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U.S. Stillbirth Surveillance: The National Fetal Death File and Other Data Sources

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Abstract

The National Vital Statistics System is the primary source of information on fetal deaths of 20 weeks of gestation or more in the United States. Data are cooperatively produced by jurisdiction vital statistics offices and the National Center for Health Statistics. In order to promote the uniformity of data, the National Center for Health Statistics issues The Model State Vital Statistics Act and Regulations, and produces standard certificates and reports, developed in collaboration with the states, to inform the development of jurisdictional vital records laws and regulations and data collection. While there are challenges in collecting national fetal death data, there are ongoing data quality improvement efforts to address them. Improved national fetal death data and data from other sources will continue to add insights into the risks, causes and prevention of fetal death.

PUBLIC HEALTH IMPORTANCE

Fetal mortality is the intrauterine death of a fetus at any gestational age (1). Since 2011, there have been slightly more fetal deaths at 20 weeks of gestation or more, often referred to as stillbirths, than infant deaths in the United States each year (1,2). The fetal mortality rate has generally declined over time, but the pace of the decline has slowed in the last two decades (1). Despite the importance of fetal death as a public health issue, fetal mortality has received substantially less attention than infant mortality in terms of research, prevention strategies, and public awareness. However, over the last decade, there has been a growing interest in understanding and preventing fetal deaths both nationally and internationally.

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Disclaimer:
The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Declaration of Competing Interest
None.

NATIONAL VITAL STATISTICS SYSTEM

DATA COLLECTION

The National Vital Statistics System (NVSS) is the primary source of information on fetal deaths in the United States. Fetal mortality data from the NVSS are cooperatively produced by jurisdiction vital statistics offices and the National Center for Health Statistics (NCHS) under a joint agreement known as the Vital Statistics Cooperative Program. Vital statistics data on fetal deaths of 20 weeks of gestation or greater were first collected by the Bureau of the Census in 1918. Beginning in 1922, the Bureau began annually collecting and tabulating these statistics from states for a limited birth-registration area. All states were admitted into the birth-registration area by 1933, allowing for the national compilation of data. In 1946, the responsibility for maintaining vital statistics data for the nation moved to the Public Health Service; this responsibility has rested with NCHS at the Centers for Disease Control and Prevention (CDC) since 1960 (3).

DEFINITION AND REPORTING REQUIREMENTS

Definitions—The United States adopted the World Health Organization's (WHO) definition of fetal death in 1950 (4):

> Death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation, 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.

This definition was intended to emphasize the absence of signs of life at delivery regardless of gestational age. Subsequently, the 1992 revision of The Model State Vital Statistics Act and Regulations (Model Law), which serves as a model for states to use in developing their own vital records laws and regulations, further expanded this definition to add "Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps" (5). Since 1950, the term "fetal death" has been used to reduce confusion among the terms, stillbirth, spontaneous abortion, and miscarriage. All U.S. vital records registration areas use definitions similar to the standard definition except Puerto Rico and Wisconsin, which have no formal definition (6). Fetal deaths do not include induced terminations of pregnancy, which the Model Law defines as "the purposeful interruption of an intrauterine pregnancy with the intention other than to produce a live-born infant, and which does not result in a live birth" (5).

Reporting Requirements—The Model Law also recommends the reporting of fetal deaths based on weight and gestational age criteria. The current Model Law recommends the reporting of all fetal deaths with a birthweight of 350 grams or more, or if birthweight is unavailable, gestational age of 20 completed weeks or greater (5). As shown in Table 1, the majority of vital records reporting areas (50 states, 5 U.S. territories, New York City, and the District of Columbia) require reporting of fetal deaths at 20 weeks or more. All jurisdictions require reporting of fetal deaths of at least 20 weeks of gestation or more, or a minimum birthweight of 350 grams (roughly equal to 20 weeks), or some combination of

the two, but some require reporting at earlier gestational ages. Six states, New York City, American Samoa, and the U.S. Virgin Islands require reporting of fetal deaths at all periods of gestation, two states require reporting beginning at 12 weeks of gestation, and one state requires reporting beginning at 16 weeks of gestation (1). Because only nine jurisdictions require reporting of fetal deaths of all ages, national information on deaths of <20 weeks is not available and NCHS bases most publications on fetal deaths at 20 weeks of gestation and greater. However, most fetal deaths occur before 20 weeks of gestation (1), and the lack of data on these fetal losses results in an incomplete picture of the true magnitude of fetal mortality.

U.S. STANDARD REPORT OF FETAL DEATH

NCHS produces standard certificates and reports, developed in collaboration with the states, that serve as models for the states and other registration areas in determining data items to be collected. In 1939, the newly developed U.S. Standard Certificate of Stillbirth replaced the earlier procedure of filing both a live birth and death certificate when reporting a fetal death. The Certificate of Stillbirth underwent several revisions before becoming the U.S. Standard Report of Fetal Death in 1978. Beginning in 1978, revisions were designed to capture information similar to that collected on the birth certificate. Since then, the U.S. Standard Report of Fetal Death has been periodically reviewed and evaluated by NCHS and the states to ensure that data items meet health and administrative needs and to serve as the model for state reports (7). Information on the cause of death has been included on the standard fetal death report since 1930 (8), but states only began to report the information to NCHS with the 1989 revision of the report.

The latest revision of the U.S. Standard Report of Fetal Death was implemented in 2003 (9). Following a review by a panel of expert consultants, many data items included on the 1989 revision were dropped or modified and a number of new demographic and health items were added (7). The cause of death section of the report was substantively redesigned to be consistent with data collection instructions in the WHO's International Statistical Classification of Diseases and Related Health Problems, Tenth Revision while providing more guidance on desired information and retaining flexibility to report any cause (7,10). As of 2018, all 50 states, the District of Columbia, Guam, the Northern Marianas, Puerto Rico, and the U.S. Virgin Islands had transitioned to the 2003 revision (1).

DATA QUALITY ISSUES AND LIMITATIONS

While vital statistics fetal death data can be a rich source of demographic and health information and crucial to helping researchers better understand the causes of pregnancy loss, the utility of this information can be limited because of data quality issues and other limitations.

Item-Specific Nonresponse—Fetal death records generally have more missing responses for individual data items than birth and death records. These higher levels of nonresponse for fetal deaths reflect both difficulty in ascertaining data for deaths occurring early in pregnancy, such as cause of death or sex, and limitations in access to necessary information, such as access by hospital staff to the appropriate medical records. Additional

factors potentially contributing to item nonresponse may include the lower priority often given to the fetal death reporting system than other vital statistics systems and fewer resources available for follow-up at both the jurisdictional and national levels. In general, percentages of missing responses are higher for fetal deaths than for births, and for fetal deaths occurring earlier in the gestational period (see Table 2).

Misclassification—An additional quality concern is the potential for misclassification of fetal deaths as live births and live births as fetal deaths (11), as well as induced abortions as fetal deaths because of differences in the clinical interpretation or understanding of the WHO/Model Law fetal death definition. To help practitioners distinguish between fetal deaths and live births in the United States, the American Academy of Pediatrics publishes the NVSS definitions and reporting requirements for fetal deaths in Guidelines for Perinatal Care (12). Additionally, NCHS and many states carefully review and adjudicate fetal death records that report induced abortion-related terms.

Unknown Cause of Fetal Death—Unknown or unspecified cause of death consistently accounts for a large percentage of deaths across studies of fetal death (13-19). However, the likelihood of establishing cause is improved when a thorough assessment of the pregnancy and the death is conducted, and clinical and laboratory information, placental pathologic examination, and autopsy findings are available (16).

Change in Measures of Gestational Age—Because risks for poor pregnancy outcomes differ across gestational periods, the accuracy of gestational age estimates is important to the interpretation and further analysis of these data. Due to increasing evidence of the greater validity of obstetric estimate of gestation (OE)-based data (20), compared to reporting based on last menstrual period (LMP), NCHS transitioned from the use of a measure based on the date of LMP to the OE as the primary measure of gestational age in 2014. While this change resulted in no difference in the total fetal mortality rate based on the two measures, the change resulted in differences in the number and rate of early and late fetal deaths (21). Accordingly, rates calculated using these two measures are considered non-comparable and, therefore, long-term trends cannot be assessed.

DATA QUALITY IMPROVEMENT EFFORTS

Over the years, many data quality improvement efforts have been implemented to help improve the quality of vital statistics fetal death data.

2003 Revision of the U.S. Standard Report of Fetal Death—The focus of the revision was to improve data quality, expedite data collection and transmission, and improve the standardization of data across the country. Details of this effort are described elsewhere (7, 22). To achieve these goals, several changes were implemented. Standard worksheets (the Patient Worksheet and the Facility Worksheet) were developed to help ensure that information included on the report of fetal death is gathered from the proper sources, and a comprehensive instruction manual, The Guide to Completing the Facility Worksheets for the Certificate of Live Birth and Report of Fetal Death (2003 revision), was developed (and updated in 2016) with detailed definitions, instructions and key words to help hospital

staff better report this information (23-25). E-Learning training was developed to increase knowledge of the importance of, and best practices for, reporting birth certificate and report of fetal death information, including instructions on how to complete the cause of death section of the Report of Fetal Death (26). The Medical Examiners' and Coroners' Handbook on Death Registration and Fetal Death Reporting was prepared to provide guidance for medical certifiers completing death certificates and fetal death reports (27). As noted above, the cause of death section of the U.S. Standard Report of Fetal Death was also redesigned with the 2003 revision to improve the quality and specificity of the information reported.

Changes to Coding Cause of Death—In an effort to improve the quality of fetal cause of death data, NCHS assumed responsibility for coding fetal cause of death for all reporting areas in 2010, revised instructions for coding that reflected the format of the cause of death information on the 2003 report revision, and developed a system for processing cause of death data. Following several years of coding, evaluation, and assessment, these efforts were successful in culminating in the first release of cause of fetal death data in 2016 (10).

Dropping of Data Items on the 2003 Revision of the U.S. Standard Report of Fetal Death from National Reporting—In 2015, a workgroup comprised of state and NCHS representatives and subject matter experts was convened to investigate the possibility of reducing the number of data items on the U.S. Standard Report of Fetal Death to a set of items that could potentially be collected more completely and accurately (28). The goal was to improve the quality of remaining items, especially fetal cause of death data. As a result of the evaluation, 36 items were recommended to be dropped either because of poor data quality and lack of potential for improvement, lack of usefulness in adding to the understanding of why the death occurred, or because of overlap and redundancy with other items on the fetal death report (i.e., between the cause of death and non-cause of death sections of the report) (28). The recommendations were approved by NCHS and the National Association for Public Health Statistics and Information Systems (NAPHSIS), and the items have been dropped from the national fetal death data file.

National Institute of Child Health and Human Development's Stillbirth Working Group of Council—In 2022, the National Institute of Child Health and Human Development formed the Stillbirth Working Group of Council as a congressionally mandated task force to examine stillbirth in the United States. It was comprised of members from federal agencies, including NCHS, CDC, and the Health Resources and Services Administration (HRSA), advocacy organizations, professional organizations, and researchers. The Working Group ultimately developed a set of recommendations in 2023 to guide future efforts to improve recordkeeping, data collection, and analysis about stillbirths, especially cause of death, address disparities in stillbirth risk, better support families after a stillbirth occurs, and reduce the U.S. stillbirth rate through research and prevention efforts (29). Congress has requested that the Working Group continue its efforts, and the group will reconvene in October 2023.

NCHS Birth Data Quality Workgroup, Fetal Death Subgroup—In 2023, a new subgroup of the NCHS/NAPHSIS Birth Data Quality Workgroup was formed to address

challenges with fetal death vital statistics data. The charge of the new subgroup, which is comprised of state and NCHS representatives, is to establish best practices for accurate and timely reporting of fetal deaths by identifying approaches to improving fetal death reporting and providing recommendations for, and facilitating implementation of, new improvement efforts.

FETAL MORTALITY COUNTS AND RATES

In 2021, 21,105 fetal deaths occurring at 20 weeks of gestation or more were reported in the United States (1). The fetal mortality rate was 5.73 fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths (Figure 1). With minor year to year fluctuations, the U.S. fetal mortality rate declined 23% since 1990 (7.49) but has remained essentially stable since 2019 (5.70) (Figure 1). From 2014 to 2021, the early fetal mortality rate (20-27 weeks gestation) declined 7%, from 3.16 to 2.95, and the late fetal mortality rate (28 weeks gestation and greater) remained essentially unchanged (from 2.83 to 2.80) (1). In 2021, as in previous years, fetal mortality rates continued to vary by race and Hispanic origin. Rates were highest for non-Hispanic Black (9.89) and non-Hispanic Native Hawaiian or Other Pacific Islander (9.87) women and lowest for non-Hispanic Asian women (3.94) (Figure 2).

Since annual counts of fetal deaths are relatively small in some jurisdictions, data for three years are combined in Table 3 to generate more stable state-specific fetal mortality rates. For combined years 2019 through 2021, the fetal mortality rate ranged from 3.46 per 1,000 births and fetal deaths in New Mexico to 10.00 in Mississippi.

In 2021, for the 41 states and the District of Columbia that met reporting thresholds (less than 50% of records assigned to unspecified cause and reported cause of death based on the 2003 report revision) (1), five broad groupings of cause of death accounted for 89.9% of fetal deaths at 20 weeks of gestation or greater (Figure 3). By order of frequency, these were: 1) Fetal death of unspecified cause (unspecified cause) (31.3%); 2) Fetus affected by complications of placenta, cord and membranes (placenta, cord, and membrane complications) (24.2%); 3) Fetus affected by maternal conditions that may be unrelated to present pregnancy (maternal conditions unrelated to pregnancy) (12.6%); 4) Fetus affected by maternal complications of pregnancy (maternal complications) (11.9%); and 5) Congenital malformations, deformations and chromosomal abnormalities (congenital malformations) (9.9%). The five most commonly selected causes of fetal death and the top two causes were the same for non-Hispanic Black, non-Hispanic White, and Hispanic women, but the order of the other causes differed.

DATA AVAILABILITY AND SURVEILLANCE

NCHS conducts ongoing surveillance of fetal death data and disseminates findings through the publication of standard annual reports, special reports, and data releases. Beginning with 2020 data, NCHS began to publish annual reports based on provisional fetal death data (30); these reports provide more timely data for public health surveillance.

Final national fetal mortality data are generally available about one year following the close of a data year. Detailed tables are published annually in the User Guide to the Fetal Death Public Use File (31), as well as in standard annual NCHS reports. NCHS also produces

public-use data files containing individual record information on all registered fetal deaths; data for 1982-2021 are currently available (32). The file contents and characteristics are described in the User Guide to the Fetal Death Public Use File for the respective year (31).

Fetal death data are also available through CDC's Wide-ranging ONline Data for Epidemiologic Research (WONDER) (33). WONDER is a web-based data query system that makes the Centers for Disease Control and Prevention's data available to public health professionals and the public.

Additionally, the first report on cause of fetal death was published in 2016 and the first data file including cause of death data for selected states was released in 2017. Cause of death data continue to be released annually, and more detailed information on cause of death is now published triennially.

OTHER DATA SOURCES AND SURVEILLANCE ACTIVITIES

The National Survey of Family Growth

Additional NCHS activities on fetal death surveillance include the National Survey of Family Growth (NSFG) (34). The NSFG serves multiple purposes as a nationally representative survey of men and women aged 15-49 years in the household population of the United States. The survey's core purpose has always been to help explain variations in the U.S. birth rate by collecting information on the proximate determinants of fertility, including sexual activity, contraception, infertility, and pregnancy outcomes, as well as sociodemographic factors associated with these proximate determinants (34). Every woman interviewed is asked to provide a full pregnancy history, including dates and outcomes of each pregnancy. Pregnancy outcome is captured in six categories: miscarriage, stillbirth, abortion, ectopic or tubal pregnancy, live birth by cesarean section, and live birth by vaginal delivery. Women can report multiple outcomes for each pregnancy, if there was more than one fetus (for example, one twin born vaginally and the other twin a stillbirth).

National Center on Birth Defects and Developmental Disabilities

CDC's National Center on Birth Defects and Developmental Disabilities has included pregnancies affected with birth defects that ended in a stillbirth in its Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS), starting at the study's inception with 2014 births and, in 2016, stillbirths without birth defects were added as outcomes of interest in Arkansas and Massachusetts (35). BD-STEPS is a case-control study based on active surveillance, and with the latest funding cycle in 2023, women experiencing stillbirths in three states (Arkansas, Massachusetts, and New York) will be invited to participate in a telephone interview (35). The interview covers a broad range of questions about demographics, maternal illness, medication use, and lifestyle factors (35).

The National Institute of Child Health and Human Development

In 2006, The National Institute of Child Health and Human Development sponsored the Stillbirth Collaborative Research Network, a major multicenter population-based case–control study of the causes and extent of stillbirth in the United States (36). Although data

collection concluded in 2009, this study continues to serve as a data source for many studies on a variety of aspects regarding stillbirths (37).

Pregnancy Risk Assessment Monitoring System

The Pregnancy Risk Assessment Monitoring System (PRAMS), a joint research project between state, territorial, or local health departments and CDC's Division of Reproductive Health, collects a wealth of information directly from women who have had a recent live birth. Linked to vital records data (birth certificate), PRAMS survey data are used to describe the experience of women and their babies before, during, and after pregnancy (38). In 2016, CDC initially funded the Utah Department of Health to expand its PRAMS survey methodology and sampling of vital records data (report of fetal death) to collect information from women who experienced a stillbirth. Utah developed the Study of Associated Risks of Stillbirths (SOARS) survey and implemented it in 2018 to gather essential data for monitoring stillbirth and related factors, such as prenatal, obstetric and postpartum health care after a pregnancy loss (39). CDC provided funding for Utah for SOARS in 2021 to support continued data collection. Information collected can fill data gaps and has helped to inform efforts to conduct stillbirth surveillance in other states (40).

Fetal and Infant Mortality Review

Fetal and Infant Mortality Review (FIMR), funded by HRSA, is a community-based program that conducts case reviews of fetal and infant deaths, with the goal of implementing findings-based recommendations to prevent future deaths (41). In 2020, there were more than 150 state and local FIMR programs in operation in the United States (41).

CONCLUSION

National data on fetal deaths have been continuously collected via the vital statistics system for the last 90 years. These data are housed within the NVSS and represent the most comprehensive source of national U.S. data on fetal deaths of 20 weeks of gestation and greater. While there are challenges in collecting national fetal death data, a number of data quality improvement efforts have been, and continue to be, implemented. Improved national fetal death data in combination with data collected from other sources will continue to add insights into the risks, causes and prevention of fetal death.

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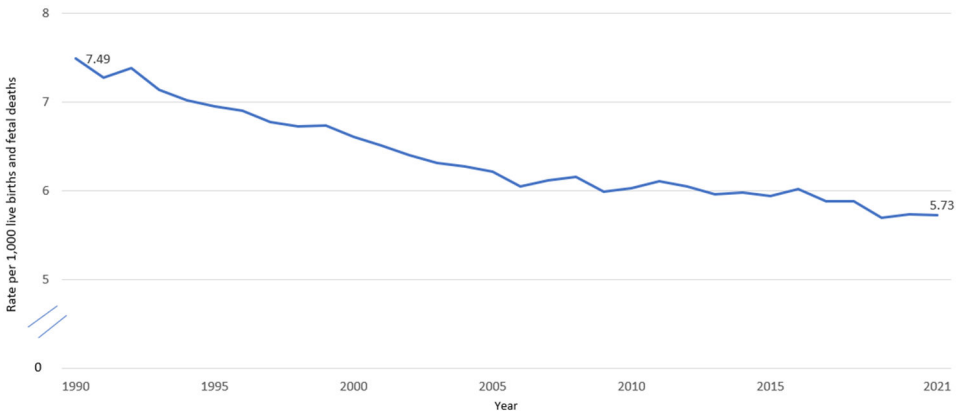

Figure 1. Fetal mortality rate: United States, 1990-2021

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

SOURCE: National Center for Health Statistics, National Vital Statistics System.

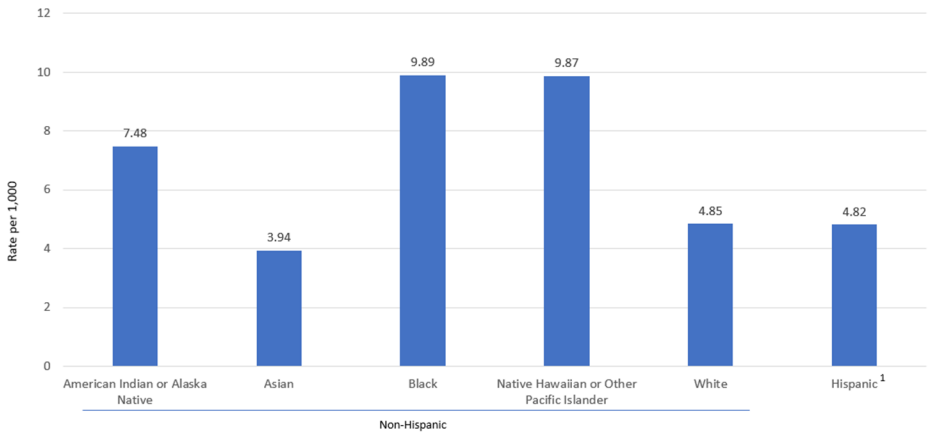

Figure 2. Fetal mortality rates by race and Hispanic origin of mother: United States, 2021

[1]People of Hispanic origin may be of any race.

SOURCE: National Center for Health Statistics, National Vital Statistics System.

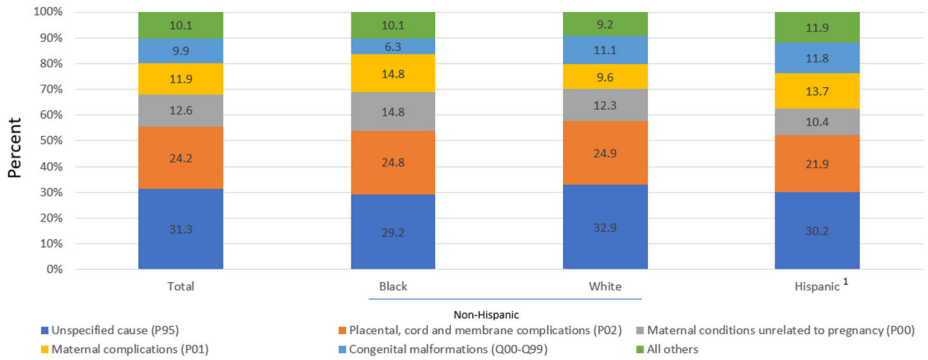

Figure 3. Percent distribution of fetal deaths by selected causes of death and race and Hispanic origin of mother: 41 states and the District of Columbia, 2021

[1]People of Hispanic origin may be of any race.

NOTE: Findings exclude data for jurisdictions (Arizona, Georgia, Hawaii, Mississippi, New York [including New York City], North Dakota, Vermont, and Wisconsin) for which the cause of death was unspecified (P95) for 50% or more of records. Also excludes data for California, which did not report cause of death based on the 2003 revision of the U.S. Standard Report of Fetal Death. Codes in parentheses are cause-of-death codes as classified by the International Classification of Diseases, Tenth Revision.

SOURCE: National Center for Health Statistics, National Vital Statistics System.

Table 1.

Reporting Requirements for Fetal Deaths by Reporting Area, 2021

Requirement	Number of Reporting Areas*
All periods of gestation	9
12 weeks	2
16 weeks	1
20 weeks	27
20 weeks or 350 grams	13
20 weeks or 400 grams	1
20 weeks or 500 grams	1
350 grams	3

*Includes all states, the District of Columbia, American Samoa, Guam, Northern Marianas, Puerto Rico, and the U.S. Virgin Islands. New York City is reported separately from New York State.

SOURCE: National Center for Health Statistics, National Vital Statistics System.

Table 2.

Percentage of Fetal Death Records on Which Selected Items Are not Stated: United States, 2021

	Fetal deaths			
	Total[1]	20-27 weeks	28 weeks or more	Live births
Maternal characteristics	Percentage			
Age	0.6	0.5	0.5	0.0
Education	14.3	15.3	13.0	1.5
Health care utilization				
Month prenatal care began	13.5	15.0	11.1	2.1
Pregnancy risk factors				
Smoking during pregnancy	8.0	8.0	7.6	0.4
Risk factors in this pregnancy	5.5	5.6	4.8	0.1
Fetal characteristics				
Sex	3.4	5.5	1.1	0.0
Birthweight	7.3	9.2	4.9	0.1

0.0 Quantity more than zero but less than 0.05

[1]Fetal deaths with stated or presumed period of gestation of 20 weeks or more.

SOURCE: National Center for Health Statistics, National Vital Statistics System.

Table 3.

Total number of fetal deaths at 20 weeks of gestation or more and fetal mortality rates: United States and each state, 2019-2021

Area	Fetal deaths[1]	Fetal mortality rate[2]
Total	63,437	5.72
Alabama	1,525	8.67
Alaska	166	5.76
Arizona	1,441	6.11
Arkansas	928	8.54
California	6,610	5.11
Colorado	989	5.25
Connecticut	444	4.28
Delaware	170	5.38
District of Columbia	221	8.24
Florida	4,590	7.06
Georgia	2,999	7.98
Hawaii	297	6.12
Idaho	341	5.14
Illinois	2,378	5.83
Indiana	1,391	5.78
Iowa	526	4.73
Kansas	559	5.32
Kentucky	962	6.09
Louisiana	914	5.23
Maine	206	5.80
Maryland	1,385	6.65
Massachusetts	866	4.21
Michigan	1,865	5.85
Minnesota	1,051	5.39
Mississippi	1,083	10.00
Missouri	1,221	5.76
Montana	137	4.12
Nebraska	328	4.43
Nevada	770	7.46
New Hampshire	182	4.99
New Jersey	1,964	6.52
New Mexico	230	3.46
New York	3,954	6.12
North Carolina	2,116	5.91
North Dakota	179	5.81
Ohio	2,355	5.95
Oklahoma	853	5.84

Area	Fetal deaths[1]	Fetal mortality rate[2]
Oregon	581	4.72
Pennsylvania	2,247	5.62
Rhode Island	168	5.44
South Carolina	978	5.72
South Dakota	212	6.24
Tennessee	1,555	6.41
Texas	4,453	3.96
Utah	790	5.64
Vermont	74	4.64
Virginia	1,444	4.99
Washington	1,383	5.46
West Virginia	252	4.76
Wisconsin	980	5.25
Wyoming	124	6.51

[1] Fetal deaths with stated or presumed period of gestation of 20 weeks or more.

[2] Rate per 1,000 live births and fetal deaths

SOURCE: National Center for Health Statistics, National Vital Statistics System.