# Perinatal Periods of Risk (PPOR)

Carol Gilbert, MS
Allison Miles, MPH
September 15, 2015

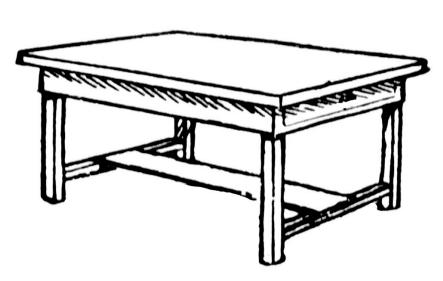
## Integrating PPOR and Fetal Infant Mortality Review

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 (Case Review Data)

- 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

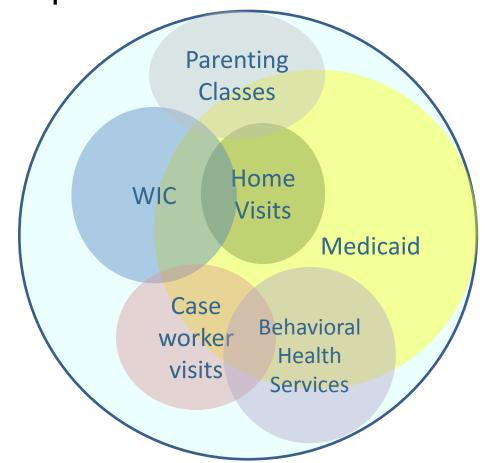


## Local Stakeholder Knowledge and Experience

- 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**

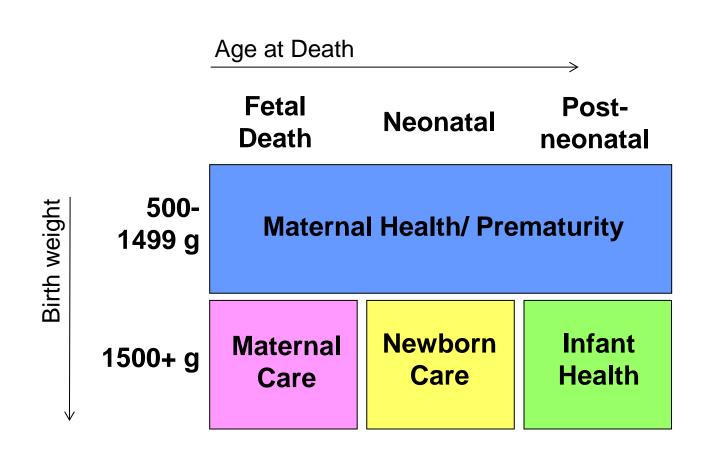
## Data Action

PPOR is a 6-stage community approach for investigating infant mortality at the local level, based on vital records data.

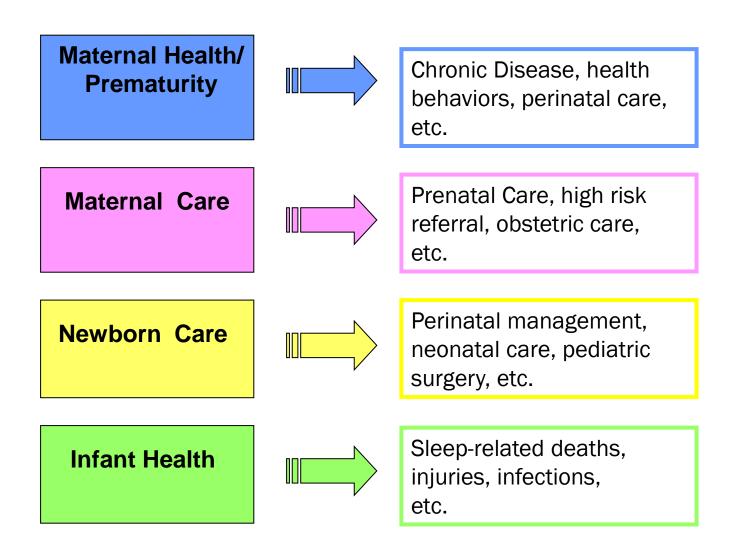
## The 6 Stages

- 1. Assure Community and Analytic Readiness
- 2. Conduct Analytic Phases of PPOR
- 3. <u>Develop</u> 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 PPOR Boxes



## Each period of risk is associated with its own set of risk and prevention factors



## 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.

## Urban County PPOR Maps

NH Black	Maternal Health/ Prematurity	Maternal Care	Newborn Care	Infant Health	Fetal- Infant Mortality
	5.7	2.9	1.8	2.7	13.2

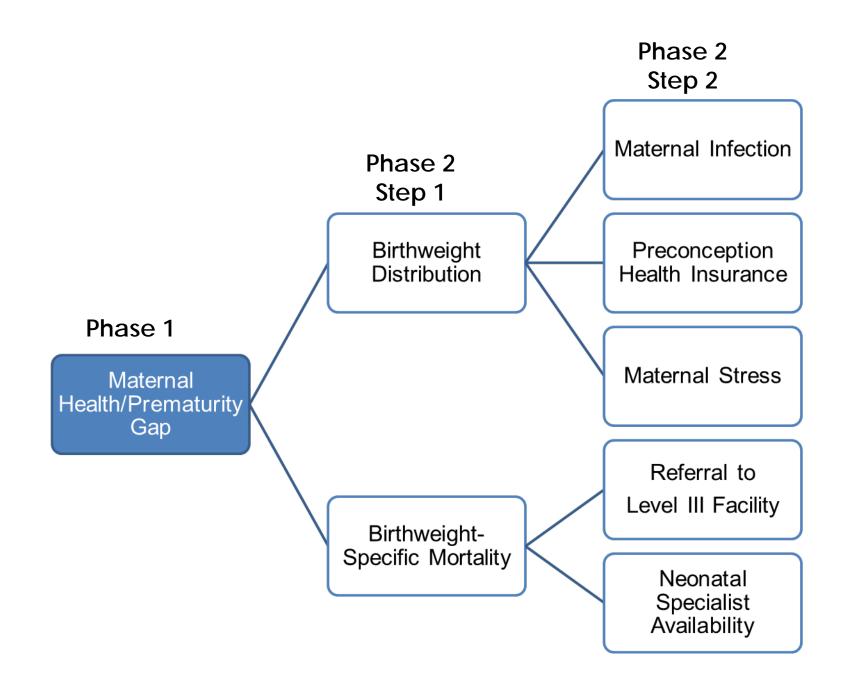
Reference Group	Maternal Health/ Prematurity	Maternal Care	Newborn Care	Infant Health	Fetal- Infant Mortality
	1.8	1.2	0.9	0.7	4.7

Excess Mortality Rate	Maternal Health/ Prematurity	Maternal Care	Newborn Care	Infant Health	Fetal- Infant Mortality
By Subtraction	3.9	0.7	0.9	2.0	8.5

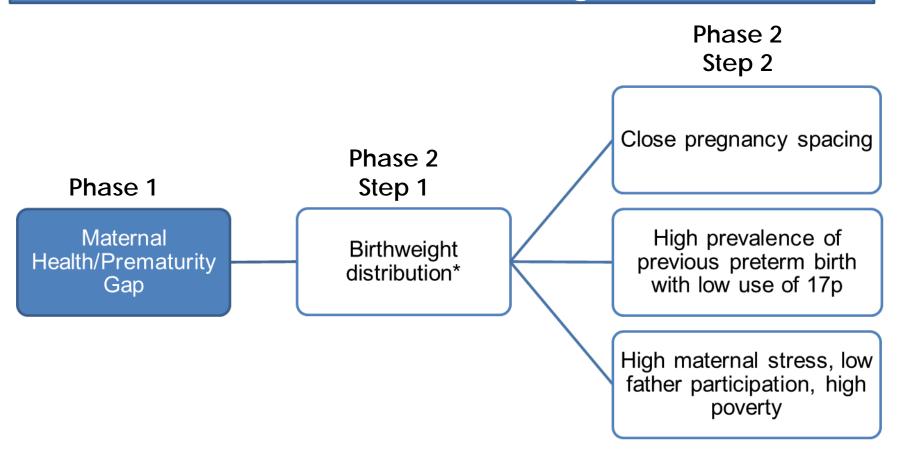
#### Phase 2

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

- Identify the most important <u>probable causes</u> for excess mortality
- 2. Examine the <u>risk factors for those causes</u> (compare study and reference populations)
- 3. Estimate the potential impact of risk factors



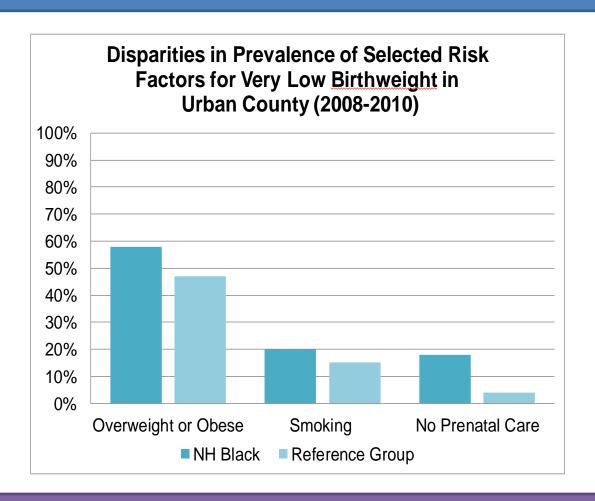
### Example of PPOR Results for Urban County



\*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.

## Phase 2 Step 2



Examine risk factors for the most probable causes by comparing the study and reference populations

## Phase 2 Step 3

- 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?"

	Black % with Risk Factor	Reference % with Risk Factor	Population Attributable Risk% for VLBW among Black Women
Not married at time of baby's birth (social support)	89%	6%	24%
Birth Spacing less than 18 Months	36%	34%	13%
High School Education or less	58%	0%	12%
Previous Preterm Birth	8%	10%	10%

## 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.





# Ask the Expert: FIMR & PPOR: Amazing Data Processes to Help Healthy Start Sites Improve Population Health Fetal and Infant Mortality Review

**September 15, 2015** 

**Jodi Shaefer, RN, PhD,** Director National Fetal and Infant Mortality Review Program (NFIMR) American College of Obstetricians & Gynecologists

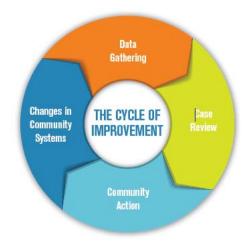
National Fetal, Infant, and Child Death Review Center





## National Fetal and Infant Mortality Review: An Approach for Examining Infant Death and Fetal Loss

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.

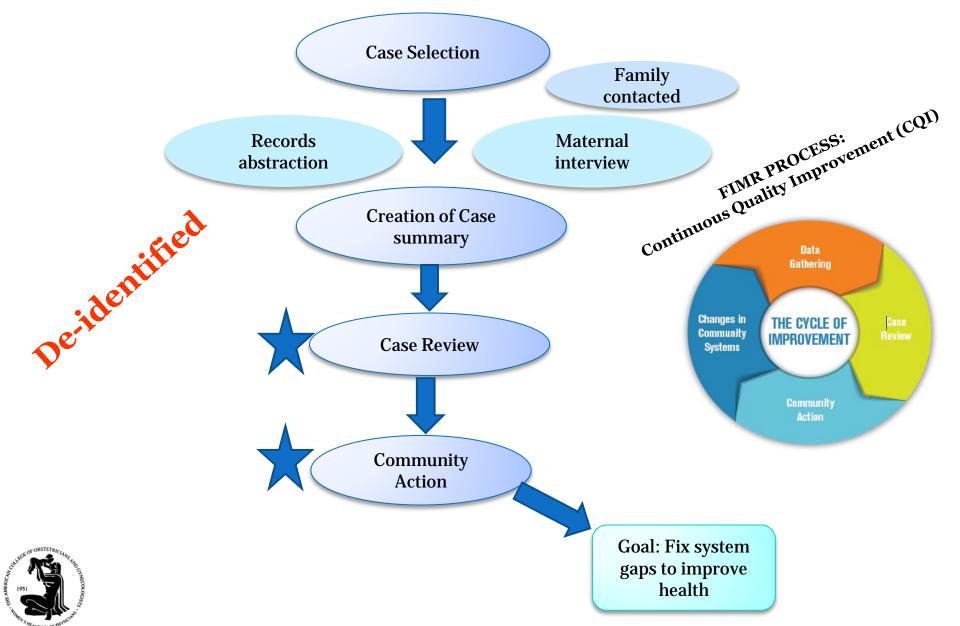


http://www.nfimr.org



#### **Key Components of FIMR Process**







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

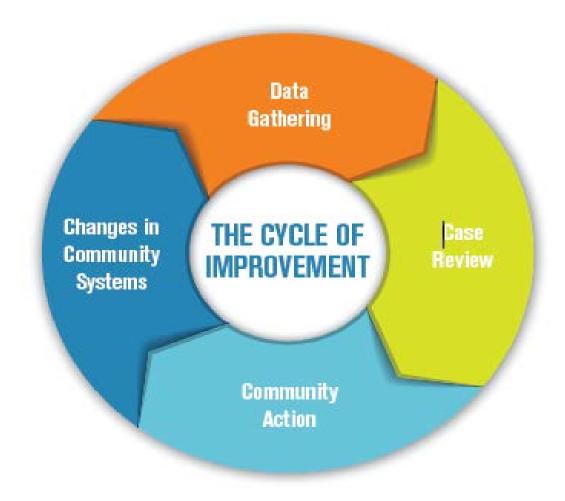
#### search for topics, list-serve, webinars, request info



#### 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



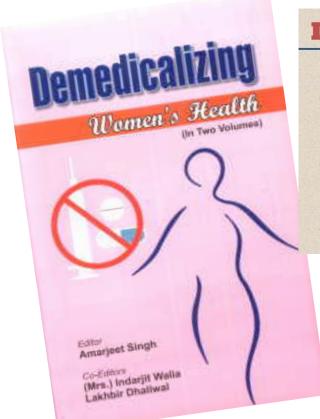




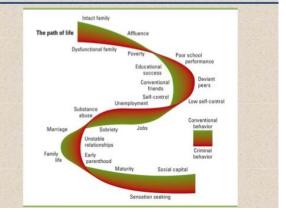
## FIMR Includes a Key Informant Interview



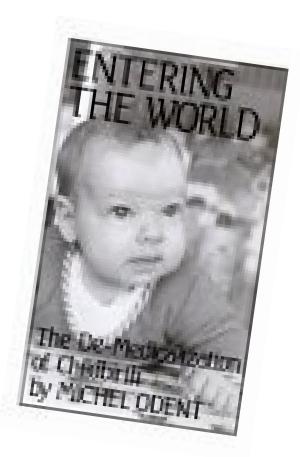




#### **Life Course Theory**











#### 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?





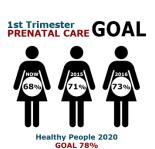






### Examples of Issues CRT Identified















Knowing is not enough,

We must APPLY.

Willing is not enough,

We must DO.

- Bruce Lee

## **CRT** recommends **ACTION**







## 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





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

Created for Healthy
Start Programs of Process
Overview



#### What is FIMR?

Fetal and Infant Mortality Review (FIMR) is a community-based and action-oriented process to improve service systems and resources for women, infants and families. This evidencebased 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?

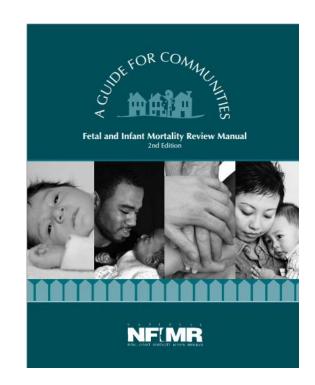
Typically, the case review team includes health care providers, social workers, mental health professionals, health department staff, and others as determined by the local FIMR. The community action team includes elected officials, community members, community leaders, health professionals, and representatives 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.nfimz.org, or contact Jodi Shaefer, Director, NFIMR, 202.863.1630, jshaefer@acogorg.







It makes a difference.

"Infant Mortality is the most sensitive measure we possess of social welfa Julia C Lathrop, Children's Bureau 1913





## Questions



#### For more information





- Call (202) 863-1630
- E-mail jshaefer@acog.org

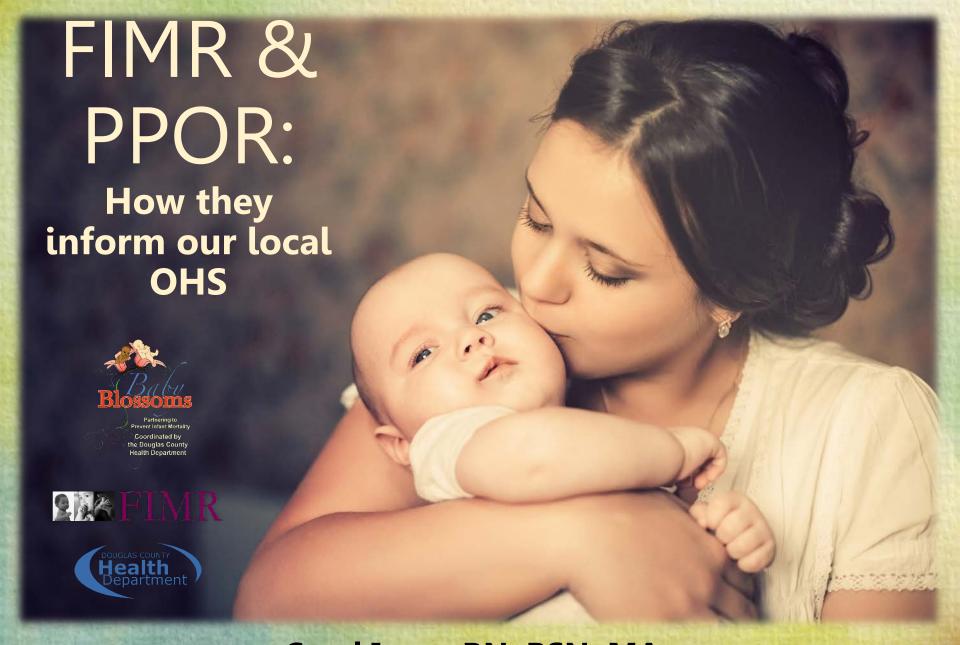




Visit http://www.nfimr.org







Carol Isaac, RN, BSN, MA
Douglas County Health Department



## **Douglas County & OHS Data Review**

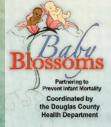
- Douglas County is the most populous county in Nebraska and contains the largest city (Omaha).
- Even though racial disparities between mothers of loss (Caucasian/African-American) are at all time low (rate of 1:1.5), infant mortality rates remain high in OHS target area.





# Population Diversity (2010 Census)

Population Diversity (2010 Census)	WHNH	%	BLNH	%	HISP	%
OHS Target Area	17,820	40.1%	20,504	46.2%	4,364	9.8%
Douglas County	379,964	73.5%	61,517	11.9%	57,804	11.2 %
Nebraska	1,499,753	82.1%	80,959	4.4%	167,405	9.2%

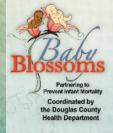






### Births: 2011-2013

Births: 2011 - 2013	OHS Target Area	Douglas County
Total Births	2,210	25,069
Infant Deaths	21	138
Infant Mortality Rate	9.5	5.5
Teen Births	289	1,556
Teen Births %	13.1%	6.2%
LBW	267	1,892
LBW %	12.1%	7.5%







### 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).



Maternal Health and Prematurity

Maternal Health

Newborn Care

Infant Health





# Examples of Integration?







## Case review and qualitative information can find underlying reasons for disparities.



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

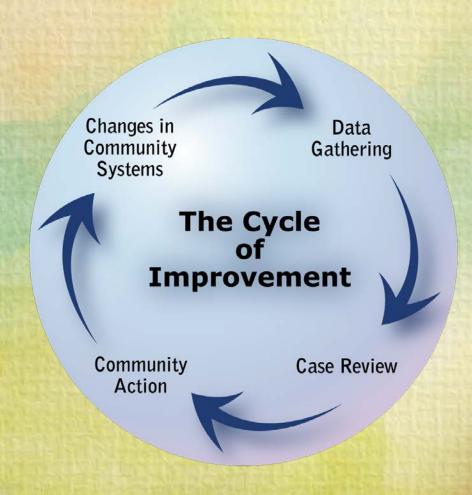
- 1. Some infant deaths led stakeholders to believe that many mothers were not seeking or receiving prenatal care.
- 2. The community was considering a broad PNC media campaign.
- 3. But vital records data indicate that 99.5% of mothers DO receive PNC.
- 4. Further analysis of vital records data showed that only certain high risk groups were not receiving PNC, and efforts were targeted toward those groups.

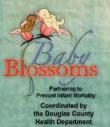




### How the FIMR Cycle works

OHS has participated in all aspects of the FIMR Cycle.



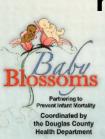






### Linkage between FIMR & CAN

- 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 longtime staff have contributed to messaging)











## Questions?

