



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

Introduction & Overview



- **CityMatCH Mission:** Improving the health and well-being of urban women, children and families by strengthening the public health organizations and leaders in their communities

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Why do we need PPOR? 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

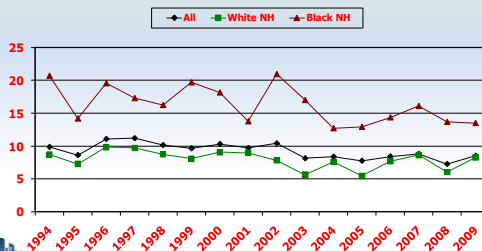


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Infant Mortality Rates
are HIGH, and even in cities where
they have decreased, **racial disparities persist**

PPOR Overall Fetal-Infant Mortality Rates in Urban County



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Communities needed help!

Dr. Bill Sappenfield, CDC's first assignee to CityMatCH, and Dr. Magda Peck, founder of CityMatCH, teamed up!



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INTERNATIONAL EXPERTISE

Dr. Brian McCarthy and colleagues at the Centers for Disease Control and Prevention and the World Health Organization knew that **causes of perinatal death** are closely related to both age at death and birth weight.



Why not use **both** pieces of information to learn more about why babies are dying?



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The PPOR approach examines fetal and infant mortality in two dimensions



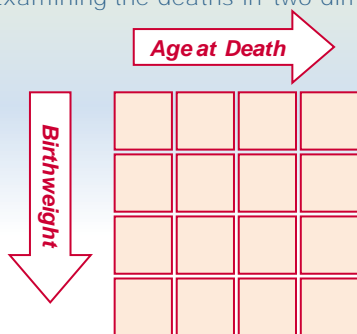
Why Include Fetal Deaths?

- (1) they are important to their families
- (2) there are almost as many fetal deaths as there are infant deaths
- (3) these deaths can provide us with a lot of information

Standard Infant Mortality Rates do not include fetal deaths. PPOR is about using every bit of information we have.



Examining the deaths in two dimensions

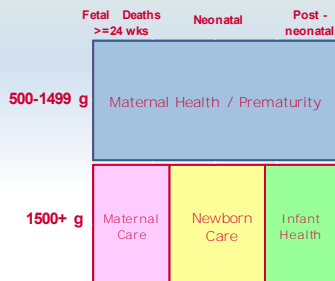


Experts used statistics to combine boxes with similar causes of death and risk factors

	Fetal Deaths	Early Neonatal	Late Neonatal	Post-neonatal
Extremely Low Birthweight 500-999 g	Blue	Blue	Blue	Blue
Very Low Birthweight 1,000-1,499 g	Blue	Blue	Blue	Blue
Low Birthweight 1,500-2,499 g	Pink	Yellow	Yellow	Green
Normal Birthweight 2,500 + g	Pink	Yellow	Yellow	Green



Four Perinatal Periods of Risk named to suggest prevention areas

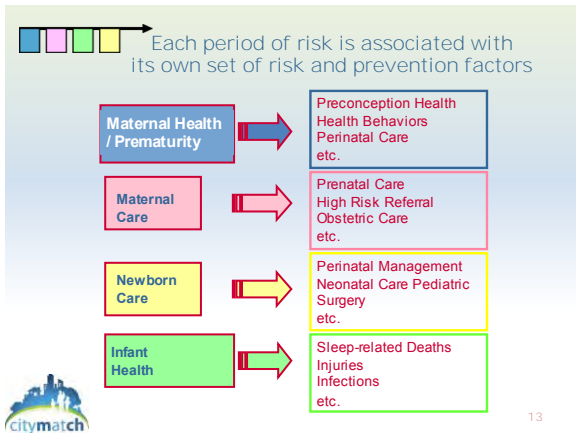


The dividing lines had been chosen so deaths in the same "box" had similar PROBLEMS:

- Causes of death
- Maternal risk factors

...which means they also had similar SOLUTIONS.





The four periods provide a framework that helps communities

- ◆ Move from *having* data to **using** data
- ◆ Prioritize limited resources
- ◆ Use evidence to maximize impact

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To use the risk periods, SORT the Fetal and Infant Deaths

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

	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

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SORT the Fetal and Infant Deaths

★ Example: boy born weighing 820 grams died at 22 days old

	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

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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

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SORT the Fetal and Infant Deaths

★ Example: Girl, Fetal death, 820 grams and 22 weeks gestation

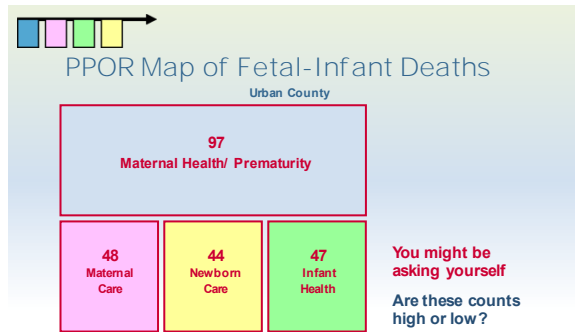
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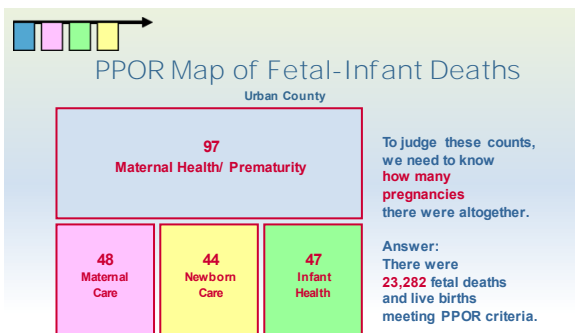
Community stakeholders in "Urban County" sorted their 2000-2003 fetal and infant deaths in this way, and made a PPOR map that looked like . . .



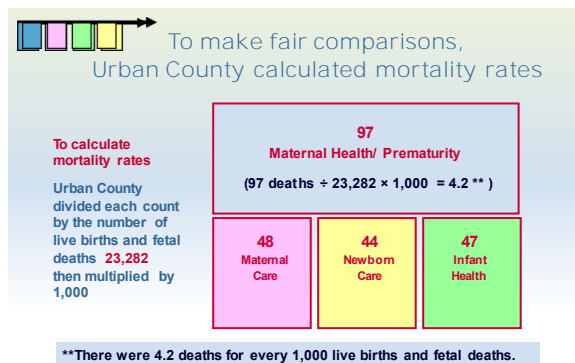
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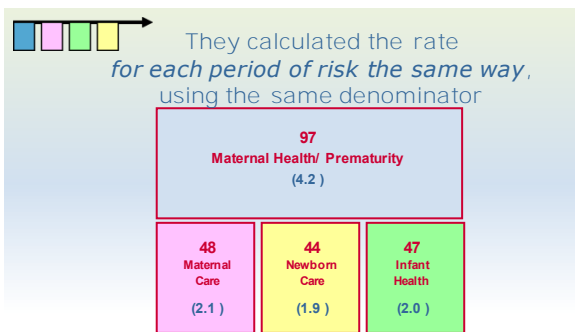
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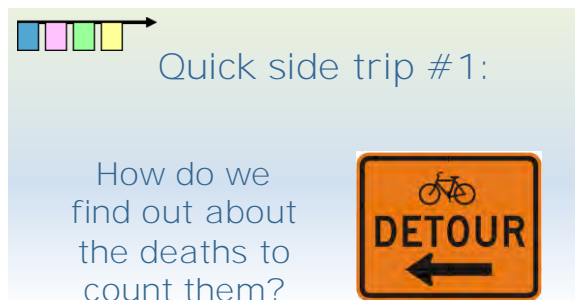


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Urban County PPOR "map"



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The US Vital Records System

- A certificate of death is required by state law for every death in the United States.
 - Fetal deaths are also recorded, though state laws and practices vary.
- All these are entered into computer data files as are live births records.



Which deaths do we count?

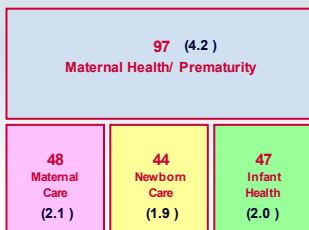
- The mother resided in the geographical area we are studying when the baby was born (or the fetus delivered).
- The birth occurred during our study time period.
- The baby died before its first birthday.
- **Infant deaths NOT counted** if under 500 grams birth weight; **Fetal deaths NOT counted** if under 500 grams **or** earlier than 24 weeks gestation (PPOR criteria)



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Back to Urban County's PPOR Map of Fetal-Infant Deaths



You might be asking yourself

Is 4.2 a good rate or a bad rate?



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“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.*



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Examples of Reference Groups



- *Well-educated Black mothers residing in your state at the time of their baby's birth*
- *White mothers in an affluent "sister city"*
- *All well-educated white, non-Hispanic women over the age of 19 who resided in your city when their baby was born*



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The Reference Group is about Justice

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



Community stakeholders **choose** the reference group. They agree that it is an appropriate standard or goal for their community.



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Urban County stakeholders chose the US Reference Group 2000-2002

- Defined by *maternal demographics*
 - 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



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US Reference Group 2000-2002

2.2		
1.5	1.1	0.9

Total Fetal-Infant Mortality Rate = 5.7



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They compared the study and reference populations by subtracting rates in each period of risk

Urban County			Reference Group			Result		
4.2			2.2			4.2 - 2.2 = 2.0		
2.1	1.9	2.0	1.5	1.1	0.9			

Interpretation:
2.0 excess deaths for every 1,000 live births and fetal deaths



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The difference between rates, or the "gap", represents "excess mortality" and it means that some of the deaths were preventable.

Urban County			Reference Group			Gap		
4.2			2.2			2.0		
2.1	1.9	2.0	1.5	1.1	0.9	0.6	0.8	1.1



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Urban County Compared different subpopulations

White non-Hispanic (Denominator=16,045)			Black non-Hispanic (Denominator = 3,291)		
3.1			8.8		
2.0	1.9	1.6	2.4	2.4	4.0



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Urban County also estimated the number of preventable deaths

$2.0 \times 23,282 \div 1,000 = 46$
estimated preventable deaths
in the Maternal Health/Prematurity Period of Risk


Excess Rate			Excess Number		
2.0			46		
0.6	0.8	1.1	13	18	26

$2.0 + 0.6 + 0.8 + 1.1 = 4.4$
Overall excess mortality rate

$46 + 13 + 18 + 26 = 103$
Estimated preventable deaths



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A simple calculation showed that two periods of risk accounted for 70% of their excess mortality.

The second phase of the Urban County investigation focused on these two periods.


Gap, Excess Mortality, Preventable Deaths

2.0		
0.6	0.8	1.1


$(2.0 + 1.1) \div 4.4 = .70$ or 70%




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SUCCESS!
Urban County completed Phase 1 of PPOR analysis



Their rewards . . .




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

Maternal Health / Prematurity	Preconception Health 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.



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SUCCESS!
The community stakeholders were still on board

They understood the numbers and saw how the data could help them prioritize further investigation.




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Data Problems


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.




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Yes, Urban County celebrated these successes, but they didn't stop there.


Phase 2 analysis helped them prioritize among the remaining potential causes of excess mortality.




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"She's got to be kidding! There's more?"




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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



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How does Phase 2 work?
We'll show you some of Urban County's investigation of its Infant Health Period of Risk.

- Other risk periods have different methods
- Other cities have different results
- The overall strategy is the same




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Phase 2 Analysis Example
for the Infant Health Period of Risk

There are many common causes of death in the Infant Health Period of Risk



SIDS/SUID
Suffocation
Drowning
Car accidents
Assault
Infections
Congenital anomalies
etc.



Step 1 is to find out which of these are causing excess mortality in **our** community.

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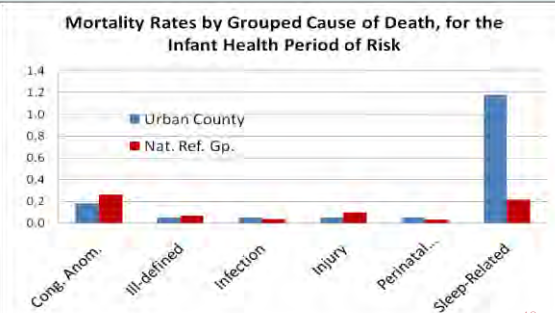
Step 1: In the infant health period of risk, PPOR uses "underlying cause" ICD-10 Code from the death certificate to investigate causes. Here is a partial list for Urban County.

ICD code	Count of Deaths	Code description
Q208	1	Other congenital malformations of cardiac chambers and connections
Q232	1	Congenital mitral stenosis
Q249	2	Congenital malformation of the heart, unspecified
Q909	1	Down's syndrome, unspecified
Q913	1	Edwards' syndrome, unspecified
V486	1	Passenger injured in traffic accident
W75	2	Accidental suffocation and strangulation in bed
W84	1	Unspecified threat to breathing
R95	15	SIDS



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Step 1. The dozens of ICD-10 codes were grouped, and mortality rates calculated for each group in both the **study** and **reference** populations.



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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* excess infant mortality, and further narrowed the scope of their investigation.

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But they could do better!

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Step 2: In Urban County, how common are the known risk factors for sleep related deaths?
 Compare study and reference groups if possible.

- Sleep position
- Maternal smoking
- Passive smoke
- Bedding
- Co-sleeping
- Crib availability and use
- Parental substance abuse
- Death scene investigation

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Step 2: Since *more* mothers in Urban County smoked, this could be contributing to the gap.

Percent Smokers (Birth Certificate)

Group	Percent Smokers
Urban County	~16
US Reference Group	10

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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.

PRAMS 2002 : % Sleeping on Back

State/County	% Sleeping on Back
Louisiana	~45
Alabama	~48
South Carolina	~50
North Carolina	~55
Ohio	~60
New Mexico	~62
Illinois	~65
Alaska	~68
Michigan	~70
Nebraska	~72
Utah	~75
Maine	~78
North Dakota	~80
Urban County	~75

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Step 2: Other important information

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

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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



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Quick side trip #2:

What is FIMR?

Why do so many cities use PPOR and FIMR together?



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What is FIMR?
Fetal Infant Mortality Review

- ◆ The Case Review Team (CRT) examines records of fetal and infant deaths, including chart abstractions and maternal interviews
- ◆ Finds patterns, systems issues
- ◆ Makes recommendations to the Community Action Team (CAT)



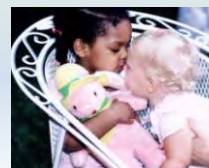
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What FIMR brings to the table

FIMR can give us answers when we don't even know what the question is yet!

FIMR can identify cause and effect relationships.

FIMR works in small neighborhoods.



FIMR "Paints faces behind the numbers"



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Step 3: Urban County estimated the impact of risk factors, and the potential impact of interventions

Statistically estimated how many lives could potentially be saved if certain risks were reduced (Population Attributable Risk)

- Which factors are modifiable?
- Do evidence-based interventions exist?
- What are our community assets, capacity, and commitment?



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The stakeholders weighed the evidence and sought more information as needed.



Phase 2 investigations can continue as questions arise and more data becomes available



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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

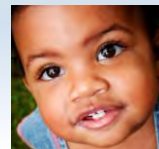


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SUCCESS!
Urban County had still more rewards. . .

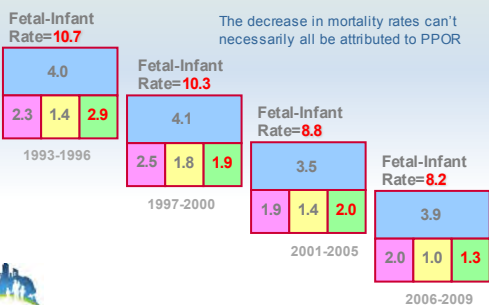
- Their time investment was focused
- They found some answers
- Action steps were more appropriate than initially envisioned ("back to sleep")



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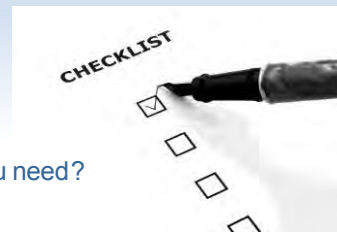
SUCCESS in Outcomes
PPOR 1993-2009
Urban County



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Can everyone use the Perinatal Periods of Risk approach?



What do you need?



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--You need at least 60 deaths--

- ◆ At least **60 fetal and infant deaths**, for each **population** being studied
- ◆ 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



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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



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You need 3 vital records data files


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



You need someone who knows what to do with the data files



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What is PPOR?

Maternal Health/
Prematurity


Maternal Care	Newborn Care	Infant Health
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... It's more than just the data!

It's a **community tool** for decreasing infant mortality



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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

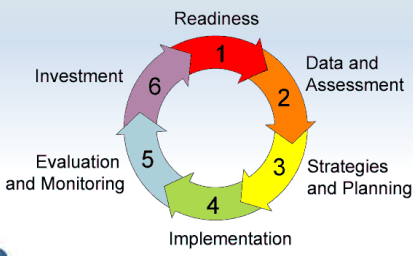

Stage 6: **Sustain** Stakeholder Investment and Political Will




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PPOR is designed for integration with your community planning cycle


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PPOR should be used *with* any existing efforts

- FIMR
- Healthy Start
- Community Health Assessments

But if you are just starting out, the PPOR approach can **frame and guide your whole infant mortality prevention process.**



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Stage 1: Assure Community and Analytic Readiness

"Data analysis alone does not produce community change."

- Because infant mortality has many social and medical causes, many **stakeholders are needed**
- Everyone has a different piece of the puzzle




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Who are your stakeholders?

Source: NACCHO'S MAPP Clearinghouse

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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.

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Tools for Assessing & Evaluating Readiness

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

Name of Collaboration Project	Date			
Statements about Your Collaborative Group:				
History Factor	Statement	Strength	Diagnose	Strategies
1	Agencies in our community have a history of working together.	1	2	
2	Trying to solve problems through collaboration has been common in this community. It's been done a lot before.	1	2	
3	Leaders in this community who are not part of your collaborative group seem to talk about what we can accomplish.	1	2	
4	Others in this community who are not a part of this collaboration would generally agree that the organizations involved in this	1	2	

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Stage 2: Analysis – Phase 1

- ◆ Calculates period-specific mortality rates in the study population
- ◆ Compares them with rates in the reference population
- ◆ Identifies the periods of risk that contribute most to “excess mortality” or preventable deaths

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Stage 2: Analysis – Phase 2

- ◆ Identifies the most important probable causes of local excess mortality
- ◆ Examines risk factors for those causes, by comparing the study and reference populations
- ◆ Estimates potential impact of risk factors


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Stage 3: Develop Action

The community stakeholders decide how best to address the specific areas found to be contributing most to preventable deaths


- ◆ Assess relevant community assets
- ◆ Find existing evidence-based programs
- ◆ Adapt or design new programs
- ◆ Determine appropriate policy changes

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Stage 4: Implementation

New programs are implemented or existing ones strengthened




Based on

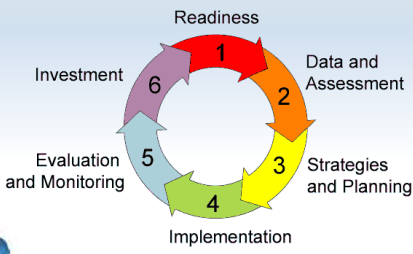

- ◆ Results of PPOR previous 3 stages
- ◆ Stakeholder knowledge
- ◆ Community assets



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Stages 5 & 6: Close the Loop by Evaluating, Monitoring, and Assuring Sustainable Community-Involved Work

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Why use PPOR?





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Logos include: Baltimore City, Chattanooga, TN, Tri-County Health Department, Cincinnati Health Department, Lane County, Oregon, Maricopa County Public Health, El Paso County Department of Health and Environment, Indiana Perinatal Network, Louisville, Healthy Start Coalition of Miami-Dade, Bay Area Data Collaborative, March of Dimes.

Your name here!



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