U.S. Cancer Statistics

Data Visualizations Tool Technical Notes

2022 Submission Diagnosis Years 1999–2020 Released June 2023





Table of Contents

Introduction	3
Contributors	5
National Program of Cancer Registries (NPCR)	6
Surveillance, Epidemiology, and End Results (SEER) Program	7
National Vital Statistics System (NVSS)	
Data Sources	9
Incidence Data Sources	10
Mortality Data Sources	
Population Denominator Data Sources	15
Screening, HPV Vaccination, and Risk Factor Data Sources	
U.S. Cancer Statistics Publication Criteria	17
Registries That Met U.S. Cancer Statistics Publication Criteria	
Statistical Methods	20
Incidence and Death Rates	22
Confidence Intervals	23
Stage at Diagnosis	25
Relative Cancer Survival	26
Cancer Prevalence	28
Screening, HPV Vaccination, and Risk Factor Prevalence Estimates	30
Risk Factor-Associated Cancers	
Incidence and Death Estimates by Congressional District	
Suppression of Rates and Counts	
Interpreting the Data	
Interpreting Incidence Data	39
Interpreting Mortality Data	
Interpreting Race and Ethnicity in Cancer Data	
Guidance for Comparing States' Cancer Data	

The Impact of Cancer

Cancer is the second-leading cause of death in the United States .¹ The 2023 release of United States Cancer Statistics data indicates that, in 2020 (the most recent year of incidence* data available), 1,603,844 people living in the United States received a new diagnosis of invasive cancer[†] and 602,347 people living in the United States died from this disease.² These counts do not include *in situ* cancers, benign and borderline brain and central nervous system tumors, and basal and squamous cell skin cancers. As of January 1, 2020, an estimated 13 million people living in the United States were alive with a history of invasive cancer diagnosed in the past 19 years.²

The Agency for Healthcare Research and Quality's (AHRQ) <u>Medical Expenditure Panel Survey</u> estimates that for 2020, the direct medical costs for cancer, including all health care expenditures, were \$172 billion.³

*2020 is the most recent year for which incidence data are available. These data include cancer cases during 1999 through 2020. Cancer mortality data for 2021 are available and can be accessed at CDC's <u>National Center for Health Statistics (NCHS) National Vital</u> <u>Statistics System (NVSS)</u>.

[†]Data are from selected central cancer registries, covering 97% of the U.S. population for 2020 diagnoses and 99.7% for cases diagnosed between 1999 and 2020, that meet the data quality criteria for all invasive cancer sites combined. See <u>registry-specific</u> <u>data quality</u> information.

Cancer Prevention

Several primary and secondary <u>prevention measures</u> could substantially reduce the number of new cancer cases and prevent many cancer-related deaths. To reduce the nation's cancer burden, the Centers for Disease Control and Prevention's (CDC's) <u>Division of Cancer Prevention and Control (DCPC</u>) aims to understand and monitor behavioral and environmental factors that may increase cancer risk. CDC also helps make high-quality screening services and evidence-based treatments available and accessible to everyone, including medically underserved populations.^{4,5} CDC has supported all 50 states, the District of Columbia, tribes and tribal organizations, U.S. Pacific Island Jurisdictions, and Puerto Rico in developing comprehensive cancer control plans, which include proven strategies and planned actions to prevent cancer in their geographic regions.⁶

How Cancer Data Are Collected

Invasive cancer is a mandatory reportable disease in the U.S. Cancer registries collect population-based data about the occurrence of cancer (incidence), the types of cancer (morphology), the site in the body where the cancer first occurred (primary site), the extent of disease at the time of diagnosis (stage), the planned first course of treatment, and the outcome of treatment and clinical management (survival and vital status).^{7,8} These cancer reports are sent to central cancer registries (at the state or territory level) from a variety of medical facilities, including hospitals, physicians' offices, radiation facilities, freestanding surgical centers, and pathology laboratories. Death data, including deaths due to cancer, are recorded on death certificates that are sent to state or territory vital statistics offices. Death data include information regarding primary cancer site, and may also include morphology according to International Classification of Diseases, Tenth Revision (ICD-10).

Uses of Cancer Data

Information derived from population-based central cancer registries and from state vital statistics systems is critical for directing effective geographic area and population-specific cancer prevention and control programs. These programs focus on preventing behaviors that may put people at an increased risk for cancer (such as tobacco use), and on reducing environmental risk factors (such as occupational exposure to known carcinogens). This information is essential for deciding where to have cancer screening programs, and for making long-term plans for adequate diagnostic and

treatment services. Combining data at the national, state or territory, congressional district, and county levels helps public health officials prioritize and monitor public health efforts and track progress toward <u>Healthy People</u> objectives.

Additional resource: Archive of the Annual Reports to the Nation

- 1. Xu, JQ, Murphy SL, Kochanek KD, Arias E. <u>Mortality in the United States, 2021.</u> NCHS Data Brief, no 456. Hyattsville, MD: National Center for Health Statistics. 2022.
- 2. U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999–2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, June 2023.
- 3. Agency for Healthcare Research and Quality. <u>Total expenditure in millions by condition, United States, 2020.</u> Medical Expenditure Panel Survey. Generated interactively: April 20, 2023.
- 4. Curry SJ, Byers T, Hewitt M. *Fulfilling the Potential of Cancer Prevention and Control.* Washington (DC): The National Academies Press; 2003.
- 5. Haynes MA, Smedley BD. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. Washington (DC): The National Academies Press; 1999.
- 6. National Comprehensive Cancer Control Program. <u>Comprehensive Cancer Control Plans.</u> Atlanta: U.S. Department of Health and Humans Services, Centers for Disease Control and Prevention.
- 7. American College of Surgeons Commission on Cancer. <u>Standards for Oncology Registry Entry (STORE)</u>. Accessed April 20, 2023.
- 8. National Cancer Institute. <u>SEER Program Coding and Staging Manual 2023.</u> Accessed April 20, 2023.

National Program of Cancer Registries (NPCR)

CDC's NPCR supports central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Pacific Island Jurisdictions, and the U.S. Virgin Islands. In 2022, CDC received information on more than 37.9 million invasive cancer cases diagnosed from January 1, 1995 through December 31, 2020. More than 1.6 million new invasive cancer cases are added each year.

Surveillance, Epidemiology, and End Results (SEER) Program

The National Cancer Institute's SEER Program collects and publishes data on cancer incidence and survival from 22 population-based cancer registries.

National Vital Statistics System (NVSS)

The nation's vital statistics are available from NVSS, which is maintained by CDC's National Center for Health Statistics. These vital statistics are provided through state-operated registration systems and are based on vital records filed in state vital statistics offices.

Partners

Those crucial to the success of cancer registration and cancer surveillance in the United States include the <u>American</u> <u>Cancer Society</u>, the <u>American College of Surgeons</u>, the <u>American Joint Committee on Cancer</u>, the <u>National Cancer</u> <u>Registrars Association</u>, and the <u>North American Association of Central Cancer Registries</u>. CDC's <u>National Program of Cancer Registries (NPCR)</u> funds 50 cancer registries: 46 states, the District of Columbia, Puerto Rico, the Pacific Island Jurisdictions, and the U.S. Virgin Islands.

NPCR is committed to-

- Monitoring the state and national burden of cancer.
- Identifying variation in cancer incidence for racial and ethnic populations and for regions within a state, between states, and between regions.
- Providing data for research.
- Providing guidance for the allocation of health resources .
- Responding to public concerns and inquiries about cancer.
- Improved planning for future health care needs.
- Evaluating activities in cancer prevention and control.

In January 2001, NPCR-funded registries began reporting their incidence data annually to CDC. The registries report data to CDC beginning with cases diagnosed in the first year for which they collected data with the assistance of NPCR funds. Data from the special population cancer registries or the SEER metropolitan area cancer registries operating in Alaska, Arizona, California, Michigan, and Washington are reported to their respective NPCR state cancer registry for inclusion in those states' incidence data and are transmitted to CDC as part of the state's annual data submission.

In the 2022 data submission, CDC received information on more than 37.9 million invasive cancer cases, and 2.75 million *in situ* cases diagnosed during 1995 through 2020. In addition, 935,508 benign and borderline brain and central nervous system tumors were reported during 2004 through 2020. More than 1.6 million new invasive cancer cases are added each year.

In conjunction with the annual release of United States Cancer Statistics (USCS) data, NPCR evaluates each funded central cancer registry's data according to NPCR's <u>standards</u> for data completeness, timeliness, and quality. Registry data must meet these standards to be included in USCS data products.

The release of USCS data in products including the Data Visualizations tool and Public Use Databases exemplifies the progress achieved in creating a national system of cancer surveillance. Viewers are able to access locally relevant cancer data at the county and congressional district levels. Since these data are collected using national standards, users can compare information across geographic areas and over time. Data from state and county levels can be used to plan and evaluate cancer control programs, conduct research, and monitor cancer trends.

Partners such as the central cancer registry are crucial to the success of cancer surveillance in the United States. The efforts and achievements of many partner organizations contribute to USCS data products and the advances in cancer surveillance in the United States.

USCS data products include-

- A web-based data visualizations tool that displays USCS data, the official federal cancer statistics.
- Public use databases for researchers to analyze more than 35 million cancer cases.
- A public use data set of pre-calculated cancer incidence and death rates on CDC WONDER.
- <u>Data briefs</u> and <u>Stat Bites</u> on cancer burden intended for general audiences.
- A website designed to help guide and prioritize cancer control activities at the state and county level at <u>State</u> <u>Cancer Profiles.</u>
- A restricted-access dataset available to researchers through the National Center for Health Statistics <u>Research</u> <u>Data Center.</u>

Surveillance, Epidemiology, and End Results (SEER) Program

The National Cancer Institute's (NCI's) <u>Surveillance, Epidemiology, and End Results (SEER) Program</u> collects and publishes data on cancer incidence and survival from population-based cancer registries in 22 U.S. geographic areas. <u>SEER</u> <u>registries</u> provide complete coverage for metropolitan regions and special populations whose data are reported to their respective state registries funded by CDC's <u>National Program of Cancer Registries</u>.

The SEER Program continues to—

- Monitor the burden of cancer in the United States.
- Provide statistics on cancer incidence and survival in the SEER coverage area, and mortality in the United States provided by CDC's <u>National Center for Health Statistics</u>.
- Monitor cancer incidence trends in geographic and demographic population groups, including diverse racial and ethnic groups.
- Provide detailed information on trends in the extent of disease at diagnosis, therapy, and patient survival.
- Provide data for research.
- Promote studies measuring progress in cancer control and etiology.
- Provide specialty training in epidemiology, biostatistics, surveillance research, tumor registry methodology, operations, and management.
- Respond to public concerns and inquiries on cancer.
- Develop new statistical methods, models, and software for the analysis and presentation of national and smallarea statistics.

The mortality data reported by SEER are provided by CDC's National Center for Health Statistics. The SEER Program issues a limited-use data set (formerly called the public use data file) for <u>additional analyses</u> by researchers and the public.

In addition to the data sets on the SEER website, NCI disseminates-

- A public use interactive website of pre-calculated cancer incidence rates called <u>SEER*Explorer</u>.
- A public use interactive tool to explore childhood, adolescent, and young adult cancer statistics called <u>NCCR*Explorer</u>.
- Cancer statistics <u>fact sheets.</u>

For information about NCI's additional tools and products, visit their <u>Cancer Statistics</u> page.

National Vital Statistics System (NVSS)

The nation's vital statistics are available from the <u>National Vital Statistics System (NVSS)</u>, which is maintained by CDC's <u>National Center for Health Statistics (NCHS)</u>. These vital statistics are provided through state-operated registration systems and are based on vital records filed in state vital statistics offices.

Recording vital events is the responsibility of the individual states and independent registration areas (District of Columbia, New York City, and five territories) in which the event occurs. Legal responsibility for the registration of vital events rests with the individual jurisdictions.

Through its Vital Statistics Cooperative Program, NCHS cooperates with state vital statistics offices to develop and recommend standard forms for data collection, model regulations, and procedures to ensure uniform reporting of the events monitored by the NVSS. Detailed annual data on births, deaths (including infant deaths), and fetal deaths are available for the United States and for states, counties, and other local areas.

The <u>NCHS restricted use data set</u> is obtained annually through NCHS's application process. Data variables include cause of death, age, race, Hispanic origin, sex, marital status, place of birth, residence of decedent, education level, and place of death.

Incidence Data

Medical records are the primary source of data on cancer incidence. Staff at health care facilities abstract data from patients' medical records, enter it into the facility's cancer registry (if it has one), and then send the data to the central registry. Other data sources include physicians' offices, radiation facilities, freestanding surgical centers, and pathology laboratories.

Mortality Data

Cancer mortality statistics are based on information from all death certificates filed in the 50 states, the District of Columbia, and Puerto Rico, and processed by the National Vital Statistics System.

Population Denominator Data

The population estimates for the denominators of incidence and death rates are race-specific, ethnicity-specific, and sex-specific county population estimates aggregated to the state or metropolitan-area level.

Population estimates used in the calculation of Puerto Rico incidence and death rates are sex-specific, are obtained from the U.S. Census Bureau, and are not available by race or ethnicity. To account for the population shift that occurred due to Hurricane Maria, the population denominators for 2017 were adjusted by dividing the U.S. Census Bureau's July 1, 2017 (vintage 2021) Puerto Rico population estimate in half.

Screening, HPV Vaccination, and Risk Factor Data

Cancer screening and risk factor data are based on information obtained from the <u>Behavioral Risk Factor Surveillance</u> <u>System</u>, which collects data in all 50 states, the District of Columbia, and three U.S. territories. Human papillomavirus (HPV) immunization data are collected through the <u>National Immunization Survey-Teen (NIS-Teen)</u>.

Incidence Data Sources

Incidence data are from the registries participating in the Centers for Disease Control and Prevention's (CDC's) <u>National</u> <u>Program of Cancer Registries (NPCR)</u> and the National Cancer Institute's (NCI's) <u>Surveillance, Epidemiology, and End</u> <u>Results (SEER) Program.</u> Data from state central cancer registries that are supported by both NPCR and SEER are presented as reported to CDC in 2022.

How Incidence Data Are Collected

The primary source of data on cancer incidence is medical records. Staff at health care facilities abstract data from patients' medical records, enter it into the facility's own cancer registry (if it has one), and then send the data to the regional or state registry. Other data sources include physicians' offices, radiation facilities, freestanding surgical centers, and pathology laboratories. Both NPCR and SEER registries collect data using uniform data items and codes as documented by the <u>North American Association of Central Cancer Registries (NAACCR)</u>. This standardization ensures that data items collected by the two federal programs are comparable.^{1 2} Information on primary site and histology was coded according to the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3)³ and categorized according to the <u>revised SEER recodes</u> dated January 27, 2003, which define standard groupings of primary cancer sites. Beginning with 2010 diagnoses, cases are coded based on ICD-O-3 updated for hematopoietic codes based on *WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues* (2008).

Reportable Cases

Invasive cancer is a mandatory, reportable disease for public health surveillance. NPCR and SEER cancer registries consider all incident cases with a behavior code of 2 (*in situ*, noninvasive) or 3 (invasive, primary site only) in the ICD-O-3 with the exception of *in situ* cancer of the cervix as reportable. Basal and squamous cell carcinomas of the skin are also excluded, with the exception of those on the skin of the genital organs.³ Several cancers are coded as malignant in ICD-O-3 (beginning with 2001 diagnoses) that were not coded as malignant in ICD-O-2³ and are noted as follows—

- Myelodysplastic syndrome (MDS) including refractory anemias (histology codes 9980, 9982–9984, 9989) are included in the "Miscellaneous" and "All Sites" categories.
- Chronic myeloproliferative disease (CMPD) including polycythemia vera and thrombocythemias (histology codes 9950, 9960–9962) are included in the "Miscellaneous" and "All Sites" categories.
- Papillary ependymomas (9393) and papillary meningiomas (9538)—cancers that occur in the central nervous system—are included in the "Brain and Central Nervous System" and "All Sites" categories.
- Some endometrial tumors (8931) are reported in the "Corpus and Uterus, NOS" and "All Sites" categories.

For comparisons with ICD-O-2 for cancers diagnosed prior to 2001, exclude all of the histology codes described above and listed as follows: 8931, 9393, 9538, 9950, 9960–9962, 9980, 9982–9984, 9989, 9990, 9991, 9992.³

Additional changes in ICD-O-3 apply to ovarian cancer: low malignant potential tumors (8442, 8451, 8462, 8472, 8473) of the ovary are no longer coded as malignant. Therefore, these cancers are not accounted for in the calculations of the incidence rate for ovarian cancer included in tables and figures. A footnote is provided as a reminder of this exclusion.

Pilocytic astrocytomas (9421) are also not coded as malignant in ICD-O-3, but these cancers are included in this report.

In Situ Bladder and Breast Cancers

In situ bladder cancers were recoded to invasive bladder cancers because the information needed to distinguish between *in situ* and invasive bladder cancers is not always available or reliable. Counts and rates for *in situ* breast cancer

cases among women are presented; these are reported separately and are not included in counts or rates for the "All Types of Cancer" category.

Unknown Sex, Age, or Race

Non-reportable cancers and cancers in patients of unknown sex or age were omitted from all calculations, but cancers in patients of unknown race were included in the "All Races" category.

Childhood Cancer

Incidence data on childhood cancer are published in two formats-

- The first is according to the SEER modification of the third edition of the International Classification of Childhood Cancer. The ICCC-3 is based on ICD-O-3/WHO 2008 classification of Tumors of Haematopoietic and Lymphoid tissues.⁴ The ICCC presents childhood cancers in 12 groups classified primarily by morphology. The <u>SEER</u> modification, which affects the classification of nervous system and bone tumors, was chosen for compatibility with other published data on rates of childhood cancer in the United States.
- The second format is according to the SEER site recode, which is based primarily on cancer site; the incidence data are presented in this format to make them comparable with published mortality data. This format allows the incidence data for childhood cancers to be categorized in the same groups as adult cancers. Although these groupings are not as appropriate for children as they are for adults, they are necessary to allow comparisons between childhood incidence and childhood mortality.

Nonmalignant Brain and CNS Tumors

Incidence data on nonmalignant primary brain and central nervous system (CNS) tumors are available in the U.S. Cancer Statistics Data Visualizations tool. Cancer registries began collecting information on nonmalignant brain and CNS tumors beginning with 2004 diagnoses. Data collection of these tumors is in accordance with Public Law 107-260, the Benign Brain Tumor Cancer Registries Amendment Act, which mandates that NPCR registries collect data on all brain and CNS tumors with a behavior code of 0 (benign) and those with a behavior code of 1 (borderline), in addition to *in situ* and malignant.⁵ SEER registries voluntarily agreed to incorporate registration of these tumors in their standard practices.⁵

Effect of Hurricanes Katrina and Rita on Presenting Cancer Incidence Data

The population of many counties along the Gulf Coast of Louisiana, Alabama, Mississippi, and Texas were displaced in the fall of 2005 by Hurricanes Katrina and Rita, resulting in incomplete case ascertainment for the latter half of the year. For these states, state- and county-level incidence rates were calculated based upon the data submitted to CDC.

Effect of Hurricane Maria on Presenting Puerto Rico's Cancer Incidence Data

Puerto Rico's 2017 incidence counts and corresponding rates are based on the first six months of the reported data coupled with half of the population estimate (January to June 2017). Cases with an unknown month of diagnosis were also included. To account for the population shift that occurred due to Hurricane Maria in September 2017, data from July to December 2017 are excluded. This population shift may have resulted in incomplete case ascertainment for the latter half of the year.

The population denominators were adjusted by dividing the U.S. Bureau of the Census's July 1, 2017 (vintage 2021) Puerto Rico population estimate in half.

Effect of COVID-19 on Cancer Incidence Data for Diagnosis Year 2020

In March 2020, the World Health Organization declared COVID-19 a pandemic. Soon after, stay-at-home orders, business and school shutdowns, and travel advisories were implemented in the United States to prevent the spread of

COVID-19. Additionally, some health care systems reduced access to routine care. These measures, along with concerns about getting COVID-19, interrupted cancer screening, diagnosis, and care, as people postponed or deferred health care visits, particularly from March to May 2020.

The 2022 data submission includes new cancer cases diagnosed in 2020, the first year of the COVID-19 pandemic. The missed cancer diagnoses resulting from disruptions in health services and delayed reporting of data to some central cancer registries caused by pandemic may have contributed to an observed decline in incidence for most cancer sites in 2020.⁶ Caution must be taken when including the 2020 incidence datapoint in trend models to avoid incorrect interpretations of the effect of cancer prevention and early detection efforts. Observed downward trends may be due largely to the lower observed incidence in 2020.⁶

- 1. National Cancer Institute. <u>SEER Program Coding and Staging Manual 2002.</u> Accessed April 20, 2023.
- 2. Thornton ML, (ed). *Standards for Cancer Registries Vol II: Data Standards and Data Dictionary, Version 23, 24th edition.* Springfield, III: North American Association of Central Cancer Registries, August 2022, revised March 2023.
- 3. Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S. *International Classification of Diseases for Oncology, Third Edition.* Geneva, Switzerland: World Health Organization; 2000.
- 4. World Health Organization. Hematopoietic codes based on WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues (2008).
- 5. McCarthy BJ, Kruchko C, and the Central Brain Tumor Registry of the United States. <u>Consensus conference on</u> <u>cancer registration of brain and central nervous system tumors</u>. *Neuro-oncology* 2005;7(2):196–201.
- Centers for Disease Control and Prevention. <u>U.S. Cancer Statistics: Highlights from 2020 Mortality and Incidence</u> <u>with Comparison to 2019 Incidence to Assess the Effect of the COVID-19 Pandemic.</u> USCS Data Brief, no. 35. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services; 2023.

How Mortality Data Are Collected

Cancer mortality statistics are based on information from all death certificates filed in the 50 states, the District of Columbia, and Puerto Rico and processed by CDC's <u>National Center for Health Statistics (NCHS)</u> <u>National Vital Statistics</u> <u>System (NVSS)</u>. The cancer mortality data were compiled in accordance with <u>World Health Organization</u> (WHO) regulations, which specify that member nations classify and code causes of death in accordance with the current revision of the *International Classification of Diseases* (ICD). Effective with deaths that occurred in 1999, the United States began using the tenth revision of this classification (ICD–10).¹²

Rules for coding the cause(s) of death may require modification when evidence suggests that such modifications will improve the quality of cause-of-death data. Before 1999, such modifications were made only when a new revision of the ICD was implemented. A process for updating the ICD that allows for mid-revision changes was introduced with ICD-10. Minor changes may be implemented every year, while major changes may be implemented every three years. These updates do not have a significant effect on the data in the U.S. Cancer Statistics Data Visualizations tool.

The ICD not only details disease classification but also provides definitions, tabulation lists, the format of the death certificate, and the rules for coding cause of death. Cause-of-death data presented in the U.S. Cancer Statistics Data Visualizations tool were coded by procedures outlined in annual issues of the <u>NCHS Instruction Manuals</u>.

Underlying Cause of Death

In the U.S. Cancer Statistics Data Visualizations tool, tabulations of cause-of-death statistics are based solely on the underlying cause of death, which is defined by WHO as "the disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury."¹ The underlying cause of death is selected from the conditions entered by the physician in the cause-of-death section of the death certificate. Generally, more medical information is reported on death certificates than is reflected directly in the underlying cause of death.^{3 4}

Cancer Site Groups

For consistency with the data on cancer incidence, the cancer sites in mortality data were grouped according to the <u>revised SEER recodes dated March 1, 2018</u>. Because NCHS uses different groupings for some sites, the death rates in this report may differ slightly from those published by NCHS. In addition, under the ICD, there are differences in mortality and incidence coding. For example, in ICD-10, mesothelioma deaths are coded by anatomic site whereas in ICD-0-3, mesothelioma incidence is coded by morphology, regardless of anatomic site.

Death Rates for Kaposi Sarcoma

Because the vast majority of Kaposi sarcoma (KS) cases have developed in association with human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS), HIV/AIDS is listed as the underlying cause of death. Therefore, KS death rates were not included.

Mortality Data Submission Process

Unlike incidence data, mortality data for a calendar year are not updated after the final data file is released. All states, the District of Columbia, and Puerto Rico submitted all of their 2020 mortality data in electronic data files to NCHS. Mortality data for the entire United States refer to deaths that occurred within the United States; data for geographic areas are by the decedent's place of residence.

- 1. Xu J, Murphy SL, Kochanek KD, Arias E. <u>Deaths: Final data for 2019.[PDF-2.5MB]</u> National Vital Statistics Reports 2021;70(8).
- 2. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision.* Geneva, Switzerland: World Health Organization; 1992.
- 3. Chamblee RF, Evans MC. TRANSAX: the NCHS system for producing multiple cause-of-death statistics, 1968–78. *Vital and Health Statistics, Series 1* 1986;(20):1–83.
- 4. Israel RA, Rosenberg HM, Curtin LR. <u>Analytical potential for multiple cause-of-death data</u>. *American Journal of Epidemiology* 1986;124(2):161–179.

The population estimates for the denominators of incidence and death rates are race-specific, ethnicity-specific, agespecific, and sex-specific county population estimates aggregated to the state or metropolitan-area level. The <u>county</u> <u>population estimates</u> that are incorporated into the National Cancer Institute's (NCI's) <u>SEER*Stat software</u> are a slight modification of the annual time series of July 1 county population estimates (by age, sex, race, and Hispanic origin) produced under a collaborative arrangement between the U.S. Bureau of the Census (Census Bureau) and CDC's <u>National Center for Health Statistics</u> with support from NCI through an interagency agreement.

NCI's modifications to the population estimates are documented in <u>Population Estimates Used in NCI's SEER*Stat</u> <u>Software</u>. Several modifications pertain to the grouping of specific counties needed to assure the compatibility of all incidence, mortality, and population data sets. Another modification only affects population estimates for the state of Hawaii. Based on concerns that the native Hawaiian population has been vastly undercounted in previous censuses, the Epidemiology Program of the Hawaii Cancer Research Center recommended an adjustment to the populations for its state. The "Hawaii adjustment" to the Census Bureau's estimates has the net result of reducing the estimated White population and increasing the estimated Asian and Pacific Islander population for the state. The estimates for the total population, Black population, and American Indian and Alaska Native population in Hawaii are not modified.

Population estimates used in the calculation of Puerto Rico incidence and death rates are sex-specific and age-specific, are obtained from the U.S. Census Bureau, and are not available by race or ethnicity.

Population Estimates

In general, July 1 population estimates are used to calculate annual incidence and death rates because these estimates are considered to reflect the average population of a defined geographic area for a calendar year. However, the populations of many counties along the Gulf Coast of Louisiana, Alabama, Mississippi, and Texas were displaced in the fall of 2005 by hurricanes Katrina and Rita.

For these states, the population estimates were adjusted to account for the displacement of people in these states. The national total population estimates are not affected by these adjustments.

The majority of the evacuees from Hurricanes Katrina and Rita relocated to the following eight states: Texas, Arkansas, Louisiana, Mississippi, Alabama, Tennessee, Georgia, or Florida. The evacuee population was included in the 2005 incidence rates since all of the relocation states met the USCS publication criteria.

Similarly, to minimize the impact of Hurricane Maria that made landfall in Puerto Rico in September 2017, modified Puerto Rico population estimates obtained from the <u>U.S. Census Bureau [PDF-332KB]</u> are used to calculate cancer incidence rates for Puerto Rico for 2017. The population denominators were adjusted by dividing the U.S. Census Bureau's July 1, 2017 (vintage 2021) Puerto Rico population estimate in half.

Data on Screening and Risk Factors

Data on cancer screening and risk factors are based on information obtained from the <u>Behavioral Risk Factor</u> <u>Surveillance System (BRFSS)</u>.

The BRFSS is a system of ongoing state-based health-related telephone surveys designed to collect data on healthrelated risk behaviors, chronic health conditions, and use of preventive services from the noninstitutionalized adult (18 years or older) population residing in the United States. BRFSS collects data in all 50 states, the District of Columbia, and three U.S. territories. BRFSS completes more than 400,000 interviews with adults each year. BRFSS is administered and supported by the Division of Population Health in CDC's National Center for Chronic Disease Prevention and Health Promotion.

Since 2011, the BRFSS has been conducting both landline and cellular telephone-based surveys. All the responses were self-reported; proxy interviews are not conducted by the BRFSS. In conducting the landline telephone survey, interviewers collect data from a randomly selected adult in a household. In conducting the cellular telephone survey, interviewers collect data from adults answering the cellular telephones residing in a private residence or college housing. Beginning in 2014, all adults contacted through their cellular telephone were eligible, regardless of their landline phone use.

The BRFSS field operations are managed by state health departments that follow protocols adopted by the states, with technical assistance from CDC. The data are transmitted to CDC for editing, processing, weighting, and analysis. An edited and weighted data file is provided to each participating health department for each year of data collection, and summary reports of geographic area-specific data are prepared by CDC. For more information, visit the <u>survey data and</u> <u>documentation</u> web page.

Data on HPV Vaccinations

Data on human papillomavirus (HPV) vaccinations are collected through the <u>National Immunization Survey-Teen (NIS-Teen</u>). The NIS-Teen is a random-digit-dialed survey of parents or guardians of teens who are 13 to 17 years old. The telephone survey is followed by a questionnaire mailed to vaccination providers to obtain the teen's vaccination history. The national sample contains more than 20,000 teens with adequate vaccination coverage data reported by their health care providers (<u>adequate provider data</u>). Vaccination coverage estimates are based on provider-reported vaccination histories.

U.S Cancer Statistics incidence data are from central cancer registries that have high-quality cancer incidence data. The U.S. Cancer Statistics publication criteria are—

- No more than 5% of cases are ascertained solely on the basis of a death certificate.
 A measure of the completeness of case ascertainment is the proportion of cases ascertained solely on the basis of a death certificate, with no other information on the case available after the registry has completed a routine procedure known as "death clearance and followback."^{1 2 3}
- No more than 3% of cases are missing information on sex.
- No more than 3% of cases are missing information on age.
- No more than 5% of cases are missing information on race.
- At least 97% of the registry's records passed a CDC-prescribed set of standard computerized edits. *Computerized edits* are computer programs that test the validity and logic of data components. For example, if an 80-year-old patient was diagnosed with cancer in 2000, and the patient's year of birth was reported as 1980, a computerized edit could identify these facts as incompatible. The computerized edits applied to the data in this report were designed by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program for use by SEER registries. During the 1990s, these edits were expanded and incorporated into <u>North</u> <u>American Association of Central Cancer Registries (NAACCR)</u> standards and into the <u>NPCR-EDITS software</u> designed and maintained by CDC. Edits, and the accompanying software, are reviewed and updated routinely to maintain consistency with clinical practices and abstracting and coding standards.

After years of analyzing completeness of case ascertainment, CDC has determined that NPCR registries consistently deliver high-quality, complete data.⁴⁵⁶⁷ The completeness of case ascertainment calculation was discontinued as a measure of eligibility for publication in U.S. Cancer Statistics data products starting with the November 2016 submission data. Although the completeness estimate is no longer a criterion for USCS, it will continue to be used to monitor and evaluate progress in meeting NPCR standards. See <u>central cancer registries that met USCS publication criteria</u>.

- 1. Havener L. Standards for Cancer Registries, Vol III: Standards for Completeness, Quality, Analysis, and Management of Data. Springfield (IL): North American Association of Central Cancer Registries; 2004.
- 2. Gress D, Mulvihill L, Corrigan L. Hill S, editors. *Cancer Registry Management: Principles and Practice*. Fourth edition. Alexandria, VA: National Cancer Registrars Association; 2021.
- 3. NAACCR Death Clearance Work Group. *Death Clearance Manual: Minimum Requirements and Best Practices for Conducting Death Clearance.* Springfield, IL: North American Association of Central Cancer Registries, December 2014.
- 4. Tucker TC, Howe HL, Weir HK. Certification of population-based cancer registries. *Journal of Registry Management* 1999;26(1):24–27.
- 5. Tucker TC, Howe HL. Measuring the quality of population-based cancer registries: the NAACCR perspective. *Journal of Registry Management* 2001;28(1):41–44.
- Johnson CJ, Weir HK, Mariotto AB, Nishri D, Wilson R, Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B (eds). *Cancer in North America: 2009–2013 Volume Four: Cancer Survival in the United States and Canada 2006–2012.* Springfield, IL: North American Association of Central Cancer Registries, Inc.; 2016.
- 7. Howe HL. *Conclusions of the Workgroup for High-Quality Criteria for Data Use: The NAACCR Narrative.* Springfield (IL): North American Association of Central Cancer Registries; 2001.

<u>Publication criteria</u> were assessed based on data submitted to CDC's National Program of Cancer Registries and the National Cancer Institute's Surveillance, Epidemiology, and End Results Program in 2022. Criteria must be met for all diagnosis years for the combined 2016 to 2020 data. Segments of a registry's data may be suppressed when that information is found to be unstable or does not meet the publication criteria.

- **2016 to 2020:** All registries except Indiana and Nevada met the publication criteria for all years during this 5-year period. Counts and rates cover 97% of the U.S. population.
- 1999 to 2020: All registries met the publication criteria for all years during 1999 to 2020 except Mississippi (2002), Indiana (2020), and Nevada (2020). Data are not available for Mississippi (1999 to 2001) and South Dakota (1999 and 2000). Counts and rates cover approximately 99.7% of the U.S. population.
- **2020:** All registries except Indiana and Nevada met the publication criteria. Counts and rates cover 97% of the U.S. population.
- 2019: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2018:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2017:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2016:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2015: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2014: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2013: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2012: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2011: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2010: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2009: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2008:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2007:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2006:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2005:** All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2004: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- 2003: All registries met the publication criteria. Counts and rates cover 100% of the U.S. population.
- **2002:** All registries except Mississippi met the publication criteria. Counts and rates cover approximately 99% of the U.S. population.

- **2001:** All registries met the publication criteria; data are not available for Mississippi. Counts and rates cover approximately 99% of the U.S. population.
- **2000:** All registries met the publication criteria; data are not available for Mississippi and South Dakota. Counts and rates cover approximately 99% of the U.S. population.
- **1999:** All registries met the publication criteria; data are not available for Mississippi and South Dakota. Counts and rates cover approximately 99% of the U.S. population.

Incidence and Death Rates

Ideally, crude, age-adjusted, and age-specific rates are used to plan for population-based cancer prevention and control interventions.

Confidence Intervals

Confidence intervals reflect the range of variation in estimating cancer rates. The width of a confidence interval depends on sample size, the amount of variability in the data, and confidence level. Narrow confidence intervals tend to imply greater certainty in the estimate, while wide confidence intervals tend to imply more variability in the data and could mean there is less certainty.

Stage at Diagnosis

Stage measures how far a cancer has spread from its origin. The staging system used by CDC's National Program of Cancer Registries (NPCR) and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) programs is called *Summary Stage*. Information on stage provided in the U.S. Cancer Statistics Data Visualizations tool is classified using a *Merged Summary Stage* variable that combines summary stage variables used during different time periods.

Relative Cancer Survival

Surveillance of cancer incidence and survival are essential in monitoring and understanding CDC's efforts to support the needs of people who have cancer now or had cancer in the past.

Cancer Prevalence

Prevalence is the number of people with a specific disease or condition in a given population at a specific time. This measure includes both newly diagnosed and pre-existing cases of the disease. It is different from incidence, because incidence measures only the number of newly diagnosed cases in a given population at a specific time. Prevalence helps identify the level of disease burden on the population and health care system at a certain point in time. It is a function of both incidence and survival.

Screening, HPV Vaccination, and Risk Factor Prevalence Estimates

Healthy behaviors such as being physically active, avoiding tobacco, limiting the amount of alcohol you drink, and getting cancer screening tests and human papillomavirus vaccine when recommended may prevent or help manage cancer.

Risk Factor-Associated Cancers

Although cancer represents many heterogeneous diseases, some cancer types share common risk factors. Because risk factor information is not routinely collected by cancer registries, estimates for risk factor-associated cancers often are based only on cancer type. Using these standard definitions for risk factor-associated cancers can help facilitate comparisons of cancer burden across states and communities.

Incidence and Death Estimates by Congressional District

Cancer incidence and death rates and counts were estimated for federal congressional districts.

Suppression of Rates and Counts

Cell suppression is used to protect patient confidentiality. By using a threshold value of 16 for cell suppression, the risk of disclosing personally identifiable information is reduced. Cell suppression is also used when the numbers of cases or deaths used to compute rates are small, because those rates tend to have poor reliability. Frequencies and percentages are suppressed for groups with fewer than 16 cases. In addition, complementary cell suppression is done to suppress data for both sexes combined if data are suppressed for one sex.

Crude rates are helpful in determining the cancer burden and specific needs for services for a given population, compared with another population, regardless of size. Crude rates are calculated as follows—

- Crude and age-specific **incidence rates** equal the total number of new cancer cases diagnosed in a specific year in the population category of interest, divided by the at-risk population for that category and multiplied by 100,000 (cancers by primary site) or by 1 million (International Classification of Childhood Cancer [ICCC] groupings of childhood cancers).
- Crude and age-specific **death rates** equal the total number of cancer deaths during a specific year in the population category of interest, divided by the at-risk population for that category and multiplied by 100,000.

Crude Rates vs. Age-Adjusted Rates

Crude rates are influenced by the underlying age distribution of the state's population. For example, if two states have the same age-adjusted rates, the state with the relatively older population generally will have higher crude rates because incidence or death rates for most cancers increase with increasing age. The age distribution of a population (the number of people in particular age categories) can change over time and can be different in different geographic areas. Age-adjusting the rates ensures that differences in incidence or deaths from one year to another, or between one geographic area and another, are not due to differences in the age distribution of the populations being compared.

2000 U.S. Standard Population Age Groups

The population used to age-adjust the rates in this report is the 2000 U.S. standard population.^{1 2} In the USCS Data Visualizations tool, the 2000 U.S. standard population is based on the proportion of the 2000 population in 19 specific age groups (younger than 1 year, 1–4 years, 5–9 years, 10–14 years, 15–19 years, ... 85 years and older); except for Puerto Rico, where it is based on 18 specific age groups (0–4 years, 5–9 years, 10–14 years, 15–19 years, ... 85 years and older); the proportions of the 2000 population in these age groups serve as weights for calculating age-adjusted incidence and death rates. Cancer death rates in the USCS Data Visualizations tool may differ slightly from those published by the National Center for Health Statistics (NCHS) because NCHS uses age groups as recommended by the U.S. Department of Health and Human Services in its adjustment of death rates. In addition, the 2000 U.S. standard population weights are not race- or sex-specific, so they do not adjust for differences in race or sex distribution between geographic areas or populations being compared. They do, however, provide the basis for adjusting for differences in the age distributions across groups defined by sex, race, ethnicity, geography, or other categories.

The 2000 U.S. standard population weights used for this report are based on single years of age from the Census P25-1130 series estimates of the 2000 U.S. population. Populations for <u>single years of age</u> are summed to form the age groups. These standard weights are used to compute age-adjusted incidence and death rates by the method of <u>direct</u> <u>standardization</u> as implemented in the National Cancer Institute's <u>SEER*Stat software</u>.

Ideally, crude, age-adjusted, and age-specific rates are used to plan for population-based cancer prevention and control interventions.²

- 1. Anderson RN, Rosenberg HM. <u>Report of the Second Workshop on Age Adjustment.</u> Vital and Health Statistics, Series 4 1998;(30):I–VI, 1–37.
- 2. Anderson RN, Rosenberg HM. <u>Age standardization of death rates: implementation of the year 2000 standard.</u> *National Vital Statistics Reports* 1998;47(3):1–16, 20.

Confidence Intervals

Confidence intervals reflect the range of variation in the estimation of the cancer rates. The width of a confidence interval depends on the amount of variability in the data. Narrow confidence intervals tend to imply greater certainty in the estimate, while wide confidence intervals tend to imply more variability in the data and could mean there is less certainty. Sources of variability include the underlying occurrence of cancer as well as uncertainty about when the cancer is detected and diagnosed, when a death from cancer occurs, and when the data about the cancer are sent to the registry or the state health department.

In any given year, when large numbers of a particular cancer are diagnosed or when large numbers of cancer patients die, the effects of random variability are small compared with the small populations where these changes cause greater variation and the confidence interval would likely be be narrow. With rare cancers, however, the rates are small and the chance occurrence of more or fewer cases or deaths in a given year can markedly affect those rates. Under these circumstances, the confidence interval will be wide to indicate uncertainty or instability in the cancer rate.

The Poisson Process

To estimate the extent of this uncertainty, a statistical framework is applied.¹ The standard model used for rates for vital statistics is the Poisson process,² which assigns more uncertainty to rare events relative to the size of the rate than it does to common events.

Parameters are estimated for the underlying disease process. For this report, we estimated a single parameter to represent the incidence rate and its variability. Of note, the Poisson model is capable of estimating separate parameters that represent contributions to the rate from various population risk factors, the effects of cancer control interventions, and other attributes of the population risk profile in any particular year.

Modified Gamma Intervals

Confidence intervals that are expected to include the true underlying rate 95% of the time are used in the Data Visualizations tool and are modified gamma intervals³ computed using <u>SEER*Stat</u>. The modified gamma intervals are more efficient than the gamma intervals of Fay and Feuer⁴ in that they are less conservative while still retaining the nominal coverage level. Various factors such as population heterogeneity can sometimes lead to "extra-Poisson" variation in which the rates are more variable than would be predicted by a Poisson model. No attempt was made to correct for this. In addition, the confidence intervals do not account for systematic (in other words, nonrandom) biases in the incidence rates.

Considerations When Comparing Rates

The use of overlapping confidence intervals to determine significant differences between two rates presented in the Data Visualizations tool is discouraged because the practice fails to detect significant differences more frequently than standard hypothesis testing.⁵

Another consideration when comparing differences between rates is their public health importance. For some rates presented in the Data Visualizations tool, numerators and denominators are large and standard errors are therefore small, resulting in statistically significant differences that may be so small as to lack importance for decisions related to population-based public health programs.

- 1. Särndal C-E, Swennson B, Wretman J. *Model-Assisted Survey Sampling*. New York (NY): Springer-Verlag; 1992.
- 2. Brillinger DR. The natural variability of vital rates and associated statistics. Biometrics 1986;42(4):693–734.

- 3. Tiwari RC, Clegg LX, Zou Z. <u>Efficient interval estimation for age-adjusted cancer rates.</u> *Statistical Methods in Medical Research* 2006;15(6):547–569.
- 4. Fay MP, Feuer EJ. <u>Confidence intervals for directly standardized rates: a method based on the gamma distribution</u>. *Statistics in Medicine* 1997;16(7):791–801.
- 5. Schenker N, Gentleman JF. On judging the significance of differences by examining the overlap between confidence intervals. *The American Statistician* 2001;55(3):182–186.

Stage at Diagnosis

Stage measures how far a cancer has spread from its origin. The staging system used by CDC's <u>National Program of</u> <u>Cancer Registries</u> and the National Cancer Institute's <u>Surveillance</u>, <u>Epidemiology</u>, and <u>End Results program</u> is called *Summary Stage*. Summary Stage characterizes invasive cancers as localized, regional, or distant. Localized cancer is confined to the primary site; regional cancer has spread directly beyond the primary site (regional extension) or to regional lymph nodes; and distant cancer has spread to other organs (distant extension) or remote lymph nodes.¹ Some cancers are unstaged or stage is unknown or unspecified.

In the U.S. Cancer Statistics Data Visualizations tool, stage is classified using a variable that combines summary stage variables used during different time periods: <u>SEER Summary Stage 2000, Derived SEER Summary Stage 2000,</u> and <u>Summary Stage 2018.</u>

The coding logic for the variable Merged Summary Stage is-

- For NPCR registries—
 - If a case was diagnosed in 2018 through 2020, stage at diagnosis is recorded using the *Summary Stage 2018* variable value.
 - If a case was diagnosed in 2016 or 2017, stage at diagnosis is recorded using the SEER Summary Stage 2000 variable value.
 - If a case was diagnosed in 2015, stage at diagnosis is recorded using the *Derived SEER Summary Stage 2000* variable value. If the *Derived SEER Summary Stage 2000* variable is blank, and the *SEER Summary Stage 2000* variable has a valid value, that value is used to populate the merged variable.
- For SEER-only registries (Connecticut, Hawaii, Iowa, and New Mexico)—
 - If a case was diagnosed in 2018 through 2020, stage at diagnosis is recorded using the *Derived Summary Stage 2018* variable value.
 - If a case was diagnosed in 2017, stage at diagnosis is recorded using the *Combined SEER Summary Stage* 2000 variable value.

For cases diagnosed in 2018 through 2020—

• The category *Regional, NOS* (code 5) is no longer used. There is an artificial increase in the category *Regional by Direct Extension Only* (code 2) for brain, CNS Other, and lymphoma cases.

Stage categories are different for two cancer sites. For brain and central nervous system tumors, the regional and distant categories have been combined. For urinary bladder tumors, *in situ* primaries are included as a category.

Merged Summary Stage data are suppressed for testis cases due to a data quality issue.

Stage distribution data are presented as case counts and percentages for two groups-

- The first group includes localized, regional, distant, and unstaged cases. Including unstaged cases helps to quantify the amount of missing data and enables comparisons with other studies using this same categorization. However, including unstaged cases will underestimate the percentages of the other stage categories.
- The second group includes only the known stage categories (localized, regional, and distant). Excluding unknown stage provides better estimates of the stage category percentages.

Frequencies and percentages are suppressed for groups with fewer than 16 cases. In addition, complementary cell suppression is done to suppress data for both sexes combined if data are suppressed for one sex.

Relative Cancer Survival

Surveillance of cancer incidence and survival are essential in monitoring and understanding CDC's efforts to support the needs of people who have cancer now or had cancer in the past, estimated to be 13 million in 2020.¹

Definition and Calculation of Relative Cancer Survival

Relative cancer survival measures the proportion of people with cancer who will be alive at a certain time after diagnosis, given that they did not die from something other than their cancer during that period of time. Relative cancer survival is defined as the ratio of the **observed** all-cause survival in a group of individuals with cancer to the **expected** all-cause survival of a similar group of individuals who do not have cancer.¹ Because the expected survival of individuals who do not have cancer is difficult to obtain, it is often approximated by the expected all-cause survival of the **general population.** This is a reasonable approximation because cancer deaths are generally a negligible proportion of all deaths. Thus, the relative cancer survival is calculated as the observed all-cause survival in a group of individuals with cancer divided by the expected all-cause survival of the general population. To learn more on this topic, visit <u>Measures of Cancer Survival</u>.

Cancer incidence data submitted to CDC's <u>National Program of Cancer Registries (NPCR)</u> in the 2022 data submission period were used to create a data set in SEER*Stat for this analysis.² The data set included data from 39 NPCR central cancer registries that met the <u>United States Cancer Statistics (USCS)</u> <u>publication criteria</u> for all years 2013 through 2019 and that conducted linkage with the National Death Index and/or active patient follow-up for all years 2013 through 2019. These registries include Alabama, Alaska, Arizona, Arkansas, California, Colorado, Delaware, Florida, Georgia, Idaho, Illinois, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, West Virginia, Wisconsin, and Wyoming. These data cover 83% of the U.S. population.

Cases from these registries were included in the analysis if-

- The case was an invasive cancer diagnosed from 2013 through 2019. Cases diagnosed in 2020 do not have adequate follow-up time to be included in the analysis.
- The age of the case was known and was 0 through 99 years.
- The sex of the case was known.
- The case was not identified solely on the basis of a death certificate or autopsy.

Analytic Methods

Survival time in months for each case was calculated. Date of start of follow-up (month, day, and year) was set to date of diagnosis. Date of last follow-up (month, day, and year) was set to date of death if the case was matched to the state death files, to the National Death Index, or to date of last contact (if case was actively followed). Cases not linking to the state death files or to the National Death Index were presumed to be alive, and the date of last follow-up was set to December 31, 2019. Where day or month for date of diagnosis, date of death, or date of last contact were missing, the full date was imputed using a standard algorithm.³ Cases that survived past the maximum age (99 years) were censored at age 99. Observed all-cause survival by sex, race, and ethnicity (all races, non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian and Alaska Native, non-Hispanic Asian and Pacific Islander, and Hispanic) for individuals with any cancer and for individuals with 25 common cancer sites was then calculated using the actuarial life table method.⁴ Cases with multiple primary cancers were included in the dataset, although only the first primary cancer during the inclusion period was included in calculating relative survival for all cancer sites combined. Where a patient had multiple primary cancer was included in calculating cancer-specific relative survival. Where a patient was diagnosed with multiple primary cancers of the **same** site at the **same** age, only the first primary cancer was included in calculating relative survival for that cancer site, and only one record per person will contribute to any life page (strata in a data visualization query).⁵

Expected all-cause survival for the general population by sex, race, ethnicity (all races, non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian and Alaska Native, non-Hispanic Asian and Pacific Islander, and Hispanic), geography (state/county), and socioeconomic status were obtained using <u>annual U.S. life tables</u> provided by the National Center for Health Statistics and modified by SEER. The life tables were embedded in SEER*Stat. See <u>Expected</u> <u>Survival Life Tables</u> for more information.

Relative cancer survival was then calculated using the Ederer II method⁶ for all cancer sites combined and for 25 common cancer sites by sex, race and ethnicity (all races, non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian and Alaska Native, non-Hispanic Asian and Pacific Islander, and Hispanic), and age group (younger than 45 years, 45 to 54 years, 55 to 64 years, 65 to 74 years, and 75 years or older). Relative cancer survival by state is presented for all cancer sites combined and for 25 common sites by sex and by race and ethnicity. Relative cancer survival by stage is presented for 24 common sites (testis excluded) by sex and by race and ethnicity (and age at the national level only). See <u>Measures of Cancer Survival</u> for more information.

The quality and completeness of individual data items used in this analysis are discussed in a study by Wilson and others.⁷

- 1. U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999–2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, June 2023.
- National Program of Cancer Registries SEER*Stat Database: NPCR Survival Analytic file 2001–2019 (39 NPCR central cancer registries). United States Department of Health and Human Services, Centers for Disease Control and Prevention. Released June 2023, based on the 2022 submission.
- 3. Johnson CJ, Weir HK, Yin D, Niu X. The impact of patient follow-up on population-based survival rates. *Journal of Registry Management* 2010;37(3):86–103.
- 4. Lee ET. Life-table analysis. In: *Statistical Methods for Survival Data Analysis,* 2nd ed. New York, NY: John Wiley & Sons, 1992: 78–100.
- 5. Brenner H, Hakulinen T. <u>Patients with previous cancer should not be excluded in international comparative</u> <u>cancer survival studies</u>. *International Journal of Cancer* 2007;121(10):2274–2278.
- Cho H, Howlader N, Mariotto AB, Cronin KA. <u>Estimating relative survival for cancer patients from the SEER</u> <u>Program using expected rates based on Ederer I versus Ederer II method.</u> [PDF-3MB] Surveillance Research Program, National Cancer Institute; 2011. Technical Report #2011-01.
- Wilson RJ, O'Neil ME, Ntekop E, Zhang K, Ren Y. <u>Coding completeness and quality of relative survival-related</u> variables in the National Program of Cancer Registries Cancer Surveillance System, 1995–2008. Journal of Registry Management 2014;41(2):65–71.

Definition and Calculation of Cancer Prevalence

Prevalence is the number of people with a specific disease or condition in a given population at a specific time. This measure includes both newly diagnosed and pre-existing cases of the disease. It is different from **incidence**, because incidence measures only the number of *newly* diagnosed cases in a given population at a specific time.

There are different types of prevalence. For example-

- Annual prevalence is the number of people with the disease at any time during a year.
- *Period prevalence* is the number of people with the disease at any time during a specified number of years, such as the last 10 years.
- <u>Limited-duration prevalence</u> is the number of people alive on a certain day who were diagnosed with the disease during a specified number of years (such as the last 5 or 19 years).

Cancer incidence data submitted to CDC's <u>National Program of Cancer Registries (NPCR)</u> in the 2022 data submission period were used to create a data set in SEER*Stat for this analysis.² The data set included data from 39 NPCR central cancer registries that met the <u>United States Cancer Statistics (USCS)</u> <u>publication criteria</u> for all years 2001 through 2019 and that conducted linkage with the National Death Index and/or active patient follow-up for all years 2001 through 2019. These registries include Alabama, Alaska, Arizona, Arkansas, California, Colorado, Delaware, Florida, Georgia, Idaho, Illinois, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, West Virginia, Wisconsin, and Wyoming. These data cover 83% of the U.S. population.

Cases from these registries were included in the analysis if-

- The case was an invasive cancer diagnosed from 2001 through 2019.
- The age of the case was known and was 0 through 99 years.
- The sex of the case was known.
- The case was not identified solely on the basis of a death certificate or autopsy.

Because NPCR data are available from 2001, 19-year limited-duration prevalence estimates are included in addition to 5-year estimates.

Calculation of Limited-Duration Prevalence

Limited-duration prevalence is the number of people alive on a certain day who were diagnosed with the disease during a specified number of years (such as the last 5 or 19 years).

In this report, the limited-duration prevalence was calculated using SEER*Stat software. It estimates, among the people diagnosed with cancer in the last 5 or 19 years, the proportion who were still alive on January 1, 2020.^{1,2} The date of start of follow-up (month, day, and year) was set to the date of diagnosis. The date of last follow-up (month, day, and year) was set either to the date of last contact (if the case was actively followed) or to the date of death if the case was matched to the state death files or to the National Death Index. Cases not linking to the state death files or to the National Death Index.

For patients diagnosed with multiple tumors, prevalence calculations include the first tumor of each cancer type in the previous x years (where x = 5 or 19 in this report). For example, assume a woman was diagnosed first with thyroid cancer 9 years ago and then breast cancer 3 years ago. The thyroid cancer would contribute to the 19-year limited-

duration prevalence estimates for all cancer sites and for thyroid cancer. The breast cancer would contribute to the 5year limited-duration prevalence estimate for all cancer sites and both the 5-year and 19-year estimates for breast cancer, but not to the 19-year limited-duration prevalence estimate for all cancer sites because it was not her first tumor in the previous 19 years as the woman is already counted in this estimate for thyroid cancer.

NPCR prevalence proportions were calculated for each combination of age, sex, and race and ethnicity group. For this section of the report, race and ethnicity were categorized as non-Hispanic White, non-Hispanic Black, non-Hispanic Indian Health Service-linked American Indian and Alaska Native, non-Hispanic Asian and Pacific Islander, and Hispanic. Cases with unknown race were combined with White race. Then, cancer prevalence counts at January 1, 2020, for the U.S. population were estimated by multiplying the age-, sex-, and race and ethnicity-specific NPCR prevalence proportions by the corresponding U.S. population estimates based on the average of the 2019 and 2020 population estimates from the U.S. Census Bureau.³ The sum of the counts by race and ethnicity was used to estimate the U.S. cancer prevalence counts for all races combined. Cancer prevalence counts and percentages for each of the 39 states by sex, race and ethnicity were estimated directly in SEER*Stat.

Prevalence percentage is the percentage of the population alive with cancer. The U.S. prevalence percentage estimates are based on the states included in the analysis.

- 1. Surveillance Research Program, National Cancer Institute SEER*Stat software version 8.4.
- 2. Gail MH, Kessler L, Midthune D, Scoppa S. <u>Two approaches for estimating disease prevalence from population-based registries of incidence and total mortality</u>. *Biometrics* 1999;55(4):1137–1144.
- 3. National Program of Cancer Registries SEER*Stat Database: NPCR Prevalence Analytic file 2001–2019 (39 NPCR central cancer registries). United States Department of Health and Human Services, Centers for Disease Control and Prevention. Released June 2023, based on the 2022 submission.

Screening and Risk Factors

Healthy behaviors such as being physically active, avoiding tobacco, limiting the amount of alcohol you drink, and getting cancer screening tests when recommended may prevent or help successfully manage cancer.¹

Monitoring health risk behaviors and use of health care is fundamental to the development of effective public health programs and policies at the state and local levels.²

Because cancer registries do not routinely collect information on health risk behaviors, the data displayed in this section are obtained from the <u>Behavioral Risk Factor Surveillance System (BRFSS)</u>. BRFSS is the nation's premier system of statebased health-related telephone surveys that collect data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. BRFSS collects data in all 50 states, the District of Columbia, and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year.

Prevalence is the measured or estimated percentage of people with an attribute or disease during a specific time period. The prevalence estimates are from the BRFSS core survey at the state level as well as model-based prevalence estimates for all the counties in the United States.

Crude and age-adjusted prevalence (standardized by direct method to the year 2000 U.S. population, distribution 9 for county estimates)³ are displayed for breast (female), cervical, and colorectal cancer screening measures, and measures for unhealthy behaviors such as physical inactivity, poor nutrition, alcohol consumption, tobacco use, and obesity. Prevalence of lung cancer screening was not included because it is not yet available for all states.

Age-adjusted prevalence is the measured or estimated percentage of people with an attribute or disease during a specific time period, standardized by direct method to the age distribution of the U.S. 2000 standard million population (for state-level estimates). Estimates in the U.S. Cancer Statistics Data Visualizations tool may differ slightly from those published by the National Center for Health Statistics (NCHS) because NCHS uses age groups as recommended by the U.S. Department of Health and Human Services in its adjustment of death rates. In addition, the 2000 U.S. standard population weights are not race- or sex-specific, so they do not adjust for differences in race or sex distribution between geographic areas or populations being compared. They do, however, provide the basis for adjusting for differences in the age distributions across groups defined by sex, race and ethnicity, geography, or other categories.

Data are suppressed if there are fewer than 50 respondents in a specific category such as sex, race, or ethnicity.

Small Area Estimates (County Level)

Small area estimates at the county level using an innovative peer-reviewed multilevel regression and poststratification approach⁴ are calculated using data from CDC's BRFSS. The primary data sources are BRFSS and the Census 2010 population. You can learn details about the <u>methodology</u>.

The following table shows the measures displayed in the U.S. Cancer Statistics Data Visualizations tool. For measures included in the <u>PLACES</u> website, links to their definitions are also provided.

Cancer screening

Up-to-date with colorectal cancer screening among adults aged 50 to 75 years

Cancer screening

Mammography use among women aged 50 to 74 years

Cancer screening

Cervical cancer screening among women aged 21 to 65 years

Physical activity

No leisure-time physical activity among adults aged ≥18 years

Physical activity

150 minutes or more of aerobic physical activity per week among adults aged ≥18 years

Nutrition

Consumed fruits less than once a day among adults aged ≥18 years

Nutrition

<u>Consumed vegetables less than once a day among adults aged ≥18 years</u>

Alcohol use

Binge drinking among adults aged ≥18 years

Tobacco use Current smoking among adults aged ≥18 years

Tobacco use Ever smoking among adults aged ≥18 years

Tobacco use Never smoking among adults aged ≥18 years

Obesity Obesity among adults aged ≥18 years

The following measures, physical activity, fruit consumption, vegetable consumption, ever smoking, and never smoking, are not available in PLACES and are defined below.

150 Minutes or More of Aerobic Physical Activity per Week Among Adults Aged ≥18 Years

Demographic group: Resident adults aged ≥18 years.

Numerator: Adults aged \geq 18 years who report 150 or more minutes of aerobic physical activity per week.

Denominator: Number of adults aged ≥18 years who reported information about any or no physical activity in the past month (excluding those who refused to answer, had a missing answer, or answered "don't know/not sure").

Measures of frequency: Annual prevalence: crude and age-adjusted (standardized by the direct method to the year 2000 standard U.S. population, distribution 9)³ with 95% confidence intervals and by demographic characteristics when feasible.

Time period of case definition: Past month.

Data resource: <u>Behavioral Risk Factor Surveillance System [PDF-603KB]</u> (BRFSS).

Consumed Fruits Less Than Once a Day Among Adults Aged ≥18 Years

Demographic group: Adults aged \geq 18 years.

Numerator: Adults aged \geq 18 years who report consuming fruits less than once per day.

Denominator: Number of adults aged ≥18 years who reported information about fruit consumption (excluding those who refused to answer, had a missing answer, or answered "don't know/not sure").

Measures of frequency: Annual prevalence: crude and age-adjusted (standardized by the direct method to the year 2000 standard U.S. population, distribution 9)³ with 95% confidence intervals and by demographic characteristics when feasible.

Time period of case definition: Per day.

Data resource: <u>Behavioral Risk Factor Surveillance System [PDF-864KB]</u> (BRFSS).

Consumed Vegetables Less Than Once a Day Among Adults Aged ≥18 Years

Demographic group: Adults aged ≥18 years.

Numerator: Adults aged \geq 18 years who report consuming vegetables less than once per day.

Denominator: Number of adults aged \geq 18 years who reported information about vegetable consumption (excluding those who refused to answer, had a missing answer, or answered "don't know/not sure").

Measures of frequency: Annual prevalence: crude and age-adjusted (standardized by the direct method to the year 2000 standard U.S. population, distribution 9)³ with 95% confidence intervals and by demographic characteristics when feasible.

Time period of case definition: Per day.

Data resource: <u>Behavioral Risk Factor Surveillance System</u> [PDF-864KB] (BRFSS).

Ever Smoking Among Adults Aged ≥18 Years

Demographic group: Resident adults aged \geq 18 years.

Numerator: Adults aged \geq 18 years who reported they ever smoked 100 cigarettes.

Denominator: Respondents aged ≥18 years who reported information about cigarette smoking (excluding those who refused to answer, had a missing answer, or answered "don't know/not sure").

Measures of frequency: Annual prevalence: crude and age-adjusted (standardized by the direct method to the year 2000 standard U.S. population, distribution 9)³ with 95% confidence intervals and by demographic characteristics when feasible.

Time period of case definition: Lifetime.

Data resource: <u>Behavioral Risk Factor Surveillance System [PDF-864KB]</u> (BRFSS).

Never Smoking Among Adults Aged ≥18 Years

Demographic group: Resident adults aged ≥18 years.

Numerator: Adults aged \geq 18 years who reported smoking fewer than 100 cigarettes.

Denominator: Respondents aged ≥18 years who reported information about cigarette smoking (excluding those who refused to answer, had a missing answer, or answered "don't know/not sure").

Measures of frequency: Annual prevalence: crude and age-adjusted (standardized by the direct method to the year 2000 standard U.S. population, distribution 9)³ with 95% confidence intervals and by demographic characteristics when feasible.

Time period of case definition: Lifetime.

Data resource: <u>Behavioral Risk Factor Surveillance System [PDF-864KB]</u> (BRFSS).

Human Papillomavirus (HPV) Vaccination Coverage

Vaccination against human papillomavirus (HPV) is recommended to prevent new HPV infections and HPV-associated diseases, including some cancers.⁵

Teen vaccination coverage data displayed in U.S. Cancer Statistics Data Visualizations tool are collected through the <u>National Immunization Survey-Teen (NIS-Teen)</u>. The NIS-Teen is a random-digit-dialed survey of parents or guardians of teens who are 13 to 17 years old. It has a sample size of more than 20,000 teens. The telephone survey is followed by a questionnaire mailed to vaccination providers to obtain the teen's vaccination history. Vaccination coverage estimates are based on provider-reported vaccination histories. Complex statistical methods are used to adjust for teens whose parents did not participate in the survey, who lived in households without telephones, or whose vaccination histories were not reported by their providers. You can learn more about how CDC estimates HPV vaccination coverage and the NIS-Teen survey in the NIS-Teen vaccination coverage <u>technical notes</u>.

The Data Visualizations Tool displays HPV vaccination coverage estimates (percentage) by sex for the entire United States, each state, and the District of Columbia, for teens aged 13 to 17 years who were reported being <u>up-to-date</u> on HPV vaccination as recommended by the <u>Advisory Committee on Immunization Practices</u>.

- Pickens CM, Pierannunzi C, Garvin W, Town M. <u>Surveillance for certain health behaviors and conditions among states and selected local areas—Behavioral Risk Factor Surveillance System, United States, 2015.</u> MMWR Surveillance Summaries 2018;67(SS-9):1–90.
- 2. Holt JB, Huston SL, Heidari K, Schwartz R, Gollmar CW, Tran A, Bryan L, Liu Y, Croft JB. <u>Indicators for chronic disease surveillance—United States</u>, 2013. *MMWR Recommendations and Reports* 2015:64(RR01):1–15.
- 3. Klein RJ, Schoenborn CA. Age adjustment using 2000 projected U.S. population. Healthy People 2010 statistical notes, no. 20. Hyattsville, MD: US Department of Health and Human Services, CDC, National Center for Health Statistics; 2001.
- 4. Zhang X, Holt JB, Yun S, Lu H, Greenlund KJ, Croft JB. <u>Validation of multilevel regression and poststratification</u> <u>methodology for small area estimation of health indicators from the Behavioral Risk Factor Surveillance System.</u> *American Journal of Epidemiology* 2015;182(2):127–137.
- Meites E, Szilagyi PG, Chesson HW, Unger ER, Romero JR, Markowitz LE. <u>Human papillomavirus vaccination for</u> <u>adults: updated recommendations of the Advisory Committee on Immunization Practices.</u> MMWR 2019;68:698– 702.

Although cancer represents many heterogeneous diseases, some cancer types share common risk factors.¹ For example, conclusive evidence links cancer at multiple sites with tobacco use, alcohol use, human papillomavirus (HPV) infection, obesity, and physical inactivity.²³⁴⁵⁶ Because risk factor information is not routinely collected by cancer registries, estimates for risk factor-associated cancers often are based only on cancer type. Using these standard definitions for risk factor-associated cancers can help facilitate comparisons of cancer burden across states and communities. Keeping in mind that individual cancer cases may occur among persons who were or were not exposed to a risk factor, population-based risk factor-associated cancer rates can help identify communities with disproportionately high cancer rates, which reflect, in part, the population's exposure to cancer risk factors. These exposures can be reduced through clinical preventive services and community-based approaches, the impact of which can be monitored with cancer surveillance data.

Definitions of Risk Factor Groupings

Alcohol-associated cancers include oral cavity and pharynx; esophagus; colon and rectum; liver; larynx; and female breast.²

HPV-associated cancers include microscopically confirmed carcinoma of the cervix and squamous cell carcinomas of the vagina, vulva, penis, anus (including rectal squamous cell carcinoma), and oropharynx.³

Obesity-associated cancers include adenocarcinoma of the esophagus; cancers of the breast (in postmenopausal women), colon and rectum, endometrium (corpus uterus), gallbladder, gastric cardia, kidney (renal cell), liver, ovary, pancreas, and thyroid; meningioma, and multiple myeloma.⁴

Physical inactivity-associated cancers include breast cancer in post-menopausal women, endometrium (corpus uterus) cancer, and colon cancer.⁵

Tobacco-associated cancers include oral cavity and pharynx; esophagus; stomach; colon and rectum; liver; pancreas; larynx; lung, bronchus, and trachea; cervix; kidney and renal pelvis; urinary bladder; and acute myeloid leukemia.⁶

The ICD-O-3 site and histology codes used to define these five variables are available in <u>Definitions of Risk Factor-Associated Cancers.</u>

- 1. Henley SJ, Singh SD, King J, Wilson RJ, O'Neil ME, Ryerson AB. <u>Invasive cancer incidence and survival—United</u> <u>States, 2013.</u> *MMWR* 2017;66:69–75.
- International Agency for Research on Cancer. IARC monographs on the evaluation of carcinogenic risks to humans. Volume 100E: Personal Habits and Indoor Combustions: <u>Consumption of Alcoholic Beverages.[PDF-2.6MB]</u> Lyon, France: International Agency for Research on Cancer; 2012.
- 3. International Agency for Research on Cancer. IARC monographs on the evaluation of carcinogenic risks to humans. Volume 90: <u>Human Papillomaviruses</u>. Lyon, France: International Agency for Research on Cancer; 2007.
- 4. Lauby-Secretan B, Scoccianti C, Loomis D, Grosse Y, Bianchini F, Straif K. <u>Body fatness and cancer—viewpoint of</u> <u>the IARC Working Group</u>. *New England Journal of Medicine* 2016;375:794–798.
- 5. World Cancer Research Fund / American Institute for Cancer Research. <u>Diet, Nutrition, Physical Activity and</u> <u>Cancer: A Global Perspective.</u> [PDF-5MB] Continuous Update Project Expert Report 2018.
- U.S. Department of Health and Human Services. <u>The Health Consequences of Smoking—50 Years of Progress: A</u> <u>Report of the Surgeon General.</u> Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2014.

Cancer death rates and counts for 2016 to 2020 were estimated for the 436 federal congressional districts according to the boundaries for the <u>116th Congress</u> of the United States.¹² **Cancer incidence** rates and counts were estimated for 424 federal congressional districts because county-level incidence data were not available for Kansas (4 congressional districts) and Minnesota (8 congressional districts) due to state legislation and regulations which prohibit the release of county-level data to outside entities. Illinois (18 congressional districts) opted not to present congressional district-specific estimated case counts and incidence rates. Indiana (9 congressional districts) and Nevada (4 congressional districts) did not meet the publication criteria for diagnosis year 2020, hence were excluded from the analysis. Data from Virginia (11 congressional districts) were suppressed due to incomplete county data. Therefore, estimated incidence rates and counts are presented from 382 congressional districts.

Methods for Creating Congressional District Estimates

A brief description of the methods for estimating congressional district rates and counts is provided below. For specific inquiries, please send email to the U.S. Cancer Statistics team at <u>uscsdata@cdc.gov.</u>

- Eight congressional districts follow state or federal district boundaries: Alaska, Delaware, District of Columbia, Montana, North Dakota, South Dakota, Vermont, and Wyoming. Those districts were estimated according to the state rates and counts.
- For the remaining districts, **rates** were estimated by assigning the county-level age-adjusted rates (age-adjusted to the 2000 U.S. standard population using 15 age groups: 0 to 19, 20 to 24, 25 to 29, 30 to 34, 35 to 39, 40 to 44, 45 to 49, 50 to 54, 55 to 59, 60 to 64, 65 to 69, 70 to 74, 75 to 79, 80 to 84, and 85 years or older) to the census block and weighting those by the block population proportion of the congressional district. Those weighted rates were then aggregated over the blocks within the congressional district to estimate the district rate. More specifically, the following steps were taken—
 - 1. Population estimates within each census block by race and sex and assigned to congressional districts were determined from the 2010 U.S. Census Summary File 1.
 - 2. The age-adjusted county-level rates by race and sex were calculated using SEER*Stat and merged with the block-level population estimates by county.
 - 3. The county rates assigned to the census blocks were weighted by the proportion of the block population within the congressional district and then aggregated over the blocks within the congressional district.
- To calculate **counts** for congressional districts, the county counts were weighted by the proportion of the county population in the congressional district to the overall county population. The weighted counts were then aggregated over the counties in the congressional district. This gives the same estimates as weighting at the block level similar to the rate calculations but is a more efficient calculation in terms of computer time. Estimates for both sexes combined were obtained by summing the male estimate and female estimate.

Available Data

Estimates are presented by sex (both sexes, male, and female) and race and ethnicity (all races, non-Hispanic White, Black, and Hispanic). Block-level population data were not available by ethnicity for races other than White. As a result, the estimates for Black people include both Hispanic and non-Hispanic Black people. Data are presented for all cancers combined and 20 leading cancers. Data are suppressed for cells with fewer than 16 estimated cases. Data for specific race groups may be suppressed at the state's request.

Since the congressional district estimates require county-level data, if any county data are missing, then the overall state counts presented in the Congressional Districts section will not match the counts in the U.S. Cancer Statistics Data

Visualizations Tool's State section. Instead, the counts in the Congressional Districts section will match the state counts calculated by aggregating across the U.S. Cancer Statistics county-level data.

- 1. Hao Y, Ward EM, Jemal A, Pickle LW, Thun MJ. <u>U.S. congressional district cancer death rates.</u> *International Journal of Health Geographics* 2006;5:28.
- 2. Siegel RL, Sahar L, Portier KM, Ward EM, Jemal A. <u>Cancer death rates in U.S. congressional districts</u>. *CA: A Cancer Journal for Clinicians* 2015;65(5):339–344.

Suppression for Reliability

When the numbers of cases or deaths used to compute rates are small, those rates tend to have poor reliability.¹ Therefore, to discourage misinterpretation or misuse of rates or counts that are unstable, incidence and death rates and counts are not shown in tables and figures when the case or death counts are below 16. A count of fewer than 16 results in a standard error of the rate that is approximately 25% (or more) larger than the rate itself. Similarly, a case count below 16 results in the width of the rate's 95% <u>confidence interval</u> being at least as large as the rate itself. These relationships were derived under the assumption of a Poisson process and with the standard population age distribution assumed to be similar to the observed population age distribution. A suppressed rate does not necessarily mean that the rate was low.

Suppression for Confidentiality

Another important reason for using a threshold value for suppressing cells is to protect the confidentiality of patients whose data are included in a report by reducing or eliminating the risk of disclosing their identity.² The cell suppression threshold value of 16, which was selected to reduce misuse and misinterpretation of unstable rates and counts in this report, is more than sufficient to protect <u>patient confidentiality</u>. [PDF-324KB]

Suppression for Other Reasons

While data meet the <u>U.S. Cancer Statistics (USCS) publication criteria</u>, a central cancer registry may suppress its data for various reasons. For example, a state may have racial and ethnic groups (American Indian or Alaska Native, Asian or Pacific Islander, Hispanic) where the algorithms to correct for unknown race or ethnicity may not function properly. In these circumstances, data are suppressed upon the state's request.

U.S. State and County Data

Cancer incidence rates are presented for each county or county equivalent as available over the most recent 5-year period. County data are not available from Kansas and Minnesota because state legislation and regulations prohibit the release of county-level data to outside entities. County data from Virginia are suppressed due to incomplete data. Additional data suppressions are applied in accordance with the rules outlined above.

Total United States

Cancer incidence rates for the United States are aggregate rates based on cancer cases reported from <u>central cancer</u> registries that met the USCS publication criteria and are the best estimates of the U.S. cancer burden available that are based on observed data. Case counts for the U.S. incidence rates for all ages combined are presented. Puerto Rico data are not included in the total U.S. counts and corresponding rate calculations.

- 1. Brillinger DR. <u>The natural variability of vital rates and associated statistics</u>. *Biometrics* 1986;42(4):693–734.
- 2. Doyle P, Lane JI, Theeuwes JM, Zayatz LM. *Confidentiality, Disclosure, and Data Access: Theory and Practical Applications for Statistical Agencies.* Amsterdam, The Netherlands: Elsevier Science; 2001.

Incidence Data

Each year when U.S. Cancer Statistics data are released, we update data products with the most recent data submission. Users of cancer incidence data published by federal agencies should be mindful of the data submission dates for all data used in their analyses.

Mortality Data

Cancer mortality statistics in the U.S. Cancer Statistics Data Visualizations tool are influenced by the accuracy of information on the death certificate.

Race and Ethnicity in Cancer Data

In cancer incidence, race and ethnicity information is abstracted from medical records and grouped into categories. When reporting cancer mortality, race and Hispanic origin are recorded separately on the death certificate by the funeral director as provided by an informant or, in the absence of an informant, on the basis of observation.

Guidance for Comparing States' Cancer Data

Careful consideration is needed in interpreting and comparing rankings of state cancer rates. A natural reaction of some readers is to seek explanations as to why their state has higher incidence or death rates for some cancers than other states or than the national average. For example, some may be alarmed that exposure to environmental carcinogens may be responsible when in fact there are several other more likely explanations.

Choice of Standard Population and Population Denominator

The U.S. Department of Health and Human Services' policy for reporting death and disease rates was motivated by a need to standardize age-adjustment procedures across government agencies.^{1 2} Because of the aging U.S. population, the 2000 U.S. standard population gives more weight to older age categories than the 1940 and 1970 standard populations did.²

Because the incidence of cancer increases with age, using the 2000 U.S. standard population results in higher incidence rates for most cancers compared to incidence rates age-adjusted to the 1940 or 1970 standard populations.

The data in the Data Visualizations tool should not be compared with cancer incidence rates adjusted to different standard populations.

Incidence rates also are influenced by the choice of <u>population denominators</u> used in calculating these rates. Because some state health departments use customized projections of the state's population when calculating incidence rates, the rates in the Data Visualizations tool may differ slightly from those published by individual states.

Registries' Data Quality

Data quality is evaluated routinely by CDC's National Program of Cancer Registries (NPCR) and the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) Program.^{3 4} Comprehensive evaluation activities are conducted to find missing cases or to identify errors in the data. Although the cancer registries meet data quality criteria for all invasive sites combined, the completeness and quality of site-specific data may vary, making in-depth analyses critical to presenting reliable data. The observed rates may have been influenced by differences in the timeliness, completeness, and accuracy of the data from one registry to another, from one reporting period to another, or from one primary cancer site to another. In rare instances, a registry may identify a data quality issue after the file is submitted to CDC. In those instances, CDC will either suppress the identified segment or exclude the registry's data from analytic products.

Reporting Time Intervals

Completeness and accuracy of the site-specific data also may be affected by the time interval allowed for reporting data to the two federal programs. The NPCR and SEER time interval for reporting data differ: for each submission year, NPCR allows a 23-month interval after the close of the diagnosis year and SEER allows a 22-month interval.

Reporting Delays

Delays in reporting cancer cases can affect timely and accurate calculation of cancer incidence rates.⁵ Cases are reported continuously to state and metropolitan-area cancer registries in accordance with statutory and contractual requirements. After the initial submission of the most recent year's data to the federal funding agency, cancer registries revise and update their data on the basis of new information received. Therefore, some cancer cases likely will have been reported to state and metropolitan-area cancer registries after the registries submitted their data to CDC or NCI. For this reason, incidence rates and case counts reported directly by state or metropolitan-area cancer registries may differ from those that appear in the Data Visualizations tool. Reporting delays appear to be more common for cancers that usually are diagnosed and treated in non-hospital settings such as physicians' offices (for example, early-stage prostate and breast cancer, melanoma of the skin). Efforts are underway to reduce reporting delays. Methods to adjust incidence rates for reporting delay were not applied to the data in this report.⁵

Continual Data Updates

Each year, central cancer registries submit an updated version of previous years' data and data for a new diagnosis year to CDC and/or NCI. Federal agencies in turn update their cancer incidence statistics with each data submission and document the registries' date of data submission whenever the data are published. These continual updates illustrate the dynamic nature of cancer surveillance and the attention to detail that is characteristic of cancer registries. Each year when United States Cancer Statistics data are released, we update data products with the most recent data submission.

Geographic Variation

Geographic variation in cancer incidence rates may result from regional differences in the exposure of the population to known or unknown risk factors.⁶⁷⁸⁹ Differences may arise because of differences in sociodemographic characteristics of the population (age, race and ethnicity, geographic region, urban or rural residence), screening use, health-related behaviors (for example, tobacco use, diet, physical activity), exposure to cancer-causing agents, or factors associated with the registries' operations (completeness, timeliness, specificity in coding cancer sites). Cancer researchers are investigating variability associated with known factors that may affect cancer rates and risks by using model-based statistical techniques and other approaches for surveillance research. Differences in registry operations are being evaluated to ensure consistency and quality in reporting data.

- 1. Anderson RN, Rosenberg HM. <u>Report of the Second Workshop on Age Adjustment</u>. *Vital and Health Statistics, Series 4*. 1998;(30):I–VI, 1–37.
- 2. Anderson RN, Rosenberg HM. <u>Age standardization of death rates: implementation of the year 2000 standard.</u> *National Vital Statistics Reports* 1998;47(3):1–16, 20.
- 3. Fritz A. The SEER Program's commitment to data quality. *Journal of Registry Management* 2001;28(1):35–40.
- 4. Hutton MD, Simpson LD, Miller DS, Weir HK, McDavid K, Hall HI. Progress toward nationwide cancer surveillance: an evaluation of the National Program of Cancer Registries, 1994–1999. *Journal of Registry Management* 2001;28(3):113–120.
- 5. Clegg LX, Feuer EJ, Midthune DN, Fay MP, Hankey BF. <u>Impact of reporting delay and reporting error on cancer</u> <u>incidence rates and trends.</u> *Journal of the National Cancer Institute* 2002;94(20):1537–1545.
- 6. Centers for Disease Control and Prevention. <u>Behavioral Risk Factor Surveillance System Operational and User's</u> <u>Guide. Version 3.0.</u> [PDF-986KB] Atlanta (GA): Centers for Disease Control and Prevention; 2005.
- 7. Devesa SS, Grauman DJ, Blot WJ, Pennello GA, Hoover RN. *Atlas of Cancer Mortality in the United States, 1950–1994.* Bethesda (MD): National Cancer Institute; 1999.
- 8. Howe HL, Keller JE, Lehnherr M. <u>Relation between population density and cancer incidence, Illinois, 1986–1990.</u> *American Journal of Epidemiology* 1993;138(1):29–36.
- Wingo PA, Jamison PM, Hiatt RA, Weir HK, Gargiullo PM, Hutton M, Lee NC, Hall HI. <u>Building the infrastructure for nationwide cancer surveillance and control—a comparison between the National Program of Cancer Registries (NPCR) and the Surveillance, Epidemiology, and End Results (SEER) Program (United States). Cancer Causes and Control 2003;14(2):175–193.
 </u>

Interpreting Mortality Data

Cancer mortality statistics in the Data Visualizations tool are influenced by the accuracy of information on the death certificate. Cause of death determined by autopsy combined with clinical data is considered the best estimate of the true cause of death.¹ Autopsy studies of mortality data coded according to the eighth or ninth revision of the *International Classification of Diseases* (ICD) (ICD-8A or ICD-9) indicate that, when neoplasms (cancers) are an underlying cause of death, the sensitivity of death certificates was 87% to 93%, and their positive predictive value was 85% to 96%.¹ ² ³ However, these studies are limited by selection bias, and less than 10% of deaths in the United States are autopsied.⁴

Death Certificates' Reliability

The percentage of cancers coded as the underlying cause of death on the death certificate that agree with the cancer diagnosis in the medical record is an indication of the reliability with which the underlying cause of death can be determined from the death certificate. In a <u>study</u> by German and others, central cancer registry records from California, Colorado, and Idaho were linked with state vital statistics data and evaluated by demographic and tumor information across 79 site categories. A retrospective arm (confirmation rate per 100 deaths) compared death certificate data from 2002 to 2004 with cancer registry diagnoses from 1993 to 2004, while a prospective arm (detection rate per 100 deaths) compared cancer registry diagnoses from 1993 to 1995 with death certificate data from 1993 to 2004 by International Statistical Classification of Diseases and Related Health Problems (ICD) version used to code deaths. The overall confirmation rate for ICD-10 was 82.8% (95% confidence interval [CI], 82.6% to 83.0%), the overall detection rate for ICD-10 was 81.0% (95% CI, 80.4% to 81.6%), and the overall detection rate for ICD-9 was 85.0% (95% CI, 84.8% to 85.2%). These rates varied across primary sites, where some rates were less than 50%, some were 95% or greater, and notable differences between confirmation and detection rates were observed. For some of the most commonly diagnosed cancers in the United States (for example, prostate, breast, and lung and bronchus), confirmation or detection rates were 95% or greater. This study recorded important unique information on the quality of cancer mortality data obtained from death certificates, particularly underlying causes of death coded in ICD-10.⁵

Improving the Accuracy of Vital Statistics

CDC's National Center for Health Statistics has worked with the Social Security Administration and the National Association for Public Health Statistics and Information Systems to develop and promote electronic systems to improve the accuracy and timeliness of vital statistics. <u>Standard certificates</u> for births and deaths were revised, and state vital registration systems are being re-engineered to collect data electronically. These systems will accommodate better certificate revisions, special studies or projects, and linkage with other health promotion programs. <u>Handbooks and guides</u> are routinely updated and provided to professionals who complete death certificates.

- 1. Kircher T, Nelson J, Burdo H. <u>The autopsy as a measure of accuracy of the death certificate</u>. *New England Journal of Medicine* 1985;313(20):1263–1269.
- Engel LW, Strauchen JA, Chiazze L Jr, Heid M. <u>Accuracy of death certification in an autopsied population with</u> <u>specific attention to malignant neoplasms and vascular diseases</u>. *American Journal of Epidemiology* 1980;111(1):99–112.
- 3. Schottenfeld D, Eaton M, Sommers SC, Alonso DR, Wilkinson C. <u>The autopsy as a measure of accuracy of the death certificate</u>. *Bulletin of the New York Academy of Medicine* 1982;58(9):778–794.
- 4. Sinard JH. <u>Factors affecting autopsy rates, autopsy request rates, and autopsy findings at a large academic</u> <u>medical center.</u> *Experimental and Molecular Pathology* 2001;70(3):333–343.
- 5. German RR, Fink AK, Heron M, Stewart SL, Johnson CJ, Finch JL, Yin D; the Accuracy of Cancer Mortality Study Group. <u>The accuracy of cancer mortality statistics based on death certificates in the United States</u>. *Cancer Epidemiology* 2011;35(2):126–131.

The North American Association of Central Cancer Registries (NAACCR) Race and Ethnicity Identifier Assessment Project confirmed the importance of publishing cancer rates by race and ethnicity (specifically, Hispanic origin).¹ When reporting cancer incidence, race and ethnicity information is abstracted from medical records and grouped into race and ethnicity categories.² Although registries use standardized data items and codes for both race and ethnicity, the initial collection of this information by health care facilities and practitioners and the procedures for assigning and verifying codes for race and ethnicity are not well standardized.¹ Thus, some inconsistency is expected in this information.

When reporting cancer mortality, race and Hispanic origin are recorded separately on the death certificate by the funeral director as provided by an informant or, in the absence of an informant, on the basis of observation.³ Inconsistencies in the collection and coding of data on race and Hispanic origin and their effect on mortality statistics have been described.⁴ The net effect of misclassification is greatest for American Indian and Alaska Native people; misclassification is smaller for Asian and Pacific Islander people and Hispanic people, and minimal for Black people and White people. Therefore, incidence and/or mortality data published in this report may be underestimated for Asian and Pacific Islander, American Indian and Alaska Native, and Hispanic people, possibly due to racial and Hispanic origin misclassification. In the U.S. Cancer Statistics Data Visualizations tool, we have restricted analysis to non-Hispanic populations to overcome racial misclassification and to better represent U.S. populations. CDC's National Center for Health Statistics is working with states to improve the reporting of race and ethnicity on death certificates.

The Data Visualizations tool presents cancer incidence and mortality data for all races combined and by race and ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic American Indian or Alaska Native, non-Hispanic Asian or Pacific Islander, and Hispanic). Use caution while comparing with data in <u>Archived Reports</u> as the differences in rates are due to changes in data presentation and not due to rate changes. Data for Puerto Rico are only available for all races and ethnicities.

Due to a coding issue reported by North Dakota and Wisconsin after data submission, state- and county-specific counts and rates by race and ethnicity are not presented for North Dakota. For Wisconsin, state- and county-specific counts and rates are not presented for Hispanic persons. These data for all races and ethnicities are presented in U.S. Data Visualizations tool and are also included in national rates.

Asian and Pacific Islander People

Although central cancer registries have designated codes for race that allow them to document the occurrence of cancer in 25 Asian and Pacific Islander subpopulations,² the subpopulations are grouped into a single Asian and Pacific Islander category because of small numbers and concerns regarding possible misclassification of race data, and restricted to non-Hispanic persons.

Studies show excellent agreement (k=0.90) between Asian and Pacific Islander race in Surveillance, Epidemiology, and End Results (SEER) registry data and self-reported data from the U.S. Census.⁵ Studies examined the misclassification of race for Asian and Pacific Islander subpopulations in cancer registries.^{6 7 8} Nearly all National Program of Cancer Registries (NPCR) and SEER registries assigned Asian, not otherwise specified to a more specific Asian race through the standardized use of the NAACCR Asian and Pacific Islander Identification Algorithm (NAPIIA) version 1.2.

For cases reported in 1999, Kansas opted not to present state- and county-specific counts and rates for non-Hispanic Asian and Pacific Islander persons. The national rates presented include data for Kansas.

A study reported 90% agreement between Asian and Pacific Islander race reported on death certificates and self-reported data from the U.S. Census.⁴

Hispanic People

The overall agreement between Hispanic ethnicity collected by SEER registries and self-reported ethnicity from the U.S.

Census was substantial (k=0.61). Hispanic people were found to be underclassified in the SEER data compared to selfreports.⁵ Nearly all NPCR and SEER registries assigned Hispanic ethnicity through the standardized use of the NAACCR Hispanic Identification Algorithm (NHIA) version 2 (NHIA v2).⁹ After applying the NHIA v2, cases not classified as Hispanic are classified as non-Hispanic, leaving no cases with unknown Hispanic status.

A study reported an 88% record-by-record agreement between Hispanic origin on death certificates and self-reported data.⁴

Death counts and rates for Hispanic people are presented at the national and state levels for all 50 states and for the District of Columbia. Hispanic origin is assigned to cancer mortality data on the basis of information collected from death certificates.

Improving Estimation of Cancer Burden among American Indian and Alaska Native People

More American Indian and Alaska Native patients are misclassified as another race in cancer registry records than patients in other racial groups. Studies have found that this racial misclassification contributes to underestimates of cancer incidence and death rates among the American Indian and Alaska Native population.^{4 10} Accurate determination of disease burden is a critical first step toward identifying health disparities. Methods that can improve the accuracy of cancer burden estimates among the American Indian and Alaska Native population are described below.

Method 1: Linkage with Indian Health Service administrative records

The Indian Health Service (IHS) provides medical services to American Indian and Alaska Native people who are enrolled members of federally recognized tribes. The IHS provides health care to about 2.2 million people, a number equivalent to about 64% of the U.S. American Indian and Alaska Native population.¹⁰ While IHS coverage of these populations varies by region, it does not include American Indian and Alaska Native people who are members of non-federally recognized tribes, and underrepresents those who live in certain urban areas. People who are eligible to receive IHS services have sufficient native ancestry in a federally recognized tribe to be classified accurately as an American Indian or Alaska Native person.

As a standard practice, central cancer registries classify race as coded in the medical record. To address American Indian and Alaska Native misclassification in cancer registry data, selected registries in CDC's NPCR and all registries in the National Cancer Institute's SEER program linked their central cancer registry data to the IHS administrative records database for cases diagnosed from 1995 to 2020 and 1988 to 2020, respectively. Results of the linkage were captured in the data element, IHS Link (NAACCR data item 192).² Central cancer registries include race and IHS Link in their annual data submissions to CDC or NCI. Using the race and IHS Link data elements, CDC and NCI created a recoded race variable. If a cancer case had an IHS Link value that indicated a match to IHS and race is White, other, or unknown, then the recoded race variable was coded as American Indian and Alaska Native. Although the linkage with IHS does not completely resolve the classification of race for American Indian and Alaska Native cases, it helps provide a more comprehensive and accurate picture of the cancer burden in this population.

Method 2: Restriction to non-Hispanic populations

Updated bridged intercensal population estimates significantly overestimated the number of American Indian and Alaska Native persons of Hispanic origin.^{11 12} Because these population estimates are used as denominators in rate calculations, larger than expected denominators can result in underestimation of rates. Studies demonstrate that restricting analysis to non-Hispanic populations can improve the accuracy of cancer incidence and death rate estimates among American Indian and Alaska Native people.¹²

Method 3: Restriction to IHS Purchased/Referred Care Delivery Areas

The IHS Purchased/Referred Care Delivery Area (PRCDA) is the geographic area within which the IHS makes purchased/ referred care available to members of an identified Indian community who reside in the area. The IHS uses it to determine eligibility for services not directly available within the IHS. The IHS PRCDA consists of counties that include all or part of an American Indian or Alaska Native reservation or have a common boundary with a federally recognized tribal land, as defined in the October 14, 2020 *Federal Register* (82 FR 47004). There are 36 states that have at least one PRCDA-designated county. The PRCDA counties have higher proportions of American Indian and Alaska Native people in relation to the total population than non-PRCDA counties, with 53.3% of the U.S. American Indian and Alaska Native population residing in the 685 counties designated as PRCDA. Linkage studies have indicated more accurate race classification for American Indian and Alaska Native persons in PRCDA counties.^{10 13 14 15 16}

Data on American Indian and Alaska Native People in the U.S. Cancer Statistics Data Visualizations Tool

The U.S. Cancer Statistics Data Visualizations tool presents national, state, and county data by race, including non-Hispanic American Indian and Alaska Native people. The national data include non-Hispanic American Indian and Alaska Native populations in all U.S. counties. These data use the results from the linkage with IHS to classify race, and are restricted to non-Hispanic people only. As described in the section above, these restrictions can improve the accuracy of cancer burden estimates among the American Indian and Alaska Native population. State- and county-specific data for non-Hispanic American Indian and Alaska Native persons are not presented for states that opted not to present these data: Illinois, Kansas, New Jersey, New York, and North Dakota.

American Indian and Alaska Native people data in the At a Glance section

The U.S. Cancer Statistics Data Visualizations tool's American Indian and Alaska Native restricted to PRCDA only module presents data from the <u>United States Cancer Statistics American Indian and Alaska Native Incidence Analytic Database</u> (<u>USCS AIAD</u>) in the tool's At a Glance section. This database uses the three methods described above to improve the accuracy of cancer burden estimates among American Indian and Alaska Native people—

- First, this database uses the recoded race variable to classify race; only people of American Indian and Alaska Native race or White race (as comparison) are included in the module.
- Second, the database is restricted to persons of non-Hispanic origin.
- Third, the database is restricted to persons residing in PRCDA counties.

This database includes data elements specific to the American Indian and Alaska Native population, such as IHS Region and PRCDA county.

The USCS AIAD data can be displayed for all IHS regions combined or by six IHS regions: Alaska, Pacific Coast, Southwest, Northern Plains, Southern Plains, and East. The states grouped by IHS region are—

- Alaska: Alaska.
- Pacific Coast: California, Idaho, Oregon, and Washington.
- Southwest: Arizona, Colorado, Nevada, New Mexico, and Utah
- Northern Plains: Indiana, Iowa, Michigan, Minnesota, Montana, Nebraska, North Dakota, South Dakota, Wisconsin, and Wyoming.
- Southern Plains: Kansas, Oklahoma, and Texas.
- **East:** Alabama, Connecticut, Florida, Louisiana, Massachusetts, Maine, Mississippi, New York, North Carolina, Pennsylvania, Rhode Island, South Carolina, and Virginia.

The percentages of the American Indian and Alaska Native population living in PRCDA-designated counties by IHS region from 2016 to 2020 were—

- Alaska=100%.
- Pacific Coast=61.0%.
- Southwest=86.4%.
- Northern Plains=54.6%.
- Southern Plains=56.3%.
- East=17.9%.
- Total United States=54.0%.

Studies have shown substantial variation in rates in the American Indian and Alaska Native population by IHS region.^{17 18} IHS regions have been presented in several publications focusing on American Indian and Alaska Native people, and this approach was determined to be preferable to the use of smaller jurisdictions, such as IHS Administrative Areas, which yielded less stable estimates.^{13, 19-21}

- 1. O'Malley C, Hu KU, West DW. North American Association of Central Cancer Registries: Race and Ethnicity Identifier Assessment Project. Springfield (IL): North American Association of Central Cancer Registries; 2001.
- 2. Havener L, Hulstrom D. *Standards for Cancer Registries Vol. II: Data Standards and Data Dictionary.* 10th ed., version 11. Springfield (IL): North American Association of Central Cancer Registries; 2004.
- 3. Miniño AM, Heron MP, Smith BL, Kochanek K. <u>Deaths: Final data for 2004. [PDF-3.4MB]</u> National Vital Statistics Reports 2007;55(19).
- 4. Arias E, Heron M, Hakes JK. <u>The validity of race and Hispanic-origin reporting on death certificates in the United</u> <u>States: An update. [PDF-3.1MB] Vital and Health Statistics 2016;2(172).</u>
- Clegg LX, Reichman ME, Hankey BF, Miller BA, Lin YD, Johnson NJ, Schwartz SM, Bernstein L, Chen VW, Goodman MT, Gomez SL, Graff JJ, Lynch CF, Lin CC, Edwards BK. <u>Quality of race, Hispanic ethnicity, and immigrant status in</u> <u>population-based cancer registry data: implications for health disparity studies.</u> *Cancer Causes and Control* 2007;18(2):177–187.
- 6. NAACCR Race and Ethnicity Work Group. <u>NAACCR Asian Pacific Islander Identification Algorithm [NAPIIA v1.2.1]</u> [PDF-132KB]. Springfield (IL): North American Association of Central Cancer Registries; 2008.
- 7. Boscoe FP. Issues with the coding of Asian race in cancer registration. *Journal of Registry Management* 2007;34(4):135–139.
- 8. Boscoe FP, Schymura MJ, Hsieh M, Williams MA, Henry KA. Issues with the coding of Pacific Islanders in central cancer registries. *Journal of Registry Management* 2008;35(2):47–51.
- 9. NAACCR Race and Ethnicity Work Group. NAACCR Guideline for Enhancing Hispanic/Latino Identification: Revised NAACCR Hispanic/Latino Identification Algorithm [NHIA v2.2.1]. Springfield (IL): North American Association of Central Cancer Registries. September 2011.
- Jim MA, Arias E, Seneca DS, Hoopes MJ, Jim CC, Johnson NJ, Wiggins CL. <u>Racial misclassification of American</u> <u>Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area</u>. *American Journal of Public Health* 2014;104(6 suppl 3):S29–S302.
- 11. Arias E, Xu J, Jim MA. <u>Period life tables for the non-Hispanic American Indian and Alaska Native population</u>, <u>2007–2009</u>. *American Journal of Public Health* 2014;104:S312–S319.
- 12. Espey DK, Jim MA, Richards TB, Begay C, Haverkamp D, Roberts D. <u>Methods for improving the quality and</u> <u>completeness of mortality data for American Indians and Alaska Natives.</u> *American Journal of Public Health* 2014;104:S286–S294.
- 13. Espey DK, Wiggins CL, Jim MA, Miller BA, Johnson CJ, Becker TM. <u>Methods for improving cancer surveillance</u> <u>data in American Indian and Alaska Native populations.</u> *Cancer* 2008;113(5 suppl):1120–1130.
- Sugarman JR, Holliday M, Ross A, Castorina J, Hui Y. <u>Improving American Indian cancer data in the Washington</u> <u>State Cancer Registry using linkages with the Indian Health Service and tribal records.</u> *Cancer* 1996;78(7 Suppl):1564–1568.

- 15. Frost F, Taylor V, Fries E. <u>Racial misclassification of Native Americans in a Surveillance, Epidemiology, and End</u> <u>Results cancer registry.</u> *Journal of the National Cancer Institute* 1992;84(12):957–962.
- 16. Kwong SL, Perkins CL, Snipes KP, Wright WF. Improving American Indian cancer data in the California Cancer Registry by linkage with the Indian Health Service. *Journal of Registry Management* 1998;25(1):17–20.
- 17. Wiggins CL, Espey DK, Wingo PA, Kaur JS, Wilson RT, Swan J, Miller BA, Jim MA, Kelly JJ, Lanier AP. <u>Cancer among</u> <u>American Indians and Alaska Natives in the United States</u>, <u>1999–2004</u>. *Cancer* 2008;113(5 suppl):1142–1152.
- White MC, Espey DK, Swan J, Wiggins CL, Eheman C, Kaur JS. <u>Disparities in cancer mortality and incidence among</u> <u>American Indians and Alaska Natives in the United States</u>. *American Journal of Public Health* 2014;104:S377– S387.
- 19. Espey DK, Wu XC, Swan J, Wiggins CL, Jim MA, Ward E, Wingo PA, Howe HL, Ries LA, Miller BA, Jemal A, Ahmed F, Cobb N, Kaur JS, Edwards BK. <u>Annual report to the nation on the status of cancer</u>, <u>1975–2004</u>. *Cancer* 2007;110(10):2119–2152.
- 20. Espey DK, Jim MA, Richards TB, Begay C, Haverkamp D, Roberts D. <u>Methods for improving the quality and</u> <u>completeness of mortality data for American Indians and Alaska Natives.</u> *American Journal of Public Health* 2014;104:S286–S294.
- 21. Melkonian SC, Chen L, Jim MA, Haverkamp D, King JB. <u>Disparities in incidence and trends of colorectal, lung,</u> <u>female breast, and cervical cancers among non-Hispanic American Indian and Alaska Native people, 1999–2018.</u> *Cancer Causes and Control* 2023.

Note: For additional information on data interpretation, please refer to the <u>USCS Technical Notes—Interpreting the</u> <u>Data.</u>

Use caution when interpreting and comparing rankings of state cancer rates.

A natural reaction of some readers when looking at figures that rank their state's cancer rates is to seek explanations as to why their state has higher incidence or death rates for some cancers than other states or than the national average. For example, some may be alarmed that exposure to environmental carcinogens may be responsible when in fact there are several other more likely explanations. Consider the following points when interpreting or comparing these rankings.

Differences Among Racial and Ethnic Populations

Some cancers have different cancer rates for different racial and ethnic populations. For example, breast cancer incidence rates are usually higher in non-Hispanic White women than in women of other racial and ethnic populations, and prostate cancer incidence rates are higher in non-Hispanic Black men. Therefore, when comparing cancer rates across states, consider the racial makeup of the state's population, which is determined through the statistical adjustment of rates by race and ethnicity. However, presentation of rates for specific racial and ethnic populations may be preferable and is more easily understood by a lay audience.

Variations in Populations and Health Behaviors

Some differences in cancer rates among states may be explained by differences in known risk factors among the populations of those states. For example, one finds higher rates of lung cancer and other tobacco-associated cancers in states with higher prevalence of smoking. Although environmental carcinogens are responsible for some cancer cases, a majority of cases appear to be related to lifestyle factors such as smoking, and geographic variations in cancer rates are thought largely to reflect variations in these lifestyle factors.^{1, 2}

Variations in Medical Care

Variations among states in medical care factors may also result in differences in cancer rates. In states where higher percentages of the population participate in cancer screening, more cancers will be diagnosed. Screening leads to earlier detection of tumors that have a better prognosis and may find tumors that grow slowly. Therefore, the cancer incidence rate without additional information only tells part of the story.

Influence of Aging on Cancer Rates

The likelihood of being diagnosed with cancer increases steadily with age. These rates have been adjusted for age so that states can be compared without concern that differences in their rates result from differences in the age distribution of their populations. However, this adjustment may be imperfect if the relationship between age and cancer risk is not the same for all states.

Measuring Burden

The importance of cancer as a public health problem in a state is more a function of the absolute rate of cancer rather than the state's relative ranking in incidence or mortality. For example, Utah has proportionately fewer people who have ever smoked cigarettes than other states, and also has the lowest lung cancer incidence rate of any state. Nevertheless, in Utah lung cancer kills more people than any other cancer, a fact that might be overlooked if one focused only on its low ranking in incidence compared with other states. Also, the true burden of cancer on the health care system and economy of a state is determined by the number of people diagnosed with or the number of people dying of cancer and not by the age-adjusted cancer rate. Therefore, the observation that the cancer rate in one state appears high compared with other states may obscure the fact that the absolute number of cases is not large.

Random Factors and Cancer Rates

There is some uncertainty in computed cancer rates because many factors contribute to the incidence and death rate in any given year or state, and some factors exhibit random behavior. Chance plays a role in determining if and when cancer develops in an individual, whether that cancer is detected, whether the information is entered into the cancer registry, and whether that cancer progresses and leads to death. For these reasons, the reported rates are expected to vary from year to year within a state even in the absence of a general trend. Caution is warranted, therefore, when examining cancer rates for a single year, and especially when the rates are based on a relatively small number of cases.

Confidence Intervals

A 95% confidence interval for the rate is an interval that is expected to contain the true underlying rate 95% of the time. Confidence intervals around the observed state age-adjusted rates are available to help with interpreting the results. Because of the variation in the population sizes and number of reported cases and deaths across states, there is more uncertainty in the incidence and death rates for some states compared with others. The confidence intervals provide a measure of the variability in the rates and some perspective for making state-specific comparisons. However, using overlapping confidence intervals to conclude that rates are not significantly different is not recommended. This is a conservative method because it may fail to detect significant differences more often than does standard statistical hypothesis testing.

Public Health Importance

Another consideration when comparing differences between rates is their public health importance. For some rates, numerators and denominators are large and the standard errors are small with the result that some statistically significant differences may be so small as to lack importance for decisions related to population-based public health programs.

- US Burden of Disease Collaborators; Mokdad AH, Ballestros K, Echko M, Glenn S, Olsen HE, et al. <u>The state of US health</u>, <u>1990–2016</u>: <u>burden of diseases</u>, <u>injuries</u>, <u>and risk factors among US states</u>. *JAMA* 2018;319(14):1444–1472.
- 2. Anand P, Kunnumakkara AB, Sundaram C, Harikumar KB, Tharakan ST, Lai OS, Sung B, Aggarwal BB. <u>Cancer is a preventable disease that requires major lifestyle changes</u>. *Pharmaceutical Research* 2008;25(9):2097–2116.