Fetal Deaths

IMPORTANCE

HISTORY

REPORTING

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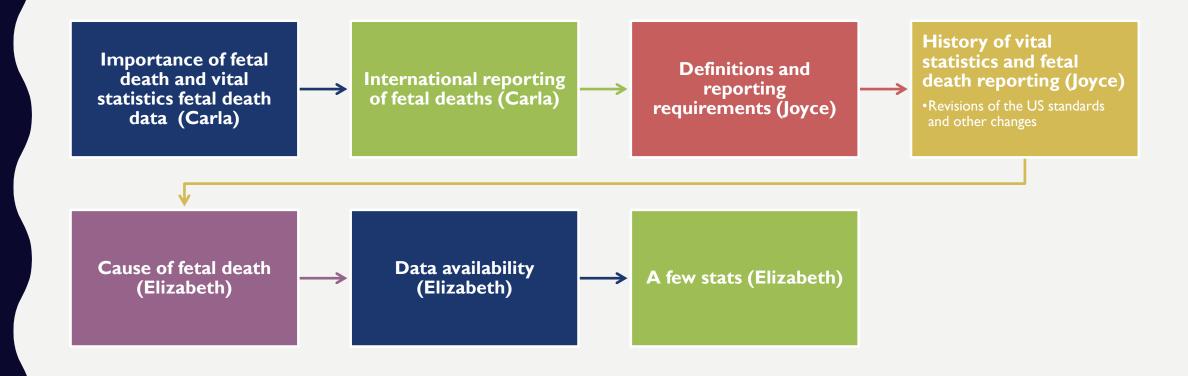
ACKNOWLEDGEMENTS

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OUTLINE



THE IMPORTANCE OF FETAL DEATH

THE IMPORTANCE OF FETAL DEATH

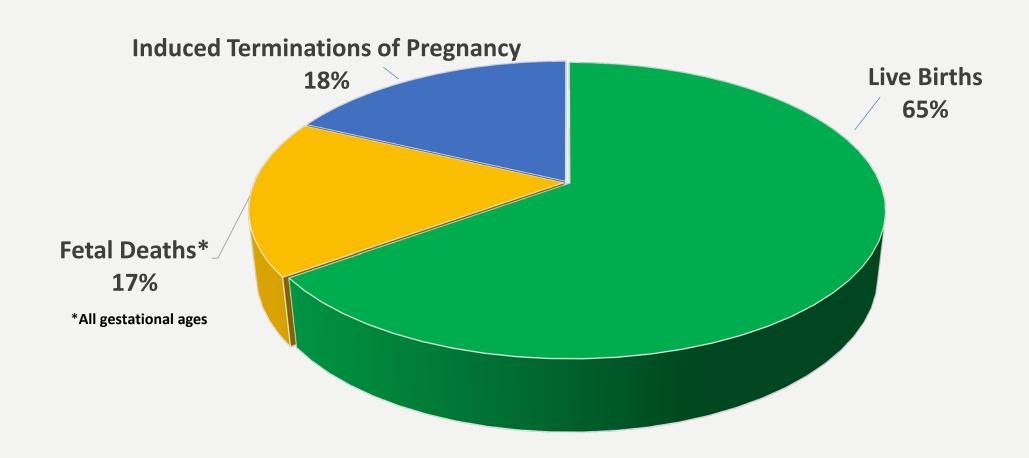
- Fetal deaths are part of the continuum of pregnancy outcomes
- Fetal death can be a heartbreaking tragedy for women and families



- Causes are poorly understood, but believed to be associated with:
 - Maternal infections
 - Non-communicable diseases
 - Chromosomal abnormalities
 - Obstetric complications



DISTRIBUTION OF ALL PREGNANCIES BY OUTCOME: UNITED STATES, 2010 (N = 6.2 MILLION)



Around the world, there are an estimated

2.6 million fetal deaths

of at least 20 weeks gestation each year



INTERNATIONAL REPORTING OF FETAL DEATHS

INTERNATIONAL REPORTING: WORLD HEALTH ORGANIZATION



- WHO has long recognized the importance of international comparison of perinatal mortality and its components.
- One of the tasks of WHO is to coordinate the compilation of health statistics and to encourage member countries to rely on the same definitions to allow for the comparison of those statistics.
- Events related to birth, death, and fetal death, and the reporting requirements for the data, are defined in the *International Classification of Diseases* (ICD).

INTERNATIONAL REPORTING: WORLD HEALTH ORGANIZATION



- WHO recommends that, if possible, all fetuses and infants weighing at least 500 g at birth, whether alive or dead, be included in the statistics.
- The inclusion in national statistics of fetuses and infants weighing between 500 g and 1000 g* is recommended both because of its inherent value and because it improves the coverage of reporting at 1000 g and over.
- Dissimilar definitions and reporting methods continue to hamper international comparisons.

*In the United States, all live births, regardless of weight or gestational age and fetal deaths of 350 grams or 20 weeks or greater are to be reported. World Health Organization .World Health Organization; Geneva: 2006. Neonatal and perinatal mortality country, regional and global estimates. Accessed at: http://whglibdoc.who.int/publications/2006/9241563206 eng.pdf.

INTERNATIONAL FETAL DEATH DATA

- Despite the importance to women and infant health, fetal deaths are still not included in the major international measures of disease burden:
 - Sustainable Development Goals
 - Global Burden of Disease estimates
- Data on fetal deaths are less frequently available than data on births and infant deaths
- Fetal death data are available for fewer countries and are less consistent than early neonatal and neonatal mortality data
- Fetal deaths are more likely underreported, especially at earlier gestational ages
 - The magnitude of underreporting likely varies by country

IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA

THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA



National Vital Statistics System

Vital statistics data are the most comprehensive source of US data on fetal deaths of 20 weeks of gestation and greater.

THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA



National Survey of Family Growth

- The only other national source of fetal death data is the National Survey of Family Growth (NSFG).
 - However, the NSFG has important limitations that vital statistics data do not have:
 - Data including gestational age information are self-reported and subject to recall bias
 - Does not include information from clinicians or medical records
 - Cannot produce state-level or lower geographic-level estimates

THE IMPORTANCE OF VITAL STATISTICS FETAL DEATH DATA

- The study of fetal deaths can provide important clues on how various health conditions and risk factors can affect pregnancy outcomes.
- In Utah, fetal death records are used to send surveys to women who have recently experienced a fetal death.
 - The study is called the Study of Associated Risks of Stillbirth (SOARS) and is an adaptation of the Pregnancy Risk Assessment Monitoring System (PRAMS).
 - Surveys include questions about:
 - Women's life experiences before and during pregnancy
 - Delivery and hospital experience
 - Health behaviors
 - Clinical testing
 - Bereavement support
 - Reliable fetal death data is the critical first step for this type of study.

POLL QUESTION

Is your state/jurisdiction currently or planning to use fetal death records to send surveys to women who have recently experienced a fetal death?

Yes, we currently have such a survey

Yes, we are planning, or are interested in planning such a survey

No, we are not planning such a survey

Don't know

DEFINITIONS

LIVE BIRTH MODEL LAW DEFINITION*

The complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy, which, after such expulsion or extraction, breathes, or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.

^{*} Model State Vital Statistics Act and Regulations. Consistent with WHO definition

FETAL DEATH MODEL LAW DEFINITION*

Fetal death is defined as death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy and which is not an induced termination of pregnancy. The death is indicated by the fact that after such expulsion or extraction, the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

* Model State Vital Statistics Act and Regulations. Consistent with WHO definition.

INDUCED TERMINATION OF PREGNANCY (ITOP)

The purposeful interruption of an intrauterine pregnancy with the intention of other than to produce a live-born infant, and which does not result in a live birth. This definition excludes management of prolonged retention of product of conception following fetal death.

* Model State Vital Statistics Act and Regulations. The WHO does not have a definition for ITOP.

Live Birth vs. Fetal Death vs. ITOP

Evidence of Life

- -Breathing*
- -Beating of the heart**
- -Pulsation of the umbilical cord
- -Definite movement of voluntary muscles

Death prior to delivery

Not an induced termination of pregnancy

No evidence of life

- -No breathing*
- -No beating of the heart**
- -No pulsation of the umbilical cord
- -No definite movement of voluntary muscles

Purposeful interruption of an intrauterine pregnancy with the intention of other than to produce a live-born infant

^{*}Respirations are to be distinguished from fleeting respiratory efforts or gasps

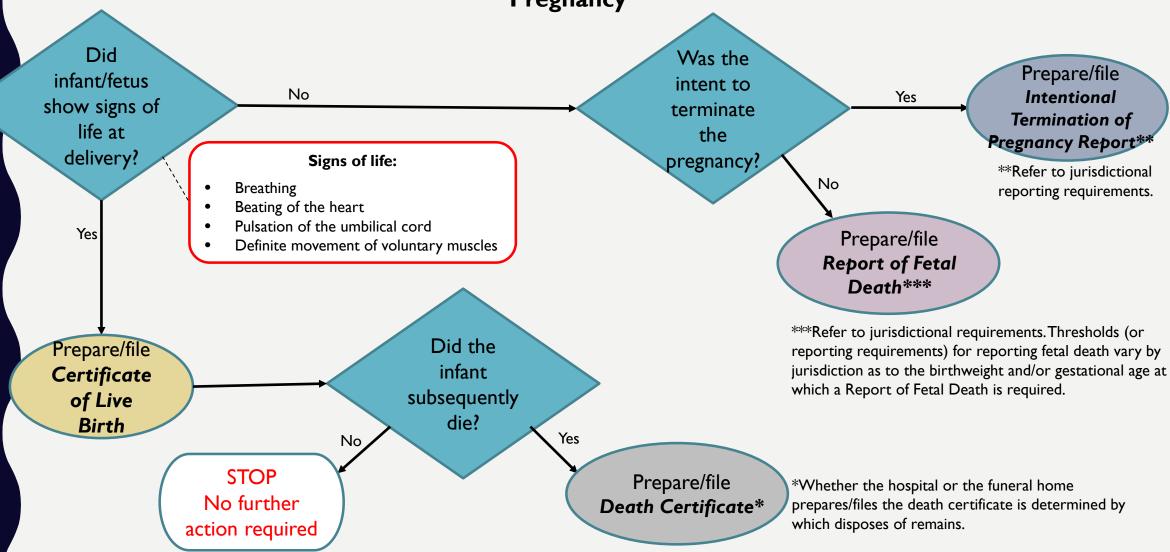
^{**}Heartbeats are to be distinguished from transient cardiac contractions

DEFINITIONS BY STATE

All states use definitions of live birth and fetal death that are fundamentally consistent with The Model Law

Live Birth vs. Fetal Death vs. ITOP Decision Tree

Guidelines for Reporting Live Births, Infant Deaths, Fetal Deaths, and Induced Terminations of Pregnancy



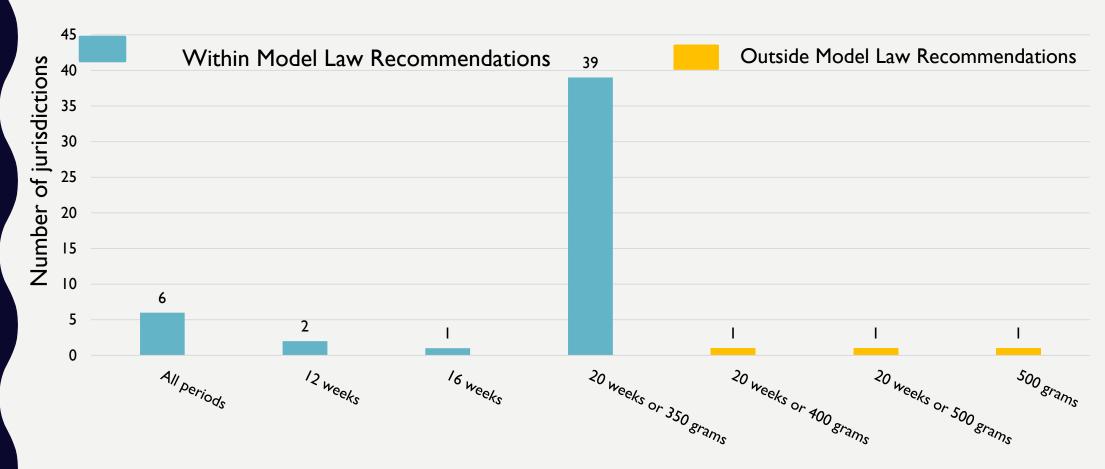
REPORTING REQUIREMENTS

RECOMMENDED REPORTING REQUIREMENTS

Model State Vital
Statistics Act and
Regulations

- Both The 1992 and The 2011 Model State Regulations and Reporting Requirements (Model Law) recommend that a fetal death be reported if it is:
 - 350 grams or more, OR if weight is unknown
 - 20 completed weeks gestation or more, calculated from the date last normal menstrual period began to the date of delivery
 - ✓ <u>All</u> live births are to be reported regardless of gestational age or viability.

GESTATIONAL AGE/BIRTHWEIGHT AT WHICH FETAL DEATH REPORTING IS REQUIRED BY STATE

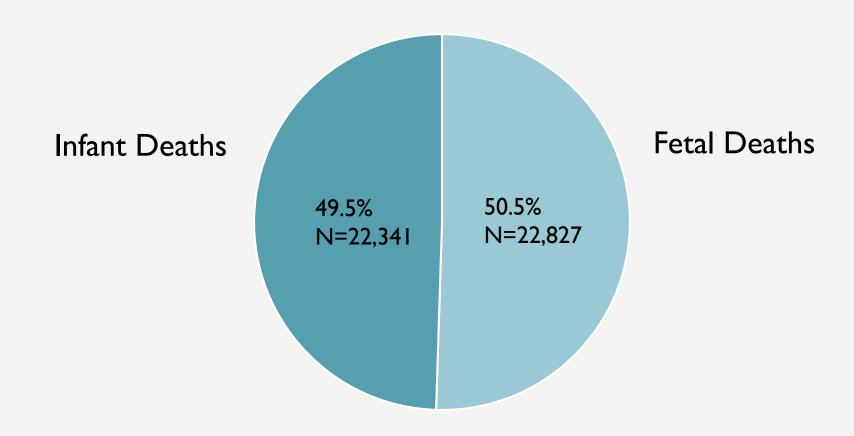


Gestational age/Birthweight at which reporting is required

REPORTING REQUIREMENTS

- National fetal death data available for 20+ weeks
- Historically, reporting of fetal deaths tends to be more complete the earlier reporting is required
- Differences in state reporting requirements can affect the completeness of national reporting at 20+ weeks
- And, accordingly, comparisons of fetal mortality rates by state
 - Solution = restrict to 24 and greater weeks for state x state comparisons

RELATIVE MAGNITUDE OF FETAL DEATHS OF 20+ WEEKS OF GESTATION, AND INFANT DEATHS: UNITED STATES, 2017



NOTE: Infant death is defined as death within the first year of life.

POLL QUESTION (POP QUIZ!)

A woman comes to the hospital and delivers at 29 weeks gestation. The infant does not appear to breathe or show any other evidence of life. How should this event be reported?

Certificate of Live Birth

Certificate of Death

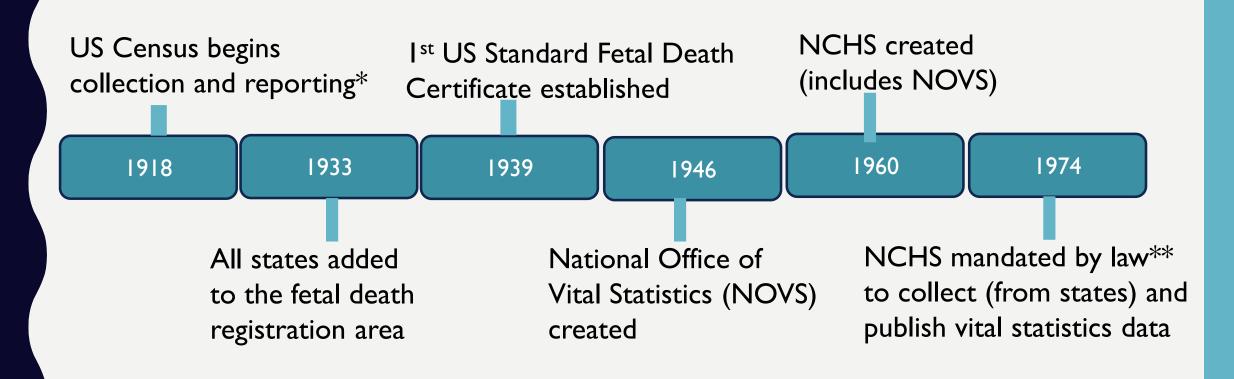
Report of Fetal Death

Certificate of Live Birth and Certificate of Death

Certificate of Live Birth and Report of Fetal Death

HISTORY

HISTORY OF FETAL DEATH REPORTING IN THE U.S.



^{*}Some states report via birth and death certificates, some use stillbirth certificate.

^{**}Health Services Research and Evaluation and Health Statistics Act of 1974 (Public Law 93–353)

REVISIONS OF US STANDARD FETAL DEATH REPORT

- Four revisions since 1939: 1955, 1978, 1989, 2003
- Beginning with 1978, revisions designed to capture information similar to that on birth certificate (COD included from 1939)
- 2003 revision expanded medical/health info captured; concerns soon grew over the amount of data collected
- Birth Data Quality Workgroup reviews/recommends dropping 36 items
 - Goal: to improve quality of other data items, especially COD
- Recommendations accepted by NAPHSIS & NCHS leadership; beginning with 2014 national file these items no longer included in national reporting

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		- game - bise - Contactment test of					e, istor sego	~ [REMINISTER PERFORMAN					
		164. OSSTETRO ESTANTE OF GESTATION AT DELAYERY OF CHAT SAVIgation, after					market.	- 1	(Tel. (Nr.) Formet					
				9.00	more time of large	tal, were not over on his touco one?								
		Comple	NE WHOLE					- 1		RESILTS USED IN DETERMINE				
								- 1		FETAL DEATH?				
REV.	19361													

2003 REVISIONS ITEMS (36) DROPPED FROM NATIONAL REPORTING

- Mother ever married (not standard marital status item or on standard fetal report but part or stional file)
- Mother married? (At delivery, conception or anytime between)
- Total number of prenatal visits for this pregnance
 - Edit flag Total number of prenatal visits for this pregnancy
- Date of last prenatal care visit*
- Mother's weight at delivery
 - Edit flag Mother's weight at delivery
- Number of other pregnancy outcomes

- Date of last other pregnancy outcome
- Mother/patient transferred for maternal medical or fetal indications for delivery?
- Previous preterm birth (Risk factors for this pregnancy)
- Other previous poor pregnancy outcomes (Risk factors for this pregnancy)*
- Hysterotomy/hysterectomy (Method of delivery)
- Vaternal transfusion (Maternal morbidity)
- This or fourth degree perineal laceration (Maternal morbidis)
- Unplanned by terectomy (Maternal morbidity)
- Unplanned operating room procedure (Maternal morbidity)

2003 REVISIONS ITEMS (36) DROPPED FROM NATIONAL REPORTING

- Infections present and/or treated during this pregnancy:
 - Gonorrhea
 - Syphilis
 - Chlamydia
 - Listeria
 - Group B strep
 - Cytomegalovirus
 - Parvovirus
 - Toxoplasmosis
 - Other (Specify)

- Congenital anomalies of the fetus
 - Anencephaly
 - Meningomyelocele/Spina bifida
 - Cyanotic congenital heart disease
 - Congenital diaphragmatic hernia
 - Omphalocele
 - Gastroschisis
 - Limb reduction defect
 - Cleft Lip with or without Cleft Palate
 - Veft palate alone
 - Dow syndrome- karyotype confirmed/pending
 - Suspecte Chromosomal disorder karyotype confirmed/pending
 - Hypospadias

CAUSE OF FETAL DEATH

IMPORTANCE OF REPORTING CAUSE OF FETAL DEATH

- While sometimes unknown, the cause of these deaths is a critical piece of information to identify why the death occurred and factors that might influence ways to prevent such losses
- Better information on the cause of fetal death can help us to prevent these tragic events in the future.

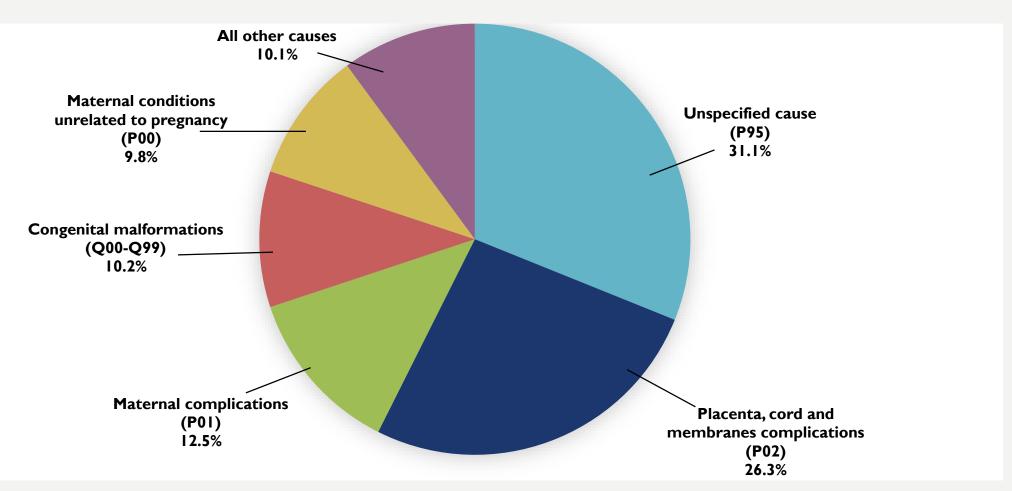
	18. CAUSE/CONDITIONS CONTRIBUTING TO FETAL DEATH			
CAUSE	18a. INITIATING CAUSE/CONDITION		18b. OTHER SIGNIFICANT CAUSES OR CONDITIONS	
OF	(AMONG THE CHOICES BELOW, PLEASE SELECT THE ONE WHICH MOST LIKELY BEGAN THE SEQUENCE OF EVENTS RESULTING IN THE DEATH OF THE FETUS)		(SELECT OR SPECIFY ALL OTHER CONDITIONS CONTRIBUTING TO DEATH IN ITEM 18b)	
FETAL DEATH	Maternal Conditions/Diseases (Specify)		Maternal Conditions/Diseases (Specify)	
	Complications of Placenta, Cord, or Membranes		Complications of Placenta, Cord, or Membranes	
1 1	□ Rupture of membranes prior to onset of labor		□ Rupture of membranes prior to onset of labor	
	□ Abruptio placenta		□ Abruptio placenta	
	□ Placental insufficiency		Placental insufficiency	
	□ Prolapsed cord		□ Prolapsed cord	
	□ Chorioamnionitis		□ Chorioamnionitis	
Mother's Name	Other Specify)		Other Specify)	
	Other Obstetrical or Pregnancy Complications (Specify)		Other Obstetrical or Pregnancy Complications (Specify)	
	Fetal Anomaly (Specify)		Fetal Anomaly (Specify)	
	Fetal Injury (Specify)		Fetal Injury (Specify)	
	Fetal Infection (Specify)		Fetal Infection (Specify)	
	Other Fetal Conditions/Disorders (Specify)		Other Fetal Conditions/Disorders (Specify)	
	Unknown		Unknown	
	18c. WEIGHT OF FETUS (grams preferred, specify unit)	18e. ESTIMATED T	IME OF FETAL DEATH	18f. WAS AN AUTOPSY PERFORMED?
	□ grams □ lb/oz			18g. WAS A HISTOLOGICAL PLACENTAL EXAMINATION PERFORMED?
			, after first assessment	□ Yes □ No □ Planned
	18d. OBSTETRIC ESTIMATE OF GESTATION AT DELIVERY			18h. WERE AUTOPSY OR HISTOLOGICAL PLACENTAL EXAMINATION RESULTS US

CAUSE OF FETAL DEATH

- Cause of fetal death data was not released by NCHS prior to 2014 because of concerns with data quality and the lack of resources needed to adequately code cause of death.
- NCHS recently revised instructions on coding, developed a system for processing cause, and assumed responsibility for coding fetal cause of death for revised reporting areas starting in 2010.
- The first NCHS report on cause of fetal death was released in October 2016; a new report, with COD data through 2017 was released earlier this month.



FETAL DEATHS BY SELECTED CAUSES, 39 AREAS: 2017



NOTES: By place of residence. Excludes CT, GA, MI, MS, ND, NY, RI, TN, VA, VT, WI, which had more than 50% of records with unspecified COD. CA was also excluded because COD data are based on the 1989 revision and are not considered comparable with the 2003 revision format.

SOURCE: NCHS, National Vital Statistics System, Fetal Deaths.

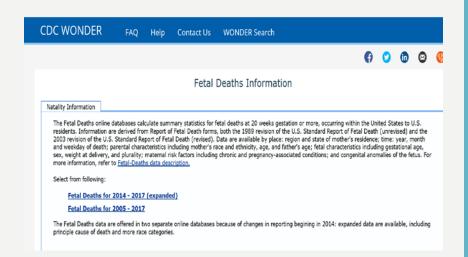
DATA AVAILABILITY

NATIONAL FETAL DEATH DATA RELEASES

- Due to the staggered implementation of the 2003 revision, there was a lack of comparable data items for many items through 2017
- For the 2018 data year, all 50 states, the District of Columbia, and New York City have revised their fetal death reports and national data based on the 2003 revision are available
 - -RELEASED THIS MONTH!
- Annual national detailed micro-data files and User Guide available at:

https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm

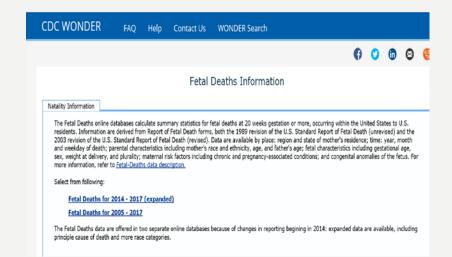
- CDC WONDER
 - Data available for 2005-2017 fetal deaths
 - Cause of Death data available for 2014-2017





NATIONAL FETAL DEATH DATA RELEASES

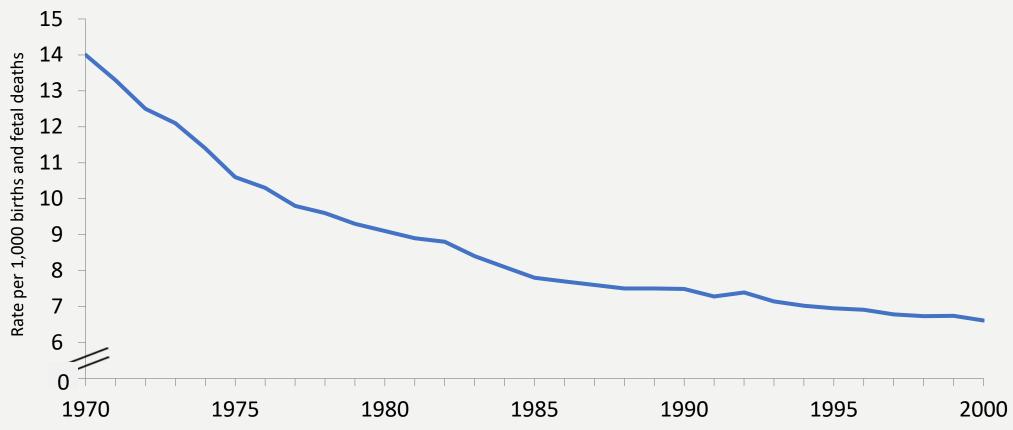
- Annual standard reports
 - Fetal death NVSR beginning with 2018 data (includes COD!)
 - Perinatal Data Brief beginning with 2018 data
- Special reports
 - NVSRs
 - Cause-of-death data from the fetal death file, 2015-2017 (Released this month!)
 - Cause of Fetal Death: Data From the Fetal Death Report, 2014 (2016)
 - Data briefs
 - Lack of Change in Perinatal Mortality in the United States, 2014 (2018)
 - Trends in Fetal and Perinatal Mortality in the United States, 2006–2012 (2014)





A FEW STATS

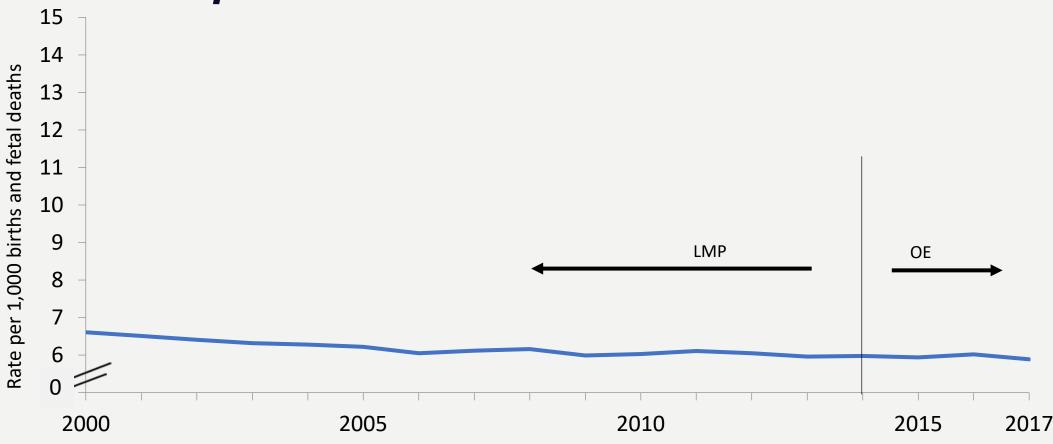
FETAL MORTALITY RATE: UNITED STATES, 1970-2000



NOTES: Fetal mortality rates are the number of fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths.

SOURCE: CDC/NCHS, National Vital Statistics System.

FETAL MORTALITY RATE: UNITED STATES, 2000-2017

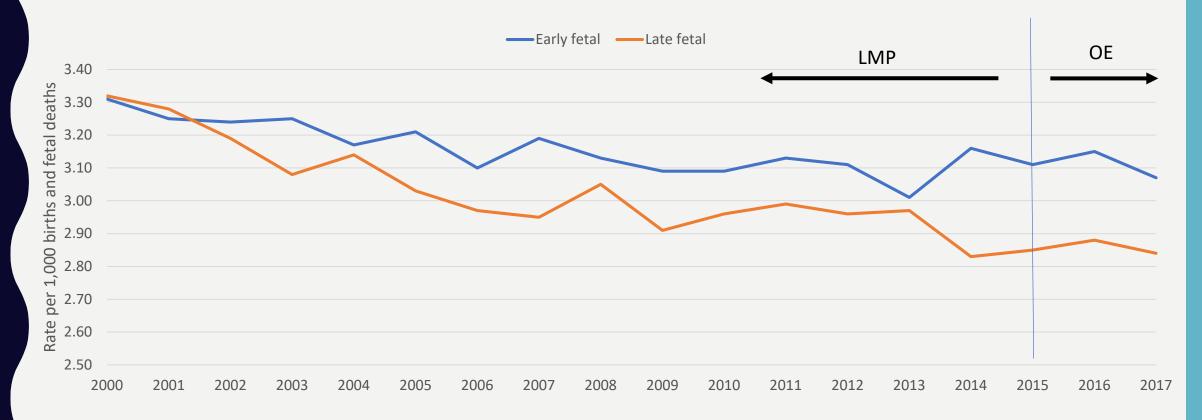


NOTES: Fetal mortality rates are the number of fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths.

Starting with 2014 data, the obstetric estimate of gestation at delivery (OE) replaced the gestational age measure based on the date of the last normal menses (LMP).

SOURCE: CDC/NCHS, National Vital Statistics System.

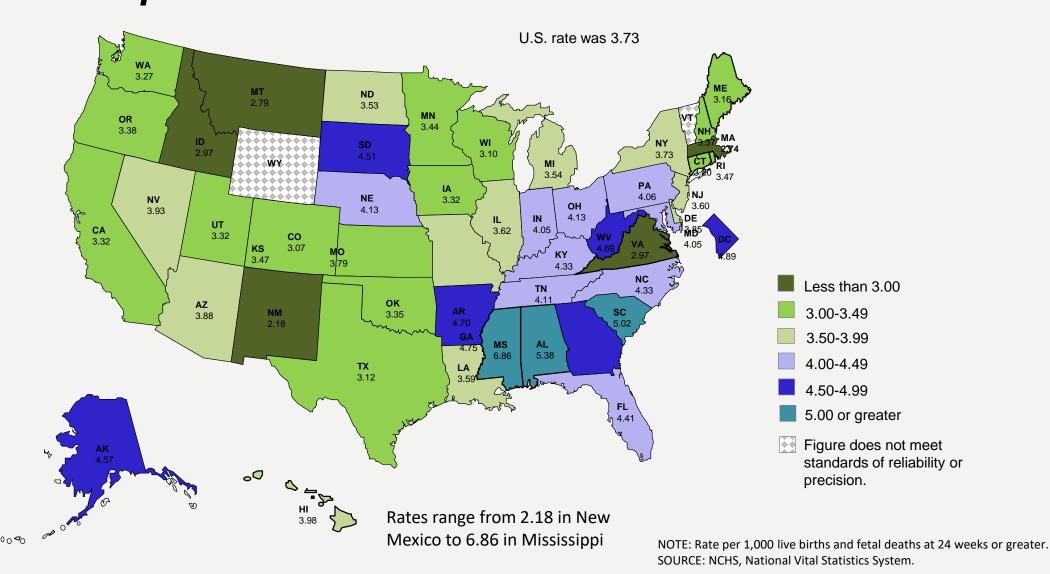
EARLY AND LATE FETAL MORTALITY: UNITED STATES, 2000-2017



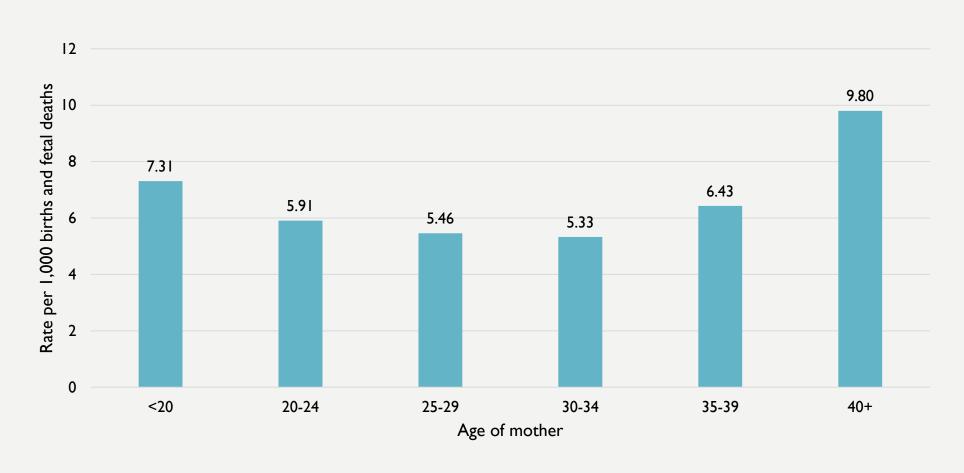
NOTE: Early fetal mortality rate is the number of fetal deaths at 20-27 weeks of gestation per 1,000 live births and fetal deaths at 20-27 weeks of gestation. Late fetal mortality rate is the number of fetal deaths at 28 weeks of gestation or more per 1,000 live births and fetal deaths at 28 weeks of gestation or more. Starting with 2014 data, the obstetric estimate of gestation at delivery (OE) replaced the gestational age measure based on the date of the last normal menses (LMP), introducing a discontinuity in early and late fetal mortality rates from earlier years; rates calculated using the different measures are non-comparable.

Source: CDC/NCHS, National Vital Statistics System.

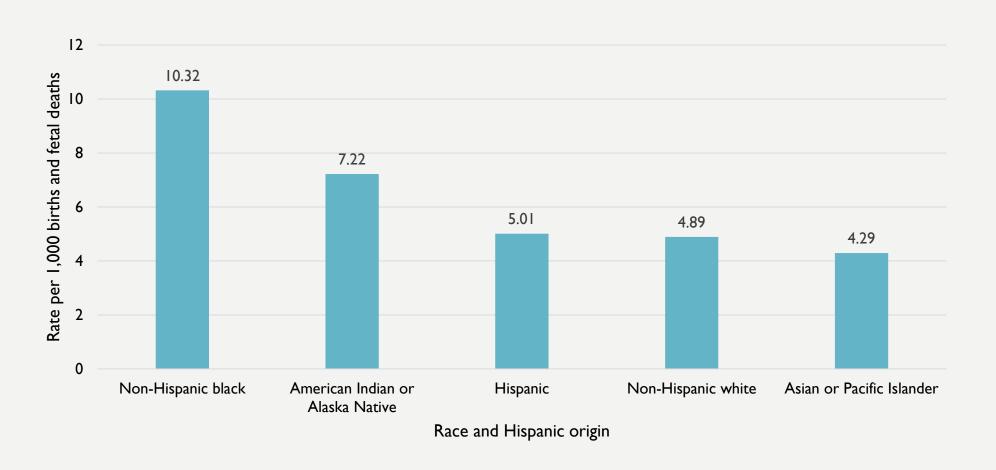
FETAL MORTALITY RATES AT 24 WEEKS OR GREATER BY STATE, 2017



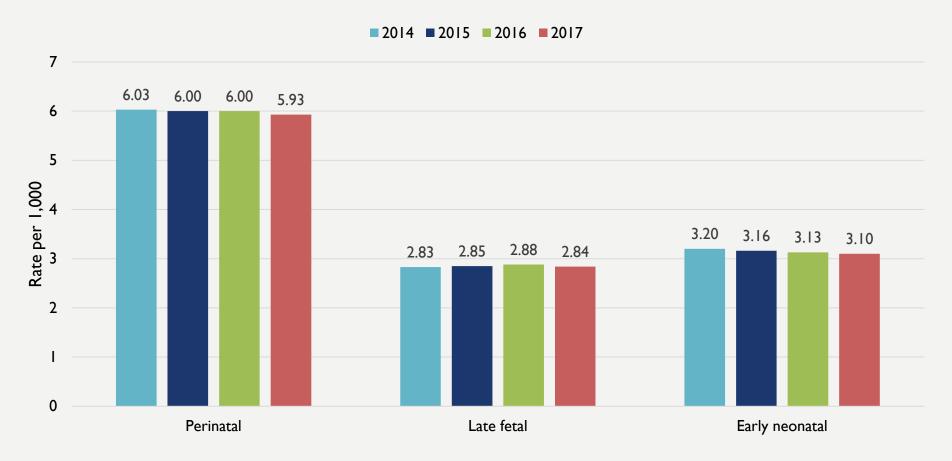
FETAL MORTALITY BY AGE OF MOTHER: UNITED STATES, 2017



FETAL MORTALITY BY RACE AND HISPANIC ORIGIN OF MOTHER: UNITED STATES, 2017



PERINATAL, LATE FETAL, AND EARLY NEONATAL MORTALITY RATES: UNITED STATES, 2014-2017



NOTES: Perinatal mortality is the number of infant deaths under age 7 days and fetal deaths at 28 weeks of gestation or more per 1,000 live births and fetal deaths at 28 weeks of gestation or more per 1,000 live births.

FETAL DEATH DATA QUALITY

Despite efforts to improve the quality of the data collected (e.g., dropping of multiple items from national reporting), the quality of fetal death data continues to be of concern

FETAL DEATH DATA QUALITY

• Please join us for our next webinar—July 15th:

ASSESSING AND IMPROVING THE QUALITY OF FETAL DEATH DATA

POLL QUESTION

Does your state publish stats on fetal deaths at least annually?

Yes

No

Plan to in the future

SUMMARY

FETAL DEATHS SUMMARY

Fetal deaths are part of the pregnancy continuum

There are more fetal deaths of 20 and greater weeks in the US than infant deaths, but are too often overlooked

Vital statistics data are the most comprehensive source of US data on fetal deaths of 20 weeks of gestation and greater

National data, including COD data based on the 2003 revision now available

Improvements in the quality of non-COD and COD data quality necessary

CONCLUSION

Fetal death data are often overlooked in the United States and around the world.

Improved fetal death data is key for improving maternal and child health.

QUESTIONS?