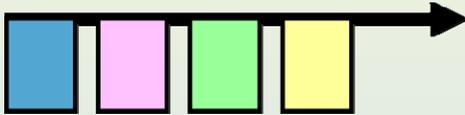


***Perinatal Periods of Risk:
Using Data and
Community Involvement to
Prevent Infant Mortality***

Tuesday, April 12, 2011

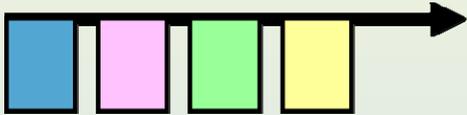
citymatch
The National Organization of Urban MCH Leaders





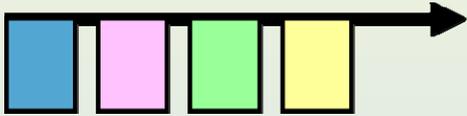
- **CityMatCH Mission:** Improving the health and well-being of urban women, children and families by strengthening the public health organizations and leaders in their communities
 - **Laurin Kasehagen Robinson, MA, PhD**
Senior MCH Epidemiologist & CDC Assignee to CityMatCH
 - **Carol Gilbert, MS**
Data Analyst, CityMatCH
- Moderated by: **Johannie Escarne, MPH: Senior Public Health Analyst**





Objectives

- Provide a general understanding of the Perinatal Periods of Risk (PPOR) Approach
 - Purpose and expected outcomes
 - Analytic methods
 - Resources and requirements for using
- Describe the 6-stage approach



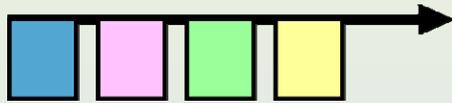
Why do we need PPOR? Infant mortality is complex

Important time periods

- Preconception health
- Prenatal
- Neonatal
- Post-neonatal
 - Life course
 - Inter-generational

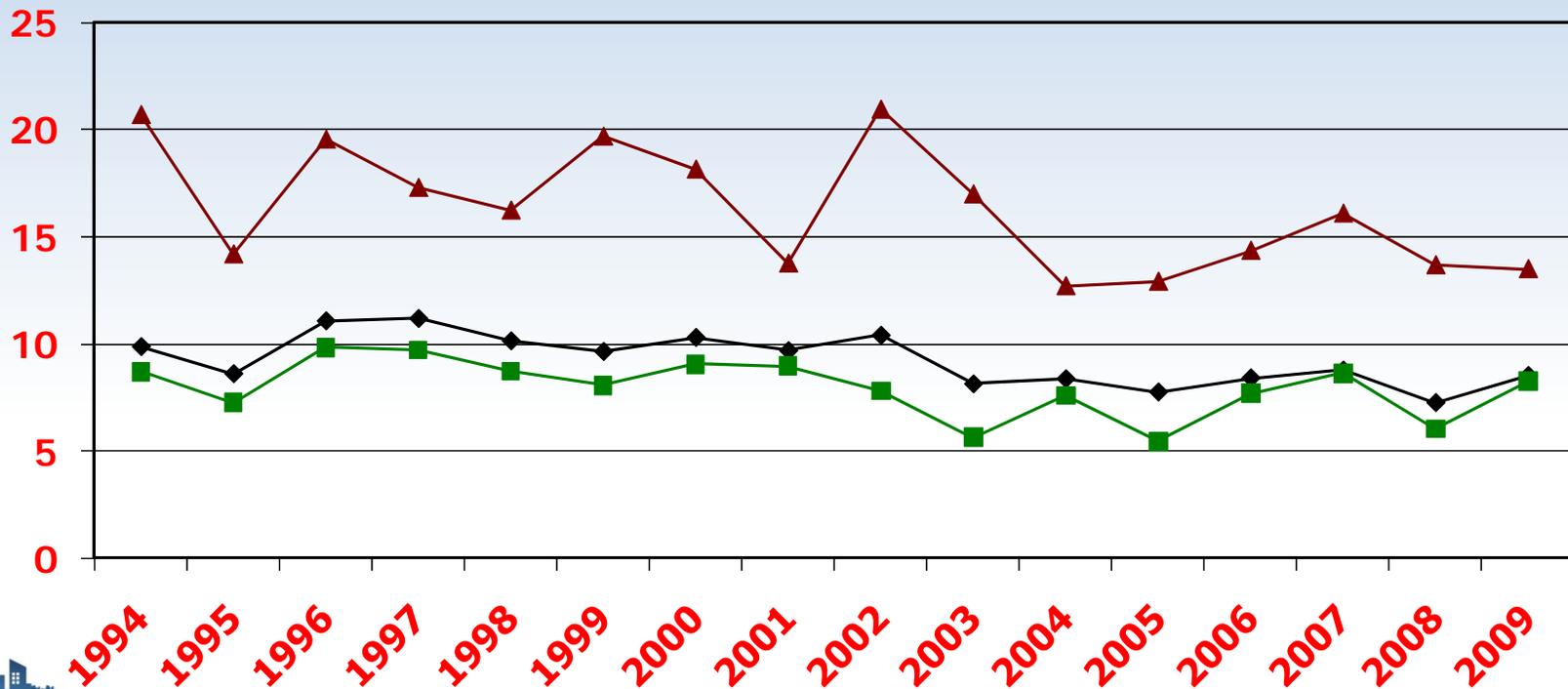
Goes beyond obstetrics

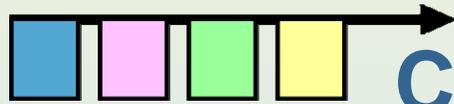
- Chronic disease
- Mental Health
- Social determinants
- Health care system
- Built Environment



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

(PPOR Fetal-Infant Mortality Rates in Urban County)

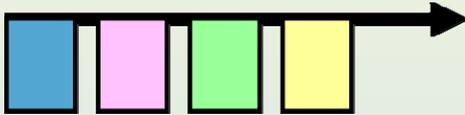




Communities needed help!

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



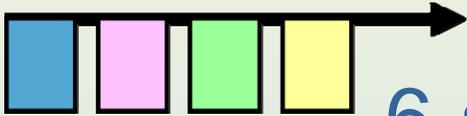


OUR EXPERTS CONSULTED WITH THEIR EXPERTS

*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?



6-stage PPOR approach following the community planning cycle

Stage 1: Assure Community and Analytic Readiness

Stage 2: Conduct Analytic Phases of PPOR

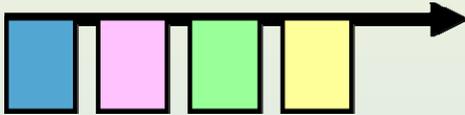
Stage 3: Develop Strategic Actions for Targeted Prevention

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

Stage 5: Monitor and Evaluate Approach

Stage 6: Sustain Stakeholder Investment and Political Will





What IS this thing called PPOR?

Stage 1: Assure Community and Analytic Readiness

Stage 2: Conduct Analytic Phases of PPOR

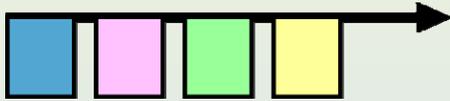
Stage 3: Develop Strategic Actions for Targeted Prevention

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

Stage 5: Monitor and Evaluate Approach

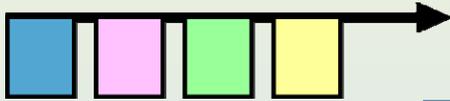
Stage 6: Sustain Stakeholder Investment and Political Will





The PPOR approach
examines fetal and infant mortality
in two dimensions



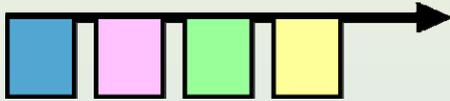


First Dimension: Birthweight



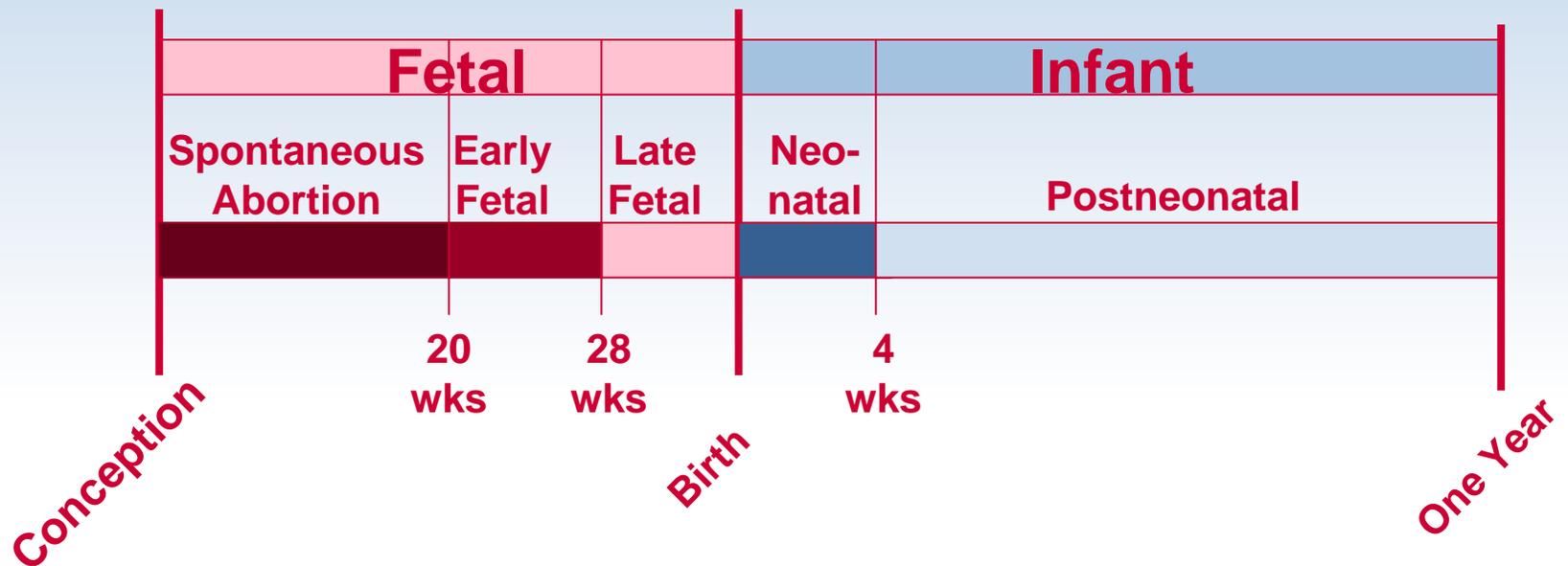
- ◆ **Extremely Low Birthweight**
= less than 1,000 grams (2.2 pounds)
- ◆ **Very Low Birthweight**
= less than 1,500 grams (3.3 pounds)
- ◆ **Low Birthweight**
= less than 2,500 grams (5.5 pounds)
- ◆ **Not low birthweight**
= 2,500 grams or larger

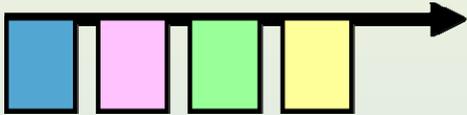
(3,400 grams is 7.5-pounds)



Second Dimension: Age at Death

Age at Death

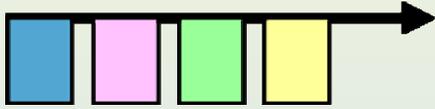




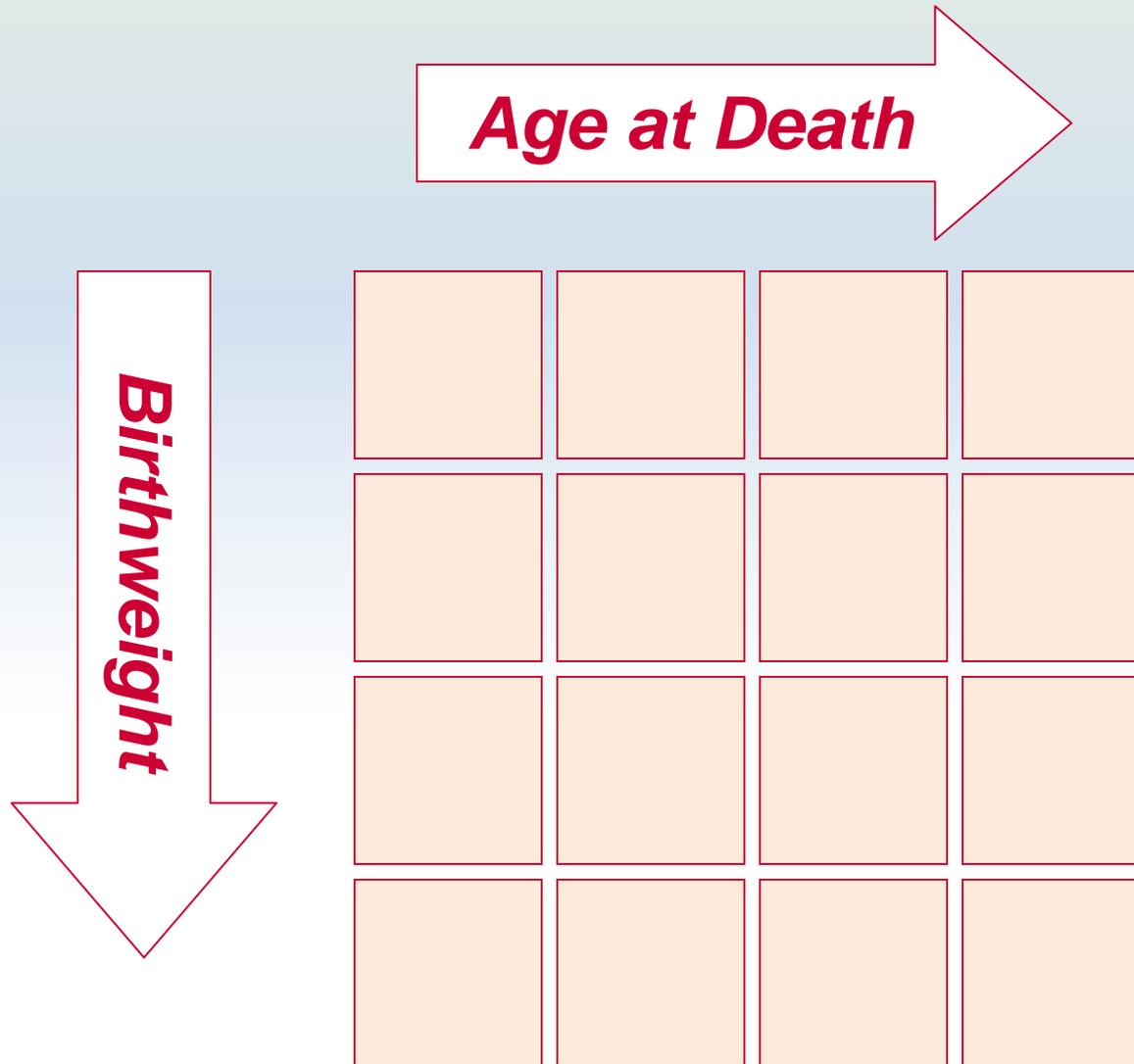
Why Include Fetal Deaths?

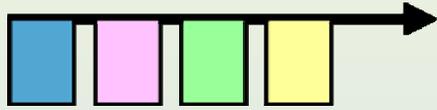
- (1) they are important to their families
- (2) there are almost as many fetal deaths as there are infant deaths
- (3) these deaths can provide us with a lot of information

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



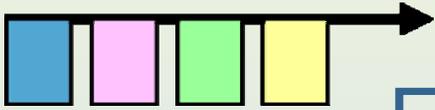
Examining the deaths in two dimensions



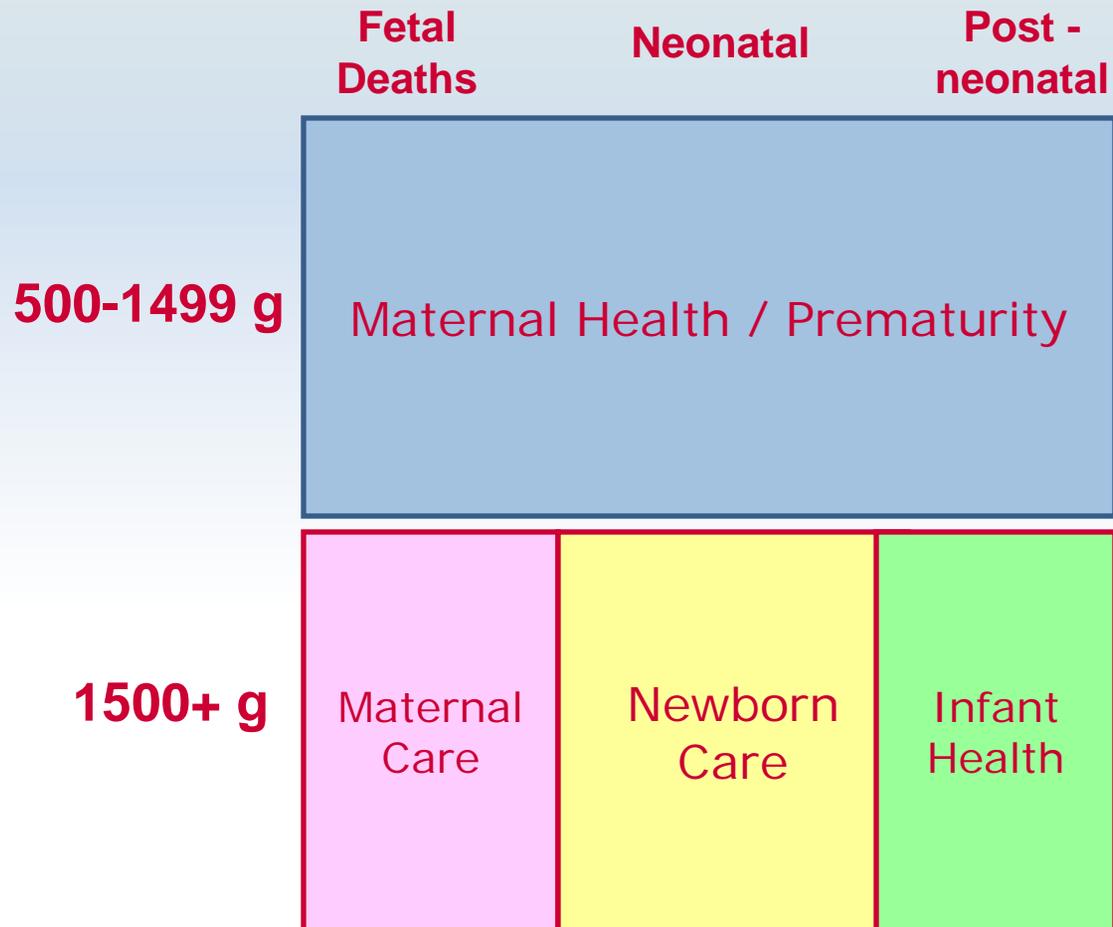


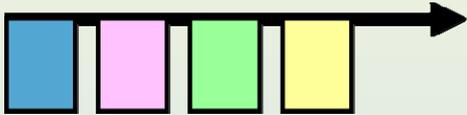
Experts used statistics to combine boxes with similar causes of death and risk factors

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



Four Perinatal Periods of Risk named to suggest prevention areas

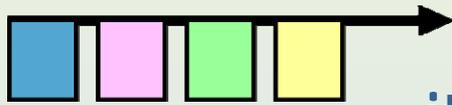




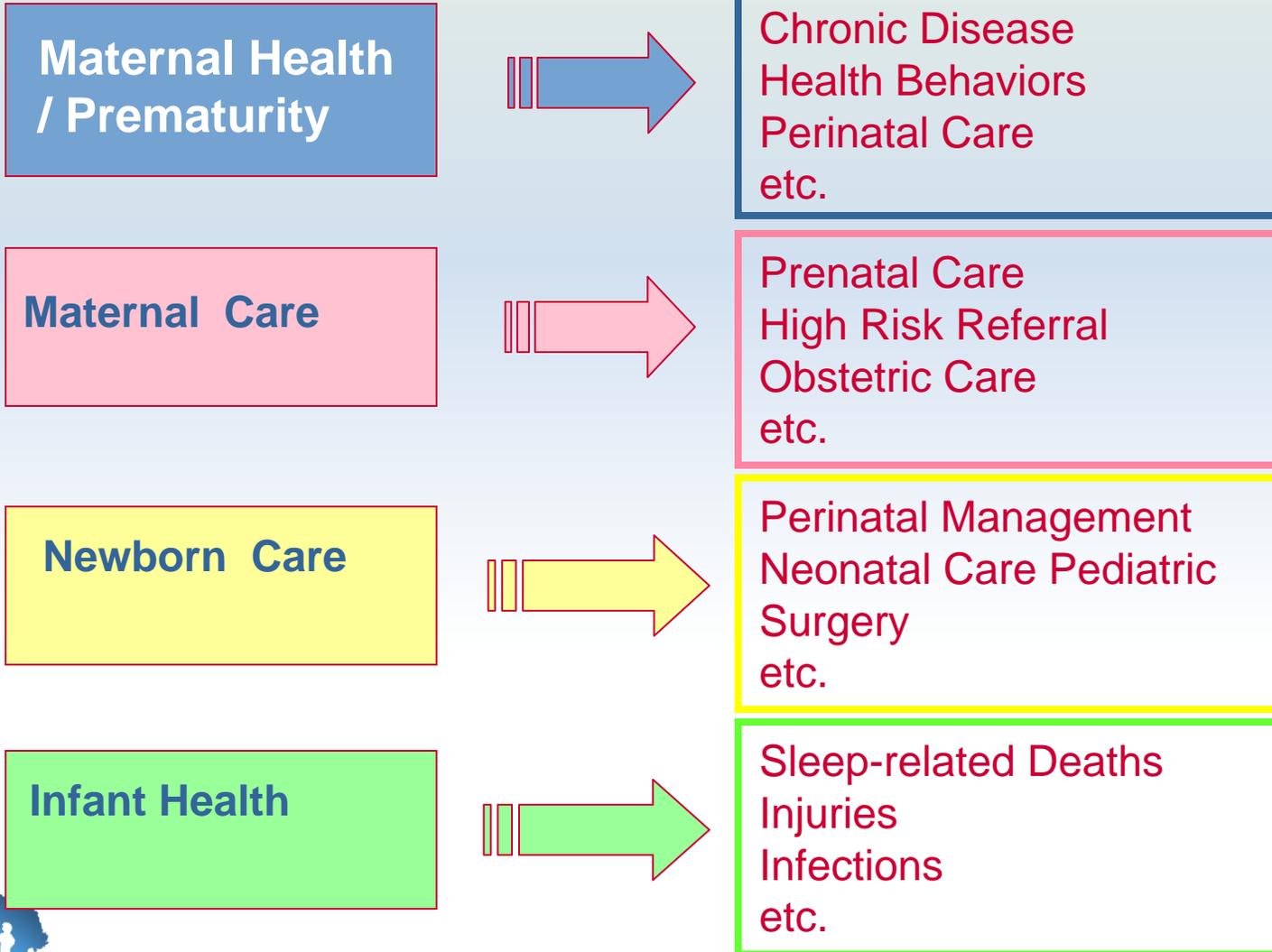
The dividing lines had been chosen so deaths in the same “box” had similar PROBLEMS:

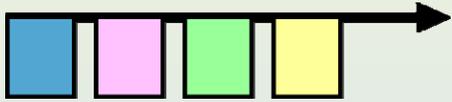
- Causes of death
- Maternal risk factors

...which means they also had similar SOLUTIONS.



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

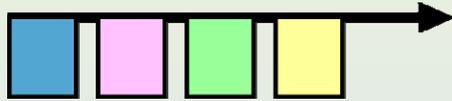




The four periods provide a framework that helps communities

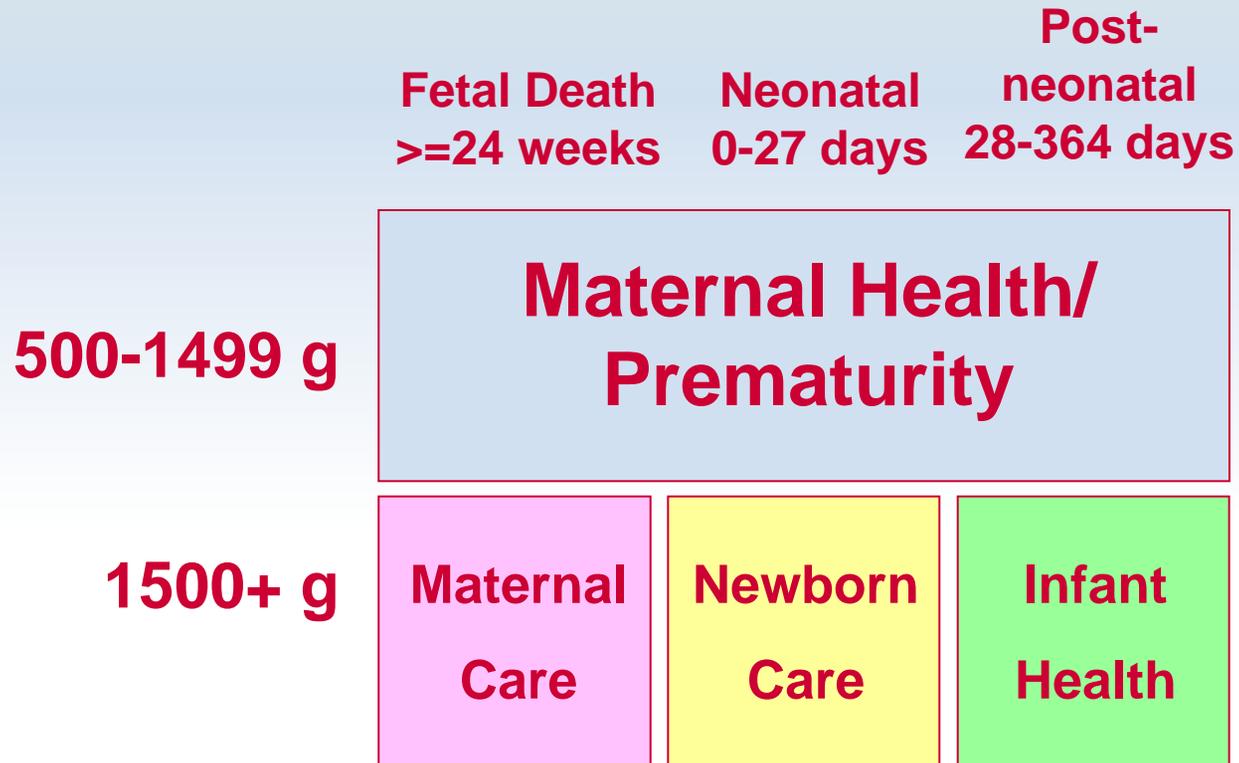
- ◆ Move from *having* data to *using* data
- ◆ Prioritize limited resources
- ◆ Use evidence to maximize impact

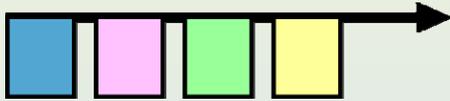




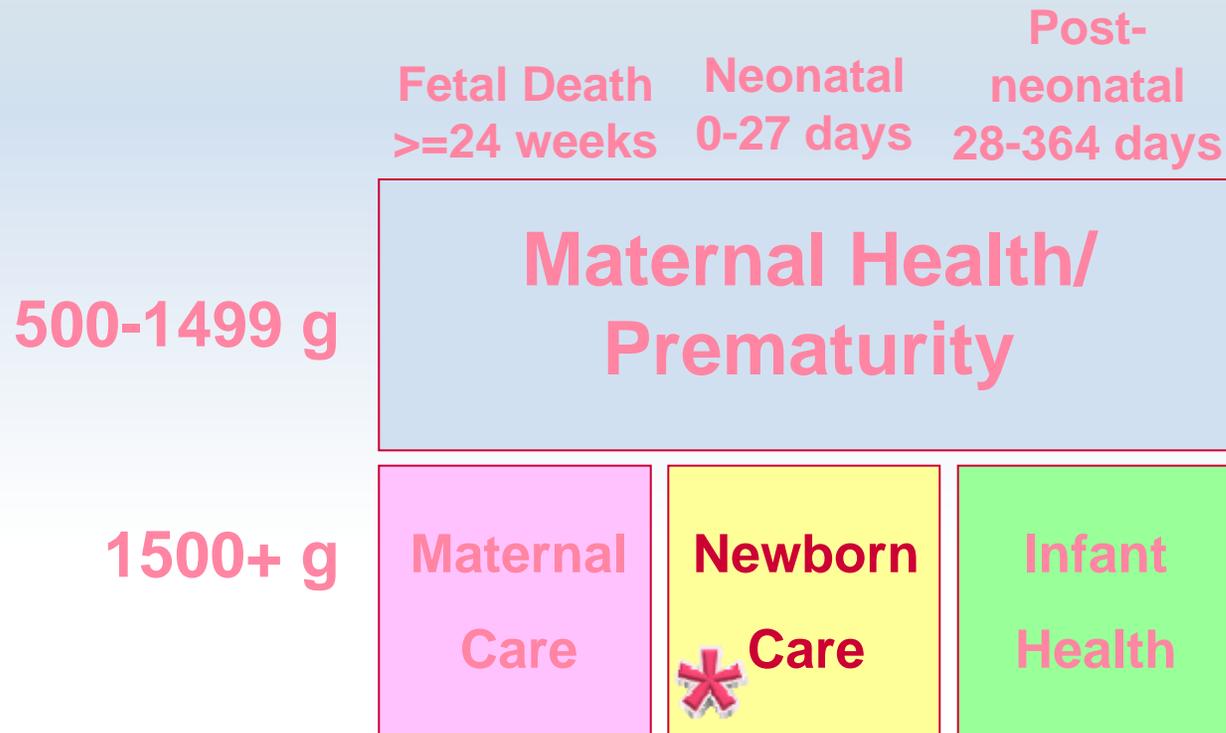
To use the boxes, SORT the Fetal and Infant Deaths

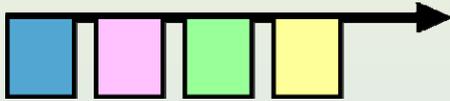
* Example: a girl weighing 2,499 grams at birth died at 22 days





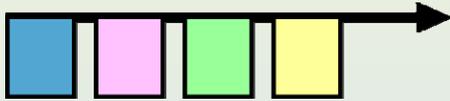
*** Example: girl weighing 2499 grams at birth, died at 22 days**
Answer: Newborn Care Period of Risk





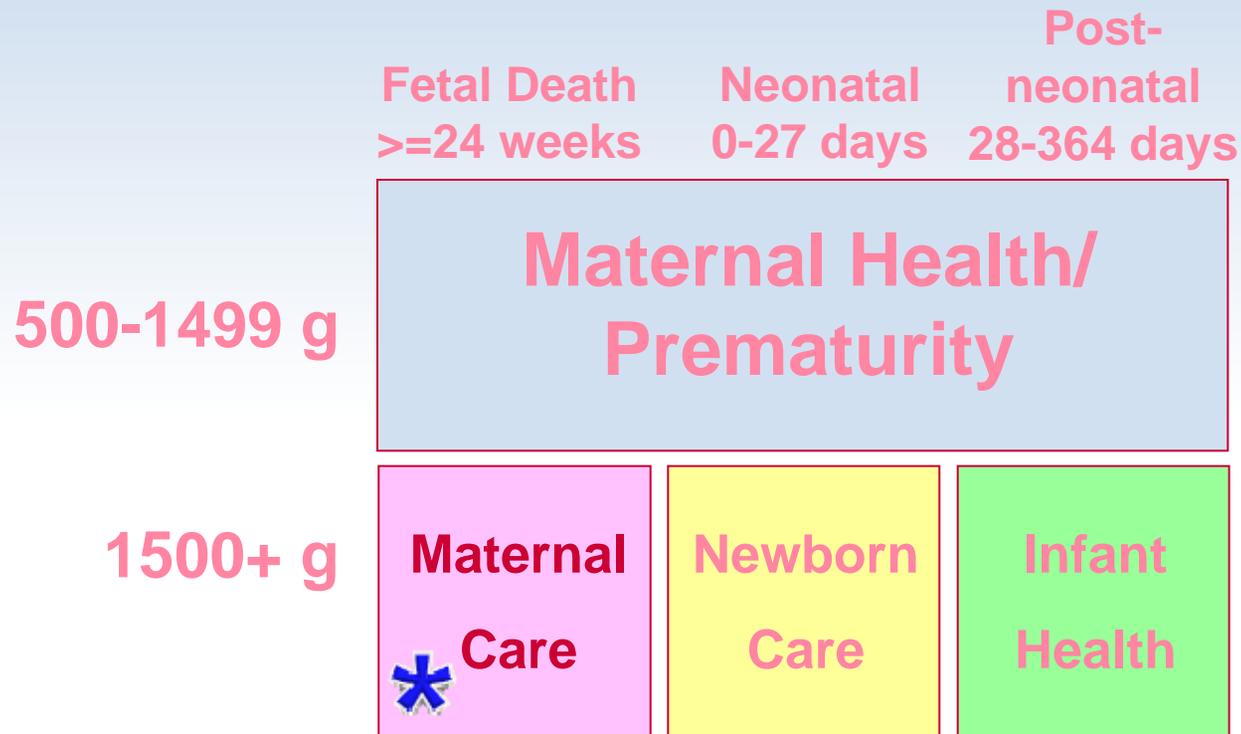
* Example: boy died before birth (fetal death); weight at delivery was 1590 grams

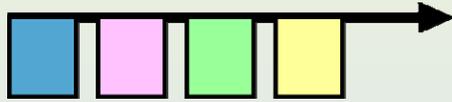
	Fetal Death ≥24 weeks	Neonatal 0-27 days	Post- neonatal 28-364 days
500-1499 g	Maternal Health/ Prematurity		
1500+ g	Maternal Care	Newborn Care	Infant Health



Example: boy died before birth (fetal death);
weight at delivery was 1590 grams

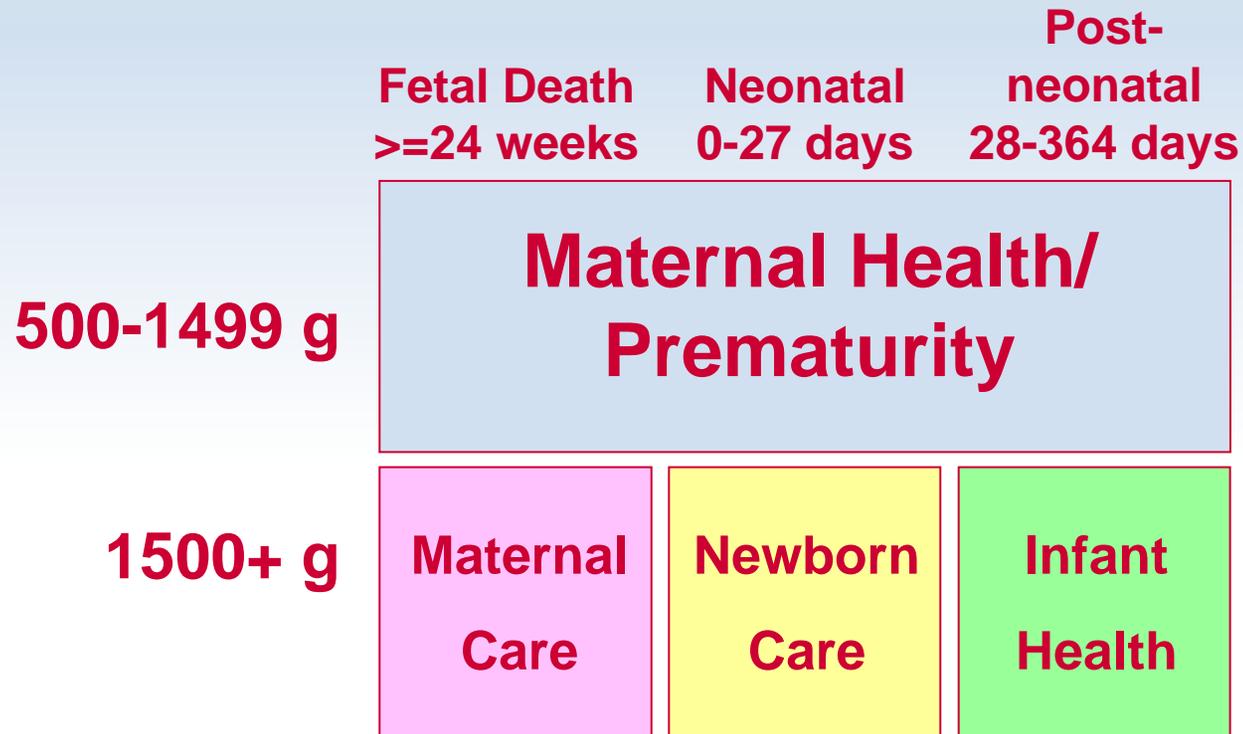
Answer: Maternal Care Period of Risk

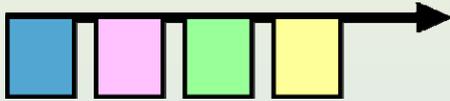




Last example of sorting fetal and infant deaths

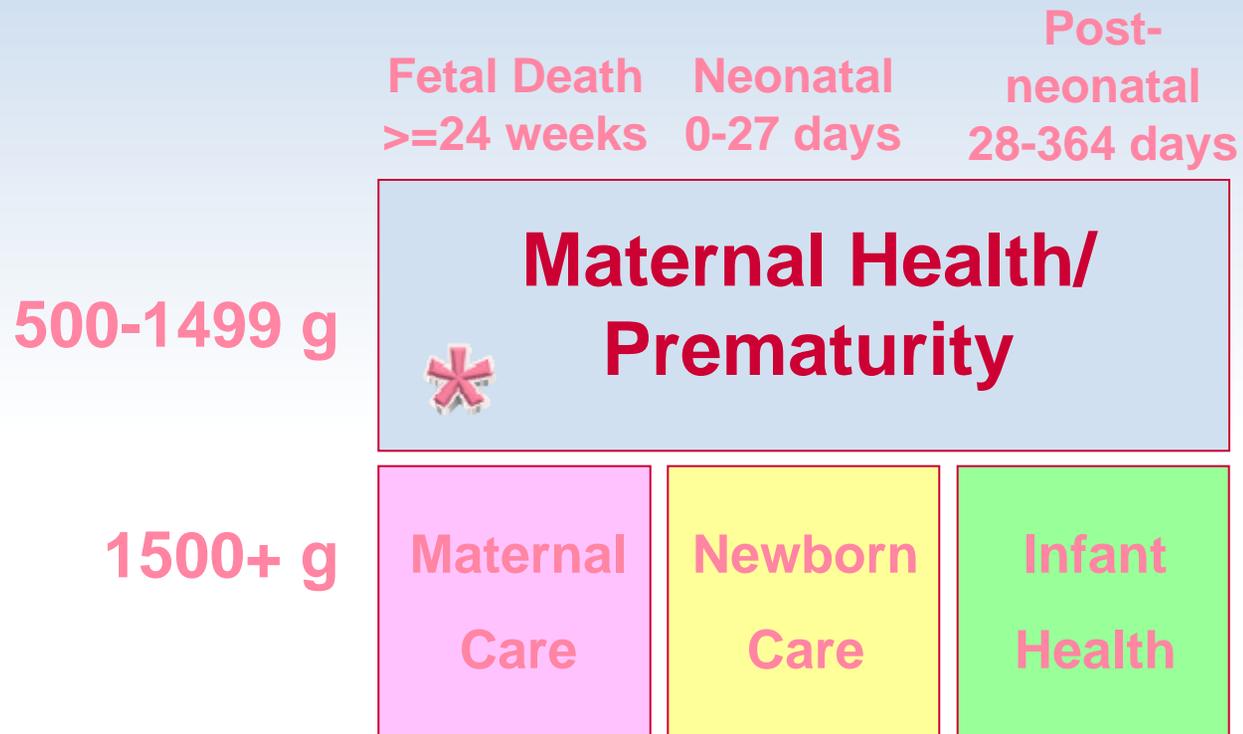
* A girl weighing 820 grams at birth died at 47 days

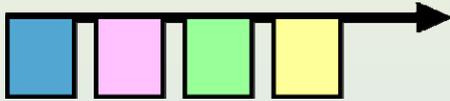




* A girl weighing 820 grams at birth died at 47 days

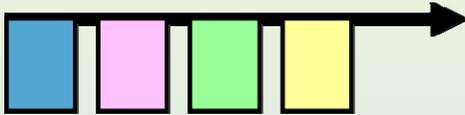
Answer: Maternal Health / Prematurity Period of Risk





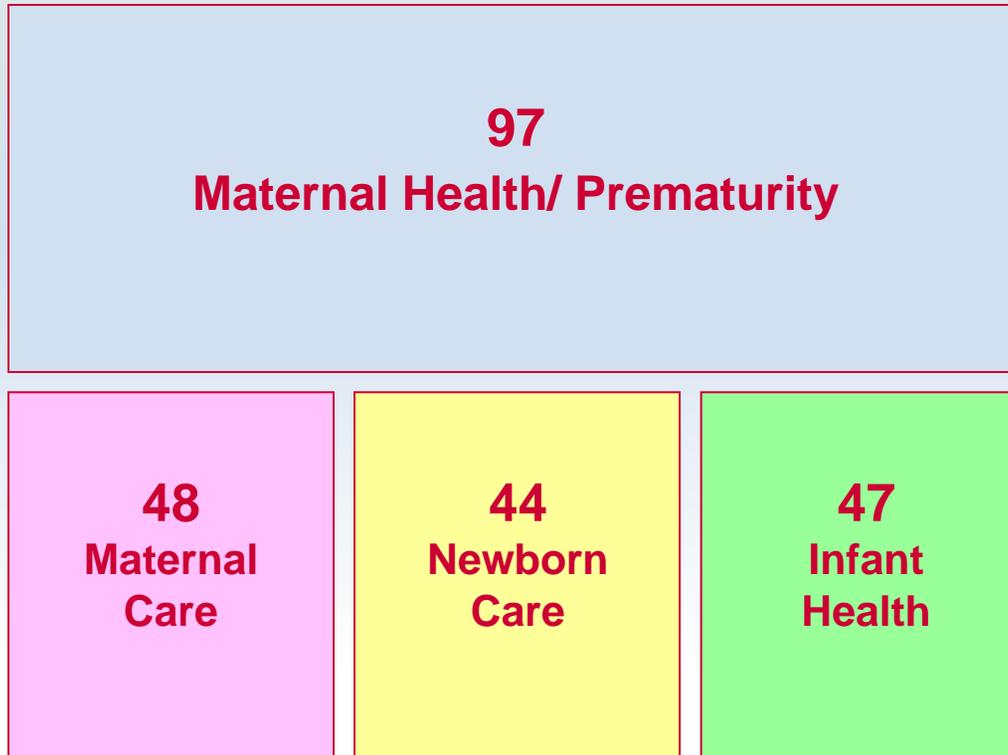
Community stakeholders in an urban county that we will call “Urban County” sorted their 2000-2003 fetal and infant deaths in this way, and made a PPOR map that looked like . . .





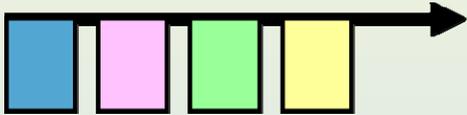
PPOR Map of Fetal-Infant Deaths

Urban County



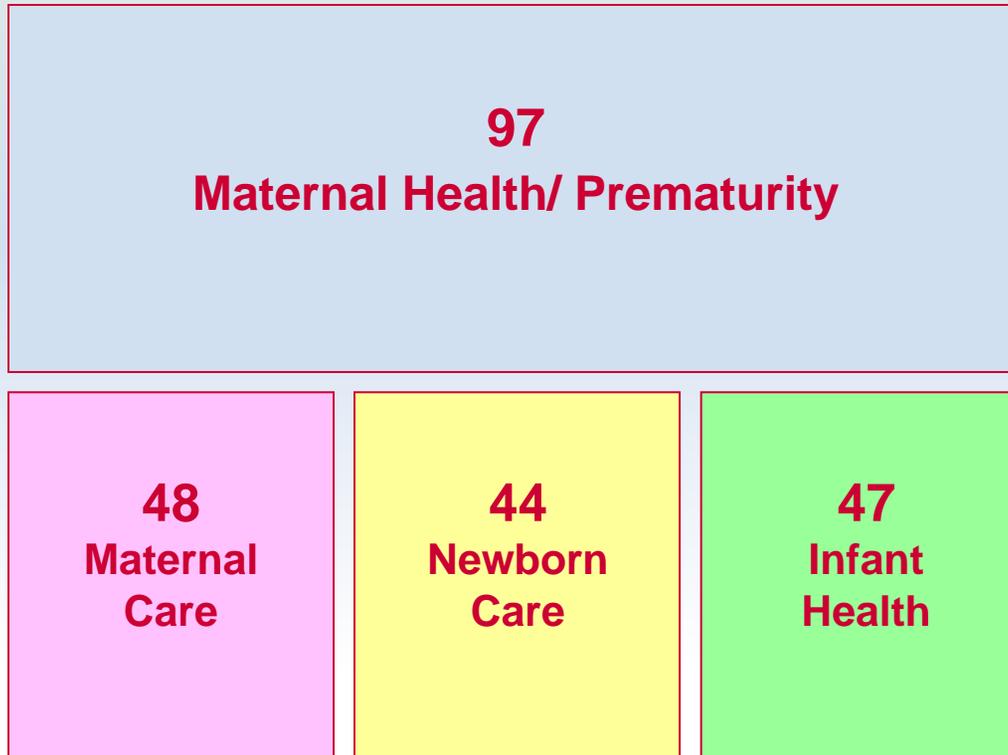
You might be asking yourself

Are these counts high or low?



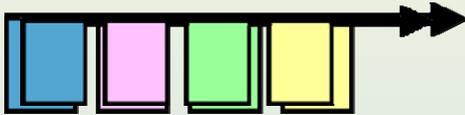
PPOR Map of Fetal-Infant Deaths

Urban County



To judge these counts, we need to know **how many pregnancies** there were altogether.

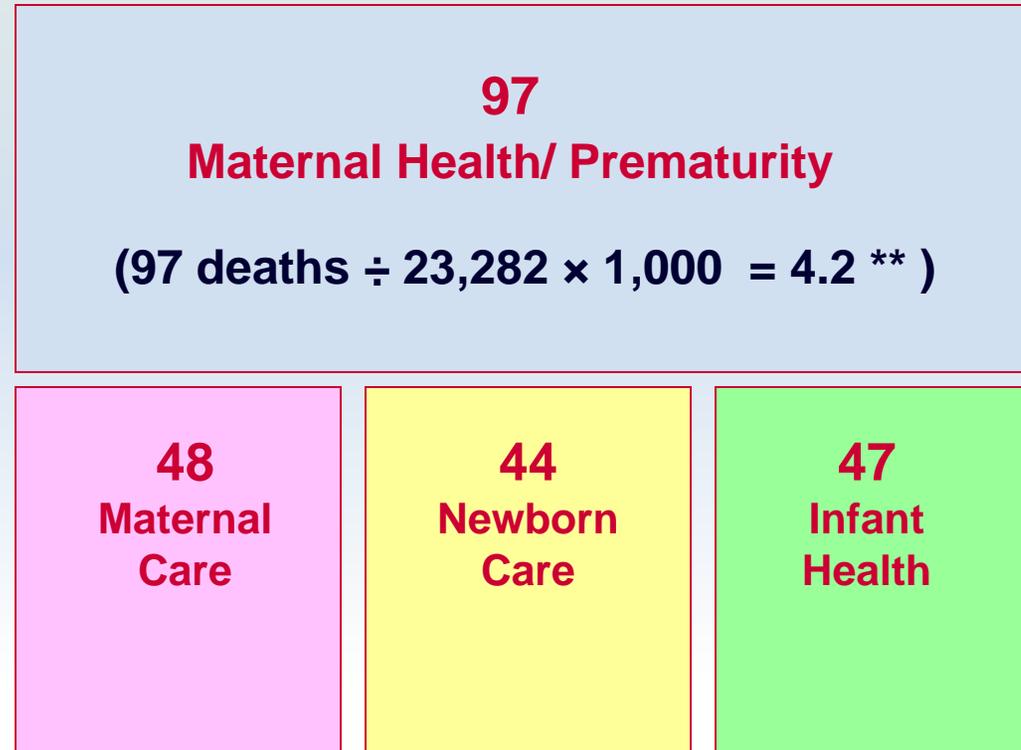
There were **23,282** fetal deaths and live births.



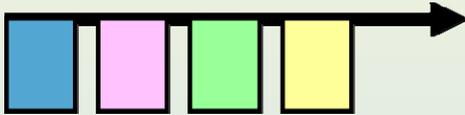
To make fair comparisons, Urban County calculated mortality rates

To calculate
mortality rates

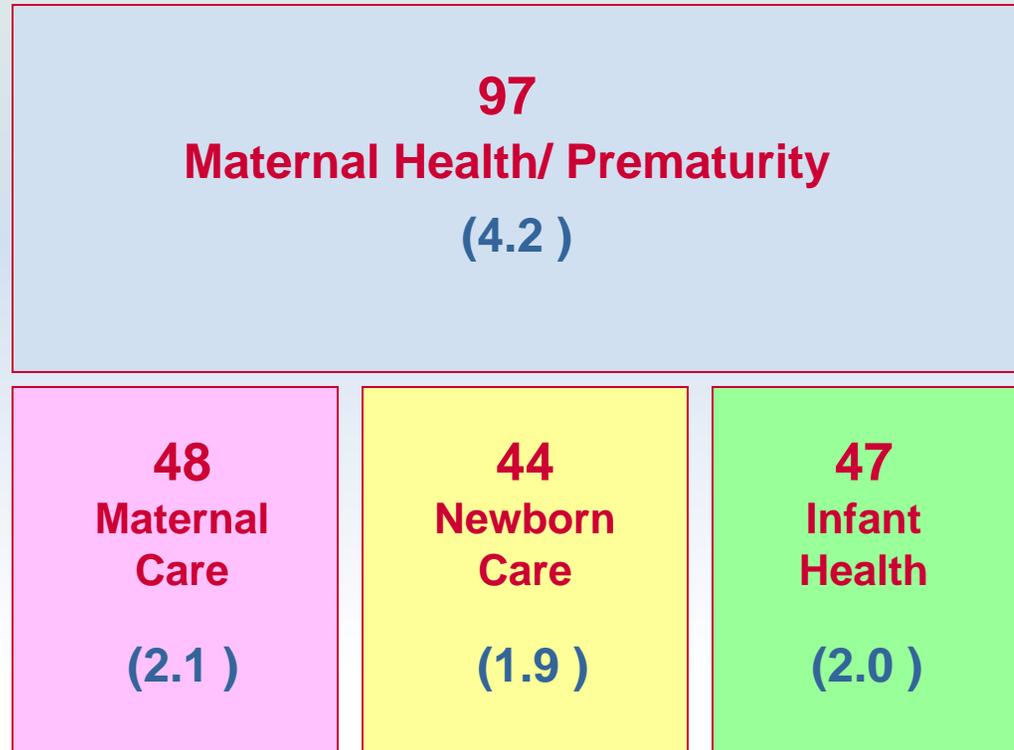
Urban County
divided each count
by the number of
live births and fetal
deaths **23,282**
then multiplied by
1,000



****There were 4.2 deaths for every 1,000 live births and fetal deaths.**

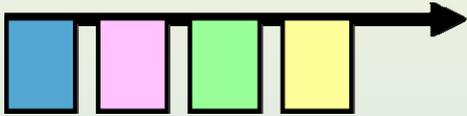


**Calculate the rate for each period of risk,
the same way,
using the same denominator**



Urban County PPOR "map"

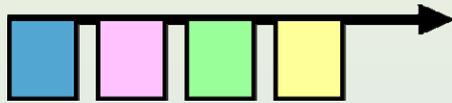




Quick side trip #1:

How do we find out about the deaths to count them?





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.

STATE OF CALIFORNIA
CERTIFICATE OF VITAL RECORDS

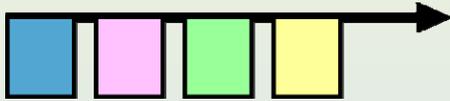
COUNTY OF LOS ANGELES
DEPARTMENT OF HEALTH SERVICES

CERTIFICATE OF DEATH

DECEASED: MICHAEL JOSEPH JACKSON
SEX: M RACE: BLACK
AGE: 35 DATE OF DEATH: JUL 6 2001
PLACE OF DEATH: 4888 FOREST LANE DRIVE, LOS ANGELES, CA
ATTENDING PHYSICIAN: RONALD REAGAN, M.D.
MEDICAL EXAMINER: JAMES THOMAS HILL

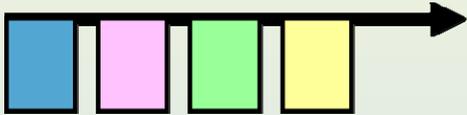
JUL - 1 2001





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.

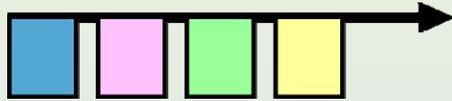


Back to Urban County's PPOR Map of Fetal-Infant Deaths



**You might be
asking
yourself**

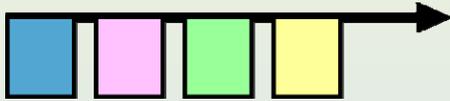
**Is 4.2 a good
rate or a bad
rate?**



“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.*

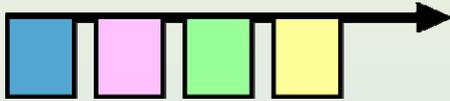




Examples of Reference Groups



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

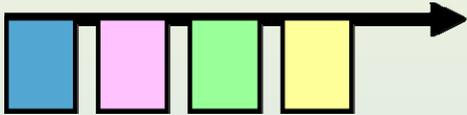


The Reference Group is about Justice

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

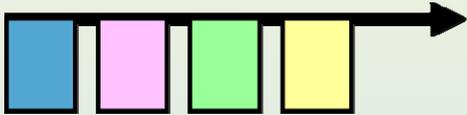


Community stakeholders **choose** the reference group. They agree that it is an appropriate standard or goal for their community.

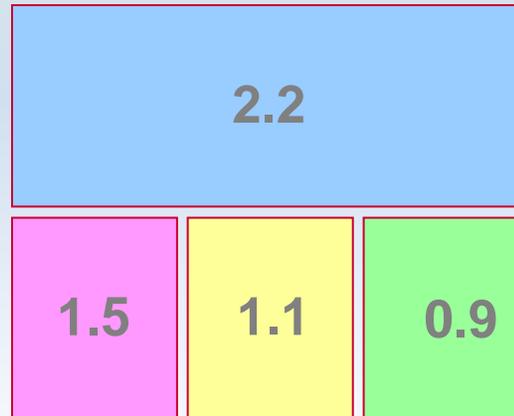


Urban County stakeholders chose the US Reference Group 2000-2002

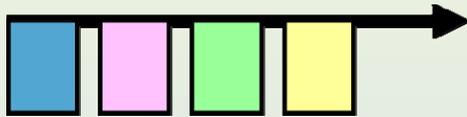
- ◆ Defined by *maternal* characteristics
 - ◆ 20 or more years of age
 - ◆ 13 or more years of education
 - ◆ Non-Hispanic white women
 - ◆ Residents of the US at the time of baby's birth



US Reference Group 2000-2002

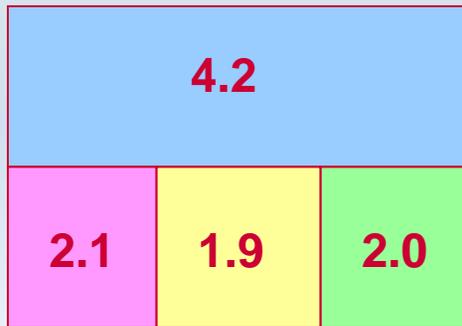


Total Fetal-
Infant
Mortality
Rate = 5.7

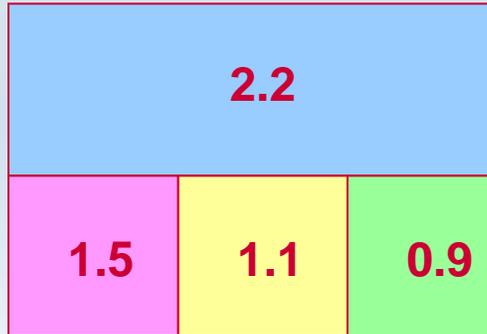


They compared the study and reference populations by subtracting rates in each period of risk

Urban County

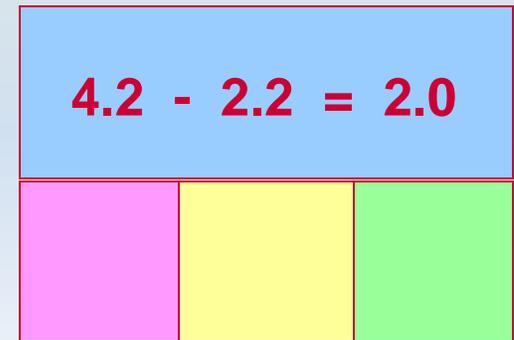


Reference Group



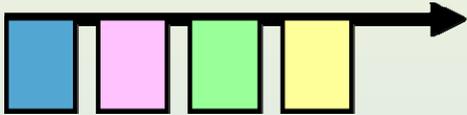
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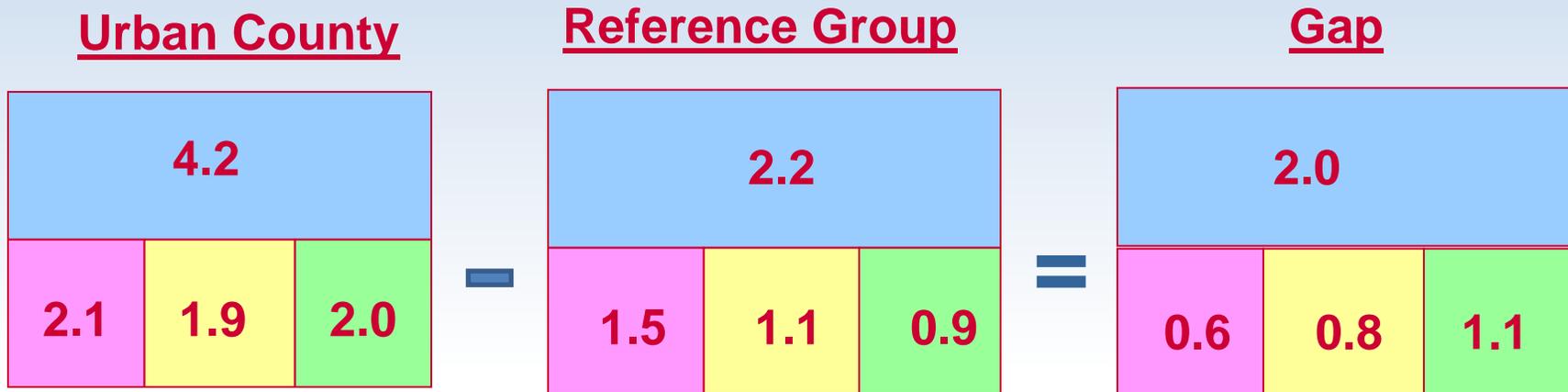


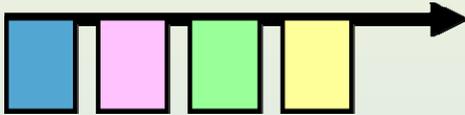
Interpretation:

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**.



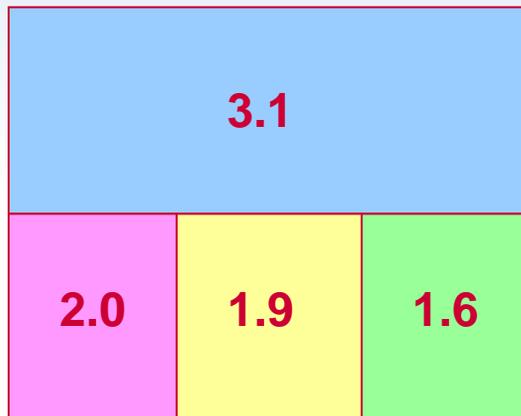


Urban County

Compared different subpopulations

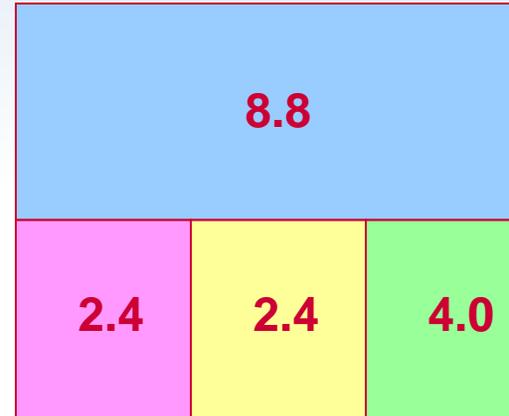
White non-Hispanic

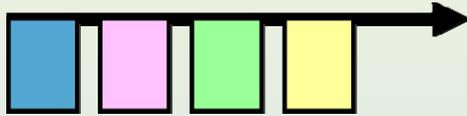
(Denominator=16,045)



Black non-Hispanic

(Denominator = 3,291)

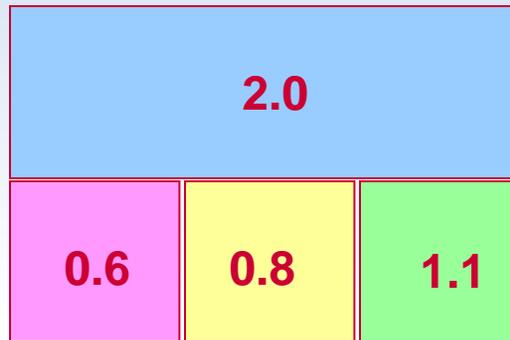




Urban County also estimated the **number** of preventable deaths

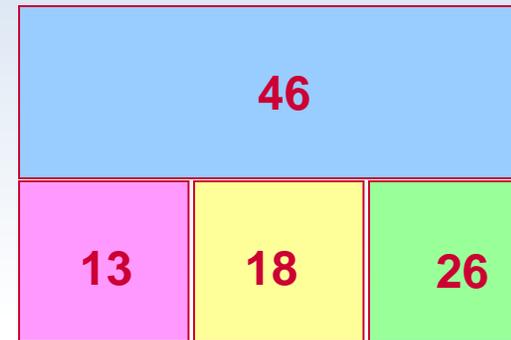
$2.0 \times 23,282 \div 1,000 = 46$
estimated preventable deaths
in the Maternal Health/Prematurity Period of Risk

Excess Rate

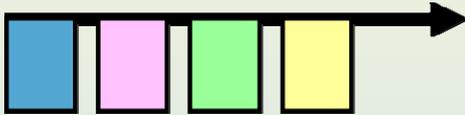


$2.0 + 0.6 + 0.8 + 1.1 = 4.4$
Overall excess mortality rate

Excess Number



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



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

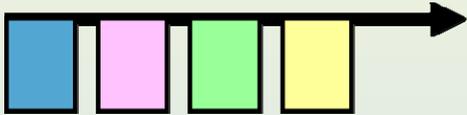
The second phase of the Urban County investigation focused on these two periods.

Gap, Excess Mortality,
Preventable Deaths

2.0		
0.6	0.8	1.1

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

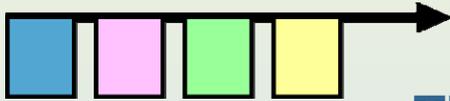
or 70%



SUCCESS!

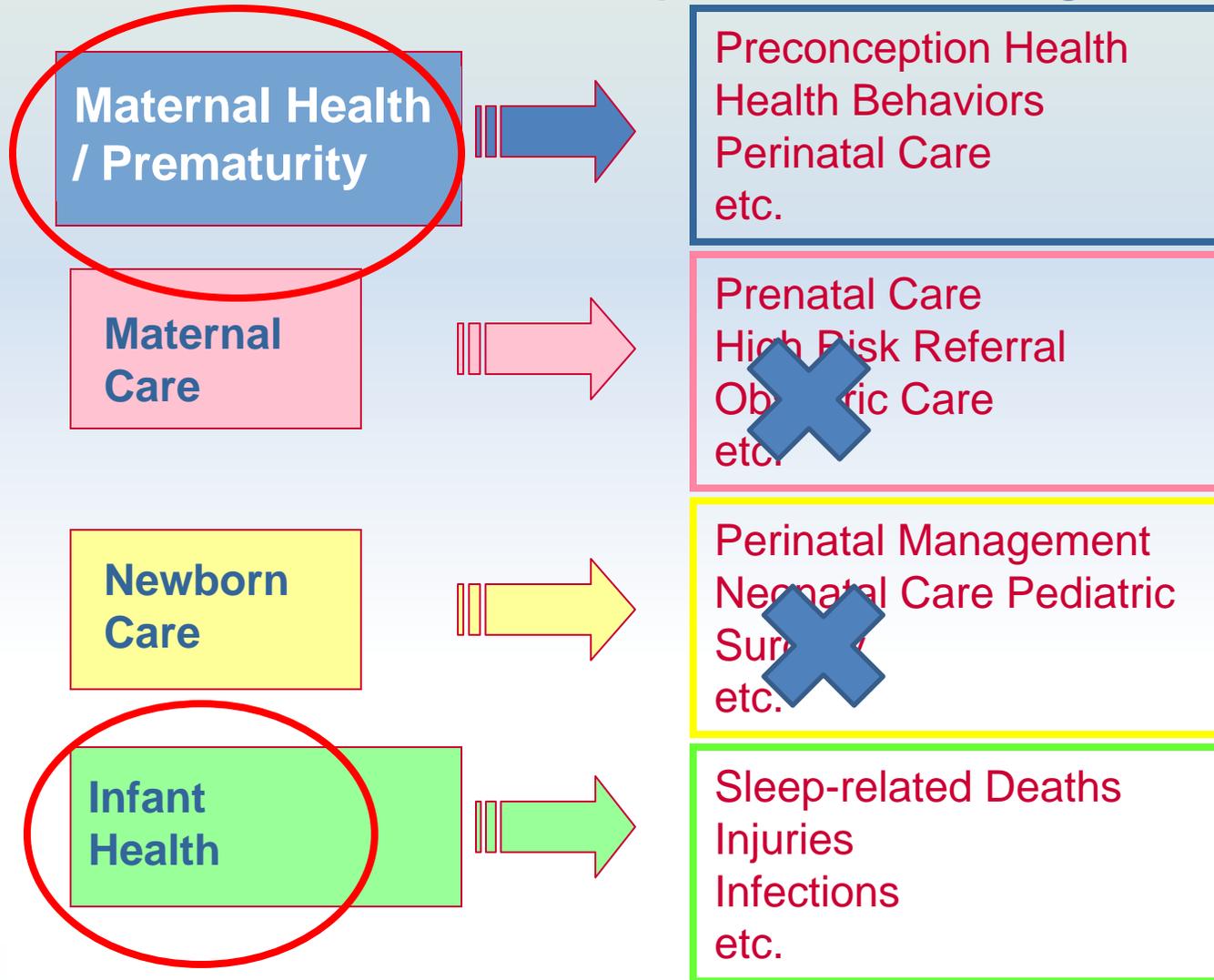
Urban County
completed Phase 1 of
PPOR analysis

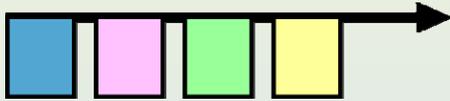
Did they win valuable
prizes?



SUCCESS!

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



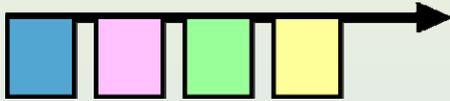


SUCCESS!

The community stakeholders were still on board

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



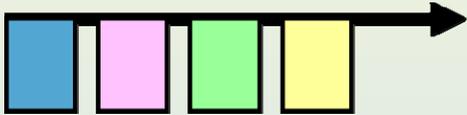


Data Issue

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.

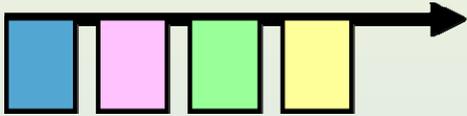
It is important to listen to and address data concerns **THROUGHOUT** the process.



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

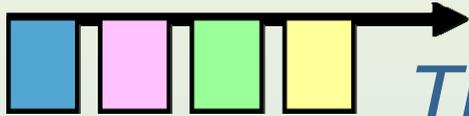
Phase 2 analysis helped them prioritize among the remaining potential causes of excess mortality.





“She’s got to be kidding! There’s more?”

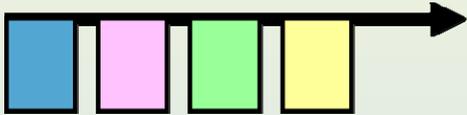




*There are three helpful steps
in Phase 2 Analysis*

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



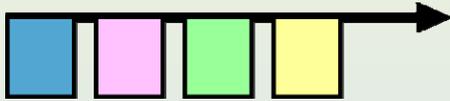


How does Phase 2 work?

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*





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.

Step 1: In IH we use “underlying cause”
ICD-10 Code from the death certificate
to investigate causes.

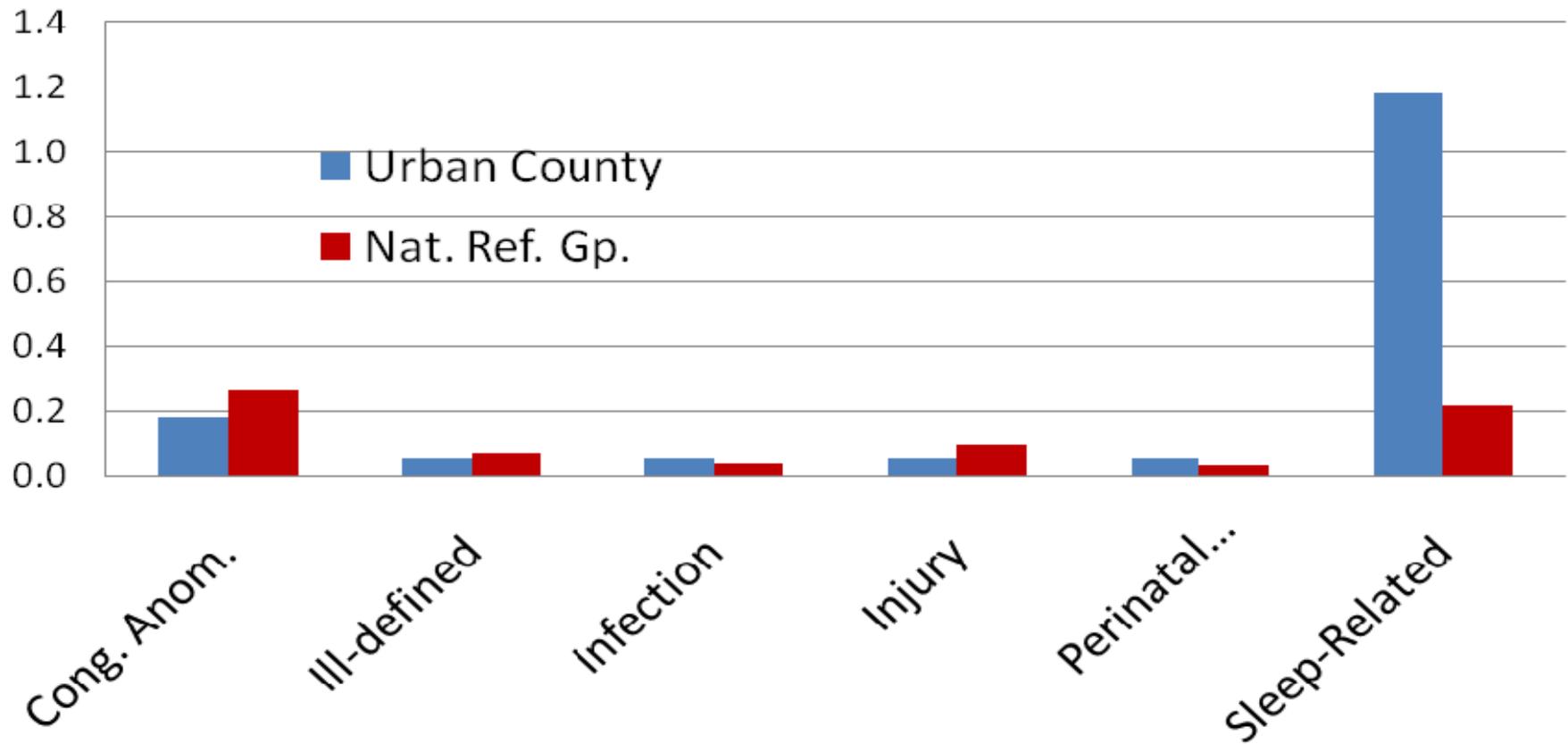
Here is a partial list for Urban County.

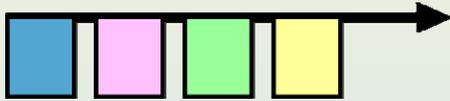
ICD code	Count of Deaths	Code description
Q208	1	Other congenital malformations of cardiac chambers and connections
Q232	1	Congenital mitral stenosis
Q249	2	Congenital malformation of the heart, unspecified
Q909	1	Down's syndrome, unspecified
Q913	1	Edwards' syndrome, unspecified
V486	1	Passenger injured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



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

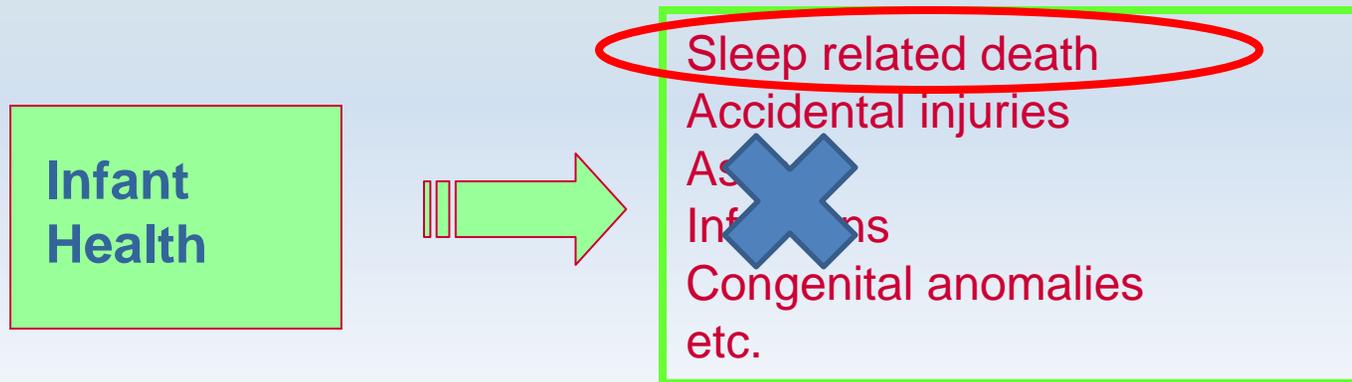
Mortality Rates by Grouped Cause of Death, for the Infant Health Period of Risk



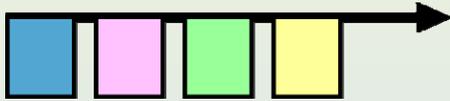


SUCCESS!

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.



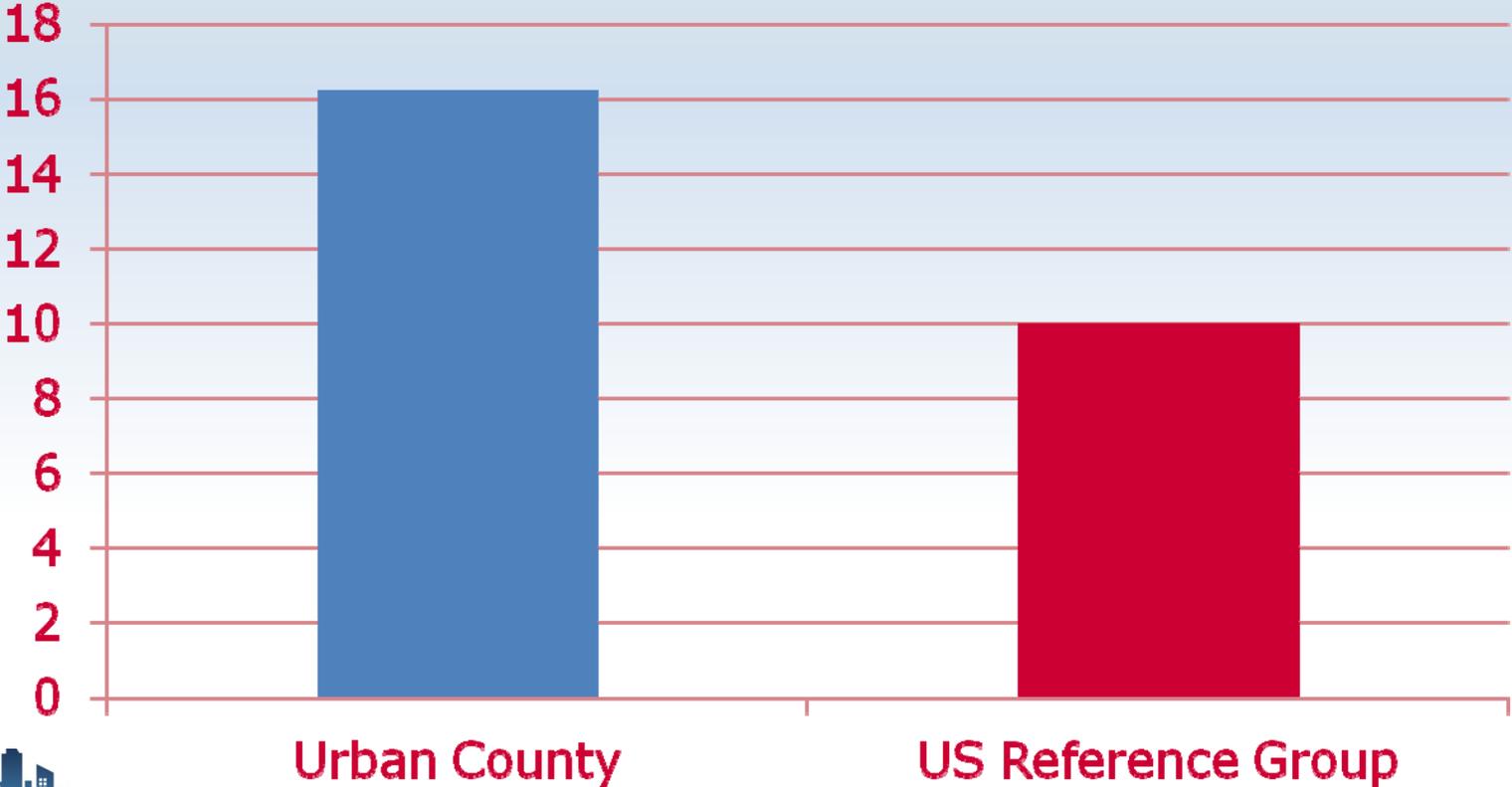
But they could do better!

Step 2: 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

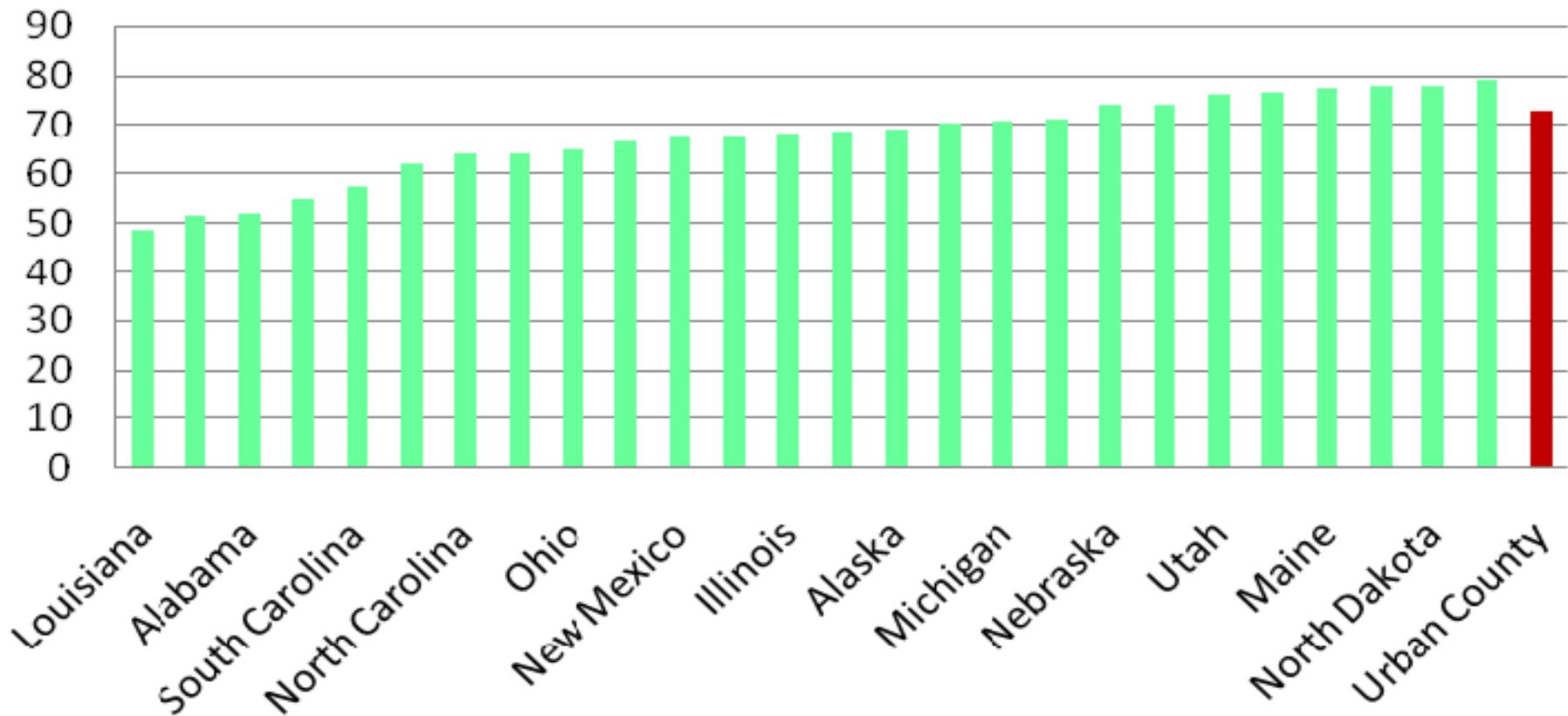
Step 2: *Since **more** mothers in Urban County smoked, this could be contributing to the gap.*

Percent Smokers (Birth Certificate)



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



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

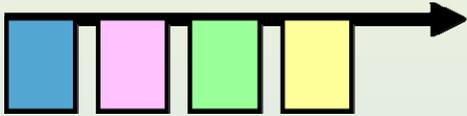


Step 2: *Guided by PPOR findings, the Fetal Infant Mortality Review team focused on Sleep-related deaths for six months.*

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

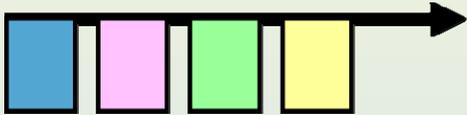




Quick side trip #2:

What is FIMR and why do so many cities use PPOR and FIMR together?

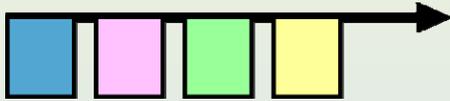




What is FIMR?

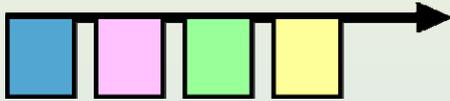
Fetal Infant Mortality Review

- 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)



Examples of how PPOR data & FIMR information helped each other

1. FIMR found that mothers of premature babies had not known how to recognize signs of early labor. Since PPOR data indicate that prematurity accounts for 80% of excess mortality, a physician education campaign was justified.
2. FIMR found that immigrant mothers did not seek or receive prenatal care, and considered a PNC media campaign. But PPOR Phase 2 data found that 99.5% of mothers DID receive PNC. A group working with immigrants agreed to address the PNC problem.



What FIMR brings to the table

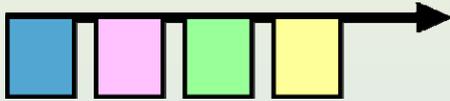
FIMR can give us answers when we don't even know what the question is yet!

FIMR can identify cause and effect relationships.

FIMR works in small neighborhoods.



FIMR “Paints faces behind the numbers”



Limitations of FIMR

Every data source has its limitations. FIMR only looks at babies that died.

The population of babies that died probably has more risk factors than the general population of mothers.

Concerns raised by FIMR should be confirmed using sources of population-based data (like birth certificates, PRAMS, BRFSS, etc.) if possible.

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?



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

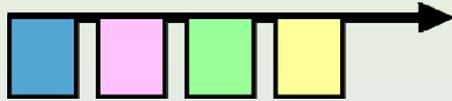


Phase 2 investigations can continue as questions arise and more data becomes available

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



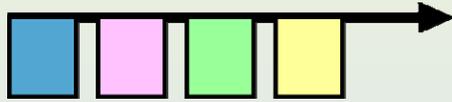


SUCCESS!

**Urban County Had won still more
valuable prizes . . .**

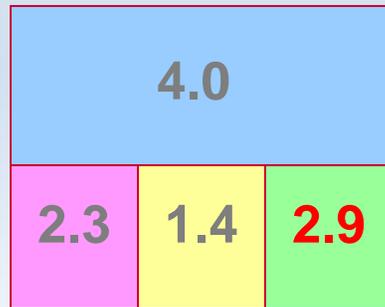
- Their time investment was focused
- They found some answers
- Action steps were more appropriate than initially envisioned (“back to sleep”)





SUCCESS in Outcomes PPOR 1993-2009 Urban County

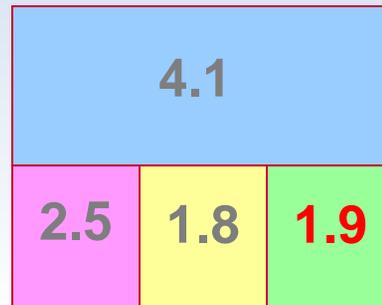
Fetal-Infant
Rate=**10.7**



1993-1996

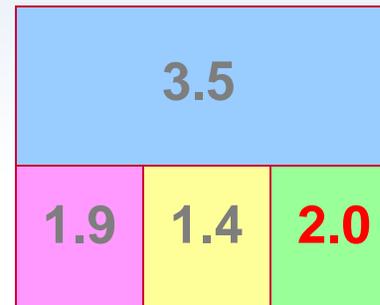
The decrease in mortality rates can't necessarily all be attributed to PPOR

Fetal-Infant
Rate=**10.3**



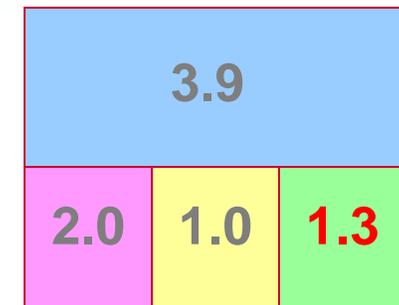
1997-2000

Fetal-Infant
Rate=**8.8**



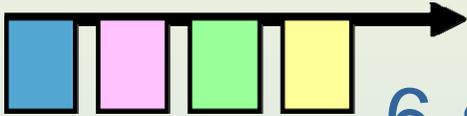
2001-2005

Fetal-Infant
Rate=**8.2**



2006-2009





6-stage PPOR approach following the community planning cycle

Stage 1: Assure Community and Analytic Readiness

Stage 2: Conduct Analytic Phases of PPOR

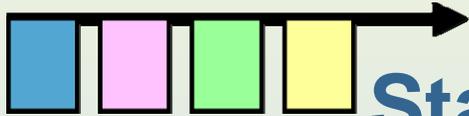
Stage 3: Develop Strategic Actions for Targeted Prevention

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

Stage 5: Monitor and Evaluate Approach

Stage 6: Sustain Stakeholder Investment and Political Will





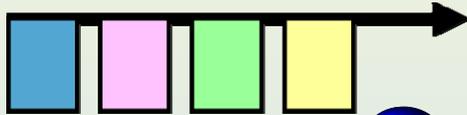
Stage 1: Assure Community and Analytic Readiness

You need community involvement

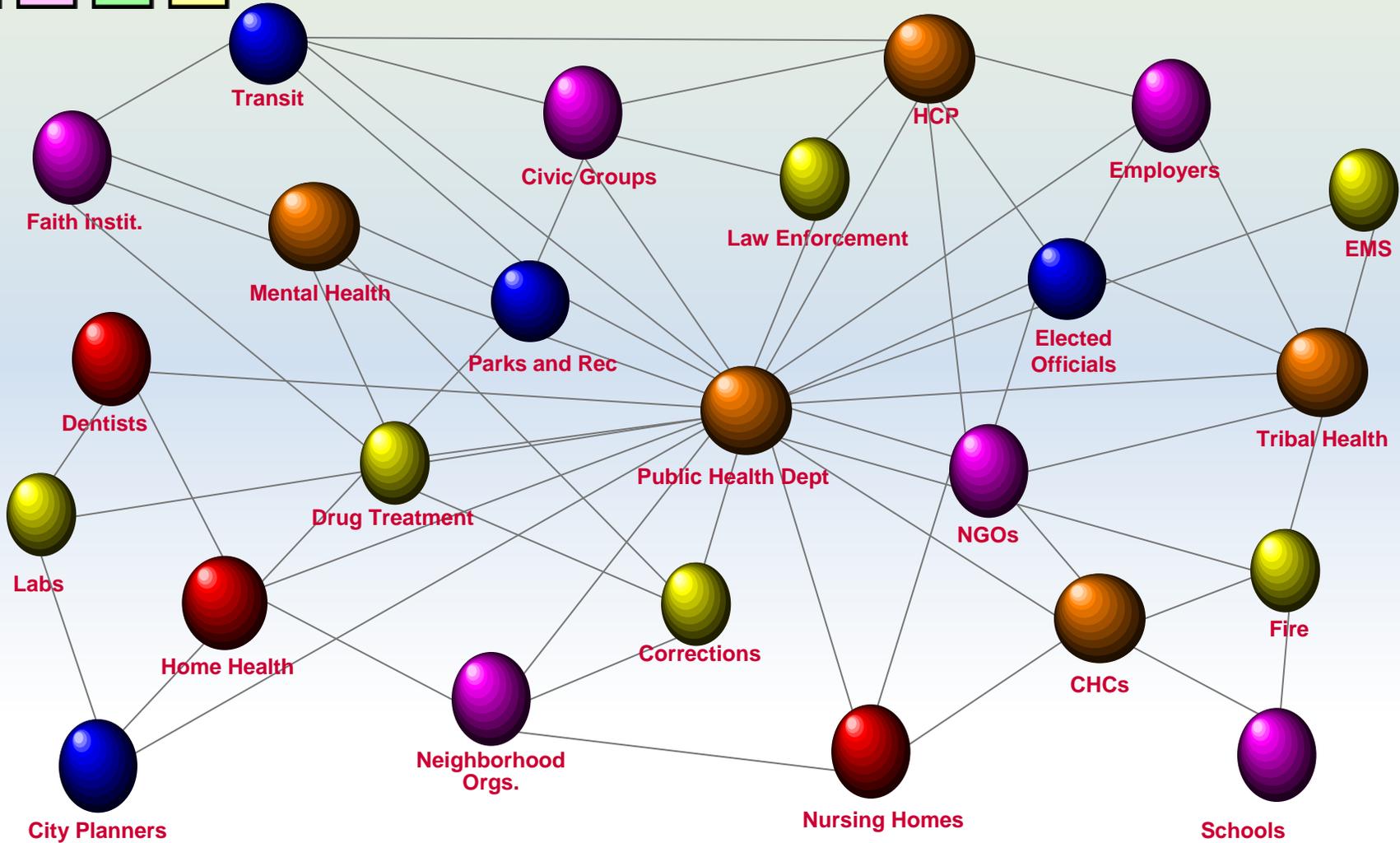
“Data analysis alone does not produce community change.”

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



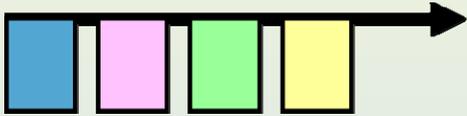


Who are your stakeholders?



Source: NACCHO'S MAPP Clearinghouse

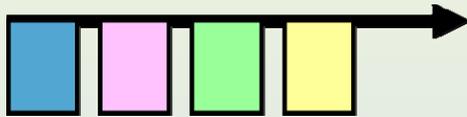




You need to be ready and have committed leadership

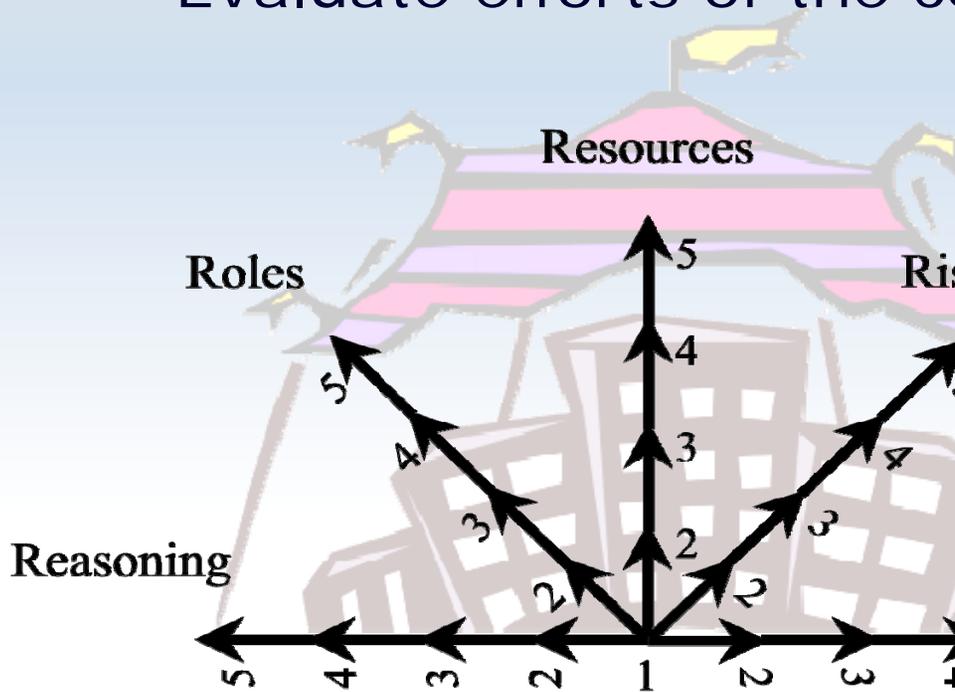
- If communities are not ready for change, or **leadership** is not **engaged** or **committed**, they will have a difficult time being successful.
- Planning helps avoid failure, which can be discouraging.





Tools for Assessing & Evaluating Readiness

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



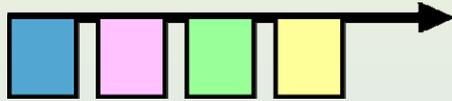
The Wilder Collaboration Factors Inventory

Name of Collaboration Project _____ Date _____

Statements about Your Collaborative Group:

Factor	Statement	Strongly Disagree	Disagree	Neutral, No Opinion	Agree	Strongly Agree
History of collaboration or cooperation in the community	1. Agencies in our community have a history of working together	1	2	3	4	5
	2. Trying to solve problems through collaboration has been common in this community. It's been done a lot before.	1	2	3	4	5
Collaborative group seen as a legitimate leader in the community	3. Leaders in this community who are not part of our collaborative group seem hopeful about what we can accomplish.	1	2	3	4	5
	4. Others (in this community) who are not a part of this collaboration would generally agree that the organizations involved in this	1	2	3	4	5

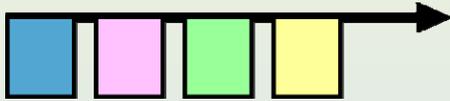




Can everyone use the Perinatal Periods of Risk approach?

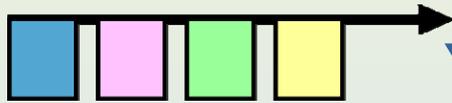
What do you need?





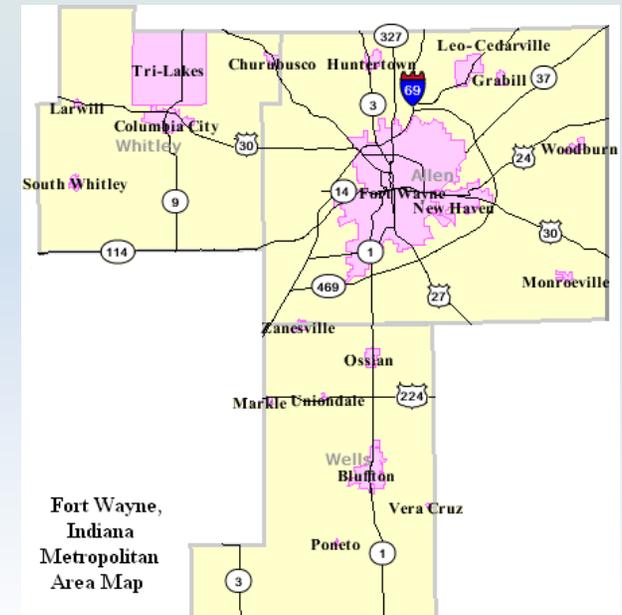
--You need at least 60 deaths--

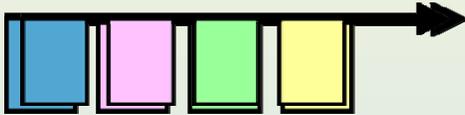
- At least **60** fetal and infant deaths, **for each population** being studied
- May combine up to **five years** (no more, due to changes in medical practice and public health systems)
- Phase 2 analyses require even more deaths



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



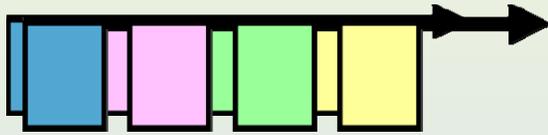


You need 3 vital records data files

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



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



What is PPOR?

... It's more than just the data!

**Maternal Health/
Prematurity**

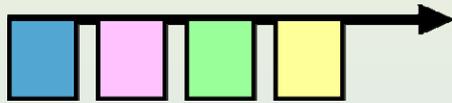
**Maternal
Care**

**Newborn
Care**

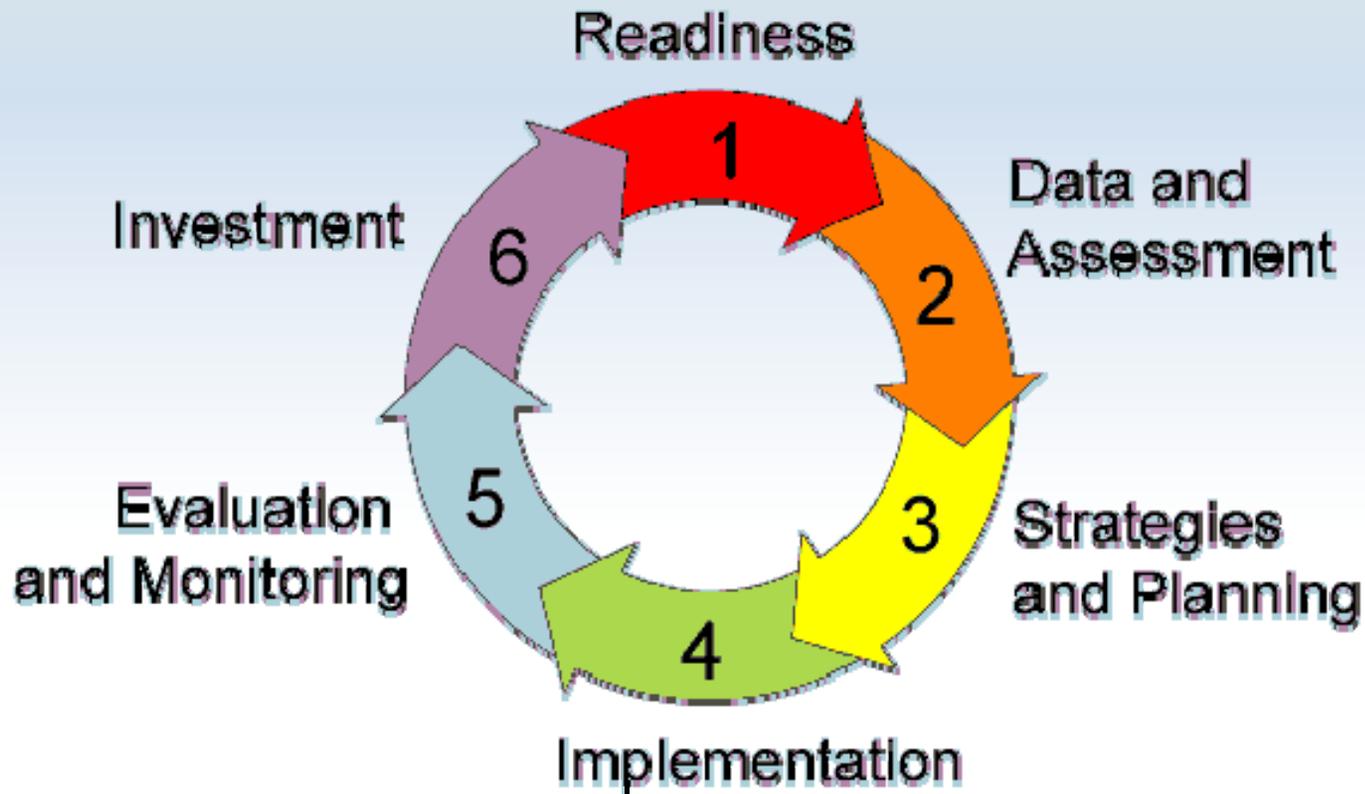
**Infant
Health**

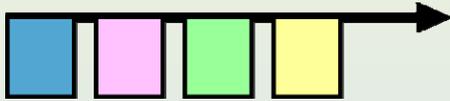
It really is a **community tool** for decreasing infant mortality





PPOR is designed for integration with your community planning cycle



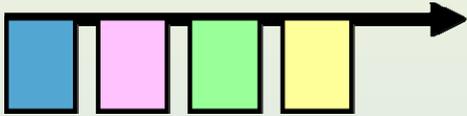


**PPOR should be used
with any existing efforts**

- **FIMR**
- **Healthy Start**
- **Community Health Assessments**

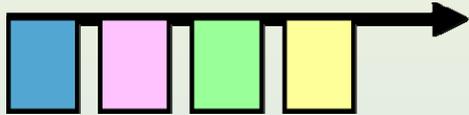
**Or, if you are just starting out,
the PPOR approach is
the whole package!**





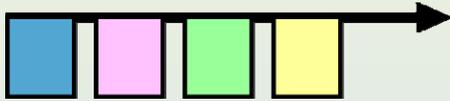
Stage 2: Analysis – Phase 1

- ◆ 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



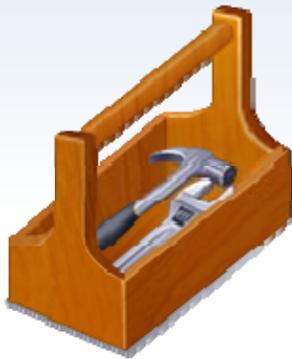
Stage 2: Analysis – Phase 2

- ◆ 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

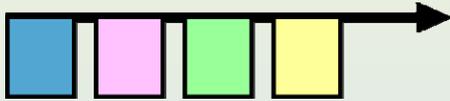


Stage 3: Develop Action

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



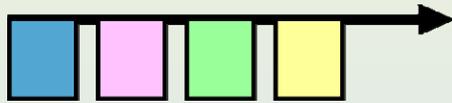
Stage 4: Implementation

New programs are implemented or existing ones strengthened

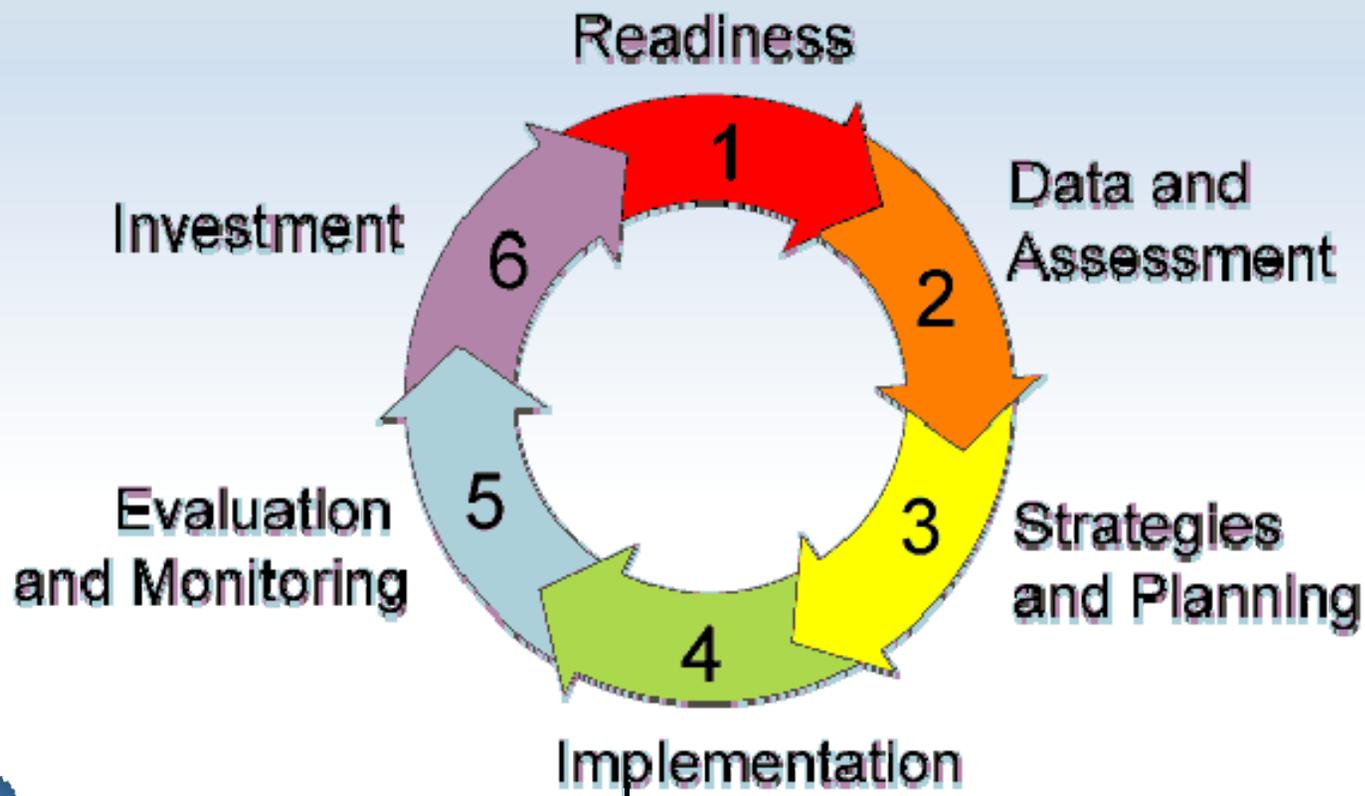


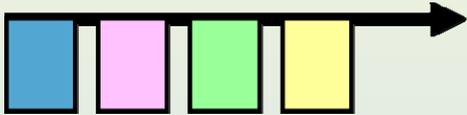
Based on

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



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



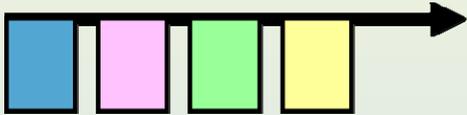


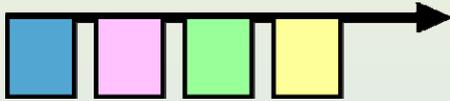
Why use PPOR?



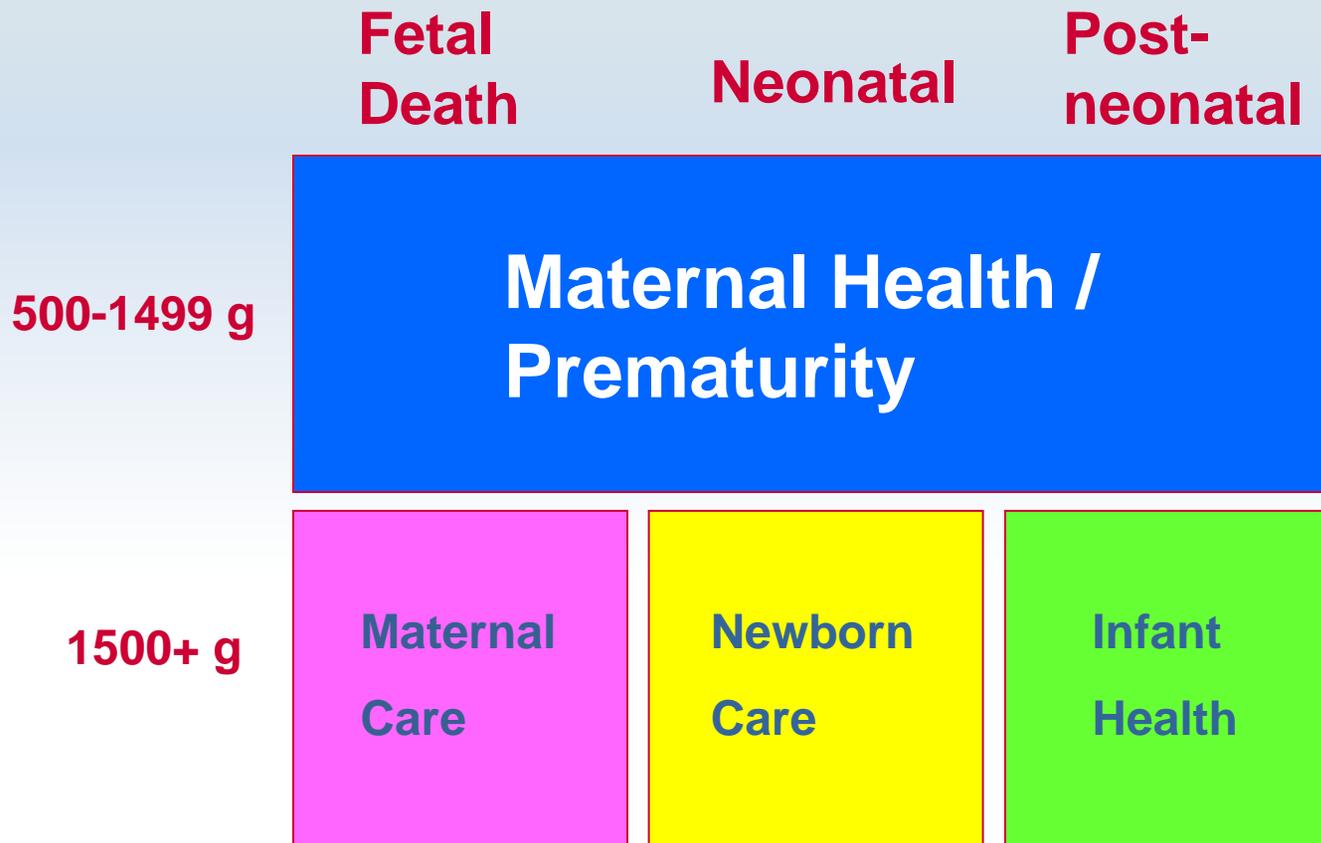
www.citymatch.org

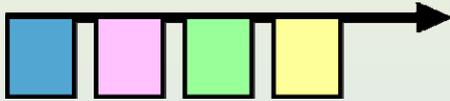






PPOR is not just another pretty face . . . the colored boxes help make PPOR “accessible”





CityMatCH has

- **Tools** for stakeholder engagement
- The **Learning Network** (a support group)
- **Ideas** for presenting findings
- **Resources** for evaluating stakeholder participation and community change processes
- Data analysis **instructions**

www.citymatch.org

CityMatCH offers PPOR workshops





Baltimore City



"The loss of any child affects us all. A part of our future is lost."



Fetal Infant Mortality Review

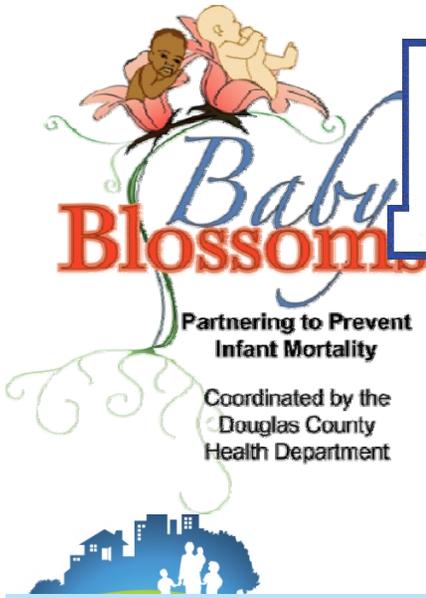
Marion County Health Department



Maricopa County Public Health

Lane County, Oregon

Chattanooga, TN



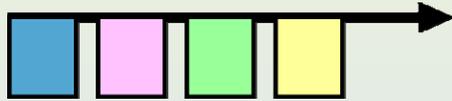
Bay Area Data Collaborative



Healthy Start Coalition of Miami-Dade

Your name here !



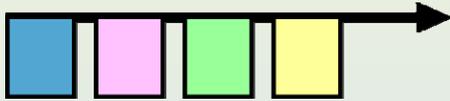


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- Questions and Answers
- Thank you for attending this event. Please complete the evaluation directly following the webcast. An archive of this events will be posted at <http://www.mchcom.com> within a few days of this broadcast.

