Appendix B: Primary Data Sources

Brief descriptions of the major data systems used in this report follow. Some of the information applies generally to the system. Sections note where the description is specific to data used in Health of Washington State chapters posted in 2012.

- **Behavioral Risk Factor Surveillance System**
- **Birth Certificate System**
- **Cancer Registry**
- **Census Population Counts and Intercensal Estimates**
- **Death Certificate System**
- **Healthy Youth Survey**
- **Hospitalization Data**
- **Infectious Disease Reporting Databases**
- **Pregnancy Risk Assessment Monitoring System**

**Behavioral Risk Factor Surveillance System (BRFSS)** (Note: Description is for BRFSS data through 2010 only.)

**Description of the System**

- **Purpose.** BRFSS provides indicators of health-risk behavior, preventive practices, healthcare use and access, knowledge and attitudes about health-related behaviors and practices, and prevalence of selected diseases in Washington.
- **Coverage.** BRFSS surveys adults ages 18 and older living in non-institutional settings in Washington.
  - From 1987–2002, the survey was offered in English only. Since 2003, it has been offered in English and Spanish.
  - From 1987–2010, BRFSS included adults living in households with landline telephones.
  - In addition to the statewide sample, since 2003, BRFSS has oversampled small counties to allow reporting of BRFSS information by county.
- **Years.** Washington conducted its first BRFSS in 1987. Over time, the Washington BRFSS added topics and questions, and so years of data for primary indicators in Health of Washington State vary. Unless noted in the chapter Technical Notes, chapters present data from the earliest to the most recent year available. Annual data are generally available six months after the close of the calendar year. Data for primary indicators are available annually or every other year.
- **Key data elements.** BRFSS data include information on:
  - Health-risk behaviors such as smoking, physical inactivity and nutrition.
  - Use of preventive and other healthcare services, such as cancer screening.
  - Attitudes and knowledge about health-related behavior, such as signs of stroke.
  - Social, economic and demographic factors, such as age, income and education.
  - Health conditions, such as asthma and diabetes.
- **Reporting system.** From 1987–2010, data are from a randomly selected sample of Washington adults living in households with landline telephones. From 2009–2011, the survey also included residents who had a cell phone, but no residential landline. Beginning in 2012, cell phone respondents are those who report using cell phone for 90% or more of their calls. A survey firm under contract to the Washington State Department of Health conducts the survey following administrative protocols established by the U.S. Centers for Disease Control and Prevention (CDC). The questionnaire includes core questions used by all states and questions on topics of specific interest to Washington. From 2003–2011, Washington BRFSS administered more than one form of the questionnaire each year. The core questions were on all forms administered during a
calendar year, while most state-added questions appeared on one form only.

To maximize the ability to generalize from the sample to Washington State residents, CDC weights respondents’ answers based on probability of selection into the sample and demographic characteristics of Washington’s population. With the incorporation of cell phone respondents, the weighting methods changed to a method often referred to as “raked weighting.” The national inclusion of cell phones and raked weighting occurred in 2011. The Washington State Department of Health developed data from the 2009 and 2010 surveys to be comparable to the 2011 data—that is, it included landlines and cell phones and used raked weighting methods. Beginning with the 2003 data, the Washington State Department of Health adjusts the weights to reflect the county oversample. Detailed documentation of the weighting method is available upon request.


- **Data quality procedures.** The survey contractor uses several procedures to improve response rates, such as call-backs to difficult-to-reach households. In 2005, the contractor began to send advance letters to households where telephone numbers could be matched to addresses. Interviewers use computer-assisted interview software to minimize errors. Interviewers receive professional training, and supervisors and project directors regularly monitor calls to assure that interviewers maintain quality standards.

CDC tests all questions to assure that respondents understand them and can answer using specific categories for replies. CDC has assessed many, but not all, questions for reliability and validity. In 2001, CDC concluded that most questions on the core BRFSS instrument were at least moderately reliable and valid. [Nelson DE, Holtzman D, Bolen J, Stanwyck CA, Mack KA. Reliability and validity of measures from the Behavioral Risk Factor Surveillance System (BRFSS). Söz Praventivmed (Soc Prev Med). 2001;1(46 Suppl):S3-S42.] While some measures on the core have been modified or rotated off since 2001, many have remained unchanged.

**Issues Related to Race and Hispanic Origin**

- BRFSS respondents identify their race and whether they are of Hispanic origin by answering two questions: “Are you Hispanic or Latino/a?” and “Which one or more of the following would you say is your race? White; Black or African American; Asian; Native Hawaiian or Other Pacific Islander; American Indian, Alaska Native; or something else?” Before 2001, interviewers recorded only one race. Beginning in 2001, interviewers could record up to six responses. For respondents who report more than one race, interviewers ask, “Which one of these groups would you say BEST represents your race?” Unless otherwise noted, Health of Washington State groups participants reporting a single race only with participants selecting the same race in response to this question.

- Appendix 1 of the Washington State Department of Health Guidelines for Using Racial and Ethnic Groupings in Data Analyses and the Caveats below discuss issues related to racial and ethnic groupings in BRFSS.

**Caveats**

- The response rate for the BRFSS decreased from 61% in 1995 to 48% in 2010. Other states and other telephone surveys have experienced similar decreases. The drop is due to a combination of people being less willing to cooperate and new technology allowing people to screen phone calls. CDC has assessed the impact of low response rates and has concluded that as long as the response rate is between 30% and 80%, the results are not biased due to response rate. (National BRFSS Conference, March 13, 2002, Peter Mariolis, Ph.D., CDC Behavioral Surveillance Branch) This conclusion is consistent with several recent reviews that found little relationship between response rates and the amount of nonresponse bias for response rates between about 25% to 85% [Groves RM, Peytcheva E. The impact of nonresponse rates on nonresponse bias. Public Opin Q. 2008;72(2):167-189. Groves RM. Nonresponse rates and nonresponse bias in household surveys. Public Opin Q. 2006;70(5):646-675. Keeter S, Kennedy C,

- Data from BRFSS surveys that include landline and cell phone respondents and use the raked (proportional iterative fitting) weighting methods are not comparable to older data that only included respondents with landlines and weighted data using a post-stratification method. Unless otherwise noted in the chapter Technical Notes, HWS presents data from the combined landline and cell phone sample respondents and uses raked weights for 2011 and later. Data from 1987–2008 includes respondents with landlines and uses post-stratification weighting. Washington data from 2009–2010 can be presented to be comparable to either 1987–2008 or 2011 and later.

- Through 2010, BRFSS excluded adults living in households without landline telephones. The 2009 National Health Interview Survey found that nearly one-quarter of American homes and 23% of adults had only a cell phone. Differences between cell phone-only households and households with landlines may contribute to bias in BRFSS data. For example, adults with only a cell phone are more likely to be young, poor, living with unrelated roommates, and renting their home. (Blumberg SJ, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, July-December 2009. Atlanta, GA: National Center for Health Statistics; May 2010.) To an extent, weighting adjustments can reduce bias stemming from excluding adults who only use cell phones, but Blumberg et al. caution against use of landline-only data for some health indicators. [Blumberg SJ, Luke JV. Reevaluating the need for concern regarding noncoverage bias in landline surveys. Am J Public Health. 2009;99(10):1806-1810.]

- BRFSS does not represent people who do not speak English or Spanish. Estimates for Washington residents of Asian heritage are especially likely to be biased due to language barriers. On the 2010 American Community Survey (offered in multiple languages), 18% (± 2%) of Washington residents of Asian heritage reported speaking English not well or not at all. Additionally, some subpopulations within the Asian community were more likely than others to report language barriers, potentially causing additional bias for this group. The percent of respondents who reported speaking English not well or not at all ranged from 4% (± 2%) for those of Japanese heritage to 36% (± 5%) for those of Vietnamese heritage.

- BRFSS does not represent people who live in institutions or other group settings, such as dormitories, group homes, hospitals, in-patient drug treatment facilities, jails or prisons.

- Characteristics of people who refuse to participate are unknown.

- BRFSS might underestimate health-risk behavior because people might be reluctant to report behaviors that others might not find acceptable.

- BRFSS might underestimate use of preventive services because people might not recall correctly. Respondents might overestimate use of preventive services because they think they “should” have had a particular service.

**Best Uses**

- Provide estimates of the prevalence of health-risk behaviors, use of preventive services, use of and access to healthcare, and prevalence of selected health conditions and attitudes

- Examine trends in risk behavior, use of preventive services, and other regularly measured indicators

- Compare county, state, and national patterns

- Investigate correlates of health risk behavior, health care use, and other indicators and compare subgroups

- Identify high-risk groups

**National Data**

- Unless otherwise noted, the national BRFSS data used in *Health of Washington State* were developed by Washington State Department of Health data analysts using datasets for all 50 states and the District of Columbia. The datasets were downloaded from CDC at [http://www.cdc.gov/brfss/data_documentation/index.htm](http://www.cdc.gov/brfss/data_documentation/index.htm). National BRFSS percentages were developed using SUDAAN or Stata statistical
programs and weights and stratification variables developed by CDC.

- BRFSS data in *Health of Washington State* are sometimes different from data presented on the CDC BRFSS website.
  - National data in *Health of Washington State* are percentages of the entire U.S. population; the contribution from each state varies according to the state’s population. The CDC BRFSS website provides median values of all states and the District of Columbia: half of the states are above the median and half are below, and each state counts once independent of its population.
  - Most BRFSS data in *Health of Washington State* are age-adjusted; the CDC BRFSS website does not currently provide age-adjusted percents.

**For Further Information**

Washington State Department of Health, Center for Health Statistics, 360-236-4322

[Washington State BRFSS home page](http://www.doh.wa.gov/DHCS/BRFSS)

[CDC Behavioral Risk Factor Surveillance System](http://www.cdc.gov/brfss)

**Birth Certificate System**

**Description of the System**

- **Purpose.** Birth certificates establish legal rights associated with birth, paternity and adoption, and provide public health information about births and newborns.

- **Coverage.** The birth certificate system covers all births to Washington State residents, including those for residents who give birth in other states; the Washington State Department of Health Center for Health Statistics estimates the system to be more than 99% complete.

- **Years.** The system maintains paper records from 1907–1991 and computerized records from 1968–present. *Health of Washington State* uses computerized records from 1980 through the most recent year of data available at the time of writing. Annual data are generally available eight to ten months after the close of the calendar year.

- **Key data elements.** Data elements used in *Health of Washington State* include year of birth; singleton or multiple birth; method of delivery; maternal race, ethnicity, age, county of residence, prenatal care, smoking during pregnancy, pre-pregnancy weight and height, weight gain during pregnancy and other pregnancy risk factors; and infant’s gender, birth weight and gestational age.

- **Reporting system.** The Washington State Department of Health implemented the Electronic Birth Certificate system in 1992. With this system, hospitals and birth attendants can enter legal and confidential patient information required for the birth certificate directly into an automated information system. Hospitals and birth attendants file approximately 99% of birth records electronically with the remaining 1% filed as paper forms. Information comes from medical records and worksheets completed by mothers.


- **Data quality procedures:** The department provides hospital staff and birth attendants with instruction manuals and training in the completion of the birth certificate and in the use of the electronic system. Data profiles are used to show hospitals how they compare to the state for selected items. Data quality procedures include range of value checks, internal consistency edits, mandatory data entry fields, and checks for consistency in trends over time. The department queries hospitals and birth attendants about possible errors or incomplete information. Formal affidavits are required to change the record for paternities, adoptions or corrections.

**Issues Related to Race and Hispanic Origin**

- The birth certificate collects data on race and Hispanic origin of the mother and father by asking the mother for the information. Since 1989, the NCHS standard for tabulating data has been to use the race of the mother, and *Health of Washington State* uses this standard.
• Birth certificates use open-ended reporting of race, allowing for multiple racial entries. Multiple race data have not been used in this report. In 2010, 3.7% of Washington’s non-Hispanic mothers reported more than one race, compared to 4% of women of childbearing age (15–44) in the 2010 U.S. Census. Thus, the birth certificate seems to adequately identify mothers of more than one race. Nonetheless, the number of mothers in any one multiple race category is too small for accurate reporting, and there is no scientific basis for grouping all mothers with more than one race. [Parker J. The role of reported primary race on health measures for multiple race respondents in the National Health Interview Survey. Public Health Rep. 2006;121:160-168.] NCHS classifies mothers reporting more than one race to a single racial group using methods described in Procedures for Multiple-Race and Hispanic Origin Data: Collection, Coding, Editing, and Transmitting (Division of Vital Statistics, NCHS, Centers for Disease Control and Prevention, May 7, 2004). Health of Washington State uses these data for analyses by racial and ethnic grouping.

• Less than 2% of birth certificates in 2008–2010 combined had missing data for Hispanic origin or missing race for non-Hispanic mothers. These certificates are not included in the analyses.

Caveats
• High unknowns in some fields (such as the month prenatal care began and pre-pregnancy obesity) may make patterns and trends difficult to interpret.

• Differences between counties might reflect incomplete extraction of information from medical records by some hospitals. For example, prenatal care can be underreported if hospital staff are unfamiliar with a patient’s history and do not have access to prenatal records.

Best Uses
• Provide information on all births to Washington residents
• Examine trends in births over time
• Compare local, state, national and international trends

• Compare population subgroups (e.g., race and age of mother)
• Combine with induced abortion and fetal death data to produce pregnancy statistics
• Use as the denominator for infant mortality statistics
• Investigate factors that affect birth outcomes

National Data
• Unless otherwise noted, the national birth certificate data used in Health of Washington State are from the National Vital Statistics Reports published annually by the NCHS. These reports are available in PDF format or can be ordered from the NCHS website.

For Further Information
Washington State Department of Health, Center for Health Statistics, 360-236-4324
Washington State Department of Health, Center for Health Statistics Birth Page

Cancer Registry

Description of the System
• Purpose. The Washington State Cancer Registry (WSCR) monitors the incidence of cancer to understand, control and reduce the occurrence and burden of cancer in Washington (RCW 70.54.230).

• Coverage. WSCR includes information on residents of Washington, including those diagnosed and treated in other states; the Department of Health WSCR program estimates that WSCR includes more than 95% of cancer cases in Washington residents.

• Years. WSCR has information beginning in 1992. Health of Washington State uses data from 1992 through the most recent year available at the time of writing. Annual data are generally available 18 months after the end of a calendar year.

• Key data elements. Data elements used in Health of Washington State include date of diagnosis, age at diagnosis, gender, race, ethnicity, type of cancer (site), stage at diagnosis, and county of residence at diagnosis.

• Reporting system. WSCR collects cancer cases through a variety of methods. Healthcare providers; healthcare facilities, such as hospitals, radiation/ oncology treatment centers
and ambulatory surgery centers; and pathology laboratories are required to report cases to WSCR directly or indirectly through the Fred Hutchinson Cancer Research Center. Washington State has agreements with other states to receive information on Washington residents who are diagnosed or treated in other states. The majority of Washington’s out-of-state cases are reported by Oregon and Idaho, followed by Texas and Arizona.

- **Classification and coding.** The cancer reporting rules (246-102 WAC) define reportable cancers as “any malignant neoplasm, with the exception of basal and squamous cell carcinoma of the skin.” Reporting is also required for cancer in situ (that is, a cancer that has not yet spread to surrounding tissue), except for cancer in situ of the uterine cervix. The record format in WSCR follows North American Association of Central Cancer Registries standards. Primary site, histology and behavior coding are based on the International Classification of Diseases for Oncology (ICD-O). In 2001, WSCR began using the Third Edition of the ICD-O, and cases diagnosed prior to 2001 were updated accordingly.

WSCR reports the stage of disease at diagnosis. For cases diagnosed in 2004 and later, WSCR uses a computer algorithm provided by the Centers for Disease Control and Prevention to compute Summary Stage 2000. The algorithm follows the national standards for Collaborative Staging, which were developed by multiple organizations and associations focusing on cancer.

- **Data quality procedures.** Many healthcare facilities have in-house certified cancer registrars to initiate case reports to WSCR. For facilities without registrars and for physician offices, WSCR staff provide tools and instructions for reporting cases. WSCR staff perform quality assurance activities, including standardized computer edits; review of a statistical sample of records to determine the accuracy of data items such as race and Hispanic origin; and hospital audits to determine the completeness of case finding and the accuracy of data abstraction and coding. In addition, WSCR links the annual death file with records in the cancer registry to assure that all Washington residents who died from cancer are appropriately included in the registry. The North American Association of Central Cancer Registries and the CDC National Program of Cancer Registries review the data annually for quality and completeness. The national program also conducts in-depth audits of WSCR on a regular basis. WSCR continues to be recognized by both organizations for the completeness and quality of its data.

**Issues Related to Race and Hispanic Origin**

- Those reporting cancer cases to WSCR record information on race and Hispanic origin from the medical record or other reliable sources available at the time. Using information from the medical record alone historically resulted in underreporting of American Indian and Alaska Native (AIAN) and Hispanic. To increase appropriate recording of AIAN, WSCR links its records with records from the Indian Health Service and the Northwest Portland Area Indian Health Board. WSCR uses two standard practices to assure the appropriate recording of Hispanic origin: (a) direct contact with healthcare providers in targeted geographical areas; and (b) the application of a Hispanic surname algorithm to all records followed by verification with the reporting source.

- Since 2000, WSCR has allowed for the reporting of more than one race, but less than 1% of current WSCR records have more than one race. Following standards set by the North American Association of Central Cancer Registries, WSCR assigns records with two races to the non-white race or to the first race recorded if both races are non-white. When more than two races are recorded, WSCR selects the first non-white race.

- To assess the quality of race, WSCR staff linked WSCR data from 1998–2001 with death certificate data from 1998–2002 and compared race and Hispanic origin in the two data sources. Approximately 99% of those recorded as white, 98% recorded as black, 96% recorded as Asian and Pacific Islander, 87% recorded as American Indian and Alaska Native, and 91% recorded as Hispanic origin on the death certificate were recorded as such in WSCR. Additionally, about one-quarter of people recorded as American Indian and Alaska Native in WSCR were recorded as white on the death certificate, and about 30% of those recorded as Hispanic origin in WSCR were recorded as non-Hispanic on the death certificate. It is difficult to determine whether WSCR is assigning people to these races appropriately.
groups who should not be assigned or whether they are misreported on the death certificate, but there is evidence that American Indian and Alaska Native race, and to a lesser extent, Hispanic origin are underreported on the death certificate. (Centers for Disease Control and Prevention, National Center for Health Statistics. Quality of Death Rates by Race and Hispanic Origin: A Summary of Current Research, 1999. http://www.cdc.gov/nchs/data/series/sr_02/sr02_128.pdf. Accessed August 8, 2007.)

Caveats

- WSCR data are more than 95% complete by 18 months after the close of a calendar year, but cases can be added (or deleted) after that time. While this does not substantively change rates for cancers included in Health of Washington State, readers might note small differences in numbers of cases between Health of Washington State and other publications or online WSCR data.
- Washington residents who are diagnosed with more than one type of primary tumor will have multiple records in WSCR if they were diagnosed in 1992 or later and lived in Washington at the time of diagnosis. In 2010, approximately 6% of records included people with more than one record. Primary tumors that recur and tumors that spread to other parts of the body from the original primary tumor are not counted as new cancer diagnoses and do not result in a new WSCR record.
- Data for American Indian and Alaska Native race and Hispanic origin are likely not comparable to national data.
- Data are not collected for noninvasive cervical cancer and non-melanoma skin cancer.
- There is limited ability to use WSCR to monitor the impact of interventions aimed at primary prevention because cancer usually takes a long time to develop.
- There are increasing challenges with collecting data in a timely manner as treatment in outpatient settings and from multiple healthcare professionals becomes more common.

Best Uses

- Examine time trends in cancer incidence
- Compare cancer incidence to mortality trends
- Compare local, state and national trends
- Compare population subgroups
- Investigate spatial patterns and correlates, including assisting with response to public concerns regarding potential clusters
- Assist with assessing disparities in treatment and screening practices

National Data

- WSCR staff used the National Cancer Institute’s SEER*Stat 7.0.9, released in April 2012 to develop national incidence data. The data include cancer incidence from 13 SEER sites across the United States and represent estimates of national incidence rates. Information about SEER is available at http://seer.cancer.gov/.

For Further Information

Washington State Department of Health, Washington State Cancer Registry, 360-236-3676 or 888-302-2227
Washington State Cancer Registry

Census Population Counts and Intercensal and Postcensal Estimates

Description of the System

- **Purpose.** The U.S. Constitution mandates a count of people living in the United States (the U.S. Decennial Census) every 10 years to determine how many seats each state will have in the U.S. House of Representatives. The U.S. Decennial Census is also used for political redistricting, distribution of federal and state funds, and other governmental needs. Locally developed intercensal and postcensal estimates provide population counts for noncensus years. Organizations and individuals use population counts for diverse purposes. Health of Washington State uses census, intercensal and postcensal counts to describe Washington’s population and as denominators for calculating rates of health events.
- **Coverage.** The U.S. Decennial Census attempts to count everyone living in Washington on April 1 of the census year. The Census Coverage Measurement program provides estimates of
coverage. In May 2012, the U.S. Census Bureau’s 2010 Census Coverage Measurement Program reported that the 2010 U.S. Census counted about 6,900 more people in Washington households, including those living in group quarters, than the actual population. This resulted in an overcount of about 1%. Nationally, the overcount was about .01%. (Davis PP, Mulligan J. Census Coverage Measurement Estimation Report: Net Coverage for the Household Population in the United States. Washington, DC: U.S. Census Bureau; 2012. http://www.census.gov/coverage_measurement/pdfs/g03.pdf. Accessed May 23, 2012.) These data are not available for people living in institutions, about 2% of Washington’s population. Intercensal and postcensal estimates also provide population counts of everyone living in Washington. However, the postcensal estimates can become inaccurate as we move away from the census year, either underestimating or overestimating counts. (See Caveats.)


- **Key data elements.** For chapters posted in 2012, *Health of Washington State* used population counts by age, gender and county.

- **Reporting systems.**
  
  **U.S. Census.** The [Bureau of the Census](http://www.census.gov), located in the U.S. Department of Commerce, develops and mails census questionnaires to all known addresses where people might live, including housing units and other places, such as hospitals and hotels in the United States, Puerto Rico and other U.S. territories. In 2010, the census questionnaire obtained information on age, gender, race and ethnicity of everyone living in the housing unit on April 1, 2010. Previous censuses asked additional information of one in six households, such as income, education, employment and housing characteristics. These questions are now asked on the [American Community Survey](http://www.census.gov). Census takers visit housing units in rural and remote areas to drop off and pick up forms and visit housing units that do not return census forms. Census workers also stage a one-day operation to obtain information on homeless people and others who might be missed in the traditional enumeration of housing units and group quarters.

  **Intercensal interpolations and postcensal estimates.** OFM provides intercensal interpolations for years between censuses and postcensal estimates for years following the most recent census. OFM develops these estimates using information from the decennial censuses; annual data on the number of births and deaths in Washington; and a variety of other data, such as housing starts, to estimate migration into and out of Washington. These estimates include population counts by age, gender and county. When new decennial census data become available, what had been postcensal estimates are adjusted to account for the new information and become intercensal estimates.

  **Data quality procedures.** U.S. Census data are subject to quality procedures employed by the U.S. Census Bureau prior to release. These procedures evaluate the completeness of the count, try to remove individuals who have been counted more than once, and make other adjustments required for an accurate count. Information on data quality procedures used in developing the intercensal and postcensal estimates is available from the [OFM Forecasting Division](http://www.wa.gov/ofm), 360-902-0599.

**Caveats**

- Although the Census Bureau attempts to obtain information from every known household, homeless people, undocumented people who deliberately avoided the census for fear of disclosure to the Immigration and Naturalization Service, urban poor living over commercial addresses, and others may not be counted by the census. There is also a small group of people who are counted more than once.

- College students are usually counted in the towns in which they attend college, although their health events might be reported at their parents’ or guardians’ residences. This has implications for several counties in Washington.

- Due to reporting rules for active military personnel, some Washington jurisdictions might have military personnel who do not actually
reside there counted as part of the population. This phenomenon might affect rates of some conditions in counties with a high proportion of people who are active military.

- Postcensal counts can become increasingly inaccurate as we move away from census years. Relative to the 2010 census, postcensal counts in Washington toward the end of the decade were extremely accurate for the total population. Counts over- or underestimated subgroups, leading to inaccuracies in rates of diseases or conditions for people of Hispanic ethnicity and for some racial groups, county level-analyses, and age-specific analyses. OFM has since adjusted the 2001–2009 counts. Health of Washington State chapters posted in 2012 use population counts only through 2010 and data are not affected by the accuracy of postcensal counts.

**Best Uses**

- Provide information on the numbers of people at the state, county and sub-county levels by age, gender, race and Hispanic origin

**For Further Information**

U.S. Bureau of Census  
Washington State Office of Financial Management

**Death Certificate System**

**Description of the System**

- **Purpose.** Death certificates establish legal benefits and provide information about causes of death and characteristics of decedents.
- **Coverage.** The Death Certificate System covers all deaths in Washington and those of Washington residents who die in other states; the Washington State Department of Health Center for Health Statistics estimates that the system includes 99% of deaths to Washington residents.
- **Years.** The system maintains paper records from 1907–present and computerized records from 1968–present. Health of Washington State uses computerized records from 1980 through the most recent year available at the time of writing. Annual data are generally available eight to ten months after the close of the calendar year.

- **Key data elements.** Data elements include age, gender, race and ethnicity, date of death, underlying and contributing causes of death, place of residence, place of occurrence, ZIP code of residence, occupation and education.
- **Reporting system.** Funeral directors gather demographic information including age and legal residence of the decedent; the attending physician or the coroner/medical examiner reports the immediate and contributing causes of death. Funeral directors submit death certificates both electronically and in paper format to county registrars in local health jurisdictions (LHJ). In 2010, about 30% of death certificates were submitted electronically, up from about 3% in 2005. The LHJ retains paper certificates for about 60 days for local issuance purposes, then transmits them to the department. The department enters the data into the electronic system. The county registrar transmits electronic death records to the department daily. The department uploads these into the Death Certificate System.

- **Classification and coding.** The department began using the 2003 Revision of the U.S. standard death certificate in 2004. Unless otherwise noted in the chapter Technical Notes, classification and coding of data on these certificates use the National Center for Health Statistics (NCHS) guidelines as defined in Death Edit Specifications for the 2003 Revision of the U.S. Standard Certificate of Death. Death certificates from 1980–2002 use classification and coding as defined in Vital Statistics Instruction Manuals parts 1-20.

Causes of death are coded according to the International Classification of Disease, World Health Organization, Eighth Revision (ICD-8) for 1968-1978; Ninth Revision (ICD-9) for 1979-1998; and Tenth Revision (ICD-10) for 1999 and later.

- **Data quality procedure.** The department’s Center for Health Statistics provides instruction manuals to physicians, coroners and medical examiners, as well as LHJs and others involved in completing and managing death certificates. It uses standardized computer edits and a physician query system to check for internal consistency and for logic and completeness of cause of death. For certificates filed electronically, standardized computer edits...
occur before certificates can be signed and submitted.

**Issues Related to Race and Hispanic Origin**

- Death certificates use open-ended reporting of race, allowing for multiple racial entries. Multiple race data have not been used in *Health of Washington State* because they are of uncertain quality and completeness. The NCHS uses an algorithm to assign people with multiple races on the death certificate to a single race. *Health of Washington State* uses these data for analyses by racial and ethnic grouping. See *NCHS Procedures for Multiple-Race and Hispanic Origin Data: Collection, Coding, Editing and Transmitting, May 2004*.

- The death certificate began collecting data on Hispanic origin separately from race in 1988. Prior to 1988, Hispanic data were provided by a racial category of "Mexican/Chicano" or "Mexican American."

- A recent national study compared self-reported race and ethnicity prior to death with race and ethnicity as recorded on the death certificate. [Arias E, Schauman WS, Eschbach K, Sorlie PD, Backlund E. *The validity of race and Hispanic origin reporting on death certificates in the United States*. *Vital Health Stat. 2008;2(148).*] For 1990–1998, the most recent time period assessed, almost all individuals reporting non-Hispanic black or non-Hispanic white were recorded as such on the death certificate. Almost 90% of individuals reporting Hispanic or non-Hispanic Asian or Pacific Islander (grouped together in this study) were recorded as such on the death certificate. For American Indians or Alaska Natives, only 55% were recorded as such on the death certificate. We have no comparable Washington State data nor national data for more recent years. To the extent that the national findings apply to Washington, deaths for American Indians and Alaska Natives might be especially undercounted.

**Issues Related to Education**

- Prior to 2004, the death certificate collected information on the number of years of education with a range of 0–17. In 2004, the death certificate began collecting information on eight categories of education. The lowest category was 8th grade or less, and the highest category was a doctorate or professional degree. These categories match those used in the 2000 U.S. Census. Due to this change, *Health of Washington State* presents death data by education for 2004 and later only. Data are restricted to decedents ages 25–64. Age groups 25–34, 35–44 and 45–64 are used to develop age-adjusted rates by educational level. (See *Appendix A, Education*.)

**Caveats**

- Unless otherwise noted, mortality rates in *Health of Washington State* use the underlying cause of death. The underlying cause of death is the disease or injury that initiated the events resulting in death. For example, if a person dies from a brain tumor that has spread from a tumor in the breast, the underlying cause is coded as breast cancer. Likewise, if a person dies from pneumonia as a complication of a stroke, the underlying cause of death is coded as stroke.

- Death rates can underestimate the magnitude of health problems for deaths that might be underreported due to social stigma (such as AIDS and suicide) and for conditions that diminish the quality of life but are not fatal (such as chronic alcoholism).

- If reporting of race and ethnicity in Washington is similar to that seen nationally, underreporting on the death certificate of American Indian or Alaska Native and to a lesser extent Hispanic, Asian, and Native Hawaiian or other Pacific Islander might lead to an underestimation of death rates for these groups. The extent of the underestimation likely differs by cause of death. (See *Issues Related to Race and Hispanic Origin*.)

- Differences in causes of death among counties might reflect differences in reporting practices by local physicians, coroners, or medical examiners.

- Revisions in ICD codes can create discontinuities in trends that must be accounted for when comparing mortality rates between time periods using different revisions. In *Health of Washington State*, mortality rates from 1980–1998 are coded following the ICD-9. Mortality rates for 1999 and later are coded following the ICD-10. Ratios of the number of deaths recoded to ICD-10 to the number originally coded using ICD-9 (obtained from a study of a large sample of 1996 U.S. deaths) can assist analysis of time trends independent of coding changes. The ratios are called comparability ratios. For more
Healthy Youth Survey (HYS)

Description of the System

- **Purpose.** The HYS provides indicators of health-related risk and protective factors and health status among youth.

- **Coverage.** State and county samples and county censuses include public school students in grades 6, 8, 10 and 12. The survey is offered in English and Spanish.

- **Years.** Since 2002, the HYS has been administered in October of even years. Many questions on the HYS are comparable to the 1999 Washington Youth Risk Behavior Survey and the Washington State Survey of Adolescent Health Behaviors from 1992, 1995, 1998 and 2000. Health of Washington State includes HYS data through the most recent year available at the time of writing. Data are generally available in February following the October administration.

Best Uses

- Understand causes of death in Washington State and its counties
- Examine trends in mortality over time
- Compare causes of death in Washington and its counties to those in other counties and states and to national and international data
- Compare population subgroups (e.g., race, age, gender, occupation)
- Investigate spatial patterns and correlates (e.g., social and environmental factors)
- Support public health surveillance in a cost-efficient manner

National Data

- National death data are available from several sources within the federal government. Sources used in Health of Washington State are referenced in each chapter.

For Further Information

Washington State Department of Health, Center for Health Statistics, 360-236-4324

Washington State Department of Health, Center for Health Statistics, Death Certificate information

Healthy Youth Survey (HYS)

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to increase consistency in administration procedures and to assure confidentiality. The contractor checks surveys for internal consistency and discards surveys based on an algorithm regarding inconsistencies and other evidence of dishonesty.

Issues Related to Race and Hispanic Origin

- HYS respondents identify their race and whether they are of Hispanic origin by answering the question, "How do you describe yourself? (Select one or more responses.)" Responses include: American Indian or Alaska Native, Asian or Asian American, black or African American, Hispanic or Latino/Latina, Native Hawaiian or Pacific Islander, white or Caucasian, and other. The final dataset includes a category of "more than one race."

Caveats

- The response rate for the statewide sample has been increasing. In 2010, response rates were 83% for grade 6, 77% for grade 8, 67% for grade 10, and 53% for grade 12. Periodic bias analysis from 2002–2010 has consistently found that the survey cannot be generalized to students in alternative schools, but otherwise it did not find evidence of bias.
- Self-reported information is not verified through other means, although some questions have been validated through special studies done elsewhere.
- Health of Washington State often provides information for 10th graders. A larger proportion of 10th graders complete the survey compared to 8th graders, and so information for items near the end of the questionnaire is more representative for 10th compared to 8th graders. Some questions might also be answered more accurately by 10th compared to 8th graders. The effect of high school dropouts on this dataset is less in 10th than in 12th grade.

Best Uses

The data can be used by schools, school districts, and local, county, and state agencies and organizations to:

- Monitor trends in behavioral risks, health status, safety, nutrition, physical activity, obesity and substance use.
- Assess needs to support program planning and grant applications for funding.
- Examine impacts of intervention and prevention programs.

National Data

- For health indicators, HYS data can be compared to the national YRBS, which is administered in the spring of the same school year as HYS. Thus, for example, the fall 2010 HYS is in the same school year as the spring 2011 YRBS. The YRBS surveys grades 9–12, and so Health of Washington State often compares HYS 10th graders to YRBS 10th graders. To compare to Healthy People 2010 targets, Health of Washington State uses synthetic estimates for grades 9–12 by developing weighted averages from HYS for grades 8, 10 and 12.

For Further Information

Washington State Department of Health, HYS page AskHYS

Hospitalization Data

Health of Washington State hospitalization data includes information for Washington residents with inpatient hospitalizations in Washington or Oregon nonfederal, acute care hospitals. The Washington State Department of Health uses hospital discharge data for Washington residents compiled and maintained by:

- Washington State Center for Health Statistics (CHS), Comprehensive Hospital Abstract Reporting System (CHARS) for hospitalizations in Washington.
- Office for Oregon Health Policy and Research, Oregon State Hospital Discharge Data (OHDD), for hospitalizations in Oregon from 1987–1999.
- Agency for Healthcare Research and Quality, Healthcare Cost and Utilization Project (HCUP) State Inpatient Databases (Oregon) (OR-SID) for hospitalizations in Oregon from 2000 and later.

Description of the System: CHARS

- **Purpose.** Hospital discharge data systems were originally developed to monitor hospitalization payment rates and contain costs. They are widely used to examine trends in causes of hospitalization, create hospital-specific case-mix indices, characterize access to and quality of healthcare, and monitor morbidity from selected health conditions.
• **Coverage.** CHARS, OHDD and OR-SID include inpatient stays for all patients treated in state-licensed acute care hospitals in Washington or Oregon, regardless of patient residence. These datasets do not include emergency room or outpatient records from these hospitals; records from federal hospitals including military, Veterans Administration, Department of Defense or Indian Health Services; or private alcoholism or long-term care hospitals such as rehabilitation facilities. CHARS does not include state psychiatric hospitals licensed by the Department of Social and Health Services. Both Washington and Oregon datasets contain 98%–100% of hospitalization records from reporting hospitals. For 2004–2009, OR-SID included all but one identified community hospital; for 2003, OR-SID was missing two community hospitals. It is not known how these might affect hospitalization records for Washington residents. CHS estimates that external cause of injury codes are 95% complete. (See Classification and coding below.)

• **Years.** The first complete year of reliable data for CHARS is 1987; annual data are generally available seven months after the close of the calendar year. The OHDD Washington dataset available through CHS includes data from 1987–1999. OR-SID includes data from 2000 through the most recent year available; CHS generally obtains OR-SID data about 10 months after the close of the calendar year.

• **Key data elements:** Data elements used in Health of Washington State include hospital, ZIP code of residence, age, gender, length of stay, discharge status, total charges, payer, primary and secondary diagnoses, primary and secondary procedures, physician, diagnosis related groups (DRGs) and DRG relative weight, and external cause of injury code. CHARS has an encoded patient identifier allowing deduplicated data analysis (i.e., counting each person once independently of the number of times hospitalized). Oregon data do not include encoded identifiers. (See Caveats.)

• **Reporting system.** Hospitals summarize information from the uniform billing form and code diagnoses and procedures. In Washington, hospitals submit information to the department by electronic file transfer within 45 days of the end of the month. The department prepares and maintains the CHARS analytic dataset. In Oregon, hospitals submit the information to a contractor working for the Oregon State Hospital Association. The contractor prepares the database and gives it to the Oregon State Hospital Association. The hospital association releases copies to the Oregon State Office for Health Policy and Research (OHPR) and the federal Agency for Healthcare Research and Quality (AHRQ) to use as part of the national dataset. Since 2000, Washington has received information on Washington residents included in the dataset through AHRQ; 1987–1999 data were obtained through OHPR.

• **Classification and coding.** Reasons for hospitalization are coded according to the International Classification of Disease, Clinical Modification, Ninth Revision (ICD-9-CM). The reason in the first diagnosis field is considered to be the primary reason the patient was admitted to the hospital. Before 1993 for CHARS and 1995 for Oregon data, the maximum number of diagnoses in addition to the primary diagnosis was five. This number has grown: both CHARS and OR-SID currently allow up to 24 secondary diagnoses. Unless otherwise indicated, Health of Washington State presents information from the primary diagnosis. Chapters that include secondary diagnoses use the primary diagnosis in addition to the first eight secondary diagnoses.

In addition to nature of injury codes, datasets include “e-codes” describing the (external) cause of an injury or poisoning. E-codes are mandatory in Washington, but not in Oregon. CHS uses a computer algorithm, to assign e-codes when they are missing. In recent years, CHS has imputed approximately 2.5% of e-codes in CHARS and 3.5% in OR-SID. These proportions were higher for earlier years because of larger proportions of missing e-codes. For example, in 2002 about 20% of Oregon records with injury or poisoning codes lacked external cause codes; in 2003 and 2004, about 9% lacked these codes.

• **Data quality procedures.** The CHARS data collection system edits the data through computerized system program checks. Several department studies have confirmed high accuracy for diagnoses using three-digit ICD-9 codes. (For information contact Washington State Department of Health, Center for Health Services.)
Issues Related to Race and Hispanic Origin (CHARS, Oregon, VA hospitals)

- Health of Washington State does not include hospitalization data by race and ethnicity. CHARS did not collect information on patients’ race and ethnicity prior to 2008. As of 2010, more than 15% of CHARS records are missing this information. The Oregon datasets do not include information on patients’ race and ethnicity.

Caveats

- Although most analyses in Health of Washington State are based upon the first listed diagnosis, some analyses use the first diagnosis, as well as up to eight additional diagnoses. (See Classification and coding.) Multiple diagnosis fields are used because some conditions, such as diabetes and high blood pressure, contribute to the reason for the hospitalization even though they are not listed first. To gauge the full impact of a condition such as diabetes, it is necessary to examine both “hospitalization from” the condition as well as “hospitalization with” the condition. In 2010, for example, almost 8,000 hospitalizations recorded diabetes as the first diagnosis; about 87,000 hospitalizations included diabetes among the first eight secondary diagnoses.

- Unless otherwise noted, the unit of observation is the hospitalization episode, not the individual. Thus, one person hospitalized three times in a year counts as three hospitalizations for that year. The number of hospitalizations gives us a better picture of the public health impact of a condition. Each hospitalization for an illness or injury is an adverse event for the person who experiences it. Many hospitalizations are potentially avoidable through reductions in the factors that cause diseases and injuries or through early detection and rapid treatment. In addition, because records from Oregon hospitals do not include a patient identifier, it is not possible to count individuals when using the combined hospitalization dataset.

- The hospitalization dataset does not include outpatient information, such as visits to emergency departments; hospital-based outpatient clinics; hospital-based outpatient surgery; and nonhospital-based surgical, birthing, mental health, substance abuse and rehabilitation centers.

- Hospitalization data are not available for Washington residents hospitalized outside Washington or Oregon and do not include information from military and Veterans Administration hospitals. (See Appendix A, Geographic Variation.) These missing data affect county level more than the state-level data presented in Health of Washington State chapters posted in 2012.

- Changes in hospitalization practices or coding conventions might affect trends over time.

- Increases in the number of diagnosis fields can result in a discontinuity in trend data.

Best Uses

- Monitor hospitalizations due to diseases severe enough to warrant hospitalization consistently over time

- Monitor use of inpatient healthcare resources and hospital costs

- Monitor sources of payment

- Assess access to care by examining trends in potentially avoidable hospitalizations

For Further Information

CHARS
Washington State Department of Health, Center for Health Statistics, 360-236-4328.

Oregon Hospital Inpatient Discharge Data: Office for Oregon Health Policy and Research, Oregon State Hospital Discharge Data 1987–1999.

Agency for Healthcare Research and Quality,
Healthcare Cost and Utilization Project (HCUP)

Infectious Disease Reporting System

Description of the System

- Purpose. This system allows public health officials to monitor incidence of infectious diseases that are required to be reported to public health—often called notifiable conditions; assure proper referral and treatment of affected individuals; and implement other actions to control the spread of infectious diseases. The data system allows monitoring of trends and
identifying populations at high risk for those diseases.

- **Coverage.** The database covers all Washington residents, but underreporting can be an issue for some diseases. (See Caveats.)
- **Years.** Years of coverage vary depending on the disease, but information on most of the current notifiable infectious diseases began in the 1980s; data are generally available on an ongoing basis with annual data compiled six to twelve months after the end of a calendar year.
- **Key data elements.** Key data elements used in Health of Washington State include diagnosis; date of diagnosis; age at diagnosis; gender, race and ethnicity; and county of residence. Selected chapters use additional data elements of importance for specific diseases.
- **Reporting system.** Following WAC 246-101, healthcare providers, hospitals, laboratories and veterinarians identifying a patient with a notifiable infectious disease are required by law to report the case to the local or state health department depending on the disease. Reporters also must provide a limited amount of information about the patient. For some notifiable infectious diseases, the health jurisdiction more actively seeks out cases or collects exposure information; for other diseases and conditions, there is little health jurisdiction involvement other than recording cases. Legally, each disease is to be reported within a specified length of time (such as immediately, within a day, within three days), but these requirements are not always met. Electronic systems have improved timeliness of laboratory reporting.
- **Classification and coding.** For most infectious diseases included in Health of Washington State, laboratory testing is used to confirm cases. Washington State follows standard case definitions developed by the Council of State and Territorial Epidemiologists in cooperation with Centers for Disease Control and Prevention (CDC). Use of standardized definitions enhances national comparisons over time and in different geographic locations.
- **Data quality procedures.** Acute communicable diseases are individually reviewed to confirm the classification, and case counts are reconciled with CDC for national summary reporting. Cases of HIV/AIDS, chronic hepatitis B and C, sexually transmitted infections and tuberculosis are reviewed to assure they meet case definitions and are matched to prior case reports to prevent counting cases more than once.

### Issues Related to Race and Hispanic Origin

- Race and Hispanic origin are often not reported or are reported based on the reporter’s opinion.
- Reduced access to healthcare facilities can result in underreporting for certain racial groups or people of Hispanic origin.
- Although all providers are required to report notifiable conditions, reporting might be more complete from public health facilities compared to other healthcare facilities. Disproportionate use of public health facilities by individuals in some racial and ethnic groups can lead to rates for these groups being disproportionately higher than rates for groups that do not use these facilities as often.

### Caveats

- The incidence of disease might be underestimated because of underdetection, underdiagnosis, and underreporting. Less serious diseases, such as those causing mild diarrhea, are more likely to be underdiagnosed and underreported than diseases with more severe health consequences, such as meningitis.
- Inconsistent level of detection or reporting in different populations because of differences in access to healthcare, source of healthcare, and reporting effort can affect comparisons across jurisdictions or population subgroups.
- For some data elements, such as race and ethnicity, reported information may be inaccurate or incomplete.

### National Data

- Unless otherwise noted, national data on infectious disease used in Health of Washington State are from the Summary of Notifiable Diseases, United States published annually by CDC as a supplement to the Morbidity and Mortality Weekly Report (MMWR).
Best Uses
- Examine trends in moderately severe disease that require a healthcare encounter but do not necessarily lead to hospitalization or death, particularly if cases are confirmed through laboratory tests.
- Characterize high-risk populations.
- Compare local, state and national trends.
- Investigate spatial patterns and correlates including outbreak identification.
- Monitor impact of intervention and prevention activities because effects are seen rapidly owing to the relatively short time between exposure to a pathogen and onset of disease for most notifiable infectious diseases.

For Further Information
Washington State Department of Health,
Notifiable Conditions home page
Washington State Department of Health, Office of Communicable Disease Epidemiology, 206-418-5500
Washington State Department of Health, Office of Infectious Disease, Assessment Unit, 360-236-3455

Pregnancy Risk Assessment Monitoring System (PRAMS)

Description of the System
- **Purpose.** PRAMS supplements birth certificate data to generate information for planning and evaluating perinatal health programs.
- **Coverage.** PRAMS surveys new mothers (two to six months postpartum) who are residents of Washington and can speak either English or Spanish. About 1,800 or 2% of Washington’s new mothers are sampled each year.
- **Years.** Washington PRAMS data are available beginning in June 1993. *Health of Washington State* chapters that use PRAMS to assess changes over time use data from the earliest complete calendar year in which the specific data were collected through the most recent year the same data were collected. These years may not be consistent across chapters even for chapters developed in the same time period, because of changes to the PRAMS survey over time. Annual data are generally available 14 months after the close of the calendar year.
- **Key data elements.** Data elements used in *Health of Washington State* include age, race, ethnicity, enrollment in the Medicaid program, health-related behaviors, healthcare during pregnancy and infant healthcare.
- **Reporting system.** Participants are selected from birth certificate data using a stratified random sample. Sampling methods have changed over time. From 1993–1999, Hispanic, African American, American Indian and Asian or Pacific Islander women were oversampled. From 2000–2010, the sampling plan included 10 strata. The state was divided into two regional samples: women in King and Snohomish counties, who account for about 30% of Washington births, were sampled as a region; and women from all other counties comprised a region. Within each region, there were five racial and ethnic substrata similar to the strata prior to 2000. In 2011, the geographic stratification was discontinued, but PRAMS continues to stratify the sample by the five racial and ethnic groups. Survey information is collected by mail through a self-administered questionnaire. Women who do not return the self-administered questionnaire are contacted by telephone for telephone interviews. Information for about one-quarter of respondents in the 2010 PRAMS was obtained through telephone interview.
- **Data quality procedures.** The Centers for Disease Control and Prevention (CDC) protocols require several procedures to improve response rates, including multiple mailings and telephone call-backs to difficult-to-reach households. Interviewers use computer-assisted interview software to minimize errors. CDC tests all questions to assure that respondents understand them and can answer using specific categories for replies. CDC has assessed many, but not all, questions for reliability and validity. Interviewers receive training, and supervisors regularly monitor calls to assure that interviewers maintain quality standards.

Issues Related to Race and Hispanic Origin
- PRAMS uses race and Hispanic origin as reported on the birth certificate (see Birth Certificate System).
Caveats

- The overall weighted response rate was 78% in 2010. The 2010 response rate was 60% for African Americans, 56% for American Indians and Alaska Natives, and 72% for Asians and Pacific Islanders. Pending bias analysis, PRAMS data for these groups should be used cautiously.

- Collection of information two to six months after delivery might affect responses to some questions and limits follow-up time for outcomes.

- Self-reported information is not verified through other means.

- Sample design prevents analysis of data for most individual counties.

National Data

- Sources for national PRAMS data used in Health of Washington State are noted in each chapter.

Best Uses

- Monitor statewide trends in behavioral risks, health care, and pregnancy outcomes over time

- Correlate birth outcomes and health-related information, socioeconomic information, and behavioral risk and protective factors

- Examine impacts of intervention and prevention programs

For Further Information

Washington State Department of Health, PRAMS home page

Washington State Department of Health, Office of Healthy Communities, PRAMS Coordinator, 360-236-3497

The national PRAMS website