Perinatal Periods of Risk: Using Data and Community Involvement to Prevent Infant Mortality

Introduction & Overview
Workshop Objectives

• Infant mortality
• What PPOR *analysis* means
• PPOR is more than analysis
• How communities use FIMR and PPOR together
• How one health department has used PPOR with FIMR to achieve results!
Infant Mortality Rates are HIGH, and even in cities where they have decreased, racial disparities persist

(PPOR Fetal-Infant Mortality Rates in Urban County)
Infant mortality is complex

Important time periods
- Preconception health
- Prenatal
- Neonatal
- Post-neonatal
  - Life course
  - Inter-generational

Goes beyond obstetrics
- Chronic disease
- Mental Health
- Social determinants
  - Health care system
  - Built Environment
Communities need help!

PPOR helps explain what is causing the excess mortality
WHAT’S NEW ABOUT PPOR ANALYSIS?

PPOR uses Fetal Deaths

WHY?

1. They are important to their families.

2. There are about as many fetal deaths as there are infant deaths.

3. These deaths can provide us with information.

PPOR is about using every bit of information we have.
WHAT’S NEW ABOUT PPOR ANALYSIS?
The PPOR approach examines mortality in two dimensions:

BIRTH WEIGHT
(VLBW, larger)
AND

AGE AT DEATH
(fetal, neonatal, postneonatal)
Periods of Risk defined by (1) weight at birth and (2) age at death

- **Fetal Deaths** >=24 wks
- **Neonatal**
- **Post-neonatal**

<table>
<thead>
<tr>
<th>Weight Range</th>
<th>Fetal Deaths</th>
<th>Neonatal Deaths</th>
<th>Post-neonatal Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>500-1499 g</td>
<td>Larger fetal deaths</td>
<td>Larger neonatal deaths</td>
<td>Larger post-neonatal infant deaths</td>
</tr>
<tr>
<td>1500+ g</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The boxes, or periods of risk, were chosen so deaths in the same “box” had similar PROBLEMS:

- Causes of death
- Maternal risk factors

...which means they also had similar SOLUTIONS.
Four Perinatal Periods of Risk
named to suggest prevention areas

- Fetal Deaths >=24 wks
- Neonatal
- Post-neonatal

500-1499 g
Maternal Health / Prematurity

1500+ g
Maternal Care, Newborn Care, Infant Health
Each period of risk is associated with its own set of risk and prevention factors.
SORT the Fetal and Infant Deaths

Example: Girl born weighing 2499 grams died at 22 days old

<table>
<thead>
<tr>
<th>Fetal Death</th>
<th>Neonatal 0-27 days</th>
<th>Post-neonatal 28-364 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;=24 weeks</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

500-1499 g

Maternal Health/ Prematurity

1500+ g

Maternal Care | Newborn Care | Infant Health
SORT the Fetal and Infant Deaths

Example: boy born weighing 820 grams died at 35 days old

- Fetal Death: >=24 weeks
- Neonatal: 0-27 days
- Post-neonatal: 28-364 days

Maternal Health/ Prematurity

- 500-1499 g
  - Maternal Care
  - Newborn Care
  - Infant Health

- 1500+ g
SORT the Fetal and Infant Deaths

Example: Boy died before birth (Fetal death), 590 grams and 25 weeks gestation

Fetal Death >=24 weeks  Neonatal 0-27 days  Post-neonatal 28-364 days

500-1499 g  Maternal Health/Prematurity

1500+ g  Maternal Care  Newborn Care  Infant Health
SORT the Fetal and Infant Deaths

Example: Girl, Fetal death, 820 grams and 22 weeks gestation
Deaths NOT used in PPOR

• Smallest deaths have inconsistent reporting (causes biased results)
  – Fetal deaths less than 24 weeks gestation or less than 500 grams
  – Infant births and deaths less than 500 grams

• No death certificate
  – Very early miscarriages
  – Elective abortions
The four periods provide a framework that helps communities

- Move from *having* data to *using* data
- Prioritize limited resources
- Use evidence to maximize impact
Community stakeholders in “Urban County” sorted their 2000-2003 fetal and infant deaths in this way, and made a PPOR map that looked like . . .
To judge whether these counts are “high”, we first need to know how many pregnancies there were altogether.

There were 23,282 fetal deaths and live births.
To make fair comparisons, Urban County calculated mortality rates.

To calculate mortality rates:

Urban County divided each count by the number of live births and fetal deaths (23,282) then multiplied by 1,000.

**INTERPRETATION:**
There were 4.2 deaths for every 1,000 live births and fetal deaths.
Urban County’s PPOR Map of Fetal-Infant Deaths

You might be asking yourself

Is 4.2 a good rate or a bad rate?

<table>
<thead>
<tr>
<th>Category</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Health/ Prematurity</td>
<td>4.2</td>
</tr>
<tr>
<td>Maternal Care</td>
<td>2.1</td>
</tr>
<tr>
<td>Newborn Care</td>
<td>1.9</td>
</tr>
<tr>
<td>Infant Health</td>
<td>2.0</td>
</tr>
</tbody>
</table>

97 (4.2)

You might be asking yourself

Is 4.2 a good rate or a bad rate?
“What rates can we expect to see in each Period of Risk?”

PPOR answers this question using a reference group, a real population of mothers that experience best outcomes: low fetal and infant mortality rates.
Examples of Reference Groups

- Well-educated Black mothers residing in your state at the time of their baby’s birth

- White mothers residing in an affluent “sister city” at the time of the birth

- Well-educated, white non-Hispanic women over the age of 19 who resided in your city when their baby was born
The Reference Group is about Justice

Community stakeholders *choose* the reference group.

- Their underlying assumption is that if the reference group can have low mortality, our study group should be able to reach that goal.

- The status quo is not acceptable.
Instead of comparing one group with another, each is compared with the reference group.

Any group might have room to improve.

Each group contributes to the overall burden.
Urban County stakeholders chose the US Reference Group 2000-2002

- Defined by *maternal* characteristics
  - 20 or more years of age
  - 13 or more years of education
  - Non-Hispanic white women
  - Residents of the US at the time of baby’s birth

Total Fetal-Infant Mortality Rate = 5.7
They compared the study and reference populations by subtracting rates in each period of risk.

**Urban County**
- 4.2
- 2.1
- 1.9
- 2.0

**Reference Group**
- 2.2
- 1.5
- 1.1
- 0.9

4.2 - 2.2 = 2.0**

**INTERPRETATION:**
2.0 excess deaths for every 1,000 live births and fetal deaths
The difference between rates, or the “gap”, represents “excess mortality” and it means that some of the deaths were preventable.
Two periods of risk accounted for 70% of their excess mortality.

The second phase of the Urban County investigation focused on these two periods.
SUCCESS!
Urban County completed Phase 1 of PPOR analysis

Their rewards . . .
SUCCESS!
They had eliminated many potential causes and narrowed the scope of their investigation.

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

- Preconception Health Behaviors
- Perinatal Care etc.
- Prenatal Care
- High Risk Referral
- Obstetric Care etc.
- Perinatal Management
- Neonatal Care
- Pediatric Surgery etc.
- Sleep-related Deaths
- Injuries
- Infections etc.
SUCCESS!
The community stakeholders were still on board

They understood the numbers and saw how the data could help them prioritize.
Some stakeholders simply do not believe in infant mortality statistics, and *sometimes they are right!*

No data source is perfect. Data quality must be checked. For example, even a few deaths without birth weight information will make PPOR rates look artificially low.

It is important to listen to and address data concerns THROUGHOUT the process.
Urban County didn’t stop there.

Phase 2 analysis helped them prioritize among the remaining potential causes of excess mortality.
“She’s got to be kidding! There’s more?”
There are three helpful steps in Phase 2 Analysis

1. Identify the most important probable causes or mechanisms for excess mortality

2. Examine risk factors for those causes, by comparing the study and reference populations

3. Estimate potential impact of risk factors
Schematic of PPOR Logical Steps

Phase 1
- Infant health period gap

Phase 2 Step 1
- Injuries
- Congenital Anomalies
- SUID

Phase 2 Step 2
- Car seats
- Child abuse/neglect
- Co-sleeping
- Bedding
- Sleep position
Phase 2 Step 1: Causal Pathway
In IH we use “underlying cause” ICD-10 Code from the death certificate to investigate. Here is a partial list for Urban County.

<table>
<thead>
<tr>
<th>ICD code</th>
<th>Count of Deaths</th>
<th>Code description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q208</td>
<td>1</td>
<td>Other congenital malformations of cardiac chambers and connections</td>
</tr>
<tr>
<td>Q232</td>
<td>1</td>
<td>Congenital mitral stenosis</td>
</tr>
<tr>
<td>Q249</td>
<td>2</td>
<td>Congenital malformation of the heart, unspecified</td>
</tr>
<tr>
<td>Q909</td>
<td>1</td>
<td>Down's syndrome, unspecified</td>
</tr>
<tr>
<td>Q913</td>
<td>1</td>
<td>Edwards' syndrome, unspecified</td>
</tr>
<tr>
<td>V486</td>
<td>1</td>
<td>Passenger injured in traffic accident</td>
</tr>
<tr>
<td>W75</td>
<td>2</td>
<td>Accidental suffocation and strangulation in bed</td>
</tr>
<tr>
<td>W84</td>
<td>1</td>
<td>Unspecified threat to breathing</td>
</tr>
<tr>
<td>R95</td>
<td>15</td>
<td>SIDS</td>
</tr>
</tbody>
</table>
Step 1. The dozens of ICD-10 codes were grouped, and mortality rates calculated for each group in both the study and reference populations.
SUCCESS!
Urban County Stakeholders had discovered that most of their Infant Health Period excess mortality was due to sleep safety issues.

They had eliminated causes that were not large contributors to their infant mortality disparity and further narrowed the scope of their investigation.
But they could do better!

Step 2: Examine risk factors for those causes, by comparing the study and reference populations
Odds Ratios for Causes of SUID

SUID is:
- SIDS
- Ill-Defined
- Accidental Suffocation

Sleep Position
- Side or Prone (OR 2.3-13.1)
- Prone with soft bedding (OR 21.0)

Bed-sharing
- (OR 2.88)

Prenatal drug and alcohol use
- (OR varies, > 3.0)

Smoke Exposure prenatal
- (OR 3.8-4.1*)

Use of soft bedding
- (OR 5.0)

Smoker Parent
- (OR 2.3-17.7)

Infant <3 months
- (OR 4.7-10.4)

Soft surfaces like couch, armchair
- (OR 5.1-66.9)

Multiple bedsharers
- (OR 5.4)

Parent consumed alcohol, drugs, or is overtired
- (OR 1.66)

Source: Rachel Moon’s CDC Grand Rounds Presentation October 2012,
Step 2: Over 70% of Urban County babies were put to sleep on their backs, which is as good as the best states. Prone sleep position is less likely to be contributing to the gap.
Step 2: Prevalence of Risk Factors. Since more mothers in Urban County smoked, this could be contributing to the gap.

Percent Smokers (Birth Certificate)
Child abuse investigators on the team reported that couches, blankets, and parental drug use had been factors in several “SIDS” death cases.

A survey of local obstetricians revealed that
- Most doctors did not discuss safe sleep with expectant mothers
- Most were not aware of available smoking cessation services
Step 2: Guided by PPOR findings, the Fetal Infant Mortality Review team focused on Sleep-related deaths for six months.

The FIMR Case Review Team reported that the physical and mental health of mothers was a factor in many of these deaths, including

- chronic stressful conditions
- lack of social support
Step 3: Estimate potential impact

- It is tempting to pick the risk and preventive factors with the biggest disparity in prevalence.

- Ideally we should address factors with the biggest potential impact.

- Estimating preventive impact of each factor on excess mortality helps prioritize the factors likely contributing to excess mortality.
Step 3: Urban County estimated the impact of risk factors, and the potential impact of interventions

We can statistically estimate how many lives could potentially be saved if certain risks were reduced (Population Attributable Risk)

But we also need to consider:
• Which factors are modifiable?
• Do evidence-based interventions exist?
• What are our community assets, capacity, and commitment?
Quick Side Trip

What is Population Attributable Risk?
## Population Attributable Risk Percent

<table>
<thead>
<tr>
<th></th>
<th>“Disease”</th>
<th>Not</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exposed</td>
<td>a</td>
<td>b</td>
<td>$n_1$</td>
</tr>
<tr>
<td>Unexposed</td>
<td>c</td>
<td>d</td>
<td>$n_2$</td>
</tr>
<tr>
<td>All</td>
<td>a+c</td>
<td>b+d</td>
<td>$n_0$</td>
</tr>
</tbody>
</table>

- $p_2 = \frac{c}{n_2}$ (rate of disease in low risk group)
- $p_0 = \frac{(a+c)}{n_0}$ (rate of disease in whole population)

Levin’s PAF = \frac{(p_0 - p_2)}{p_0}
How to Calculate Crude Population Attributable Risk: Example

15 sleep related deaths in a population of 8,550 were cross-tabulated by sleep safety and cause of death.

<table>
<thead>
<tr>
<th></th>
<th>Sleep-related death</th>
<th>Not sleep-related death</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exposed to risk (e.g. tummy-sleeping)</td>
<td>12</td>
<td>3408</td>
<td>3420</td>
</tr>
<tr>
<td>Unexposed (e.g. back sleeping)</td>
<td>3</td>
<td>5127</td>
<td>5130</td>
</tr>
<tr>
<td>Total</td>
<td>15</td>
<td>8535</td>
<td>8550</td>
</tr>
</tbody>
</table>

**PAR/PAF answer the question:** What if the entire population had the lower, “safe sleep” rate of SUID deaths?
Mortality rate due to SIDS and unsafe sleep among those who slept safely:

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<tr>
<td>Total</td>
<td>15</td>
<td>8535</td>
<td>8550</td>
</tr>
</tbody>
</table>

\[
\text{Mortality rate due to SIDS and unsafe sleep among those who slept safely:} \quad \frac{3}{5130} \times 1,000 = .58 \text{ deaths per thousand}
\]

If all 8550 babies slept safely, the estimated number of deaths would be:

\[
.58 \times 8,550 = 5 \text{ deaths}
\]

We would reduce the number of sleep-related deaths by 10, or 67% if all babies slept safely.
Fun Use of PAR: If only a fraction (40%, for example) of the babies slept safely, we could expect to save 40% of the babies, or 4 instead of 10, and our attributable risk fraction would be 4/15 or 40% of 67% (27%).
Population Attributable Risk Percent:

• Compares the rate for the entire population to the rate for those WITHOUT the risk factor.
• Is a rough measure of potential impact (only one factor at a time).
• Is not good at estimating the impact of multiple factors.

Interpretation: “Percent of the population that would not experience the poor outcome if the risk factor were eliminated from the entire population.”
Step 3: Estimate the impact

- Crude Estimate of Population Attributable Risk
- Population Attributable Risk based on published adjusted relative risk
- Adjusted Population Attributable Risk based on RR adjusted using regression in local population
- Which factors are modifiable? By how much?
The stakeholders weighed the evidence and sought more information as needed.

Phase 2 investigations can continue as questions arise and more data becomes available.
Urban County’s Community Stakeholders decided on these **initial action steps:**

- Message changed from “sleep on back” to a broader “safe sleep” message
- Physician education about smoking cessation services for pregnant women
- Partnered with a group that was already working on maternal mental health issues
SUCCESS!
Urban County Had won still more valuable prizes . . .

• Their time investment was focused

• They found some answers

• Action steps were more appropriate than initially envisioned ("back to sleep")
Step 1: Identify Causal Pathways or Biologic Mechanisms for Excess Mortality

Cause of VLBW fetal and infant deaths is

- Multifactorial
- Complex
- Inconsistent
- Varies by training

ICD-10 Cause of Death Codes are not very helpful
Steps for Phase 2 Analysis

Maternal Health/Prematurity Period

Step 1. “Causal pathway”

- What causes of death contribute the most to excess mortality in this risk period?
- Can “patterns” in mortality disparities help us understand the underlying mechanism for excess mortality in this risk period?
### Maternal Health/Prematurity Period

#### A Tale of Two Cities

<table>
<thead>
<tr>
<th>Nonicu City</th>
<th>Tinybaby City</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,000 births</td>
<td>1,000 births</td>
</tr>
<tr>
<td>10 VLBW deaths</td>
<td>10 VLBW deaths</td>
</tr>
</tbody>
</table>

For both cities, the "Blue Box" mortality rate is 10 VLBW deaths per thousand live births.

**What can these cities do?**
What is the difference between these two cities . . . Let’s take a closer look

<table>
<thead>
<tr>
<th>Nonicu City</th>
<th>Tinybaby City</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,000 births</td>
<td>1,000 births</td>
</tr>
<tr>
<td>10 VLBW births</td>
<td>100 VLBW births</td>
</tr>
<tr>
<td>10 VLBW deaths</td>
<td>10 VLBW deaths</td>
</tr>
</tbody>
</table>

We were missing an important fact. The number of VLBW births sets these two cities apart.
What does this difference mean?

<table>
<thead>
<tr>
<th>Nonicu City</th>
<th>Tinybaby City</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 VLBW births</td>
<td>100 VLBW births</td>
</tr>
<tr>
<td>10 VLBW deaths</td>
<td>10 VLBW deaths</td>
</tr>
<tr>
<td><strong>Mortality rate for</strong></td>
<td><strong>Mortality rate for</strong></td>
</tr>
<tr>
<td>a baby born VLBW</td>
<td>a baby born VLBW</td>
</tr>
<tr>
<td>in Nonicu City</td>
<td>in Tinybaby City</td>
</tr>
<tr>
<td><strong>is 100%</strong></td>
<td><strong>is 10%</strong></td>
</tr>
</tbody>
</table>
Kitagawa’s formula tells us:
Which city we resemble, and
What we need to focus on?

93%  7%

Maternal Health/Prematurity Period

- Birthweight Distribution: 93%
- Birthweight Specific Mortality: 7%
### Phase 2 Analysis—MH/P Period

Partial list of risk factors by contributor

<table>
<thead>
<tr>
<th>Birthweight Distribution (VLBW Births)</th>
<th>Birthweight-Specific Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking</td>
<td>Gestational age</td>
</tr>
<tr>
<td>Prenatal care</td>
<td>Referral system</td>
</tr>
<tr>
<td>Preconception care</td>
<td>Perinatal care</td>
</tr>
<tr>
<td>Parity</td>
<td>NICU system</td>
</tr>
<tr>
<td>Stress</td>
<td>Mat. complications</td>
</tr>
<tr>
<td>SES/Education</td>
<td>Neonatal conditions</td>
</tr>
<tr>
<td>Birth Interval</td>
<td>Pay source</td>
</tr>
<tr>
<td>Maternal HTN/Diabetes</td>
<td>Etc.</td>
</tr>
<tr>
<td>Etc.</td>
<td></td>
</tr>
</tbody>
</table>
Maternal Health/Prematurity

Step 2: Analysis plan depends on result of Kitagawa

Maternal Health/Prematurity

OUTCOME

Birthweight Distribution

Percent VLBW

Birthweight-Specific Mortality

Mortality Rate

POPULATION AT RISK

All Births And Fetal Deaths

VLBW Births and Fetal Deaths

Percent VLBW

VLBW Births and Fetal Deaths
Phase 2 Analysis Strategy

- Eliminate consideration of risk and preventive factors that are **UNLIKELY** to be contributing
- Find and target **KNOWN** factors that are likely to be contributing
SUCCESS in Outcomes
PPOR 1993-2009
Urban County

<table>
<thead>
<tr>
<th>Year Range</th>
<th>Fetal-Infant Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993-1996</td>
<td>10.7</td>
</tr>
<tr>
<td>1997-2000</td>
<td>10.3</td>
</tr>
<tr>
<td>2001-2005</td>
<td>8.8</td>
</tr>
<tr>
<td>2006-2009</td>
<td>8.2</td>
</tr>
</tbody>
</table>

The decrease in mortality rates can’t necessarily all be attributed to PPOR
6-stage PPOR approach following the community planning cycle

Stage 1: Assure Community and Analytic Readiness

Stage 2: Conduct Analytic Phases of PPOR

Stage 3: Develop Strategic Actions for Targeted Prevention

Stage 4: Strengthen Existing and/or Launch New Prevention Initiatives

Stage 5: Monitor and Evaluate Approach

Stage 6: Sustain Stakeholder Investment and Political Will
You need to be ready and have committed leadership

- If communities are not ready for change, or leadership is not engaged or committed, they will have a difficult time being successful.

- Planning helps avoid failure, which can be discouraging.
Because infant mortality has many social and medical causes, many stakeholders are needed.

Everyone has a different piece of the puzzle.

“Data analysis alone does not produce community change.”
Who are your stakeholders?

Source: NACCHO’S MAPP Clearinghouse
Tools for Assessing & Evaluating Readiness

- Help engage partners, reach consensus, identify assets, reveal gaps, develop strategies
- Evaluate efforts of the collaborative

The Wilder Collaboration Factors Inventory

<table>
<thead>
<tr>
<th>Statements about Your Collaborative Group:</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral, No Opinion</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>History of collaboration or cooperation in the community</td>
<td>1. Agencies in our community have a history of working together.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2. Trying to solve problems through collaboration has been common in this community. It’s been done a lot before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Collaborative group seen as a legitimate leader in the community</td>
<td>3. Leaders in this community who are not part of our collaborative group seem hopeful about what we can accomplish.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4. Others (in this community) who are not a part of this collaboration would generally agree that the organizations involved in this</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Name of Collaboration Project: __________________________ Date: __________________________
Can everyone use the Perinatal Periods of Risk approach?

What do you need?
--You need at least 60 deaths--

◆ At least **60** fetal and infant deaths, **for each population** being studied (including reference group)

◆ May combine up to **five years** (no more, due to changes in medical practice and public health systems)

◆ Phase 2 analyses require even more deaths (at least 200 to do initial step)
Rates based on smaller numbers (the red line) are less stable due to random variation without any real underlying change.
You need a clearly defined study population

A small area may not have enough deaths, and population-based data may be available only down to the city or county level.
You need 3 vital records data files

1. Fetal deaths
2. Infant deaths, linked to birth records
3. Live births

4. You need someone who knows what to do with the data files
PPOR should be used with any existing efforts

- FIMR
- Healthy Start
- Community Health Assessments

Or, if you are just starting out, the PPOR approach is the whole package!
If you have too few deaths, you can:

- use Phase 1 results from region or state
  - possibly adjust for demographic differences (synthetic estimate)

- use the reference group concept

- use the births to compare prevalence of relevant risk factors and estimate impact
If you have missing data, you can...

- impute birthweight from gestational age and vice versa

- impute using more complex regression methods

- use sensitivity analysis (different hypothesized ways missing cases could be distributed)
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