Perinatal Periods of Risk (PPOR)

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Integrating PPOR and Fetal Infant Mortality Review

Population-based data

Case review data

Research

Stakeholder knowledge of the community
PPOR (Population-Based Data)

• Population-based data—
  – Very limited set of factors to study
    • May not be meaningful
  – Small areas have unstable rates
  – Slow turnaround time
  – Does not show cause and effect
FIMR is a formalized method for gathering **QUALITATIVE** information about individual cases of infant and fetal death, which are considered “sentinel events”.

- FIMR brings a human face to the problem
- In-depth case reviews can provide a missing piece of the infant mortality puzzle.
Points to Remember...

• Case reviews—
  – Only utilized a **small** number of cases
  – Are selected in a **non-random** way from a special subgroup of the population
  – Should **not** be interpreted as **representative** of the population
Research

- Scientific evidence, what is known
- Limitations to research studies:
  - Special populations may not be relevant to the community
  - Difficult to replicate conditions of the intervention, etc.
  - Slow process
Local Stakeholder Knowledge and Experience

• Stakeholders have limitations:
  – Stakeholders often believe their experiences carry a lot of weight (i.e. bias)
  – Everyone has a different set of past experiences or beliefs
  – Stakeholders do not share experiences with the whole population
Why use population-based data?

Population-based data provides a different perspective

Program data and personal experiences are important, but should be framed with birth certificate data for a more complete picture.
Why use population-based data?

- Vital records data includes ALL babies
  - Deaths are not a random sample of live births
  - Studying only infant deaths results in bias, and does not provide a representative picture of the population
What do you need to conduct a PPOR analysis?

- Vital records data
  - Fetal death files
  - Birth files
  - Linked birth-death files
- Data analyst
- Statistical software package, like SAS
Why include fetal deaths?

1. Fetal deaths are important to families.
2. There are almost as many fetal deaths as there are infant deaths.
3. Fetal deaths can provide us with even more information about infant mortality in the community.

Standard infant mortality rates do not include fetal deaths. But, PPOR uses all of the available information to investigate infant mortality.
What information is available on vital records data?

- **Demographics**—maternal age, education, race, marital status, county of origin, etc.
- **Medical history**—previous births or other outcome, preterm birth, birth spacing, etc.
- Prematurity
- Elective early term delivery
- **Chronic conditions**—pre-pregnancy BMI, diabetes, hypertension, etc.
- WIC status, insurance coverage, etc.
PPOR Basics

Data → Action

PPOR is a 6-stage community approach for investigating infant mortality at the local level, based on vital records data.
1. Assure Community and Analytic **Readiness**
2. Conduct **Analytic** Phases of PPOR
3. **Develop** Strategic Actions for Targeted Prevention
4. Strengthen Existing and/or **Launch** New Prevention Initiatives
5. **Monitor** and Evaluate Approach
6. **Sustain** Stakeholder Investment and Political Will
The PPORR Boxes

Age at Death

- Fetal Death
- Neonatal
- Post-neonatal

Birth weight

- 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.

- **Maternal Health/Prematurity**: Chronic Disease, health behaviors, perinatal care, etc.
- **Maternal Care**: Prenatal Care, high risk referral, obstetric care, etc.
- **Newborn Care**: Perinatal management, neonatal care, pediatric surgery, etc.
- **Infant Health**: Sleep-related deaths, injuries, infections, etc.
What rates should we expect to see in each period of risk?

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

A typical reference group includes NH white women, 20 or more years of age, with a college education.
<table>
<thead>
<tr>
<th>NH Black</th>
<th>Maternal Health/ Prematurity</th>
<th>Maternal Care</th>
<th>Newborn Care</th>
<th>Infant Health</th>
<th>Fetal-Infant Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5.7</td>
<td>2.9</td>
<td>1.8</td>
<td>2.7</td>
<td>13.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reference Group</th>
<th>Maternal Health/ Prematurity</th>
<th>Maternal Care</th>
<th>Newborn Care</th>
<th>Infant Health</th>
<th>Fetal-Infant Mortality</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>1.8</td>
<td>1.2</td>
<td>0.9</td>
<td>0.7</td>
<td>4.7</td>
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<table>
<thead>
<tr>
<th>Excess Mortality Rate</th>
<th>Maternal Health/ Prematurity</th>
<th>Maternal Care</th>
<th>Newborn Care</th>
<th>Infant Health</th>
<th>Fetal-Infant Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Subtraction</td>
<td>3.9</td>
<td>0.7</td>
<td>0.9</td>
<td>2.0</td>
<td>8.5</td>
</tr>
</tbody>
</table>
Phase 2

• Periods of risk with the highest excess mortality are investigated to determine causes and areas for prevention.

1. Identify the most important probable causes for excess mortality
2. Examine the risk factors for those causes (compare study and reference populations)
3. Estimate the potential impact of risk factors
Phase 1

Maternal Health/Prematurity Gap

Phase 2

Step 1

Birthweight Distribution

Preconception Health Insurance

Maternal Stress

Referral to Level III Facility

Neonatal Specialist Availability

Step 2

Maternal Infection
Example of PPOR Results for Urban County

Phase 1
- Maternal Health/Prematurity Gap

Phase 2
Step 1
- Birthweight distribution*

Phase 2
Step 2
- Close pregnancy spacing
- High prevalence of previous preterm birth with low use of 17p
- High maternal stress, low father participation, high poverty

*91% of the excess mortality in the blue box is caused by having too many very low birth weight babies born in Urban County. (Determined using a Kitagawa analysis.)
Examine risk factors for the most probable causes by comparing the study and reference populations.

Disparities in Prevalence of Selected Risk Factors for Very Low Birthweight in Urban County (2008-2010)

- Overweight or Obese
- Smoking
- No Prenatal Care

NH Black vs Reference Group
• Estimate potential impact of risk factors using Population Attributable Risk (PAR)
  – “If the risk in the high risk group could be reduced to the risk in the low risk group, how much would overall VLBW decrease in Urban County?”

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<tr>
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<tbody>
<tr>
<td>Not married at time of baby’s birth (social support)</td>
<td>89%</td>
<td>6%</td>
<td>24%</td>
</tr>
<tr>
<td>Birth Spacing less than 18 Months</td>
<td>36%</td>
<td>34%</td>
<td>13%</td>
</tr>
<tr>
<td>High School Education or less</td>
<td>58%</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>Previous Preterm Birth</td>
<td>8%</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>
Phase 2 Analysis Strategy

• In Phase 2, we eliminate risk and preventive factors that are unlikely contributors to the health disparity.

• Then, we find and target known factors that likely contribute to the health disparity.
The “Four Legs” Work Together

• Case reviews and qualitative information can find underlying reasons for disparities.
• Population-based data can confirm case review findings.
• Population-based data can test stakeholder assumptions.
• Research provides a theoretical framework and causal information.
Questions?
Purpose: To develop an action-oriented community process that continually assesses, monitors, and works to improve service systems and community resources for women, infants, and families.

http://www.nfimr.org
http://www.nfimr.org/

search for topics, list-serve, webinars, request info
The FIMR Process

4 minute video
Fetal and Infant Mortality Review: The Community Makes the Difference

LOCAL HEALTH CARE
SOCIAL
ECONOMIC
PUBLIC HEALTH
EDUCATIONAL
ENVIRONMENTAL
SAFETY ISSUES

ACTION ORIENTED

NURSES
AGENCIES
CONSUMERS
DOCTORS
ADVOCATES
LEADERS
FAMILIES
FIMR Includes a Key Informant Interview
FIMR: A Two Part Process

CRT
Case Review Team

CAT
Community Action Team
Case Review Team Meeting

- Multidisciplinary
- Represents community
- 1-2 hour, *closed* meeting
- 3-5 cases/meeting
- Average 12-15 consistent members
- Hear de-identified cases, identify issues, make recommendations
FIMR CRT Team Members

- Health professionals
- Social services
- Community agencies
- Schools
- Consumers
- Programs, e.g., WIC
- Transportation

What are issues within the cases-agency/person for insight/solutions?

Confidentiality is key. Goal is system change.
Examples of Issues CRT Identified

Bereavement support

Mental Health

1st Trimester Prenatal Care GOAL

Healthy People 2020
GOAL 78%

Substance Abuse

Addiction
Knowing is not enough,
We must APPLY.
Willing is not enough,
We must DO.

- Bruce Lee

CRT recommends ACTION

MOVE ALONG, MOVE ALONG
FIMR: A Two Part Process – Community Action Team

Creative Solutions

CAT power for system changes
CAT Meeting

- Community representation
- Open meeting quarterly or biannually
- Reviews CRT recommendations for change
- Summary of issues/not individual cases
- Develop strategies for implementation
- Identify potential resources/change agents
- May request more information from CRT before acting
Tell us two possible CAT/CAN members in your community
Laying the groundwork

- Identify target population/geographic area
  - Type and number of cases to be reviewed
  - Establish case identification system
- Coordinate with other death reviews
- Identify legal & institutional issues
- Select data collection, processing methods
- Formalize policies and procedures
- Community support and training
Created for Healthy Start programs - overview of process

http://www.nfimr.org/ search Healthy Start

What is FIMR?
Fetal and Infant Mortality Review (FIMR) is a community-based and action-oriented process to improve services systems and resources for women, infants, and families. This evidence-based process examines fetal and infant deaths, determines preventability, and engages communities to take action.

How does the FIMR process work?
FIMR engages a multi-disciplinary case review team to review the case summaries from de-identified infant and fetal deaths. These case summaries include maternal interviews for their perspective on why the death occurred. Based on these reviews, the team makes recommendations for system changes. A team of community leaders (community action team) is then assembled to take recommendations to action.

Who participates in FIMR?
Typically, the case review team includes health care providers, social workers, mental health professionals, health department staff, and others as determined by the local FIMR. The community action team includes elected officials, community members, community leaders, health professionals, and representatives from the health department, justice system, transportation, housing, and other leaders who are key to system change.

How are FIMR data used?
FIMR data inform a continuous quality improvement process. The case review data are used to identify issues and gaps in service systems that may contribute to fetal and infant deaths, and may be used to augment community needs assessments and help to analyze root causes of infant health disparities. Actions taken based on recommendations from these case reviews are monitored and their effectiveness tracked. A new NFIMR database provides the ability to aggregate case information, recommendations, and actions taken.

The National FIMR Program can help you establish a FIMR program in your community.
Established in 1990, the National Fetal and Infant Mortality Review (NFIMR) Program is a collaborative effort between the federal Maternal and Child Health Bureau and the American College of Obstetricians and Gynecologists. NFIMR's national resource center offers several publications, guides, and technical materials to support and sustain state and local FIMR programs. Use NFIMR's map to search for FIMR programs in your region. For more information visit the NFIMR website, www.nfimr.org, or contact Joel Shantez, Director of NFIMR, 202.880.1639, jshantez@acog.org.
Thank you for your commitment to preventing infant death. It makes a difference.

“Infant Mortality is the most sensitive measure we possess of social welfare.”
Julia C Lathrop, Children’s Bureau 1913
Questions

For more information

- Call (202) 863-1630
- E-mail jshaefer@acog.org
- Visit http://www.nfimr.org
FIMR & PPOR:
How they inform our local OHS

Carol Isaac, RN, BSN, MA
Douglas County Health Department
Douglas County & OHS Data Review

• Douglas County is the most populous county in Nebraska and contains the largest city (Omaha).

• Even though racial disparities between mothers of loss (Caucasian/African-American) are at all time low (rate of 1:1.5), infant mortality rates remain high in OHS target area.
## Population Diversity (2010 Census)

<table>
<thead>
<tr>
<th>Population Diversity (2010 Census)</th>
<th>WHNH</th>
<th>%</th>
<th>BLNH</th>
<th>%</th>
<th>HISP</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>OHS Target Area</td>
<td>17,820</td>
<td>40.1%</td>
<td>20,504</td>
<td>46.2%</td>
<td>4,364</td>
<td>9.8%</td>
</tr>
<tr>
<td>Douglas County</td>
<td>379,964</td>
<td>73.5%</td>
<td>61,517</td>
<td>11.9%</td>
<td>57,804</td>
<td>11.2%</td>
</tr>
<tr>
<td>Nebraska</td>
<td>1,499,753</td>
<td>82.1%</td>
<td>80,959</td>
<td>4.4%</td>
<td>167,405</td>
<td>9.2%</td>
</tr>
</tbody>
</table>
## Births: 2011-2013

<table>
<thead>
<tr>
<th></th>
<th>OHS Target Area</th>
<th>Douglas County</th>
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</thead>
<tbody>
<tr>
<td>Total Births</td>
<td>2,210</td>
<td>25,069</td>
</tr>
<tr>
<td>Infant Deaths</td>
<td>21</td>
<td>138</td>
</tr>
<tr>
<td>Infant Mortality Rate</td>
<td>9.5</td>
<td>5.5</td>
</tr>
<tr>
<td>Teen Births</td>
<td>289</td>
<td>1,556</td>
</tr>
<tr>
<td>Teen Births %</td>
<td>13.1%</td>
<td>6.2%</td>
</tr>
<tr>
<td>LBW</td>
<td>267</td>
<td>1,892</td>
</tr>
<tr>
<td>LBW %</td>
<td>12.1%</td>
<td>7.5%</td>
</tr>
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Integration of FIMR with PPOR

Anchor Organizations:

- Omaha Healthy Start
- CityMatCH
  - Perinatal Periods of Risk (PPOR)
- Douglas County Health Department
  - Baby Blossoms Collaborative (BBC)

FIMR added in 2006

- BBC became Community Action Team (CAT)
Integration of FIMR with PPOR

- PPOR helps determine where excess deaths are coming from and assists in developing medical criteria for case selection.
- It gives us a population-based perspective.
- Highest rates in Douglas County have been in blue box (maternal health/prematurity) and green box (infant mortality).
Examples of Integration?
PPOR indicates that among African American mothers, 60% of excess mortality is in the Infant Health Period of Risk and the SIDS mortality rate is higher among AA infants than in other groups.

The stakeholder’s group uses case reviews and community meetings to learn about infant sleep practices in the African American Community.
Population based data can confirm case review findings.

- Mothers in death review cases said they didn’t know how to recognize signs of early labor. The community considered an educational campaign.

- PPOR data indicate that “too many VLBW births” accounted for 80% of local excess mortality.

- PRAMS data indicate that only 60% of high risk moms report that their prenatal care provider talked about the signs of early labor.
Population based data can test stakeholder assumptions

1. Some infant deaths led stakeholders to believe that many mothers were not seeking or receiving prenatal care.

2. The community was considering a broad PNC media campaign.

3. But vital records data indicate that 99.5% of mothers DO receive PNC.

4. Further analysis of vital records data showed that only certain high risk groups were not receiving PNC, and efforts were targeted toward those groups.
How the FIMR Cycle works

OHS has participated in all aspects of the FIMR Cycle.
Linkage between FIMR & CAN

- Who sits on CAN?
- BBC – brings experience in area of Collective Impact to the table

Examples:
- Count the Kicks (grassroots campaign initiated by home visitation programs)
- SUID/SIDS Community Campaign (matriarchs and long-time staff have contributed to messaging)
Questions?