Using Fetal and Infant Mortality Review to Inform Title V Programs on NPM 14.1: Smoking During Pregnancy

National Center Guidance Report
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Using Fetal and Infant Mortality Review to Inform Title V Programs on NPM 14.1: Smoking During Pregnancy

Introduction

One in 14 women who gave birth in the United States in 2016 (7.2%) reported smoking during pregnancy.¹ Fetal and Infant Mortality Review (FIMR) is an important tool to help communities understand and address National Performance Measure 14.1: Smoking During Pregnancy, including how community, racial, ethnic and socioeconomic factors impact pregnant women. This document is intended to inform Title V programs on how they can use the data and findings from FIMR to support interventions to reduce maternal smoking frequency during pregnancy.

Current Title V Engagement

Title V programs are engaged in FIMR in a variety of ways, often leading programs at the state and/or local level, providing funding, and supporting prevention recommendations. FIMR is uniquely equipped to inform Title V programs about the challenges that exist in communities that are barriers to progress across the National Performance Measures (NPMs). In 2018, 66% of local FIMR teams reported formal coordination with their Title V Maternal and Child Health Block Grant Program.²


Title V Testimonial

“Lifting the voices of families is critical to inform systems change, while addressing the immediate needs of families. The information shared by families, as part of FIMR, provides firsthand information about resiliency in the midst of challenges. Michigan Title V is committed to responding to the families we serve and removing identified barriers.”

Dawn Shanafelt, Michigan Title V Director & Michigan Department of Health & Human Services (MDHHS) Division of Maternal & Infant Health Director
The purpose of this document is to advise Title V programs on how data collected from FIMR and FIMR findings can inform efforts to reduce maternal smoking and improve birth outcomes.

FIMR is not always funded by Title V, but regardless of how the state health department is structured, authentic collaboration can occur in a variety of ways.

- In states where FIMR is based outside of state or local health departments, collaboration can focus on resources, staff participation in reviews, or shared prevention activities.

- In communities where FIMR’s administrative home lies outside of local or state government, FIMR findings, data, and recommendations are shared to inform programs and prevention.

- Depending on the timeline for case review, FIMR teams can provide more timely access to data and allow for the early identification of systems challenges and trends.

- In states where with active Perinatal Quality Collaboratives (PQCs), FIMR findings can help identify health care processes that need to be improved and work together with PQCs to enhance the quality of care for mothers and babies.
Fetal and Infant Mortality Review

Overview of FIMR

Fetal and Infant Mortality Review (FIMR) is an evidence-based method to examine and prevent fetal and infant deaths. It is a community-owned and action-oriented process to improve service systems and resources for women, infants, and families.

FIMR offers the community:

- A warning system that describes effects of health care systems and services change
- A method for implementing continuous quality improvement (CQI): to identify problems, analyze underlying factors contributing to the problem, re-design system approaches or resource allocation to resolve the problems, and subsequently determine if change in the process is successful
- A means to implement the essential public health functions of needs assessment, quality assurance, and policy development at the local level.
A Two-Tiered Approach

The FIMR process brings multidisciplinary community groups together to review de-identified fetal and infant death cases in a two-tiered process using a Case Review Team and Community Action Team.

The Review Team is composed of health, social service, and other experts. This team examines an abstracted case summary, identifies issues, collects data, and makes recommendations for community change where appropriate. The Action Team is made up of community leaders representing government, consumers, key institutions, and health and human service organizations. This team acts to implement recommended systems improvements based on findings from the Review Team’s reviews.

Objectives of FIMR:

1. To examine and identify the significant health, social, economic, cultural, safety, and education systems’ factors associated with fetal and infant mortality through review of individual cases.

   - Teams examine present and contributing risk factors in individual cases of fetal and infant mortality. Teams may review stillbirths as well as infants born live who do not survive until their first birthday.

   - Reviews examine outcomes through an equity lens, focusing on social determinants of health as a driving factor for outcomes.

2. Give voice to the families.

   - The family interview is a unique and defining feature of the FIMR process. The interview informs communities of the needs and challenges parental and infant populations encounter, elevating the experiences of bereaved parents. Trusting and valuing the stories parents tell allows fatality review teams to better understand the context of the deaths and the resulting fatality review data, providing a lens through which to more accurately examine the case. FIMR teams learn from the parent’s stories of loss and maximize the impact of those stories by using them to craft compelling, relevant interventions to increase the health and safety of their communities.
Identify barriers to care and trends in service delivery and suggest ideas to improve policies and services that affect families.

- Teams often identify challenges communities face with access to vital resources and services, referrals, and culturally-appropriate communication.

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

- Common interventions include education for professionals, health messaging, eliminating barriers to service access or safe practice, and policy or regulation change.
- Short and long-term recommendations and incremental change allow teams to achieve improvement at multiple community systems levels.

Assess the progress of community-based interventions.

- The purpose of continuous quality improvement (CQI) programs is to improve health care by identifying problems, implementing and monitoring corrective action, and studying its effectiveness. The two-tiered FIMR process offers CQI around the systems that affect mothers and babies by monitoring the success of change in community, medical, and social support systems through ongoing reviews and recommendations. Many FIMR programs use the CAT to monitor the progress of actions and recommendations.
Cycle of Improvement
FIMR is Continuous Quality Improvement

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

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

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.

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.

Learn more about FIMR on the National Center's FIMR Process page (URL: https://www.ncfrp.org/fmr/fmr-process/), or by viewing the National Center's FIMR 101 module (URL: https://mediasite.mihealth.org/Mediasite/Catalog/catalogs/cnpi).
Current Status and Location of FIMR Programs

In 2018, there were 174 local FIMR programs operating in the United States, Puerto Rico, and the Commonwealth of the Northern Mariana Islands (CNMI). Most FIMR teams (82%) are coordinated by state or local health departments. Others are led by hospitals, Federally Qualified Health Centers and Healthy Start programs.
The selection of cases that teams bring to care review varies by program. Most communities select cases for review based on risk and/or population factors such as vital statistics data. Many organizations attempt to review all cases of fetal and infant death that occur in a calendar year to give them a better picture of the community’s risk and protective factors and its services and resources overall. Some programs select cases from known high-risk areas such as a city or residents of specific zip codes. Especially in more rural settings, a FIMR program may include multiple counties for case selection and review, creating a regional team. Using the Perinatal Period of Risk (PPOR) analysis may be another strategy a community chooses to use for case selection. PPOR Provides an analytic framework for investigating feto-infant mortality at a local level and helps communities prioritize where they can have a large, measurable impact. A community using the PPOR analysis for FIMR case selection would sample cases from the cells in the matrix that contribute the most to excess infant mortality. Each period of risk is associated with its own set of risk and prevention factors.

About the National Center

The National Center for Fatality Review and Prevention (National Center) is the technical support and data center serving Child Death Review (CDR) and Fetal and Infant Mortality Review (FIMR) programs across the country. Funded by the Maternal and Child Health Bureau at the Health Resources and Services Administration, the National Center offers a wide variety of technical assistance services that are available via site visits, virtual meetings, email, and phone.

The National Center is funded by the Health Resources and Services Administration to:

1. Provide technical assistance, training, and assistance with strategic planning to help support teams to develop, implement, and sustain prevention-focused fatality review processes.

2. Maintain the National Fatality Review-Case Reporting System (NFR-CRS), a database for fatality review teams to enter data related to the circumstances of the individual deaths they review.

3. Offer consultation to coordinate with other reviews, including domestic violence, serious injury, maternal mortality, elder/vulnerable adult fatality reviews, Citizen Review Panels, and collaboration between FIMR and CDR, and others.

4. Support for the network of fatality review program leaders.

5. Provide resources such as a listserv, website, written guidance documents, webinars, and training modules.

6. Build partnerships at the state and local level to move CDR and FIMR review findings into recommendations and actions that will improve agency systems and prevent deaths.
The National Center aligns with several MCHB priorities and performance measures such as:

- Healthy pregnancy
- Child and infant mortality
- Injury prevention
- Safe sleep

Data Collection

The NFR-CRS is a free, web-based data system available to FIMR teams. Teams can easily access and download their own data and run standardized reports. The NFR-CRS is currently used by 64 FIMR programs in 19 states. A data use agreement must be completed to participate. Additionally, data are owned by the FIMR program which allows the state to retain control over how the data are used at a national level and for research. As a result, not all FIMR programs allow for their data to be included in research publications.

Given all this information, NFR-CRS data can help in the following ways:

- Local teams have access to their own data to identify trends and major risk factors that inform prevention. These data can be shared with Title V programs for real-time monitoring of Title V activities.
- State teams review local findings (when available) to identify trends and major risk factors and to develop recommendations and action plans for state policy and practice improvements.
- State teams match review findings with vital records and other sources of mortality data to identify gaps in the reporting of deaths.
- State and local teams use the findings as a quality assurance tool for their review processes.
- Local teams and states use the reports to demonstrate the effectiveness of their reviews and advocate for funding and support for their program.
- National groups use state and local findings for national policy and practice changes.

Learn more about NFR-CRS (URL: https://www.ncfrp.org/data/).
Overview of Maternal Smoking

National Data

One in 14 women who gave birth in the United States in 2016 (7.2%) reported smoking during pregnancy. There is an abundance of literature describing the health effects of smoking and exposure to secondhand smoke on pregnancies.

The Centers for Disease Control and Prevention (CDC) highlights these:

- Women who smoke have more difficulty becoming pregnant and have a higher risk of never becoming pregnant.
- Smoking during pregnancy can cause tissue damage in the unborn baby, particularly in the lungs and brain, and some studies suggest a link between maternal smoking and certain birth defects such as cleft lip.
- Studies also suggest a relationship between tobacco and miscarriage. Carbon monoxide in tobacco smoke can keep the developing baby from getting enough oxygen.

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7 National Cancer Institute. 4 Reasons Why Quitting Matters When You’re Pregnant [accessed 2020 Sept. 30].
Furthermore, specific health effects of smoking and secondhand smoke on babies include:

- Greater risk of pregnancy complications, premature delivery, low birth weight infants, and stillbirth.\(^8\)

- Increased risk to die from sudden infant death syndrome (SIDS).\(^9\)

- Nicotine exposure in utero has potentially devastating effects on fetal growth and development and is associated with changes in learning, behavior problems, cognitive difficulties, ADHD, conduct disorders, behavior problems, depression, and an increased risk of nicotine addiction in children exposed to tobacco in utero.\(^10\)

- Smoking during pregnancy leads to increased childhood hospitalizations for respiratory infections, and an increased prevalence of childhood asthma.\(^11\)

What is less understood is the impact of social-environmental influences on smoking cessation during pregnancy. FIMR, with its in-depth analysis of systems issues, gaps in care, impacts of Adverse Childhood Experiences (ACES) and social determinants of health, and inclusion of parental interviews is uniquely situated to understand factors that influence parents'/families' decisions to quit smoking and can help inform interventions.

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Data from the National Fatality Review-Case Reporting System

FIMR case information is a compilation of information from multiple sources. Medical records chart abstraction includes maternal preconception, prenatal, and postpartum care records, infant delivery, well baby and sick baby care, and information from a variety of social services agencies and other public health programs as well as law enforcement records and coroner/medical examiner information. With the addition of parental/family interviews, case review team members can see all the pieces aggregated together and thus are privy to the most comprehensive information about provision of services, community resources, and institutional policies.

There are some limitations to using data from the NFR-CRS. The case reporting system does not include all fetal and infant deaths occurring in specific jurisdictions and thus cannot be compared one-to-one with vital statistics or other population-level data. Rates cannot be calculated, nor can the data be assumed to be a representative sample of all deaths without detailed analysis. There is variation among teams in the types of cases reviewed and the timing of death reviews so that comparison state-to-state and even by teams within a state may vary. There can be differences in the quality of data between teams and states, especially for states new to the system. The NFR-CRS, and indeed the full FIMR process, may be used as a quality improvement tool.

An exploration of data for 2,330 FIMR cases entered in the NFR-CRS for deaths in 2015-2020, revealed the following:

- 28% of mothers smoked in the three months before pregnancy.
- Of those using tobacco in the three months before pregnancy, 59% smoked 10–20 cigarettes per day.
- 26% of mothers reported smoking at some time during pregnancy.
- 1 in 10 of mothers who smoked three months before pregnancy stopped smoking during pregnancy.

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13 Analysis only done on cases for which it was marked "Data Complete" and exclude cases with missing data.
Of mothers reporting tobacco use at any time during pregnancy, mothers decreased the number of cigarettes per day, with the number of cigarettes per day dropping slightly from first to second to third trimester, as shown in the graph above. The average number of cigarettes per day dropped from 11.7 cigarettes per day in the first trimester to 10 cigarettes per day in the second and 9.4 per day in the third trimester.

Health education topics were discussed with parents/families between the first prenatal care visit and delivery in 90.8% of cases.

Of those parents/families who received any health education between prenatal care and delivery, 37% reported education on tobacco use.

Health education topics were discussed with parents/families between hospital admission for delivery and discharge in 94% of cases.

Of those parents/families who received any health education between hospital admission for delivery and discharge, 19% reported education on tobacco use.

Families were referred to health or human services during or after pregnancy in 52% of cases.

Of families referred to any health or human services during or after pregnancy, referrals to smoking cessation were very low – only 7%.
According to the NFR-CRS, when compared to mothers who did not smoke during pregnancy, mothers who reported smoking during pregnancy experienced more stressors during pregnancy, regardless of how much they smoked. This is consistent with previous research into stress and smoking in pregnancy.14

**Mothers who smoked during pregnancy reported higher rates of:**

- Financial problems
- Involvement in a physical fight
- Someone close to them having a drinking or drug problem
- Experiencing physical abuse

For the cases in which a parental interview was obtained, mothers who smoked during pregnancy reported having ACES or psychosocial/lifestyle problems as a child in 52% of cases versus 24% of nonsmoking mothers with history of ACES. Two in five mothers (41%) who smoked reported having current psychosocial or lifestyle problems.

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Anytime there is a death, responsibility lies not just on an individual’s choices and behaviors, but on the circumstances that were shaped by society and the environment.

1. It is important to focus prevention work on systems gaps in order to avoid blaming the individual and to have the broadest prevention impact.

   A community looking at previously-outlined maternal smoking data might ask, “What factors do current systems hold in place that may cause parents/families to turn to tobacco for stress reduction?” rather than “Why do parents continue to smoke during pregnancy?”

2. The lens through which communities review factors that contribute to fetal and infant death can dictate the type of discussion and guides the substance of the subsequent recommendations and actions.

   Additionally, interventions targeting providers on standard, universal screening of parents and families for stress, anxiety, and depression during prenatal care, birth, and postpartum, and standard, universal education of all families on resources and referrals to culturally appropriate smoking cessation programs are validated by these findings.
FIMR Adds Value to the Understanding of Maternal Smoking

The process provides context through review and data collection.

**Data/Analytics/Standardized Reports:** FIMR aids communities in identifying service gaps, duplications, barriers, and unintended consequences of interventions. FIMR activities help monitor and evaluate outcomes and impacts of policies and programs selected to address a given NPM.

**Assessment:** The FIMR process can help state Title V programs to prioritize needs, and, based on their data, to select which national MCH priority areas are most critical for their state. The recommendations developed by FIMR teams can help states to establish meaningful performance objectives.

**Partnerships:** Multidisciplinary reviews foster collaboration with community partners and help manage shared challenges. FIMR teams partner effectively in advocacy efforts, including aligning messaging for communications related to each measure. FIMR teams identify and engage with non-traditional partners, as these partners’ perspectives of respective performance measures enrich teams’ ability to participate in Title V efforts.
**Multiple sources of data:** In creating the de-identified case summary, multiple sources of data are utilized, giving the whole picture of the case and not just a piece of the puzzle. The Review Team members may be 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. Inclusion of the qualitative data, as further described below, helps teams to understand the social factors such as geography, access to education, experience with discrimination, trauma (including historical trauma), and access to physical and behavioral healthcare can contribute to infant death and reduce the stigma associated with maternal smoking during pregnancy.

**Qualitative data:** The stories shared by families provide unique insight into the circumstances in which they make decisions, the resources and health care options they have and don't have, and the forces that influence their ability to achieve health and wellbeing. When these individual stories are combined with others, review teams see the trends and differences across populations emerge.

- The family interview underlines injustices that the family may have experienced in navigating and achieving optimum health. The findings from interviews provide the parents'/families' perspective on the infant's death and yield information not typically available in routinely-collected health records.

- The family interview represents a critical opportunity to partner with families in identifying solutions. Family/consumer partnership is the intentional practice of working with families for the goal of positive outcomes in all areas through the life course.

- The inclusion of families to partner in decision making with Title V programs at the federal, state, and community levels is a critical strategy in helping states to improve national outcomes. The Health Resources and Services Administration (HRSA) directs states to work closely with family/consumer partnerships when selecting their evidence-based or evidence-informed strategy measures to address unique state needs. Family engagement reflects a belief in the value of family leadership at individual, community, and policy levels.
Community Engagement & Partnerships

By its very nature, multidisciplinary review leads to collaboration with formal and informal community leaders and groups. Bringing key stakeholders around a common table to improve the care, resources, and services available to families encourages openness and knowledge sharing. True collaboration is about the process, not the people.

The fatality review process is much more than just getting the right people to the table; it is about engaging the community in solving problems and making decisions.

Collaboration takes work, and if done well, the process can build trust, openness, and ownership. The solutions that arise from the collaborative, community-owned process is often more informed, innovative, and more likely to work.

Health Disparities

FIMR findings can be used to understand mothers'/families' experiences of racism and how those experiences may have impacted maternal and child outcomes. Throughout the FIMR process, members strive to understand implicit bias, gather and summarize the right records to help teams understand parents'/families' experiences of racism, the impacts of other social determinants of health, and how those experiences may have impacted maternal and child outcomes. Most importantly, once teams have their findings, they make and implement meaningful recommendations that address disparities and the social determinants of health and Birth Equity.

THE NATIONAL BIRTH EQUITY COLLABORATIVE DEFINES BIRTH EQUITY AS:

“The assurance of the conditions of optimal births for all people with a willingness to address racial and social inequalities in a sustained effort.”

Success Stories

OKLAHOMA CITY-COUNTY HEALTH DEPARTMENT FIMR PROVIDES SMOKING QUIT KITS

Oklahoma City-County Health Department identified a high number of premature and low birth weight infant deaths that were highly correlated with tobacco use among pregnant women.

FIMR findings and data have helped them to shape their strategies, including:

- Conducting focus groups with men who smoke to understand community smoking patterns that affect mothers and infants through second and third-hand exposure.

- Developing a strategic plan to design messages that educate on second and third-hand smoke. The plan includes creating a video and materials on second and third-hand smoke, increasing the visibility of a local quit helpline for pregnant Medicaid members, and providing nicotine replacement therapy.

- Partnering with the Healthy Living Grant at Oklahoma City-County Health Department, the FIMR project provided items to create 2,000 smoking cessation quit kits to be given to pregnant women and their families who indicated their desire to quit smoking.

Thorough fatality review continues to underscore the risk of prenatal and second-hand smoke exposure as a risk factor for sleep-related infant death. Many states have expanded the “ABC’s of Safe Sleep”—recommendations that infants sleep Alone, on their Backs, and in a Crib—to also address smoking in pregnancy and second-hand smoke exposure for babies.
THE METRO PUBLIC HEALTH DEPARTMENT FIMR OF NASHVILLE, TENNESSEE

In 2018, 12.8% of Davidson County mothers who experienced a poor pregnancy outcome resulting in fetal or infant death and who met criteria for inclusion in the FIMR cohort* smoked tobacco 3 months prior to pregnancy. Of those, 10.6% continued to smoke during their pregnancy. Recognizing that maternal smoking is a strong risk factor for sudden unexpected infant death (SUID) they developed and implemented a plan to include safe sleep education in the Baby and Me Tobacco Free Program (BMTFP) curriculum. The BABY & ME – Tobacco Free Program™ is an evidence based, smoking cessation program created to reduce the burden of tobacco on the pregnant and postpartum population.15

Through this FIMR and BMTFP partnership, participants of the BMTFP meet with the FIMR Infant Vitality Coordinator during their second prenatal session for education on tobacco cessation and infant safe sleep. A presentation is provided, and a copy is sent as a follow-up to participants by email. Literature on smoking cessation and infant safe sleep is also provided to support safe sleep practices once the baby arrives.

Outcomes:

☐ Safe sleep education paired with tobacco cessation education reaches the at-risk population of maternal smokers in a timely manner to impact maternal choices.

☐ A total of 5 collaborative sessions have been taught from May 2020 to December 2020.

*FIMR Cohort for Davidson County/ Nashville, TN:

☐ Fetal Deaths – At least 24 weeks gestation OR at least 500 grams

☐ Infant Deaths – At least 20 weeks gestation AND less than 1500 grams (3 pounds 4 oz)

☐ Infant Deaths – Any gestation birth weight IF the cause of death is SIDS, SUIDS, or Undetermined

15 https://www.tn.gov/health/health-program-areas/fhw/baby-me-tobacco-free.html
Summary

Fatality Review can offer valuable tools and information to enhance and inform state Title V needs assessments, action planning, data collection, and analysis.

**FIMR benefits Title V programs by:**

- Examining social, cultural, safety, and health systems factors that are associated with fetal and infant mortality through review of individual cases
- Identifying system barriers and problems that need improvement through interdisciplinary case reviews
- Improving service systems and community resources to reduce future fetal, infant, and child deaths
- Providing valuable qualitative data to use with states’ quantitative infant and child mortality data
- Informing a state’s broader needs assessment and state action plan

For specific inquiries on how fatality reviews can support the work of Title V maternal child health programs, contact the National Center at info@ncfrp.org.
Prevention Resources

- Health Resources and Services Administration, Maternal Child Health Bureau (URL: https://www.hrsa.gov/sites/default/files/quality/toolbox/508pdfs/qualityimprovement.pdf). HRSA works to increase access to comprehensive, coordinated, confidential health care.

- Association of Maternal Child Health Programs (AMCHP), Family Engagement in Title V (URL: http://www.amchp.org/programsandtopics/family-engagement/ToolsandResources/Documents/FamilyEngagementinTitleV.pdf). AMCHP works with MCH professionals to achieve the following adolescent health goals: 1) Improve the health of women, children, youth, families, and children and youth with special health care needs; 2) Promote the health of adolescents by strengthening the state-level capacity; 3) Pursue the elimination of health disparities and inequities; 4) Advance leadership practices for MCH at the national, state and local levels.

- Association of State and Territorial Health Officials (ASTHO), Smoking Cessation Strategies for Women, Before, During, and After Pregnancy (URL: https://www.astho.org/Prevention/Tobacco/Smoking-Cessation-Pregnancy/). ASTHO represents the public health agencies of all 50 states in the United States, the District of Columbia, the five U.S. territories, and the three freely associated states.
• American Association for Respiratory Care (AARC), Smoking Cessation for Pregnant Women (URL: https://www.aarc.org/nn18-smoking-cessation-for-pregnant-women/) AARC advances professional excellence and science in the practice of respiratory therapy, serving the profession, patients, caregivers, and the public.

• Centers for Disease Control and Prevention (CDC), Tobacco Use and Pregnancy: Resources for Smokers and their Families (URL: https://www.cdc.gov/reproductivehealth/maternalinfanthealth/tobaccousepregnancy/resources.html).

• Women's Health Issues (WHI) (URL: https://doi.org/10.1016/j.whi.2014.02.004). WHI is a peer-reviewed, bimonthly, multidisciplinary journal that publishes research and review manuscripts related to women's health care and policy.
