W.H.O. Perinatal Periods of Risk Approach: The U.S. Urban Experience

For over a decade, the Perinatal Periods of Risk Approach has been used by the World Health Organization (W.H.O.) in developing and developed countries. The approach offers a new way to monitor and investigate feto-infant mortality.

Until recently, the W.H.O. approach has never been formally tested in the U.S. or in a U.S. urban setting. In May 1997, CityMatCH and the Centers for Disease Control and Prevention (CDC) partnered to sponsor the Perinatal Periods of Risk (PPOR) Work Group--a multi-city learning cluster of public health practitioners and researchers--to validate and test the feasibility of the approach in a U.S. urban setting. In December 1998, the National March of Dimes Birth Defects Foundation joined the sponsoring partnership and became part of the Work Group effort.
The Perinatal Periods of Risk Work Group has five major partners: Public Health Seattle-King County, Boston Public Health Commission, the Hawaii State Department of Health, CityMatCH and the CDC. The project would not have been possible without the strong collaborative efforts of these partners. Although funding was available to support collaboration, communication, and meetings among partners and members, and to support research at the national level, the time and efforts of the three urban health department collaborators--Seattle, Boston, and Honolulu--was supported primarily by local resources. In addition, the Work Group wants to thank the many individuals across the country who provided input and advice to the project including public health practitioners at local, state and national levels, and academic and government-based researchers.
The Perinatal Periods of Risk Approach was developed by Dr. Brian McCarthy from the W.H.O. Perinatal Collaborative Center at CDC and other W.H.O. colleagues. The intent was to develop a simple method that is based on a strong conceptual prevention framework and can be used by community partners to mobilize the community to prioritize prevention efforts. The approach also forms one of the core components of an ongoing Maternal and Child Health (MCH) surveillance system.

For over a decade, this approach has been used to monitor and investigate feto-infant mortality problems in developing countries. The approach has only recently been used in the U.S. and in urban settings. Based on the PPOR Work Group efforts, the following is the recommended Perinatal Periods of Risk Approach for use in U.S. settings.
Why a New Approach to Infant Mortality?

- A simple approach that can be easily used by communities nationwide.
- An approach that can identify gaps in the community.
- An approach that can target resources for prevention activities.
- An approach that can mobilize the community to action.

Reducing infant mortality has been a long-standing problem addressed by the public health community, and in recent decades, has been highlighted as a major public health success. So, why a new approach to examine infant mortality? There were four key factors that spurred the PPORWork Group to look more in depth at this new approach.

First, there is currently not a simple, standardized, widely-accepted approach for a community to examine infant mortality. This requires communities to find or develop their own approach to examine the problem or to use information readily provided to them.

Second, current approaches do not readily identify potential gaps in the community where further reductions in infant mortality are possible.

Third, current approaches do not directly lead a community to action to target further studies, investigation or preventive activities.

Fourth, current approaches are not simply and easily communicated to community partners and members, inhibiting the community’s ability to mobilize to action.
Perinatal Periods of Risk Approach: 5 Major Steps

1) Engage community partners early to gain consensus and support.
2) Map feto-infant mortality by birthweight & age at death.
3) Focus on reducing the overall feto-infant mortality rate.
4) Examine potential opportunity gaps between population groups.
5) Target further investigations and prevention efforts on the gaps.

The Perinatal Periods of Risk Approach has 5 major steps: 1) engage community partners, 2) map feto-infant mortality, 3) focus on reducing the overall feto-infant mortality rate, 4) examine potential opportunity gaps, and 5) target further investigations and prevention efforts. Each of these steps are essential building blocks, with each building upon the previous.
1. Engage Community Partners Early

- Improving feto-infant mortality requires mobilization and change in many sectors and by many individuals in the community.
- Consensus about and ownership of the problem is essential in developing community support for solutions.
- Monitoring the problem and the solutions and necessary strategy adjustments require effort by many partners.

The first and most important step: community partners must be engaged early in the process. Perinatal Periods of Risk (PPOR) is more than just an analytic approach. It is an information approach that can be used to engage the community to improve the health of women, children and families. This requires that important community partners and key individuals be engaged early to become involved in the investigation as well as the solutions. Consensus about the ownership of the infant mortality problem and its causes is essential to developing community support for solutions. Community partners come into the process with: 1) their own thoughts about causes and contributors to feto-infant mortality rates and 2) their own understanding of the overall problem.

A group investigation that begins with developing a common understanding of the problem can lead to successful consensus building regarding the solutions. Most important, the understanding of the problem and the needed solutions will need to change over time to reflect ongoing learning of the problem and solutions. Infant mortality is a complex issue in any community and it takes time to understand the unfolding dimensions and implement the evolving solutions. The many community partners will need to be involved in monitoring the problem and solutions, and making the necessary adjustments. Early involvement helps improve and sustain the quality and usefulness of the information.
2. Map Feto-Infant Mortality

The second PPOR step is to “map” feto-infant mortality. This map can provide a simple framework upon which to build greater prevention efforts. The map’s framework includes two dimensions: age at death and birthweight.
Traditionally, infant mortality has been examined by the first dimension of the map, age of death. This has prompted the development of many different indicators. The conceptual basis for this approach is the tremendous growth and development that occurs throughout pregnancy and continues after birth. Different problems occur at different developmental stages due to differing risk factors. Specific interventions have been developed to specifically address these differing windows of opportunity. Therefore, high mortality during a specific time period may reflect an opportunity for intervention.
The second mapping component is birthweight, the strongest predictor at birth of a child’s survival. In fact, feto-infant mortality can be divided into two major mortality components: birthweight distribution and mortality at those birthweights. The risk factors that cause lower birthweight births and the risk factors that cause mortality at a particular birthweight are different or manifest differently. Thus, the necessary interventions to ameliorate these different risk factors are different. And, health care access mechanisms and issues are also different.
Combining age at death and birthweight yields the two dimensional map of feto-infant mortality. The three categories for age at death start with fetal deaths, continue with neonatal deaths (first month of life), and end with postneonatal deaths (remainder of the first year). These time periods are associated with different causes of death. Birthweight can be divided into two major birthweight categories: those less than 1,500 grams (very low birthweight--VLBW) and those 1,500 grams or more (higher birthweight--HBW). Much of the mortality impact of low birthweight can be captured in the VLBW experience. Combining these two dimensions provides a 2 by 3 matrix of 6 cells. The original W.H.O. approach proposed 4 categories by 4 categories which yields a 16 cell matrix. Further investigations by the PPOR Work Group demonstrated that this complexity added little informational value to the approach.

It is important to note that this matrix uses two clearly defined cutoffs. First, fetal deaths are limited to fetal deaths with gestational ages of 24 weeks or more. Second, fetal deaths and live births are limited to birthweights of 500 grams or more. These are necessary because there are large reporting differences in vital records across U.S. cities for events below these two cutoffs. For an added benefit, these cutoffs generally limit pregnancy events to those that are physically viable, assuming no underlying congenital defect or medical condition.
Before focusing on the 6 cells, it is important to note which adverse pregnancy events are missing from the feto-infant mortality map. First, there is a gestational age restriction on fetal deaths. Fetal deaths less than 24 weeks are excluded. This cutoff may exclude as much as half or more of all reported fetal deaths depending on the state’s legal reporting requirements. Second, the birthweight minimum of 500 grams for both fetal deaths and live births also excludes many reported fetal and infant deaths. Due to these cutoffs, the combined exclusions of pregnancy events in some places may be larger in number than the actual number of deaths included within the 6 cell map. In such a situation, Perinatal Periods of Risk may not identify the greatest opportunity for prevention of all adverse pregnancy events.

Two other important groups of adverse reproductive events are excluded from this approach. First, roughly 16% of all pregnancies nationally are thought to end in spontaneous abortions and are not routinely reported through vital records systems. This magnitude of pregnancy events clearly outnumbers the reported fetal and infant deaths included in the six cell approach. Second, induced abortions account for another significantly large group of pregnancy terminations. They may account for the largest percentage of all pregnancy events short of live births.

It is important to recognize such limitations when considering the use of this or any other infant mortality approach.
The PPOR approach clusters these six cells into four primary groups. First, the VLBW (500-1499g) fetal, neonatal, and postneonatal deaths become one group. The higher birthweight (1500+ g) cells form the three remaining groups.
In the PPOR approach, these four groups are given labels that suggest the primary preventive direction for the deaths for that group. VLBW-related deaths can best be prevented by addressing maternal health issues and by preventing and treating prematurity. For HBW-related deaths, fetal deaths can best be prevented by providing maternal care; neonatal deaths, by providing newborn care; and postneonatal deaths, by improving infant health.
These labels were designed to suggest preventive action. For Maternal Health and Prematurity, prevention may need to focus on preconceptional health, unintended pregnancy, smoking, drug abuse, and specialized perinatal care. For Maternal Care, prevention may need to focus on early continuous prenatal care, referral of high risk pregnancies and good medical management of diabetes, seizures, postmaturity or other medical problems. For newborn care, the focus may need to be on advanced neonatal care and treatment of congenital anomalies. And for infant health, communities may need to focus on SIDS prevention activities such as sleep position education or breast-feeding promotion, access to medical homes and injury prevention.
This framework or map examines the major components that make up the feto-infant mortality rate. For example, we have mapped the feto-infant deaths in Phoenix, Arizona for 1995-1997. The 710 feto-infant deaths occurred among the 68,275 births. The largest number of deaths, 252, occurred in the Maternal Health/Prematurity group followed by 177 deaths in the Infant Health group. Newborn Care had the smallest number of deaths at 124.
3. Focus on Reducing the Overall Feto-Infant Mortality Rate

- The overall rate includes fetal deaths which are often excluded.
- Cell or group specific mortality rates are calculated such that they add up to the total feto-infant mortality rate.
- Excess mortality rates and numbers are also calculated such that they relate to the total feto-infant rate.

The third major step in the Perinatal Periods of Risk Approach is that the approach focuses on reducing the overall feto-infant mortality rate. All data measures used in this approach either add up to the overall feto-infant mortality rate or are directly related to the overall rate. In this way, every measure can be used to interpret or understand what contributes to the overall rate.

First, fetal death must be included in the overall picture. Many U.S. cities continue to focus only on infant mortality and do not recognize the very large role that fetal deaths contribute to their adverse perinatal events. In fact, in many cities there are more fetal deaths than infant deaths.

Second, the cell- or group-specific mortality rates are calculated in such a way as to add up to the overall feto-infant mortality rate.

Third, the excess mortality rates and numbers for the four groups are calculated from the overall rate.
**Focus on Overall Mortality**

*Cell- or Group-Specific Mortality Rates*

\[
\text{Number of deaths in cell} \quad 3 \\
\text{Number of live births} \\
\quad \& \text{fetal deaths} \\
\text{Number of deaths} \\
\quad \text{in a group} \\
\text{Number of live} \\
\quad \text{births} \quad \& \quad \text{fetal deaths}
\]

Cell- and group-specific mortality rates are easily calculated. These rates are simply the number of feto-infant deaths in a cell or group divided by the total number of all live births and fetal deaths meeting the cutoffs. By using the same denominator, the rates calculated can be directly added together to equal the overall feto-infant mortality rate. Thus, the group-specific mortality rates are a direct reflection of their contribution to the overall feto-infant mortality rate.
Map Feto-Infant Mortality
Phoenix, Arizona, All Races
1995-97

710 Feto-Infant Deaths
68,275 Fetal Deaths & Live Births

For example, take the number of feto-infant deaths in Phoenix for each of the cells and groups and divide them by the 68,275 fetal deaths and live births. This calculation yields the cell- and group-specific mortality rates.
Thus, 3.7 feto-infant deaths per 1,000 live births and fetal deaths is the group-specific mortality rate for Maternal Health/Prematurity, 2.3 for Maternal Care, 1.8 for Newborn Care, and 2.6 for Infant Health. Added together, these rates equal the directly calculated overall feto-infant mortality rate of 10.4. In this map, it is again clear to see that the highest group rate is Maternal Health/Prematurity, the component related to VLBW births. The second highest rate is Infant Health, postneonatal deaths among HBW infants.
Focus on Overall Mortality

Learn by Comparisons

- Compare within feto-infant mortality rates by examining the 4 group rates.
- Compare overall and group rates over time.
- Compare overall and group rates between different population groups.

These group rates can be used to reflect the individual group rates contribution to the overall feto-infant mortality rate. They can also be used to compare group rates over time among the same population, or to compare group rates across different population groups and geographic areas. This comparison permits one to see how the contribution to feto-infant mortality rate can vary, and is not necessarily consistent across subpopulations and geographic areas.
Focus on Overall Mortality

Comparison of Socio-Demographic Groups

- Maternal Race and Ethnicity
  - white, black & other
  - Hispanic & non-Hispanic
- Maternal Age and Education
  - <20 years of age
  - 20+ years and <13 years of education
  - 20+ years and 13+ years of education
- Geography
- Health Care Payment Source

The group rates can be used to compare various socio-demographic groups if there are a sufficient number of feto-infant deaths in each of the groups. For example, these rates can compared across different maternal race and ethnic groups, different maternal age and education groups, different geographic areas and different health care payment sources. Each feto-infant mortality map may have a different story to tell. The maternal categories of race, ethnic, age and education listed above are generally more available on vital records in sufficient numbers to permit comparisons across cities.
Are you familiar with the computer game, “Where in the U.S. is Carmen Sandiego?” These feto-infant mortality maps are from three different cities across the U.S. (1995-97). As you can see, the overall rates are very similar from 12.0 to 12.8. However, the group rates that make up the overall rates are somewhat different. In other words, the components that account for the higher overall rates are different. All three have high maternal health/ prematurity rates, as is generally true for most U.S. cities. However, the second highest rates can vary. One city has a high Maternal Care rate of 3.4, and another one has a high Infant Health rate of 3.5. Can you guess which cities these are?
The three cities are Tulsa, Oklahoma; Omaha, Nebraska; and New Orleans, Louisiana. These are their 1995-97 rates. New Orleans, which has a very high percentage of births to African-American women, has a lower Maternal Health/Prematurity rate than Omaha, which has only 17% of its births to African-American women. Tulsa has the highest Maternal Care rate. New Orleans has the highest Infant Health rate. These findings suggest that each city will need to examine different strategies to reduce their overall feto-infant mortality rates.
4. Examine the “Opportunity Gap” Between Population Groups

- Identify the potential for reduction in the community.
- Decide on internal reference groups for comparison.
- Consider external reference groups for comparison.
- Calculate excess mortality rates by components.

The fourth step is to focus on the opportunity gap between population groups. These gaps can be used to estimate the potential for reduction in the community, assuming that the whole population could experience the same lower mortality experience. This is important because many people believe that the feto-infant mortality rate cannot decline much further. This same statement was made during the 1980s; however, reductions have continued to occur in the 1990s.

To estimate the potential for reduction, one must first focus on a reference group, generally an internal reference group or subpopulation from within the community that experiences good mortality rates. Use of an internal reference group suggests that it is both possible and desirable for any population group in the community to reach a lower level of adverse pregnancy outcomes.

In contrast, it may be beneficial to have an external reference group, a population group that is from outside the community. First, the rates for an external reference group can readily be applied across cities and population groups. This external approach holds all communities to the same standard and the ability to reach the same level of mortality. Second, an external reference group can help a community identify potential excess mortality when there is not a sufficient number of deaths to calculate stable rates for an internal reference group.

Regardless of choice, either reference group is used to calculate both excess mortality rates and the number of excess deaths. Not only can this excess mortality be calculated, but it is also possible to determine which population groups are contributing most to excess mortality.
Examine the “Opportunity Gap”

Reference Groups

Attempt to choose a simple optimal group; at least 15% of the population

U.S. studies:

- 20 or more years of age
- 13 or more years of education
- Non-Hispanic white women

For an internal reference group, a community should attempt to select a population group with better or optimal pregnancy outcomes for the community, a population group that can serve as a model. In general, this group should represent roughly 15% or more of the population. For the U.S., a suggested reference group is infants and fetuses born to non-Hispanic white mothers of 20 or more years of age having 13 or more years of education. This group usually represents more than 15% of the population and has the optimal outcomes in most U.S. cities. Moreover, the mortality rates for this population group are readily available through current vital records system. There are potentially better reference groups that could lead to more specific actions, but frequently quality information may not be available for that population group within the community. Clearly, the community group that is using this approach needs to develop consensus on the reference group. Otherwise, the findings will have little meaning or purpose.
So how are excess mortality rates and numbers calculated? Let’s take an example. The excess mortality rates for Phoenix, Arizona for 1995-97 would be calculated as follows: the Maternal Health/Prematurity rate for all races, 3.7, minus the Maternal Health/Prematurity rate for the previously recommended reference group, 1.6, gives the excess mortality rate, 2.1. The overall excess feto-infant mortality rate is 10.4 – 6.0 = 4.4. The numbers may not add up exactly because of rounding. The actual number of excess deaths can be calculated by multiplying the excess mortality rate by the total number of fetal deaths and live births. Excess mortality rates are calculated and shown for the remaining 3 groups.
Examine the “Opportunity Gap”

- Examine excess overall mortality, both rate and number.
- Examine excess mortality across the four groups.
- Calculate the percentage of excess mortality by racial and socio-economic groups.

The excess mortality rate can be examined in similar fashion as the group-specific mortality rates. The overall number and rate can be calculated to give an overall estimate of potential preventability. The excess numbers and rates by group can be further compared within a community to determine which group(s) account(s) for the largest share of excess mortality. In addition, the excess can be further examined by subpopulations to determine which subpopulations contribute most to the overall rate.
For example, 4.4 of 10.4, roughly 42% of Phoenix’s overall feto-mortality rate may be preventable based on the reference group rate. The greatest potential for reduction, almost half, is in the Maternal Health/Prematurity group followed next by the Infant Health group. As you can see, the PPOR approach can lead a community to ask a specific series of questions prompted by the analytic findings. Instead of looking at everything possible related to feto-infant mortality, Phoenix can focus on specific issues and areas. Better neonatal care may not be the best approach for further reductions.
5. Target Investigations & Prevention Efforts on the Gap

- **Shift effort** and attention to the group(s) that contributes most to the gap.
- **Conduct further studies or mortality reviews** on the group(s) that contributes to the gap (Phase 2 studies).
- **Examine current prevention efforts** on the group(s) that contributes to the gap (Phase 2 policy/program reviews).

The last step is to focus further investigations or prevention efforts based on identified gaps. This step is called Phase II investigations and activities. Many U.S. cities have stopped and not gone to this next step. They simply use the mapping of the four primary groups to make decisions. That shortcut may be problematic because the broad findings may not provide sufficient specificity for targeted action.

For example, further studies should focus on why rates are highest for maternal health/prematurity in Phoenix. This could include conducting epidemiologic studies or conducting fetal and infant death reviews. In addition, further examination could include a review of current prevention efforts targeted at one of the four feto-infant mortality groups, in an attempt to determine gaps and needed prevention strategies and services.

Through this step, community prevention efforts can be efficiently and effectively targeted at specific components or populations.
To assist with further studies, the Work Group has developed study protocols to specifically investigate elevated maternal health/prematurity and infant health mortality rates. For maternal health/prematurity rates, the protocol focuses on whether the difference is due to birthweight distribution or to birthweight-specific mortality rates. This division can be used to further focus studies. Should the community examine prevalence and impact of risk factors causing high VLBW/prematurity in their community, or should the community examine aspects of their perinatal care system that are responsible for higher birthweight-specific infant mortality rates in their community?

In terms of infant health, the first step is to investigate underlying cause-of-death. Each cause-of-death category has its own specific set of risk or preventive factors. Therefore, further investigation can focus on a specific underlying cause and its related factors. For SIDS, the factors might be the prevalence of infants sleeping on their belly or of infants in a smoking environment?

Again, this step investigates the reasons behind elevated rates.
Fetal & Infant Mortality Reviews

- Focus FIMR activities on the group contributing to the gap.
- Describe in greater depth the risk factors, events or services that may contribute to the gap.
- Validate the quality of vital records and other information.

“Paint the faces behind the numbers”

An alternative for further investigation might be to target a community’s FIMR efforts specifically on one of the four feto-infant mortality groups. Besides being a more efficient way to focus existing labor-intensive FIMR efforts, this approach can also provide structure for FIMR findings by reporting the major gaps in mortality through the same analytic framework. FIMR can also be used to describe in greater depth the risk factors, events or services that contribute to the high rate overall or for a specific population. In addition, FIMR can be used to study the validity of vital records and other information by comparing it to the information collected through FIMR. Of importance, the FIMR stories can be used to paint the faces behind the Perinatal Periods of Risk numbers.
Perinatal Periods of Risk Approach

*Lessons Learned*

- Make sure the community is on board to understand the results.
- Obtain direct access to the data.
- Have at least 60 feto-infant deaths to make sense of the 4 mortality groups.
- Investigate the unlinked infant deaths.
- Look out for the unknowns.
- Be prepared to go further.

With our U.S. urban experience, we have learned some important lessons. First, it is important that the community be on board with the approach as much as possible and the community has some basic understanding of how the process works. Without it, they may not really understand, believe or use the results. Second, this type of analysis requires either direct access to the vital records information, or to have someone with access to the information to conduct the investigation for you. Each step of the investigation leads to the next deeper step of investigation to better understand the causes. The approach does not stop at just Phase 1. Obtaining direct access to vital records is a necessary but possibly long bureaucratic process.

Third, this approach requires at least 60 feto-infant deaths be present among the four feto-infant mortality groups and that little information be missing on those 60 deaths. With fewer deaths, the group rates become more unstable (not enough numbers). Moreover, additional numbers of deaths will be needed to study the feto-infant mortality maps for different subpopulations and risk factors. Fourth, a linked birth and infant death certificate file is needed to conduct this analysis. Some death certificates cannot be linked to birth certificates and are therefore excluded from study. As the number of unlinked records increases, the number of deaths studied decreases. This can bias the analysis.

Fifth, the quality of vital records is not consistently high. Make sure you study missing information to be sure that your analysis is not biased because of it. Sixth, be prepared to go further with the investigation by planning to do further studies, to do death reviews or to do a health systems review. Phase 1 analysis, by itself, is of limited value without more specific findings to target efforts.
In summary, the Perinatal Periods of Risk Approach focuses prevention efforts through the following five major steps: 1) engaging community partners, 2) mapping feto-infant mortality, 3) focusing on reducing overall feto-infant mortality rate, 4) examining potential opportunity gaps, and 5) targeting further investigations and prevention efforts.

PPOR is a straight-forward approach that can be easily used by communities nationwide. The approach can readily identify gaps in the community and among various subpopulations. Furthermore, the approach can target resources for further study and prevention activities, and mobilize communities to action in preventing feto-infant mortality.