contract with a part-time interviewer from another maternal child health program. Working knowledge of pregnancy, labor and delivery, and infant care is very helpful in the interview context. The interviewer should also be well-versed in the breadth of available culturally relevant and specific programs and resources for families in the community, what resources different agencies provide, and how to refer clients to these agencies and procure resources for them.

When training and onboarding a new interviewer, ensure that they have time to become intimately familiar with the content of the interview script, outline, or other interview content guide so they can collect comprehensive information without relying on those resources in the interview. When possible, FIMR program leadership should make every attempt possible to match the interviewer with the race of the family/infant. This is a particularly sensitive time when mistrust may be heightened. Consequently, the family may be uncomfortable sharing their experience with someone outside of their racial, ethnic or cultural group. When summarizing the interview, the parent's own words should be honored. Care needs to be taken that the interviewer does not document the information or present it to the review team through a specific lens (popular narrative, racist and/or biased connotations, heteronormative, etc.).

Confidentiality

A paramount concern related to the request for the interview, the interview itself, and any notes or recordings taken in the interview is confidentiality. While this is a broad consideration across the entire FIMR process, when it comes to the interview, great care should be given to ensuring anonymity and confidentiality for the parents/families, their story, and the story of their child.



To do this:

- Ensure all letters sent to the parent do not identify the FIMR program from the outside or indicate the reason for the letter.
- If recording on a device, ensure that it is protected when being transported or downloaded.
- If the interview recording must be sent as a digital file, ensure that it is sent and stored securely until it can be deleted. Consider encryption or secure file-sharing platforms.
- Do not name the recording in a way a participant could be identified. Consider using a case number instead.
- Only listen to the recording in places where others cannot hear.
- Delete the recording or shred interview notes after summarizing the interview for the FIMR case summary.

Cultural Humility

The interviewer must stay open, curious, and nonjudgmental about cultural aspects of family's lives with which they are unfamiliar. Even when a family's choices may seem confusing or risky, it is essential to withhold judgment. Family choices are often limited by factors outside their control or dictated by cultural traditions or deeply held beliefs.



Similarly, home environments vary significantly. Therefore, it is incumbent on the interviewer to maintain an open-minded demeanor and withhold judgment of different homes and environments. While interviewers cannot know every detail of every family's culture, there are ways to ensure that families' homes, cultures, and traditions are respected.

1

Do the homework. Do available records indicate that the family speaks a different language? Use available resources from the health department or hospital to support the translation of materials and interview if needed. Do records indicate other types of cultural differences the family may have had? Dig into available records and read up!

2

Check with the parents to confirm if it is culturally appropriate to use the infant's name after death; this is considered taboo in some cultures. Consider asking, "How would you like me to refer to your baby?"

3

Ask parents if there are any special traditions, practices, or rituals they used in pregnancy, labor, birth, with their baby, or at/after the time of death.

4

Remember that people's choices are limited by their options and informed by their culture. If families used a nontraditional, unsafe sleep space, for instance, it might have been because they did not have a safer option or because it is within their cultural practices and priorities.

Referrals

Finally, the interview provides an important intervention point for families who are in grief and have experienced trauma. Often, the families have previously experienced economic or housing instability, increasing risk for infant mortality. Once an interviewer is engaging with the parent(s), it is an opportunity to refer them to needed resources, such as:



Bereavement services



Family planning



Well-woman care



Medicaid



Housing assistance



Employment assistance



Mental health services



Genetic evaluation or counseling



Supplemental Nutrition Assistance Program (SNAP)



WIC, if there are other young children in the home

The interviewer needs to be up to date on changes to services and resource in the community to connect families effectively.



Resources for FIMR Parental Interviews

There are many rich resources related to FIMR parental interviews outside the scope of this manual. They will be helpful when creating a position description for an interviewer, in the training and onboarding process, and as reference material.

For the purposes of the program manual, the primary resources are highlighted below:

1

[Parental Interview Guidance: National Center Guidance Report](https://bit.ly/3etfkCz)
(URL: <https://bit.ly/3etfkCz>)

The Parental Interview Guidance is a process guide for programs and for interviewers that takes a more in-depth examination of this topic than the current chapter, including community benefits and benefits to bereaved families, sample scripts for contacting families, common challenges, alternative methods, and an extensive appendix of resources for interviewers. The resources include, but are not limited to, sample materials, letter of consent, position description, and bereavement resources.

2

Training Modules:

The National Center has created a series of video training modules to support fatality review activities.

The following modules would be especially helpful for interviewers:

- [Maternal Interviews](https://bit.ly/2W5wMUz) (URL: <https://bit.ly/2W5wMUz>)

This module is co-led by the national FIMR director and a local team interviewer from Detroit, Michigan. It addresses diverse aspects of the interview process, when it may not be appropriate to conduct an interview, the role of mandated reporters, and effective timing for making contact with families among other helpful topics.

- [Working with Grieving Families](https://bit.ly/2VuXB6R) (URL: <https://bit.ly/2VuXB6R>)

This module was intended for both FIMR and child death review (CDR) teams and provides a broad overview of the burdens of leading causes of death nationally. It also covers factors affecting the grief experience, psychological theories related to mourning, and key considerations when working with bereaved families, including ways to express relational condolences.

3

Webinars:

The National Center has produced several educational webinars that are relevant to the interview process, including:

- The Benefits of Parental/Family Interviews in the FIMR Process: The Power of Stories.
- Bereavement Support for Families and Professionals.
- Recognizing and Responding to Vicarious Trauma in Fatality Review.

Note:

All of the webinars are [archived on the NCFRP website](https://bit.ly/3i6dLvd) (URL: <https://bit.ly/3i6dLvd>).



Endnotes

- 1 © 2021 Oxford University Press. Chandler, D. and Munday, R. A Dictionary of Media and Communication.

Chapter Six: Core Concepts

Operationalizing a FIMR Program

Introduction

The previous chapters focused on building community support and collaboration for FIMR. A typical FIMR may take between six to eight months to fully develop all the programmatic components of a successful FIMR.

This chapter describes the important aspects of building the FIMR Case Review Team (CRT) and Community Action Team (CAT).

TWO-TIERED PROCESS

From the very beginning of FIMR, the model included a community-based two-tiered process with separate groups to review and analyze deaths and another to develop prevention actions.



The Role of the Case Review Team (CRT)

The FIMR CRT reviews and analyzes de-identified cases of infant deaths in the community. Data is obtained through interviews with the parent(s) and family and clinical and service records, including medical records, Special Supplemental Nutrition Program for Women, Infants and Children (WIC), social service agencies, and birth and death certificates. The purpose of the review is to understand and identify those factors that contributed to the death, plan interventions to address the risks, and prevent deaths in the future. Additionally, the racial disparities in fetal and infant deaths require incorporating an analysis that unpacks, examines, and provides a more expansive understanding of the root causes of these deaths. This type of analysis will illuminate the underpinnings of the Social Determinants of Health (SDoH) and provide a more effective pathway to racial and health equity.

Membership

Fatality review teams use a process that, if followed, helps complete thorough reviews that address the service and systems issues surrounding fetal and infant deaths. Choosing the right mix of individuals to serve on both the CRT and the CAT is crucial to the success of the program, particularly as it aims to advance racial and health equity.

Guiding Principles

The guiding principles for fatality review team membership include:

1

Diversity/Equity/Inclusion (DEI): CRT membership should first and foremost incorporate the concepts of Diversity, Equity, and Inclusion, or DEI. **Diversity in the composition of teams and organizations means that non-dominant or historically less privileged individuals are represented.** Teams in formation need to seek a wide array of personal and professional knowledge, expertise, and experience while representing the community's racial, ethnic, and cultural makeup. Diversity of identity may relate to socialized and visible race, gender identity, religion, nationality, body shape or size, age, or sexual orientation, to name a few. Diversity in the community may incorporate a creative range of organizations, including some who may not have been included in traditional maternal and child health consortia.

Equity, as defined by the World Health Organization, is “the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically.”¹ **To maintain equity in the CRT membership, teams need to acknowledge that everyone has different needs, experiences, and opportunities.** People from groups that have been disadvantaged and without power often have more barriers to overcome when accessing resources and opportunities than those from dominant or more privileged groups. Including members from comparable backgrounds will help the team identify and address or disrupt barriers and inequities and help to elevate communities on the margins to an equitable playing field.

The **racial demographics** of the community should be represented in the membership of review and prevention teams.

Inclusion is more about making sure that all CRT members are valued. It has been said that *diversity* is an invitation to a party, whereas *inclusion* is being asked to dance.² A CRT that values inclusion will ensure that in meetings, the voices and opinions of all members are solicited, respected, and appreciated equally.



2

Influence: Members with influence include policymakers, institutional and professional leaders, and/or organizational spokespersons who have the power to make decisions and mobilize fiscal and programmatic resources on behalf of their agency or organization.

3

Commitment: Choose team members with a proven track record of putting what is good for parents, infants, children, and families before what is expected or convenient for their organizations or professional interest. Champions of health equity make the best team members.

4

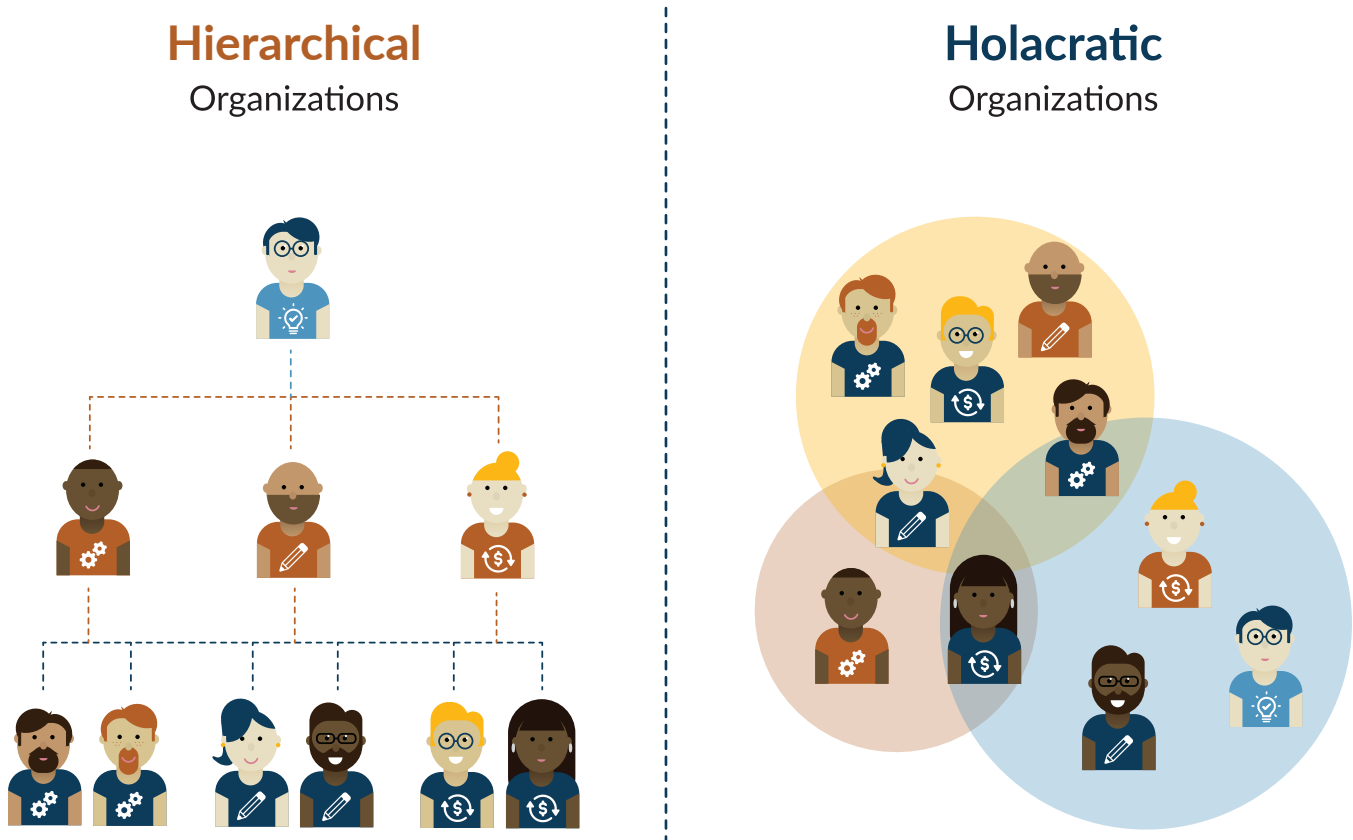
Experience: It is important to include individuals who understand, respect, and honor the community in addition to experience serving the community, familiarity with community agencies, and an understanding of clinical care. The CRT should benefit from a clear understanding of the community's resources and how they are navigated and delivered. The expertise of certain professionals who provide services and healthcare is also necessary. Additionally, involving persons with lived experience is another asset to include on CRT membership. Centering persons who are users or potential users of care and services in the community are critical to unpacking the multiple systemic and structural elements contributing to disparities. They will offer the most authentic insight into their realities and enable the process to achieve the best results and direction for community and institutional change.

The size of an average CRT varies, but typically 12-25 members allow for broad participation in professional, organizational, and personal composition. If teams are too small, the elements of DEI may be challenging to obtain. If teams are too large, the group dynamics may become unwieldy and undermine the opportunity for inclusion.

CRT Leadership

In a DEI framework, leadership is not considered a hierarchical power structure or bureaucracy. Each team member has equal value and presence, regardless of professional position. Like most traditional organizations, fatality review teams have structure and roles assigned to positions. Fatality review team coordinators and directors recruit members, facilitate meetings, and oversee the operations of the panels, among other responsibilities. These are important roles that cannot be replaced, and it is important that coordinators lead with vigilance for achieving health equity, integrity, building agency, and sharing power with team members. Leaders should adopt a collaborative facilitation style, making sure every voice has an opportunity to be heard and is valued equally. Holacracy takes powers traditionally reserved for executives and managers and spreads them across all team members. This may require the coordinator to intentionally hold or modulate their own opinions in the interest of collaborative consensus. The following diagram helps to illustrate the principles of a non-hierarchical approach for review teams' structure and leadership.

Figure 5. *Hierarchical vs. Holacratic Organizations*





Coordinators should consider how to facilitate in a way that helps the team avoid making assumptions that are typically grounded in existing racialized narratives. When team assumptions do not consider historical and contemporary social determinants of health or racial equity, there is the risk of fewer effective recommendations being passed along to the Community Action Team.

LEADERS OF FATALITY REVIEW

Leaders of fatality review teams should operate as a spokesperson to the team, with full transparency of their position and bias, while meaningfully addressing the social determinants of health through their leadership.

The leader's voice should never be the filter through which all recommendations flow. However, the leader's voice should portray a commitment to an approach that makes visible the often-nuanced institutional practices and messages that, in effect, perpetuate racialized outcomes. Effective, candid, and trusting communication between team members encourages systemic change and internal accountability, building a leadership pipeline.

Orientation

Team charter and ground rules:

When establishing a new CRT or recruiting new members to an existing CRT, every new member should receive orientation or onboarding. It takes time for the individuals on the team to develop a process by which they can work together. Careful planning on the part of the team leader or facilitator can ensure that the team members will feel comfortable with the FIMR process, its aims, and one another.

SKILLED LEADERS

A skilled team leader will strike a balance between creating a comfortable atmosphere for team members to voice their opinions and engage in constructive discussions while keeping the process moving so that the team does not get bogged down in non-essential issues and lose sight of the fundamental contributors of health inequity.

Teams have found it valuable to establish ground rules or a **team charter** to guide the operations of the CRT. A team charter will succinctly spell out the expectations of both the sponsoring agency and the expectations of the volunteer members. A sample team charter can be found in the template package, [Appendix A](#).

An introduction to health equity should be an essential component of new team member orientation. Reading or viewing materials on social determinants of health, including historical and contemporized racism and internal bias, will give new members language with which to enter into discussion with team members. They need not be experts on racial equity yet, but acknowledging their own bias and understanding the basic tenets of the social determinants of health are sufficient for the first few months of participation in lieu of in-depth training. However, new members must commit to being “anti-racist” and further development of their capacity to function within a racial equity framework. An extensive set of resources for training and onboarding team members with social determinants of health inequities and racial equity can be found in the [guidance document: Improving Racial Equity in Fatality Review](#) (URL: <https://bit.ly/2WwdGpS>).

Orientation meeting:

It is wise to devote the first CRT meeting entirely to an orientation that includes an introduction to employing an analytical frame that systematically unpacks the root causes of fetal and infant mortality when establishing a new team. Alternately, a special meeting can be convened outside the regularly scheduled CRT meeting to orient new members. Ideally, all new members will attend together.

Activities for this meeting should include the following:

- Create and distribute a packet of information to each team member. This should include a brief description of the FIMR program, FIMR staff and CRT rosters, a CAT roster, program mission statement, sample case summaries and forms, a community resource guide if available, and a glossary of technical terms (see the template package, [Appendix A](#)). Resources should incorporate valuable articles and other literature, including articles discussing obstetric racism.³ These materials can be presented to each member in a binder to which additional information can be added over time.
- Have individuals introduce themselves and share personal and professional backgrounds and current positions, roles, responsibilities, and relevant community involvement or service.
- Place tented name cards on the table beforehand to help distribute members around the table and allow members to link names and faces more quickly during the meeting. Leaving titles off name cards and addressing all members in the same way, without honorifics, is one way to build a sense of inclusion among team members. For example, first names may be universally used, versus titles such as “Dr. Johnson” for a physician member and “Alice” for a nurse on the team. It is helpful for the name cards also to identify the members’ home agency or organization.
- Review the need for absolute confidentiality and anonymity. Some teams incorporate a statement of confidentiality into the sign-in document for every meeting (see sample in the template package, [Appendix A](#)).
- Review the specific objectives for FIMR case reviews, including systems-level solutions and prevention, and describe how the review team will carry them out.
- Share with the members how case information is collected and summarized. If the team uses the National Fatality Review-Case Reporting System, share a print copy of the Report Form.
- Review the role of the CRT in developing *global* recommendations focused on improving systems versus slipping into individual case management.
- Outline the relationship of the CRT to the CAT, the process for sending the CRT’s annual recommendations to the CAT, and subsequent community and institutional action.

Note:

A sample agenda for a CRT meeting orientation can be found in the template package, [Appendix A](#).



Conducting Subsequent Review Meetings

The job of the CRT is to be the information processor of the FIMR program. The team reviews and analyzes all the information collected from the interviews and records abstractions in such a way as to apply a racial equity lens in the overall process. The CRT will summarize findings and create recommendations to improve the community's service delivery systems, including hospital systems and resources.

FIMR staff will coordinate and schedule all the meetings of the Case Review Team and prepare the summary of the cases. Creating the case summary is one of the more time-consuming tasks for FIMR staff. [Chapter Four: Abstracting Medical and Service Records](#) also includes a description of how to create the de-identified case summary. Summaries of 3-5 cases that include information from birth and death certificates, autopsy reports, hospital records, outpatient records, related social services records, and the parental/family interview, if available, are prepared by FIMR staff before the meeting. The National Center has a FIMR Case Summary that auto-generates once a case has been abstracted and put into the NFR-CRS. For programs not participating in the NFR-CRS, a two to five-page case summary is typical. The format for the case summaries may vary from program to program. Still, teams have found that using a case summary as opposed to actual medical records is essential to the FIMR process because it allows the program to de-identify and condense the information.

An effective case summary includes the following information, if available:

- The parent/family's experiences leading up to the fetal or infant death, including the time of conception, the pregnancy, and birthing experience. The reader should understand whether the situation was stressful or stable, whether the living conditions were adequate, and whether the family seemed overwhelmed.
- What happened from the family's standpoint, from the medical providers' perspectives, and the perspective of other agencies.
- Detailed medical information (blood gases, periodic vital signs, daily assessments, etc.) generally is not needed in the summary, except on the occasions when it directly relates to a systems problem presented in the case. If the FIMR records abstractor does not have a clinical background, the program should provide guidance to the abstractor about how to identify what medical information is most relevant to outcomes in different types of fatality cases.
- Information from the family may include both issues pertaining to medical/provider systems issues such as those that may be characterized as obstetric racism as well as non-medical system issues; neither should be overlooked.
- Services or community resources the family was known to have received or not received. If the family had an obvious need for services, were referrals made? If referrals were made, was there follow-up, and if not, why not? Were there specific reasons that explained why the family did not receive services? (This is important to ask during the family interview.)
- Any events since the loss that are relevant to the case, such as subsequent pregnancies, changes in the family, resolution of problems identified in the case, etc.

Many FIMR teams have chosen to mail or email the **de-identified** case summaries to the team members one week before the meeting to allow members time to read the cases beforehand and be familiar with the issues they want to raise during the case discussion.

If the summaries are paper copies, the envelope that contains the documents, as well as each page of the summaries, should be marked “confidential.” Members should be reminded not to make copies of the summaries. If the summaries are mailed electronically, it is recommended that an encrypted email system is used, and the email should be and formatted so that it may not be forwarded to anyone else. The team members should also be instructed not to share the downloaded email document with anyone else, and the document itself should be marked “confidential.” Some FIMR programs upload cases to a secure site such as SharePoint or Google Docs, using a password to protect and control who has access to the documents.



At the end of the meeting, all paper copies of the cases and case summaries reviewed should be collected from team members and shredded by FIMR staff. Immediately after the meeting, any emailed cases should be retracted and deleted by FIMR staff or deleted by team member recipients.

The FIMR coordinator or program director usually presents each case summary for discussion at the first few meetings. As team members become more comfortable with the process, responsibility for presenting cases may rotate among CRT members, with assignments being made in advance. As the summary is being presented orally by a team member, the CRT may listen and can refer to the somewhat longer written summaries. Seasoned FIMR teams have shared that over time, it is not necessary to orally “read” or present each case, but having a team member bring out highlights of the case leads to rich discussion or the factors that were present and contributed to the deaths.

For the purposes of the program manual, the primary resources are highlighted below:

1

Recognition of Sentinel Events:

Sentinel events are defined as clear warning signals that the quality of services needs to be improved. They include those cases that in themselves exemplify a problem or situation contributing to infant mortality. Sentinel events are outside of the norm of what is expected as “best practices” and standards of care in service delivery. In reviewing cases with sentinel events, it will be clear that swift and immediate action is warranted!

2

Trends:

Over the course of time, several cases will illustrate similar problems or situations. Trends over time, taken together, may be a very compelling way to illustrate a problem.

3

Incidental Findings:

Incidental findings are often discovered as part of the FIMR process, gaps in care or services that may not be directly related to the cause of death (such as lack of bereavement services). Incidental findings may include those aspects of a case that the team did not necessarily set out to discover but are issues that warrant action.



What FIMR programs do not accomplish:

- They are not conducting case reviews to determine individual causes of death or to categorize the deaths.
- FIMRs do not attempt to assess individual preventability; that is often speculative, or critical information is lacking or inconsistent.
- They are not fault-finding, nor do they assign blame for the death. Blame cannot be determined with the subsets of information that FIMR abstracts, nor should it be attempted. Comprehensive local and state professional peer review and institutional QA programs already exist to respond to this issue.
- FIMRs do not conduct research on the causes of infant death. Rather, they are tracking the racial, social, economic, and systems factors associated with death for improving the care and resources available to families in their specific community.

Findings and Recommendations: A Guide to Team Deliberation

A FIMR CRT has much to accomplish during each meeting. In a two-hour meeting, 3-5 cases will be reviewed on average. Teams may spend 30-40 minutes on each case, depending on the complexity of the issues and expertise of the members. Prolonged discussion about any one case may hinder getting the work done. The team leader should keep an eye on the clock and gently keep the team on track.

After reading the FIMR summary of a case, the team should discuss the following:

- What economic, health services systems, community resources, or personal factors helped this family?
- Did the family receive the services and resources they needed?
- Was the quality of medical care and services acceptable?
- Were the systems and services culturally and linguistically acceptable to the family?
- What quality of care, gaps in care, or duplication of services systems are apparent or suggested by this case?
- Is it possible to design and implement more responsive medical and community resources or service delivery systems? How should they look?
- Does this case tell us anything about how families can access existing local services and resources?



The discussion of these key questions will, in turn, lead the team to develop a list of all possible issues related to the case. Many teams find it helpful to use a tool to guide case deliberations.

Section O of the NFR-CRS is meant to be used primarily for local teams to identify gaps in services and needs for improvement in the quality of care.

Teams identify issues present in each case, and issues 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. **Once teams have identified gaps or areas of improvement in the quality of service delivery systems, they are ready to create their findings.** Various team deliberation tools exist, and the template package, [Appendix A](#) includes several samples that CRTs have adopted. At a minimum, the team needs to identify where improved linkages, changes, and improvements in care and services are indicated. The following grid may be a mechanism for guiding teams to consider all the areas for initial recommendations and eventual action:

Figure 6. Example of a mechanism for guiding teams to consider all the areas for initial recommendations and eventual action

Service	Significant Issues	Proposed CRT Actions	Medical Systems Actions	Community Actions
Preconception				
Prenatal				
Labor & Delivery				
Postpartum				
Newborn Care				
Infant Health				
Bereavement				

The heart of the FIMR process is a careful, thorough study of every case by the CRT to determine the adequacy and quality of local systems of care and community resources for parents, infants, and families and to make recommendations for their improvement. Preliminary discussion of recommendations occurs at each case review session; however, the team may not finalize them until several months or a year of reviews has occurred. The team should be encouraged to think creatively and systemically and not be dissuaded totally by feasibility.

In making recommendations, the team should ask one another:

- What can be done at the systems or agency level to improve the quality and reduce risk in cases like this?
- Do we need to design more responsive service systems, referral systems, or systems to identify clients/patients at risk?
- Were there issues related to historical and contemporary racism, stereotyping, or bias observed in this case?



After reviewing their data and findings, the CRT must identify the significant trends recognized through the reviews that require systemic change and prioritize the most important ones as recommendations to be transmitted to the CAT.

The FIMR coordinator usually provides a brief update on the reviews at the CAT quarterly or semiannual meetings. This update usually includes information about the process, the number of meetings held in the period, the number of cases reviewed by age at death (fetal, neonatal, postneonatal), and trends in findings. Often, the CRT recommendations are only forwarded to the CAT on an annual basis. Refining and overseeing the implementation of recommendations is the job of the CAT and will be discussed in the next section.

Maintaining Case Integrity and Confidentiality, Protecting Families and Providers

FIMR involves medical, nursing, and social services review as well as all the systems of care involved in the case. At each meeting, before the case review, make a practice of telling the team that if any of them think they were providers for the patient, or know who the providers for the case were, not to identify themselves, others, or the institution. Emphasize that if they know other information about the case that has not been presented, or if it has been presented incorrectly, not to identify themselves or give out the additional information, but to contact the FIMR coordinator separately after the case review. If requested, the FIMR coordinator can inform the team that the case will be re-abstracted for clarification or correct representation. However, the case can only include information found in the medical records, not anecdotal information from team members which is not in the chart.

Most FIMR programs ask their information abstractor and home interviewer to sit in on all meetings and be prepared to answer occasional questions that may arise about information abstracted or obtained in the home interview but not necessarily included in the case summary. For example, a medical provider might ask, "Was a repeat sonogram done?" or a public health official may ask, "Was a follow-up home visit made?" The best way to handle these questions is to anticipate them and include the information in the original case summary. The abstractor may know the answer from their memory of the case. To be prepared to answer such questions, FIMR staff are encouraged to have the complete copy of the abstracted records and the home interview at the review meeting (but stored in a locked file) so that they can refer to it if necessary. When called upon to supply additional information, FIMR staff must be very mindful of the need to maintain the confidentiality of all concerned, both providers and families, as they convey additional information. These requests for the team tend to diminish over time as the abstractor becomes more familiar with the information that the team would like to see and begins to include it in the case summary.

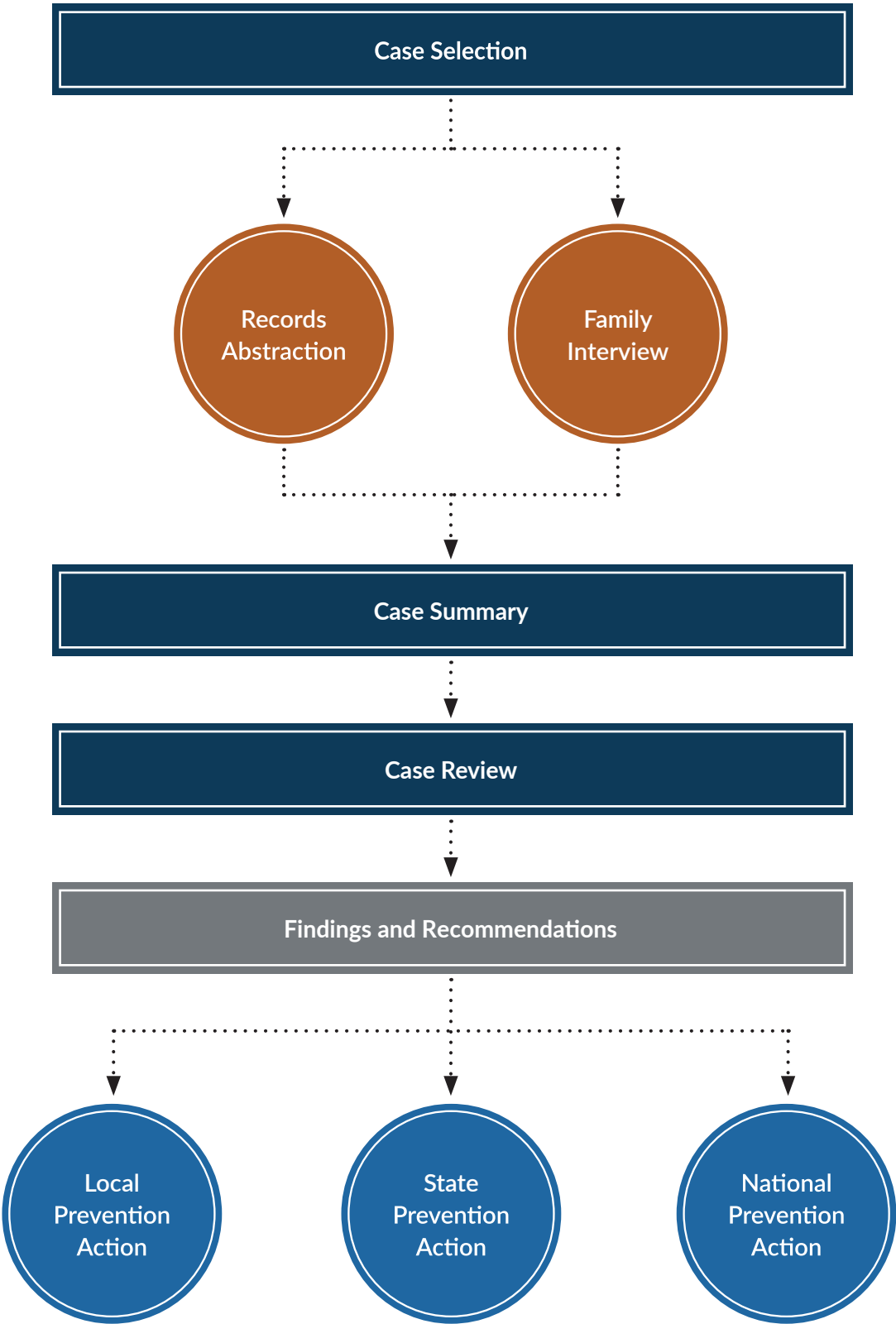
The Role of the Community Action Team (CAT)

There is great variety in the way CATs are constructed, but the ongoing role of the CAT is to:

- Develop new and creative solutions that are grounded in racial equity and centers families to improve services, quality of care, and resources for families from the recommendations made by the Case Review Team.
 - Enhance the credibility and visibility of issues, including those resulting from racial inequities, related to parents, infants, and families.
 - Inform the medical provider community and the broader community of the need for specific actions through presentations, media events, and written reports.
 - Work with the community and medical providers to implement interventions to improve services, resources, and quality of care.
 - Determine if the demographics and needs of the community are changing over time (periodically fed by the recent team finding of the CRT) and decide which interventions should be added or altered to meet them.
 - Safeguard successful systems changes initiated by FIMR that have been implemented from being discontinued in the future.
-

In the course of their work, the CAT may respond to issues that are broad or politically complex, that change over time, and that require substantial time and resources to implement change. The following diagram depicts that the relationships among the Case Review Team, the Community Action Team, and the community are meant to be dynamic and responsive to community issues or problems:

Figure 7. The FIMR Process



Membership

There is often quite a bit of crossover in FIMR programs; members of the CRT are also engaged and members of the CAT. In general, the CAT is composed of two types of members:

- Those who have the **political will and financial resources** to create and implement large scale systems change
- Those who can **define or communicate a community perspective** on how best to create those desired changes in the community

Successful FIMR programs across the country report that depending on the size and complexity of the community and its needs, an average CAT ranges from 15-35 members.

SKILLED LEADERS

More important than the size of the team is the composition. Recruiting and retaining the right members to the CAT can make the difference between a FIMR program that accomplishes a robust action agenda and one that struggles with prevention implementation.

The CAT does not necessarily have to be sponsored or led by the same organization or agency that administers the CRT. Health Departments, hospitals, and Federally Qualified Health Centers (FQHC) are typical agencies overseeing the CRT. The CAT may find its home in perinatal consortia, community coalitions, or universities. Some communities have taken an existing panel or task force and incorporated the functions of the CAT team into their activities. Examples may include adopting the Community Action Network (CAN) from the local Healthy Start as the CAT. Perinatal Quality Improvement Collaboratives, SUID prevention coalitions, Healthy Mothers Healthy Babies Coalitions, home visiting advisory boards, and other existing community collaborative bodies are common partners for the FIMR CAT.

As with the membership for the CRT, the guiding principles of CAT membership should first and foremost incorporate the concepts of Diversity, Equity, and Inclusion, or DEI, and implement the process within a racial equity framework.





While not an inclusive list, these are suggested community members that FIMR teams have found to be helpful CAT members



KEY COMMUNITY LEADERS

- Mayor
- County Executive
- Business Leaders (Chamber of Commerce)
- Civic, Social, or Fraternal Groups (Kiwanis, Jaycees)
- Law Enforcement
- Religious Leaders
- Educators



PUBLIC HEALTH

- City or County
- WIC
- MCH/Title V
- Family Planning
- Immunizations
- Medicaid
- Outreach Workers
- Home Visitors
- Medical Examiner



HUMAN SERVICE PROVIDERS

- Child Welfare
- Substance Abuse Services
- Mental Health Services
- Domestic Violence Shelters/Services
- Department of Corrections
- Housing Authority/Tenants Rights Groups
- Transportation Authority



HEALTH CARE PROVIDERS

- OB/GYN/Nurse-Midwives
- Maternal-Fetal Medicine
- Home Visiting Staff
- Pediatrician
- Emergency Medicine
- Family Practice
- Nursing (OB/PEDS, L&D)
- Social Workers
- Dieticians/Nutritionists
- Discharge Planners
- Hospital Administrators
- HMO/Managed Care Rep.
- Childbirth Educators/
Lactation Consultant
- State/County
Medical Society
- EMS Personnel
- Dentist/Dental Technician
- Midwives/Doulas



CONSUMER/ADVOCACY GROUPS

- March of Dimes
- Healthy Mothers/
Healthy Babies
- MCH Coalitions
- Perinatal Infant
Grief Professionals
- Consumer Representative,
Bereaved Family Member
- Family Support Groups
- Racial & Ethnic Consumer/
Advocacy Groups
- Women's Rights Groups
- Union/Workers
Rights Groups



Tips for recruiting members:

- Members can recruit members!
 - Use their interagency influence and connections to recruit other potential partners
 - Tap the informal power of personal friendships among agency leaders in building support for FIMR
 - Contact community leaders for suggestions or recommendations
 - Retirees make great recruits
-

CAT Orientation

Experienced FIMR programs have found that it is imperative to devote a staff person to coordinate the CAT, to set the tone for overall community collaboration, and ensure that the actions and recommendations are effectively implemented. With dedicated personnel, FIMR CATs can make meaningful changes in systems and improvements in the quality of care, services, and resources available to parents, infants, and families. This staff person is not necessarily the chair of the CAT. The chair may be the director of the FIMR lead agency or another individual. Ideally, a chair should be chosen who is knowledgeable about and skilled in dealing with diverse groups, grounded in racial and health equity, non-partisan, and well respected by all as a community leader. As with the leadership of the CRT, the chair of the CAT should be committed to leading with a racial equity framework.

Leading for racial and health equity and committing to an action agenda means that the FIMR CAT chair encourages the team to grow continually, reflect, and keep laser-focused on improving MCH outcomes as reflected in the data. The stagnation of fetal and infant death rates and widening in deaths of infants of color signifies there is more systems work to be done after the review process.

Members of a new CAT or new members introduced to an existing CAT will need time to become acquainted with the FIMR goals and objectives, to become familiar with their role and responsibilities, and to become comfortable with one another. The first team meeting usually occurs three or four months after the first CRT meeting and should be devoted solely to orientation.

Activities for this meeting are somewhat like the CRT orientation meeting and should include the following:

- Establishing an approach and processes grounded in racial and health equity, including examining the structures and systems that form the foundation of health disparities.
- Create and distribute a packet of information to each team member. This should include a brief description of the FIMR program, program mission statement, FIMR staff, and CRT rosters, a CAT roster, useful articles, and other literature on fetal and infant mortality, a community resource guide if available, and a compilation of services and resources in the community that are available to pregnant and childbearing persons, caregivers, and families. These materials can be presented to each member in a binder to which additional information can be added over time. Some FIMR programs also include a snapshot of the communities' overall fetal and infant mortality using existing vital statistics or other population data to define the problem's scope clearly. The packet needs to include information about the relationship of health disparities and inequities to SDoH, including racism.
- Have team members introduce themselves individually, telling their personal and professional backgrounds and current positions.
- Placing tented name cards on the table beforehand will help distribute members around the table and allow members to link names and faces more quickly during the meeting. Leaving titles or honorifics off of the name cards allows all members to be addressed in the same manner, reducing the appearance of rank or importance of certain members over others. For example, first names may be universally used, versus titles such as "Dr. Johnson" for a physician member and "Alice" for a nurse on the team.
- Review the specific objectives for FIMR and describe how the CAT will carry them out within a racial equity framework.
- Describe how the CRT develops the case findings and how the CAT develops action plans based on these findings and the implementation of the actions aimed towards changes in the systems that serve families.

Subsequent CAT Meetings

Regularly, the CAT will continue to meet and receive the formal CRT summary of the findings and recommendations of the cases reviewed. The community may play a role in deciding how frequently the CAT will meet. For a very large urban area that is reviewing multiple cases per meeting, a CAT may decide to meet monthly. For smaller FIMR programs with fewer cases and less frequent findings, a quarterly CAT meeting may be sufficient. In general, a CAT will begin to prepare an action plan after receiving review findings over the previous 12 months. This is general guidance only. Some CATs will be moved to action immediately after hearing the results of the first several CRT meetings, especially if they identify solutions that could be readily implemented.

Translating Recommendations into Action

The CAT is responsible for ensuring that proposed recommendations are translated into local action within the context of health equity. The CAT must decide who will do what, when, and with what resources to improve quality, services, and resources for families.

Several action steps will help teams in creating their action plans:

- Develop a list of actions or interventions responsive to the issues. The CAT may have to take into consideration the limited number of resources in the community and limit the plan to a reasonable number of actions.
- Specify a person/agency that will be accountable for each action.
- Prioritize the actions as needed with a specific focus on those that will impact racial and health equity.
- Formulate a simple work plan for achieving the actions recognizing that some will be a heavier lift than others.



A community Action Work Sheet or other similar tools will help teams to document and track progress on activities. Teams have adopted tools such as the one below:

Figure 8. Community Action Work Sheet

Action Steps	Person/Agency Responsible	Timeline	Resources	Status of Proposed Action
1.				
2.				
3.				
4.				
5.				

Greater detail on translating FIMR findings into action is covered in Chapter 7. A 40-minute [online training module on Translating FIMR Findings into Action](https://bit.ly/36l6xxK) (URL: <https://bit.ly/36l6xxK>) is available on the National Center’s website.

Characteristics of Effective FIMR CATs

FIMR evaluation findings⁴ indicated that the two-tiered structure for FIMR enhanced program effectiveness in several important ways. FIMRs with CAT teams were more likely than those with a one-tier system to report implemented actions in the following ten topic areas:



Prenatal care



Substance use disorder



Sudden Unexpected Infant Death (SUID)



Smoking



Infections during pregnancy



Domestic violence



Monitoring of maternal complications



Family strengths



Low birth weight



Multiple pregnancies

FIMRs with a two-tiered structure reported carrying out more activities associated with five of the essential MCH Title V services, including:

- Data assessment and analysis
- Policy development
- Partnerships and mobilization
- Public information and education
- Quality assurance and improvement

In general, FIMRs with a two-tiered structure address a greater number of perinatal health issues. FIMR programs and their CATs that have functioned successfully over multiple years have many of these characteristics in common:

1

They address a wide range of community actions. Rather than choose a single focal issue for action, longstanding FIMR programs can point to a wide array of issues they have identified and a comparable range of activities they have accomplished.

2

They are flexible. They can develop an action agenda on many different fronts simultaneously and can enact plans that change over time, as well.

3

They view improving services and resources as a continuing journey. Long-lasting FIMR programs have come to embrace the fact that improving service systems and community resources for parents, infants, and families is not a one-time job. Rather than becoming discouraged that a problem identified cannot be addressed fully in one stroke, these programs realize that the most meaningful change frequently occurs a bit at a time. FIMR actions accomplished in one year often become the basis for building enhanced improvements down the road. A new FIMR action may advance and expand the previous actions.

WHAT IS KAIZEN?

Kaizen is a Japanese term meaning “change for the better” or “continuous improvement.” Kaizen is a principle that embraces a journey of change, not a race to a finish line. Although FIMR programs sometimes make a quantum leap in improving service systems, many FIMR actions come from slow, steady progress. Much is accomplished a step at a time.

Maintaining the Momentum

These final tips and strategies apply to the building, maintaining, and sustaining both the CRT and CAT membership and functions. Consider the team's needs and availability when scheduling meetings. The day, time, and location can make a big difference.

1

Day of the Week:

Give team members a voice by sending out a Doodle poll or similar survey to identify ongoing conflicts with other obligations.

2

Time of Meetings:

- Early AM works for busy physicians, allowing them to attend hospital rounds then attend CRT meeting.
 - Lunchtime is sometimes successful. Even busy clinicians need to take time out to eat. "Brown Bag" lunch or provide refreshments.
 - Late afternoon or early evening can work for some. A 4 pm to 6 pm meeting allows participants to put in a full workday and then attend the meeting.
-

3

Location:

To cut down on the length of time participants must travel to and from other jobs and work obligations, consider where your team will meet. Hold meetings at the FQHC if there are several participants from that organization. The local health department, hospital cafeteria side room, library, city hall, or department of human services are all options that have worked well for FIMRs.

4

Virtual Meetings:

Fatality review teams may have to consider converting in-person fatality review team meetings to virtual meetings during times that warrant an innovative, responsive public health approach. A [guidance document on planning for Remote Fatality Reviews](https://bit.ly/3yHNWbE) (URL: <https://bit.ly/3yHNWbE>) is available.

5

Childcare:

Childcare may be needed for community members. A stipend may need to be provided for their engagement.

6

“Blitz” Reviews:

Some review teams meet less frequently and review a larger quantity of cases at a time to accommodate hectic schedules or rural areas with prohibitive travel restrictions.

7

Feed People:

If possible, offer light refreshments or a modest meal when meeting over breakfast, lunch, or evenings. If the administrative agency does not have the financial resources to provide food, consider alternating the responsibility among participant agencies. It takes a bit of coordinating, but most agencies could spring for a meal once a year.

8

Lay Down Ground Rules and Stick To Them:

Value and respect all participants’ time, voice, and contributions to the FIMR process. (See a sample of a team charter in the template package, [Appendix A](#)).

9

Provide CEUs:

Consider providing physician and other professional CEUs for FIMR CRT meetings.

10

Celebrate Successes!

From time to time, take a break from review activity to host a social gathering and present a year’s worth of review findings and successful interventions driven by FIMR. Nothing keeps folks engaged more than the realization that they are making a big difference in the community. Consider these ways to celebrate milestones:

- Annual holiday party or summer break/celebration.
- Give awards or certificates of appreciation to longstanding members.
- Do quarterly newsletters featuring members in the “spotlight” to highlight FIMR findings and successes.



Endnotes

- 1 https://www.who.int/health-topics/health-equity#tab=tab_1.
- 2 <https://www.cultureamp.com/blog/how-to-define-diversity-equity-and-inclusion-at-work/>.
- 3 Davis DA. Obstetric Racism: The Racial Politics of Pregnancy, Labor, and Birthing. *Med Anthropol*. 2019 Oct;38(7):560-573. doi: 10.1080/01459740.2018.1549389. Epub 2018 Dec 6. PMID: 30521376.
- 4 Misra, D, et al, The Nationwide Evaluation of Fetal and Infant Mortality Review (FIMR) Programs: Development and Implementation of Recommendations and Conduct of Essential Maternal and Child Health Services by FIMR Programs, *Maternal and Child Health Journal*, Vol. 8, No. 4, December 2004.

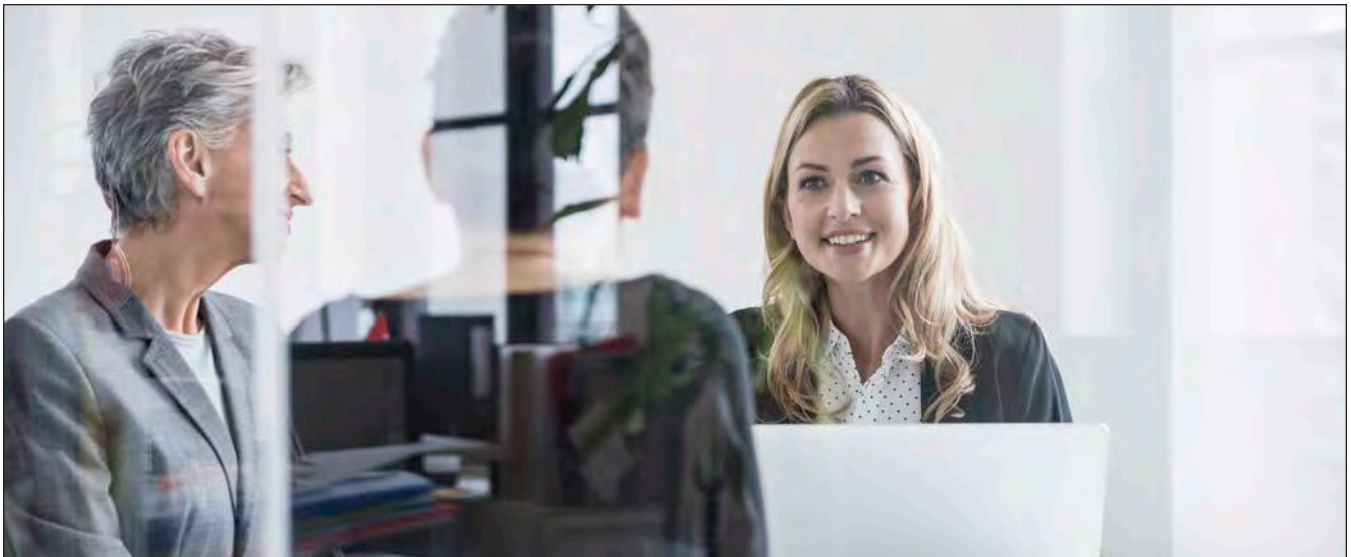
Chapter Seven: Translating FIMR Findings into Action

Introduction

FIMR's purpose is to learn about fetal and infant deaths through family interviews and available service records to improve medical and community systems and prevent similar deaths in the future. The FIMR staff and the CRT will spend much of their time finding records, abstracting them, locating parents, conducting interviews, scheduling meetings, engaging partners, summarizing and presenting cases, and ultimately, reviewing them together. **However, all those things are done with the goal of community action to improve systems that serve parents, pregnancies, and infants.** It may seem that improving health equity, the community, and implementing changes in multiple systems are the responsibility of the Community Action Team (CAT), but without a forward, process-focused approach grounded in racial and health equity, the CAT will not receive actionable, effective recommendations nor advance health equity.

This chapter focuses on the essential steps to ensuring that FIMR findings translate into meaningful community action to improve service delivery systems and communities. The chapter is broken up into two parts: the responsibilities of the CRT and those of the CAT.





The CRT

To ensure that case reviews ultimately lead to meaningful prevention activities within the context of racial and health equity, the Case Review Team (CRT) must identify risk and protective factors in case reviews, create **findings**, review these findings to prioritize the issues that most need to be addressed in the community, and ultimately, craft recommendations to be taken up by the CAT.

Figure 9. Process to Identify Risk and Protective Factors in Case Reviews



Create and Document Findings for Each Case

The health disparities in fetal and infant deaths are staggering and warrant deeper analysis, frequently referred to as a “root cause analysis.” Root cause analyses provide a pathway to uncovering and unpacking the structural contributors to racialized disparities and inequities. Findings are objective facts that illustrate risk and protective factors; however, these factors must be understood beyond the surface to generate sustainable and systemic changes that will move the needle on health equity.

While the CRT may see their role as reviewing the case to identify risk and intervention points, it is important to identify what went well in cases, even when there is a poor outcome. This allows teams to identify and promote effective policies and procedures and provide direct feedback to agencies about successful interventions.

It may be helpful to develop a standard list of findings to compare them between multiple cases. Commonly, findings will focus on community characteristics, such as quality of medical and health care, the family’s physical or social environment, agency practices or collaboration between systems, unique jurisdictional considerations, and most importantly, the social determinants of health, including racialized experiences.

If a FIMR program participates in the NFR-CRS, findings should be documented in **Section L: Findings Identified During the Review**. This short section has five questions; three are open-ended, providing an opportunity for the team to share their findings and ideas for recommendations.

Findings should contain three key components:

- The system to be engaged (e.g., health care, public health, child welfare)
- Policy or program area (e.g., home visiting, transportation, substance-exposed infant, risk assessment)
- Case-specific rationale (e.g., lack of access to appropriate medical care, language barrier, etc.)

Review and Prioritize Aggregate Findings

In order to move from individual case findings to broader program and systemic recommendations, there should be a dedicated time set aside to review and prioritize findings. The National Center recommends this be done annually. Some programs may choose to have the CRT prioritize findings. Others may select additional MCH community collaborators or engage the CAT in this effort.



The NFR-CRS' standardized report #30—**Findings from the Review**—will be beneficial. It will provide an aggregate summary of the following data from selected cases:

- | | |
|--|---|
| <input type="checkbox"/> Age of infants | <input type="checkbox"/> Key protective factors (findings) |
| <input type="checkbox"/> Cause of death | <input type="checkbox"/> Recommendations to prevent future deaths |
| <input type="checkbox"/> Manner of death | <input type="checkbox"/> Whether agency changes were implemented |
| <input type="checkbox"/> Key risk factors (findings) | <input type="checkbox"/> Preventability |

Example Findings:

- 1 Family had access to Medicaid funded transportation to community services and medical care
- 2 Caregiver was not provided with infant safe sleep education at birth
- 3 Healthcare staff explained away or minimized the mother's concerns when she said she hadn't felt the baby kick

Next, the findings should be grouped by system. The group should examine what findings are relevant to each service system identified. Identifying where the most findings are grouped can help the team prioritize what systems should be prioritized in the FIMR recommendations.

Alternately, examining the findings alongside population-level statistics, including demographics that reveal disparities, can allow the team to consider the systems and their area's overall burden of fetal and infant mortality. Communities may also want to identify if deaths have increased, decreased, or stayed relatively constant over time, if the proportions of cause-specific fatalities are shifting, or if there are any emerging trends since the last time they examined the data in this way.

Finally, the team should come to consensus about what themes they identify within the findings and which system(s) should be prioritized within the FIMR recommendations.

Resources to Support Prioritizing

- [Prevention Matrix](https://bit.ly/3DaWREo) (URL: <https://bit.ly/3DaWREo>)
- [Fatality Review Facilitation Guidance](https://bit.ly/3DISiHL) (URL: <https://bit.ly/3DISiHL>)
- [Nominal Group Technique](https://bit.ly/3mwuSbC) (URL: <https://bit.ly/3mwuSbC>)
- [Health Impact Pyramid](https://bit.ly/3mnShfo) (URL: <https://bit.ly/3mnShfo>)
- [Multi-voting](https://bit.ly/3DI13BP) (URL: <https://bit.ly/3DI13BP>)
- [Delphi Model](https://bit.ly/3DfKrev) (URL: <https://bit.ly/3DfKrev>)



Write Recommendations

The goal of the findings is to contribute to systems-level recommendations for change, so even if summarized **findings** will be focused on individual events when writing recommendations, **the team should consider how the systems around the individual and the family interacted to help produce the poor and/or racialized outcomes.**

This may require continued reframing from a facilitator or coordinator grounded in racial and health equity. The coordinator may need to remind the team that they are not meant to evaluate and change an individual's behavior in retrospect; they need to think about the ways systems can promote racial and health equity, remove barriers, and provide better options and quality of care in the services delivered to individuals and families.

Prioritizing the voice of the community itself and those most likely to be impacted by FIMR recommendations is vital to ensure that recommendations are equitable, just, realistic, and welcomed. FIMR teams should do this through membership on the team that prioritizes community representatives and advocates.

When the time comes to write the recommendations, it is important that the team has used the prioritization process to identify which actions the CAT can reasonably work on to advance racial and health equity. One strategy teams may use is to think in terms of short-term and long-term initiatives. The short-term initiatives are often things that the CAT team has direct influence on, such as adjusting an agency policy in an agency they lead. The long-term initiatives are often things that the team members do not have direct influence on, such as public policy that may require multiple years of advocacy.

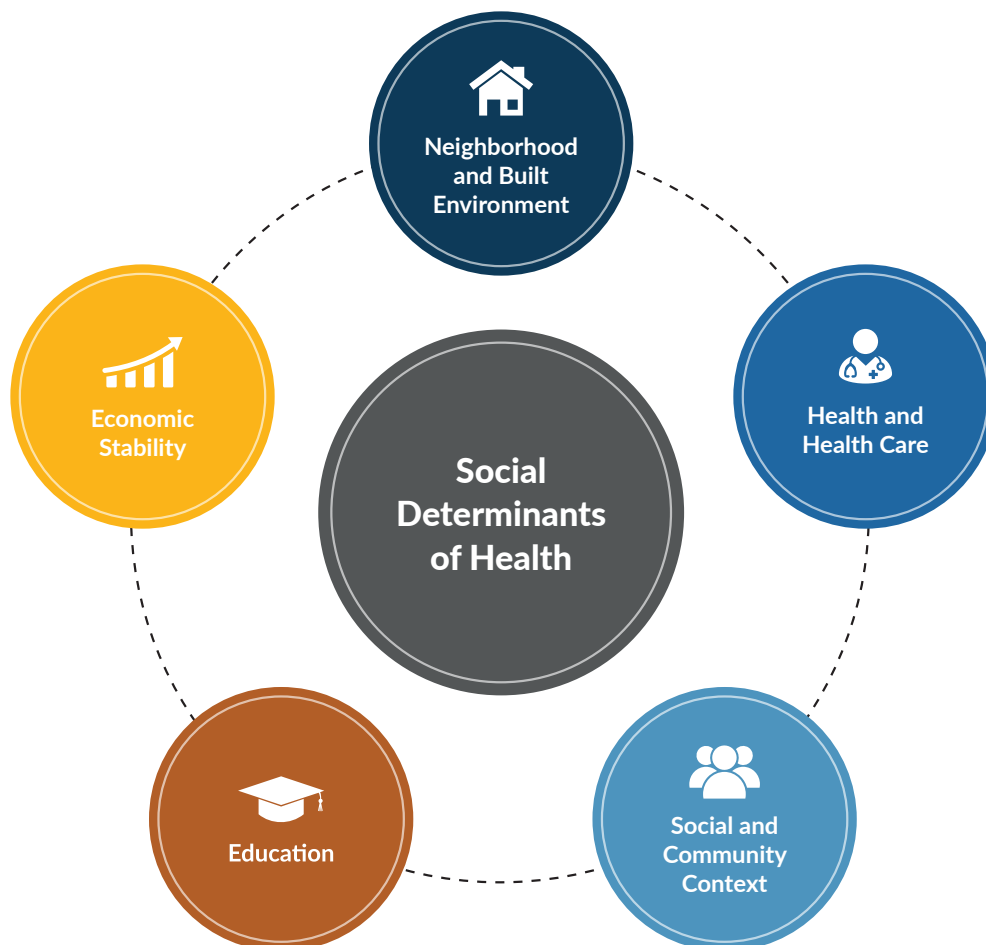
Frameworks

While teams can choose from a variety of frameworks to use in crafting recommendations, it is important that recommendations incorporate the social determinants of health (SDoH).

Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.¹

Racism is a social determinant of health that affects many others, including housing access, employment, and educational attainment. Incorporating a root cause analysis in the FIMR process will clarify the socio-ecological systems and structures that impact outcomes and warrant disruption.

Figure 10. Social Determinants of Health



Social Determinants of Health:

The table below shows some examples of the types of SDoH-related issues (or systems) that may impact pregnancy outcomes and that teams may identify. They include service delivery and quality of care, psychosocial, economic/resource, and environmental issues. (This list is by no means exhaustive.) For each, there are more specific areas on which recommendations could focus.

Figure 11. Examples of SDoH-Related Issues or Systems Impacting Pregnancy Outcomes

Type of Issues	Recommendations Could Focus On
Service Delivery Issues	Gaps in care; Access to care; Barriers to care; Quality of care; Ineffective communication; Discrimination in health care and service delivery
Psychosocial Issues	Racialized trauma; Social support for the family; Coping skills of family members; Trauma-informed smoking cessation; Domestic violence
Economic/Resource Issues	Lack of living wage; Lack of basic family needs; Food deserts; Uninsured/underinsured; Limited childcare options
Environmental Issues	Community safety; Sanitation; Air/water quality; Urban planning; Housing safety

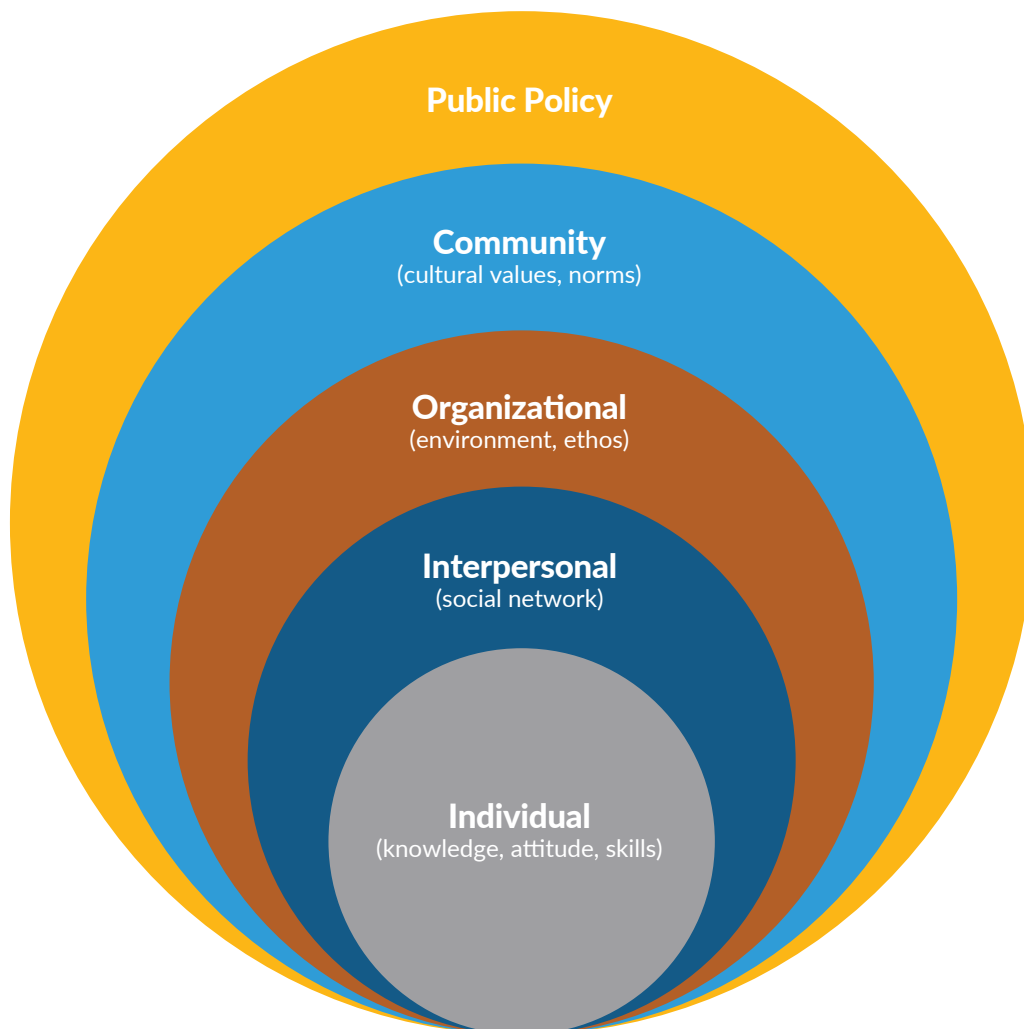
Recommendations themselves typically fall into one of the following domains:

- Activities to promote racial and health equity
- Community-based education
- Professional training
- Organizational practices
- Services system and quality of care improvements or linkages
- Policy advocacy
- Individual knowledge and skills

Social-Ecological Model

The Social-Ecological Model can help teams think about working at the systems level and across systems. It illustrates how public policy, community, and organizational factors create the systems and context in which individuals operate and relate. It also provides a way for teams to think expansively about the types of interventions to recommend. Layering and aligning recommendations from within organizations, the community, and public policy have the potential for the most significant and sustainable impact. Evaluating team recommendations to ensure they focus on organizational, community, or policy levels will help decrease the likelihood that teams are focused on individual behavior and blame and seek systems-level solutions that will have the broadest and most powerful impact.

Figure 12. *Social-Ecological Model*





SMARTIE Goals:

The National Center has recently endorsed the SMARTIE goals framework developed by The Management Center.² It provides a way to ensure that recommendations are specific, actionable, and measurable while placing a high value on the process and the resulting goals being both equitable and inclusive.



Specific: Answers the who, what, where, when, which, and why related to the recommending. Who will implement the change? What is it? Where and when will it be?



Measurable: A tangible plan for measuring impact is determined. How will the team know if the recommendation has succeeded?



Ambitious: The recommendation should be challenging enough that achieving it would mean significant progress.



Realistic: Are there sufficient resources to achieve the goal or implement the change? In the FIMR context, resources include political and social will.



Time-Bound: The recommendation should include a clear deadline.



Inclusive: Those most impacted should be centered in the process of creating the recommendations. This can be addressed by having well-rounded FIMR teams that reflect the community.



Equitable: The recommendations should seek to address systemic injustice, inequity, and oppression.

Evidence-based

Evidence-based programming is the gold standard for public health practice as it has proven through rigorous evaluation and peer-review to improve outcomes. This rigorous evaluation includes measurement of population outcomes before and after intervention or comparison to a control population of some kind. It uses a continuum of integrated policies, strategies, activities, and services whose effectiveness has been proven or informed by research and evaluation.³

Evidence-Based, Evidence-Informed, and Promising Practices

When thinking through recommendations, it is important for the team to be familiar with what is already working and proving effective for MCH populations. It helps that many FIMR participants are knowledgeable about these programs. However, there are times when it will be helpful to do research into new findings and opportunities.

- Evidence-informed:** While evidence-based programming is ideal, programs do not always benefit from the resources or ability to conduct rigorous evaluation, go through peer review, and prove a program is effective. In these instances, however, there are proven strategies that can be applied to new problems. Evidence-informed practice is used to design health promotion programs using information about what works, using the best available evidence from research. In this way, evidence from research into specific methods, such as motivational interviewing or the stages of change model, can be applied to or incorporated into new programs.⁴

- Cutting-Edge, Emerging, Promising, and Best Practices:** This is a continuum of practices, developed by the Association for Maternal and Child Health Programs (AMCHP), that ranges from program practice focused on key populations with early signs of success, all the way to practices that have been rigorously evaluated using relevant measures and methods, assessing even unintended impacts of the efforts.⁵ A free database of these practices from MCH programs across the country is available at [AMCHP's Innovation Station website](https://bit.ly/3iEqkyl) (URL: <https://bit.ly/3iEqkyl>).

Elevating Findings to the CAT

Once the CRT has examined aggregate findings and written recommendations grounded in racial and health equity, they are sent to the CAT to implement. **The most important thing when determining how and how frequently recommendations will be elevated to the CAT is to ensure it is a strategic process that works for both the CRT and CAT.**

Teams have successfully approached this in multiple ways. Two of the common ways are outlined in this section, but teams are free to determine what makes the most sense for their local context when it comes to designing a process.

Periodic Reporting

Often, the CRT creates a formal document or report to be presented to the CAT, outlining case review data, findings, and the formal CRT recommendations. Members of the CRT will present this information to the CAT in a meeting—often annually—and make themselves available for questions.

Overlapping Membership

In this model, select team members participate on both the CRT and the CAT. Often this member is the coordinator of the CRT. This person may bring the formal recommendations to the CAT and should address any questions or concerns that the CAT may raise. The benefit of this is that the CRT coordinator can also update the CRT on the CAT's activities, ensuring both teams are well-apprised of each other's status, priorities, and activities.

Members of both the CRT and CAT may also serve in other fatality review teams, including maternal mortality review (MMR) or child death review (CDR). For more information about collaboration between these processes, including shared membership, review [Enhancing Collaboration Between Child Death Review and Fetal and Infant Mortality Review: National Center Guidance Report](https://bit.ly/3gdL52e) (URL: <https://bit.ly/3gdL52e>).



Tips for Determining the Process

1

If the CRT and CAT are being established at the same time, design the process from the beginning with community collaborator engagement from both teams. Revisit the process annually to determine if it is working well or if the process can be improved.

2

If the CAT is already established when a FIMR program launches—if it has been an existing infant mortality reduction coalition, for instance—ask the team and coordinator how and how often they would like to receive the recommendations and align the CRT review of findings with the timing that makes the most sense. Often, this process occurs quarterly, biannually, or annually.

3

Provide a high-level data summary and/or findings summary along with the recommendations to inform the CAT about what kind of information contributed to the recommendations themselves. Some CAT members may simply want to know the recommendations and move forward. Others may prefer to understand the findings that led to the recommendations to see a direct through-line. If a FIMR is not reviewing a census of the fetal and infant deaths in its community, it will be helpful to also include a summary of population-level statistics along with information from the FIMR reviews.

Include information like:

- How many case reviews were aggregated and examined when crafting the recommendations?
- What were the causes of death in these cases? If reporting requirements related to small numbers allow, indicate the number of cases for each cause of death.
- What were the ages of the infants? Consider breaking this down into fetal deaths, infants that die in the first week of life, neonatal (first 27 days) deaths, and post-neonatal (infants who die between 28 and 364 days of life) deaths.
- What were the demographics of the cases? Were racial, socioeconomic, or geographic disparities in access, care, or outcomes noted? If so, what was said?
- What were the contextual factors and leading stressors identified among the cases?
- Were there common findings across cases? It may be helpful to have these grouped by the type of issue, with all the aggregated, corresponding findings from across cases reported together.

Common types of population-level data that are considered alongside FIMR case findings include:

- State and local vital statistics, including leading causes of fetal-infant mortality
- Local Census data, including social, economic, and demographic information
- State or regional data from the Pregnancy Risk Assessment Monitoring System (PRAMS)



The CAT

Prioritizing Action

Even if care has been given not to elevate too many recommendations to the CAT, the CAT may need to prioritize from within the recommendations provided by the CRT. At times, this may be as simple as reaching consensus about the team's highest priority. Other times, the prioritization process for the CAT may have different compelling factors that are not considered by the CRT. Agency leadership often identifies opportunities or barriers based on political, fiscal, or other issues that can positively or negatively impact the timing of moving a recommendation forward. CAT members may realize there is a limited window of opportunity to implement a recommendation or that it may be more effective to wait to implement another. This is the benefit of CAT members' positions in their agencies and the community.

Implementing Action

Chapter 6 has already outlined the importance of having a CAT with the influence, fiscal resources, commitment to racial and health equity, and political will to implement meaningful changes in systems. The CAT has been formed or engaged for this purpose, and members should see themselves as change agents. **Their first obligation to implement recommendations is to serve as community champions and ambassadors back to their own agencies.** Many of those represented will serve in leadership in agencies that serve maternal and infant populations. When recommendations focus on efforts in their professional sphere, the team members should individually advocate for the needed changes identified by the CRT.

Members are often on other task forces, coalitions, or well-positioned boards to help operationalize FIMR recommendations. CAT members are ambassadors for racial and health equity and the FIMR recommendations in multiple contexts, including local government, potential funders, and program partners.

Some teams find that using a work plan approach to implementation is helpful. It allows the team to stay focused on their priorities and keep track of implementation status.

This requires that the team:

- Identify a goal or objective (the recommendation to be implemented).
- Outline individual activities necessary to meet the final objective.
- Identify who will initiate or implement each action.
- Determine any associated costs and how efforts will be funded.
- Create a timeline for the start and completion of the individual activities and the final goal.

Figure 13. Sample FIMR Workplan

For each community action identified, complete a brief entry. Identify the action steps necessary to effect change, the person or agency that will be responsible for implementing these action steps, the timeline for action, the resources needed for action. Leave space to document the status and progress of the proposed action at later meetings.

Action Steps	Person/Agency Responsible	Timeline	Resources	Status of Proposed Action
1.				
2.				
3.				
4.				
5.				

Adapted from: a FIMR/HIV CAT Workplan developed by CityMatCH, NFIMR, the American College of Obstetricians and Gynecologists (ACOG), the Maternal and Child Health Bureau of HRSA. This project is supported by cooperative agreements 1U65PS000813-01 and #U50/CCU300860 from the CDC Division of HIV/AIDS Prevention.

Incremental Progress and Tracking

Regardless of how the team may decide to approach implementation, it is important for the larger team to receive periodic updates and track progress toward the individual action steps and ultimate goals. This both encourages the team to stay focused on and engaged with the process and provides an opportunity for other team members to support efforts as needed. Advancing racial and health equity should be integrated in the goals and action steps. CATs are made of creative problem solvers, and the team should strive to create an environment that supports individual members in removing barriers and making progress toward shared goals. Teams should also consider sharing challenges as they arise, not merely at planned meetings—creating dialogue and opportunities for shared problem solving to avoid derailing implementation timelines.

Subcommittees

Some CAT teams are successful in having topic-specific subcommittees that focus on implementing certain types of recommendations. This allows CAT members to focus on the most relevant issues to their work, agency, or expertise with community access, influence, or understanding.

Common subcommittees include:

- | | |
|--|--|
| <input type="checkbox"/> Sudden unexpected infant death (SUID) or sleep-related infant death | <input type="checkbox"/> Social determinants of health (SDoH) or health equity |
| <input type="checkbox"/> Healthcare/provider education | <input type="checkbox"/> Intimate partner violence |
| <input type="checkbox"/> Substance use | <input type="checkbox"/> Teen pregnancy prevention |

Funding FIMR Initiatives

FIMR teams are funded in different ways, but all teams benefit from a CAT team that understands the lay of the land when it comes to funding. Members often work in highly resourced environments, including those who fund local initiatives.

Many FIMR teams benefit from a partnership with Title V Maternal Child Health Block Grant programs. These are government grants from the Health Resources and Service Administration (HRSA) that support MCH work statewide and in local communities, often through county-level health departments. Private grants, through hospital foundations or local philanthropies, are also valuable potential funders. Many teams align their prevention work with other programs working on similar issues, and both programs can leverage funding to make their dollars go further. Read more about collaborating with Title V programs in chapter 8.

In whatever manner a team decides to fund their prevention work, the CAT plays an important role in strategizing for funding and program sustainability.

Tracking and Reporting on Progress and Building Community Support

A critical component of the FIMR process is the periodic assessment of the status of proposed actions to ensure their implementation. Effectively tracking progress has multiple benefits. It keeps the team on track, particularly when participating in the CAT in addition to their work duties from their employers. It helps the team build momentum and credibility in the community, making it easier to work with similar partners to implement future recommendations. It can also help the broader FIMR program build momentum and maintain team morale.

FIMR programs are creative, and the additional monitoring strategies they use can take different forms. Some programs have developed an anonymous survey method to check on the status of an action. Others rely on team members reporting back to the larger group.

Another effective strategy is for the CAT to incorporate monitoring for selected actions into periodic community needs assessments (such as those conducted by the local health department) whenever possible. In this way, the FIMR monitoring process becomes a part of the more extensive community assessment process.

FIMR program monitoring and evaluation will be explored in greater depth in Chapter 9.



Tracking Recommendations in the NFR-CRS

Teams maintain records in different ways. If a FIMR team participates in the National Fatality Review-Case Reporting System, they can take advantage of the Prevention Outcomes section of the web-based platform. This allows teams to summarize their prevention recommendations and implementation over time, along with their case reviews. To learn more, please visit the [NFR-CRS website](https://bit.ly/2WYNvfO) (URL: <https://bit.ly/2WYNvfO>).

Regardless of how the team decides to document their efforts, tracking recommendations and prevention activities over time will allow the team to see how the needs of the community may have changed, progress being made to advance racial and health equity, what ultimate impact the activities may have had, and how they can execute or improve similar endeavors in the future.

Record CAT Decisions and Progress

In addition to tracking prevention activities and plans the CAT agrees on, it may be helpful also to track what their decision-making process looked like, including items that were not selected as priorities and why. This will allow the team to revisit the recommendations that are not prioritized in the future to determine if it may be a better time to prioritize those efforts due to changing political, programmatic, or funding opportunities.



Annual Report

Many FIMR programs prepare and publish an annual report detailing findings and actions proposed and progress to date. It is essential to share the results with varied audiences, such as the community at large, professional groups and agencies, state Title V directors, business leaders, elected officials, and funders. While the content and format of the annual report may vary, common components include the following:

- | | |
|--|--|
| <input type="checkbox"/> FIMR mission statement, one that embraces racial and health equity | <input type="checkbox"/> Vignettes/stories contextualize the data (always de-identified and details obscured to protect the confidentiality of families) |
| <input type="checkbox"/> General overview of the FIMR process | <input type="checkbox"/> Population data to frame the FIMR findings and give the scope of the problem |
| <input type="checkbox"/> Purpose of FIMR | <input type="checkbox"/> Actions/recommendations, and progress to date on implementation |
| <input type="checkbox"/> The geographic area covered by the FIMR program | <input type="checkbox"/> Names of CRT and CAT members |
| <input type="checkbox"/> Aggregate case review findings: <ul style="list-style-type: none">• <i>Special concerns or sentinel events</i>• <i>Trends over time</i>• <i>Incidental findings</i> | <input type="checkbox"/> Acknowledgment of all sources of funding and in-kind donations |

It is recommended that every effort should be made to present service systems and resources in the community in a positive light. FIMR should not be seen as the antagonist but rather a constructive part of the system making suggestions for advancing racial and health equity and the enhancement of existing services or resources.

Presentations

To accompany the annual report, it is helpful for FIMR programs to develop presentations to support their written document. These presentations can be tailored to specific audiences and are a good way to keep key issues related to FIMR findings, their relationship to health inequities, and action in the public eye. Presentations can be shared at lunch-n-learns sessions for hospital and clinic staff or as an educational offering for child protective service workers. More formal presentations can be made at medical professional grand rounds or professional meetings and conferences. These provide an excellent way to present findings and recommendations, recruit team members, and build support for taking specific recommendations to action as a strategy for advancing racial and health equity. Local FIMRs can also invite community collaborators to learn about FIMR at special meetings, such as a city council meeting or the mayor's task force meeting on infant mortality. FIMRs can also reach many public health and human service experts by presenting posters or papers at professional association meetings.

Building Support

FIMR programs share that a key to longevity and success is making sure that their efforts are publicized throughout the larger community. These FIMR programs have developed ongoing, effective communication with the broader community as a continuing strategy in their CAT action plan. Some savvy CATs have even designated several CAT team members as an informal "speakers bureau" on issues related to fetal and infant mortality. These members may act as the standing media subcommittee with the purpose of exploring multiple opportunities to get the word out to local policymakers, funders, providers, the committee at large, and the community most at risk for poor outcomes. This type of publicity can:

- Promote broad-based community ownership and pride in the local process
- Help recruit new and diverse team members for the future
- Keep action stories on the community's radar over time
- Gain confidence, support, and community buy-in
- Enhance visibility of family health issues and credibility of the program
- Enhance visibility of systems that have incorporated changes to improve racial and health equity

FIMR programs can utilize a variety of communication tools; however, no one communication strategy works for every person or entity. The CAT may play a role in determining who it is the program wants to reach, what information would be important to them, and the best way to reach them.

Effective tracking is an essential part of building community support for the efforts of FIMR. Community partnership and support make the case review process more effective, as enthusiastic partners readily share records and look for ways to eliminate barriers and improve the quality of care provided. Prevention efforts need buy-in and support from partners and the community to be effective. It is also a way to show current and potential funders that FIMR is a sound investment.

Effective tracking of prevention efforts proves to current and future partners and the community that FIMR is a vital, effective, and action-oriented process.

Telling the story of FIMR is something team members should be prepared to do generally. Still, team members and leaders should look for opportunities to talk to the public about prevention activities. The team may consider developing an information flyer that describes the process and some of the more notable outcomes. They should look for opportunities to present on FIMR at local conferences, board meetings, or relevant task force meetings. Organizations whose work aligns with FIMR's should know about FIMR's work.

The team should maintain an updated website highlighting the benefits of FIMR, its commitment to racial and health equity, prevention activities, and member agencies. They should also consider partnering with local media to highlight efforts at strategic times, including:



Black Maternal Health Week in early April



Infant Mortality Awareness Month in September



Safe Sleep and SIDS Awareness Month in October



Prematurity Awareness Month in November

And finally, they should take full advantage of social media and leverage earned media from their partners.

Closing the Loop

There are multiple important audiences for the findings and outcomes of FIMR efforts, but there is none more important than local review team members. Case review is difficult work and seeing case review findings moved to meaningful action in the community is an important part of maintaining team morale and retaining team members. Every effort should be made to ensure that Case Review Team members are up to date on efforts from the CAT team and are aware of successful prevention activities to which their case reviews have contributed.

Each audience may require a different channel or style of communication to be most effective, but building effective community partnership by thoughtfully considering these audiences and their needs will ensure greater buy-in from the community in prevention efforts and improve team effectiveness over time.

When considering audiences who should be informed of FIMR's recommendations and successful prevention activities, consider the following audiences:

- | | |
|--|--|
| <input type="checkbox"/> The community | <input type="checkbox"/> Task forces with whom FIMR aligns |
| <input type="checkbox"/> Partner agencies | <input type="checkbox"/> The broader public |
| <input type="checkbox"/> Local Title V programs | <input type="checkbox"/> CRT members |
| <input type="checkbox"/> Current and potential funders | |

Resources for Moving FIMR Findings to Action

- [Findings Guidance](https://bit.ly/3maElhS) (URL: <https://bit.ly/3maElhS>)
- Webinars
- Implementation Science Resources



Endnotes

- 1 Office of Disease Prevention and Health Promotion: <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>.
- 2 <https://www.managementcenter.org/resources/smart-to-smartie-embed-inclusion-equity-goals/>.
- 3 <https://healthysafechildren.org//topics/evidence-based-interventions>.
- 4 http://www.dhhs.tas.gov.au/wihpw/principles/evidence_informed_practice.
- 5 <http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/Pages/Best-Practices-Program.aspx>.

Chapter Eight: Other Maternal and Child Programs, Case Reviews, and Related Processes

Opportunities for Collaboration

Introduction

There are multiple types of case review processes at both state and local levels that examine events occurring to women, children, and their families to improve the health and welfare of this population over time.

This chapter provides brief descriptions of the most common case review processes and programs with which FIMR teams can collaborate, identifies resources that provide additional details about each approach/program, and describes opportunities for alignment and collaboration.

As with the FIMR methodology, some variations exist in implementing each type of case review process across the country, with no one model being used in all states or communities.



Title V Maternal and Child (MCH) Block Grant

The Title V Maternal and Child Health Services Block Grant of the Social Security Act of 1935, United States Code 701-710, Subchapter V, Chapter 7, Title 42 (Title V), creates federal/state partnerships that enable each state or jurisdiction to address the health services needs of its mothers, infants, and children, including children and youth with special healthcare needs. Title V is a key source for promoting and improving the health of America's mothers and children.

Many FIMR programs are housed within state Title V maternal child health programs, are funded by them, or collaborate closely with them at local and state levels. The rich information gathered in the fatality review provides a deeper level of detail than other sources, complementing data such as vital records and other administrative data. Additionally, FIMR processes collect unique data relevant to the Title V programs. As a result, fatality review processes are well-positioned to inform Title V programs about the challenges and inequities in communities that are barriers to progress across the Title V National Performance Measures (NPMs).¹



Title V legislation requires states to prepare and complete a statewide needs assessment every five years as part of their applications. The results of each state's needs assessments are due with the next Block Grant Report/application. The findings of the five-year needs assessment serve as the “drivers” in determining state Title V program priority needs related to racial and health equity and developing a five-year action plan to address them. In the intervening years, states are expected to be evaluating the needs of the MCH population on an ongoing basis. FIMR findings can be continuously integrated into these efforts. States can shift their selected NPMs or change strategies in response to findings from ongoing needs assessment processes.

The systematic review of individual fetal and infant deaths cases helps identify what may be lacking in a community for pregnant women, mothers, infants, and children and uncover the drivers of health inequities. Fatality review teams may review sentinel events, those cases that can alert the community to glaring problems or situations with systems, services, or resources that need prompt attention. Teams often identify trends. Over time, multiple case reviews may illustrate similar issues or concerns. Incidental findings may be uncovered through the fatality review process and gaps in the service delivery area that need to be addressed, including quality of care issues. FIMR also highlights services for children with special health care needs. FIMR can play a unique role in identifying when the death of a child with special needs or disabilities results from caregiver maltreatment or if the family lacked needed supports to keep their child with a disability healthy and safe, or if the quality of care and services are incompatible with optimal outcomes.

Fatality review can help state Title V programs prioritize needs and, based on their data, select which national MCH priority areas are most critical for their state to advance health equity. In addition, the recommendations developed by FIMR teams can help states establish meaningful performance objectives.



In summary, FIMR informs Title V programs by:

- Examining social, cultural, safety, and health systems factors and inequities associated with fetal and infant mortality through review of individual cases.
- Identifying system barriers and problems that need improvement through de-identified case reviews.
- Including parental/family interview information to convey the families' perspectives on the problems faced, how well the systems served them, and their knowledge, attitudes, and beliefs about health.
- Addressing ways of improving service systems and community resources to prevent future fetal and infant deaths.
- Providing valuable qualitative data to complement states' quantitative infant mortality data.



Follow this link to learn more about the [Title V Maternal and Child Healthy \(MCH\) Block Grant](https://bit.ly/3AqNGxQ) (URL: <https://bit.ly/3AqNGxQ>).

Healthy Start

The Healthy Start initiative, Eliminating Disparities in Infant Mortality, is a federally funded program aimed at strengthening the community and service delivery at the local, state, and national levels to help women, infants, and families reach their fullest potential. Close collaboration with local, state, regional, and national partners is key to Healthy Start's success. Healthy Start and FIMR have had a collaboration spanning several years. An evaluation of FIMR conducted by Johns Hopkins University found that local health departments were two times more likely to report progress in meeting goals and objectives for pregnant women if they had either a FIMR or another perinatal initiative (PI). If both FIMR and a PI, such as Healthy Start, worked together, they were nine times more likely to report progress. This remarkable synergistic relationship can be a significant benefit to Healthy Start communities.² Furthermore, the collective effort provides a force for advancing racial equity.

FIMR aligns closely with the four overarching **Healthy Start** goals:



Reduce differences in access to and use of health services



Improve the quality of the local health care system



Empower women and their families



Increase consumer and community participation in health care decisions

There are many ways that Healthy Start Programs and FIMR collaborate. Some Healthy Start programs report that reviewing the few fetal and infant deaths in the Healthy Start caseload is a vital part of working together. FIMR findings may spur a community to apply for a Healthy Start grant. Healthy Start may fund FIMR in whole or part. FIMR may ask the Healthy Start Community Action Network (CAN) to act as its FIMR Community Action Team (CAT). Healthy Start staff may serve on the FIMR Case Review Team (CRT) and/or Community Action Team (CAT).

For example, in Marion County, Indiana, a unique partnership grew between FIMR and Healthy Start. The Grassroots Maternal and Child Health Leadership Training (GMCHL) Initiative Project,³ primarily funded by Riley Children’s Foundation with secondary funding from the Indiana Department of Health and private philanthropists, trains and mentors local women who reside in traditionally low resourced communities to become community development leaders. This effort is aimed at improving inequitable social and economic systems that underlie adverse birth outcomes. Three African American women trained through this initiative were invited to join the Marion County FIMR CAT team. They directly link FIMR CAT members to the Black maternal health experiences in zip codes with persistently high infant mortality rates. The women help build connections between their communities and the CAT community-based workgroups.

Sheree Holmes Keitt, Senior Program Manager, National Healthy Start Association, said, “As the Maternal and Child Health Bureau’s signature program for infant mortality reduction, Healthy Start projects are natural partners to the Fetal and Infant Mortality Review (FIMR). Healthy Start was designed to take a community-level, grassroots approach to addressing infant mortality by engaging the community and Healthy Start consumers in the overall work. Each Healthy Start is required to have a Community Action Network (CAN) that serves as an advisory board to provide input on their local Healthy Start program’s strategies, policies, services, and other governance decisions to reduce infant mortality. Healthy Start CANs play a critical role in partnering with consumers, hospitals, community-based organizations, and other cross-sector stakeholders to have a collective voice towards making a change in their community. Many Healthy Start CANs or a representative from the CAN are actively engaged in the FIMR, working collaboratively to create solutions that address policy and systems change in their community...with the inclusion of community members and Healthy Start consumers in the CAN, they use their voices to share their lived experiences and provide insight into issues in the community. In addition, if there are relationships in the community, the CAN may serve as a liaison to engage families that have experienced infant loss and, in turn, increase participation in the maternal interviews.”

More information about Healthy Start and information on grant awardees can be found on the [Maternal & Child Health page on the HRSA website](https://bit.ly/3lmtuZV) (URL: <https://bit.ly/3lmtuZV>).



Child Death Review

Child death review (CDR), also known as child fatality review, undertakes a comprehensive, multidisciplinary review of child deaths to better understand how and why children die and to use the findings to prompt action that can prevent other deaths and improve the health and safety of children. The primary purpose of CDR is to improve investigations and agency systems and services to children and families, to implement prevention policies and programs. There are commonly CDR teams in all 50 states, the District of Columbia, and some Native American tribes.

These programs may operate at state or local levels and are often administered in health departments or child welfare agencies. A prominent difference between FIMR and CDR is that CDR reviews are confidential but not anonymous; CDR team members bring their agencies' individual case records to the review for discussion. Reports of CDR program findings (in aggregate form) may serve as vehicles to educate the public and policymakers alike.

Infant deaths of all kinds, but particularly those related to SUID and injuries, are commonly reviewed by both FIMR and CDR teams. These teams often have overlapping membership at the local level and may rely on record sharing to conduct comprehensive reviews in these cases. For more information on how to collaborate with CDR, see [Enhancing Collaboration Between Child Death Review and Fetal and Infant Mortality Review](https://bit.ly/3gdL52e) (URL: <https://bit.ly/3gdL52e>).

Maternal Mortality Review

Maternal Mortality Review is a process by which a multidisciplinary committee at the state or local level identifies and reviews deaths of women and birthing persons during or within one year of pregnancy. Maternal Mortality Review is a standard and comprehensive system that primarily operates at the state level to identify, review pregnancy-associated deaths, analyze data, disseminate findings, and work with partners to act on recommendations. Maternal Mortality Review Committees (MMRCs) have existed in the United States for more than a century. Although these committees were initially comprised primarily of medical professionals, MMRCs have expanded their membership to include a vast array of professionals and partners who engage with and serve people during pregnancy and the postpartum period. The goal of maternal mortality review is not merely to prevent maternal death but to put in place recommendations that support health and wellness during pregnancy, childbirth, and postpartum. Because maternal mortality is a rare event, most MMRCs in the US operate at the state rather than the local level. They are predominantly based in state health departments. To learn more, visit the [Centers for Disease Control and Prevention](https://bit.ly/3pnGcaY) (URL: <https://bit.ly/3pnGcaY>).

Figure 14. Summary and comparison of the review elements and selected components of FIMR, CDR, and MMR programs and methodologies, as of December 2021

Review Elements	FIMR	CDR	MMR
Scope of programs in the US	152 local FIMRs in 27 States, the District of Columbia, Puerto Rico, and the Commonwealth of the Northern Mariana Islands	All 50 states have a CDR program manager and support state; there are approximately 1,350 local review teams throughout the U.S.	47 States, the District of Columbia, New York City, and Philadelphia have a formal MMRC
Case Selection Criteria	Teams review stillbirths (fetal deaths) and live-born infants who die before reaching their first birthday	Children 0-19 years of age	Mothers/birthing persons who die during or within one year of pregnancy, regardless of age
Team Structure	Two-Tiered: Case Review Team and Community Action Team	Most teams consist of one review board that conducts case reviews, usually includes agency professionals directly involved in the case; can be at the state or local level	Generally, a single multidisciplinary statewide team convenes periodically or yearly
Case Preparation	Cases are abstracted from a variety of medical and social service records; a case summary is prepared in advance for team members	Team members bring their records to review and share information from them	Generally, a full case presentation with patient hospital record abstraction
Confidentiality	Confidential and anonymous; cases are de-identified	Reviews are confidential	Confidential and anonymous; cases are de-identified
Family Involvement	Yes; a voluntary interview is conducted with families who consent and is included in the case review	No	Some sites beginning to conduct key informant interviews





Domestic Violence Review

The primary purpose of Domestic Violence Fatality Review (DVFR) is to preserve the safety of victims, hold accountable both the perpetrators of domestic violence and the multiple agencies and organizations that encounter the parties, and prevent other deaths. DVFR teams review the deaths of persons during domestic disputes or in relation to ongoing family violence. One unique component of domestic violence review is analyzing the protections afforded victims before their deaths. Teams tend to have more representation from law enforcement, the court systems, and victim advocates than other reviews. The administrative home varies by state, but many teams are based out of the attorney general or state court offices, with strong representation from victims' service agencies. Forty-two states have a DVFR presence, some are state-level, and others conduct local reviews. There are standardized protocols for DVFR but no national reporting tool, though work is being done to conceptualize one. Most states with DVFR have case report instruments and issue state-level reports, but no nationally aggregated data is compiled from the reviews. Training and technical assistance is provided by the National Domestic Violence Death Review Initiative,⁴ funded by the Office on Violence Against Women (OVW), a branch of the US Department of Justice.

Other MCH Sentinel Event Reviews

A sentinel event is defined by The Joint Commission (TJC) as any unanticipated event in a healthcare setting resulting in death or serious injury to a patient.⁵ Many jurisdictions have adapted the FIMR methodology of information gathering, interviews, multidisciplinary case review, and community action to help communities identify and address missed opportunities associated with these events.

Congenital Syphilis

A nearly four-fold increase in US cases of congenital syphilis between 2013 and 2018 prompted many communities to turn to the FIMR methodology to investigate and identify opportunities to prevent the disease. Like the FIMR/HIV Prevention Methodology, cases selected for review are not necessarily fatalities but cases where infants were born to mothers with untreated or inadequately treated syphilis at delivery. The goal for conducting a congenital syphilis review is to gather data on preventable congenital syphilis cases to inform change in community provider practices and/or health department response. Multidisciplinary committees convene to examine case(s) for missed prevention opportunities and areas for follow-up.

Prenatal Exposure to Alcohol

In 2004, the CDC's National Center for Birth Defects and Developmental Disabilities funded two pilot projects (Detroit, MI, and Baltimore, MD) to examine ways to adapt the FIMR methodology to prevent Fetal Alcohol Syndrome Disorders. The pilot reviewed cases of infants born to women who had consumed alcohol during pregnancy and had a fetal or infant loss and non-fatal cases of any woman who had consumed alcohol during pregnancy and had a live-born infant.

Using FIMR as a prototype, the FIMR/HIV Prevention Methodology was created to help communities identify and address missed opportunities associated with perinatal HIV exposure and transmission. In 2005, a pilot project was funded by the Centers for Disease Control and Prevention (CDC), and three sites were selected to bring together key community members to review information on cases of HIV-exposed infants. The experiences of the three pilot sites (Baton Rouge, LA; Detroit, MI; and Jacksonville, FL) served to improve the methodology and demonstrate its unique effectiveness in improving systems of care for HIV-infected women and their families. Ten additional FIMR/HIV Prevention Methodology sites were funded and brought on board from 2008-2012. CityMatCH's current FIMR/HIV Prevention Methodology project continues to collaborate with the CDC and other national partners to work toward the goal of elimination of vertical transmission of HIV.⁶ This project continues to work to broadly disseminate the methodology to up to 60 health departments across the country.

Preterm Birth Review

Another example of a non-fatal review board can be seen in the examination of cases of infants born preterm or low birth weight who survive. The same process used in FIMR review, medical records abstraction that includes prenatal care, delivery, postpartum care, is used to identify family strengths, challenges, and systems-related factors that might have contributed to the low birth weight or premature birth. The findings from these reviews are used to improve quality of care and services for mothers and infants and to prevent these poor pregnancy outcomes in future patients.

Coordination Across Review Processes

Each of the review processes described above was developed and operates independently of the others. However, there is much value in improving the coordination of the different review programs at the community and state levels. Deaths across the age span often have intertwined risk factors⁷ and most definitely contribute to racialized health inequities. Coordination can help review teams share information and findings on these intertwined risk factors, thereby better understanding the relationships between fetal, infant, child, and maternal deaths and health inequities. Collaboration can reveal that different types of deaths are associated with similar issues within the same service agency or across agencies and encourage further cooperation among agencies and systems. In addition, coordination can also minimize duplication of efforts and create economies of scale. Most importantly, when review programs coordinate their findings and recommendations for action, the potential for adoption and implementation of recommendations to prevent deaths exponentially increases, especially when improvements in major systems are warranted.

The overarching goals of collaboration include:

- 1 Recognizing that each fatality review system has distinct but complementary processes that can push the levers for changes in systems serving pregnant people, infants, and children.
- 2 Preserving the integrity and methodology of each program and the unique perspective it brings to provide additional insights and thought.
- 3 Capitalizing on opportunities for shared resources, such as leveraging funding and use of data to drive prevention initiatives that can collectively advance health equity.



As more communities launch fatality review programs, the need to think creatively about effective collaboration will increase. States are innovating ways for MCH sentinel event reviews and fatality review programs to coordinate their efforts strategically. As the processes are similar and often examining the same types of cases, collaboration between the programs can enrich the work of each and probe for systemic inequities and opportunities for improvement. In addition, effective coordination will significantly impact the systems all processes seek to improve through case reviews and recommendations for prevention.

Resources

- For more information on Collaborating Across Review Systems, [access the 37-minute training module here](https://bit.ly/2Yw6oXM) (URL: <https://bit.ly/2Yw6oXM>).
- A guidance document on [Enhancing Collaboration Between Child Death Review and Fetal and Infant Mortality Review](https://bit.ly/3gdL52e) (URL: <https://bit.ly/3gdL52e>) can be found on the NCFRP website.



Endnotes

- 1 <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>.
- 2 Misra DP, Grason H, Liao M, Strobino DM, McDonnell KA, Allston AA. The nationwide evaluation of Fetal and Infant Mortality Review (FIMR) programs: Development and implementation of recommendations and conduct of essential maternal and child health services by FIMR programs. *Matern Child Health J* 2004;8(4):217-29.
- 3 IUPUI Richard M. Fairbanks School of Public Health. (2020). Retrieved from Grassroots Maternal and Child Health Leadership Training Initiative: <https://fsph.iupui.edu/research-centers/centers/cheer/grassroots/index.html>.
- 4 <https://ndvfri.org/about/>.
- 5 <https://www.jointcommission.org/resources/patient-safety-topics/sentinel-event/>.
- 6 <http://www.fmrhiv.org/>.
- 7 The Coordination & Integration of Fatality Reviews: Improving Health & Safety Outcomes Across the Life Course. Findings from the National Invitational Meeting December 7-8, 2011 A Report to the Maternal and Child Health Bureau, Health Resources Services Administration, U.S. Department of Health and Human Services.

Chapter Nine: Evaluation for FIMR

Introduction

The recommendations for service improvement or interventions that result from an established fetal and infant mortality (FIMR) process may not take immediate effect. Many FIMR recommendations may seek to change long-standing processes and systems or seek funding for new initiatives that require buy-in from diverse community partners. When looking at the overwhelming and often intractable challenges of infant mortality, how do Fetal and Infant Mortality Review (FIMR) programs understand or describe the value of the fatality review process to the community? How can teams best identify opportunities for program improvement? When might the answers to these questions be necessary?

This chapter will provide an overview of program evaluation concepts for FIMR, the benefits, guiding principles, key evaluation questions, and potential data sources programs can use to evaluate their processes and outcomes.

It is intended to provide a starting place, whether a program is well-established or just getting off the ground.





What Is Program Evaluation and Why Should FIMR Programs Be Evaluated?

The recommendations for service improvement or interventions that result from program evaluation is the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgements about the program, improve program effectiveness, and/or inform decisions about future program development.¹ Many people’s experience with evaluation is simply as a respondent to an evaluation or satisfaction survey, and there may be misconceptions that program evaluation is a programmatic “thumbs up” or “thumbs down.” This perspective can miss the point of evaluation, which is ultimately to better understand program impacts and improve programs. **In the same way that FIMR collects data, makes findings, and crafts recommendations as continuous quality improvement for systems that serve women, infants, and families, program evaluation provides a similar opportunity for the FIMR program itself.**

While some programs may be required by a funder or a lead agency to conduct program evaluation, the process is valuable whether it is required or not, as it provides a framework in which the program can be closely examined, partners can reflect on their experiences with the program, and multiple sources of information on the program can be examined together for a comprehensive picture of the status of the program and its progress toward health equity and related goals.

The goals of program evaluation for FIMR may include:

- 1 Monitoring FIMR program effectiveness.** A well-planned evaluation is designed to capture data—both quantitative and qualitative—to answer key evaluation questions on either a periodic or ongoing basis. This allows the FIMR program to track program achievements, growth, and progress to advance health equity over time.
- 2 Improving the FIMR program and its processes.** Answers to key evaluation questions, as well as incidental evaluation findings, provide opportunities for teams to grow and improve. Evaluations highlight program strengths and areas where a FIMR program can improve its processes to maximize progress towards health equity and the overall impact of the program.
- 3 Ensuring program accountability throughout the FIMR process.** The evaluation process provides an opportunity for the program to highlight how it is using community resources and how it is embodying its commitments to participating partners, funders, and the community.
- 4 Understanding how FIMR contributes to reductions in infant mortality and advancement of health equity.** Effective evaluation describes the ways in which the work of FIMR is directly and indirectly related to health equity and infant mortality risk reduction. It can describe the ways in which FIMR may be a hub for partners focused on health equity and infant mortality to come together to understand and address community and systems-level risk by implementing FIMR recommendations.

Timing

While evaluation considerations are ideally a focus of early program implementation or adoption, they can be conducted retrospectively based on secondary (already available) and newly collected data. The sooner an evaluation is initiated, the sooner the program can reap the benefits of the evaluation.



Evaluators

The Evaluator

A program evaluator can be conducted by a single individual or a team of evaluators. If the evaluation is conducted by a single individual, as may be the case if the program coordinator is tasked with conducting evaluation as part of their duties, they may not have experience with conducting evaluations, and the process itself may be intimidating. If FIMR staff members or partners find themselves in this situation, this chapter will provide helpful guidance and additional resources.

Alternately, an evaluator may be assigned from the lead agency, likely from an epidemiology section, or the program may contract out the evaluation activities.

Regardless of whether the evaluator is new or seasoned, they will benefit from setting aside time to meaningfully reflect on the evaluation design and its key questions. They will also benefit from asking partners to suggest questions and metrics to include in the evaluation. Suggestions for both key evaluation questions and metrics are provided later in the chapter.

The Evaluation Team

If the program opts for—and can support—a group approach, the evaluation team may include:

- Internal program staff
 - Invested external partners or collaborators
 - Those with evaluation and data experience
 - Persons with experience in evaluating health equity as an outcome
-

Broad representation with different types of connectivity to the program itself will ensure that the evaluation is designed to answer the most important programmatic questions; that multiple partners weigh in on types of data and data collection; and that the findings and recommendations from the evaluation are feasible and action-oriented across the various parts of the FIMR process. A lead evaluator may be chosen from among the partners to keep the project on track and finalize evaluation findings and reports. Natural participants are maternal child health (MCH) epidemiologists, partners who measure movement on advancing racial and health equity, and those evaluating other MCH programs.

CONDUCTING EVALUATIONS

Whether the evaluation is conducted by a single evaluator or a team, it is important that those conducting it are committed to racial and health equity and a process that engages and solicits input from diverse partners participating in the full breadth of the FIMR program, from those who collect data, to those who are interviewed following a child's death, to the teams making findings and implementing recommendations.

Planning the Evaluation: Frameworks and Principles

Especially if it is the program's first program evaluation, but even if the evaluators are very experienced, FIMR evaluators may find it helpful to familiarize themselves with some of the frameworks for evaluating public health programs and health equity. Following is a high-level description of the Centers for Disease Control and Prevention's Framework for Program Evaluation.

Centers for Disease Control and Prevention's (CDC) Framework for Program Evaluation²

Following is the six-step process the CDC recommends for conducting program evaluation.



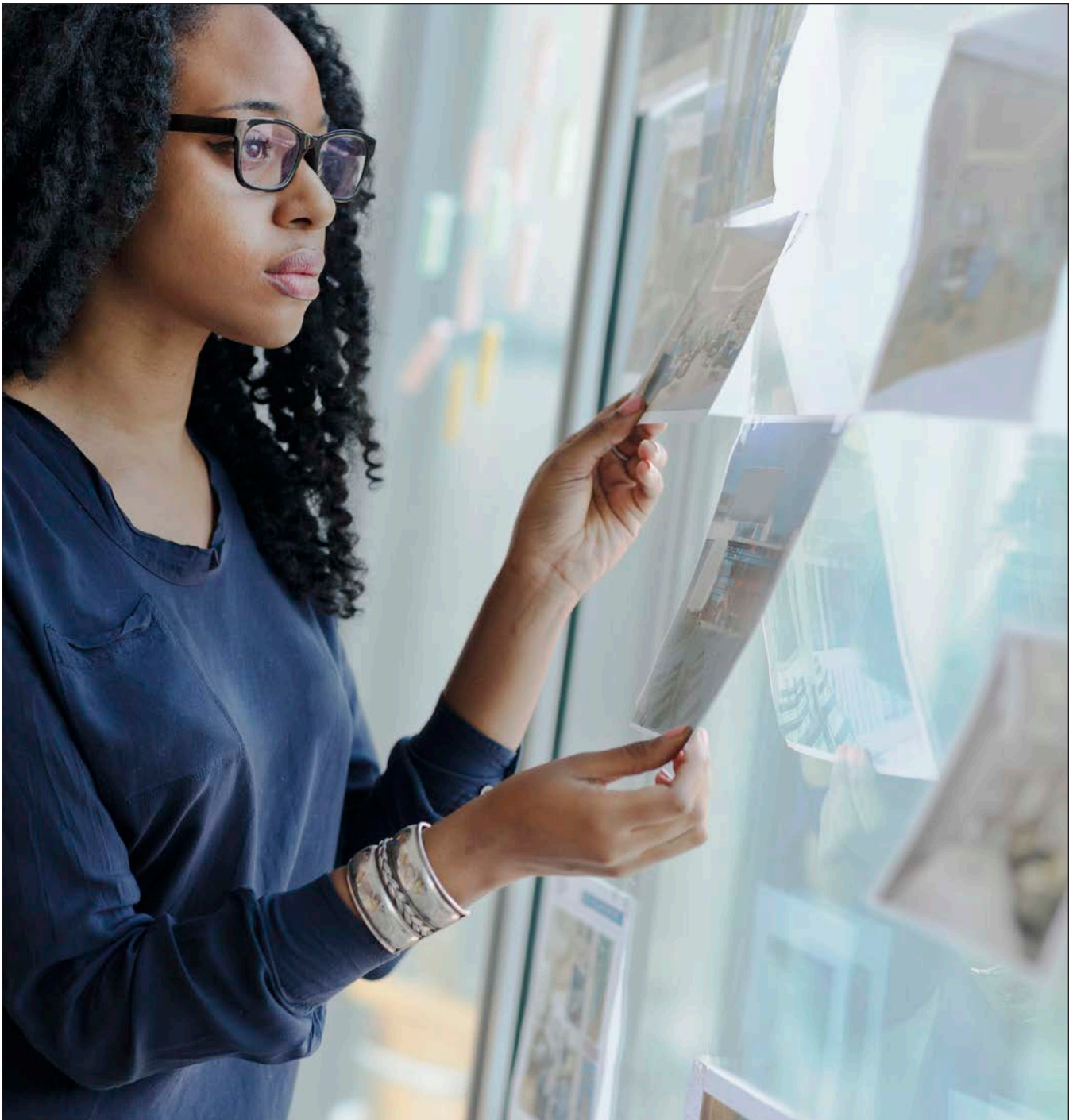
- 1 Engage Stakeholders:**
Include those involved, those affected, and primary intended users
- 2 Describe the Program:**
Need, expected effects, activities, resources, program maturity, and logic models
- 3 Focus on Evaluation Design:**
Purpose, users, uses, questions, methods, and agreements
- 4 Gather Credible Evidence:**
Indicators, sources, quality, quantity, and logistics
- 5 Justify Conclusions:**
Standards, analysis/synthesis, interpretation, judgement, and recommendations
- 6 Ensure Use and Share Lessons Learned:**
Design, preparation, feedback, follow-up, and dissemination



The model also focuses on the practice standards that CDC recommends be applied throughout the process:

- **Utility:** Serve the information needs of intended users.
- **Feasibility:** Be realistic, prudent, diplomatic, and frugal.
- **Propriety:** Behave legally, ethically, and with due regard for the welfare of those involved and those affected.
- **Accuracy:** Reveal and convey technically accurate information.

The remainder of this chapter will use this recommended six-step framework, describing how the steps can be applied to conduct a program evaluation for FIMR. Many of the suggestions contained in the following sections were provided by FIMR team leaders who convened to share their experiences with FIMR programs and evaluation. More information about the framework will be helpful for evaluators and can be found on the [Centers for Disease Control and Prevention's Program Performance and Evaluation Office website](https://bit.ly/30HKceB) (URL: <https://bit.ly/30HKceB>).



Evaluation Practice Standards

Through each of the steps in the process, the practice standards can be kept in mind to ensure that the evaluation aligns with the needs, resources, and ethical commitments of the program and that the information collected and communicated through the evaluation most accurately describes the program, its function, and its impact.

Utility

An overarching goal of the evaluation is to create an actionable evaluation report that can be easily understood by the intended audiences. It will describe data, but it should avoid sounding scientific and research-oriented in nature and instead communicate data and findings in ways that will be the most accessible and actionable to the largest audience.

Feasibility

When well designed, the evaluation design fits within the contextual limitations of the program from a funding, staffing, and skills-based perspective. Consider what data are already available to use in the evaluation before creating and implementing new data collection methods. Be realistic about the time and resources the evaluation will require and prioritize the most pressing evaluation questions, including questions relative to racial and health equity.

Propriety

Evaluators hold themselves and their process to the highest ethical standards. Data should be de-identified and protected. Those providing input into the evaluation process deserve assurance of the confidentiality of their responses. Full disclosures related to potential conflicts of interest ensure transparency and build trust. Centering the community's voice, or including the people most affected by local interventions, is essential to the evaluation process.

Accuracy

The evaluation should be held to the highest standards of precision in describing the program, its functions, progress toward its goals, and community impacts. The evaluation process employs sound data analysis methods and descriptions of those methods.

Preparing for the Evaluation: Engage Partners

A well-established and effective FIMR program is well-practiced in engaging diverse partners from across the community and systems that serve women, infants, and families. For the purposes of the FIMR evaluation, these partners would minimally include:

- FIMR team members from both the CRT and CAT
 - FIMR funding partners
 - FIMR's lead agency
 - Partner agencies and non-profit partners serving childbearing families
 - Academic partners
 - Organizations to whom recommendations are made
 - Bereaved families who have experienced fetal and infant losses
-

Each of these audiences can provide a unique perspective on the effectiveness and impacts of the FIMR process, and the complete picture of FIMR in the community requires varying levels of participation from all of them. Engagement may look different across these different types of partners, but ideally, these relationships will be well-established prior to implementing the evaluation. FIMR programs may have to consider how to most meaningfully collect input from these diverse groups, but the effectiveness of the program relies so heavily on these partnerships that the evaluation will not be the first context in which broad partner engagement is considered.





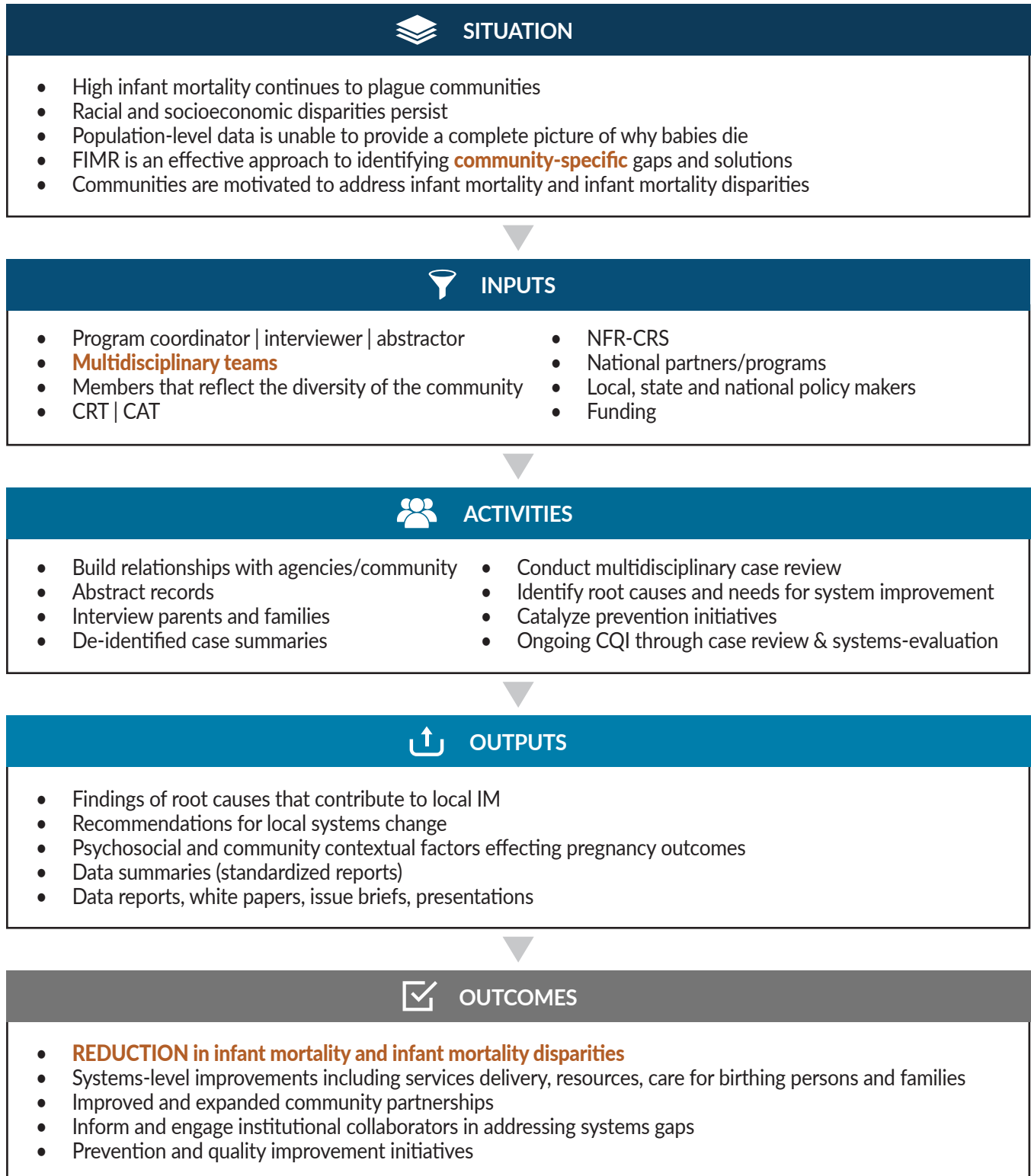
Preparing for the Evaluation: Describe the Program

The evaluators should thoroughly understand the program, explain the program as it is implemented in the local context, and present its intent to advance health equity. This will require both an understanding of the FIMR model as designed and the unique programmatic considerations of the local FIMR context in relation to racial equity. The program description considers the ways in which available resources, support, and political will allow the process to operate as intended. It also discusses the development and maturity of the program and its commitment or contribution to advancing health equity.

Logic models are a common tool employed by public health programs, intended to describe the community context, programmatic inputs, activities, outputs, and intended outcomes. The following logic model for FIMR, also shared in chapter 1, outlines these aspects of FIMR and the relationships between them. The logic model will also provide a helpful framework for considering data collection and drawing and justifying evaluation conclusions.

Figure 15. FIMR Logic Model

Goal: Decrease infant mortality and disparities through records abstraction, family interviews, case review, findings that relate to the root causes and recommendations and initiatives to improve systems of care.



Follow this link for an editable version of the [FIMR logic model](https://bit.ly/3uJrCMZ) (URL: <https://bit.ly/3uJrCMZ>).

Preparing for the Evaluation: Focus on Evaluation Design Purpose

Before undertaking the evaluation, the evaluator/evaluation team should clarify the purpose of the evaluation. Is it to determine if the FIMR program is functioning well? Is it to determine how FIMR is contributing to infant mortality reduction? Is it to determine the extent to which FIMR contributes to health equity? Clarifying the purpose matters because it will help shape the type of evaluation conducted and the methodology used.

Evaluation Types and Questions

The evaluation questions will guide every choice made by the evaluator. The evaluation questions create a boundary around the process, ensuring the evaluators know if and when the evaluation is complete. In the context of FIMR there are two common types of evaluations, and thus, two types of evaluation questions that may be appropriate.

1

Process Evaluation:

Process evaluations provide insights into program implementation, operations, and fidelity to a program model. Information from the process evaluation is used to plan, revise, or improve the program.³ Some examples of process evaluation questions FIMR teams have shared include:

- Is the program being implemented successfully?
- Are the case review meetings effective?
- Are team members meaningfully engaged and satisfied with their roles and level of participation?
- Is the team meeting the expectation of the number of review meetings, cases reviewed, interviews, etc.?
- What impact did external events, such as a pandemic, have on the FIMR process, and how did FIMR respond to challenges?
- How is FIMR mainstreaming information and data on the social determinants of health?
- How is FIMR incorporating processes that will advance racial and health equity?

2

Outcome Evaluation:

Outcome evaluations provide concrete insights into the programs' progress toward its goals and objectives; they measure the effects of the program.³ Some outcome evaluation questions FIMR teams have shared include:

- Is the FIMR program contributing to meaningful infant mortality reduction efforts in the short term? Interim? Long term? What do these efforts look like?
 - To what extent can changes in the community or systems be attributed to the FIMR program?
 - To what extent can changes in health equity be attributed to the FIMR program?
 - Did specific features or context of the program make a difference?
 - Were there any unintended outcomes—positive or negative—resulting from the FIMR's efforts?
 - Does the community (citizens, agencies, businesses, etc.) recognize FIMR as a legitimate prevention initiative?
-

Potential Audiences

Once the purpose has been established, determine to whom the information will be disseminated. What potential audiences will find the information helpful? Common audiences include the partners the program has initially engaged, including funding partners, lead agencies, FIMR team members, and partner agencies. If local or state-level policymakers are focused on issues related to maternal or infant health, it may be appropriate for the results to be shared with them.

Implementing the Evaluation: Gather Credible Evidence

Those familiar with the FIMR process are familiar with different types of data collection processes, whether it is more quantitative in nature, such as teams may see from abstracted vital records, medical records, or service records, or qualitative data from a family interview or case narrative. Program evaluation allows a similarly diverse approach to data collection, focusing on collecting data that demonstrates the effectiveness and impact of FIMR activities, identification of outputs, and measurement of outcomes. Using both quantitative and qualitative data provides a more robust understanding of local issues and personal experiences.

In addition to other available data, it will prove helpful to solicit input on the process from FIMR team members. Many FIMR programs create surveys for this purpose. The survey will allow evaluators to determine team members' satisfaction with case summaries, case reviews, case findings, commitment to health equity, recommendations, and implementation. This is also a good opportunity for them to provide feedback on the working relationship and feedback loops that exist between the FIMR CRT and the CAT.

An example of a FIMR evaluation survey is provided in the template package, [Appendix A](#).

Potential Data Sources

While not an exhaustive list, the following will provide some valuable data sources to support gathering evidence for the FIMR evaluation.

1

Key Informant Interviews:

Evaluators may conduct interviews with FIMR leaders, team members, or key partners to determine program strengths and opportunities for improvement. This may be helpful as a first step to help inform evaluation design and further data collection efforts.

2

Surveys:

Surveys are an appropriate data collection tool for evaluation and can be administered to FIMR CRT or CAT team members, community partners, and even family members who participate in FIMR parental interviews. This allows the evaluators to collect specific, quantitative data.

3

FIMR Work Plans, Membership Lists, and Strategic Planning Documents:

Program work plans will allow evaluators to compare outcome metrics to program goals, including number of cases reviewed and number of interviews conducted. Membership lists and strategic planning documents allow evaluators to understand and describe diversity and representativeness of team membership and ensure community voices are at the table for case reviews and CAT meetings.

4

NFR-CRS Data, Standardized Reports, and Data Quality Summaries:

FIMR case review data itself is helpful when understanding the effectiveness of records access, case abstraction, case review, findings, and recommendations. Standardized reports are built into the NFR-CRS to allow teams to easily access aggregated data around specific topics. Data quality summaries are provided to FIMR teams who enter 30 or more cases a year as part of the Data Quality Initiative. The report compares completeness, timeliness, and consistency of local program data entry for FIMR priority variables to national averages.

- [NFR-CRS and the Data Quality Initiative](https://bit.ly/3FNms82) (URL: <https://bit.ly/3FNms82>)
-

5

Vital Statistics Data

Vital statistics data can provide a clear picture of the burden of fetal and infant mortality across the community, disparities in the burden of mortality, and key demographic information related to the populations most at risk. Local or state health departments may conduct a Perinatal Periods of Risk (PPOR) analysis that will enrich understanding of excess mortality and populations most at-risk for poor outcomes. In addition to requesting data from the local or state health department, CDC's Wide-ranging Online Data for Epidemiologic Research (CDC Wonder) or Web-based Injury Statistics Query and Reporting System (WISQARS) may be helpful when determining if the findings, recommendations, and process improvements resulting from FIMR are aligned with the communities most at-risk as the team works to advance health equity.

- [PPOR](https://bit.ly/3BckQDi) (URL: <https://bit.ly/3BckQDi>)
- [WONDER](https://bit.ly/311J8IX) (URL: <https://bit.ly/311J8IX>)
- [WISQARS](https://bit.ly/32x0fg3) (URL: <https://bit.ly/32x0fg3>)

6

Pregnancy Risk Assessment Monitoring System (PRAMS) Data:

State-level PRAMS data provide teams with an understanding of experiences, risk factors, and protective factors that are common before, during, and after pregnancy and in a child's first months of life. It can also highlight disparities across maternal and infant populations.

- [PRAMS](https://bit.ly/3CJ0wsJ) (URL: <https://bit.ly/3CJ0wsJ>)
-

7

Community Needs Assessment Data:

Local health departments can provide data from community needs assessments to use in conjunction with FIMR data to determine if the findings and recommendations from the FIMR team reflect the pressing needs of the community and maternal and infant populations.

8

Other Population-Level Data

Population-level data from the U.S. Census, CDC's Social Vulnerability Index, and other sources focused on social determinants of health can provide rich contextual and social information at the local and even census-tract level to shed light on risk and protective factors in the communities experiencing fetal and infant mortality.

- [Census Data](https://bit.ly/3DUiNob) (URL: <https://bit.ly/3DUiNob>)
- [Social Vulnerability Index from CDC's Agency for Toxic Substances and Disease Registry](https://bit.ly/30W9g18) (URL: <https://bit.ly/30W9g18>)
- [Additional Sources for Data on Social Determinants of Health from CDC](https://bit.ly/3CIW88) (URL: <https://bit.ly/3CIW88>)

Note:

A more detailed description of what data can be used as credible evidence for FIMR evaluation can be found in the [Evaluation Supplement](https://bit.ly/3Elmann) (URL: <https://bit.ly/3Elmann>).





Community Commitment

There is one evaluation question that FIMR programs have asked, and it is significant enough to be highlighted here on its own. Most FIMR programs will seek family interviews with the intention of understanding and elevating the experience of the family in the community throughout the FIMR process. They will recruit diverse community members to ensure equitable reviews and recommendations. But are there ways to know if they have hit the mark? **How does a FIMR program determine if the community's voice has been heard?**

FIMR programs have suggested the following methods of assessing if the FIMR process is indeed hearing and prioritizing the community's voice in fatality review, findings, and recommendations.

- **Ensure that cases selected for review reflect the distribution of the burden of infant mortality in the community:** Commit to reviewing the cases likeliest to provide insights into community-level risk factors.
- **Conduct culturally congruent focus groups in the community:** Share FIMR findings and recommendations and ask if they align with the community's experiences.
- **Seek input from home visiting programs:** Ask home visiting programs if the findings and recommendations align with the family contexts they observe and the experiences families describe to them in the service delivery context.
- **Invite equity-focused organizations, such as NAACP, to speak on findings and recommendations:** Prioritize the voice of community advocates to craft key FIMR messaging and outcomes.
- Use existing infant mortality reduction coalitions such as Healthy Start Community Action Networks (CANs), evidence-based home visiting advisory boards, and similar community-oriented, action-focused coalitions and taskforces to support community engagement and prioritize community experts. Consider asking them to support focus groups or other community-level assessment efforts.

Implementing the Evaluation: Justify Conclusions

If collecting the data is the science of evaluation, justifying conclusions is the art. Interpreting the available data, creating findings, and making recommendations rely heavily on all of the previous steps of the evaluation process—effective partner engagement; thorough understanding and description of the way the program operates within the community context; clearly articulated evaluation purpose and potential audiences, and clear understanding of the quantitative and qualitative data—all in the larger context of the community. The conclusions will include findings and recommendations.

Evaluation Findings

Evaluation findings highlight the key takeaways from the qualitative and quantitative data and partner input and provide answers to the key evaluation questions. They summarize the data that were collected and summarize conclusion statements based on the data. Effective evaluation findings require the evaluator to weave a through-line between different data sources and feedback to draw conclusions.

Findings may identify program strengths as well as opportunities for improvement or growth. Some of the findings may not be directly related to the prescribed evaluation questions but may come into clear focus as incidental findings throughout the evaluation process. When sharing findings, it is valuable to include quantitative data and quotes from qualitative data collection that are illustrative of the conclusions.

Example Findings:

- 1 Based on input from partners and identified membership, the FIMR program continues to successfully engage partners across the community to address risk for infant mortality focusing on the social determinants of health and racial/health inequities.
- 2 FIMR case reviews would benefit from higher rates of family interviews to ensure findings and recommendations focus on the families' priorities and needs.



Evaluation Recommendations

They may look like program-improvement recommendations, focusing on suggested solutions or program improvement opportunities rooted in the feedback provided in the evaluation data. To ensure feasibility and a commitment to health equity, the National Center endorses a SMARTIE framework⁴ for recommendations to ensure recommendations are:

- Strategic
- Ambitious
- Time-bound
- Equitable
- Measurable
- Realistic
- Inclusive

Example Recommendations:

- 1 Seek interview before finalizing case selection: To prioritize family and community voices and increase rate of family interviews, prioritize following years' case selection and record abstraction **after** families have agreed to be interviewed, ensuring more family voices are heard in case review meetings.
- 2 Use local media to promote FIMR recommendations: Create and distribute press releases and share talking points with relevant local media outlets for SIDS awareness month in mid-September.

After the Evaluation: Share Lessons Learned

Once the data are collected and analyzed and conclusions have been drawn, maintaining a focus on the utility of the process, evaluators share what's been learned through the evaluation, as well as their programmatic recommendations, with their identified audiences. In some instances, it may be appropriate for evaluation findings and recommendations to be shared broadly with partner agencies, care providers, and coalitions. How a team chooses to disseminate evaluation findings, and what information is shared may vary based on program needs, resources, or intended audience.

A comprehensive evaluation report may have an outline somewhat different than the one described below, but it should minimally contain the following sections:

- Executive Summary:** The executive summary should be a brief, high-level summary focusing on the goals, process, findings, and recommendations. It should include the main points a reader should remember from a thorough read of the entire report.
- Project Introduction:** The project introduction should describe the program, including an overview of the local FIMR process; key partners; the Case Review Team (CRT) and Community Action Team (CAT); records access; case abstraction; family interviews; case review meetings; data collection and data entry; making findings; crafting recommendations; and implementing prevention activities.
- Evaluation Purpose and Objectives:** The purpose should be clearly stated early in the report, focusing on program improvement and monitoring. The objectives should outline key evaluation questions the evaluation and report seek to answer.
- Methodology:** The methodology section should summarize *who, what, and why*.
 - **Who** was given the opportunity to provide feedback? FIMR team members, community partners, partner agencies, and bereaved families should all be given the opportunity to engage and participate.
 - **What** data were used to answer the key evaluation questions? Describe the sources of the data and identify how data were collected, how many respondents surveys may have had, or how many interviews were conducted.
 - Briefly describe **why** these data and methods were appropriate to use in answering the evaluation questions.



- Evaluation Findings:** Evaluators may choose to group and present conclusions or findings in different ways, either by data source, by topics, or some other way that is meaningful and makes sense in the larger context of the evaluation report. There are several ways to organize this information in the report, including:
 - A broad data summary, followed by conclusions, or findings statements
 - Individual conclusion/findings statements, followed by justifications for each from the data

- Evaluation Recommendations:** The final section should highlight the recommendations of the evaluators based on the methods, data, findings, and broad community context.

Conclusion

Program evaluation for FIMR provides the opportunity to thoughtfully and critically consider the ways in which FIMR is maximizing its partnerships, resources, and impact, and ways to strengthen the program to support infant mortality reduction and health equity in communities. It gives programs the opportunity to celebrate and communicate their strengths while identifying feasible, actionable program improvements to further refine the FIMR process. It further builds accountability into the process, increasing the program's credibility and evidence base.

The National Center welcomes inquiries into effective evaluation strategies for FIMR at info@ncfrp.org.

Resources

The following resources will be helpful to any FIMR evaluator, but especially to those new to the process.

- [*The Nationwide Evaluation of Fetal and Infant Mortality Review \(FIMR\) Programs: Development and implementation of recommendations and conduct of essential maternal and child health services by FIMR programs*](https://bit.ly/2ZqgPwY) (URL: <https://bit.ly/2ZqgPwY>)
- [*Utilizing the Lean Process Improvement Methodology to Improve the Michigan FIMR Recommendation Process*](https://bit.ly/3oY1ZX5) (URL: <https://bit.ly/3oY1ZX5>)
- [Equitable Evaluation Framework](https://bit.ly/3r7WsA4) (URL: <https://bit.ly/3r7WsA4>): This evolving framework provides principles for conducting evaluations in an equitable way, and to evaluate equity in programs.
- [The Time is Now to Embed Equity in Evaluation Practices](https://bit.ly/3HKPzdT) (URL: <https://bit.ly/3HKPzdT>)
- [Equitable Evaluation Framework Applies to all Evaluation](https://bit.ly/3xiTdgy) (URL: <https://bit.ly/3xiTdgy>)
- [Equity and Evaluation: Models of How Equity Can and Does Impact Evaluation](https://bit.ly/3p4kCZI) (URL: <https://bit.ly/3p4kCZI>)

Endnotes

- 1 Centers for Disease Control and Prevention. *Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide*. U.S. Department of Health and Human Services; Atlanta, Georgia. October, 2011. Retrieved from: <https://www.cdc.gov/eval/guide/cdcevalmanual.pdf>.
- 2 Centers for Disease Control and Prevention. *A Framework for Program Evaluation*. Program Performance and Evaluation Office, May 15, 2017: <https://www.cdc.gov/eval/framework/index.htm>.
- 3 Issel, L. M., Wells, R., & Williams, M. (2014). *Health Program Planning and evaluation a practical, systematic approach for Community Health* (Third). Jones & Bartlett Learning.
- 4 <https://www.managementcenter.org/resources/smartie-goals-worksheet/>.

Appendix A: Template Package

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Position Descriptions: Fetal and Infant Mortality Review (FIMR)

PROGRAM DESCRIPTION

The overall goal of Fetal and Infant Mortality Review is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to these families. FIMR brings together key members of the community to examine information from individual cases of fetal and infant death to identify the factors that contributed to those deaths, determine if those factors represent system problems that require change, fashion recommendations for change and assist in the implementation of change.

1. Project Director

JOB RESPONSIBILITIES

This position is responsible for the management of the ongoing Fetal and Infant Mortality Review Program and supervision of staff as well as assuring adequate training for staff including abstractors and home interviewers. The director will work with key members of the community to determine how best to ensure that together these community leaders are able to develop recommendations and implement FIMR actions. The director serves as the program's liaison to community leaders, physicians, hospitals, related family service providers and agencies, as well as to civic groups, advocates and consumers. The director may be responsible for chairing team meetings, and developing written reports, grant proposals and other documentation pertaining to the program. Position reports directly to the County Commissioner of Health.

QUALIFICATIONS

A master's in Public Health, Public Administration, Nursing, Social Work or related field is preferred. The candidate must also demonstrate proven experience/skills in the health care field (pediatrics, obstetrics or related field), background in health program development and administration, complete understanding of the structure and functions of county and community health and related systems and resources, knowledge of the theory and practice of the continuous quality improvement model as it relates to community development, experience with data analysis, organizational and interpersonal skills; and have experience working with diverse populations and chairing complex, multi-organization meetings.

SALARY

Commensurate with skills and experience.

2. Project Coordinator

JOB RESPONSIBILITIES

This position is responsible for implementation of the day to day Fetal and Infant Mortality Review Program. This coordinator will supervise other FIMR staff who abstract case information, and conduct home interviews. Other activities include developing case summaries, scheduling and attending all team meetings and developing written minutes resulting from meetings. Also may include conducting some interviews with bereaved families, also tracking some medical records and serving as program liaison to the other community interviewers and to hospital medical records' departments. Position will report to program director.

QUALIFICATIONS

Bachelor's degree and minimum five years' experience in the health care field (pediatric, obstetric, public health or related fields). Understanding of community health care systems and resources, data analysis methods; organizational and interpersonal skills required for scheduling interviews. Background or training in bereavement counseling skills and cultural competency is mandatory.

SALARY

Commensurate with skills and experience.

3. Medical Human Service Records Abstractor

JOB RESPONSIBILITIES

The abstractor reviews and abstracts information from the medical records for the Fetal and Infant Mortality Review program. The abstractor regularly receives cases and forms from the program coordinator and completes them within a specified time period.

The abstractor is responsible for contacting hospitals to retrieve medical records for specified cases, reviewing records at each hospital, filling out appropriate abstraction forms and providing additional information on each case based on clinical interpretation of records. Most records are found at area hospitals, while additional records may be sought occasionally at other facilities. The abstractor will prepare medical records information and attend Case Review Team meetings, when possible. Position will report to the FIMR program coordinator.

QUALIFICATIONS

Clinical background in obstetrics and pediatrics, neonatology or perinatology. Medical or nursing degree preferred, strong knowledge of maternal and infant health required. Attention to detail. Flexibility, ability to accomplish tasks in short time frames. Computer skills, including familiarity with Microsoft Word. Must have own automobile with valid insurance.

SALARY

Commensurate with skills and experience.

4. Parent/Family Interviewer

JOB RESPONSIBILITIES

This position involves carrying out FIMR program tasks which include finding, contacting and interviewing the mother or another family member who has experienced the loss of a fetus or infant; gathering additional case information as needed; maintaining links with contract agencies and local providers; assisting in the development of case summaries; participating in case review group meetings; assisting in dissemination of program results to the community. Position will report to the FIMR program coordinator.

QUALIFICATIONS

Experience in home visiting, community outreach, case finding or conducting interviews. Excellent communication skills, sensitivity to needs and experiences of grieving families. Ability to work independently, with a flexible schedule, including some evenings and weekends. Knowledge of pregnancy and perinatal issues. Bachelor's degree preferred, with at least five years' experience in a community agency, health provider or similar setting. Must have car with valid insurance.

SALARY

Commensurate with skills and experience.



Fetal and Infant Mortality Review

Building/Maintaining Community Review Team (CRT) & Community Action Team (CAT) membership

1. Guiding principles for FIMR CRT and CAT membership
 - a. **Diversity:** memberships represent a wide array of personal and professional knowledge, expertise and experience, the ethnic and cultural diversity in the community and a broad, creative range of organizations including some who may not have been included in traditional maternal and child consortia.
 - b. **Influence:** refers to those policy makers, institutional and professional leaders, and/or organizational spokespersons who have the power to make decisions for and mobilize fiscal and programmatic resources on behalf of their agency or organization.
 - c. **Commitment: Champions!** Choose team members with a proven track record over time of putting what is good for women, infants and families before what is expected or convenient for his or her own organization or professional interest.
2. Family and Consumer Participation: It is recommended that consumers and individuals who live, work, worship, and play in the community chosen for FIMR and use its services and resources be included on CRT & CAT membership. Teams often include a family member who has suffered a fetal or infant loss in the roster of both the CRT and the CAT.
3. Work with existing groups or perinatal initiative that has the characteristics necessary to fulfill the role of the CRT & CAT when possible. Examples of such entities might include:
 - Prenatal/perinatal regional consortium
 - Community advisory board such as Home Visiting, NFP
 - Mayor's or county executive's blue ribbon panel on infant mortality
 - Healthy Mothers, Healthy Babies Coalition
 - Consortium for a federal Healthy Start project

4. Inviting Members: Members invited to the CRT and CAT will vary depending on the needs in the community. While not an inclusive list, these are suggested community members:

Agency/Individual	Agency/Individual	Agency/Individual
Key Community Leaders:	Public Health:	Health Care Providers:
Mayor	City or County Health Department representative	OB/GYN
County Executive	WIC	Maternal Fetal Medicine
Business Leaders (Chamber of Commerce)	Family Planning	Pediatrician
Civic, Social, or Fraternal groups (Kiwanis, Jaycees, etc.)	Immunizations	Emergency Medicine
Religious Leaders	Medicaid	Family Practice
Educators	Outreach Workers	Nursing (OB/PEDS)
Law Enforcement	Home Visitors	Social Workers
	Medical Examiner	Dieticians
Consumer/Advocacy Groups:	Human Service Providers:	Discharge Planners:
March of Dimes	Child Welfare	Childbirth Educators
Healthy Mothers/Healthy Babies	Substance Abuse Services	Hospital Administrators
MCH Coalitions	Mental Health Services	HMO/Managed Care Rep.
Perinatal Infant Grief Professionals	Domestic Violence Shelters/Services	State/County Medical Society
Consumer Representative, Bereaved Family Member	Department of Corrections	EMS Personnel
Family Support Groups	Housing Authority/Tenants Rights Groups	Dentist/Dental Technician
Racial & Ethnic Consumer/Advocacy Groups	Transportation Authority	Midwives
Women's Rights Groups		Doulas
Union/Workers Rights Groups		

Tips for recruiting:

- Members can recruit members!
- Use their interagency influence and connections to recruit other potential partners
- Tap the informal power of personal friendships among agency leaders in building support for FIMR
- Retirees make great recruits

5. Maintaining the momentum

- a. Consider the team's needs and availability when scheduling meetings, day, time and location can make a big difference
 - i. Day of the week - Give team members a voice, do a doodle poll or similar survey to determine if any ongoing conflicts with other obligations.
 - ii. Time of meetings:
 1. Early AM works for busy physicians, making hospital rounds then attending CRT meeting
 2. Lunch time is sometimes successful, even busy clinicians need to take time out to eat! "Brown Bag" lunch or provide refreshments
 3. Late Afternoon, early evening - a 4 p.m. to 6 p.m. meeting allows for participants to put in a pretty full work day and then attend the meeting
 - iii. Location: helpful to cut down on the amount of time participants have to travel to and from other jobs, work obligations. Hold meetings at the FQHC if there are several participants from that organization. Local Health Department, Hospital Cafeteria side room, Library, City Hall, Department of Human Services are all suggestions that have worked for other FIMRs.
 - iv. "Blitz" reviews – review teams meet less frequently and review multiple cases at a time to accommodate very busy schedules or rural areas with prohibitive travel restrictions.
- b. Feed people! If at all possible, offer light refreshments or a modest meal when meeting over breakfast, or lunch time. If the administrative agency does not have the financial resources to offer food, consider alternating the responsibility among participant agencies. It takes a bit of coordinating, but most agencies could spring for a meal once a year.
- c. Lay down ground rules, and stick to them! Value and respect all participants time, their voice, their contributions to the FIMR process (See a sample of a team "Charter").
- d. Consider providing physician and other professional CEUs for FIMR CRT meetings.
- e. Celebrate successes! From time to time, take a break from review activity to do a social gathering, do a presentation on a year's worth of review findings and successful interventions driven by FIMR. Nothing keeps folks engaged more than the realization that they are making a big difference in the community.
 - i. Annual Holiday Party or Summer break/celebration
 - ii. Give awards or certificates of appreciation to long standing members
 - iii. Do quarterly newsletters featuring members in the "spot light", highlight FIMR findings and successes

Letterhead or logo

Date _____

Dear Dr. Smith,

My name is Jennifer Miller, and I work with the Saginaw County Department of Community Health. I am getting in touch to alert you to a growing public health crisis. Last year in Saginaw County, 24 babies died before reaching their first birthday, for a rate of 8.2 infant deaths for every 1,000 live births (***insert your own community statistics***). While infant mortality in the United States has improved in the past few years, disparities persist between whites and persons of color, especially African Americans, Latinos and Native Americans. The Black infant mortality rate for residents of Saginaw County last year was 16.5 deaths per 1,000 live births, a rate 3 times higher than their white counterparts.

Infant mortality serves as a measure of a community's general health status as well as its social and economic well-being. Fetal and Infant Mortality Review (FIMR) is a community owned, action-oriented process that results in improved service systems and resources for women, infants and families. The FIMR process brings a community team together to examine ***confidential, de-identified*** cases of infant deaths. The purpose of these reviews is to understand how a wide array of local social, economic, public health, educational, environmental and safety issues relate to the tragedy of infant loss. After the review, a broad forum of interested community members-leaders, elected officials, providers, agencies, and advocates make recommendation to prevent future fetal and infant deaths.

We are developing an implementation plan for a FIMR in Saginaw County. We invite you to learn more about the process and hope to gain your commitment and buy in at upcoming community Town Hall Meeting:

March 3, 2018
Janes Street Community Health Center
5 p.m. – 7 p.m.
Speaker: Joseph F. Marshall, MD, FACOG
Light refreshments will be served

If no meeting is planned, end with general information on how stakeholders could communicate their willingness to participate to the sender.

We hope to see you at the meeting, along with your colleagues in Obstetrics, Pediatrics, Maternal Fetal Medicine, Nursing, Social work, lactation support, and mental health just to name a few. If you cannot make the Town Hall meeting but are interested in FIMR, please contact: Jennifer Miller: 517-326-8319, or jmiller@scdph.org (***insert program coordinator's name and contact information***).

Most sincerely,

Jennifer Miller, RN, MSN
Saginaw County Department of Community Health
1214 Addison Street, Saginaw, MI 48365

A sample agenda for a CRT meeting orientation may look like:

Sample Agenda for an orientation meeting for the Case Review Team

What	How (Process)	Who	When
<ul style="list-style-type: none"> • Welcome/Purpose • Ground Rules • Review of Agenda 	<ul style="list-style-type: none"> • Review • Clarify • Agree 	Meeting Leader	1:00 p.m. - 1:15 p.m.
Introductions, getting acquainted exercise		Group, Meeting Leader	1:15 p.m. - 1:30 p.m.
Racial and Health Equity in FIMR	<ul style="list-style-type: none"> • Inform 		1:30 p.m. - 3:30 p.m.
Break			3:30 p.m. - 3:45 p.m.
Confidentiality and the FIMR process	<ul style="list-style-type: none"> • Review 	Meeting Leader	3:45 p.m. - 4:00 p.m.
Objectives of the FIMR program	<ul style="list-style-type: none"> • Review • Clarify 	Meeting Leader	4:00 p.m. - 4:15 p.m.
Data collection <ul style="list-style-type: none"> • Records abstraction • Family interviews 	<ul style="list-style-type: none"> • List • Clarify 	Group, Meeting Leader	4:15 p.m. - 4:30 p.m.
Mock cases and team deliberation tools	<ul style="list-style-type: none"> • Practice/ • Explore 	Group	4:30 p.m. - 4:50 p.m.
Q&A for New Members	<ul style="list-style-type: none"> • Discuss 		
Next meetings - set schedule	<ul style="list-style-type: none"> • Agree 	Group	4:50 p.m. - 5:00 p.m.
Adjourn			5:00 p.m.

If time and schedules do not permit a half day orientation meeting, it may be divided into two sessions holding the Racial and Health Equity session as its own meeting.



Outline of Duties Fetal Infant Mortality Review (FIMR) Program Abstractor

The role of the FIMR program abstractor is to create the de-identified case summary of the fetal or infant death that will be reviewed by the CRT (Case Review Team).

The Abstractor:

- i. Receives case information (birth and death certificates) from the Program Coordinator.
- ii. Retrieves and reviews the medical records information from the mother and infant hospital charts.
- iii. Retrieves and reviews the medical records information from the prenatal care provider.
- iv. Retrieves and reviews the medical records information from the pediatric care provider or family practice provider.
- v. Retrieves and reviews all records from the medical examiner's office in event of Post Neonatal deaths, including death scene investigation.
- vi. Obtains histories and case information from local law enforcement.
- vii. Acts as liaison to other program service agencies to retrieve information on the support services the mother and family may have had during the pregnancy and after deliver, to include but may not be limited to:
 - a. Department of Human Services (Child Protective Services)
 - b. Substance Abuse Coordinating Agencies
 - c. Local Public Health
 - i. WIC
 - ii. Home Visiting
 - iii. Family Planning
 - iv. Children's Special Health Care
- viii. Prepares all the available case information, including the Home Interview into the de-identified case summary that will be presented to the Case Review Team.
- ix. Attends Case Review Team meetings whenever possible.
- x. Enters case information into the National Fatality Review Case Reporting System (NFR-CRS) or other designated database.

Mission:

To protect, promote & improve the health of all people in Florida through integrated state, county & community efforts.



Ron DeSantis
Governor

Scott A. Rivkees, MD
State Surgeon General

Vision: To be the Healthiest State in the Nation

March 16, 2020

Dear Health Care Provider/Facility Administrator:

Reducing the number of infant deaths is a national and state public health priority. In partnership with health care providers of mothers and infants, the Florida Department of Health (Department) has a Fetal and Infant Mortality Review (FIMR) process in place. The purpose of FIMR is to review fetal, neonatal, and post-neonatal deaths in order to identify system factors that may have been associated with these deaths. Reviews are conducted by local Case Review Teams with a primary objective to identify possible gaps in the health care system or in services. The review team recommends community activities and actions to improve outcomes. Your support of the FIMR process is vital. I urge you, as a key partner in this process, to facilitate access to information for review of these cases.

The Health Insurance Portability and Accountability Act (HIPAA) privacy regulations allow release of protected health information without specific client consent for public health investigations, 45 CFR 164.512(b). In addition to HIPAA, the Department is afforded review authority under sections 395.3025(5), 405.01, and 405.02, Florida Statutes.

During the FIMR process, trained professionals operate under strict federal and state confidentiality rules to abstract information from the records of FIMR-identified cases. FIMR abstractors gather information from birth and death certificates, medical records, autopsy reports, and family interviews. Standard medical abstraction forms are used to collect relevant information that FIMR abstractors summarize for the review process. All names of providers, institutions, and families are carefully redacted from these summaries. The summaries are then presented to a local interdisciplinary Case Review Team for interpretation, conclusions, and recommendations. The review team identifies gaps in care or service delivery and makes recommendations regarding the health care system and related policies, noting both assets and needed improvements. Community-based activities to increase knowledge and to address issues such as prematurity, racial disparities, substance abuse, interconception health, perinatal health, safe sleep, and bereavement support have been implemented as a result of previous FIMR recommendations.

The intent of the FIMR process is not to imply blame or substitute for institutional or professional peer review. The FIMR process plays an important role toward achieving the goal set by the Department's Health Equity Program Council's Florida Healthy Babies Initiative to reduce racial disparity in infant mortality. Through the initiative, the Department's 67 county health departments are working with public and private sector partners to identify, evaluate, prioritize, and address health disparities with evidence-based interventions.

I appreciate your cooperation in this endeavor to further promote and protect the health and safety of Florida's infants.

Sincerely,

Scott A. Rivkees, MD
State Surgeon General

Florida Department of Health
Office of the State Surgeon General
4052 Bald Cypress Way, Bin A-00 • Tallahassee, FL 32399-1701
PHONE: 850/245-4210 • FAX: 850/922-9453
FloridaHealth.gov

Accredited Health Department
Public Health Accreditation Board

Date

Name of Hospital or Provider's office
Street Address
City, State, Zip Code

Dear:

_____ (*Name of supporting agency*) _____ and the **Fetal and Infant Mortality Review (FIMR) Project** is a countywide effort to better understand the issues associated with fetal and infant mortality and morbidity and to develop strategies that improve perinatal systems of care, locally and statewide.

FIMR is supported by the federal Maternal Child Health Bureau of the Health Resources and Service Administration (HRSA). Florida adopted the FIMR model in 1992. The Healthy Start Coalition of Miami-Dade has been contracted by the State of Florida to implement FIMR locally. FIMR of Miami-Dade County is one of 12 FIMR projects statewide organized under Florida Statute 766.101 and funded by the State of Florida (**insert state and local FIMR information**).

The project gathers information from birth and death certificates, hospital and provider medical records, law enforcement records, Medical Examiner reports, and family interviews on standardized abstraction forms from National Center for Fatality Review and Prevention's **National Fatality Review Case Reporting System (NFR-CRS)**. Abstracted information is summarized and identifying information such as **names of providers, patients, and facilities are removed from the summaries in order to maintain confidentiality**. These **anonymous, de-identified summaries or cases** are presented to a Case Review Team (CRT), comprised of a multidisciplinary team of professionals, for review, conclusions, and recommendations. **The purpose of the review is not to find fault but to discover patterns of contributing factors and develop strategies that improve perinatal systems of care in _____ (name of county and state) _____.**

Under the Health Insurance Portability and Accountability Act (HIPAA), as a healthcare provider/facility administrator you are specifically permitted to release protected health information to the public health authority without patient consent for public health surveillance, investigations or interventions (45 CFR § 164.512(b)). Florida Law also provides protection from liability for disclosing the information for "...any study for the purpose of reducing morbidity or mortality." (405.01, F.S.). **Attach any relevant state statute or public health code.** All FIMR Project staff have HIPAA training on protecting private health information (PHI) and the HSCMD has internal policies that protect PHI.

You have been a key partner in the FIMR process in the past and we hope that you will continue to facilitate access to information for this public health endeavor to promote and protect the health and wellbeing of women, infants, and families in our community.

We are requesting case information on the following client:

Request for Medical Records

Infant Death Fetal Death

--	--

Infant Name: _____

Infant Record #: _____

Mother's Name: _____

Mother's Record #: _____

Dates of Treatment:

The following information from this patient's record is requested:

- | | | |
|------------------------|---------------------------|---------------------------|
| Admission History | Pathology (fetal autopsy) | Bereavement Notes: |
| Obstetrical History | Labor & Delivery Summary | (Social worker, pastoral) |
| Obstetrical Flow Sheet | Lab Results | Discharge Summary |
| Pathology (Placental) | Ultrasound Reports | Consultations |

If you have any questions, please call me _____ (name), FIMR Medical Records Abstractor, at _____ (phone number). Thank you in advance for your assistance and cooperation.

Sincerely,

Name of abstractor
FIMR Medical Record Abstractor
Organization
Address
Email
Phone number
Fax number



Sample Consent for Parental Interview

Purpose of the Interview

(NAME of sponsoring agency) is conducting a Fetal and Infant Mortality Review (FIMR) Program. The purpose of this program is to identify ways we can strengthen the systems of care and resources available to families, to prevent future deaths. We talk to parents and families who have who have recently experienced a loss, with the hope of learning from you how we can prevent other families from experiencing such a loss. Your participation is voluntary. If you agree to participate, a trained interviewer from the **(NAME of sponsoring agency)** will listen to your story and ask you some questions about the death of your baby and about your pregnancy, health, family and use of health care and social services. The interview will take place in your home, **by phone**, or in a convenient location of your choosing, at a time that is best for you. The interview will take about one hour. Although participation in this program may not benefit you or your family directly, it may help to prevent other families in the future from losing their baby.

Description of Potential Risk

Talking about the death of your baby may be sad or difficult for you. The interviewer is not a professional counselor but if you wish, will give you the names of professional people who can help you deal with the loss of your baby. If, during the interview, you feel you do not want to continue, you may ask the interviewer to stop the interview at any time. You may also choose not to answer any specific question. There is no expected risk of injury for participants in this study.

Description of Potential Benefits

Participation in the interview may be a positive experience for you. You may find that talking about the death of your baby can help ease the pain of your loss. In addition, the information you provide to this program may help prevent the loss of a baby for future families.

Confidentiality of Records

All information that identifies you, your family or your health providers will be removed before the interview questionnaire is reviewed. All Fetal and Infant Mortality Review staff and consultants have signed an oath of confidentiality. Therefore, confidentiality will be protected to the full extent permitted by law. Your information will only be shared with the multidisciplinary community team.

Mandated Reporters

The FIMR interviewer is a mandated reporter, by law. Every effort is made keep all information you share with the program confidential and anonymous. If, however, during the interview, abuse or neglect of your baby, or suspected abuse or neglect of surviving children in the home is revealed, the interviewer must follow state law about reporting it to the appropriate Child Welfare Agency.

Voluntary Participation

Your participation in this program is completely voluntary and you may decline to answer any questions that you do not wish to answer. You are also free to end the interview at any time without any consequences to you or your family.

Questions

If you have questions concerning the interview or the Fetal and Infant Mortality Review Program, you may call (*name of contact person*), collect, at the (*name of sponsoring Agency*) at (*contact phone number*).

Consent

I have read this form and understand the purpose and conditions for participation in the Fetal and Infant Mortality Review Program. I agree to participate in an interview. I understand that all information obtained from the interview will be strictly confidential, and that neither my name, my baby's name nor the name of anyone else in my family will appear in any publications or reports or be given to anyone else.

Consent to release name and contact information (optional)

I give consent for my name and contact information to be released for the purpose of referrals for additional services.

Date _____ Signature _____

I consent to receiving future follow-up visits from the FIMR personnel. I understand that these are voluntary, and I may discontinue these services at any time.

Date _____ Signature _____

Print Name:

Signature:

Date:

Interviewer's Name:

Interviewer's Signature:

Date:

Template for a FIMR “Team Charter”

The Carroll County Fetal and Infant Mortality Review team includes dynamic community leaders such as public and private non-profit agency heads, business owners, public health professionals, health care providers, community members and others interested in and able to take the lead to actively implement community specific, culturally competent actions that will lead to healthier mothers and babies.

As the sponsor agency, the Carroll County Health Department will be responsible for:

- The Carroll County Health Department will apply for and administer a grant from the Center for Maternal and Child Health of the Maryland Department of Health and Mental Hygiene. The Health Department will maintain minimal staff to operate the FIMR program, including the FIMR Coordinator/abstractor, a maternal interviewer, and a Community Action Team meeting facilitator.
- Meetings will start and end on time and will be held quarterly on the first Friday of the month unless otherwise designated by the FIMR coordinator.
- All meetings will be held at the Carroll County Health Department, 290 South Center Street, Westminster, MD 21157 from 12:00 to 2:00 with a light lunch provided.
- Meetings will be facilitated to ensure that all members are listened to respectfully, every member has the opportunity to speak, and one person speaks at a time.
- Nominal group process will be used to resolve difficult and to make difficult decisions.
- The Carroll County Health Department will generate an annual FIMR report that will be disseminated to community and state level leaders.

As a voluntary member of the Carroll County FIMR Case Review Team (or Community Action Team) I will be responsible for:

- All FIMR team members will strive to serve in a capacity which meets the Mission of the FIMR program, with strict attention to professionalism and respect in working with other team members and community groups to implement change.
- All FIMR team members will agree to serve a 2-year term with the option of extension of that term of office.
- Each team member must pledge to work actively to implement annual changes in service systems and resources for women, infants and families.
- As an effective team member, I will:
 - Listen respectfully
 - Be tough on ideas, not team members (no personal attacks)
 - Not tolerate the use of stereotypes or prejudicial comments
- Refrain from discussing or sharing information about the case, the case summary and the proceedings of the CRT outside of the CRT meeting.

Signature: _____

Date: _____



FIMR Glossary

National Fatality Review Case Reporting System

Version 5.0



Data entry website: <https://data.ncfrp.org>

1-800-656-2434

info@ncfrp.org

www.ncfrp.org

SAVING LIVES TOGETHER

Glossary of Terms, Diagnoses and Procedures

This glossary contains basic information to assist non-medical members of the Case Review Team to understand common terms, diagnoses and procedures that they might encounter in review of individual cases. (It may also be of use to the Community Action Team members.) Local programs should feel free to add or delete items, as needed.

Please do not feel that these terms need to be memorized. Use this document as a dictionary and refer to it as needed. Experience tells us that after a year or so of reviewing cases, all team members will naturally come to an understanding of these terms, as well as others, without making any special effort.

The following definitions are adopted from: American College of Obstetricians and Gynecologists. Your pregnancy and birth. 4th Ed. Washington, DC: ACOG; 2005 pp 353–361.

Amniocentesis: A procedure in which a small amount of amniotic fluid and cells are taken from the sac surrounding the fetus and tested.

Amniotic Fluid: Water in the sac surrounding the fetus in the mother's uterus. **Analgesics:** A type of drug that relieves pain without loss of muscle function. **Anemia:** Abnormally low levels of blood or red blood cells in the bloodstream.

Anencephaly: A type of neural tube defect that occurs when the fetus's head and brain do not develop normally.

Anesthetics: A type of drug that relieves pain by causing a loss of sensation.

Antibodies: Proteins in the blood produced in reaction to foreign substances, an antigen.

Antigen: A substance, such as an organism causing infection or a protein found on the surface of blood cells, that can induce an immune response.

Apgar Score: A measurement of a baby's response to birth and life on its own, taken two and five minutes after birth.

Autopsy: An exam performed on a deceased person in an attempt to find the cause of death.

Bacterial Vaginosis: A type of vaginal infection caused by the overgrowth of a number of organisms that are normally found in the vagina.

Bilirubin: A reddish-yellow pigment that occurs especially in bile and blood and may cause jaundice.

Biophysical Profile: An assessment by ultrasound of fetal breathing, fetal body movements, fetal muscle tone and the amount of amniotic fluid. May include fetal heart rate.

Braxton Hicks Contractions: False labor pains.

Breech: A situation in which a fetus' buttocks or feet would be born first.

Carrier: A person who shows no signs of a particular trait or disorder but has the gene and could pass the gene on to his or her children.

Cephalopelvic Disproportion: A condition in which a baby is too large to pass safely through the mother's pelvis during delivery.

Cerclage: A procedure to sew the cervix shut.

Cervix: The lower, narrow end of the uterus, which protrudes into the vagina

Cesarean Delivery: Birth of a baby through an incision made in the mother's abdomen and uterus.

Chlamydia: A sexually transmitted disease that can lead to pelvic inflammatory disease, infertility and problems during pregnancy.

Chorioamnionitis: Inflammation or infection of the membrane surrounding the fetus.

Chorionic Villus Sampling (CVS): A procedure in which a small sample of cells is taken from the placenta and tested.

Cleft Palate: A congenital defect in which a gap or space occurs in the roof of the mouth.

Clubfoot: A misshaped foot twisted out of position from birth.

Congenital Disorder: A condition that is present in a baby when it is born.

Contraction Stress Test: A test in which mild contractions of the mother's uterus are induced and the fetus's heart rate in response to the contractions is recorded using an electronic fetal monitor.

Corticosteroids: Hormones given to mature fetal lungs, for arthritis or other medical conditions.

Crowning: The appearance of the baby's head at the vaginal opening during labor.

Cytomegalovirus (CMV): A virus in the herpes virus family that can be passed on to a baby during pregnancy, birth or breastfeeding and can cause problems with the liver, hearing, vision and mental functioning.

Diabetes: A condition in which the levels of sugar in the blood are too high.

Diastolic Blood Pressure: The force of the blood in the arteries when the heart is relaxed; the lower blood pressure reading.

Doppler: A form of ultrasound that reflects motion—such as the fetal heartbeat—in the form of audible signals.

Down Syndrome: A genetic disorder in which mental retardation, abnormal features of the face and medical problems such as heart defects occur.

Ectopic Pregnancy: A pregnancy in which the fertilized egg begins to grow in a place other than inside the uterus, usually in the fallopian tubes.

Edema: Swelling caused by fluid retention.

Effacement: Thinning of the cervix during the beginning stages of labor.

Electrode: A small wire that is attached to the scalp of the fetus to monitor the heart rate.

Electronic Fetal Monitor: An electronic instrument used to record the heartbeat of the fetus and contractions of the mother's uterus.

Embryo: The developing fertilized egg of early pregnancy.

Epidural Block: Anesthetic that numbs the lower half of the body.

Episiotomy: A surgical incision made into the perineum (the region between the vagina and the anus) to widen the vaginal opening for delivery.

Fetal Alcohol Syndrome: A pattern of physical, mental and behavioral problems in the baby that are thought to be due to alcohol abuse by the mother during pregnancy.

Fetal Monitoring: A procedure in which instruments are used to record the heartbeat of the fetus and contractions of the mother's uterus during labor.

Fetus: A baby growing in the woman's uterus.

Fibronectin: A type of protein made by the fetus that can be measured in secretions from the cervix.

Forceps: Special instruments placed around the baby's head to help guide it out of the birth canal during delivery.

Fragile X Syndrome: A genetic disease, inherited through the X-chromosome, that is the most common inherited cause of mental retardation.

Fraternal Twins: Twins, developed from two fertilized eggs, who are not genetically identical.

General Anesthesia: The use of drugs that produce a sleep-like state to prevent pain during pregnancy.

Gestational Diabetes: Diabetes that arises during pregnancy.

Gestational Hypertension: High blood pressure that occurs during the second half of pregnancy and disappears soon after the baby is born.

Glucose: A sugar that is present in the blood and is the body's main source of fuel.

Gonorrhea: A sexually transmitted disease that can lead to pelvic inflammatory disease, infertility and arthritis.

Hepatitis B Immune Globulin: A substance given to provide temporary protection against infection with hepatitis B virus.

Hepatitis B Virus: A virus that attacks and damages the liver, causing inflammation.

Human Chorionic Gonadotropin (hCG): A hormone produced during pregnancy; its detection is the basis for most pregnancy tests.

Human Immunodeficiency Virus (HIV): A virus that attacks certain cells of the body's immune system and causes acquired immunodeficiency syndrome (AIDS).

Human Papillomavirus (HPV): The common name for a group of related viruses, some of which cause genital warts and are linked to cervical changes and cervical cancer.

Hydramnios: A condition in which there is an excess amount of amniotic fluid in the sac surrounding the fetus.

Hyperemesis Gravidarum: Severe nausea and vomiting during pregnancy that can lead to loss of weight and body fluids.

Identical Twins: Twins, developed from a single fertilized egg, who usually are genetically identical.

Jaundice: A buildup of bilirubin that causes a yellowish appearance.

Kick Counts: Records kept during late pregnancy of the number of times a fetus moves over a certain period.

Labor Induction: Using medical or surgical methods to stimulate contractions of the uterus.

Local Anesthesia: The use of drugs that prevent pain in a part of the body.

Macrosomia: A condition in which a fetus grows very large.

Meconium: A greenish substance that builds up in the bowels of a growing fetus.

Miscarriage: Early pregnancy loss.

Multiple Pregnancy: A pregnancy in which there are two or more fetuses.

Neural Tube Defects: Birth defects that result from incomplete development of the brain, spinal cord or their coverings.

Nonstress Test: A test in which changes in the fetal heart rate are recorded, using an electronic fetal monitor.

Nuchal Translucency Screening: A special ultrasound test of the fetus to screen for the risk of Down syndrome and other birth defects.

Oxytocin: A hormone used to help bring on contractions of the uterus.

Perineum: The area between the vagina and the rectum.

Pica: The urge to eat nonfood items.

Placenta Previa: A condition in which the placenta lies very low in the uterus, so that the opening of the uterus is partially or completely covered.

Placenta: Tissues that provides nourishment to and takes away waste from the fetus.

Placental Abruption: A condition in which the placenta has begun to separate from the inner wall of the uterus before the baby is born.

Polydactyly: The condition of having more than the normal number of fingers or toes.

Postpartum Blues: Feelings of sadness, fear, anger or anxiety occurring about three days after childbirth and usually going away (ending) within 1-2 weeks.

Postpartum Depression: Intense feelings of sadness, anxiety or despair after childbirth that interfere with a new mother's ability to function and that do not go away after two weeks.

Pre-eclampsia: A condition of pregnancy in which there is high blood pressure and protein in the urine.

Premature Rupture of Membranes: A condition in which the membranes that hold the amniotic fluid rupture before labor.

Preterm: Born before 37 weeks of pregnancy.

Pyelonephritis: An infection of the kidney.

Respiratory Distress Syndrome: A condition causing breathing difficulties in some babies in whom the lungs are not mature.

Rh Factor: A kind of protein in some types of blood that causes responses in the immune system.

Rh Immunoglobulin (Rhlg): A substance given to prevent an Rh-negative person's antibody response to Rh-positive blood cells.

Rupture of Membranes: The breaking of the amniotic sac that surrounds the fetus. Spina Bifida: A neural tube defect that results from incomplete closure of the fetal spine. Spinal Block: A form of anesthesia that numbs the lower half of the body.

Stillbirth: Delivery of a baby at 20 or more weeks' gestation that shows no sign of life. While state's definitions of stillbirth may vary and be different from this one, please use this definition for the purposes of the Case Reporting System.

Sudden Infant Death Syndrome (SIDS): The unexpected death of an infant in which the cause is unknown.

Surfactant: A substance, coating the air sacs in the lungs that helps the lungs expand.

Syphilis: A sexually transmitted disease that is caused by an organism called *Treponema pallidum*; it may cause major health problems or death in its later stages.

Systemic Analgesics: Drugs that provide pain relief over the entire body without causing loss of consciousness.

Systolic Blood Pressure: The force of the blood in the arteries when the heart is contracting; the higher blood pressure reading.

Teratogens: Agents that can cause birth defects when a woman is exposed to them during pregnancy.

Tocolytics: Medications used to delay preterm labor.

Toxoplasmosis: An infection caused by *Toxoplasma gondii*, an organism that may be found in raw and rare meat, garden soil and cat feces and that can be harmful to the fetus.

Transducer: A device that emits sound waves and translates the echoes into electrical signals.

Trichomoniasis: A type of vaginal infection caused by a one-celled organism that usually is transmitted through sex.

Trimesters: The three-month periods into which pregnancy is divided.

Ultrasound: A test in which sound waves are used to examine internal structures; during pregnancy, it can be used to examine the fetus.

Umbilical Cord: A cord-like structure containing blood vessels that connects the fetus to the placenta.

Vacuum Extraction: The use of a special instrument attached to the baby's head to help guide it out of the birth canal during delivery.

Vertex Presentation: A normal position of a fetus in which the head is positioned down, ready to come through the vagina first.

Vibroacoustic Stimulation: The use of sound and vibration to wake the fetus during a nonstress test.

Confidentiality Statement/Meeting Sign-in Sheet

Meeting Date _____

The purpose of FIMR to examine confidential, de-identified cases of fetal and infant deaths for the purpose of identifying gaps in care and make recommendations to improve services and systems of care for women, infants, and families. Information for the case summaries prepared for this meeting has been gathered from a variety of sources, many of which are covered entities under the Privacy Rule.

The grant of authority for local teams to carry out Fetal Infant Mortality Review activities comes from _____ **(enter specific authority here)** The Department considers FIMR to be an investigation into the causes of mortality for which disclosure of protected information by covered entities is authorized by 45 CFR § 164.517 (b) of the federal Privacy Rule. **(If there is any jurisdiction public health code to support, enter here.)** Communities are charged to "...collect and utilize vital and health statistics and make investigations and inquiries as to the causes of disease and the causes of morbidity and mortality."

While every effort is made by the FIMR staff to de-identify cases, it is understood that team members will refrain from naming individuals (if recognized) including family members, providers, and institutions. Team members will not share anecdotal information during the review, nor will they share or discuss information about individual cases and the FIMR proceedings outside of the meeting. Public statements about the general purpose of FIMR and Infant Mortality Reduction strategies may be made, as long as they are not identified with any specific case.

The undersigned has read the above statement, understands its meaning, and agrees to abide by the terms of this confidentiality statement:

_____	_____
Name	Agency
_____	_____
Name	Agency
_____	_____
Name	Agency
_____	_____
Name	Agency
_____	_____
Name	Agency

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Sample Agenda* for a first FIMR Planning Meeting

A 1½ hour town meeting including MCH providers, agencies and community members who will participate as team members in the FIMR process.

Purpose: To build consensus to implement the FIMR process.

Desired Outcomes:

- Introduce FIMR community team members
- Increase participants' understanding of the benefits of FIMR
- Compose an action plan to initiate FIMR

What	How (Process)	Who	When
<ul style="list-style-type: none"> • Welcome/Purpose • Ground Rules • Review of Agenda 	<ul style="list-style-type: none"> • Review • Clarify • Agree 	Meeting Leader	5:00 p.m. - 5:15 p.m.
Introductions, getting acquainted exercise	<ul style="list-style-type: none"> • List 	Group, Meeting Leader	5:15 p.m. - 5:30 p.m.
Brief Overview of MCH Vital Statistics	<ul style="list-style-type: none"> • Review 	Meeting Leader	5:30 p.m. - 5:45 p.m.
Benefits of FIMR	<ul style="list-style-type: none"> • Review • Clarify 	Meeting Leader	5:45 p.m. - 6:00 p.m.
Mission Statement Development	<ul style="list-style-type: none"> • List • Clarify • Agree 	Group, Meeting Leader	6:00 p.m. - 6:15 p.m.
Next steps	<ul style="list-style-type: none"> • List • Clarify • Agree 	Group, Meeting Leader	6:15 p.m. - 6:25 p.m.
Adjourn			6:30 p.m.

* Note: Communities should modify this agenda to best suit their needs.



Preliminary Recommendations and Actions

Case Number: _____

Date of Review: _____

<i>Issues</i>	<i>Working Recommendations</i>	<i>Referred To:</i>
Medical		
Psycho-Social		
Environmental		

Sample FIMR Evaluation Survey

Assessing FIMR Case Review and Community Action Team members' satisfaction with the process

Sample Survey:

We welcome your feedback on how well this FIMR team is doing. For each item, please circle the number that best shows your satisfaction with that aspect of the FIMR team. Provide additional comments if you wish.

1= very dissatisfied 2=dissatisfied 3= neither satisfied nor dissatisfied 4=satisfied 5= very satisfied

1. Clarity of the mission for where the FIMR team should be going	1	2	3	4	5
2. Planning process used to prepare the FIMR team's objectives	1	2	3	4	5
3. Follow through on FIMR team activities	1	2	3	4	5
4. Strength and competence of staff	1	2	3	4	5
5. Processes used to assess the community's needs	1	2	3	4	5
6. Quality of FIMR collaborative actions	1	2	3	4	5
7. Number of systems changes carried out by the FIMR team	1	2	3	4	5

Evaluating components of the FIMR process

Data Collection:

- Number of cases identified for review
- Number of cases fully abstracted
- Home interviews
 - Number of completed home interviews
 - Number attempted but lost to follow-up
 - Barriers/reasons for not completing home interviews

Case Review:

- Membership of the Case Review Team
 - Number of members
 - Organizations/agencies represented
 - Distribution by professional background
 - Distribution by race/ethnicity
 - Length of team members' service
 - Reasons for turnover
- Number of meetings held annually
- Number of cases reviewed by CRT
 - Fetal deaths
 - Infant deaths

Community Action:

- Membership of the CAT
 - Number of members
 - Number and type of leadership roles
 - Organizations/agencies represented
 - Distribution by professional background
 - Distribution by race/ethnicity
 - Length of team members' service
 - Reasons for turnover
- Number of meetings held annually; reasons

Assessing FIMR Case Review and Community Action Team members' satisfaction with the process

FIMR programs need time for their program to operate and initiate actions before attempting to measure related changes in community systems. Selection of measures for this category will depend on the issue-driven actions promoted by the program.

Examples of measures might be:

- Expansion of needed services available in community
- Number and type of new services instituted during a selected time
- Percentage of previously instituted services that are still sustained
- Elimination of duplication of community resources
- Improved linkages among services/facilities
- Changes in providers' or agencies' performance
- Positive shifts in community issues



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