





## "IT'S IN THE NEWS, IT'S IN THE HOSPITAL, BUT WHAT ARE WE REALLY DOING ABOUT IT? ADDRESSING MATERNAL AND NEONATAL MORTALITY"

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#### PERINATAL SELF STUDY MODULE:

#### "IT'S IN THE NEWS, IT'S IN THE HOSPITAL, BUT WHAT ARE WE REALLY DOING ABOUT IT? ADDRESSING MATERNAL AND NEONATAL MORTALITY"

We are excited to offer a self study module on addressing maternal and neonatal mortality. We have applied for nursing continuing education credit. When the module becomes available, please complete the module and the evaluation/post-test. You may return the post-test/evaluation to our office by Fax (803,434-4309 or E-mail: perinatalystems@paimettoheait.hgr

Prisma Health Richland is an approved provider of continuing nursing education by the South Carolina Nurses Association, an accredited approver by the 'American Nurses Credentialing Center's Commission on Accreditation'. Please contact Michelle Flanagan 803-434-7943 or Cathy White 803-434-2913 for more information concerning contact hours. The ANCC neither endorses nor approves any products that may be associated with this continuing education activity. Cathy White, N NP-BC - Neonatal Outreach Educator Michelle Flanagan, BSN, RNC - Obstetric Outreach Educator "Let me be clear." EVERY mother, regardless of race, or background deserves to have a healthy pregnancy and childbirth." Serena Williams

Directions







MODULE AND DIRECTIONS WILL BE EMAILED OUT TO PARTICIPANTS

- Please read the following module and complete the Post-Test and Evaluation.
- This module was designed to be completed on your computer, rather than printed if possible.
- If you have any questions, please contact Perinatal Systems at 803-434-2912 or <u>PerinatalSystems@PalmettoHealth.org</u>

#### Objectives

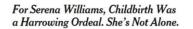
By the end of the program, participants will be able to:

- verbalize definitions of maternal mortality and morbidity (Maternal morbidity, Maternal mortality, Pregnancy related death versus Pregnancy associated death)
- identify leading causes of maternal deaths
  - a. Importance of Maternal time of death (during pregnancy, within 42 days postpartum, 43 days to 1 year postpartum
  - b. Review other characteristics associated with maternal mortality rates (age, ethnicity, etc)
- identify challenges of preventability, themes for improvement current federal/state law associated with Maternal mortality
  - a. Preventability (contributing factors)
  - b. Improvement (safety bundles)
  - c. Current laws/regulations
- verbalize definitions and rates of neonatal mortality (Neonatal Mortality Definition/Rates, Neonatal Death, Infant Death)
- identify leading causes and increased efforts to prevent neonatal deaths
  - a. Birth Defects
  - b. Preterm Birth/Low birth weight
  - c. SIDS
  - d. Maternal Pregnancy complications
  - e. Injuries (suffocation)
  - f. Prevention
    - 1. Improvements/advancements in neonatal care
    - 2. Education/Safe sleep environment
    - 3. Improved newborn screening test



Maternal Mortality

The New Hork Times





By Maya Salam

women

Not even the tennis dynamo Serena Williams is immune from the complications and challenges new mothers face during and after

#### IN THE NEWS...

attention?



A 15-year-old gave birth in D.C., then was taken off life support. Her case is why looking deeper than statistics



Among developed nations, the U.S. has the highest rate of women dying in childbirth and it continues to go up



NEWS PAYERS POLITICS & POLICY DRUG MANAGEMENT CURRENT ISSUE





Are we paying

Beyoncé, Serena Williams bring attention to risks of childbirth for black

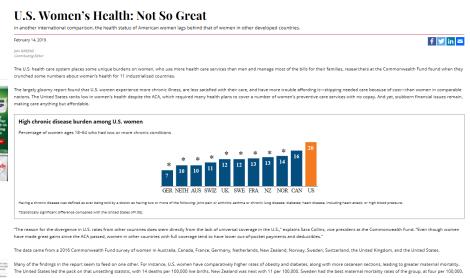
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says that even after all she has been through — the helicopters circlin





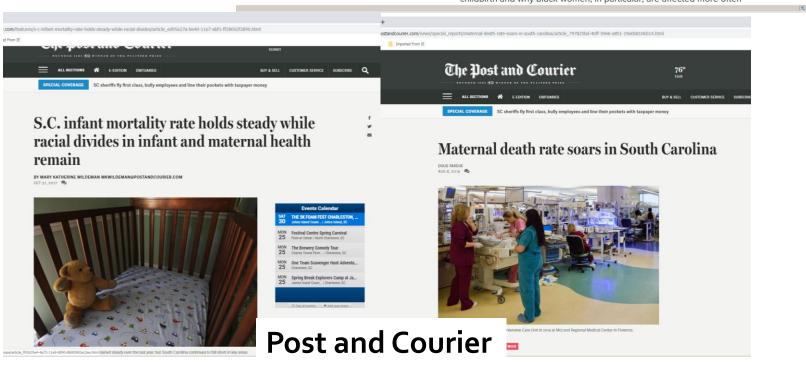


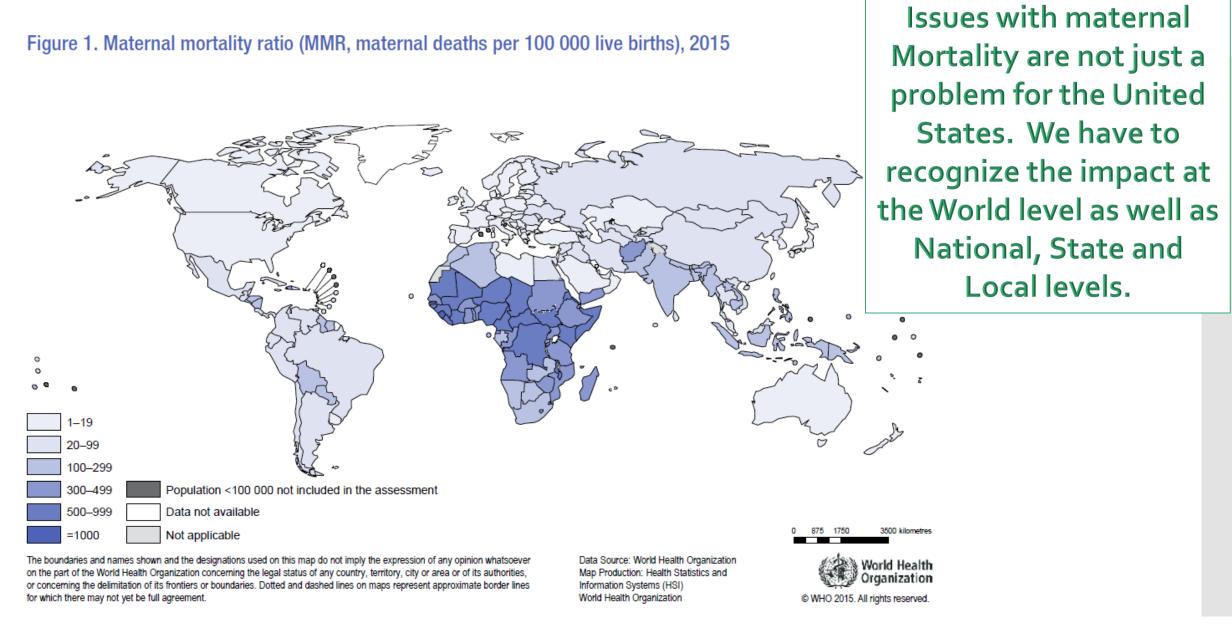
https://www.managedcaremag.com/archives/2019/2/us-women-s-health-not-sogreat

# Local Headlines – Maternal and Neonatal Mortality

- https://www.wltx.com/article/news/in vestigations/mothers-matter/southcarolina-ranks-8th-in-highest-deathrates-among-new-mothers/101-609147671
- https://www.postandcourier.com/fea tures/s-c-infant-mortality-rate-holdssteady-while-racialdivides/article\_ed95e27a-be40-11e7abf1-ff28002f2890.html
- https://www.postandcourier.com/infa nt-mortality-in-southcarolina/pdf\_393d8d28-be4a-11e7adcb-3784862941da.html







Trends in Maternal Mortality: 1990-2015 – Estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division - Executive Summary https://apps.who.int/iris/bitstream/handle/10665/193994/WHO\_RHR\_15.23\_eng.pdf;jsessionid=1AoCE15A1D4C2E1B71ACF44oF186B536?sequence=1

#### Who? What? When? Where? Why? And How?

- We know from the news recently that maternal mortality in the United States is high. With that knowledge, we also know that there is a racial disparity associated with maternal mortality.
- To begin to answer the questions of who, what, when, where and how pregnant women are dying related to their pregnancy we first need a defined way to capture and review women's cases.
- This leads us first to defining maternal deaths.....

## What is Maternal Mortality?

- World Health Organization (WHO) Definitions
  - Maternal Death: "death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes."
  - Pregnancy-Related Death: "death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the cause of death."
  - Late Maternal Death: "death of a woman from direct or indirect causes, more than 42 days, but less than 1 year, after termination of pregnancy."

# What is Maternal Mortality? Continued

- World Health Organization (WHO) Definitions continued
  - Maternal Mortality Ratio: "number of maternal deaths per 100,000 live births"
  - Maternal Mortality Rate: "ratio of maternal deaths to the woman-years of exposure for women aged 15–49 years."
    - Although maternal mortality is reported per 100,000 live births, it is a ratio rather than a rate because some of the deaths occur in women with nonviable pregnancies (e.g., ectopic pregnancies, miscarriages, terminations, stillbirths), which are not in the denominator of live births.
    - Because the proper denominator, the total number of pregnant women, is unknowable (there is no system for collecting early pregnancy losses), the countable number, live births, is used as an approximation, which leads to the correct term, a maternal mortality ratio.
    - Most investigators and public health agencies utilize maternal mortality ratios, and occasionally maternal mortality rates, when considering maternal deaths.

#### Are You Confused Yet?



Just wait, there's more...

# More breakdown in defining Maternal Mortality:

- Sometimes maternal deaths are subdivided into direct and indirect.
  - **Direct obstetric deaths** are those resulting from obstetric complications of the pregnant state
    - pregnancy, labor, and puerperium
    - consequence of interventions, omissions, or incorrect treatment or from a chain of events resulting from any of these.
  - Indirect obstetric deaths are those resulting from previous existing disease or disease that developed during pregnancy and that was not the result of direct obstetric causes, but was aggravated by the physiologic effects of pregnancy.
    - As the US maternal population has aged and developed more underlying conditions (e.g., morbid obesity), the number of indirect deaths has increased.
  - The distinction between direct and indirect is more useful for understanding causes than for clinical care.
  - Deaths of unknown cause are not classified as either direct or indirect.

### What Does This Tell Us?

As we begin thinking about Maternal Mortality, we need to think in a systematic way.

- We need to agree on terms defining maternal death and mortality related terms
- 2. We need consistent ways to measure or collect data about maternal deaths
- 3. We need to take time to determine why and when those deaths are occurring so that we can have an impact on preventing future maternal deaths.

### CDC Terms for Maternal Deaths

- The CDC has set up a process for reviewing maternal deaths
- The cases are reviewed and placed into a database to allow for better data collection and ultimately to be able to determine system processes or education at the provider or individual level to increase prevention steps.



https://www.cdc.gov/reproductivehealth/mat ernalinfanthealth/pregnancy-mortalitysurveillance-system.htm

#### Maternal Mortality Related Definitions -

#### There are a variety of terms connected with maternal mortality

- Maternal death: Used by World Health Organization death of a woman while pregnant or within 42 days of termination of pregnancy, regardless of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not for accidental or incidental causes.
- **Pregnancy-associated:** The death of a woman while pregnant or within one year of the termination of pregnancy, regardless of the cause.
- **Pregnancy-related:** The death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy
  - This is further defined as the death of a pregnant or postpartum woman was related to her pregnancy
  - In other words...if this woman was not pregnant, she would not have died.
- Pregnancy-associated, but NOT related: The death of a woman during pregnancy or within one year of the end of the pregnancy from a cause that is not related to pregnancy.
  - This is a woman died for a reason, but not related to the fact that she was pregnant.
- Unable to determine if pregnancy-related or pregnancy-associated, but NOT related
- Not pregnancy-related or associated (i.e., false positive, woman was not pregnancy within one year of her death)

#### Maternal Morbidity Definition

• "Severe maternal morbidity (SMM) includes unexpected outcomes of labor and delivery that result in significant short-or long-term consequences to a woman's health."

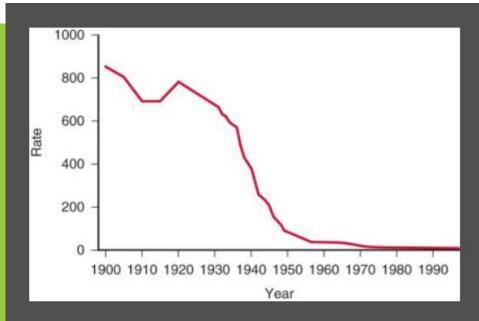
#### Indicators from the CDC:

- Acute myocardial infarction
- Aneurysm
- Acute renal failure
- Adult respiratory distress syndrome
- Amniotic fluid embolism
- Cardiac arrest/ventricular fibrillation
- Conversion of cardiac rhythm
- Disseminated intravascular coagulation
- Eclampsia
- Heart failure/arrest during surgery or procedure
- Puerperal cerebrovascular disorders
- Pulmonary edema / Acute heart failure

- Severe anesthesia complications
- Sepsis
- Shock
- Sickle cell disease with crisis
- Air and thrombotic embolism
- Blood transfusion
- Hysterectomy
- Temporary tracheostomy
- Ventilation

We will not focus on this topic today, but it is important to understand maternal morbidity has a very large impact on overall maternal outcomes and health.

#### What Do We Know?





#### **IMAGE**

#### **Maternal Mortality**

Creasy and Resnik's Maternal-Fetal Medicine: Principles and Practice.

Metz, Torri, MD, MS; Silver, Robert M., MD. Published December 31, 2018. Pages 852-861.e2. © 2019.

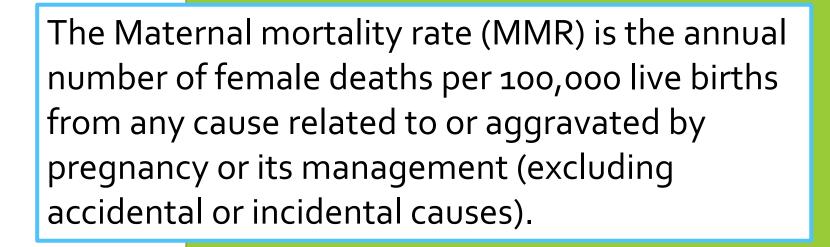
Figure 50.1

US maternal mortality rate, 1900-1997.

Rate is the number of deaths per 100,000 live births.

- Maternal deaths in the United States have decrease over the last century
  - Rates went from an estimated 900 per 100,000 births in 1901 to 9 per 100,000 in 1991
- Why?
  - Success for both public health programs and obstetrics providers
  - Multiple factors:
    - the movement of most births to hospitals
    - improved hygiene and aseptic technique
    - common use of prenatal care, including screening for preeclampsia
    - the introduction of blood transfusions and antibiotics
    - widespread availability of obstetric anesthesia
    - an increase in training and expertise of obstetrics providers
    - improvement in the overall health of the population
- This leads us to the next questions
  - "Are we happy with the amount of improvement that occurred from 1901 1990's?
  - Are we done with the work?

| 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 | 1996 |



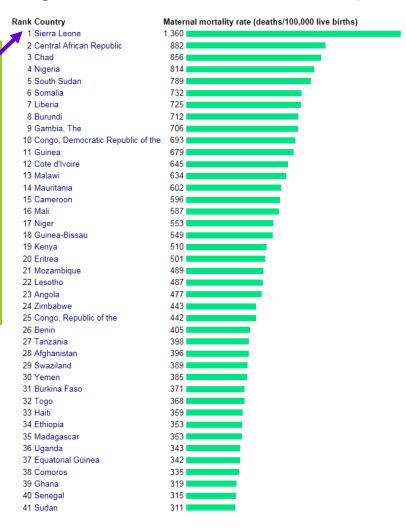
2018 - US is # 137 from the highest maternal mortality rates with 14 per 100,000.

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#### Are we the worst?

No, Sierra Leone's rate 1,360 deaths per 100,000 births

#### Highest rates of maternal mortality



#### But look at the best!

Finland, Greece, Iceland & Poland each with a rate of 3/100,000

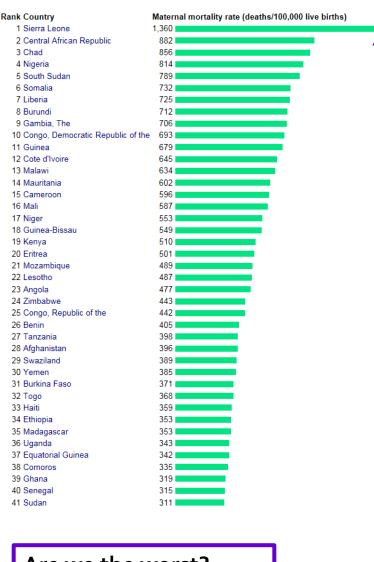
#### Lowest rates of maternal mortality

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	135 Bahrain	15
	136 Puerto Rico	14
	137 United States	14
	138 Qatar	13 I
	139 Saudi Arabia	12
	140 Kazakhstan	12
	141 Korea, South	11 [
	142 New Zealand	11 [
	143 Bosnia and Herzegovina	11
	144 Bulgaria	11 [
	145 Portugal	10
	146 Lithuania	10
	147 Luxembourg	10
	148 Singapore	10
	149 Slovenia	91
	150 United Kingdom	91
	151 Libya	91
	152 Malta	91
	153 Estonia	91
	154 Ireland	81
	155 France	81
	156 Croatia	81
	157 Macedonia	81
	158 Netherlands	71
	159 Montenegro	71
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https://www.indexmundi.com/g/r.aspx?v=2223 Source: CIA World Factbook - January 1, 2018



#### Highest rates of maternal mortality



#### Are we the worst?

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#### Lowest rates of maternal mortality

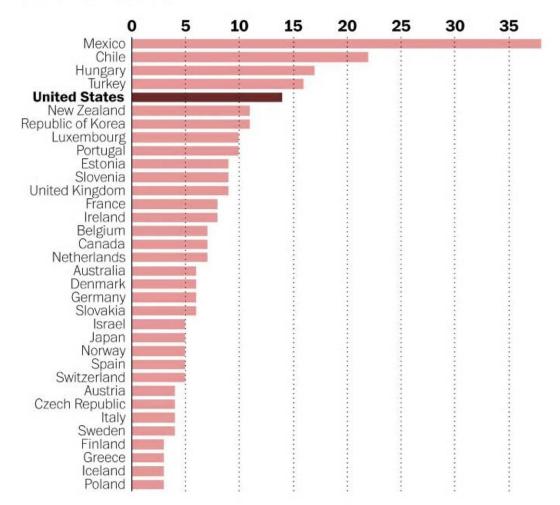


https://www.indexmundi.com/g/r.aspx?v=2223

Source: CIA World Factbook - January 1, 2018

#### U.S. lags behind other rich nations on maternal mortality

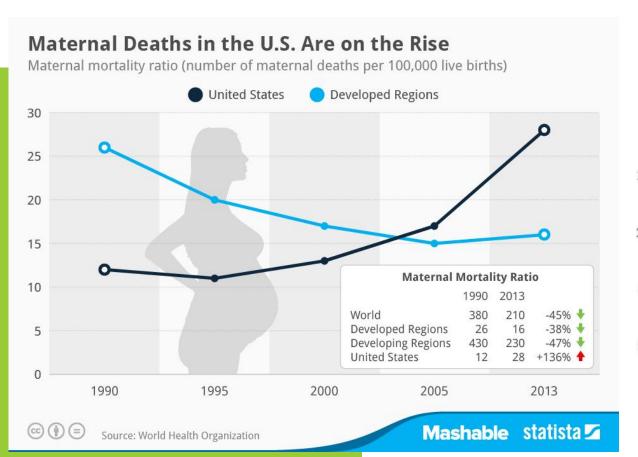
Maternal deaths due to pregnancy or labor complications per 100,000 live births, OECD countries

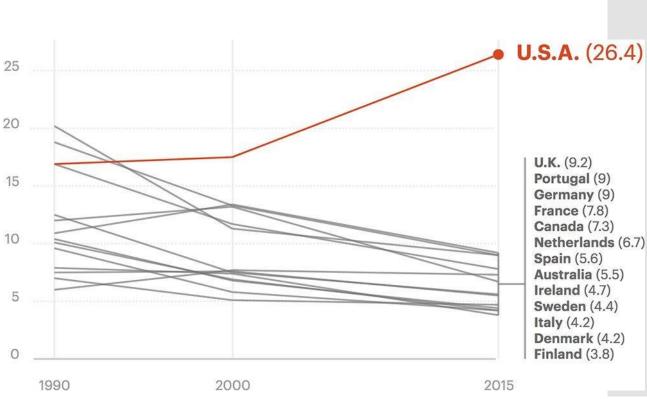


#### Quote from Washington Post article 11/18/2015

• "In the U.S., 14 out of every 100,000 mothers died due to complications of pregnancy or childbirth. That puts it between Qatar (13 deaths) and Bahrain (15) in the ranking of all 184 countries for which the WHO has data. The United States is ranked 46 out of those 184 countries, barely in the top 25 percent. By contrast, in Canada only 7 out of 100,000 mothers died in pregnancy or childbirth. American women are over four times as likely to die in pregnancy or childbirth as women in Greece, Iceland or Poland, where the rate is 3 out of every 100,000...

• ...We're one of the world's wealthiest countries, and we spend way more on healthcare than other rich nations. So how did we end up here?"



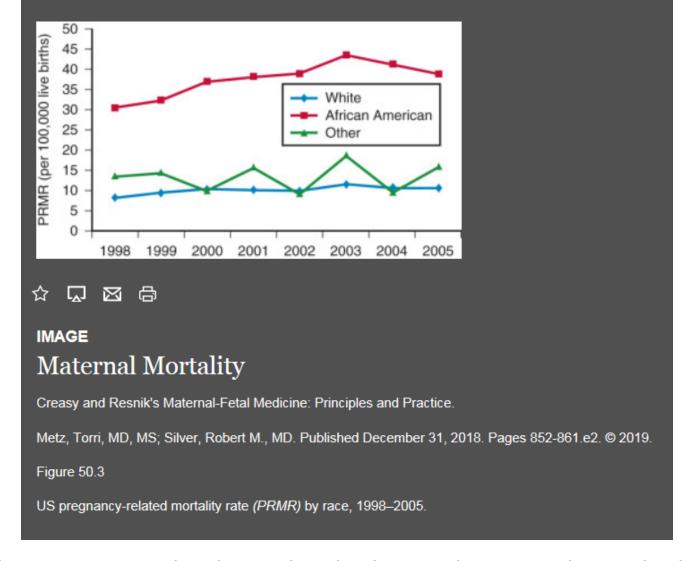


#### **Notes**

"Global, regional, and national levels of maternal mortality, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015," The Lancet. Only data for 1990, 2000 and 2015 was made available in the journal.

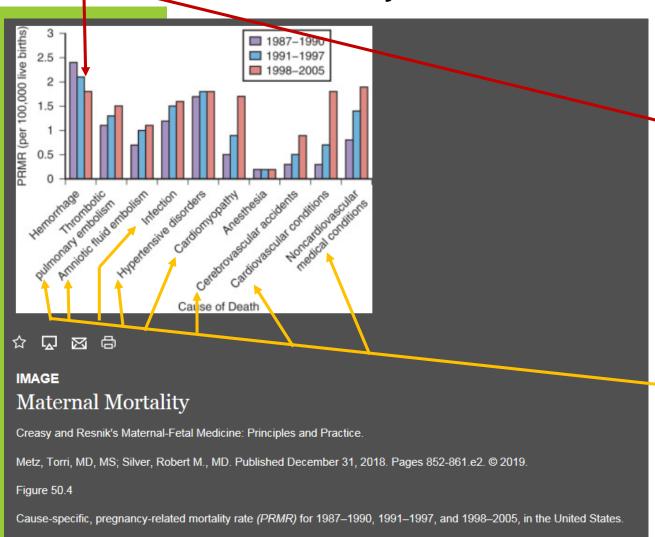
Source: The Lancet Credit: Rob Weychert/ProPublica

## A Little More from the Data Perspective



- When we compare maternal deaths by ethnicity, we immediately visualize the disparity between White and Other versus African American.
  - This is not acceptable to have one ethnic group have a 3 times higher rate of mortality related to pregnancy.
- This should lead us to consider two questions:
  - 1. Why are women dying in pregnancy? 2. Why is there a disparity among ethnicity?

This bar graph highlights the changes that have occurred over the last several years in reasons women are dying related to pregnancy.



Let's compare Hemorrhage There is a steady decrease

However, comparing thrombotic pulmonary embolism, AFE, Infection, Cardiomyopathy, CVA, Cardiovascular conditions and non-cardiovascular medical conditions, these are all steadily increasing!

#### Thus far we KNOW:

- 1. Women are dying related to pregnancy.
- 2. There is a change in why women are dying.(decreasing rates of hemorrhage, increasing rates of cardiovascular complications)
- 3. There is a very large disparity related toAfrican-American women

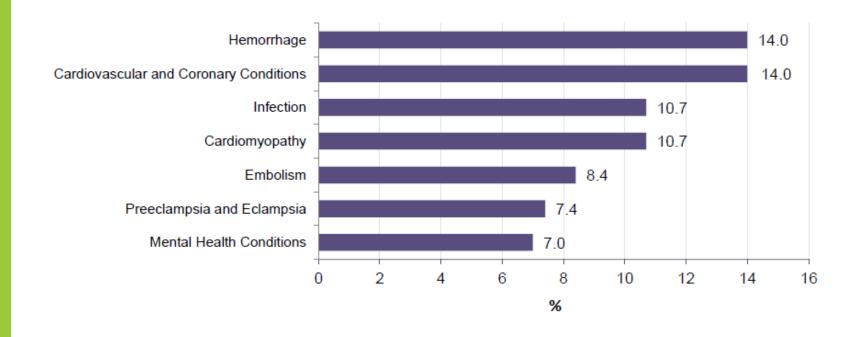


How can we understand better the WHY and WHEN associated with maternal mortality? Who needs to have the conversation?

# Why are women dying in pregnancy and postpartum?

• Let's look again at the overall cause of maternal deaths:

Figure 4. Leading Underlying Causes of Pregnancy-Related Deaths\*



<sup>\*</sup> Amniotic fluid embolism is not included in the embolism grouping due to differences in etiology and opportunities for prevention.

• BUT...This question has to be further broken down into the three different time periods associated with pregnancy.

<sup>&</sup>lt;sup>†</sup> The underlying cause of death, as defined by the World Health Organization (WHO), is "disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury."

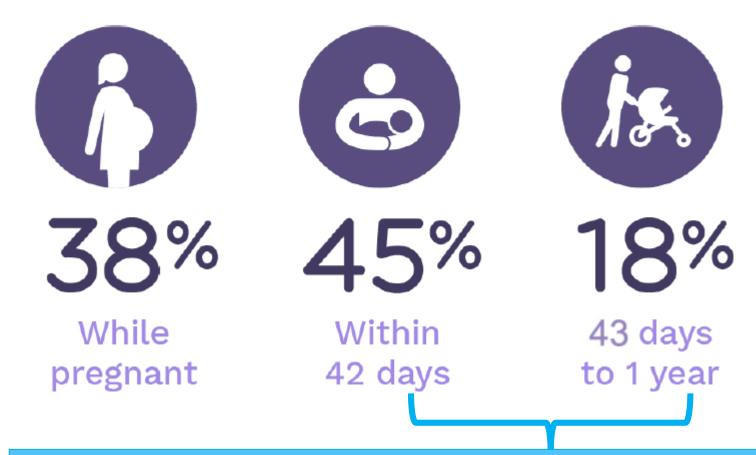
#### Step – by – Step

#### Reviewing Maternal Mortality

- The next step in reviewing maternal mortality is to look at when pregnant or postpartum women are dying.
- There are three categories:
  - 1. During Pregnancy
  - 2. Within 42 days Postpartum
  - 3. 43 days to 1 year Postpartum
- The next set of data comes from the CDC's pregnancy surveillance system and "Report from Nine Maternal Mortality Review Committees"
  - In order to gather the best evidence and data surrounding maternal deaths, it has been suggested that states have a team to collect or abstract de-identified data about each maternal death, then a maternal mortality review committee will review each case to determine the pregnancy relatedness that was discussed in the definitions.

When are our moms dying?

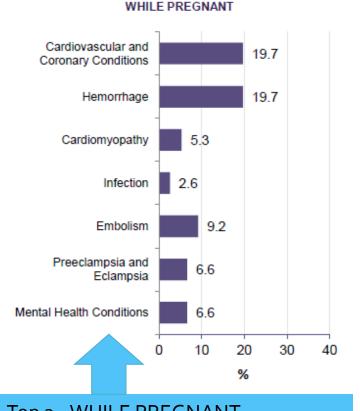
**Figure 1.** Distribution of Pregnancy-Related Deaths by Timing of Death in Relation to Pregnancy



- 63% of Maternal deaths occur in the postpartum time period!
- This data shows us the importance of the postpartum time period and the associated risk of death related to the pregnancy.

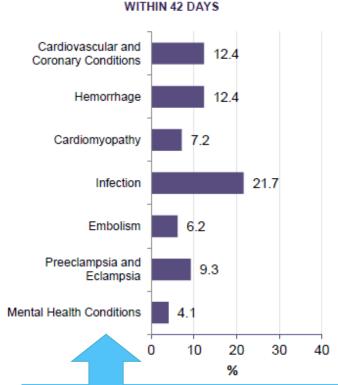
 When we break down the timing of the death in relation to pregnancy we can begin to see more clearly components of why women are dying and then we can begin to address issues to prevention

Figure 7. Leading Underlying Causes of Pregnancy-Related Deaths, by Timing of Death in Relation to Pregnancy



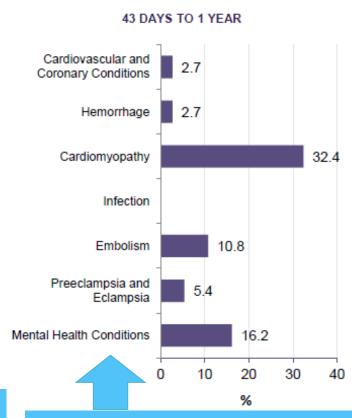
#### Top 2 - WHILE PREGNANT:

 Tied: Cardiovascular and Coronary Conditions & Hemorrhage



Top 2 - WITHIN 42 DAYS POSTPARTUM:

- Infection
- Tied: Cardiovascular and Coronary Conditions & Hemorrhage



#### Top 2 - 42 DAYS – 1YEAR POSTPARTUM:

- 1. Cardiomyopathy
- 2. Mental Health Conditions

Within the overall assessment of when the deaths are occurring, Race-Ethnicity and Maternal Age demographics needs to be considered.

Figure 2. Proportion of Pregnancy-Associated Deaths Determined to be Pregnancy-Related, by Race-Ethnicity

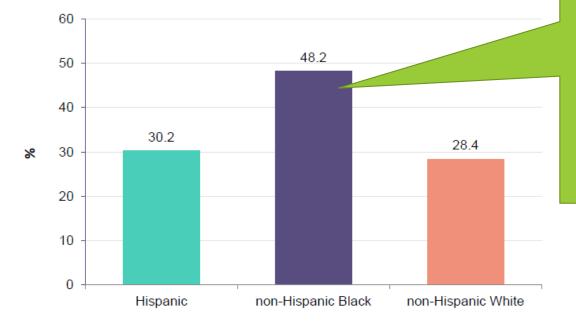
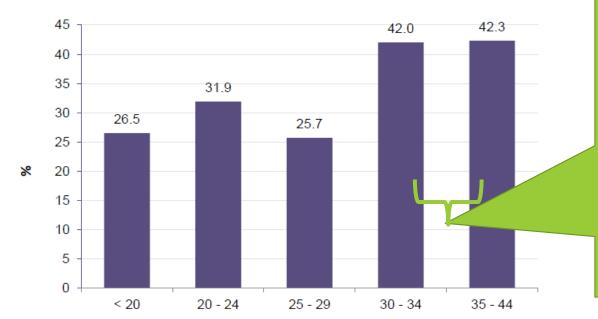


Figure 3. Proportion of Pregnancy-Associated Deaths Determined to be Pregnancy-Related, by Age at Death

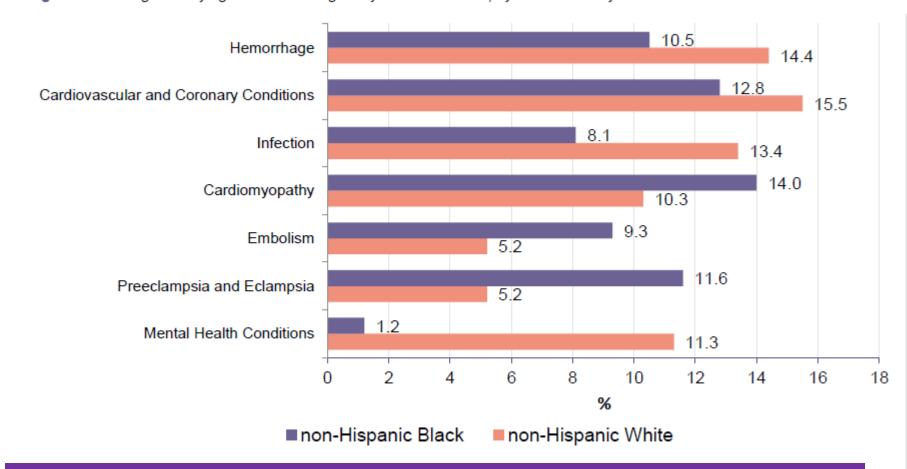


Non-Hispanic Black women are dying at 18% higher rate than Hispanic women and nearly 20% higher ate than non-Hispanic White women

Clearly, pregnant /
postpartum
women over the
age of 30 are at a
higher rate of
dying than women
under the age of
30.

How do we compare in overall cause of pregnancy-related deaths by Race?

Figure 5. Leading Underlying Causes of Pregnancy-Related Deaths, by Race-Ethnicity



Non-Hispanic Black women leading causes of death are: Cardiomyopathy, Cardiovascular & Coronary Conditions, and Preeclampsia/Eclampsia

Non-Hispanic White women leading causes of death are: Cardiovascular & Coronary conditions, Hemorrhage & Infection

# What does this mean to YOU & to ME as Perinatal Nurses?

We take all of the data presented and need to begin to think about how we associate maternal deaths in our daily work and how do we make an impact on these rates.

Things to think about moving forward:

- 1) Do I understand **when** women are dying related to pregnancy and childbirth?
- 2) Do I understand why women are dying related to pregnancy and childbirth?
- 3) Is there a way to prevent maternal deaths?
- 4) How do we address the disparities associated with maternal deaths?

#### Reviewing Maternal Deaths to Gather Data

- Currently the CDC has a system to capture information gained from Maternal Mortality Review Committees in the US to review each maternal death and determine:
  - Was the death pregnancy-related?
  - How complete was the medical record information associated with the maternal death?
  - What was the cause of death
    - Further assessed by Immediate/Contributing/Underlying/Other significant factors
  - Then assess the relatedness of obesity, mental health, substance use, suicide/homicide.
  - Preventability:
    - This is defined by the CDC for Maternal Mortality Review Boards as "A
      death is considered preventable if the committee determines that there
      was at least some chance of the death as being averted by one or more
      reasonable changes to the patient, community, provider, facility, and/or
      systems factors
    - Then preventability is further determined
      - 1. Decide Yes or No the death was preventable
      - 2. Determine the chance to alter outcomes with the following scale: No chance, Some chance, or Good Chance

### Categories of preventability

- In order to determine preventability, the Maternal Review Committees must first determine was the Death Related to the Pregnancy as discussed previously.
- Then the causation of death is looked at

MMRIA		MATER	RNAL MORTALITY REVIEW COMMITTEE DECISIONS FORM 1		
REVIEW DATE	RECORD ID #	COMMITTEE DETER	MINATION OF CAUSE(S) OF DEATH		
		ТҮРЕ	CAUSE (DESCRIPTIVE)		
PREGNANCY-RELATEDNESS:	SELECT ONE	IMMEDIATE			
	PREGNANCY-RELATED  The death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy  PREGNANCY-ASSOCIATED, BUT NOT -RELATED  The death of a woman during pregnancy or within one year of the end of pregnancy from a cause that is not related to pregnancy				
end of pregnancy from					
by the physiologic effec					
The death of a woman of			IF PREGNANCY-RELATED, COMMITTEE DETERMINATION OF UNDERLYING CAUSE OF DEATH		
	INE IF PREGNANCY-RELATED OR ATED, BUT NOT -RELATED		ause of death list. If more than one is selected, list in order of most compelling (1-2; no more than 2 may be selected in the system).		
■ NOT PREGNANCY-RELATED OR -ASSOCIATED (i.e. false positive, woman was not pregnant within one year of her death)					
		DID OBESITY CONTRIBUTE TO			
ESTIMATE THE DEGREE OF RELEVANT INFORMATION (RECORDS)		DID MENTAL HEALTH CONDI CONTRIBUTE TO THE DEATH?	TYES PROBABLY NO UNKNOWN		
AVAILABLE FOR THIS CASE:		DID SUBSTANCE USE DISOR CONTRIBUTE TO THE DEATH?			
COMPLETE All records necessary for adequate review of the case were available  SOMEWHAT COMPLETE Major gaps (i.e. information that would have been crucial to the review of the case)	_	WAS THIS DEATH A SUICIDE?	☐ YES ☐ PROBABLY ☐ NO ☐ UNKNOWN		
	WAS THIS DEATH A HOMICID	e?			
MOSTLY COMPLETE Minor gaps (i.e. informat that would have been beneficial but was not essential to the review of the case)	review (i.e. death certificate and no additional records)	IF HOMICIDE, SUICIDE, OR ACCIDENTAL DEATH, LIST THE MEANS OF FATAL INJURY	FIREARM		
DOES THE COMMITTEE AGR UNDERLYING CAUSE OF DEA ON DEATH CERTIFICATE?		IF HOMICIDE, WHAT WAS THE RELATIONSHIP OF THE PERPETRATOR TO THE DECEDENT?	□ NO RELATIONSHIP     □ OTHER     □ UNKNOWN       □ PARTNER     □ ACQUAINTANCE     □ NOT APPLICABLE       □ EX-PARTNER     □ OTHER, SPECIFY:       □ OTHER RELATIVE		

■ 92.1 Epilepsy/seizure disorder



#### IF PREGNANCY-RELATED, COMMITTEE DETERMINATION OF UNDERLYING CAUSE OF DEATH\* PMSS-MM

If more than one is selected, please list them in order of importance beginning with the most compelling (1-2; no more than 2 may be selected in the system).

\*PREGNANCY-RELATED DEATH: THE DEATH OF A WOMAN DURING PREGNANCY OR WITHIN ONE YEAR OF THE END OF PREGNANCY FROM A PREGNANCY COMPLICATION, A CHAIN OF EVENTS INITIATED BY PREGNANCY, OR THE AGGRAVATION OF AN UNRELATED CONDITION BY THE PHYSIOLOGIC EFFECTS OF PREGNANCY.

10	Hemorrhage (excludes aneurysms or CVA)	83	Collagen vascular/autoimmune diseases
10.1	Hemorrhage – rupture/laceration/	83.1	Systemic lupus erythematosis (SLE)
	intra-abdominal bleeding	83.9	Other collagen vascular diseases/NOS
10.2	Placental abruption	85	Conditions unique to pregnancy (e.g.
10.3	Placenta previa		gestational diabetes, hyperemesis, liver
10.4	Ruptured ectopic pregnancy		disease of pregnancy)
10.5	Hemorrhage - uterine atony/postpartum	88	Injury
	hemorrhage	88.1	Intentional (homicide)
10.6	Placenta accreta/increta/percreta	88.2	Unintentional
10.7	Hemorrhage due to retained placenta	88.9	Unknown/NOS
10.8	Hemorrhage due to primary DIC	89	Cancer
10.9	Other hemorrhage/NOS	89.1	Gestational trophoblastic disease (GTD)
20	Infection	89.3	Malignant melanoma
20.1	Postpartum genital tract (e.g. of the uterus/	89.9	Other malignancies/NOS
	pelvis/perineum/necrotizing fasciitis)	90	Cardiovascular conditions
20.2	Sepsis/septic shock	90.1	Coronary artery disease/myocardial
20.4	Chorioamnionitis/antepartum infection		infarction (MI)/atherosclerotic
20.5	Non-pelvic infections (e.g. pneumonia, TB,		cardiovascular disease
	meningitis, HIV)	90.2	Pulmonary hypertension
20.6	Urinary tract infection	90.3	Valvular heart disease congenital and
20.9	Other infections/NOS		acquired
30	Embolism - thrombotic (non-cerebral)	90.4	Vascular aneurysm/dissection (non-cerebral)
30.9	Other embolism/NOS	90.5	Hypertensive cardiovascular disease
31	Embolism - amniotic fluid	90.6	Marfan Syndrome
40	Preeclampsia	90.7	Conduction defects/arrhythmias
50	Eclampsia	90.8	Vascular malformations outside head and
60	Chronic hypertension with superimposed		coronary arteries
	preeclampsia	90.9	Other cardiovascular disease, including CHF,
70	Anesthesia complications		cardiomegaly, cardiac hypertrophy, cardiac
80	Cardiomyopathy		fibrosis, non-acute myocarditis/NOS
80.1	Postpartum/peripartum cardiomyopathy	91	Pulmonary conditions (excludes ARDS-Adult
80.2	Hypertrophic cardiomyopathy		respiratory distress syndrome)
80.9	Other cardiomyopathy/NOS	91.1	Chronic lung disease
82	Hematologic	91.2	Cystic fibrosis
82.1	Sickle cell anemia	91.3	Asthma
82.9	Other hematologic conditions including	91.9	Other pulmonary disease/NOS
	thrombophilias/TTP/HUS/NOS	92	Neurologic/neurovascular conditions
			(excluding CVAs)

92.9	Other neurologic diseases/NOS
93	Renal disease
93.1	Chronic renal failure/End-stage renal
	disease (ESRD)
93.9	Other renal disease/NOS
95	Cerebrovascular accident (hemorrhage/
	thrombosis/aneurysm/ malformation)
	not secondary to hypertensive disease
96	Metabolic/endocrine
96.1	Obesity
96.2	Diabetes mellitus
96.9	Other metabolic/endocrine disorders
97	Gastrointestinal disorders
97.1	Crohn's disease/ulcerative colitis
97.2	Liver disease/failure/transplant
97.9	Other gastrointestinal diseases/NOS
100	Mental health conditions
100.1	Depression
100.9	Other psychiatric conditions/NOS
999	Unknown COD

Once the death is determined to be pregnancy-related, the review committee selects the underlying cause of death

# Other Contributing Factors?

• Then the review board determines if the following conditions contribute to the death

**Figure 15.** Committee Decisions Form, Select Questions and Checkboxes Related to Mental Health Conditions, Substance Use Disorder, Suicide, and Homicide.

DID OBESITY CONTRIBUTE TO	THE DEATH?	☐ YES	☐ PROBABLY	□ NO	□ UNKNOWN
DID MENTAL HEALTH CONDIT CONTRIBUTE TO THE DEATH?	TIONS	☐ YES	☐ PROBABLY	□ NO	□ UNKNOWN
DID SUBSTANCE USE DISORE CONTRIBUTE TO THE DEATH?	DER	☐ YES	☐ PROBABLY	□ NO	□ UNKNOWN
WAS THIS DEATH A SUICIDE?		☐ YES	☐ PROBABLY	□ NO	□ UNKNOWN
WAS THIS DEATH A HOMICIDE	E?	☐ YES	☐ PROBABLY	□ NO	□ UNKNOWN
IF HOMICIDE, SUICIDE, OR ACCIDENTAL DEATH, LIST THE MEANS OF FATAL INJURY	☐ FIREARM ☐ SHARP INST ☐ BLUNT INST ☐ POISONING/ OVERDOSE ☐ HANGING/ STRANGULA SUFFOCATIO	RUMENT /	KICKING/BEATING EXPLOSIVE DROWNING	OT UN	TENTIONAL GLECT HER, SPECIFY: KNOWN T APPLICABLE
IF HOMICIDE, WHAT WAS THE RELATIONSHIP OF THE PERPETRATOR TO THE DECEDENT?	□ NO RELATIO □ PARTNER □ EX-PARTNER □ OTHER RELA	R 🗆	OTHER ACQUAINTANCE OTHER, SPECIFY:	_	KNOWN T APPLICABLE

## Reviewing Maternal Deaths

- The review board also considers if the available records that were used to review the case were complete.
  - Meaning, was there access to a medical record to give enough information to review the case?



# The BIG Question: Could the Maternal Death have been prevented?

Was there a chance that the death could have been avoided? • After reviewing the case carefully, the review board looks to determine preventability, contributing factors and recommendations.

MMRIA				MATERNAL	MORTALI	TY REVIEW COMMIT	TEE DECISIO	ONS FORM 2					
COMMITTEE D	ETERMINATION C	F PREVENTABIL	ITY	WAS THIS DEATH PREVENTABLE?		☐ YES	□NO						
at least some chance	d preventable if the com e of the death being aver amily, provider, facility, sy	ted by one or more reas	sonable	CHANCE TO ALTER OUTCOME?		☐ GOOD CHANCE ☐ NO CHANCE	☐ SOME CHANCE ☐ UNABLE TO DETERMIN						
CONTRIBUTING	G FACTORS WOR	KSHEET	RECOM	RECOMMENDATIONS OF THE COMMITTEE									
				If there was at least some chance that the death could have been averted, what were the specific and feasible actions that, if implemented or altered, might have changed the course of events?									
CONTRIBUTING FACTOR LEVEL	CONTRIBUTING FACTO OF ISSUE	R AND DESCRIPTION	RECOMME	ENDATIONS OF THE COMM	ITTEE	LEVEL OF (SEE BELO	PREVENTION W)	LEVEL OF IMPACT (SEE BELOW)					
PATIENT/FAMILY													
PROVIDER													
FACILITY													
SYSTEM													
COMMUNITY													
CONTRIBUTING FAC	CTOR KEY (DESCRIPTION	PREVENT	TION LEVEL EXPECTED IMPACT LEVEL										
Delay     Adherence     Knowledge     Cultural/religious     Environmental     Violence     Mental health conditions     Substance use disorder - alcohol, illicit/prescription drugs	Tobacco use     Chronic disease     Childhood abuse/ trauma     Access/financial     Unstable housing     Social support/ isolation     Equipment/ technology     Policies/procedures     Communication	Continuity of care/ care coordination Clinical skill/ quality of care Outreach Enforcement Referral Assessment Legal Other	factor bef • SECOND of the cor occurred • TERTIAR progressic factor one	f: Prevents the contributing ore it ever occurs ARY: Reduces the impact stributing factor once it has (i.e. treatment) Y: Reduces the impact or on of an ongoing contributing se it has occurred (i.e. ent of complications)	promotion • MEDIUM: of well-wo • LARGE: L recognition • EXTRA LA healthy livi	iducation/counseling (com and education activities) Clinical Intervention and c man visits through obstetr ong-lasting protective inte and response to obstetri RGE: Change in context ing/ensure available and ac ddress social determinants	coordination of o ics (protocols, protocols, protocols), impro- comergencies/li promote environcessible service	care across continuum prescriptions) ve readiness, _ARC) nenents that support					



#### CONTRIBUTING FACTOR DESCRIPTIONS

#### DELAY OR FAILURE TO SEEK CARE

The woman was delayed in seeking or did not access care, treatment, or follow-up care/actions (e.g. missed appointment and did not reschedule).

#### ADHERENCE TO MEDICAL RECOMMENDATIONS

The woman did not accept medical advice (e.g. refused treatment for religious or other reasons or left the hospital against medical advice).

### KNOWLEDGE - LACK OF KNOWLEDGE REGARDING IMPORTANCE OF EVENT OR OF TREATMENT OR FOLLOW-UP

The woman did not receive adequate education or lacked knowledge or understanding regarding the significance of a health event (e.g. shortness of breath as a trigger to seek immediate care) or lacked understanding about the need for treatment/follow-up after evaluation for a health event (e.g. needed to keep appointment for psychiatric referral after an ED visit for exacerbation of depression).

#### CULTURAL/RELIGIOUS, OR LANGUAGE FACTORS

Demonstration that any of these factors was either a barrier to care due to lack of understanding or led to refusal of therapy due to beliefs (or belief systems).

#### ENVIRONMENTAL FACTORS

Factors related to weather or terrain (e.g. the advent of a sudden storm leads to a motor vehicle accident).

#### VIOLENCE AND INTIMATE PARTNER VIOLENCE (IPV)

Physical or emotional abuse other than that perpetrated by intimate partner (e.g. family member or stranger); IPV: Physical or emotional abuse perpetrated by the woman's current or former intimate partner.

#### MENTAL HEALTH CONDITIONS

The woman carried a diagnosis of a psychiatric disorder. This includes postpartum depression.

#### SUBSTANCE USE DISORDER - ALCOHOL, ILLICIT/ PRESCRIPTION DRUGS

Substance use disorder is characterized by recurrent use of alcohol and/or drugs causing clinically and functionally significant impairment, such as health problems or disability. The committee may determine that substance use disorder contributed to the death when the disorder directly compromised a woman's health status (e.g. acute methamphetamine intoxication exacerbated pregnancy-induced

hypertension, or woman was more vulnerable to infections or medical conditions).

#### TOBACCO USE

Woman's use of tobacco directly compromised the woman's health status (e.g. long-term smoking led to underlying chronic lung disease).

#### CHRONIC DISEASE

Occurrence of one or more significant pre-existing medical conditions (e.g. obesity, cardiovascular disease, or diabetes).

#### CHILDHOOD SEXUAL ABUSE/TRAUMA

Woman experienced rape, molestation, or other sexual exploitation during childhood plus persuasion, inducement, or coercion of a child to engage in sexually explicit conduct; or woman experienced physical or emotional abuse or violence other than that related to sexual abuse during childhood.

#### LACK OF ACCESS/FINANCIAL RESOURCES

System issues, e.g. lack or loss of healthcare insurance or other financial duress, as opposed to woman's noncompliance impacted woman's ability to care for herself (e.g. did not seek services because unable to miss work or afford postpartum visits after insurance expired). Other barriers to accessing care: insurance non-eligibility, provider shortage in woman's geographical area, and lack of public transportation.

#### UNSTABLE HOUSING

Woman lived "on the street" or in a homeless shelter or lived in transitional or temporary circumstances with family or friends.

#### SOCIAL SUPPORT/ISOLATION - LACK OF FAMILY/ FRIEND SUPPORT SYSTEM

Social support from family, partner, or friends was lacking, inadequate, and/or dysfunctional (e.g. domestic violence, no one to rely on to ensure appointments were kept).

#### INADEQUATE OR UNAVAILABLE EQUIPMENT/ TECHNOLOGY

Equipment was missing, unavailable, or not functional, (e.g. absence of blood tubing connector).

#### LACK OF STANDARDIZED POLICIES/PROCEDURES

The facility lacked basic policies or infrastructure germane to the woman's needs (e.g. response to high blood pressure or a lack of or outdated policy or protocol).

#### POOR COMMUNICATION/LACK OF CASE COORDINATION OR MANAGEMENT/ LACK OF CONTINUITY OF CARE (SYSTEM PERSPECTIVE)

Care was fragmented (i.e. uncoordinated or not comprehensive) among or between healthcare facilities or units, (e.g. records not available between inpatient and outpatient or among units within the hospital, such as Emergency Department and Labor and Delivery).

#### LACK OF CONTINUITY OF CARE

Care providers did not have access to woman's complete records or did not communicate woman's status sufficiently. Lack of continuity can be between prenatal, labor and delivery, and postpartum providers.

#### CLINICAL SKILL/QUALITY OF CARE

Personnel were not appropriately skilled for the situation or did not exercise clinical judgment consistent with current standards of care (e.g. error in the preparation or administration of medication or unavailability of translation services).

#### INADEQUATE COMMUNITY OUTREACH/RESOURCES

Lack of coordination between healthcare system and other outside agencies/organizations in the geographic/cultural area that work with maternal child health issues.

#### INADEQUATE LAW ENFORCEMENT RESPONSE

Law enforcement response was not in a timely manner or was not appropriate or thorough in scope.

#### LACK OF REFERRAL OR CONSULTATION

Specialists were not consulted or did not provide care; referrals to specialists were not made.

#### FAILURE TO SCREEN/INADEQUATE ASSESSMENT OF

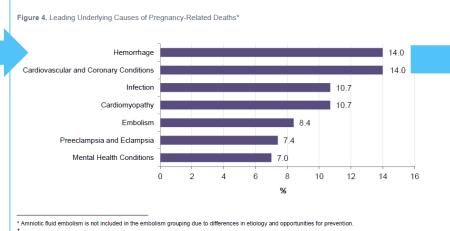
Factors placing the woman at risk for a poor clinical outcome recognized, and the woman was not transferred/transported to a provider able to give a higher level of care.

#### LEGAL

Legal considerations that impacted outcome.

Recall the leading underlying causes of pregnancy related deaths...

## Preventability



<sup>†</sup> The underlying cause of death, as defined by the World Health Organization (WHO), is "disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury."

When the Question of Preventability is considered, Maternal Mortality review committees found the following data:











#### CARDIOVASCULAR AND CORONARY CONDITIONS







#### HEMORRHAGE

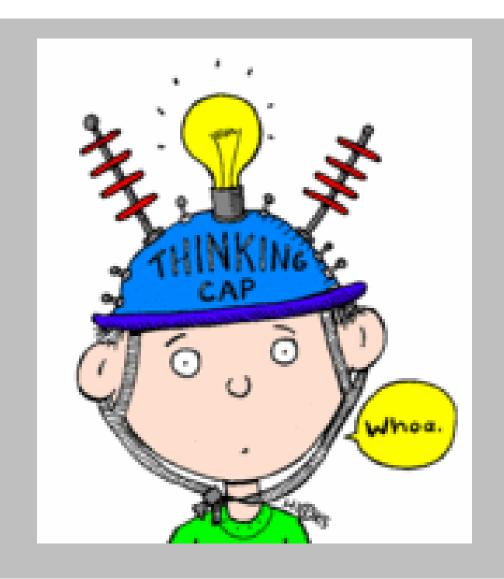






Now you have a better understanding of the depth of the problem...

What is Next?



# Getting the information out to everyone

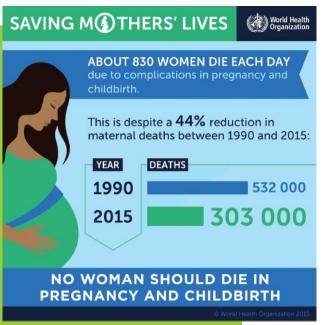
# Everyone needs to begin to see this as an problem and look at the prevention steps.

- The following slides are from the World Health Organization (WHO).
- They highlight through infographics the significance of maternal mortality at a global level.

# World Health Organization Maternal Mortality Facts:

- Every day, approximately 830 women die from preventable causes related to pregnancy and childbirth.
- 99% of all maternal deaths occur in developing countries.
- Maternal mortality is higher in women living in rural areas and among poorer communities.
- Young adolescents face a higher risk of complications and death as a result of pregnancy than other women.
- Skilled care before, during and after childbirth can save the lives of women and newborn babies.
- Between 1990 and 2015, maternal mortality worldwide dropped by about 44%.
- Between 2016 and 2030, as part of the Sustainable Development Goals, the target is to reduce the global maternal mortality ratio to less than 70 per 100 000 live births.

### WHO: Preventing Maternal Death Infographics

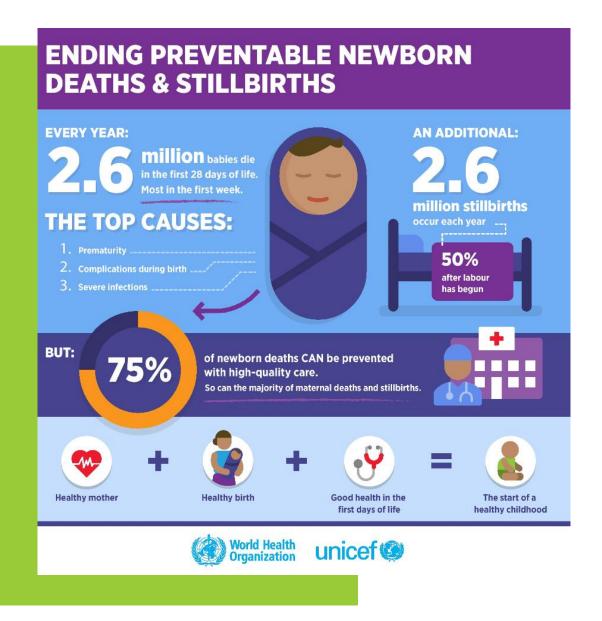




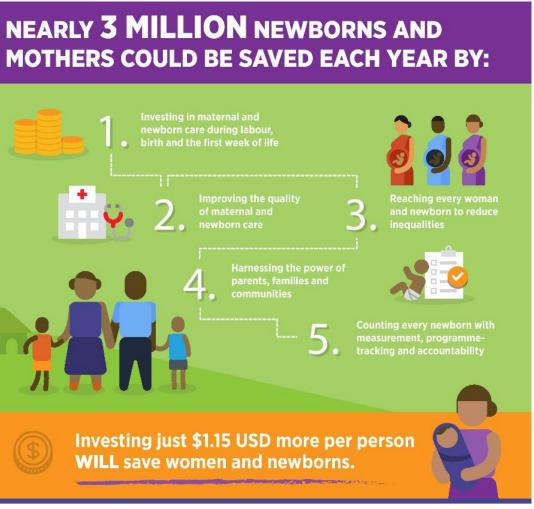








# Maternal – Child Infographics WHO







# Better Data to Save Mothers' and Babies' Lives The day of birth can be a dangerous time for mothers and babies. Every year: 303 000 mothers die during childbirth 2.7 million babies die during the first 28 days of life

2.6 million

These are only estimates.

They do not tell the whole story

stillbirths occur

Better Data to Save Mothers' and Babies' Lives



~60% of countries lack adequate systems for counting births and deaths



Many deaths are unreported



Most death reviews focus on medical causes and overlook solutions

Better Data to Save Mothers' and Babies' Lives

The majority of maternal deaths and stillbirths, and 75% of newborn deaths, are preventable.

In order to **prevent future deaths, WHO** is helping countries to:

Maternal – Child Infographics

**WHO** 



Produce a birth and death certificate for everyone, including stillbirths



Form death review committees



Create policies to repor and review all deaths

#### For more information check out:

https://www.who.int/news-room/fact-sheets/detail/maternal-mortality

World Health Organization





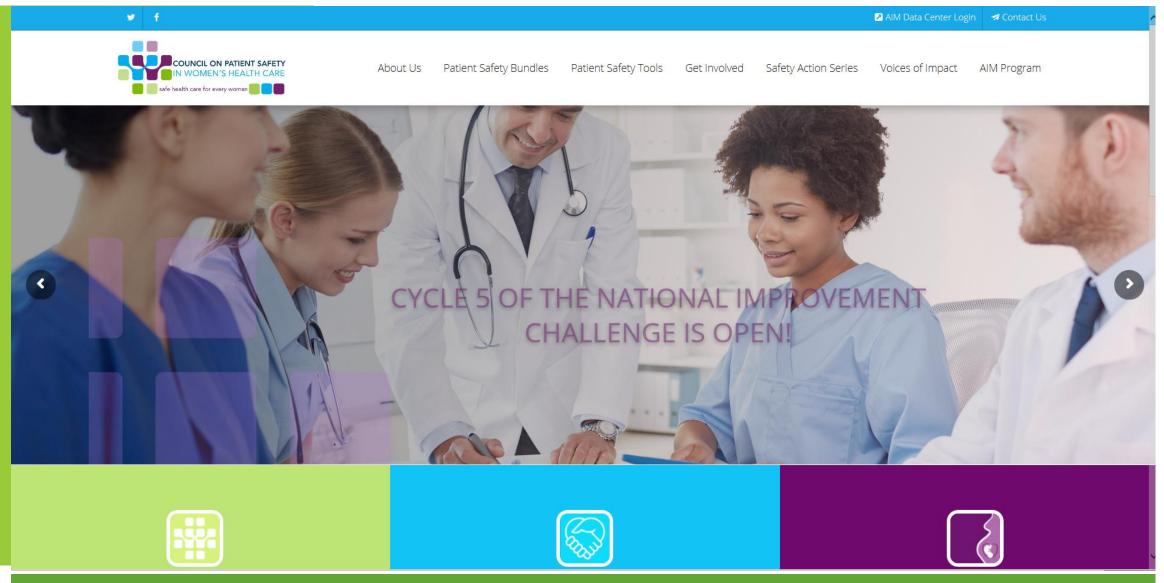
Let's bring this a little closer to home.

Initiatives at work at US and State of South Carolina levels.





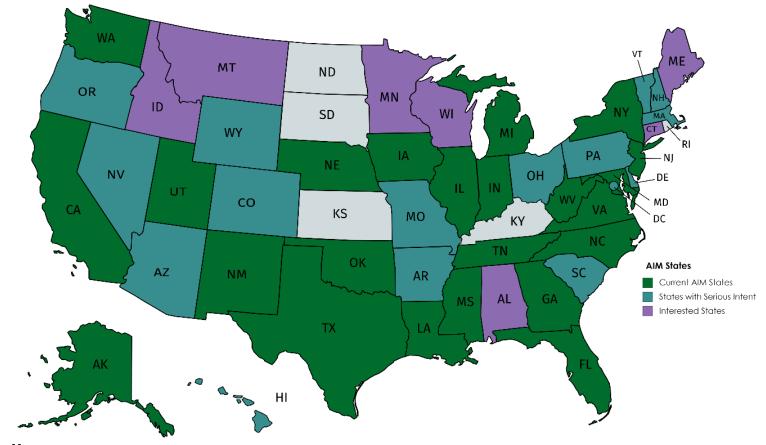
# Council on Patient Safety in Women's Health Care – Safe Healthcare for Every Woman https://safehealthcareforeverywoman.org



- Resources for individuals and hospitals to work on Patient safety initiatives.
- Through this council, the AIM Program information is housed.

### What is AIM?

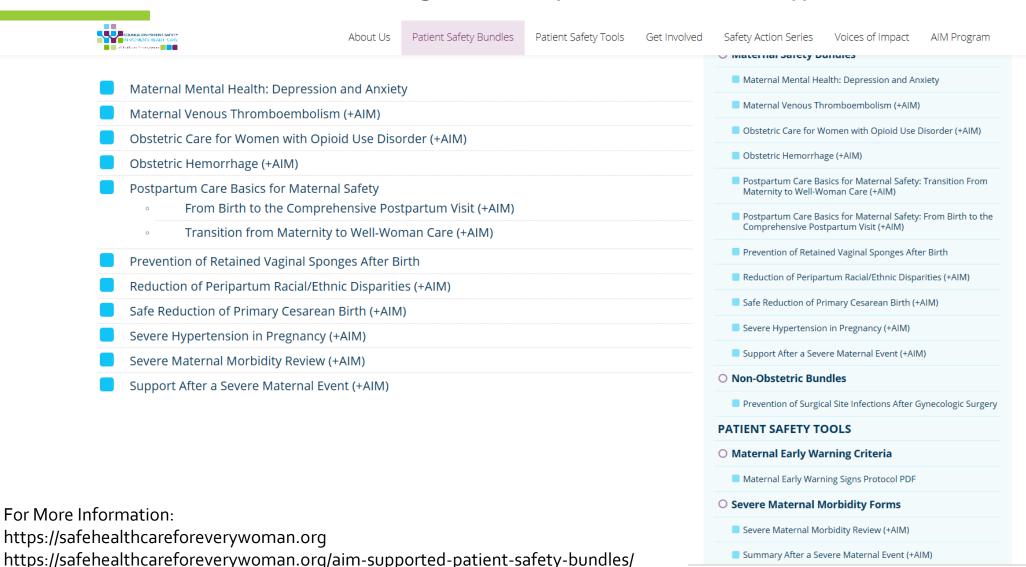
# The Alliance For Innovation On Maternal Health Program



#### **Details:**

- Multiple partners with a vested interest in improving maternal outcomes.
- National data-driven maternal safety and quality improvement initiative based on proven implementation approaches to improving maternal safety and outcomes in the U.S. Our end goal is to eliminate preventable maternal mortality and severe morbidity across the United States.
- The states in Green have been established as AIM states
- South Carolina is in the application process

- Initiatives are set through adoption and implementation of Patient Safety Bundles. Here is a list of the current bundles.
  - A bundle is a collection of 10-13 best practices for improving safety in maternity care that have been vetted by experts in practice.
- GOAL OFTHE BUNDLES: Move established guidelines into practice with a standard approach.



# Sample Safety Bundle





#### **READINESS**

#### Every unit

- Hemorrhage cart with supplies, checklist, and instruction cards for intrauterine balloons and compressions stitches
- Immediate access to hemorrhage medications (kit or equivalent)
- Establish a response team who to call when help is needed (blood bank, advanced gynecologic surgery, other support and tertiary services)
- Establish massive and emergency release transfusion protocols (type-O negative/uncrossmatched)
- Unit education on protocols, unit-based drills (with post-drill debriefs)



#### RECOGNITION & PREVENTION

#### Every patien

- Assessment of hemorrhage risk (prenatal, on admission, and at other appropriate times)
- Measurement of cumulative blood loss (formal, as quantitative as possible)
- Active management of the 3rd stage of labor (department-wide protocol)



#### **RESPONSE**

#### Every hemorrhage

- Unit-standard, stage-based, obstetric hemorrhage emergency management plan with checklists
- Support program for patients, families, and staff for all significant hemorrhages



#### **REPORTING/SYSTEMS LEARNING**

#### Everv unit

- Establish a culture of huddles for high risk patients and post-event debriefs to identify successes and opportunities
- Multidisciplinary review of serious hemorrhages for systems issues
- Monitor outcomes and process metrics in perinatal quality improvement (QI) committee

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Standardization of health care processes and reduced variation has been shown to improve outcomes and quality of care. The Council on Patient Safety in Women's Health Care disseminates patient safety bundles to help facilitate the standardization process. This bundle reflects emerging clinical, scientific, and patient safety advances as of the date issued and is subject to change. The information should not be construed as dictating an exclusive course of treatment or procedure to be followed. Although the components of a particular bundle may be adapted to local resources, standardization within an institution is strongly encouraged.

The Council on Patient Safety in Women's Health Care is a broad consortium of organizations across the spectrum of women's health for the promotion of safe health care for every woman.

PATIENT SAFETY BUNDLE

# bstetric Hemorrhag

https://safehealthcareforeverywoman.org/patient-safety-bundles/obstetric-hemorrhage/



H. R. 1318

# New Legislation – National

### One Hundred Fifteenth Congress United States of America

AT THE SECOND SESSION

Began and held at the City of Washington on Wednesday, the third day of January, two thousand and eighteen

#### An Act

To support States in their work to save and sustain the health of mothers during pregnancy, childbirth, and in the postpartum period, to eliminate disparities in maternal health outcomes for prognancy-related and prognancy-associated deaths, to identify solutions to improve health care quality and health outcomes for mothers, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

#### SECTION 1. SHORT TITLE.

This Act may be cited as the "Preventing Maternal Deaths

#### SEC. 2. SAFE MOTHERHOOD.

Section 317K of the Public Health Service Act (42 U.S.C. 247b-12) is amended-

> in subsection (a)— (A) in paragraph (1)—

(i) by striking "purpose of this subsection is to develop" and inserting "purposes of this subsection are to establish or continue a Federal initiative to support State and tribal maternal mortality review committees, to improve data collection and reporting around maternal mortality, and to develop or support

(ii) by striking "population at risk of death and" and inserting "populations at risk of death and severe"; and (B) in paragraph (2)—

(i) by amending subparagraph (A) to read as fol-

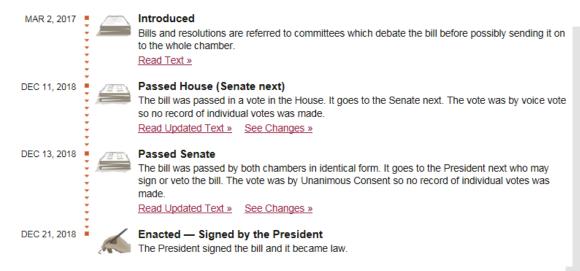
"(A) The Secretary may continue and improve activities related to a national maternal mortality data collection and surveillance program to identify and support the review of pregnancy-associated deaths and pregnancyrelated deaths that occur during, or within 1 year following, pregnancy."; and

(ii) by inserting after subparagraph (C) the fol-

"(D) The Secretary may, in cooperation with States, Indian tribes, and tribal organizations, develop a program to support States, Indian tribes, and tribal organizations in establishing or operating maternal mortality review committees, in accordance with subsection (d)."; (2) in subsection (b)(2)-

(A) in subparagraph (A)—

#### History



#### Preventing Maternal Death Act

- Introduced-
  - Mar 2, 2017
  - 115th Congress, 2017–2019
- Status:
  - Enacted Signed by the President on Dec 21, 2018
  - This bill was enacted after being signed by the President on December 21, 2018.
- Law: Pub.L. 115-344

# Summary of the Bill – Now called Maternal Deaths Act of 2018

#### Preventing Maternal Deaths Act of 2017

- This bill directs the Department of Health and Human Services (HHS) to establish a program under which HHS may make grants to states for the purpose of:
  - 1) reviewing pregnancy-related and pregnancy-associated deaths (maternal deaths);
  - 2) establishing and sustaining a maternal mortality review committee to review relevant information;
  - ensuring that the state department of health develops a plan for ongoing health care provider education in order to improve the quality of maternal care, disseminate findings, and implement recommendations;
  - disseminating a case abstraction form to aid information collection for HHS review and preserve its uniformity; and
  - providing for the public disclosure of information included in state reports.
- The bill defines "pregnancy-associated death" as the death of a woman while pregnant or during the oneyear period following the date of the end of pregnancy, irrespective of the cause of death.
- It defines "pregnancy-related death" as the death of a woman while pregnant or during the one-year period following the date of the end of pregnancy, irrespective of the pregnancy's duration, from any cause related to, or aggravated by, the pregnancy or its management, excluding any accidental or incidental cause.
- States shall develop procedures for mandatory reporting to their departments of health by health facilities and professionals concerning maternal deaths and for voluntary reporting of such deaths by family members.
- States shall investigate each case and prepare a case summary for each case, to be reviewed by the committee and included in applicable reports.
- The bill amends the Public Health Service Act to direct HHS to take specified steps to eliminate disparities in maternal health outcomes.

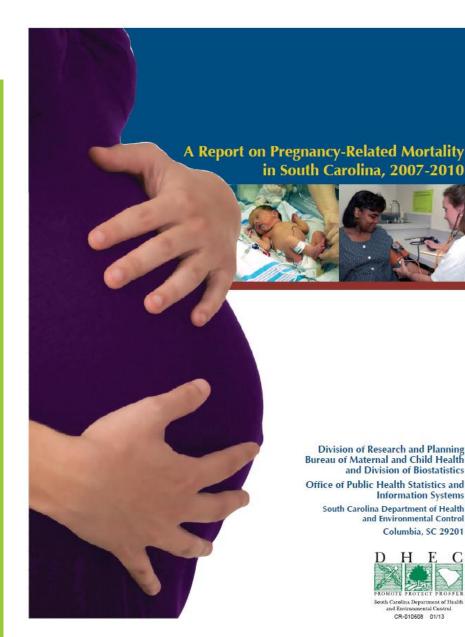
# What does the new law provide?

• The new law will establish and support Maternal Mortality Review Committees at the state level and provides \$12 million a year in new funds for 5 years for states. The committees will be required to review every pregnancy-related death as well as develop recommendations to prevent future deaths.

(<a href="https://www.contemporaryobgyn.net/legislation/major-maternal-health-legislation-signed-law">https://www.contemporaryobgyn.net/legislation/major-maternal-health-legislation-signed-law</a>)

 "The Preventing Maternal Deaths Act authorizes federal funding for multidisciplinary entities known as maternal mortality review committees (MMRCs) that review individual cases of maternal death. MMRCs are key to developing locally relevant strategies to eliminate maternal mortality."

(<u>https://www.acog.org/About-ACOG/News-Room/Statements/2018/US-House-Passes-Landmark-Legislation-to-Prevent-Maternal-Deaths</u>)



#### **MATERNAL MORTALITY IN SOUTH CAROLINA 2011-2015**

Daniela K. Nitcheva<sup>1</sup> and Michael G. Smith<sup>2</sup>

Division of Biostatistics, Public Health Statistics and Information Services, SC DHEC; Division of Research and Planning, Maternal and Child Health Bureau, SC DHEC

#### Introduction

- Maternal mortality has been increasing in incidence across the United States in recent years<sup>1</sup>.
- In 2016 a bill was passed to create a maternal mortality review process for pregnancy-related deaths in SC.

#### Objective

 The purpose of this analysis is to use SC vital records data to provide some basic incidence and demographic estimates related to maternal mortality until more detailed data are available from the maternal mortality review process.

#### Methods

- South Carolina birth certificate and death certificate data were linked (where applicable) for potentially pregnancy-related deaths occurring from 2011-2015.
- The World Health Organization's definition of maternal deaths was
- all deaths during pregnancy or within 42 days of delivery with an ICD-10 cause of death code including: O00 – O95, A34, O98, or O99
- It is important to note that this definition differs from the one that is being used by the South Carolina Maternal Mortality and Morbidity Review Committee.

# Number of pregnancy-related deaths by year, 2011-2015 Number of pregnancy-related deaths by year, 2011-2015 Number of pregnancy-related deaths by time relative to pregnancy-related deaths by time relative to pregnancy 2011-2013

Maternal Age at Time of Deati

Maternal Race/Ethnicity, 2011-2015









- There were a total of 64 maternal deaths meeting the World Health Organization's maternal mortality definition in South Carolina from 2011-2015.
- The rate of maternal mortality increased from 19.2 deaths per 100,000 live births in South Carolina in 2011 to 33.0 deaths per 100,000 live births in 2014 before dropping to 20.6 deaths per 100,000 live births in 2015.
- Of these 64 deaths, many (43.8%) occurred during pregnancy or on the day the infant was delivered.
- The rate was highest for women 35 years of age or older (64.9 deaths per 100,000 live births).
- Non-Hispanic Black women had a rate of maternal mortality that was 3.7 times greater than the rate among non-Hispanic White women (45.4 deaths per 100,000 live births compared to 12.0 deaths per 100,000 live births, respectively).
- While the majority of the women died in a hospital, 17.2% of the deaths occurred outside of a hospital.

#### Conclusion & future directions

- Maternal mortality continues to be a substantial public health concern in South Carolina as well as across the United States.
- Demographic disparities in maternal mortality exist in South Carolina, including a substantial racial disparity.
- The upcoming results of the South Carolina maternal mortality review process will be essential to improving our understanding of the causes of maternal deaths and the potential for preventing similar deaths from occurring in the future.

References

Madavas M. Rahing S, Grisch S. Motor. C (2005) US. Water of Morally Track. Griss Special (1995) 101-00.

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- 1. http://www.reviewtoaction.org/sites/default/files/portal\_resources/SC%2oPegnancy%2oRelated%2oMortality%2oReport\_2007-2010%2oData.pdf
- . http://www.reviewtoaction.org/sites/default/files/portal\_resources/South%2oCarolina%2oVR%2oData\_Maternal%2oMortality%2o2o11-2015%2oPoster.pdf

# SC law Signed by Governor 3/14/2016 – Allows for Maternal Mortality Review Committee to review maternal deaths

#### South Carolina Legislature

March 26, 2019, 02:04:16 pm

Session 121 - (2015-2016)

03/17/16

H\*3251 (Rat #0146, Act #0142 of 2016) General Bill, By G.M. Smith, G.R. Smith and J.E. Smith

Summary: Maternal Morbidity and Mortality Review Committee

Act No. 142

AN ACT TO AMEND THE CODE OF LAWS OF SOUTH CAROLINA, 1976, BY ADDING SECTION 44-1-310 SO AS TO REQUIRE THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL TO ESTABLISH THE MATERNAL MORBIDITY AND MORTALITY REVIEW COMMITTEE TO REVIEW AND STUDY MATERNAL DEATHS AND TO REPOR THE FINDINGS TO THE GENERAL ASSEMBLY, ENVIRONMENTAL TO THE STANDARD OF THE STANDARD ASSEMBLY.

MORDIDII	I AND W	ORTALITI NEVIEW COMMITTEE TO NEVIEW AND STODY MATERIAL DEATHS AND TO RE
THE FIND	INGS TO	THE GENERAL ASSEMBLY ratified title
12/18/14	House	Prefiled
12/18/14	House	Referred to Committee on Medical, Military, Public and Municipal Affairs
01/13/15	House	Introduced and read first time (House Journal-page 172)
01/13/15	House	Referred to Committee on Medical, Military, Public and Municipal Affairs (House Journal-p 172)
02/25/15	House	Committee report: Favorable with amendment Medical, Military, Public and Municipal Affa (House Journal-page 5)
03/04/15	House	Debate adjourned until Mon., 3-5-15 (House Journal-page 33)
03/05/15	House	Member(s) request name added as sponsor: J.E.Smith
03/05/15	House	Amended (House Journal-page 40)
03/05/15	House	Read second time (House Journal-page 40)
03/05/15	House	Roll call Yeas-106 Nays-1 (House Journal-page 40)
03/05/15	House	Unanimous consent for third reading on next legislative day (House Journal-page 42)
03/06/15	House	Read third time and returned to Senate with amendments (House Journal-page 2)
03/10/15	Senate	Introduced and read first time (Senate Journal-page 13)
03/10/15	Senate	Referred to Committee on Medical Affairs (Senate Journal-page 13)
02/23/16	Senate	Committee report: Favorable with amendment Medical Affairs (Senate Journal-page 10)
02/24/16	Senate	Committee Amendment Adopted (Senate Journal-page 27)
02/24/16	Senate	Read second time (Senate Journal-page 27)
02/24/16	Senate	Roll call Ayes-39 Nays-0 (Senate Journal-page 27)
02/25/16	Senate	Read third time and returned to House with amendments (Senate Journal-page 22)
03/02/16	House	Concurred in Senate amendment and enrolled (House Journal-page 43)
03/02/16	House	Roll call Yeas-73 Nays-0 (House Journal-page 43)
03/10/16		Ratified R 146
03/14/16		Signed By Governor
03/16/16		Effective date 03/14/16

A142, R146, H3251

AN ACT TO AMEND THE CODE OF LAWS OF SOUTH CAROLINA, 1976, BY ADDING SECTION 44-1-310 SO AS TO REQUIRE THE DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL TO ESTABLISH THE MATERNAL MORBIDITY AND MORTALITY REVIEW COMMITTEE TO REVIEW AND STUDY MATERNAL DEATHS AND TO REPORT THE FINDINGS TO THE GENERAL ASSEMBLY.

Legislative findings

SECTION 1. The General Assembly finds that:

- (1) the South Carolina rate of maternal death is higher than the United States average;
- (2) maternal deaths are a serious public health concern and have a tremendous family and societal impact;
- (3) maternal deaths are significantly underestimated and inadequately documented, preventing efforts to identify and reduce or eliminate the causes of death;
- (4) no processes exist in this State for the confidential identification, investigation, or dissemination of findings regarding maternal deaths;
- the federal Centers for Disease Control and Prevention and the American College of Obstetricians and Gynecologists have determined that maternal deaths and severe maternal morbidity should be investigated through state-based maternal morbidity and mortality reviews in order to institute the systemic changes needed to decrease maternal mortality; and
- there is a need to establish a program to review maternal deaths and maternal morbidity to develop strategies for the prevention of maternal deaths in South Carolina.

#### Maternal Morbidity and Mortality Review Committee -

#### SECTION 2. Chapter 1, Title 44 of the 1976 Code is amended by adding: "Section 44-1-310.

- (A) The Department of Health and Environmental Control shall establish a Maternal Morbidity and Mortality Review Committee to review maternal deaths and to develop strategies for the prevention of maternal deaths. The committee must be multidisciplinary and composed of members deemed appropriate by the department. The committee also may review severe maternal morbidity. The department may contract with an external organization to assist in collecting, analyzing, and disseminating maternal mortality information, organizing and convening meetings of the committee, and performing other tasks as may be incident to these activities, including providing the necessary data, information, and resources to ensure successful completion of the ongoing review required by this section.
- (B) The committee shall:
  - (1) identify maternal death cases, as defined as a death within one year of pregnancy with a direct or indirect causation related to the pregnancy or postpartum period;
  - (2) review medical records and other relevant data;
  - (3) contact family members and other affected or involved persons to collect additional data;
  - (4) consult with relevant experts to evaluate the records and data;
  - (5) make determinations regarding the preventability of maternal deaths;
  - (6) develop recommendations for the prevention of maternal deaths; and
  - (7) disseminate findings and recommendations pursuant to subsection (F).

(C)

- (1) Health care providers and pharmacies licensed pursuant to Title 40 shall provide reasonable access to the committee to all relevant medical records associated with a case under review by the committee.
- (2) A health care provider, health care facility, or pharmacy providing access to medical records pursuant to this subsection are not liable for civil damages or subject to criminal or disciplinary action for good faith efforts in providing the records.

#### Maternal Morbidity and Mortality Review Committee -

#### SECTION 2. Chapter 1, Title 44 of the 1976 Code is amended by adding: "Section 44-1-310.

(D)

- (1) Information, records, reports, statements, notes, memoranda, or other data collected pursuant to this section are not admissible as evidence in any action of any kind in any court or before another tribunal, board, agency, or person. The information, records, reports, statements, notes, memoranda, or other data must not be exhibited nor their contents disclosed, in whole or in part, by an officer or a representative of the department or another person, except as necessary for the purpose of furthering the review of the committee of the case to which they relate. A person participating in a review may not disclose the information obtained except in strict conformity with the review project.
- (2) All information, records of interviews, written reports, statements, notes, memoranda, or other data obtained by the department, the committee, and other persons, agencies, or organizations authorized by the department pursuant to this section are confidential.

(E)

- (1) All proceedings and activities of the committee, opinions of members of the committee formed as a result of the proceedings and activities, and records obtained, created, or maintained pursuant to this section, including records of interviews, written reports, and statements procured by the department or another person, agency, or organization acting jointly or under contract with the department in connection with the requirements of this section, are confidential and are not subject to the provisions of Chapter 4, Title 30 relating to open meetings or public records, or subject to subpoena, discovery or introduction into evidence in any civil or criminal proceeding.

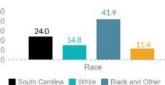
  However, this section must not be construed to limit or restrict the right to discover or use in any civil or criminal proceeding anything that is available from another source and entirely independent of the committee's proceedings.
- (2) Members of the committee must not be questioned in a civil or criminal proceeding regarding the information presented in or opinions formed as a result of a meeting or communication of the committee. However, this section must not be construed to prevent a member of the committee from testifying to information obtained independently of the committee or which is public information.
- (F) Reports of aggregated nonindividually identifiable data for the previous calendar year must be compiled and disseminated by March first of the following year in an effort to further study the causes and problems associated with maternal deaths. Reports must be distributed to the General Assembly, the Director of the Department of Health and Environmental Control, health care providers and facilities, key governmental agencies, and others necessary to reduce the maternal death rate.
- (G) Members shall serve without compensation, and are ineligible for the usual mileage, subsistence, and per diem allowed by law for members of state boards, committees, and commissions."

## Legislative Brief 2017 -From the SC Maternal Mortality and Morbidity Review Committee

# **South Carolina Maternal Mortality** and Morbidity Review Committee Legislative Brief 2017

The South Carolina Maternal Mortality and Morbidity Review (MMMR) Committee, established by state law in 2016, investigates the death of mothers associated with pregnancy to determine which ones can be prevented. A pregnancy-related death occurs when a woman dies while pregnant or within 1 year after the pregnancy. The cause must be related to or made worse by her pregnancy or its management. This does not include accidental or incidental causes.\*

#### Pregnancy-Related Death in South Carolina, 2012-2016\*\* (Rate per 100,000 live births)



Healthy People 2020 Goal

Across the United States, approximately 700 women die each year from the result of pregnancy or delivery complications. Some groups of women in South Carolina experience this tragic event at a much higher rate than other groups.\*\*

During 2012-2016, the maternal death rate in South Carolina was higher than the Healthy People 2020 goal of 11.4 maternal deaths per 100,000 live births.

#### Goals of the South Carolina MMMR Committee



Determine the annual number of pregnancyassociated deaths that are pregnancy-related.



Identify trends and risk factors among preventable pregnancy-related deaths in South Carolina.



Develop actionable strategies for prevention and intervention.

#### 2016-2017 MMMR Committee Accomplishments

#### Established the Committee

stakeholders from

multiple disciplines





Trained members on the mission, goals, best practices, and data

Best Practices

structure.

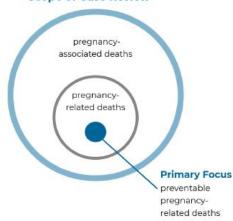


Identified cases through voluntary hospital reporting. Collected and reviewed data on 8 deaths.

Began Data Review



#### Scope of Case Review



#### **MMMR Committee Findings**

During 2016-2017, 7 of the 8 total maternal deaths reviewed in S.C. were determined to be pregnancy-related.

87.5%

As reported nationally\*, the findings from South Carolina's MMMR Committee show that the common causes of maternal death include cardiovascular and coronary conditions. hemorrhage, infection, and embolism.

Once access to vital records is gained, a complete, more robust analysis will be possible. Review of all pregnancy-related deaths will provide the committee with the ability to see trends in contributing factors and make recommendations for prevention.

#### **MMMR Committee Recommendations**

Since 2016, the committee has identified actions that could improve South Carolina's ability to understand causes of pregnancy-related death.



#### **Remove Barriers** to Accessing Data



**Identify Funding** 



Improve Reporting of Maternal Deaths

case identification. This information provide resources for the would provide the true burden of maternal death in S.C. and would enable a more representative number of cases to be reviewed.

Allow linkage to vital records to improve Identify funding that would Establish routine hospital and birthing center reporting, review of all pregnancy-related which would allow more cases to be reviewed.

#### South Carolina's Contribution to National Efforts

In partnership with the Centers for Disease Control and Prevention (CDC), South Carolina recently contributed its aggregate data to national surveillance efforts in the 2018 "Report from Nine Maternal Mortality Review Committees"\*. This effort allows the committee to better understand trends in maternal deaths, contributing factors, and recommendations for prevention in our state.

South Carolina's partnership with the CDC has led the state to the deployment of the Maternal Mortality Review Information Application (MMRIA), a comprehensive database that can be used for surveillance, monitoring, and research of maternal mortality. MMRIA will support the work of the committee and improve case investigation efforts.



# Other South Carolina Actions

- South Carolina Birth Outcomes Initiative (SC BOI) meets monthly to work on a variety of perinatal safety, quality and evidencebased practice initiatives.
- Patient safety bundles are being implemented in delivery hospitals around the state
- Simulation education provided with the SimCOACH™ gives opportunities for hospital staff to prepare for common and rare obstetric and neonatal emergencies
- South Carolina working to officially become an AIM state











Neonatal/Infant Mortality

## Definition

#### Neonatal Death

- Neonatal death is when a baby dies in the first 28 days of life
- Neonatal death happens in about 4 in 1, 000 babies each year in the United States
- Non-Hispanic black women are more likely to have a baby die than women of other races or ethnicities

#### Infant Death

Death of an infant before his or her first birthday

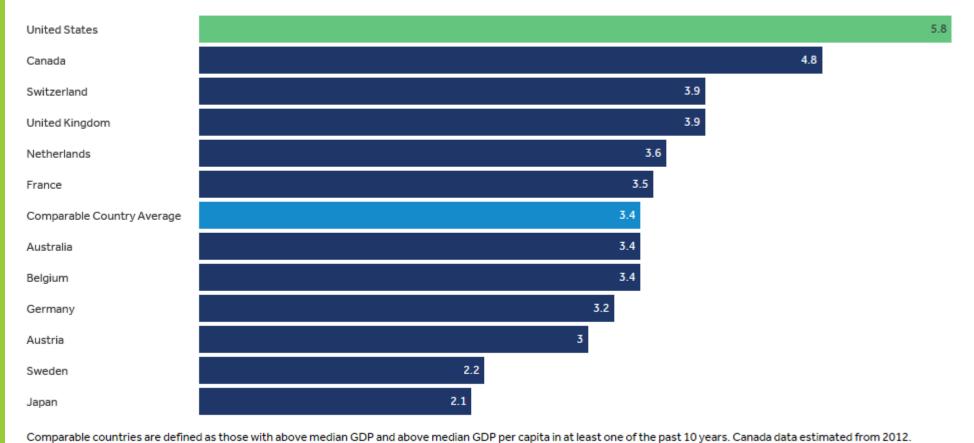
## Mortality Rate

- The infant mortality rate is the number of infants deaths for every 1,000 live births.
- The infant mortality rate is an important marker of the overall health of a society.
- Lack of access to health care, poor maternal health, and prenatal and postnatal care all contribute to infant mortality

#### Infant mortality is higher in the U.S. than in comparable countries

Infant mortality per 1,000 live births, 2014





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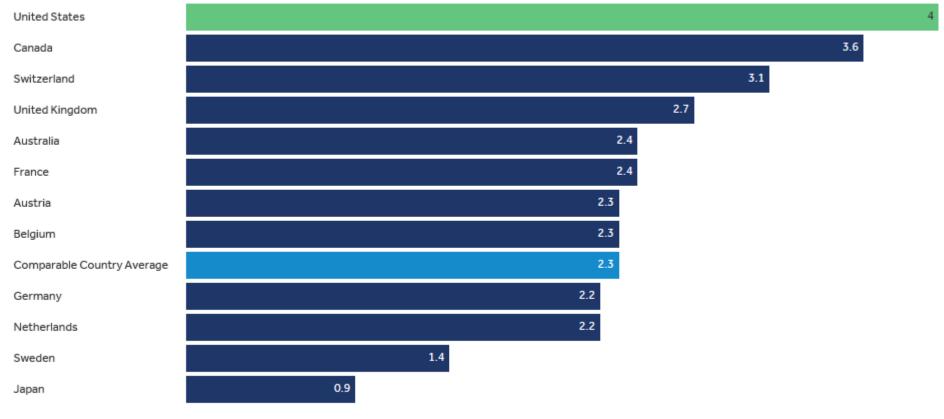
Source: Kaiser Family Foundation analysis of data from OECD (2017), "OECD Health Data: Health status: Health status indicators", OECD Health Statistics database. (Accessed on July 5, 2017) • Get the data • PNG

Peterson-Kaiser
Health System Tracker

# Infant Mortality Rate in U.S.

#### Neonatal mortality in the U.S. is higher than in comparable countries

Neonatal mortality per 1,000 live births, 2014



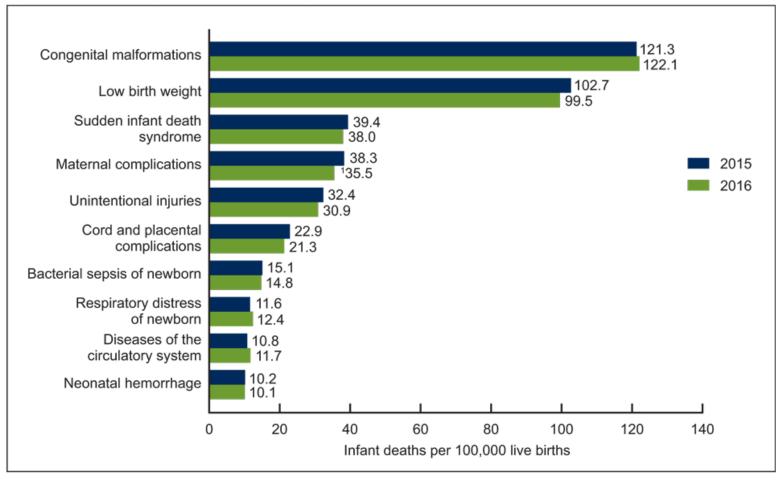
Comparable countries are defined as those with above median GDP and above median GDP per capita in at least one of the past 10 years. In cases where 2014 data were unavailable, data from the last available year are shown.

Source: Kaiser Family Foundation analysis of data from OECD (2017), "OECD Health Data: Health status: Health status indicators", OECD Health Statistics database. (Accessed on July 5, 2017). • Get the data • PNG

Peterson-Kniser
Health System Tracker

# Leading Causes of Infant Deaths in U.S.

Figure 5. Infant mortality rates for the 10 leading causes of infant death in 2016: United States, 2015 and 2016



<sup>1</sup>Statistically significant decrease in mortality rate from 2015 to 2016 (p < 0.05).

NOTES: A total of 23,161 deaths occurred in children under age 1 year in the United States in 2016, with an infant mortality rate of 587.0 infant deaths per 100,000 live births. The 10 leading causes of infant death in 2016 accounted for 67.5% of all infant deaths in the United States. A total of 23,455 infant deaths occurred in 2015, with an infant mortality rate of 589.5 infant deaths per 100,000 live births. Rankings for 2015 data are not shown. Causes of death are ranked according to number of deaths. Access data table for Figure 5 at: https://www.cdc.gov/nchs/data/databriefs/db293\_table.pdf#5.

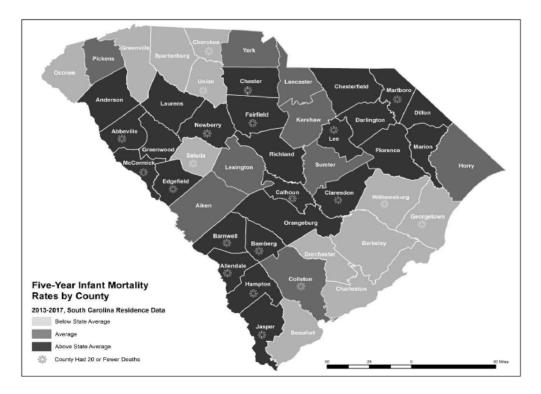
SOURCE: NCHS, National Vital Statistics System, Mortality.

# Infant Mortality Rate in South Carolina

- The infant mortality rate in South Carolina decreased from 7.0 infants deaths per 1,000 live births in 2016 to 6.5 deaths per 1,000 births in 2017. Thirty fewer infants died in 2017 than in the previous year.
- From 2016 to 2017, there was a 24.7 percent decrease in infant deaths from birth defects. Preterm/low birthweight deaths decreased by 8.8 percent.
- The number of infant deaths due to maternal complications of pregnancy increased 70 percent, from 20 in 2016 to 34 in 2017.

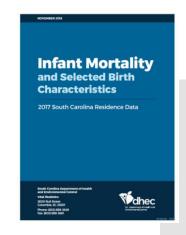
Figure 2.

Five Year Infant Mortality Rates<sup>1</sup> by County
South Carolina
2013-2017
(Residence Data)

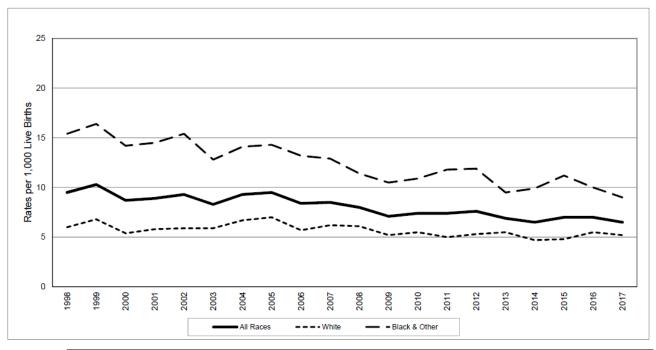


Above State Average indicates a rate greater than 7.2. State Average indicates a rate between 5.8 and 7.2 inclusive. Below State Average indicates a rate lower than 5.8.

<sup>1</sup>Rate per 1,000 live births. Rates calculated with 20 or fewer deaths are unreliable and should be used cautiously.



### South Carolina Infant Mortality Rates<sup>1</sup> by Race<sup>2</sup> Residence Data, 1998-2017



	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
All Races	9.5	10.3	8.7	8.9	9.3	8.3	9.3	9.5	8.4	8.5	8.0	7.1	7.4	7.4	7.6	6.9	6.5	7.0	7.0	6.5
White	6.0	6.8	5.4	5.8	5.9	5.9	6.7	7.0	5.7	6.2	6.1	5.2	5.5	5.0	5.3	5.5	4.7	4.8	5.5	5.2
Black & Other	15.4	16.4	14.2	14.5	15.4	12.8	14.1	14.3	13.2	12.9	11.4	10.5	10.9	11.8	11.9	9.5	9.9	11.2	10.0	9.0
1																				

<sup>1</sup>Rates per 1,000 live births

Source: SC DHEC, Vital Statistics

<sup>&</sup>lt;sup>2</sup>Race of mother

# Causes of Infant Mortality

- The leading causes of infant mortality are:
  - Birth Defects
  - Preterm Birth/Low Birth Weight
  - SIDS
  - Maternal Pregnancy Complications
  - Injuries
- The US infant mortality rate is 5.87 deaths per 1000 live births
- The South Carolina infant mortality rate is 6.7 deaths per 1000 live births
- Birth Defects remained the leading cause for infant mortality in 2015 and 2016

### Birth Defects

- CDC estimates that birth defects occur in about 1 in every 33 infants born in the United States each year
- Birth defects can occur in any pregnancy but there are some factors that increase a pregnant women's risk
  - Lack of folic acid: Recommended dose for women who are pregnant or planning a pregnancy is 400 micrograms per day. Folic acid is recommended to help prevent neural tube defects. According to the CDC, only 2 out of every 5 women of childbearing age take the recommended dose of folic acid
  - Drinking alcohol: Drinking alcohol during pregnancy can lead to a variety of problems. Fetal Alcohol Syndrome is characterized by intellectual or developmental disability, physical challenges, and behavioral problems
  - Smoking cigarettes: Smoking can lead to certain birth defects with the heart and intestines
  - Drug Use: Can lead to birth defects, pregnancy loss and stillbirths

## Birth Defects

#### Medication use:

Certain medications taken during pregnancy can lead to birth defects.
 Thalidomide, is currently used to treat certain cancers. This drug was once used to treat morning sickness until it was found to cause severe birth defects. The defects ranged from structural and functional problems, misshapen ears and shortened limbs. Majority of medications currently used by pregnant women have not been tested for safety or efficacy in pregnant women. NICHD Obstetric-Fetal Pharmacology Research Units Network is focusing on addressing this issue

#### • Infections:

 Some of the most common infections that are linked to birth defects such as cytomegalovirus, a common virus that spreads through body fluids and usually causes no symptoms. Toxoplasmosis, a parasitic infection that spreads through contact with cat feces, raw meat, and contaminated food and water. Zika Virus is linked to microcephaly in newborn babies

#### Obesity and uncontrolled diabetes:

Obesity has been linked to heart and neural tube defects

#### Types of Birth Defects

#### There are two main categories of birth defects:

- Structural Birth Defects
  - Defects related to a problem with the structure of body parts:
- Functional or Developmental Birth Defects
  - Defects related to a problem with how a body part or body system works or functions

### Types of Birth Defects: STRUCTURAL

- Structural Birth Defects
  - Defects related to a problem with the structure of body parts:
    - Cleft lip or Cleft palate
    - Heart Defects
    - Abnormal limbs
      - Clubfoot
    - Neural Tube Defects
      - Spina Bifida

## Structural Birth Defects in South Carolina

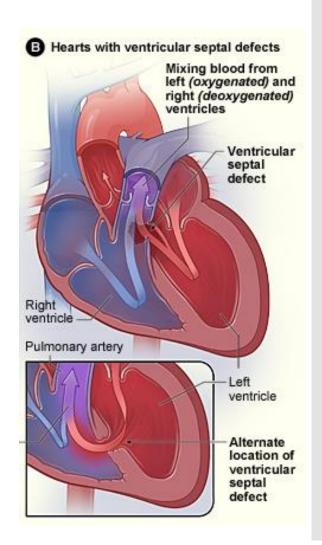
Birth Defect	Birth Year 2016	Birth Year 2017	Birth Year 2018
Ventricular Septal Defect	238	223	186
Down Syndrome	76	69	45
Atrial Septal Defect	40	55	52
Microcephaly	64	41	28
Coarctation of Aorta	37	25	21
Atrioventricular Septal Defect	35	23	25
Renal Agenesis, Unilateral	22	31	29
Tetralogy of Fallot	27	26	21
Congenital Pulmonary Valve Stenosis	28	23	17
Gastroschisis	19	28	16

## Structural Birth Defects in South Carolina

- Ventricular Septal Defect is the number one structural birth defect seen in South Carolina. Ventricular septal defect is one of the most common congenital heart defects and the cause is unknown. It occurs in nearly half of all children with congenital heart disease.
- Let's do a quick review of how the heart works:
  - The heart has two sides, separated by the septum. With each heartbeat, the right side of your heart receives oxygen-poor blood from your body and pumps it to your lungs. The left side of your heart receives oxygen-rich blood from your lungs and pumps it to your body.
- The Ventricular septal defect is a hole in the wall (septum) of the two lower chambers (ventricles) of the heart.
  - This defect allows blood to pass from the left side of the heart to the right side. This means that oxygen-rich blood can mix with oxygenpoor blood. As a result, some oxygen-rich blood is pumped to the lungs instead of out to the body.

### Types of Ventricular Septal Defect

- Listed below are common locations and names of VSD's
  - Membranous Ventricular Septal Defect
    - Located near the heart valves. These VSD's can close at any time
  - Muscular Ventricular Septal Defect
    - Located in the lower part of the septum.
       They are surrounded by muscle and most close on their own during early childhood
  - Inlet Ventricular Septal Defect
    - Located close to where the blood enters the ventricles. They are less common than membranous and muscular VSD's.
  - Outlet Ventricular Septal Defect
    - Found in the part of the ventricle where blood leaves the heart. These are the rarest type of VSD's.



## Signs and Symptoms Ventricular Septal Defect

- Murmur is usually present at birth and may be the only sign or symptom. Infants who have medium or large sized VSD's are at risk for heart failure.
- Signs and symptoms of heart failure
  - Failure to thrive
  - Difficulty feeding
- Signs and symptoms are rare after infancy because the defect either decreases in size on its own or is repaired

#### Diagnosing and Treatment of Ventricular Septal Defect

- Diagnosing
  - Referral to Pediatric Cardiologist
  - Echocardiogram
  - EKG
  - Chest X-Ray
  - Cardiac Catheterization
- Treatment will depend on our the infant is doing. More than half of VSD's eventually close, usually by the time a child is in preschool.
- Surgery may be recommended if the infant's VSD:
  - Is large
  - Causing symptoms
  - Is medium-sized and causing enlarged heart chambers
  - Affects aortic valve
- Most VSD's that require surgery are repaired in the first year of life

### Types of Birth Defects: FUNCTIONAL / DEVELOPMEMENTAL

- Functional or Developmental Birth Defects are defects related to a problem with how a body part or body system works or functions:
  - Nervous System
    - Down Syndrome
    - Fragile X Syndrome
  - Sensory
    - Hearing loss
    - Visual problems
  - Metabolic Disorders
    - Phenylketonuria
    - Hypothyroidism
  - Degenerative Disorders
    - Muscular
  - Degenerative Disorders
    - Muscular Dystrophy
    - X-linked Adrenoleukodystrophy

#### Most Common Birth Defect in South Carolina



- The most common functional or developmental birth defect we see in South Carolina is hearing loss.
- Hearing loss occurs in newborn infants more frequently than any other condition for which newborn infant screening is required.
- Studies show hearing loss occurs in approximately 2-4 out of 1,000 babies.
- Hearing is very important with development of language skills.
- Infants begin developing speech and language at birth. 80% of language ability is established by the age of 18 months.

### Birth Defects in South Carolina

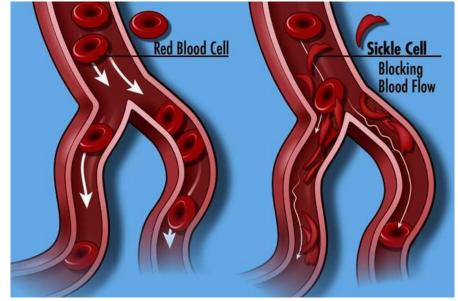
- The top four newborn screening conditions identified in South Carolina in 2016 were:
  - Congenital Hypothyroidism
  - Sickle C Disease
  - Sickle Cell Disease
  - Cystic Fibrosis
- The top four newborn screening conditions identified in South Carolina in 2017 were:
  - Sickle Cell Disease
  - Sickle C Disease
  - Congenital Hypothyroidism
  - Cystic Fibrosis

#### Sickle Cell Disease

- Sickle cell disease is a group of disorders that affects hemoglobin.
- The hemoglobin molecule is atypical and are called hemoglobin S, which can distort red blood cells into a sickle, or crescent shape.
- Signs and symptoms usually begin in early childhood.
   Characteristic features include anemia, repeated infections, and periodic episodes of pain.
  - The signs and symptoms are caused by the sickling of red blood cells. When red blood cells sickle, they break down prematurely, which can lead to anemia.
  - Painful episodes can occur when sickled red blood cells, which are stiff and inflexible, get stuck in small blood vessels. These episodes deprive tissues and organs of oxygen rich blood and can lead to organ damage.
  - A serious complication of sickle cell disease is pulmonary hypertension (high blood pressure in the blood vessels that supply the lungs). Pulmonary hypertension may lead to heart failure and affects one-third of adults with sickle cell disease.

#### Sickle Cell Disease

 Sickle cell disease is the most common inherited blood disorder in the United States, affecting 70,000 to 80,000 Americans. The disease is estimated to occur in 1 in 500 African Americans and 1 in 1,000 to 1,400 Hispanic Americans. The condition is inherited and is autosomal recessive.



#### Sickle Cell Disease: Autosomal Recessive

- Autosomal recessive disorder means two copies of an abnormal gene must be present in order for the disease or trait to develop.
  - If an infant is born to parents who carry the same autosomal recessive mutation, the infant has a 1 in 4 chance of inheriting the abnormal gene from both parents and developing the disease. The infant has a 50% chance of inheriting one abnormal gene, this would make them a carrier.
- An infant is born to a couple who both carry the gene (but do not have signs of disease), the expected outcome for each pregnancy is:
  - 25% chance the infant is born with two normal genes (normal)
  - 50% chance the infant is born with one normal and once abnormal gene (carrier, without disease)
  - 25% chance infant is born with two abnormal genes (at risk for the disease)

#### Sickle Cell C Disease (Hemoglobin SC)

- Hemoglobin SC disease is the second most common type of sickle cell disease.
- The SC variant is when one gene is mutated to the S form (sickled form) and the other is mutated to the C variant, which is also abnormal.
- For people with one S and one C mutation, they have less episodes of their blood cells clumping together compared to people with SS disease, so they have less pain crises. Sickle Cell C disease is also autosomal recessive.

#### Congenital Hypothyroidism

- Congenital hypothyroidism is a partial or complete loss of function of the thyroid gland that affects infants from birth. The thyroid gland makes iodine-containing hormones that play an important role in regulating growth, brain development, and metabolism.
- Two Types of Congenital Hypothyroidism
  - Thyroid Dysgenesis is when the thyroid gland is absent, severely reduced in size or abnormally located.
  - Thyroid Dyshormonogenesi is when the thyroid gland is normal in size or enlarged thyroid gland (goiter) is present. Production of thyroid hormones are decreased or absent.

#### Congenital Hypothyroidism

- Signs and symptoms of Congenital Hypothyroidism appear secondary to the shortage of thyroid hormone. Some infants have no symptoms and some are less active and sleep more than other infants. Infants may also have difficulty feeding and experience constipation. If untreated, congenital hypothyroidism can lead to intellectual disability and slow growth. If infants receive treatment in the first two weeks after birth, they usually develop normally
- Diagnosing and Treatment:
  - The Newborn State Screening test will show a low T4 (low level of thyroid hormone) and a high TSH (thyroid stimulating hormone).
     The infants physician will be contacted and confirmation lab testing will be done.
  - Treatment: The infant will be started on a medication called Levothyroxine.

#### Cystic Fibrosis

- Cystic Fibrosis is an inherited disease caused by mutations in a gene called cystic fibrosis transmembrane conductance regulator (CFTR) gene.
  - This gene provides instructions for the CFTR protein. CFTR protein is located in every organ of the body that makes mucus, including the lungs, liver, pancreas, intestines and sweat glands.
  - The mutations in the CFTR gene cause the CFTR protein to not work properly by causing thick, sticky mucus and blockages in the lungs and digestive system. Normally mucus coats the cilia in the airways of the lungs, which sweep the mucus particles up to the nose and mouth where the body can rid of them. People with cystic fibrosis, this process does not work properly.

#### Screening:

- Every infant in the United States are screened for Cystic Fibrosis by their Newborn State Screening test. Genetic testing may also look for carriers or the CFTR mutation gene.
- Diagnosing can be done by genetic testing or sweat test
- Treatment:
  - While there is no cure for Cystic Fibrosis, advancements in treatment are allowing people to live longer, healthier lives

#### Causes of Neonatal Death

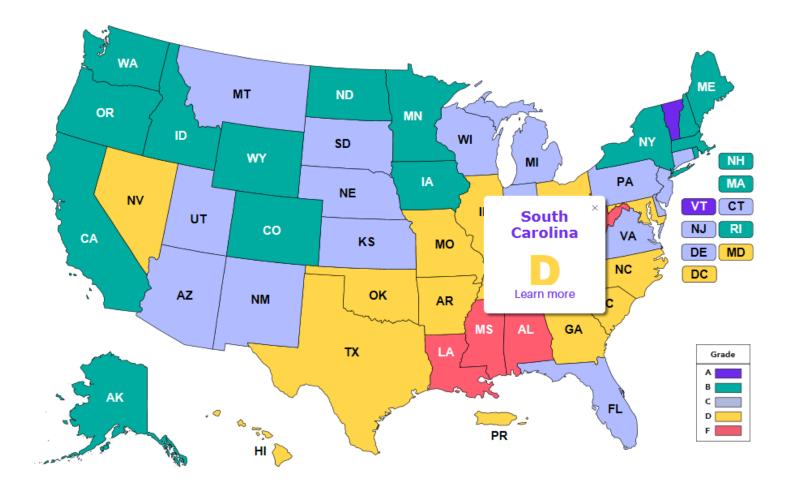
- The number one cause of neonatal death is prematurity.
- Respiratory distress syndrome is the leading cause of death with the premature infant
  - About 380,000 babies are born prematurely in the United States each year
  - The premature birth rate has increased for the third year in a row. The United States has the highest rates of premature birth in the industrial world

## 2018 Premature Birth Report Card

#### **2018 PREMATURE BIRTH REPORT CARDS**

Moms and babies face higher risks than ever before. The preterm birth rate in the United States has worsened for a third year, rising to 9.93 percent in 2017. Premature birth and its complications are the largest contributors to infant death in this country and globally. March of Dimes is working to solve this problem, and the most serious health threats to moms and babies, so all families can get the best possible start.

Choose your state to see how it ranks on this year's Report Card.



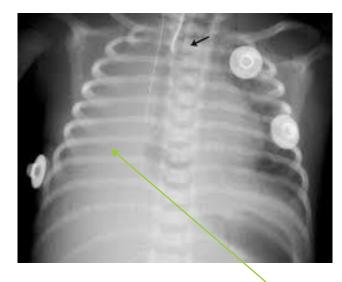
Source: Preterm birth rates are from the National Center for Health Statistics, 2017 final natality data. Grades assigned by March of Dimes Perinatal Data Center.

#### Prematurity in South Carolina

- In South Carolina, 1, 118 infants are born per week. Of these infant's, 123 were born preterm, 85 were born late preterm, and 22 were born very preterm
  - Preterm is less than 37 weeks
  - Late Preterm is 34 to 36 weeks
  - Very Preterm is less than 32 weeks
- In 2017, there were 6, 396 preterm births in South Carolina, representing 11.2% of live births
  - 1 in 9 babies were born preterm in South Carolina in 2017

## What is Respiratory Distress Syndrome?

- Respiratory Distress Syndrome is caused by pulmonary surfactant deficiency in the neonates lungs.
- It is more commonly seen in infants that are less than 37 weeks gestation.
- Surfactant production begins at 25 weeks gestation but adequate amounts of surfactant are not produced until 34-36 weeks gestation.
  - Pulmonary surfactant is needed to decrease the surface tension of the water film that lines the alveoli.
  - It is needed to help prevent the alveoli from collapsing and decrease the work required to inflate the alveoli.
  - When the lungs are surfactant deficient, greater pressure is needed to open the alveoli. Without adequate airway pressure, the lungs become diffusely atelectatic.



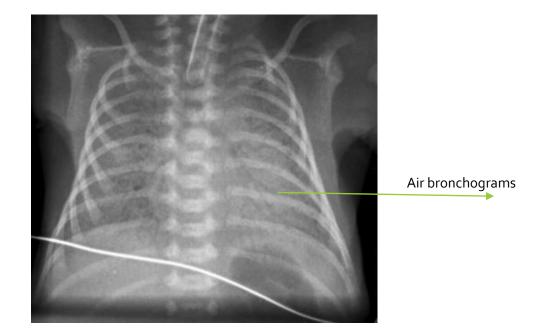
Total atelectasis of right lung

#### Respiratory Distress Syndrome

- Infant's who have respiratory distress syndrome or RDS will typically be symptomatic at birth or a few hours after birth.
- They may present with nasal flaring, retractions, grunting and tachypnea.
- As the atelectasis worsen, signs and symptoms will worsen.
- Infant will become apneic, lethargic and have cyanosis.
- Neonates weighing less than 1000 grams may have lungs that are so stiff they are unable to initiate or sustain respirations in the delivery room

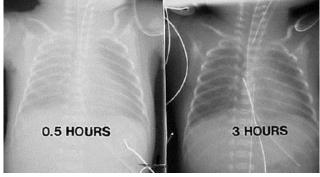
#### Respiratory Distress Syndrome

• Diagnosis of respiratory distress syndrome is by clinical presentation. Arterial blood gases will show hypoxemia and hypercapnia. Chest x-ray will show diffuse atelectasis with visible air bronchograms.



#### Respiratory Distress Syndrome

- Specific treatment of respiratory distress syndrome is endotracheal surfactant therapy. This therapy requires endotracheal intubation which also may be necessary to achieve adequate ventilation and oxygenation.
- Respiratory Support:
  - CPAP (Continuous Positive Airway Pressure)
    with the combination of surfactant therapy,
    the goal is to prevent the infant with
    respiratory distress syndrome from
    requiring mechanical ventilation.
  - Mechanical ventilation may be necessary especially for the very low birth weight infant's (VLBW).
    - The goal is to monitor these infant's closely and wean the oxygen and ventilator settings whenever possible.
    - The concerns when using mechanical ventilation is the long term damage that can occur such as chronic lung disease.



Before Surfactant

After Surfactant

# What Is Being Done To Improve Mortality Rates?

- Improving birth outcomes requires public health agencies working together with health care providers, communities, and partners to reduce infant deaths in the United States. CDC is committed to improving birth outcomes and listed below are programs they are using to help understand and reduce infant mortality.
  - Perinatal Quality Collaborative are state or multi-state networks of teams working to improve the quality of care for mothers and babies. Perinatal Quality Collaborative have contributed to improvements in health care and outcomes for mothers and babies, including:
    - Reductions in deliveries before 39 weeks of pregnancy without a medical reason
    - Reductions in healthcare associated bloodstream infections in newborns
    - · Reductions in severe pregnancy complications
  - SUID is the sudden and unexpected death of an infant less than 1 year old without an obvious cause of death before investigation. The CDC has SUID monitoring programs in 16 states and 2 jurisdictions. Participating states and jurisdictions use data about SUID and circumstances to develop strategies to reduce future deaths
  - Pregnancy Risk Assessment Monitoring System (PRAMS) was established in 1987 to reduce infant morbidity and mortality. PRAMS data can be used to identify groups of women and infants at high risk for health problems, and to measure progress toward goals in improving the health of mothers and infants
  - National Center on Birth Defects and Developmental Disabilities. The CDC works to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with birth defects

# What Is Being Done To Improve Mortality Rates?

- The March of Dimes aims to reduce preterm birth rates across the United States to 8.1 percent of live births by 2020. Every baby in South Carolina deserves the chance to be born healthy.
- Prematurity Research Initiative: In 2004, the PRI began and it funds research into the causes of prematurity. The PRI are exploring how genetics or a combination of genetic and environmental factors may influence a woman's chances of going into premature labor.
- The Processes of Development: Some of March of Dimes grantees are studying basic biological processes of development. This research should improve our understanding of how genes and other factors direct the transformation from a single cell into a complete being.
- Genetic Causes: Genetics has been a main theme of March of Dimes research. Grantees have discovered genes that cause or contribute to a number of common birth defects, including fragile X-syndrome, cleft lip and palate and heart defects



Conclusion/Wrap-Up

### Congratulations! You have finished the module.

Last Step: Complete the Post-Test & Evaluation

- All participants must complete the Post-Test and Evaluation.
- New This Year Online Post-Test and Evaluation (Preferred Methods)
- Please click on the following link
   <a href="https://www.surveymonkey.com/r/PKHHQMJ">https://www.surveymonkey.com/r/PKHHQMJ</a> or open
  your I-Phone Camera and scan the QR Code located to
  the right to access the online Post-Test and Module
  Evaluation
- Alternate option, please complete the paper version of the post-Test utilizing the Answer Sheet and Evaluation
  - Return Answer sheet/Evaluation Form to Perinatal Systems:
    - Fax: (803)434-4309
    - E-mail: <u>PerinatalSystems@prismahealth.org</u>
- Questions?

Contact Cathy White (<u>Cathy.White@prismahealth.org</u>) or Michelle Flanagan (<u>Michelle.Flanagan@prismahealth.org</u>)





