Consulting Population-Based Data to Inform Fetal and Infant Mortality Review and Community Action Decisions

National Center Guidance Report
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FIMR Overview

The purpose of the Fetal and Infant Mortality Review (FIMR) process is to conduct comprehensive multidisciplinary reviews 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. FIMR teams use the findings from review meetings to take action that can prevent future infant deaths and improve the systems of care and resources for birthing persons, infants, and families. 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.

FIMR is Public Health Surveillance: Defined by the Centers for Disease Control and Prevention, Public Health Surveillance is the ongoing, systematic collection, analysis, interpretation, and dissemination of health data to help guide public health decision making and action.¹

From its very beginnings, FIMR was a community-level Continuous Quality Improvement (CQI) process. CQI methods are often used in health care 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. FIMR applies CQI to multiple systems that affect health.

FIMR Limitations

While FIMR is uniquely valuable in identifying causes and system contributors to deaths and informing communities’ action plans, it has limitations. Many local sites do not have the capacity to review all their fetal and infant deaths and employ a variety of strategies for case selection. There is also significant variation in the timing of reviews, the case abstraction processes, the success rates of obtaining parental/family interviews, and the representativeness of interviews obtained. FIMR information cannot be considered population data and cannot be used to estimate risk or compare jurisdictions, even in the same states.

The Purpose of this Guidance Document is to inform communities on the several ways that population data, when combined with FIMR information and findings, can lead to better-informed decisions on community action strategies to reduce fetal and infant deaths.
Population Data

What is Population Data?

Population data is defined as information about a set of individuals who share a characteristic or set of characteristics. Simply put, population data includes or represents everyone. A population may be determined by geographies, such as all births and fetal deaths to persons living in a specific county or neighborhood. A population can also be defined in terms of demographic characteristics (e.g., people of child-bearing age).

Examples of Population Data include:

- Vital records (includes all live births and fetal deaths)
- Decennial Census (includes all people or households)
- The Census Bureau’s American Community Survey (represents all people or households)
- Pregnancy Risk Assessment Monitoring (PRAMS) (represents all live births)
- Behavioral Risk Factor Surveillance System (BRFSS) (represents adults)

Data from special subpopulations can also be useful if limitations are recognized. Examples include:

- Medicaid Claims data, all-payer claims data
- Hospital discharge data
- Program data such as Healthy Start or WIC
Population Data Sources

Vital Records

Vital Records data (births, infant deaths, and fetal deaths) are most closely related to FIMR, so highlighted here are some typical measures and methods that use this source of population data. Though deaths at any age are part of the vital records system, a special data set of infant deaths where each baby's death information is linked to its birth record is explored. Fetal deaths are cases where the infant died before delivery. Most states record fetal deaths at 20 weeks of gestation or later, but some record even earlier fetal deaths in their vital records systems.

General use of Vital Records Data

A common measure is the infant mortality rate (IMR) which is the number of infant deaths multiplied by 1,000 and divided by the number of live births. Expressing mortality as a rate allows us to compare across places, subpopulations, or overtime.

A note about small numbers: When the number of deaths is small, the rate becomes more unstable. This means that the rate will fluctuate so widely from one time to the next that decisions should not be based on this data. Solutions include combining years, places, or subpopulations until the number is larger, using process control techniques that look for trends and outliers, or using a different measure entirely. For example, instead of death, the focus could be on prematurity as an outcome. Still, it is recommended that confidence intervals should be used to distinguish between real underlying differences and random variation due to small numbers of events.

Vital records data allows communities to compare populations in terms of birth characteristics such as the percent of preterm births (the number of births at less than 37 weeks gestation divided by the total number of births), the percent that are low birth weight (less than 2,500 grams), and the percent that are very low birth weight (less than 1,500 grams). Another strategy is to compare mortality rates within a risk group, such as preterm births. If two populations have different mortality rates among their preterm births, it could indicate a difference in access to quality care for preterm babies.
There are many more outcomes and measures used in Maternal, and Child Health based on vital records and other data sources. The Interactive Compendium of Maternal and Child (MCH) Health Measures (CAHMI) (URL: https://bit.ly/3MyMb7X) is a resource that allows users to quickly browse through more than 1,000 MCH measures by measure set, data source category, and topics. Each measure is clearly defined, including its title and/or description, numerator, denominator, unit of analysis, specific data source, and target population.

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Using the Perinatal Periods of Risk (PPOR) to analyze vital records data

Perinatal Periods of Risk (PPOR) is a comprehensive approach to help communities use data to reduce infant mortality. Developed by CityMatCH and the CDC, PPOR brings community collaborators together to build consensus and partnership based on local data. PPOR provides an analytic framework and steps for investigating and addressing the specific local causes of high fetal and infant mortality rates and disparities. Initial analyses are based only on vital records data (births, deaths, and fetal deaths); later steps utilize all available data sources and information.

The PPOR process starts by sorting a community's fetal and infant deaths into four periods of risk based on weight at birth and age at death:

- **Maternal Health/Prematurity**
- **Maternal Care**
- **Newborn Care**
- **Infant Health**

A rate is calculated for each period (the number of deaths x 1,000 divided by the number of births). Next, an estimate of the preventable mortality or the “excess” deaths is calculated by subtracting reference group rates. A reference group is a real population of birthing persons in a community that experience the best outcomes—low fetal and infant mortality rates. One example would be non-Hispanic white birthing persons, 20 or more years of age, with a college education.

The final step is to conduct an in-depth investigation of the period(s) of risk with the most preventable mortality. A visual depiction of the four periods of risk is found on the next page.
Figure 1. *Four Periods of Risk*

- **Maternal Health/Prematurity**
- **Maternal Care**
- **Newborn Care**
- **Infant Health**

- **Preconception Health**
  - Health Behaviors
  - Early Prenatal Care

- **Prenatal Care**
  - High Risk Referral
  - Obstetric Care

- **Perinatal Management**
  - Neonatal Care
  - Pediatric Surgery

- **Safe Infant Sleep**
  - Pediatric Care
  - Injury Protection

**Resources**


Learn more from the CityMatCH website (URL: https://bit.ly/3xt60IM).
Other Sources of Population Data

Pregnancy Risk Assessment Monitoring System

The Pregnancy Risk Assessment Monitoring System (PRAMS) (live births) is an ongoing survey of new childbearing parents through a partnership between the Centers for Disease Control and Prevention (CDC) and state health departments. Nearly all states have a PRAMS or PRAMS-like survey. PRAMS collects information on attitudes, behaviors, and experiences before, during, and shortly after pregnancy. Summary data is usually available. Researchers use PRAMS data to investigate emerging issues in the field of reproductive health and by state, territory, and local governments to plan and review programs and policies aimed at reducing health problems among birthing persons and babies. Learn more from the Centers for Disease Control and Prevention (URL: https://bit.ly/3NuPUUf).

Hospital Discharge Data

Hospital discharge data reveal diagnoses and procedures related to inpatient stays. The same system tracks Emergency Department visits and, increasingly, ambulatory surgery, hospital observation services, and other hospital outpatient services. Hospital discharge data may be extremely useful to examine policy, care delivery, and clinical issues. However, the use of discharge data does have limitations that affect their usefulness and accuracy for some analyses. Schoenman et al. described the limitations as falling into three types: quality of data elements, missing data elements, and excluded populations. Learn more from the Agency for Healthcare Research and Quality (URL: https://bit.ly/3H5BZBN).

Claims Data

An insurance claim is made when an insured person has a medical visit, hospitalization, procedure, or fills a prescription. Each claim becomes an electronic administrative record that can be compiled and used for health research and surveillance. For example, Medicaid Claims data could be used to estimate the percent of birthing persons covered by Medicaid who receive postpartum contraception services or prescriptions. Although claims data only includes individuals who the particular insurer covers, some states are developing "all-payer" claims datasets. Learn more from the Agency for Healthcare Research and Quality (URL: https://bit.ly/3aEBOkJ) and the APCD Council (URL: https://bit.ly/3zmC0PN).

Census

Census data (individuals, households) includes every member of a population by place of residence. The US Census Bureau, part of the US Department of Commerce, does a complete count every ten years and administers the ongoing American Community Survey for a more detailed annual view of the population. The bureau assembles these and many other datasets about the individuals, housing units, and businesses to estimate counts or percentages of social and economic characteristics for different geographic areas. Learn more from the United States Census Bureau (URL: https://bit.ly/3tgAV8s).

Behavioral Risk Factor Surveillance System

Behavioral Risk Factor Surveillance System (adults) is an ongoing telephone survey about health care, health risks, chronic conditions, and the use of preventive services. A project of the Centers for Disease Control and Prevention (CDC) (URL: https://bit.ly/3wzGNvO), with sponsorship from many organizations, it is administered by states. BRFSS collects data in all 50 states, Washington, DC, and three US territories. It is the largest continuously conducted health survey system in the world.

Electronic Health Records

Some hospital and health care systems make electronic health records available for public health purposes. This could include the fact that there was a visit with tests or a procedure (as in the claims data) and the test results or procedure findings. If making use of administrative electronic health records that are available, FIMR teams may want to restrict the data to patients who resided in the jurisdiction at the time the infant was born and should be aware that care in other health systems would not be included. Learn more from the Centers for Medicare & Medicaid Services (URL: https://go.cms.gov/3GVLNya).

Program Data

Program data, such as data from participants in Healthy Start, Home Visiting, or WIC, may be helpful to augment population data. It is important to remember that this data would exclude non-enrolled segments of the population, even if eligible. A further limitation is that eligibility is based on factors associated with higher risk, so risk factors and poor outcomes may be more common than in the general population. Comparisons should be made to the population that is eligible but not participating.
Where to Find More Population Data

**Government Health Departments**

Vital records data is collected and controlled by local and state health departments, and these are usually the best source of the most complete and up-to-date individual-level data. "Individual-level" means there is a record for each individual person. This provides the most flexibility to create meaningful summary statistics, assess relationships (correlation), and investigate data quality issues that may cause bias. Many FIMR programs and other public health efforts are associated with state or local health departments. They may have access to individual-level data files or summary data on births, infant deaths, and fetal deaths.

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**United States Census Bureau**

The United States (US) Census Bureau's mission is to serve as the nation's leading provider of quality data about its people and economy. The type of data they collect and how and when it is collected can be found at the United States Census Bureau (URL: [https://bit.ly/3wlVgUM](https://bit.ly/3wlVgUM)). Examples of census data that might be helpful to FIMR programs are the American Community Survey (ACS) which focuses on information about America's changing population, housing, and workforce, and the Decennial Census of Population and Housing, which county every resident in the United States. This takes place every ten years.

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**Integrated Public Use Microdata Series**

The Integrated Public Use Microdata Series (IPUMS) is a window for data from the Census Bureau, the Bureau of Labor Statistics, health surveys, and more. Based at the University of Minnesota and funded by federal and private sources, it processes data and provides summary datasets for counties, census tracts, etc. Click here to access the IPSUMS website (URL: [https://bit.ly/3lxgW0U](https://bit.ly/3lxgW0U)). IPUMS also houses data from national health surveys.
CDC WONDER

CDC WONDER is a source of customized summary information from vital records data collected and processed by the states and forwarded to the CDC’s National Vital Statistics System. WONDER stands for the Wide-ranging ONline Data for Epidemiologic Research. Using an easy-to-use, menu-driven system, users can query the birth and infant death datasets for county or state data and the fetal death dataset for state data. WONDER can provide tables, maps, and charts, including counts, adjusted rates, and confidence intervals. CDC Wonder may be a year or two behind what your state may have, and its data may not exactly match state data. CDC WONDER suppresses rows with small numbers, so tabulations should be checked against totals. Click here to access Wonder on the CDC website (URL: https://bit.ly/311J8lX). The National Center hosted a webinar that featured an overview of CDC WONDER and PPOR (URL: https://bit.ly/3wUpMNd).

PeriStats

PeriStats is a website developed by the March of Dimes Perinatal Data Center to provide summary data related to prematurity and infant health from multiple government agencies and organizations. Point and click menus allow users to create tables, maps, graphs, and charts at national, regional, state, and county or city levels (depending on the topic and data source). A primary goal of the website is to present health indicators that are comparable across the entire United States. PeriStats also produces annual info-graphic style reports for states using several sources’ most recently available data. Click here to access the March of Dimes PeriStats website (URL: https://bit.ly/3yNNpbe).

County Health Rankings

The County Health Rankings & Roadmaps website provides summary data on health outcomes, health care, and social and environmental factors. It includes information from the Census Bureau, the US Vital Statistics System, the Behavior Risk Factor Surveillance System (BRFSS), and others. Their rankings provide a starting point for motivating change, and their Roadmaps (URL: https://bit.ly/38L2yiO) provide guidance and tools to understand the data and strategies for moving from education to action. County Health Rankings and Roadmaps is a program of the University of Wisconsin Population Health Institute (URL: https://bit.ly/3sP2gOK), funded by the Robert Wood Johnson Foundation, to measure the progress of building a Culture of Health (URL: https://rwjf.ws/3lxghfY). Click here to learn more about County Health Rankings (URL: https://bit.ly/3sPSuw1).
How Can Population Data Inform a Community’s Decisions?

A FIMR Community Action Team (CAT) receives the review team findings, reviews other mortality and population data and trends, makes and acts on prevention recommendations. The process of finalizing an action plan can benefit from a review of community-specific vital statistics (population-based) information, a review of scientific literature, and the expertise of the community and its leadership. That way, proposed actions based on case findings can be readily linked to similar problems documented in the larger population, if present.

Questions that may be answered by analyzing population data are:

- How widespread is this problem? What is the scope of the problem, prevalence, incidence?
- Is the problem more common in some groups or some places?
- How widespread are the risk factors, and how dangerous? (correlation)
- Does this problem lead to others?
- Does another characteristic increase or decrease the danger?

Limitations of Using Population Only Data

Regardless of the source, it is critical to recognize the limitations of using population data only to make and act on prevention recommendations. First, essential pieces of the puzzle may be missing from data sources. The motives, intentions, and perceptions of parents and families will not be captured. Life-course factors are not considered, such as previous medical events or previous poor pregnancy outcomes, exposure to trauma, and historical trauma. Information on sensitive topics such as domestic violence, drug use, racism and discrimination, food insecurity, and housing instability are notably absent from population data. Root causes of fetal and infant mortality are far more complex than an ICD code. Lastly, and very importantly, population data do not focus on systems failures and how they impact the health of parents and infants.
Scenarios

Below are several scenarios that blend population-based and FIMR information. These examples emphasize the investigation process but do not necessarily steer a community toward one solution or another. Some relevant published evidence about causes and effective interventions are included in the Appendix.

Scenario 1:

A county’s MCH coalition prioritized the population of non-Hispanic White birthing persons with a high school education or less because it had persistently high infant mortality rates and accounted for 40% of the county’s fetal and infant deaths.

- The investigation began with a PPOR analysis which found that the Infant Health Period of Risk accounted for 60% of their excess (preventable) mortality, and over half of these excess deaths were due to Sudden Unexpected Infant Death (SUID, including ICD codes R95, R99, and W75).

- Their FIMR reviewed 100% of SUID deaths among this priority population for the next six months.

- At the same time, their MCH Epidemiologist:
  - Used vital records to investigate risk and protective factors in this population (preterm birth, smoking, and initiation of breastfeeding).
  - Used BRFSS data to investigate smoking in general because second-hand smoke is also a risk factor.
  - Requested and received state PRAMS data on infant safe sleep practices, continued breastfeeding, and second-hand tobacco smoke exposure for the priority population.
  - Compared zip code maps of priority population births from vital records data and age of housing stock and population density from the US Census Bureau.

- The coalition lead consulted recent community needs assessments that reported problems with poorly heated homes and vermin, which may lead to increased co-sleeping.
Scenario 2:
A FIMR program identified a trend or pattern across multiple FIMR cases. They found several deaths among families of recent immigrants, where the birthing person had received late or no prenatal care.

- Overall, the jurisdiction had high rates of receiving first trimester prenatal care based on vital records data. However, when the team's data analyst cross-tabulated receipt of first trimester prenatal care vs. country of the childbearing parent's birth, it was found that late prenatal care was common among certain immigrant groups.

- The analyst also used both vital records and census data to investigate whether lack of health insurance could be a barrier for immigrants whose first language was not English.

- The CAT met with community groups to share the information, asking members of the immigrant communities to help them interpret their findings and suggest system changes or needed health education messages.

- CAT leadership met with the appropriate agencies serving the immigrant community to set up changes.
Scenario 3:

The local health department had observed that the rate of third trimester stillbirths (27 weeks gestation and later) had been rising slowly among the county’s Black birthing persons for more than eight years.

- The problem analysis included:
  - An assessment of possible vital records reporting changes: Had the criteria for using the fetal death certificate instead of the live birth certificate changed due to changes in equipment, training, or staff? Had missing information in fetal death records (such as race of birthing person) caused some deaths to not be counted in the past?
  - Vital records data was used to determine whether changes in risk factors such as older maternal age, asthma, or obesity could account for the change.
  - The team used American Community Survey data to show that poverty and unemployment had increased for this population during the same timeframe.
  - They obtained air quality information from the environment division of the health department over time and found that particulate matter concentrations and air quality alerts had also been rising.

- The FIMR team agreed to work on obtaining parental/family interviews for all deaths where a relevant diagnosis was found among Black birthing persons.

- They contacted a non-profit group working on stillbirth prevention and sent them a report.
Scenario 4:

A pattern observed in FIMR cases revealed that many childbearing parents who had preterm deliveries or fetal deaths, including several who had a previous preterm birth, reported that their health care providers had not told them about symptoms of early labor.

- The team requested state PRAMS data on:
  - Conversations pregnant persons had with health care providers about early labor symptoms, focusing on those who had a previous preterm birth.
  - Health insurance just prior to pregnancy and for prenatal care for those who had a previous preterm birth.

- The epidemiologist used local vital records data to investigate whether birthing persons who had a previous preterm birth were significantly less likely to receive early prenatal care.

- FIMR leadership met with representatives from health care provider groups to report this information, asking them to consider system factors that might contribute to the problem.
Conclusion

In conclusion, there are many strengths to using FIMR data and findings in conjunction with PPOR and other population data. While each has its strengths and limitations, used together, FIMR and population data can support public health decision-making, processes, and outcomes. The parental interview contextualizes all the other data that has been abstracted from various records that the FIMR 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. FIMR may discover new issues. 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. FIMR helps understand causal relationships and the underlying social circumstance that gives rise to individuals’ behaviors, assuring that the proposed interventions will be appropriate. FIMR helps with messaging and advocacy because it engages multi-sector experts and persons with lived experience.

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. The team should be encouraged to think creatively and systemically - using both FIMR findings and population data can add value and vital information to the community’s effort to prevent fetal and infant deaths.
Appendix

References with Key Quotations


“The prone position places infants at high risk of SIDS (odds ratio [OR]: 2.3–13.1), side is similar.”


“Recommendations for a safe sleep environment include supine positioning, use of a firm sleep surface, room-sharing without bed-sharing, and avoidance of soft bedding and overheating. Additional recommendations for SIDS risk reduction include avoidance of exposure to smoke, alcohol, and illicit drugs; breastfeeding; routine immunization; and use of a pacifier. Quitting smoking before pregnancy is important because brain development begins at the beginning, and brainstem problems can cause the infant to be more intrinsically vulnerable to exogenous stressors like prone sleep position, over bundling, and airway obstruction. Having two or more risk factors often increases SIDS risk even further. For example, prematurity increases the risk of SUID by a factor of two or more, and prone sleeping increase the risk of SIDS by a factor of 13.9, but for premature infants sleeping prone the odds are increased to 48.8.”


“Receipt of provider advice was associated with increased use of safe sleep practices, ranging from 12% for room-sharing without bed-sharing (adjusted prevalence ratio: 1.12; 95% confidence interval: 1.09-1.16) to 28% for back sleep position (adjusted prevalence ratio: 1.28; 95% confidence interval: 1.21-1.35).”

“Black mothers tend to believe that SUIDS/SIDS is a random occurrence and is not preventable, so they see a little reason to make their infant sleep in a cold, hard crib, when they could sleep in a warm, comfortable bed with them.”


“Parental sleep decisions seemed to be driven by perceptions of what would make their infant most comfortable and safe, and what would be most convenient. Parents were aware of safe sleep recommendations but unaware of the rationale. Because they generally did not believe that their infants were at risk for a sleep-related death, day-to-day decisions seemed to focus on what was most effective in getting their infant to sleep.”


“Prematurity increases risk of SIDS The SIDS rates by gestational age categories of 24 to 28 weeks, 29 to 32 weeks, 33 to 36 weeks, and 37 or more weeks were 3.52, 3.01, 2.27, and 1.06 = 2.27/1.06 = odds = 2.14 double the odds, more for earlier preterm deaths/1000 live births.”


“Odds ratios (ORs) for prone and side sleeping compared with supine sleeping for the last sleep were 13.9 (95% confidence interval 8.2-24) and 3.5 (2.1-5.7). Infants 13 to 24 weeks old had particularly high risk in prone and side sleeping, at 28.5 (7.9-107) and 5.9 (1.6-22)...We found strong combined effects of sleeping position and prenatal risk factors (more than multiplicative). The OR for prone and side sleeping was increased for infants with birth weight <2500 g, at 83 (25-276) and 36.6 (13-107); for preterm infants, at 48.8 (19-128) and 40.5 (14-115); and for intrauterine growth retarded, at 38.8 (14-108) and 9.6 (4.3-22)."

"Ever having breastfed was associated with a lower risk of SIDS (adjusted summary OR: 0.64; 95% confidence interval [CI]: 0.51–0.81)...exclusive breastfeeding at 1 month of age halved the risk of SIDS (adjusted OR: 0.48; 95% CI: 0.28–0.82)...The protective effect of breastfeeding increased with exclusivity, with a univariable summary OR of 0.27 (95% CI: 0.24– 0.31) for exclusive breastfeeding of any duration."


"Advanced Maternal Age (AMA) increased the risk of stillbirth (OR 1.75, 95%CI 1.62 to 1.89) with a population attributable risk of 4.7%...This is not wholly explained by maternal co-morbidities and use of Assisted Reproductive Technology. We propose that placental dysfunction may mediate adverse pregnancy outcome in AMA."


"Many disorders associated with stillbirths are potentially modifiable and often coexist, such as maternal infections (population attributable fraction: malaria 8.0% and syphilis 7.7%), non-communicable diseases, nutrition and lifestyle factors (each about 10%), and maternal age older than 35 years (6.7%). Prolonged pregnancies contribute to 14.0% of stillbirths."


"Any active maternal smoking was associated with increased risks of stillbirth (summary relative risk (sRR) = 1.46, 95% confidence interval (CI): 1.38, 1.54 (n = 57 studies))...The risks of stillbirth, neonatal death, and perinatal death increased with the amount smoked by the mother."

“Overall, these studies suggest that exposure to air pollutants such as particulate matter (PM), carbon monoxide (CO) and cooking smoke may be associated with higher risk for stillbirth and spontaneous abortion.”


“Maternal overweight and obesity (body-mass index >25 kg/m(2)) was the highest ranking modifiable risk factor, with PARs of 8-18%...across all high-income countries. Advanced maternal age (>35 years) and maternal smoking yielded PARs of 7-11%.”