Celebrating 15 Years since the Perinatal Periods of Risk’s “conception” with contributions by...

Chad Abresch  Kelly Belling  Giannina Donatoni  Cynthia A. Harding  Theresa Mickiewicz  William Sappenfield
Hani Atrash  Carol Brady  Carol Gilbert  Angel Hopson  Magda Peck  Patrick Simpson
Mary Balluff  Shin Margaret Chao  Violanda Grigorescu  Brian McCarthy  Ann Salyer-Caldwell  Jennifer Skala
As CityMatCH’s Executive Director, I am pleased to bring you this issue celebrating the 15th Anniversary of the Perinatal Periods of Risk (PPOR). For over twenty years, CityMatCH has strived as an organization to reduce health disparities and translate the science of public health to practice. PPOR has played a key role in our history by demonstrating that addressing feto-infant mortality rates in a way that empowers the community and utilizes the available data is not only possible, but achievable. Thanks to PPOR, our members once again demonstrated that we can address our shared urban MCH problems using a science-based approach to public health practice.

As we look to the future, we recognize that using data strategically is key to the transformation of family and community health. In order to accomplish this goal, CityMatCH plans to analyze the most recent national data sets and provide updated PPOR data for large cities and counties in the coming year. This will give urban jurisdictions across the nation a “sneak preview” of their phase 1 PPOR data, allowing local health departments to determine whether to allocate resources for a full PPOR analysis and community process.

In the following pages, you will find unique stories told by the key figures involved in PPOR’s adaptation, and by the many CityMatCH members who have utilized PPOR in order to accomplish our common goal of improving the health and well-being of women, children, and families. These friends and colleagues form just part of the wider community of city and county health departments who have demonstrated their leadership by addressing these disparities in their communities. They have been gracious enough to continue the CityMatCH storytelling tradition by sharing their stories with us – stories which highlight the collaborations and partnerships that the success of CityMatCH’s work relies upon.

I trust you will enjoy this unique edition of CityLights. Many thanks also to the Centers for Disease Control and Prevention and the National March of Dimes Birth Defects Foundation for their support in the development of PPOR, and to the Health Resources and Services Administration/Maternal and Child Health Bureau. Happy 15th PPOR!
What is it about the Perinatal Periods of Risk (PPOR) approach that ignited our imaginations - and still does so many years later? Three things endure:

First, PPOR models, and invites, great public health practice. It relies upon access to timely, high quality linked perinatal data. Phase 1 analysis establishes a friendly, colorful way of partitioning and displaying complex data that lets all sorts of people discover where they should focus next. It embodies a comprehensive planning cycle that helps us translate date into action.

Second, PPOR is grounded in our core principles of health equity and social justice. It insists that we together ask a basic question of health disparities: Why can’t all our babies do as well as some babies are already doing? It assumes that lower feto-infant mortality rates manifest by a selected referent group (commonly white, educated women 20 years or older) can and should be achieved by most.

Third, PPOR’s toolbox lets everyone committed to preventing fetal and infant deaths and promoting women’s health become citizen scientists, working together to unravel the tightly knotted conundrum of infant mortality. It requires ongoing, authentic community engagement and collaborative leadership.

When we first brought a strategic mix of MCH researchers, policy leaders, scientists and practitioners to Omaha 15 years ago, with the intent of adapting Dr. Brian McCarthy’s antecedent periods of risk approach, we dared to declare on a flip chart that PPOR would become a standard part of MCH practice in urban communities in the next 5 – 10 years. Since then, a powerful combination of creativity, ongoing communications, consultation, collaboration and chutzpah has braided the way for PPOR to take off and fly. The practice collaborative approach to team-based urban learning, an accessible website, countless workshops, and conference calls have spawned a dynamic virtual learning community. Over time the suite of papers (finally) were published in MCHJ and a new generation of CityMatCH staff now supports PPOR practice in the field.

It is remarkable that what we anticipated (and hoped for) has in large part come true. Now that PPOR has become a regular urban MCH tool allowing for a shared discovery of where to focus next, the breakthrough moments have become memorable. I recall some of the early “aha moments” - such as the time when then Boston MCH director Dr. Barbara Ferrer saw that the greatest disparity was in the ‘blue box’ – and had to ask “what about WOMEN’s health?” I also remember when Carol Brady in Jacksonville was facing a similar pattern over ten years ago and was able to justify opening a dedicated service site for women BEFORE they became pregnant. These and similar discoveries led to paradigm shifts in preconception health and the Life Course approach.

The bottom line is that PPOR has been a durable catalyst for strategic local and national shifts in MCH practice. As one of its co-creators and champions, it is wonderful to see how PPOR has entered the portfolio of community practice and collaborative leadership to measurably improve the health and well-being of women and infants in this generation and the next.

Many thanks to CityMatCH for providing the ongoing canvas for this innovative body of work; to the many cities who have adopted the approach so as to have greater impact; and to Dr. Bill Sappenfield for being my colleague and co-creator from the very start. May PPOR remain fresh and durable and useful in our quest for urban MCH.

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What’s Different about PPOR?

Fundamental adaptations include:

• The 16 cells of the WHO analytic matrix were combined into 4 periods to simplify the analysis and the presentation to community groups. This also ensured sufficient numbers of deaths in each cell for reasonably stable rates.

• Phase 2 steps and analyses were clearly defined and extensively revised, especially in the Maternal Health/Prematurity period of risk, where (because “underlying cause of death” was uninformative) we moved toward Kitagawa for determining the relative importance of survival of very low birth weight infants vs. birth weight distribution.

• PPOR was used in the context of the community assessment and planning cycle. The PPOR six-step community process included community stakeholder involvement in analytic issues such as selection of the reference group and Phase 2 investigations.

The practice and use of the Perinatal Periods of Risk approach to infant mortality has far exceeded what I imagined fifteen years ago. At the time, public health agencies and their partners were struggling to understand their community’s infant mortality problem. They frequently found themselves lost in data, needing further analyses, or going down the wrong path. Their findings were difficult to share because they were confusing to community partners. We needed a new methodology, but when Dr. Brian McCarthy first presented his model – back then it was simply called the Risk approach – as a possibility, I and several others, especially epidemiologists, were initially very skeptical. Was the approach well-grounded scientifically? Would a simple, standardized approach lead to major errors? Despite our doubts, we started with a learning cluster group, with CityMatCH taking the lead on the analytic pieces while working with three community groups on the community approach: testing the process, methods, feasibility, and utility.

For the community approach, we worked closely with three communities: King County (Seattle); Honolulu, HI; and Boston, MA. This process included extensive data analyses, comparisons of PPOR results with FIMR and other data source findings, and the testing of the process and feasibility of using PPOR in community settings.

By the time we finished the analyses in the 3 communities, and using national data, we felt we had sufficiently validated the PPOR approach with both detailed qualitative as well as quantitative analyses. A forum with national experts confirmed our thoughts. The new, adapted approach helped communities and community leaders identify their infant mortality issues, explain these issues to their community partners, and start developing community prevention strategies. This process really wasn’t about doing the analyses, but about pulling together the right partners to use the analysis as a community tool for planning and not as an epidemiological approach. Instead of being left in “analysis paralysis,” community groups were able to develop clear communication messages and data-driven community plans. Communities embraced the idea that you can discuss and capture excess mortality.

The results in many communities have been exciting, although it can take sever-
al years to achieve measurable outcomes. One major surprise was that state public health agencies wanted to adopt the use of the PPOR approach at the state level, even though they could have selected more sophisticated epidemiological methods due to having a large number of infant deaths. However, they too saw the benefits of the PPOR approach’s simplicity and the ease of framing messages in the same way that their communities were framing them. Instead of spending time talking about specificities, health departments have been able to communicate global themes and messages – which is key to getting community stakeholders interested in what’s going on with infant mortality.

Maternal Health/ Prematurity

The PPOR boxes divide fetal and infant deaths into four periods of risk based on birth weight and age at death.

Dear CityMatCH:

Congratulations on the profound impact CityMatCH has had on the dissemination of the PPOR concepts in the US. CityMatCH has increased its members’ capacity to translate data into information for action: a skill needed throughout the world if we are to achieve the Millennium Development Goals (MDGs) for Maternal and Child Health. As I recall, a little more than fifteen years ago I presented the ABCs (Age-at-death, Birthweight, Cells) of maternal and infant surveillance to CityMatCH and its members and partners who were searching for a new way to address infant mortality. The ABCs approach was a means of answering the two most important questions program managers must ask when solving a problem:

- Have we chosen the right approach?
- Are we doing that approach correctly?

Birthweight proportionate rates can tell us which approach to choose, and birthweight specific mortality rates can tell us whether we are using that approach correctly.

During the course of the presentation I gave fifteen years ago, participants began to refer to the different cells as different “Periods of Risk” with specific intervention packages for each cell. It wasn’t long before CityMatCH was off and running with the Perinatal Periods of Risk (PPOR) and fine-tuning the PPOR process into a Quality Assurance/Quality Improvement (QA/QI) instrument for local use. CityMatCH led the way in using fetal deaths along with infant deaths to get a more complete picture of local Maternal and Child Health. PPOR has helped communities understand the need to differentiate between maternal health and maternal care because these are not one and the same.

CityMatCH has led the way in preventing feto-infant mortality, not just infant mortality. Racial disparities in birth outcomes are man-made and, therefore, unacceptable in a democratic society. Your use of PPOR as a means of obtaining social justice deserves praise. May CityMatCH continue to perform that leadership function around infant mortality here in the US... and maybe abroad, as well.

Brian McCarthy, MD, MSc
Captain, US Public Health Service (Retired)
“WHAT IS PPOR?”
by Carol Gilbert, MS | Health Data Analyst, CityMatCH

The Perinatal Periods of Risk (PPOR) is a comprehensive approach for addressing high infant mortality rates and disparities in those rates. Adapted by CityMatCH and the CDC from the periods of risk approach used in developing nations, PPOR is detailed in a suite of articles in the Maternal and Child Health Journal.

PPOR brings community stakeholders together to build consensus, support, and partnership around vital records data, which are collected for (nearly) every birth, infant death, and fetal death in the US. Designed as a “data to action” tool for use in US cities, PPOR has also been used successfully by Healthy Start sites, suburban counties, groups of rural counties, and tribal organizations. It has even become a common part of state infant mortality surveillance. All six stages of the PPOR process (readiness, data analysis, planning, implementation, evaluation, and re-investment) contribute to making data a powerful agent for systems change, but at the core of PPOR are its analytic methods (see the MCH Planning Cycle, p. 7). The phase one and phase two analyses comprise the second stage of PPOR, the data and assessment stage.

Phase 1 Analysis
The PPOR Phase One analysis produces the familiar PPOR “map,” the boxes (blue, pink, yellow, and green) that divide fetal and infant deaths into four periods of risk based on birth weight and age at death. A mortality rate is then calculated for each period, and compared to the rate for a best-case population of mothers (known as the reference group). If the study population’s infant mortality rate exceeds the reference group’s rate, then the study community has excess mortality, and, we assume, preventable deaths (see “The Reference Group and Justice,” p. 7).

One key reason why PPOR helps guide action is that deaths within a period of risk have similar risk factors (that’s how the periods were defined). If you can find out which period of risk has the highest excess mortality, you can narrow your focus to the potential causes of infant mortality that are associated with that period.

Phase 2 Analysis
After the Phase One analysis has shown which period of risk has the greatest excess mortality, community stakeholders can use vital records and other data for systems change, but at the core of PPOR are its analytic methods (see the MCH Planning Cycle, p. 7). The phase one and phase two analyses comprise the second stage of PPOR, the data and assessment stage.

The step-by-step, data driven PPOR analysis can help a diverse group of stakeholders reach consensus and prioritize actions based on the best available evidence, seasoned with their own knowledge of their community and what works for the people they serve.

The PPOR “map” of fetal-infant mortality

- **Age at death**
  - Fetal Death
    - >=24 weeks
  - Neonatal
    - 0-27 days
  - Post-neonatal
    - 28-364 days

- **Birth weight**
  - 500-1499 g
  - 1500+ g

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


[3] Ibid. 2
sources to find appropriate solutions. Phase Two is really a series of analyses that help the investigators zero in on likely causes and determine which risk factors appear to have the largest impact on infant mortality in their community.

- If excess mortality exists in the blue box, the Maternal Health and Prematurity period of risk, they begin by using Kitagawa analysis to determine what is causing the excess mortality (see “What is Kitagawa Analysis,” p. 8). In the green box, the Infant Health period, they analyze the underlying cause of death from the death certificate to identify the predominant causes.

- After identifying a primary cause for the excess mortality, the investigators must determine which of the risk factors known to be related to that cause are significant in their community.

- Stakeholders then use data to estimate how much each possible action around identified risk factors could “move the needle” on excess infant mortality in their community. However, they also must assess existing, evidence-based interventions or best

The Reference Group and “Justice”

*Should every baby have the same chance to survive, regardless of his or her parents’ race and income?* If you believe the answer is “yes”, then you understand the principle behind the use of a reference group in PPOR. If one group can achieve low fetal and infant mortality rates, why shouldn’t every group expect to achieve the same results?

The reference group is a real population of mothers with near optimal outcomes. It can be internal (such as white, educated, adult women within the city) or external (regional, state, etc.). Stakeholders select a reference group that they agree provides a realistic benchmark or target for their community. They calculate excess mortality (the difference between their community’s rate and the reference group’s rate), but they take a further step by proclaiming that the excess mortality is *unacceptable*, i.e. it represents *preventable* deaths. Although it is not always possible to determine whether an individual death was preventable, the reference group allows the stakeholders to *estimate preventability on a population basis* and focus action where it is most needed.

**Phase Two Discoveries**

Some cities find that most of the Infant Health period excess mortality is caused by SIDS and SUID. Those communities examine the most current and most local data available on known risk factors for sleep-related deaths, such as bedding, sleep position, and tobacco smoke exposure, to determine which are significant in their community.

Other cities discover that a high rate of extreme prematurity is the primary cause of excess fetal and infant mortality. These cities can use several data sources to examine the known risk factors related to preconception health and early prenatal care, and determine which of those factors are likely to be contributing to their problem.
What is Kitagawa Analysis?

Dr. Evelyn Kitagawa was a Chicago demographer who published several methods papers, one of which included the algebraic formula we use to determine the reasons for death in the blue box, the Maternal Health/Prematurity period of risk.

Using high-school algebra, the formula partitions a community’s “blue box” excess mortality into two parts:

1. The “birthweight distribution,” when an excess number of babies are born very low birth weight, or VLBW; and
2. The “birthweight specific mortality,” when an excess number of VLBW babies die.

If the Kitagawa analysis determines that the blue box’s excess mortality is primarily due to birthweight distribution, the best strategy is preventing VLBW births. If the analysis determines that birthweight specific mortality is causing the excess mortality, the best strategy is improving VLBW infants’ survival rates. In essence, Kitagawa tells us whether our problem is that too many babies are born way too small, or whether those very small babies are not surviving as well as they should. From an action point of view, it is a very important distinction.

What is the PPOR Learning Network?

The Perinatal Periods of Risk (PPOR) Learning Network is an effort to continue the advancement, dissemination, utilization, integration, and standardization of the Perinatal Periods of Risk Approach in the U.S. Membership in the Learning Network is free and recommended for communities using or planning to use the PPOR Approach. To join the Learning Network, visit the CityMatCH website at http://www.citymatch.org/ppor_join.php.
Using PPOR, you can follow a data-driven process and be grounded in science without having perfect data. This is because you don’t need perfect data for program implementation – you can get enough information even with minimal data. In fact, beginning to use imperfect data begins to improve it, because once you begin to collect it, there is more of a public demand for it.

Hani Atrash, MD, MPH
Director, Division of Health Start and Perinatal Services at Health Resources and Services Administration

In Douglas County, Nebraska, PPOR data has driven our community’s infant mortality prevention efforts for over a decade. It has motivated us to keep working on sleep-related deaths, broadening our focus beyond just sleep position. PPOR has shown us that although black infant mortality rates are much higher than white rates, there are also preventable deaths among whites and other groups in our community. This has helped us realize that infant mortality is a problem for the whole county and not just for a particular group. PPOR has led us to adopt ACOG’s FIMR process to improve our understanding of community systems. Together, PPOR and FIMR have helped us keep a good representation of local stakeholders involved in analyzing local systems and planning infant mortality prevention strategies. Both tools have been integrated into our formal prevention planning cycle, with PPOR being used to guide the selection of FIMR cases, and FIMR findings often driving PPOR Phase 2 investigations.

In Douglas County, we typically re-do PPOR Phase 1 analysis every two years, with each analysis based on four years of data. This provides us with enough data (i.e. deaths) to allow us to analyze blacks and Hispanics in separate PPOR maps. Phase 2 analyses generally involve comparing the prevalence of risk factors in the target population vs. the reference population. In Douglas County, Phase 2 analyses are based on vital records, PRAMS, and BRFSS data, and may soon include YRBS data. Phase 2 results are formally presented in alternate years to the Baby Blossoms Collaborative (which plays the role of FIMR Community Action Team), but also serve to inform ongoing work groups, as questions arise and action priorities are decided.

Our experience has been that the PPOR data provide an anchor that has at many times kept us from being carried away by the currents of our enthusiasms and biases. FIMR case stories are powerful, as are the personal and professional experiences of our community stakeholders. When the case review teams or other stakeholders have strong opinions, it has been important to be able to test whether those are reflected by the population-based data. For example, when partners were convinced that teen mothers were the cause of our county’s high infant mortality rate, PPOR Phase 1 data for different age groups illustrated that this was not the case, and we were forced to look more deeply for the real causes. When several FIMR cases led the case review team to believe that immigrants from Africa were a major issue for the county, census and birth certificate data convinced them that this small subpopulation could not account for a significant portion of our excess deaths.

Vital records data on timing of prenatal care confirmed the suspicions of a subcommittee that receipt of prenatal care in itself could...
PPOR AND THE HEALTHY START MODEL: A “MATCH” FOR COMMUNITY ENGAGEMENT

by Kelly Bellinger, LMSW
Health Program Manager, San Antonio Healthy Start, Metro Health Department, City of San Antonio

In San Antonio the PPOR six-step process takes place in the context of a group of representatives and advocates who are very familiar with the community, its needs, strengths, changes over time, and service structure: our Healthy Start Consortium. The Healthy Start model addresses infant mortality prevention on multiple levels, including community awareness, systems improvement, neighborhood engagement, provider training, and individual case management that all converge to lead to better birth outcomes. As a core component of the model, the Consortium is utilized by Healthy Start to help guide their community and programmatic decision-making. At its best, the Consortium is a group of community leaders, health care providers, advocates, and community residents. These partners come to the table highly invested in the future of their community through the babies born there each year. The Consortium provides the key partnerships and resources needed to place the data into the proper context for strong community engagement.

Map of Fetal-Infant Mortality Rate 1996-2011
Douglas County, NE, All Races

Fetal-Infant Rate=10.5
4.3
2.8 1.5 1.9
1996-1999
Fetal-Infant Rate=9.6
3.9
2.0 1.8 1.9
2000-2003
Fetal-Infant Rate=8.3
3.6
1.8 1.2 1.7
2004-2007
Fetal-Infant Rate=7.7
3.4
2.0 1.1 1.2
2008-2011

from IMPLEMENTING PPOR page 9

not explain our excess mortality, and PRAMS data showed that there WERE important disparities in the timing and content of prenatal care. When one physician raised concerns that birth defects were a major contributor to mortality, the PPOR analysis illustrated that birth defects were not a contributor to EXCESS mortality in our community, since the reference population was experiencing higher rates of birth defects than the population with high mortality rates.

In each case, having population-based data helped the community avoid impulses and look deeper to seek the real underlying causes of excess mortality. PPOR allows us to transform moments of questioning and doubt into real, in-depth conversations based on facts. This data can help all of us understand what is likely having a large impact on our community’s infant mortality rates, and what is not.
San Antonio Healthy Start, a part of the San Antonio Metropolitan Health District, recognized PPOR as a valuable mechanism to systematically analyze infant mortality data as well as move that information into action. Leveraging the existing model of the Healthy Start Consortium made these efforts attractive, realistic and affordable. In 2011, San Antonio Healthy Start began its first work towards PPOR Phase 1 data. The State of Texas was gearing up its efforts in combating infant mortality around the same time, and as a result San Antonio Healthy Start was able to expand its existing Consortium to include the PPOR process through a Healthy Texas Babies Initiative Grant. The work of the Consortium and its three work groups is informed by member experience, input from community forums, and PPOR.

The Phase 1 analysis of 2006-2010 fetal and infant deaths, done in the summer of 2011, shows that very few infant deaths are associated with newborn care. However, large excess mortality exists for African-American and Hispanic populations as compared to the internal reference group. With areas of San Antonio experiencing a teen pregnancy rate over 4 times the national average, there were enough cases to calculate PPOR results specifically for teens, showing excess mortality for this sub-group as well.

By the fall of 2012, Phase 2 was initiated for an in-depth look at risk factors among specific sub-groups, and preliminary risk factors were presented to the Healthy Families Network. Unfortunately, too significant a rise in congenital syphilis cases, along with too few deaths for Phase 2 epidemiological methods among subpopulations in the higher birth weight periods, stirred a desire to investigate these deaths in a more qualitative fashion using Child Fatality Review data or a Fetal Infant Mortality Review (FIMR) process.

The marriage of PPOR and the Healthy Start Consortium model has already begun to make an impact. It has validated preconception health efforts that were already underway and provided support for the development of a FIMR process which is expected to examine both congenital syphilis and mortality. Healthy Start benefits from the structure and focus that this data driven process provides, and PPOR benefits from the Consortium’s connection to an existing group of invested partners who are already at the table and dedicated to better birth outcomes.

Momentum builds as the process moves towards Phase 3, when the Consortium will develop strategic action plans based on PPOR Phase 2 data, as well as PRAMS (Pregnancy Risk Assessment Monitoring System) and Child Fatality Review data available from the State. This union demonstrates that data should be used within the context that an involved community group provides, but it is possible, even without a Healthy Start Consortium, to engage other existing community coalitions to leverage their resources and incorporate the PPOR process toward better birth outcomes. For more information, contact Kelly at Kelly.bellinger@sanantonio.gov or 210-207-4725.

“As one Healthy Start Consortium member puts it, ‘So now that we know what is causing these babies to die, what are we going to do about it?’”
At the NE Florida Healthy Start Coalition, the Perinatal Periods of Risk changed the way we did business and how we viewed infant mortality. The Coalition was established in 1992 under Florida’s Healthy Start Program, which provides case management, education and support to at-risk pregnant women and newborns. As part of our responsibilities, we are required to develop a regional maternal and child health plan to determine needs and allocate state and federal resources. In our early plans, we did the usual analyses, examining infant mortality rates and their antecedents like low birth weight. Despite these efforts, our infant mortality continued to increase while other areas of the state experienced marked improvements. We had the data but we had no guidance for action. Did we need more prenatal care? More NICUs?

After yet another community meeting in 1998 on our worsening rates, I called Dr. Richard Hopkins, the state epidemiologist at the time, who had just learned about PPOR at a CityMatCH meeting.

He suggested that PPOR might be the solution to our problems. As soon as I saw that the PPOR boxes were linked to interventions, I was hooked. I remember thinking, what a great way of moving data to action! Soon after that initial introduction to PPOR, Dr. Hopkins helped us acquire the data and I ran the first PPOR analysis – at home using Epi Info™, DOS version no less!

At a community meeting where we presented these results to a very critical audience, the public health community was stunned to learn that there were no statistically significant differences between black and white outcomes in the Newborn Care and Infant Health PPOR boxes. Local providers were really moved by this, because prior to this revelation, I think there was an assumption that disparities were not only intractable but virtually inevitable. The PPOR analysis was the first step in changing that opinion, and helped persuade the health department to participate when the first CityMatCH practice collaborative was announced six months later.

Another significant way PPOR impacted us was by showing us that we needed to be working with women before and between pregnancies if we were going to affect birth outcomes. In 1999, we submitted a proposal in response to a federal Healthy Start RFP which was specifically looking at disparities in infant mortality. Even though the RFP focused on care for pregnant women and newborns, the PPOR analysis gave us the confidence to say that we needed to work with women before and between pregnancies, not just prenatally, as we now had the community data to support this claim. This grant allowed us to establish the Magnolia Project, and helped us

“Because infant mortality is so complex, before data can become actionable information it needs to be ‘massaged’ so that it can be communicated to communities how important this is.”

Hani Atrash, MD, MPH
Director, Division of Health Start and Perinatal Services at Health Resources and Services Administration
forge a new approach focusing not just on pregnant women and new families, but on at-risk women of childbearing age who were sexually active and likely to become pregnant in the near future.

At Dr. Hopkins’ suggestion, we also linked PPOR with our Fetal Infant Mortality Review (FIMR) findings. This provided a third “aha” moment for us on our PPOR journey, and we routinely sort our FIMR findings into the boxes to see whether the theories match up with actual drivers we find in our case reviews. For instance, Kitagawa told us that preventing very low birth weight (VLBW) births would have the most impact, and our FIMR case reviews basically confirmed that. FIMR findings also reinforced the impact of the general health of the mother prior to pregnancy. We have used PPOR to guide our case reviews in FIMR as well: oversampling for FIMR based on problem areas PPOR uncovers.

Today, PPOR sets the stage for where we direct our resources and what the Coalition focuses on. Every 5 years, when we update the regional plan and the Periods of Risk analysis, we see the changes that have occurred, and it’s as eye-opening now as it was at those community meetings long ago. Overall, we’ve seen improvements in our overall rates, but we still struggle with disparities. Results from a longitudinal evaluation of Magnolia Project supports a preconceptional approach to addressing this distressing gap. Our challenge is to find resources to bring it to scale. There’s no question that PPOR has continued relevance today, and we will continue to use it actively to monitor what’s going on in our community.

PERINATAL PERIODS OF RISK (PPOR):
A FRAMEWORK AND ANALYTICAL TOOL TO MOVE COMMUNITIES TO PRODUCTIVE ACTION –THE LOS ANGELES COUNTY (LAC) STORY

Shin Margaret Chao, PhD, MPH
Chief of the Research, Evaluation, and Planning Unit of the Maternal, Child and Adolescent Health Programs

Cynthia A. Harding, MPH
Director of Maternal, Child and Adolescent Health Programs

Giannina Donatoni, PhD, MT (ASCP)
Staff Analyst, Maternal, Child and Adolescent Health Programs

Angel Hopson, RN, MSN, MPH
Fetal and Infant Health Program Manager, LA County Department of Public Health

Since 2002, the Los Angeles County (LAC) Department of Public Health, Maternal, Child, and Adolescent Health (MCAH) Programs have been incorporating the Perinatal Periods of Risk (PPOR) into the existing Fetal and Infant Mortality Review (FIMR) to monitor fetal and infant health in LAC. To develop the required skills and learn from others, we attended a PPOR training led by CityMatCH and in early 2000 joined the PPOR National Learning Network. Our chance to fully execute PPOR began in April 2004 when infant deaths increased in one region of LAC: the Antelope Valley (AV). Our experience provides a good example of how PPOR serves as a framework and analytic tool that moves communities to productive action in addressing infant mortality.
The AV is the most geographically isolated, sparsely populated region of LAC. In April 2004, a review of the 2002 infant death statistics found that the infant mortality rate in the AV increased from 5.0 to 10.6 per 1,000 live births between 1999 and 2002. Of particular concern, infant mortality among African Americans in the AV rose from 11.0 per 1,000 live births (7 cases) in 1999 to 32.7 per 1,000 live births (27 cases) in 2002. In response, we partnered with a community task force to develop an action plan to address the issue. Three stages of the PPOR approach were implemented over the course of one year: 1) Community Readiness; 2) Data and Assessment; and 3) Strategy and Planning.

### Community Readiness

Community readiness was crucial to implementing PPOR. Although the AV is a newly developed area, the Department of Public Health (DPH) Area Health Officer, who had an established working relationship with the Antelope Valley Partners in Health, a leading community stakeholder, connected the DPH, local providers, faith-based organizations, politicians, and the media. A community task force was quickly formed to define priorities for intervention, identify solutions, and sustain on-going work. As a result, the AV community was engaged and ready to investigate the local rise in infant mortality, and a collective sense of urgency motivated community stakeholders to review data and take ownership of the problem.

### Periods of Risk

- **Maternal Health/Prematurity**
  - Neonatal death (< 1500 g, 0-28 days)

- **Infant Health**
  - Infant death (> 1500 g, 29-365 days)

### Interventions

1. Preconception care
2. Interconception care
3. Prenatal care
4. High risk Ob care
5. Psychosocial issues

### Task Force Recommendations

- **Increase capacity and target access to high risk family support programs for African American women and their families.**

- **Conduct education on healthy life practices and develop and outreach/marketing campaign aimed at African American women and the local community.**

- **Decrease barriers to accessing care by increasing the number of women and infants with medical insurance.**

- **Collaborate with and educate local health care providers to ensure higher quality care for African American women and their infants.**

- **Conduct additional research to determine the causes of infant mortality in AV.**
Data and Assessment

The next stage of PPOR gave the task force a clearer picture of the causes of infant mortality in the AV. During the first task force meeting in April 2004, the DPH reviewed the data with stakeholders and explained how PPOR could illustrate where infant mortality could be reduced and what interventions were likely to be the most effective. After seeing the data, the community stakeholders adopted the PPOR approach as the guiding framework for the entire investigation.

The PPOR analysis identified Maternal Health/Prematurity and Infant Health as the most important periods of risk for further investigation and potential intervention. To follow up on these findings, trained Public Health Nurses conducted Infant Mortality Review (IMR) investigations over a 6-month period and developed a better understanding of the problems experienced by fifty-three mothers and infant pairs. A salient finding was the lack of social support networks for women who had lost infants. Many of the women who were interviewed reported that this was not their first experience with infant loss, yet there had been no medical or social support interventions to help them prepare for their next pregnancy.

However, the task force understood that infant death was only the tip of the iceberg. To improve birth outcomes in the AV, additional information was needed to understand the underlying risk factors that could not be established from medical records alone. Consequently, in October 2004, DPH implemented the Los Angeles Mommy and Baby (LAMB) project, a population-based case-control study which could identify potential factors associated with adverse birth outcomes. The LAMB findings in the AV clearly pointed to women’s health prior to pregnancy (preconception health) and prenatal care as having impacts on birth outcomes, each needing to be addressed to improve infant health.

Identifying Strategy and Planning

Finally, in response to the findings from the PPOR analyses, the task force gathered in April 2005 to develop strategic actions for targeted prevention activities addressing infant mortality. At the meeting, community stakeholders reviewed IMR and LAMB data to address maternal health issues and infant health issues, and the task force made a series of recommendations (as detailed in Figure 1). Subsequently, key funders infused resources into the community, resulting in expanded case management for high-risk women, increased family planning services and resources, better training for nurses, and public health initiatives focused on infant safety. In 2007, an analysis of infant mortality data pointed out a significant, long-term reduction of the AV’s infant mortality rate. Between 2002 and 2003, the infant mortality rate among African Americans dropped from 32.7 deaths per 1,000 live births to 16 per 1,000 live births and continued to decline from 2004 to 2005.

Conclusions

Community readiness, mobilization, and alignment in addressing a public health concern in LAC enabled the integration of PPOR into the established Infant Mortality Review structure. This facilitated the implementation of a population based case-control study (LAMB) to monitor the factors associated with adverse birth outcomes. Collectively, the resulting integrated approaches paint a broader picture of the risk and preventive factors than each process could have on its own, and LAC continues to successfully use PPOR to monitor fetal and infant health.

Figure 1. Periods of Risk for Interventions and Task Force Recommendations PPOR Framework

Map 1. Antelope Valley, Los Angeles County, 2005

In 1999, the Healthy Start program was in full swing at several sites, including three neighborhoods in Jefferson County, Kentucky. As an enthusiastic evaluator of this home visiting program in Kentucky, I had the unique opportunity to connect with and provide assistance to these communities. It did not take me too long to learn that the communities’ passions and commitments to reducing infant mortality were strong, but that there was little understanding of the need for an evaluation of their programs’ impacts and health outcomes. Mixing their passion with a commitment to science allowed me to develop a good evaluation plan that received strong support from community stakeholders.

Reducing infant mortality was the main goal of Healthy Start, and using vital records and linking files to better understand these devastating events was the priority. However, I soon came to the realization that the secondary data sources were not enough to gain a true understanding of the underlying causes of infant mortality, an understanding which was needed to develop more effective strategies for prevention. Needless to say, the complexity of infant mortality is overwhelming, and comprehending the intertwined influences of medical and social issues on infant mortality has always been a challenge. These challenges prompted me to think of new strategies to add more evidence and science to the communities’ commitment to reducing infant mortality within the context of an evaluation for Healthy Start, and also to think of ways to integrate the strategies with other program-related efforts. This marked the beginning of a chain of successful and very rewarding activities for me, including my personal collaboration with the CityMatCH leadership and its members.

**Being a “student” again.**
In 2000, a team from the Jefferson County Health Department, myself included, applied and was accepted to the CityMatCH Data Use Institute. Our project was the Fetal Infant Mortality Review (FIMR), a longtime dream that had not yet become a reality. Fetal and Infant Mortality Review is an action-oriented community process that continually assesses, monitors, and works to improve service systems and community re-

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**THE PPOr VISION AND PASSION: MAKING A DIFFERENCE WITH KNOWLEDGE AND COMMITMENT**

by Violanda Grigorescu, MD, MSPH
Chief, Applied Sciences Branch, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention

In 1999, the Healthy Start program was in full swing at several sites, including three neighborhoods in Jefferson County, Kentucky. As an enthusiastic evaluator of this home visiting program in Kentucky, I had the unique opportunity to connect with and provide assistance to these communities. It did not take me too long to learn that the communities’ passions and commitments to reducing infant mortality were strong, but that there was little understanding of the need for an evaluation of their programs’ impacts and health outcomes. Mixing their passion with a commitment to science allowed me to develop a good evaluation plan that received strong support from community stakeholders.

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**VISION AND PASSION**
continued on page 18
New Method of Analyzing Fetal and Infant Mortality
in Jefferson County, Kentucky

Infant mortality is viewed as a sentinel event that serves as a measure of a community’s social and economic well-being as well as its health. The United States has made progress in reducing infant deaths, yet infant mortality rates differ significantly among various racial and ethnic, as well as socio-economic groups. Economic status is a strong predictor of health status and mortality, and this relationship is evident in levels of infant mortality. The infant mortality rate in Jefferson County has decreased, but in some areas, those with a high percentage of African American residents, the rate still remains high.

Traditionally, infant mortality has been examined by age of death and has led to the development of many different indicators. Various problems can arise at different stages of development due to diverse risk factors. In fact, interventions must be developed to specifically address these different windows of opportunity. Not only must we consider these variant risk factors for infant mortality, we need also look at fetal mortality. Thus, a new method of analyzing the fetal and infant mortality in Jefferson County is necessary. This new method is a two-step process:

I: analyze the fetal infant mortality death using the Perinatal Periods of Risk (PPOR) approach to identify the higher group mortality

II: target Fetal and Infant Mortality Review (FIMR) efforts specifically on the higher group mortality

I: PPOR

Dr. Brian McCarthy from the World Health Organization (WHO) Perinatal Collaborative Center at Centers for Disease Control and Prevention (CDC) and fellow WHO colleagues have developed the PPOR as a simple and standardized approach. As one of the core components of an ongoing Maternal and Child Health (MCH) surveillance system, the new approach to monitoring and investigating fetal-infant mortality: is simple;

- has strong conceptual basis;
- mobilizes communities to action;
- prioritizes prevention efforts;
- establishes on-going surveillance;
- has been used in developing and developed countries for over a decade, and
- has been tested in the US urban settings.
sources for women, infants, and families. A fetal or infant death is the event that begins the process.

With high hopes and great enthusiasm, we all embarked on this adventure, learning about new tools and developing skills which were taught to us by well-known national leaders and other local public health colleagues along the way. By the time of “graduation” we had the very first FIMR implemented in Jefferson County and had developed plans to better integrate it with the Healthy Start project. However, we soon learned that we did not have enough resources to review all infant deaths through FIMR. Therefore, we had to use a convenient sample of infant death cases and utilize the available staff to collect crucial information through home interviews and medical chart reviews. Our lack of resources became a significant barrier in being able to translate the findings which indicated a strong association between a woman’s health prior to pregnancy and infant mortality. As a result, making recommendations for improving women’s health with the ultimate goal of reducing infant deaths became a daunting challenge.

We were not alone in facing that challenge, and again we were lucky to be in the right place at the right time to take advantage of another national initiative: the Perinatal Periods of Risk (PPOR). PPOR is uniquely designed to walk participants through a process that begins with assessing knowledge and resources to using the data findings and then implementing targeted strategies. The PPOR process was exactly what Jefferson County needed to fully realize their vision of integrating MCH programs with services for women of reproductive age living in that community. It was the missing piece of the puzzle, and as the MCH epidemiologist, I could have not been happier to discover PPOR. I still remember the FIMR meeting when I proudly introduced PPOR phase 1 (which highlights differences in outcomes due to changes in the perinatal system of care) as a tool to identify excess fetal and infant deaths. After a review of cases selected through this approach, the first recommendation for presumptive eligibility into Medicaid was adopted. Other recommendations for improving the referral process and availability of services for women at risk who were enrolled in the Healthy Start program followed and have been successfully implemented.

The preconception and interconception periods have now been identified as crucial times to implement strategies focused on improving mothers’ and infants’ health outcomes. In collaboration with other colleagues (i.e., Dr. Barbara Ferrer, Executive Director of Boston Public Health Commission) who have also been using PPOR, a “woman’s health status assessment” has been developed for and utilized by women enrolled in Healthy Start. Since then, PPOR, FIMR, and Healthy Start have also been used collectively by the Jefferson County Health Department to address both women’s and infants’ health in the county.

The end as a new beginning
My professional ventures and my passion for using the best epidemiological tools to improve program strategies and health outcomes did not end after leaving the Jefferson County Health Department. PPOR has always been my companion, and I have promoted and used it extensively. I have shared my knowledge about PPOR with colleagues, young professionals, staff I supervised, academic fellows, partners, and even high-level administrators and deputies at a time when PPOR Phase 2 was the only tool available to show differences in mortality versus birth weight distribution due to changes in perinatal regionalization.

My many years in health care and experiences gained from different health care systems have helped shape my vision for public health activities, from epidemiology and research studies to program strategies. At times, I needed new tools to transform my ideas into action. PPOR is one of these tools, and I think of it as the best approach for engaging communities in assessing and monitoring infant mortality, because it identifies gaps that may be missed by other classic epidemiologic methods. I will always think of CityMatCH as an organization that encourages and supports imagination, creativity, and the use of evidence at the local level, which made a significant difference for all of us. Thank you, CityMatCH!
At Denver Public Health, we have completed Phase I of the Perinatal Periods of Risk (PPOR). To run the PPOR analyses, we created and used several types of reference groups. We created reference groups within Denver County to compare, for example, rates among Black and Hispanic women to rates among White women. We also used an affluent county (adjacent to Denver) that experiences low infant mortality rates as a reference group for all Denver women. Comparisons against all reference groups returned fairly consistent results: our opportunity gap in Denver County (excess mortality) is driven by maternal preconception and interconception health.

To help build community interest and political will, we created an innovative reference group based on the eleven city council districts of Denver. We mapped infant deaths, fetal demises and live births by council district to generate a feto-infant mortality rate for each district. These rates ranged from 5.1 to 9.4 deaths per 1,000 live births (and fetal deaths). To maintain an adequate number of deaths for analysis, we created tertiles, with three districts falling into the lowest category (the reference group) and four falling into the middle and highest categories. Again, results indicated that maternal preconception and interconception health require action.

The PPOR approach provides additional benefits: it allows Denver Public Health to visualize the significant geographical differences between straight infant mortality rates and feto-infant mortality rates. It also allows us to capitalize on momentum generated by existing partnerships between Denver Public Health, the communities, City Council members, and like-minded community-based organizations.

PPOR has improved our understanding of Denver’s adverse birth outcomes and has given us confidence that we are moving in the right direction by focusing on preconception health to reduce infant and fetal death. PPOR is a powerful methodology that has revealed new and detailed information about infant mortality in Denver, but has also revealed something unexpected, as the mapping results have been very powerful. We are looking forward to Phase II of the analysis!

“I was the coordinator at CityMatCH working with the three pilot communities (King County, Seattle; Honolulu, HI; and Boston, MA), and I remember that we were the first group to use the Risk approach in a smaller setting, as Dr. McCarthy’s model – the 16 cell model – had really only been used on a nationwide basis in developing countries. Our contribution – I think of it as an adaptation of a very clear strategy – was to make PPOR a simpler, easier to understand model that could be used to engage the community. Dr. Sappenfield, the then-CDC assignee to CityMatCH, and the pilot communities, really propelled it forward by collapsing the cells and also developing the language and the concept of community engagement. We wanted PPOR to be not just an analytic tool, but a tool you went into a community with to discuss infant mortality. Some health departments use just the analytic methods, not quite bridging the gap between data and practice. However, many have successfully used PPOR to achieve important changes. I still think that PPOR is a good framework for exploring the different causes of infant mortality instead of just using a single number—the infant mortality rate.”

Patrick Simpson, MPH
Program Officer, W.K. Kellogg Foundation
THE PERINATAL PERIODS OF RISK APPROACH: THE TARRANT COUNTY EXPERIENCE

Ann Salyer-Caldwell, MPH, RD, LD
Associate Director, Community Health Promotion, Tarrant County Public Health

Anita Kurian, DrPH, MBBS
Epidemiology Division Head & Chief Epidemiologist, Tarrant County Public Health

For over a decade, the infant mortality rate (IMR) in Tarrant County, Texas has exceeded the rates seen elsewhere in Texas. In 2005, the IMR in Tarrant County was 8.2 deaths per 1,000 live births, and ranked highest among counties in Texas with 5,000 or more live births. The IMR in African-American women was 19.5, approximately 3 times that of White and Hispanic women.

Until 2003, Tarrant County Infant Mortality Network (now called the Network) used the traditional approach to investigate infant mortality – assessing the overall infant mortality rate. The Network, composed of health professionals, school leaders, community representatives, elected officials, religious leaders, and public health personnel who work with women or have a specific interest in infant mortality, used descriptive data to increase awareness of this significant community health indicator.

However, close scrutiny of the overall infant mortality rate did not lead to a greater understanding of the factors that contributed to infant mortality in the Tarrant County community. Consequently, after much deliberation, the Network adopted the Perinatal Periods of Risk (PPOR) approach to identify potential gaps in the Tarrant County community with regards to the public health issue of infant mortality.

Our first PPOR analysis was completed in 2003 using 2000-2002 vital statistics data from the Texas Department of State Health Services (DSHS). The Maternal Health/Prematurity period of risk was found to have the highest fetal-infant mortality rate (4.0 per 1,000 live births & fetal deaths) followed by the Maternal care period of risk (1.9 per 1,000 live births & fetal deaths). Further analyses by race/ethnicity indicated that African-Americans had the highest fetal infant mortality rates in all four of the periods of risk.

Excess fetal infant mortality rates were calculated using internal and USA reference groups. In both cases, the highest excess fetal infant mortality rate was in the Maternal Health/Prematurity period of risk (excess rate using internal reference group – 1.2 per 1,000 live births & fetal deaths; excess rate using external reference group – 1.8 per 1,000 live births & fetal deaths). African-Americans continued to experience the highest excess fetal infant mortality rates.

Until the PPOR findings were publicized, most people were of the opinion that the problem of infant mortality could be addressed through better prenatal care alone. The Network developed a plan to raise awareness about the PPOR findings at the annual infant mortality summit, in addition to media reports, meetings with elected officials, and community
Jennifer Skala shepherded PPOR through the second and third stages of its development, assisting the CityMatCH Practice Collaborative cities in their efforts to analyze their data and test and refine the analytic and community methods. Jennifer, now Vice-President of Community Impact with the Nebraska Children and Families Foundation, says:

“Oftentimes we know the problem and the evidence-based practices, but we’re not utilizing both at the same time to make a clear case for where you need to focus. PPOR is such a data-driven process that instead of leaving you mired in analysis forever, it becomes very clear what should be targeted and where in the community the intervention needs to happen. It’s probably the most user-friendly methodology and community planning tool that I’ve ever been a part of, both during my time at CityMatCH and since then. The framework that PPOR provides leads to solid, evidence-based practices, and that’s what CityMatCH is all about – using data to plan and move policy, to bring people to action and change the systems and practices for good outcomes.”

Jennifer Skala, MEd
After our work with CityMatCH on the development of PPOR concluded, we continued to push the limit internationally in trying to introduce the concept that “Every pregnancy counts, so account for every pregnancy.” In our work abroad, we advocate recording pregnancies in the Maternal—Infant Mortality and Morbidity Matrix (MIM) as soon as a woman realizes that she is pregnant. For maternal events, we use a MOMS matrix (Monitoring of Maternal Status), and a BABIES matrix (Birthweight, Age-at-death, Boxes for Intervention and Evaluation System) for baby events. We also use the BABIES matrix in our MARS (Method for Assessing Reported Statistics) analytical function to evaluate the current local reporting system for infant deaths in Georgia.

Another concept we have emphasized is that “Every newborn has weight (value), so weigh every newborn.” The latter concept is especially important in low resource settings (LRS) because these often “fail to weigh” even late 3rd trimester stillbirths occurring in birthing facilities. While we take for granted the quality of our US intrapartum care, the four delays (delay in recognizing the problem, in deciding to seek care, in arriving at the appropriate facility, and in receiving quality care) have hit LRS much harder, and considerable excess mortality occurs during labor and delivery.

CityMatCH’s use of PPOR as a means of obtaining social justice deserves the most praise, as it has used PPOR as a means to identify the disparities that exist. These disparities are man-made and, therefore, unacceptable in a democratic society. Some of the developing nations that we have worked with are contending with extremely high infant mortality rates, which gives me a sense of thankfulness for what we have here in the US, but I believe that we in the U.S. can still learn something from their experiences. After seeing the ingenuity of what other countries are willing to do with so much less, it gives me a sense that we could do more with what we have. I hope that CityMatCH will continue to perform a leadership function around infant mortality here in the US, as it has already set an example for others.


6 http://www.pphprevention.org/files/AMTSL_FacilitatorGuide_AddTopic2_English.pdf
The State Infant Mortality (SIM) Toolkit, released in 2012, is the culmination of a vision to develop a structured guide for analyzing infant mortality data in an urban, local, tribal, or state setting by a team of diverse staff to determine the underlying factors associated with infant deaths. The SIM toolkit provides practical guidance on the application of maternal and child health epidemiology to discern the underlying factors responsible for excess infant mortality and identify opportunities for intervention. Objectives of the SIM Toolkit are defined as:

- Highlight the importance of infant mortality as a measure of population health.
- Provide a framework to assist states, localities, tribes, or communities in selecting appropriate indicators of infant mortality.
- Outline useful indicators for infant mortality assessment, defining selected indicators, and identifying data sources.
- Demonstrate methodological and statistical approaches to analyzing data and provide guidance on the interpretation of findings.
- Provide recommendations for incorporating findings into programs and policies to reduce infant mortality.

The toolkit was developed by the Maternal and Child Health Epidemiology Program (MCHEP) in partnership with the Association of Maternal & Child Health Programs (AMCHP) and the March of Dimes Foundation. Look for more on the toolkit and its application for local health departments in an upcoming issue of CityLights!