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Sources of Public Health Data

LEARNING OBJECTIVES

By the end of this chapter the reader will be able to:

- Describe the major sources of health data on U.S. and international populations.
- Describe the issues involved in appropriately interpreting these data sources.

Introduction

There is a wealth of easily accessible information on the health status of the U.S. population. Most of these public health data are collected by governmental and nongovernmental agencies on a routine basis or by special surveys. Information is obtainable on deaths and a wide variety of diseases and conditions, including acute illnesses and injuries, chronic illnesses and impairments, birth defects, and other adverse pregnancy outcomes. Data are also available on characteristics that influence a person's risk of illness (such as ambient air pollution levels; nutritional habits; immunizations; and the use of cigarettes, alcohol, and drugs) and on the impact of these illnesses on the utilization of health services, including hospitalizations and visits to office-based physicians and hospital emergency and outpatient departments. Several sources of international data are compiled by the World Health Organization and the United Nations. Although the international data are not as extensive as those about the United States, they include information about births, deaths, and major health indicators.

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This chapter provides short descriptions of the major sources of descriptive public health data including the data collection methods. It is important for epidemiologists to understand data collection methods in order to interpret the information appropriately. In particular, it is important to know the specific population that is covered by a data collection system. For example, although U.S. birth and death data pertain to the whole U.S. population, the target population for most national surveys consists of noninstitutionalized civilians. The latter group excludes members of the armed services and individuals living in institutions such as correctional facilities and nursing and convalescent homes. These groups are usually excluded because of technical and logistical problems.

It is also important to understand the calendar period covered by the data collection system and the frequency with which the data are updated. Generally, the most current available data in the United States lags a year or two behind the present. This is because it takes researchers a long time to collect data, computerize the information, check it for errors, and conduct statistical and epidemiologic analyses.

Every data collection system has some incomplete and inaccurate material. If data come from interview-based surveys, they are limited by the amount and type of information that a respondent can remember or is willing to report. For example, a person may not know detailed information on medical diagnoses and surgeries or may not want to report sensitive information on sexually transmitted diseases and prior induced abortions.
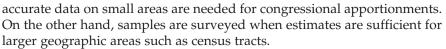
Census of U.S. Population

The U.S. Constitution requires that a census—that is, a complete count of the U.S. population—be taken every 10 years. The primary purpose of the census is to assign members of the House of Representatives to the states.[1] The decennial census of the population has been conducted since 1790, and a census of housing characteristics has been conducted since 1940. Permanently established in 1902, the U.S. Bureau of the Census currently oversees the population and housing census, compiles relevant statistics, and produces reports and computerized data files that are available to the public.

In recent years, the census has obtained information on certain characteristics (such as name, race, gender, age, and relationship of household members) from the entire population and information on additional characteristics (such as ancestry, income, mortgage, and size of housing unit) from a representative sample of persons. (About 17% of the U.S. population answers these additional questions.) The Census Bureau uses this approach to obtain the most comprehensive data possible while keeping costs reasonable. The complete population is surveyed on characteristics for which precise data are needed on small geographic areas. For example,

accurate data on small areas are needed for congressional apportionments. On the other hand, samples are surveyed when estimates are sufficient for larger geographic areas such as census tracts.

The Census Bureau tabulates complete count and sample population statistics for geographic areas in increasing size from census tracts; to cities, counties, and metropolitan areas; to states; and to the entire nation. Information is also collected for Puerto Rico and other areas under U.S. sovereignty. These population counts are crucial components of most public health indicators because they are typically used as the denominators of incidence and prevalence measures.

Although the census attempts to account for every person in the U.S. population, it is well known that some miscounting occurs. While an evaluation of the 2000 Census found a small net overcounting (~0.5%) due to duplicate submissions or submissions of non-U.S. residents, undercounting was observed for certain racial and ethnic groups, including Blacks (1.84%) and Native Hawaiians or Pacific Islanders (2.12%).[2]

Vital Statistics

The National Vital Statistics System of the National Center for Health Statistics (NCHS) compiles and publishes data on births, deaths, marriages, divorces, and fetal deaths in the United States.[3] Registration offices in all 50 states, the District of Columbia, and New York City have provided information on births and deaths since 1933. Birth and death registration is considered virtually complete. Most states also provide marriage and divorce registration records.

Most birth and death certificates used in the 50 states correspond closely in content and organization to the standard certificate recommended by NCHS. Although some modifications are made to accommodate local needs, all certificates obtain a minimum amount of information on demographic characteristics. Examples of the standard live birth and death certificates appear in **Figures 4–1** and **4–2**.

Public health data collected currently on birth certificates includes birth weight; gestational age; and adverse pediatric conditions such as the presence of congenital malformations (birth defects), complications during pregnancy, and cigarette smoking. Birth certificates are completed by hospital personnel in consultation with parents. The physician (or other professional) who performs the delivery subsequently verifies the accuracy of the information. Certificates are then sent to the local health departments who, in turn, send them to state health departments and then to the NCHS.

Death certificates collect information on "the chain of events—diseases, injuries, complications—that directly caused the death."[3] Thus, the certificate lists the immediate cause of death, any intermediate causes, and the

U.S. STANDARD CERTIFICATE OF LIVE BIRTH

LOCAL FILE NO. | BIRTH NUMBER:

| CHILD | 1. CHILD'S NAME (First, Middle, Last, Suffix) | 2. TIME OF BIRTH (24hr) | 3. SEX | 4. DATE OF BIRTH (Mo/Day/Yr) |
| | 5. FACILITY NAME (If not institution, give street and number) | 6. CITY, TOWN, OR LOCATION OF BIRTH | | 7. COUNTY OF BIRTH |

MOTHER	8a. MOTHER'S CURRENT LEGAL NAME (First, Middle, Last, Suffix)	8b. DATE OF BIRTH (Mo/Day/Yr)
	8c. MOTHER'S NAME PRIOR TO FIRST MARRIAGE (First, Middle, Last, Suffix)	8d. BIRTHPLACE (State, Territory, or Foreign Country)
	9a. RESIDENCE OF MOTHER-STATE	9b. COUNTY	9c. CITY, TOWN, OR LOCATION
	9d. STREET AND NUMBER	9e. APT. NO.	9f. ZIP CODE	9g. INSIDE CITY LIMITS? ☐ Yes ☐ No

| FATHER | 10a. FATHER'S CURRENT LEGAL NAME (First, Middle, Last, Suffix) | 10b. DATE OF BIRTH (Mo/Day/Yr) | 10c. BIRTHPLACE (State, Territory, or Foreign Country) |

| CERTIFIER | 11. CERTIFIER'S NAME: _____ TITLE: ☐ MD ☐ DO ☐ HOSPITAL ADMIN. ☐ CNM/CM ☐ OTHER MIDWIFE ☐ OTHER (Specify)_____ | 12. DATE CERTIFIED ___/___/___ MM DD YYYY | 13. DATE FILED BY REGISTRAR ___/___/___ MM DD YYYY |

INFORMATION FOR ADMINISTRATIVE USE

| MOTHER | 14. MOTHER'S MAILING ADDRESS: ☐ Same as residence, or: State: City, Town, or Location: Street & Number: Apartment No.: Zip Code: |

15. MOTHER MARRIED? (At birth, conception, or any time between) ☐ Yes ☐ No If No, Has Paternity Acknowledgment Been Signed In The Hospital? ☐ Yes ☐ No | 16. SOCIAL SECURITY NUMBER REQUESTED For Child? ☐ Yes ☐ No | 17. FACILITY ID. (NPI)

18. MOTHER'S SOCIAL SECURITY NUMBER: | 19. FATHER'S SOCIAL SECURITY NUMBER:

INFORMATION FOR MEDICAL AND HEALTH PURPOSES ONLY

| MOTHER | 20. MOTHER'S EDUCATION (Check the box that best describes the highest degree or level of school completed at the time of delivery) ☐ 8th grade or less ☐ 9th–12th grade, no diploma ☐ High school graduate or GED completed ☐ Some college credit but no degree ☐ Associate degree (e.g., AA, AS) ☐ Bachelor's degree (e.g., BA, AB, BS) ☐ Master's degree (e.g., MA, MS, MEng, MEd, MSW, MBA) ☐ Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) | 21. MOTHER OF HISPANIC ORIGIN? (Check the box that best describes whether the mother is Spanish/Hispanic/Latina. Check the "No" box if mother is not Spanish/Hispanic/Latina) ☐ No, not Spanish/Hispanic/Latina ☐ Yes, Mexican, Mexican American, Chicana ☐ Yes, Puerto Rican ☐ Yes, Cuban ☐ Yes, other Spanish/Hispanic/Latina (Specify)_____ | 22. MOTHER'S RACE (Check one or more races to indicate what the mother considers herself to be) ☐ White ☐ Black or African American ☐ American Indian or Alaska Native ☐ (Name of the enrolled or principal tribe)_____ ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian (Specify)_____ ☐ Native Hawaiian ☐ Guamanian or Chamorro ☐ Samoan ☐ Other Pacific Islander (Specify)_____ ☐ Other (Specify)_____ |

| FATHER | 23. FATHER'S EDUCATION (Check the box that best describes the highest degree or level of school completed at the time of delivery) ☐ 8th grade or less ☐ 9th–12th grade, no diploma ☐ High school graduate or GED completed ☐ Some college credit but no degree ☐ Associate degree (e.g., AA, AS) ☐ Bachelor's degree (e.g., BA, AB, BS) ☐ Master's degree (e.g., MA, MS, MEng, MEd, MSW, MBA) ☐ Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) | 24. FATHER OF HISPANIC ORIGIN? (Check the box that best describes whether the father is Spanish/Hispanic/Latino. Check the "No" box if father is not Spanish/Hispanic/Latino) ☐ No, not Spanish/Hispanic/Latino ☐ Yes, Mexican, Mexican American, Chicano ☐ Yes, Puerto Rican ☐ Yes, Cuban ☐ Yes, other Spanish/Hispanic/Latino (Specify)_____ | 25. FATHER'S RACE (Check one or more races to indicate what the father considers himself to be) ☐ White ☐ Black or African American ☐ American Indian or Alaska Native ☐ (Name of the enrolled or principal tribe)_____ ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian (Specify)_____ ☐ Native Hawaiian ☐ Guamanian or Chamorro ☐ Samoan ☐ Other Pacific Islander (Specify)_____ ☐ Other (Specify)_____ |

Mother's Name_____ Mother's Medical Record No._____

| 26. PLACE WHERE BIRTH OCCURRED (Check one) ☐ Hospital ☐ Freestanding birthing center ☐ Home birth: Planned to deliver at home? ☐ Yes ☐ No ☐ Clinic/Doctor's office ☐ OTHER (Specify)_____ | 27. ATTENDANT'S NAME, TITLE, AND NPI NAME:_____ NPI:_____ TITLE: ☐ MD ☐ DO ☐ CNM/CM ☐ OTHER MIDWIFE ☐ Other (Specify)_____ | 28. MOTHER TRANSFERRED FOR MATERNAL MEDICAL OR FETAL INDICATIONS FOR DELIVERY? ☐ Yes ☐ No IF YES, ENTER NAME OF FACILITY MOTHER TRANSFERRED FROM:_____ |

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FIGURE 4–1 Sample of U.S. Standard Certificate of Live Birth

Source: Reproduced from the Centers for Disease Control and Prevention. National Center for Health Statistics. *2003 Revisions of the U.S. Standard Certificates of Live Birth and Death and the Fetal Death Report*. Certificate of Live Birth available at: http://www.cdc.gov/nchs/data/dvs /birth11-03final-ACC.pdf. Accessed February 6, 2013.

MOTHER	29a. DATE OF FIRST PRENATAL CARE VISIT M M D D YYYY ☐ No Prenatal Care	29b. DATE OF LAST PRENATAL CARE VISIT M M D D YYYY	30. TOTAL NUMBER OF PRENATAL VISITS FOR THIS PREGNANCY _____ (If none, enter "0".)

31. MOTHER'S HEIGHT _____ (feet/inches)	32. MOTHER'S PREPREGNANCY WEIGHT _____ (pounds)	33. MOTHER'S WEIGHT AT DELIVERY _____ (pounds)	34. DID MOTHER GET WIC FOOD FOR HERSELF DURING THIS PREGNANCY? ☐ YES ☐ NO

35. NUMBER OF PREVIOUS LIVE BIRTHS (Do not include this child)

36. NUMBER OF OTHER PREGNANCY OUTCOMES (spontaneous or induced losses or ectopic pregnancies)

37. CIGARETTE SMOKING BEFORE AND DURING PREGNANCY
For each time period, enter either the number of cigarettes or the number of packs of cigarettes smoked. IF NONE, ENTER "0".
Average number of cigarettes or packs of cigarettes smoked per day.

	# of cigarettes		# of packs
Three Months Before Pregnancy	_____	OR	_____
First Three Months of Pregnancy	_____	OR	_____
Second Three Months of Pregnancy	_____	OR	_____
Third Trimester of Pregnancy	_____	OR	_____

38. PRINCIPAL SOURCE OF PAYMENT FOR THIS DELIVERY
☐ Private Insurance
☐ Medicaid
☐ Self-pay
☐ Other (Specify) _____

35a. Now Living Number _____ ☐ None
35b. Now Dead Number _____ ☐ None
36a. Other Outcomes Number _____ ☐ None

35c. DATE OF LAST LIVE BIRTH MM Y Y Y Y
36b. DATE OF LAST OTHER PREGNANCY OUTCOME MM Y Y Y Y
39. DATE LAST NORMAL MENSES BEGAN M M D D YYYY
40. MOTHER'S MEDICAL RECORD NUMBER

MEDICAL AND HEALTH INFORMATION

41. RISK FACTORS IN THIS PREGNANCY (Check all that apply)
Diabetes
☐ Prepregnancy (Diagnosis prior to this pregnancy)
☐ Gestational (Diagnosis in this pregnancy)
Hypertension
☐ Prepregnancy (Chronic)
☐ Gestational (PIH, preeclampsia)
☐ Eclampsia
☐ Previous preterm birth
☐ Other previous poor pregnancy outcome (Includes perinatal death, small for gestational age/intrauterine growth restricted birth)
☐ Pregnancy resulted from infertility treatment—If yes, check all that apply:
☐ Fertility-enhancing drugs, artificial insemination or intrauterine insemination
☐ Assisted reproductive technology (e.g., in vitro fertilization (IVF), gamete intrafallopian transfer (GIFT))
☐ Mother had a previous cesarean delivery. If yes, how many _____
☐ None of the above

42. INFECTIONS PRESENT AND/OR TREATED DURING THIS PREGNANCY (Check all that apply)
☐ Gonorrhea ☐ Hepatitis B
☐ Syphilis ☐ Hepatitis C
☐ Chlamydia ☐ None of the above

43. OBSTETRIC PROCEDURES (Check all that apply)
☐ Cervical cerclage
☐ Tocolysis
External cephalic version:
☐ Successful
☐ Failed
☐ None of the above

44. ONSET OF LABOR (Check all that apply)
☐ Premature Rupture of the Membranes (prolonged, ≥ 12 hrs.)
☐ Precipitous Labor (< 3 hrs.)
☐ Prolonged Labor (≥ 20 hrs.)
☐ None of the above

45. CHARACTERISTICS OF LABOR AND DELIVERY (Check all that apply)
☐ Induction of labor
☐ Augmentation of labor
☐ Non-vertex presentation
☐ Steroids (glucocorticoids) for fetal lung maturation received by the mother prior to delivery
☐ Antibiotics received by the mother during labor
☐ Clinical chorioamnionitis diagnosed during labor or maternal temperature ≥ 38°C (100.4°F)
☐ Moderate/heavy meconium staining of the amniotic fluid
☐ Fetal intolerance of labor such that one or more of the following actions was taken: in-utero resuscitative measures, further fetal assessment, or operative delivery
☐ Epidural or spinal anesthesia during labor
☐ None of the above

46. METHOD OF DELIVERY
A. Was delivery with forceps attempted but unsuccessful? ☐ Yes ☐ No
B. Was delivery with vacuum extraction attempted but unsuccessful? ☐ Yes ☐ No
C. Fetal presentation at birth
☐ Cephalic
☐ Breech
☐ Other
D. Final route and method of delivery (Check one)
☐ Vaginal/Spontaneous
☐ Vaginal/Forceps
☐ Vaginal/Vacuum
☐ Cesarean
If cesarean, was a trial of labor attempted? ☐ Yes ☐ No

47. MATERNAL MORBIDITY (Check all that apply) (Complications associated with labor and delivery)
☐ Maternal transfusion
☐ Third- or fourth-degree perineal laceration
☐ Ruptured uterus
☐ Unplanned hysterectomy
☐ Admission to intensive care unit
☐ Unplanned operating room procedure following delivery
☐ None of the above

NEWBORN INFORMATION

NEWBORN

48. NEWBORN MEDICAL RECORD NUMBER:

49. BIRTHWEIGHT (grams preferred, specify unit)
☐ grams ☐ lb/oz

50. OBSTETRIC ESTIMATE OF GESTATION: _____ (completed weeks)

51. APGAR SCORE:
Score at 5 minutes: _____
If 5 minute score is less than 6,
Score at 10 minutes: _____

52. PLURALITY—Single, Twin, Triplet, etc. (Specify)_____

53. IF NOT SINGLE BIRTH—Born First, Second, Third, etc. (Specify)_____

54. ABNORMAL CONDITIONS OF THE NEWBORN (Check all that apply)
☐ Assisted ventilation required immediately following delivery
☐ Assisted ventilation required for more than 6 hours
☐ NICU admission 9 Newborn given surfactant replacement therapy
☐ Antibiotics received by the newborn for suspected neonatal sepsis
☐ Seizure or serious neurologic dysfunction
☐ Significant birth injury (skeletal fracture[s], peripheral nerve injury, and/or soft tissue/solid organ hemorrhage that requires intervention)
☐ None of the above

55. CONGENITAL ANOMALIES OF THE NEWBORN (Check all that apply)
☐ Anencephaly
☐ Meningomyelocele/Spina bifida
☐ Cyanotic congenital heart disease
☐ Congenital diaphragmatic hernia
☐ Omphalocele
☐ Gastroschisis
☐ Limb reduction defect (excluding congenital amputation and dwarfing syndromes)
☐ Cleft Lip with or without Cleft Palate
☐ Cleft Palate alone
☐ Down Syndrome
☐ Karyotype confirmed
☐ Karyotype pending
☐ Suspected chromosomal disorder
☐ Karyotype confirmed
☐ Karyotype pending
☐ Hypospadias
☐ None of the anomalies listed above

Mother's Name _____
Mother's Medical Record No._____

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56. WAS INFANT TRANSFERRED WITHIN 24 HOURS OF DELIVERY? ☐ Yes ☐ No
IF YES, NAME OF FACILITY INFANT TRANSFERRED TO:_____

57. IS INFANT LIVING AT TIME OF REPORT? ☐ Yes ☐ No
☐ Infant transferred, status unknown

57. IS INFANT BEING BREASTFED AT DISCHARGE? ☐ Yes ☐ No

NOTE: This recommended standard birth certificate is the result of an extensive evaluation process. Information on the process and resulting recommendations as well as plans for future activities is available on the Internet at: http://www.cdc.gov/nchs/vital_certs_rev.htm.

FIGURE 4–1 Sample of U.S. Standard Certificate of Live Birth *(Continued)*

Source: Reproduced from the Centers for Disease Control and Prevention. National Center for Health Statistics. *2003 Revisions of the U.S. Standard Certificates of Live Birth and Death and the Fetal Death Report.* Certificate of Live Birth available at: http://www.cdc.gov/nchs/data/dvs/birth11-03final-ACC.pdf. Accessed February 6, 2013.

U.S. STANDARD CERTIFICATE OF DEATH

LOCAL FILE NO.   STATE FILE NO.

NAME OF DECEDENT — For use by physician or institution

To Be Completed/Verified By: FUNERAL DIRECTOR

1. DECEDENT'S LEGAL NAME (Include AKA's if any) (First, Middle, Last)   2. SEX   3. SOCIAL SECURITY NUMBER

4a. AGE—Last Birthday (Years)   4b. UNDER 1 YEAR [Months] [Days]   4c. UNDER 1 DAY [Hours] [Minutes]   5. DATE OF BIRTH (Mo/Day/Yr)   6. BIRTHPLACE (City and State or Foreign Country)

7a. RESIDENCE-STATE   7b. COUNTY   7c. CITY OR TOWN

7d. STREET AND NUMBER   7e. APT. NO.   7f. ZIP CODE   7g. INSIDE CITY LIMITS ☐ Yes ☐ No

8. EVER IN U.S. ARMED FORCES? ☐ Yes ☐ No   9. MARITAL STATUS AT TIME OF DEATH ☐ Married ☐ Married, but separated ☐ Widowed ☐ Divorced ☐ Never Married ☐ Unknown   10. SURVIVING SPOUSE'S NAME (If wife, give name prior to first marriage)

11. FATHER'S NAME (First, Middle, Last)   12. MOTHER'S NAME PRIOR TO FIRST MARRIAGE (First, Middle, Last)

13a. INFORMANT'S NAME   13b. RELATIONSHIP TO DECEDENT   13c. MAILING ADDRESS (Street and Number, City, State, Zip Code)

14. PLACE OF DEATH (Check only one: see instructions)

IF DEATH OCCURRED IN A HOSPITAL: ☐ Inpatient ☐ Emergency Room/Outpatient ☐ Dead on Arrival   IF DEATH OCCURRED SOMEWHERE OTHER THAN A HOSPITAL: ☐ Hospice facility ☐ Nursing home/Long term care facility ☐ Decedent's home

15. FACILITY NAME (If not institution, give street and number)   16. CITY OR TOWN, STATE, AND ZIP CODE   17. COUNTY OF DEATH

18. METHOD OF DISPOSITION: ☐ Burial ☐ Cremation ☐ Donation ☐ Entombment ☐ Removal from State ☐ Other (Specify):_____

19. PLACE OF DISPOSITION (Name of cemetery, crematory, other place)

20. LOCATION-CITY, TOWN, AND STATE   21. NAME AND COMPLETE ADDRESS OF FUNERAL FACILITY

22. SIGNATURE OF FUNERAL SERVICE LICENSEE OR OTHER AGENT   23. LICENSE NUMBER (Of Licensee)

To Be Completed By: MEDICAL CERTIFIER

ITEMS 24–28 MUST BE COMPLETED BY PERSON WHO PRONOUNCES OR CERTIFIES DEATH   24. DATE PRONOUNCED DEAD (Mo/Day/Yr)   25. TIME PRONOUNCED DEAD

26. SIGNATURE OF PERSON PRONOUNCING DEATH (Only when applicable)   27. LICENSE NUMBER   28. DATE SIGNED (Mo/Day/Yr)

29. ACTUAL OR PRESUMED DATE OF DEATH (Mo/Day/Yr) (Spell Month)   30. ACTUAL OR PRESUMED TIME OF DEATH   31. WAS MEDICAL EXAMINER OR CORONER CONTACTED? ☐ Yes ☐ No

CAUSE OF DEATH (See instructions and examples)

32. PART I. Enter the chain of events—diseases, injuries, or complications—that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.   Approximate interval: Onset to death

IMMEDIATE CAUSE (Final disease or condition resulting in death)---------> a._____ _____

Sequentially list conditions, if any, leading to the cause listed on line a.   Due to (or as a consequence of): b._____ _____

Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**   Due to (or as a consequence of): c._____ _____

Due to (or as a consequence of): d._____ _____

PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I.   33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No
34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ☐ Yes ☐ No

35. DID TOBACCO USE CONTRIBUTE TO DEATH? ☐ Yes ☐ No ☐ Probably ☐ Unknown   36. IF FEMALE: ☐ Not pregnant within past year ☐ Not pregnant, but pregnant within 42 days of death ☐ Unknown if pregnant within the past year ☐ Pregnant at time of death ☐ Not pregnant, but pregnant 43 days to 1 year before death   37. MANNER OF DEATH ☐ Natural ☐ Homicide ☐ Accident ☐ Pending Investigation ☐ Suicide ☐ Could not be determined

38. DATE OF INJURY (Mo/Day/Yr) (Spell Month)   39. TIME OF INJURY   40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area)   41. INJURY AT WORK? ☐ Yes ☐ No

42. LOCATION OF INJURY: State: City or Town: Street & Number: Apartment No.:   Zip Code:

43. DESCRIBE HOW INJURY OCCURRED: 44. IF TRANSPORTATION INJURY, SPECIFY: ☐ Driver/Operator ☐ Passenger ☐ Pedestrian ☐ Other (Specify)_____

45. CERTIFIER (Check only one): ☐ Certifying physician—To the best of my knowledge, death occurred due to the cause(s) and manner stated. ☐ Pronouncing and Certifying physician—To the best of my knowledge, death occurred at the time, date, and place, and due to the cause(s) and manner stated.   ☐ Medical examiner/Coroner—On the basis of examination, and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner stated.   Signature of certifier:_____

46. NAME, ADDRESS, AND ZIP CODE OF PERSON COMPLETING CAUSE OF DEATH (Item 32)

47. TITLE OF CERTIFIER   48. LICENSE NUMBER   49. DATE CERTIFIED (Mo/Day/Yr)   50. **FOR REGISTRAR ONLY**—DATE FILED (Mo/Day/Yr)

FIGURE 4–2 Sample of U.S. Standard Certificate of Death

Source: Reproduced from the Centers for Disease Control and Prevention. National Center for Health Statistics. *2003 Revisions of the U.S. Standard Certificates of Live Birth and Death and the Fetal Death Report*. Certificate of Death available at: http://www.cdc.gov/nchs/data/dvs/DEATH11-03final-ACC.pdf. Accessed February 6, 2013.

| To Be Completed By: FUNERAL DIRECTOR | 51. DECEDENT'S EDUCATION (Check the box that best describes the highest degree or level of school completed at the time of death)
☐ 8th grade or less
☐ 9th–12th grade; no diploma
☐ High school graduate or GED completed
☐ Some college credit, but no degree
☐ Associate degree (e.g., AA, AS)
☐ Bachelor's degree (e.g., BA, AB, BS)
☐ Master's degree (e.g., MA, MS, MEng, MEd, MSW, MBA)
☐ Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) | 52. DECEDENT OF HISPANIC ORIGIN? (Check the box that best describes whether the decedent is Spanish/Hispanic/Latino. Check the "No" box if decedent is not Spanish/Hispanic/Latino)
☐ No, not Spanish/Hispanic/Latino)
☐ Yes, Mexican, Mexican American, Chicano
☐ Yes, Puerto Rican
☐ Yes, Cuban
☐ Yes, other Spanish/Hispanic/Latino (Specify) _____ | 53. DECEDENT'S RACE (Check one or more races to indicate what the decedent considered himself or herself to be)
☐ White   ☐ Vietnamese
☐ Black or African American   ☐ Other Asian (Specify)
☐ American Indian or Alaska Native (Name of the enrolled or principal tribe) _____   ☐ Native Hawaiian
☐ Asian Indian   ☐ Guamanian or Chamorro
☐ Chinese   ☐ Samoan
☐ Filipino   ☐ Other Pacific Islander (Specify) _____
☐ Japanese   ☐ Other (Specify) _____
☐ Korean |
| | 54. DECEDENT'S USUAL OCCUPATION (Indicate type of work done during most of working life. DO NOT USE RETIRED) | | 55. KIND OF BUSINESS/INDUSTRY |

Cause-of-death—Background, Examples, and Common Problems

Accurate cause of death information is important
•to the public health community in evaluating and improving the health of all citizens, and
•often to the family, now and in the future, and to the person settling the decedent's estate.

The cause-of-death section consists of two parts. **Part I** is for reporting a chain of events leading directly to death, with the **immediate cause** of death (the final disease, injury, or complication directly causing death) on line a and the **underlying cause** of death (the disease or injury that initiated the chain of events that led directly and inevitably to death) on the lowest used line. **Part II** is for reporting all other significant diseases, conditions, or injuries that contributed to death but which did not result in the underlying cause of death given in **Part I. The cause-of-death information should be YOUR best medical OPINION.** A condition can be listed as "probable" even if it has not been definitively diagnosed.

Examples of properly completed medical certifications:

CAUSE OF DEATH (See instructions and examples)	Approximate interval:
32. PART I. Enter the <u>chain of events</u>—diseases, injuries, or complications—that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.	Onset to death

IMMEDIATE CAUSE (Final disease or condition --------> resulting in death)
a. Rupture of myocardium — Minutes
Due to (or as a consequence of):
Sequentially list conditions, if any, leading to the cause listed on line a.
b. Acute myocardial infarction — 6 days
Due to (or as a consequence of):
c. Coronary artery thrombosis — 5 years
Due to (or as a consequence of):
Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**
d. Atherosclerotic coronary artery disease — 7 years

PART II. Enter other <u>significant conditions</u> contributing to death but not resulting in the underlying cause given in PART I.	33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No
Diabetes, Chronic obstructive pulmonary disease, smoking	34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ☐ Yes ☐ No

35. DID TOBACCO USE CONTRIBUTE TO DEATH? ☐ Yes ☐ Probably ☐ No ☐ Unknown	36. IF FEMALE: ☐ Not pregnant within past year ☐ Not pregnant, but pregnant within 42 days of death ☐ Pregnant at time of death ☐ Unknown if pregnant within the past year ☐ Not pregnant, but pregnant 43 days to 1 year before death	37. MANNER OF DEATH ☐ Natural ☐ Homicide ☐ Accident ☐ Pending Investigation ☐ Suicide ☐ Could not be determined

CAUSE OF DEATH (See instructions and examples)	Approximate interval:
32. PART I. Enter the *chain of events*—diseases, injuries, or complications—that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.	Onset to death

IMMEDIATE CAUSE (Final disease or condition --------> resulting in death)
a. Aspiration pneumonia — 2 Days
Due to (or as a consequence of):
Sequentially list conditions, if any, leading to the cause listed on line a.
b. Complications of coma — 7 weeks
Due to (or as a consequence of):
c. Blunt force injuries — 7 weeks
Due to (or as a consequence of):
Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**
d. Motor vehicle accident — 7 weeks

PART II. Enter other *significant conditions* contributing to death but not resulting in the underlying cause given in PART I.	33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No
	34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ☐ Yes ☐ No

35. DID TOBACCO USE CONTRIBUTE TO DEATH? ☐ Yes ☐ Probably ☐ No ☐ Unknown	36. IF FEMALE: ☐ Not pregnant within past year ☐ Not pregnant, but pregnant within 42 days of death ☐ Pregnant at time of death ☐ Unknown if pregnant within the past year ☐ Not pregnant, but pregnant 43 days to 1 year before death	37. MANNER OF DEATH ☐ Natural ☐ Homicide ☐ Accident ☐ Pending Investigation ☐ Suicide ☐ Could not be determined

38. DATE OF INJURY (Mo/Day/Yr) (Spell Month) August 15, 2003	39. TIME OF INJURY Approx. 2320	40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area) road side near state highway	41. INJURY AT WORK? ☐ Yes ☐ No
42. LOCATION OF INJURY: State: Missouri City or Town: near Alexandria			
Street & Number: Mile marker 17 on state route 46a Apartment No.: Zip Code:			
43. DESCRIBE HOW INJURY OCCURRED: Decedent driver of van, ran off road into tree		44. IF TRANSPORTATION INJURY, SPECIFY: ☐ Driver/Operator ☐ Passenger ☐ Pedestrian ☐ Other (Specify) _____	

FIGURE 4–2 Sample of U.S. Standard Certificate of Death *(Continued)*

Source: Reproduced from the Centers for Disease Control and Prevention. National Center for Health Statistics. *2003 Revisions of the U.S. Standard Certificates of Live Birth and Death and the Fetal Death Report*. Certificate of Death available at: http://www.cdc.gov/nchs/data/dvs /DEATH11-03final-ACC.pdf. Accessed February 6, 2013.

underlying cause. For example, respiratory arrest may be the immediate cause of death, pneumonia the intermediate cause, and acquired immune deficiency syndrome (AIDS) the underlying cause of death. Other significant conditions contributing to the death may also be listed.

In order to generate national mortality statistics, "every death is attributed to one underlying condition, based on information reported on the death certificate and utilizing the international rules." These rules, now termed the International Classification of Diseases (ICD), were first developed in 1900 and have been revised about every 10 years by the World Health Organization. The tenth revision of the ICD has been used to classify mortality information for statistical purposes since 1999.

Any time that the ICD is revised, a number of artifactual changes in the mortality statistics typically occur. Some revisions have led to small changes, and others have resulted in large ones. For example, male and female breast cancer used to be grouped together but now are classified separately. Because male breast cancer is so rare, comprising less than 1% of all breast cancers,[4] it is unlikely that this change made much of a difference in breast cancer mortality data. On the other hand, a large increase in Alzheimer's disease deaths is attributed, in part, to changes in the ICD classification of this disease.[5] Most of the increase is due to diagnoses previously considered Presenile Dementia being reclassified as Alzheimer's disease.

Death record information in the United States has been computerized at a national level since 1979.[6] The National Death Index is administered by the NCHS. Epidemiologists often use this data source to determine if study subjects have died. It is necessary to write to individual state offices to acquire copies of death certificates for information on cause of death.

National data on fetal deaths are kept separately by the NCHS. These data have been reported in the United States and District of Columbia since 1982.[7] However, fetal death reporting depends on state requirements; most states require reporting deaths that occur at 20 or more weeks' gestation. Because most pregnancy losses occur earlier in gestation, the reported data represent only a small proportion of pregnancy losses.

National Survey of Family Growth

The purpose of this survey is to "provide reliable national data on marriage, divorce, contraception, infertility, and the health of women and infants in the United States," including information on sexual activity, marriage, contraception, sterilization, infertility, breastfeeding, pregnancy loss, low birth weight, use of medical care for infertility, family planning, and prenatal care.[8] To date, seven surveys have been conducted from 1973 to 2010.

Over time, the National Survey of Family Growth (NSFG) has expanded in scope and coverage. For example, women who have never been married were excluded from the first two surveys but were included in the later ones. Men were included for the first time in the 2002 survey. The 2006–2010 survey was based on a national sample of 22,682 men and women aged 15 to 44 years from the noninstitutionalized population of all 50 states. Statistical weighting procedures were applied to produce estimates for the entire country. In-person interviews were conducted by trained interviewers. Questions for women focused on their ability to become pregnant, pregnancy history, use of contraceptives, family planning, infertility services, breastfeeding, maternity leave, childcare, and adoption. Questions for men also focused on their reproductive health, including nonmarital childbearing and child support. In 2011, the 2006–2010 NSFG data files, including information from over 22,000 interviews along with code books and relevant documentation, were released for public use.

National Health Interview Survey

Mandated by the National Health Survey Act of 1956, the National Health Interview Survey (NHIS) is currently the principal source of information on the health of the civilian noninstitutionalized population of the United States.[9] Administered on a yearly basis since 1957, the NHIS provides data on major health problems, including incidence of acute illnesses and injuries, prevalence of chronic conditions and impairments, and utilization of health services. The data are used to monitor trends in illness and disability and to track progress toward achieving national health objectives.

NHIS uses a stratified, multistage sampling scheme to select a sample of households that form a representative sample of the target population. Each year, approximately 39,000 households, including approximately 97,200 people, are selected for interview. Participation is voluntary, but more than 90% of eligible households respond each year. Nonresponse stems mainly from refusal or the inability to find eligible individuals in a household. Survey results are statistically weighted and adjusted for nonresponse in order to produce national estimates.

Personal interviews are conducted by the permanent interviewer staff from the Bureau of the Census. All adult household members aged 17 years and older who are home at the time of the survey are invited to participate and respond for themselves. A responsible adult aged 18 and older also responds for adults who are not at home and for children. Every year, basic demographic and health information is collected on age; race; gender; educational level; family income; and acute and chronic conditions and associated disability days, physician visits, and hospital stays. Supplemental data collection on special health topics varies from year to year.

National Health and Nutrition Examination Survey

Since 1960, NCHS has conducted the National Health and Nutrition Examination Survey (NHANES) to gather information on the health and diet of the U.S. population.[10] Participants are selected using a census-based stratified random sample. The survey includes both a home interview and health tests done in a mobile examination center. The current NHANES, the eighth in this series of surveys, was started in 1999 and will continually survey 15 locations throughout the United States and enroll 5,000 people each year.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System is a telephone health survey that has been conducted in all 50 states and the District of Columbia since 1984.[11] The purpose of this state-based survey is to monitor a wide variety of health risk behaviors that are related to chronic disease, injuries, and death, including use of screening and preventive services, smoking, alcohol use, physical activities, fruit and vegetable consumption, seatbelt use, and weight control. Participants are adults from randomly selected households. About 350,000 interviews are conducted annually, making it one of the largest continuous telephone surveys in the world.

National Health Care Surveys

The National Health Care Surveys provide information on the use and quality of health care and the impact of medical technology in a wide variety of settings, including hospital inpatient and outpatient departments, emergency rooms, hospices, home health agencies, and physician's offices.[12] The following paragraphs describe the component surveys.

The National Hospital Discharge Survey (NHDS) was a national probability survey that was conducted annually from 1965 to 2010. Its purpose was to collect information, including data on diagnoses, procedures, length of stay, and characteristics of inpatients discharged from nonfederal short-stay hospitals in the United States.

The National Hospital Ambulatory Medical Care Survey (NHAMCS) began in 1992 to collect information on the utilization and provision of ambulatory services in hospital emergency and outpatient departments. The annual survey is based on a national sample of visits to the emergency and outpatient departments of noninstitutional general and short-stay hospitals in all 50 states and the District of Columbia. A random sample of visits during a randomly assigned 4-week period is chosen from randomly selected facilities. Data are collected on patient demographic

characteristics, source of payment, reason for visit, physician diagnoses, diagnostic and screening services, therapeutic and preventive services, surgical procedures, and facility characteristics.

In 2012, the National Hospital Care Survey (NHCS) began incorporating data formerly collected from the National Hospital Discharge Survey and the National Hospital Ambulatory Medical Care Survey. Its purpose is to describe national patterns of healthcare delivery using a new sample of hospitals and a sample of freestanding ambulatory surgery centers.

The National Ambulatory Medical Care Survey (NAMCS), which has been conducted since 1973, collects information on the provision and use of ambulatory medical services in the United States. The survey is based on a sample of visits to non–federally employed office-based physicians who are primarily engaged in direct patient care. Specialists such as anesthesiologists, pathologists, and radiologists are excluded. Data are collected from the physician, not the patient. Each physician is randomly assigned to a 1-week reporting period. Information is obtained on demographic characteristics of patients and services provided for a random sample of visits during the reporting period.

The National Nursing Home Survey (NNHS) is a periodic survey of nursing homes. Seven surveys have been conducted to date (from 1973 to 2004). The most recent survey included a sample of 1,174 freestanding nursing homes in the United States and nursing care units of hospitals, retirement centers, and similar institutions. The survey is based on self-administered questionnaires and interviews with administrators and staff in a sample of facilities. Information is collected on the characteristics of the facility such as size and ownership, and the characteristics of the residents such as age, race, health status, and services received.

The National Health Provider Inventory (NHPI) conducted in 1991 is a national listing of nursing homes, residential care facilities, hospices, and home health agencies that serves as a sampling frame for several surveys and as a source of information on the number, type, and geographic distribution of health providers in the United States. It provides the names, addresses, and other information on more than 7,800 home health agencies and hospices and 56,000 facilities (including more than 15,500 nursing homes and more than 31,000 board and care homes).

The National Survey of Ambulatory Surgery (NSAS) was conducted from 1994 to 1996 and again in 2006 to collect information on the use of ambulatory surgical services in the United States. For the purposes of the survey, ambulatory surgery refers to surgical and nonsurgical procedures performed on an outpatient basis in a hospital or freestanding center's general operating rooms, dedicated ambulatory surgery rooms, and other specialized rooms such as cardiac catheterization labs. NSAS data, including patient characteristics, sources of payment, and medical diagnoses and procedures, are available for 52,000 ambulatory surgery cases from

a nationally representative sample of ambulatory surgery centers (ASCs). Beginning in 2009, ASCs were included in the scope of NHAMCS.

The National Home and Hospice Care Survey (NHHCS), most recently completed in 2007, is a continuing series of surveys of home and hospice care agencies in the United States. The survey is based on a probability sample of qualifying agencies. Data are collected about the agencies and their current patients and discharges through personal interviews with administrators and staff. In particular, information is collected on the agency's ownership and affiliation, Medicare and Medicaid certification, as well as patient diagnoses, services received, and caregiver arrangements.

The National Survey of Residential Care Facilities (NSRCF), conducted in 2010, was the first survey of state-regulated residential care providers. It was designed to provide national estimates of residential care facilities, assisted living residences, board and care homes, congregate care enriched housing programs, homes for the aged, personal care homes, shared housing establishments, and their residents. Information, including facility size; certification; and staffing and resident demographics, health status, and services, were obtained via in-person interviews with administrators, caregivers, and staff.

National Notifiable Diseases Surveillance System

Managed by the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists, the National Notifiable Diseases Surveillance System collects weekly provisional data and compiles annual summaries on the occurrence of more than 60 notifiable diseases throughout the United States.[13] The CDC's Morbidity and Mortality Weekly Report[14] defines a notifiable disease as "one for which regular, frequent and timely information regarding individual cases is considered necessary for the prevention and control of the disease." These diseases include acquired human immune deficiency syndrome (AIDS), human immunodeficiency virus (HIV) infection, botulism, gonorrhea, leprosy, all forms of hepatitis, malaria, plague, paralytic poliomyelitis, human and animal rabies, syphilis, toxic-shock syndrome, and severe acute respiratory syndrome (SARS). Reports of notifiable diseases are sent to the CDC voluntarily by the 50 states, New York City, the District of Columbia, and five U.S. territories. Completeness of reporting depends on the disease and local notification practices. Morbidity and Mortality Weekly Report publishes weekly reports and annual summaries of these diseases.

Surveillance of HIV Infection

Since 1985, the CDC has collected information on the occurrence of HIV/AIDS cases from all 50 states; the District of Columbia; and U.S. dependencies, possessions, and independent associated countries (such as

Puerto Rico).[15] The HIV and AIDS surveillance case definitions have been modified several times in order to improve the accuracy of reporting. Every change in definition has led to artifactual changes in incidence estimates. In 2008, the surveillance case definitions for HIV and AIDS were combined and revised to require laboratory-confirmed evidence of HIV infection. The new definition included three categories of HIV infection increasing in severity from stage 1 through stage 3 (AIDS) based on CD4 T lymphocyte count; an unknown stage also is included. The diagnosis of an AIDS-defining condition alone became insufficient to classify an adult or adolescent as HIV infected for surveillance purposes. For every person meeting the HIV case definition, data are gathered on demographic characteristics, exposure category (such as injecting drug users and men who have sex with men), AIDS-indicator conditions (such as Kaposi's sarcoma and Pneumocystis carinii pneumonia), and diagnosis date.

Reporting delays between the time of diagnosis of HIV infection and AIDS vary according to geographic area, race, age, gender, and exposure categories. For some AIDS cases, delays have been as long as several years. The CDC makes adjustments to AIDS and HIV infection statistics to account for these delays.

Induced Abortion Statistics

Since 1969, the CDC has maintained a surveillance system to document the number and characteristics of women obtaining abortions, to monitor unintended pregnancies, and to assist in the effort to eliminate preventable morbidity and mortality associated with abortions.[16] The CDC receives annual reports on the number and characteristics of women obtaining legal abortions from centralized state reporting systems, hospitals, and other medical facilities in almost all states, the District of Columbia, and New York City. Data are collected on the type of abortion procedure; the number of weeks' gestation when the abortion was performed; and the patient's age, race, and marital status. The Alan Guttmacher Institute, the research and development division of the Planned Parenthood Federation of America, Inc., also conducts annual surveys of abortion providers including hospitals, nonhospital clinics, and physicians.

National Immunization Survey

Several surveys, including the National Immunization Survey, currently collect information on the immunization coverage of children in the United States.[17] The National Immunization Survey began in 1994 as a continuing survey to provide estimates of vaccination coverage among children aged 19 to 35 months in 78 geographic areas designated as "Immunization Action Plan areas." These areas consist

of the 50 states, the District of Columbia, and 27 large urban areas. Vaccinations included in the survey are diphtheria and tetanus toxoids, acellular pertussis vaccine, poliovirus vaccine, measles–mumps–rubella vaccine, hepatitis B vaccine, and influenza vaccine. The survey is administered to households via random digit-dialing as well as vaccination providers. The latter are identified by parents who respond to the household survey.

The National Health Interview Survey[9] and the Behavioral Risk Factor Surveillance System,[11] described earlier, also collect information on immunizations among U.S. children and adults. Vaccinations included in the adult surveys include influenza, pneumococcal, and tetanus vaccines.

Survey of Occupational Injuries and Illnesses

Since 1971, the Department of Labor has gathered annual data on occupational injuries and illnesses among employees in the private sector.[18] Data are collected from a national sample of approximately 230,000 establishments representing the total private economy (except for mines and railroads). Self-employed individuals; small farm employees; and local, state, and federal government employees are excluded. Typically, about 95% of selected employers respond to the survey.

The survey data are based on records of injuries and illnesses that employers are required to maintain under the federal Occupational Safety and Health Act.[18] An occupational illness is defined as

> any abnormal condition or disorder, other than one resulting from an occupational injury, caused by exposure to factors associated with employment. It includes acute and chronic illnesses or diseases which may be caused by inhalation, absorption, ingestion, or direct contact.[18]

In addition, an occupational injury is defined as "any injury, such as a cut, fracture, sprain, amputation, and so forth, which results from a work-related event or from a single instantaneous exposure in the work environment."

National Survey on Drug Use and Health

Since 1971, the National Survey on Drug Use and Health has obtained information on the use of alcohol, tobacco products, and illicit drugs, including the initiation of substance use, prevention-related issues, and substance dependence, abuse, and treatment.[19] The survey includes civilian, noninstitutionalized individuals living in all 50 states and aged 12 years and older. In the 2010 survey, 147,608 addresses were screened for eligible participants

and 68,487 completed interviews were obtained. Recent changes in the survey instrument make it difficult to assess trends over time.

Aerometric Information Retrieval System

The federal Clean Air Act of 1970 requires the Environmental Protection Agency to collect data on the levels of certain ambient air pollutants because they pose serious threats to public health.[20] These pollutants include particulate matter less than 10 microns in size, lead, carbon monoxide, sulfur dioxide, nitrogen dioxide, reactive volatile organic compounds, and ozone. Currently, more than 4,000 monitoring sites, located mainly in highly populated urban areas, provide data that are used to determine if a particular geographic area complies with the National Ambient Air Quality Standards. These standards include an adequate margin of safety that protects even the most sensitive members of the population (such as asthmatics) and define a maximum concentration level for each pollutant that cannot be exceeded during a prescribed time period.

Surveillance, Epidemiology and End Results Program

Mandated by the National Cancer Act, the Surveillance, Epidemiology and End Results (SEER) Program has collected data on the prevention, diagnosis, and treatment of cancer in the United States since 1973.[21] In particular, the SEER Program monitors trends in the incidence, mortality, and survival of about 40 types of cancer according to geographic and demographic characteristics.

Currently, SEER statistics are based on 17 population-based registries, including Connecticut, Hawaii, Iowa, New Mexico, Utah, California, Kentucky, Louisiana, New Jersey, Detroit, Atlanta, Seattle-Puget Sound, and selected counties and populations in Georgia, Arizona, and Alaska. The populations living in these areas cover about 26% of the U.S. population.

Reporting systems have been set up in each region that gather data on all newly diagnosed cancer cases among area residents. Information is gathered from a variety of sources, including medical records, death certificates, laboratories, and radiotherapy units, to ensure complete ascertainment of the cancer cases. Data are gathered on the cancer patients' demographic characteristics, primary cancer site (e.g., the lung), method of diagnostic confirmation (such as a pathology report), severity of the disease, and first mode of therapy. Patients are actively followed to provide survival information.

Birth Defects Surveillance and Research Programs

From 1970 through 1994, the CDC operated the Birth Defects Monitoring Program (BDMP), the first national system for monitoring occurrence of congenital malformations.[22] The system was launched, in part, in response to the epidemic of limb reduction defects among children whose mothers had taken the sedative thalidomide during pregnancy in the 1960s.

While it was operating, BDMP was the largest single source of uniformly collected data on birth defects in the country. Collected data include dates of birth and discharge, diagnoses and surgical procedures, gender, race, and birth weight. BDMP data were reviewed quarterly to determine if the prevalence of a birth defect had increased. If increases were identified, investigators explored both real and artifactual explanations, sometimes by conducting more detailed studies.

In 1998, Congress passed the Birth Defects Prevention Act, which authorized the CDC to (1) collect, analyze, and make available data on birth defects; (2) operate regional centers for applied epidemiologic research on the prevention of birth defects; and (3) educate the public about the prevention of birth defects.[23] To date, nine Centers for Birth Defects Research have been established to accomplish this mission in Arkansas, California, Iowa, Massachusetts, New York, North Carolina, and Utah. The CDC also operates its own research center in Atlanta, Georgia, and provides funding to 14 additional states to help improve their birth defects surveillance activities.
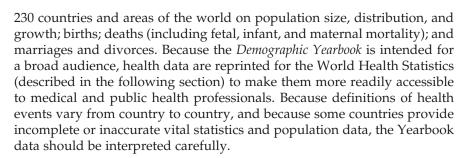
Health, United States

The publication *Health, United States* is one of the most comprehensive sources of information on the current health status of the U.S. population.[24] Published yearly, the report compiles information from various branches of the CDC (including the National Center for Health Statistics; the National Center for HIV, STD, and TB Prevention; and the Epidemiology Program Office), the Substance Abuse and Mental Health Services Administration, the National Institutes of Health (including the National Cancer Institute), and the Bureau of the Census. A compilation of data from these and other sources, this publication includes the most recent data on mortality, morbidity, health behaviors, reproductive health, healthcare access and utilization, and substance use. Each edition of *Health, United States* focuses on a major health topic. The 2010 edition included a special feature on death and dying.

Demographic Yearbook

Since 1948, the Statistical Office of the United Nations has compiled official demographic statistics from countries throughout the world for its annual *Demographic Yearbook*.[25] Currently, data are collected from over

230 countries and areas of the world on population size, distribution, and growth; births; deaths (including fetal, infant, and maternal mortality); and marriages and divorces. Because the *Demographic Yearbook* is intended for a broad audience, health data are reprinted for the World Health Statistics (described in the following section) to make them more readily accessible to medical and public health professionals. Because definitions of health events vary from country to country, and because some countries provide incomplete or inaccurate vital statistics and population data, the Yearbook data should be interpreted carefully.

World Health Statistics

The World Health Organization (WHO) has reported international morbidity and mortality data since 1951.[26] Its most recent statistics are presented in *World Health Statistics 2010*, and describe 150 health indicators among WHO's 193 Member States. This edition also focuses on equity between and within countries.

Cancer Incidence on Five Continents

Since the 1960s, WHO's International Agency for Research on Cancer (IARC) has collected data on cancer incidence and mortality from many countries around the world.[27] Currently, about 300 populations around the world contribute their data. Most of the registries rely on medical records, laboratory records, and death certificates as their data sources. All registries record the cancer case's name, address, gender, and cancer site. Most registries also collect information on age or date of birth, occupation, and the method of cancer diagnosis. The IARC processes the submitted data, assessing its quality, completeness, and comparability. The IARC publishes the information every few years in a monograph titled Cancer Incidence on Five Continents. A main goal of the monograph is to allow international comparisons of incidence that will lead to the formulation of hypotheses about the causes of cancer.

Other Resources

A number of additional sources of information are collected by state and local health departments.

■ *State cancer registries:* In addition to the SEER cancer registries, almost all U.S. states currently have population-based cancer registries. For example, the Massachusetts Cancer Registry began operation in 1982 and uses a system of hospital-based tumor registrars to collect data on cancer incidence. Compilation of these

data has enabled the Massachusetts registry to monitor trends in cancer incidence over time and according to demographic characteristics such as age, gender, race, and geographic area.

■ *Internet resources:* Numerous data sources are available through the Internet. Because the quality of information on the Internet is often unknown, it is best to rely only on resources from the U.S. government and other reliable sources. For example, the home page for the National Center for Health Statistics is located at http://www/cdc/gov/nchs.

■ *Wide-Ranging Online Data for Epidemiologic Research (WONDER):* This computerized information system provides online access to a wide variety of epidemiologic and public health datasets.[28] WONDER has data and documentation for many of the data sources listed in this chapter and allows the user to access both published documents and public use datasets about mortality, cancer incidence, HIV and AIDS, behavioral risk factors, diabetes, births and census data. WONDER can be accessed through the Internet at http://wonder.cdc.gov.

Summary

Many sources of information are readily available on a wide variety health-related states and events, including diseases, injuries, disabilities, and death among individuals living in the United States and around the world. The types and sources of information described in this chapter are summarized in **Table 4–1**. When interpreting data from these sources, it is important to consider (1) the population about which the information was obtained, (2) the calendar period that was covered, and (3) the level of missing and inaccurate data. It is also important to know about any changes in data collection methods that may have created artifactual changes in the frequency of disease.

TABLE 4–1   Sources of Public Health Data

Type of information	Source of information
Population size and characteristics	U.S. Census, Bureau of Census, Department of Commerce
Births	National Vital Statistics System, National Center for Health Statistics
Deaths	National Vital Statistics System, National Death Index, National Center for Health Statistics
Fetal deaths	Fetal Death Data, National Center for Health Statistics

(*continues*)

TABLE 4–1   Sources of Public Health Data (*continued*)

Type of information	*Source of information*
Childbearing, adoption, maternal and child health, family planning	National Survey of Family Growth, National Center for Health Statistics
Major health problems and utilization of health services	National Health Interview Survey, National Center for Health Statistics
Indicators of nutrition and health	National Health and Nutrition Examination Survey, National Center for Health Statistics
Use and quality of health care in a wide variety of settings	National Health Care Survey, National Center for Health Statistics
Notifiable diseases	National Notifiable Diseases Surveillance System, Centers for Disease Control and Prevention
HIV and AIDS	AIDS and HIV Surveillance, Centers for Disease Control and Prevention
Cancer incidence, mortality, and survival	Surveillance, Epidemiology, and End Results Program, National Cancer Institute; state cancer registries
Birth defects	Birth Defects Surveillance, Center for Birth Defects Research and Prevention, Centers for Disease Control and Prevention
Induced abortion	Abortions Surveillance, Centers for Disease Control and Prevention, Alan Guttmaker Institute, Planned Parenthood Federation of America
Immunizations	National Immunization Survey, National Health Interview Survey, Behaviorial Risk Factor Surveillance System, National Center for Health Statistics, Centers for Disease Control and Prevention
Occupational health	Survey of Occupational Injuries and Illnesses, U.S. Department of Labor
Behaviors affecting health	Behavioral Risk Factor Surveillance System, Centers for Disease Control and Prevention
Alcohol, cigarette, and drug use	National Survey on Drug Use and Health, Substance Abuse and Mental Health Services Administration
Air pollutant levels	Aerometric Information Retrieval System, Environmental Protection Agency

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CHAPTER QUESTIONS

1. Undercounting in the U.S. Census could affect the accuracy of which of the following epidemiologic activities?
    A. Assessing the prevalence of a disease in the U.S. population
    B. Assessing the incidence of a disease in the U.S. population
    C. Comparing the occurrence of disease in different segments of the U.S. population
    D. All of the above

2. In 2012, the Centers for Disease Control and Prevention announced that the prevalence of autism spectrum disorder in the United States increased by 78% during 2002–2008. Among the possible explanations for this marked increase are
    A. The incidence of the disorder truly increased
    B. Awareness of the disorder increased and so previously unrecognized cases were more likely to be identified and diagnosed
    C. Both A and B

3. In 2012, the American Psychiatric Association proposed that the definition of autism spectrum disorder be narrowed. Under the proposed new definition, a person would need to exhibit three deficits in social interaction as well as at least two repetitive behaviors. This is a much stricter standard than previously used. If adopted, what impact would this change have on the incidence of this disorder?
    A. The incidence would increase
    B. The incidence would decrease
    C. The incidence would remain the same