

Background

Cancer is the second leading cause of death among Americans. One of every four deaths in the United States is due to cancer.^{1,2} The American Cancer Society estimates that in 2006, about 1,399,790 Americans will receive a new diagnosis of invasive cancer, and 564,830 Americans will die of this disease. These estimates do not include *in situ* cancers or the more than 1 million cases of basal and squamous cell skin cancers expected to be diagnosed this year. The National Cancer Institute (NCI) recently estimated that on January 1, 2003, 10.5 million Americans were alive with a history of invasive cancer.³

According to the 2006 *Annual Report to the Nation on the Status of Cancer*,⁴ age-adjusted incidence rates for all cancers combined were stable from 1995 through 2003 in men, but rates in women have increased 0.3% annually since 1987. U.S. death rates for all cancer sites combined decreased significantly beginning in 1994.⁴ However, the number of Americans diagnosed with cancer each year is expected to double in the next 50 years, from 1.3 million to 2.6 million. The anticipated growth and aging of the U.S. population are factors that will increase the number of people who are diagnosed with and treated for cancer.⁵

For 2005, NCI estimated that direct medical costs were about \$74.0 billion for cancer treatment.⁶ The National Heart, Lung, and Blood Institute has estimated that in 2006, the overall annual cost of cancer would be about \$206.3 billion,⁷ broken down as follows:

- Direct medical costs, including health expenditures: \$78.2 billion.
- Indirect costs associated with lost productivity due to illness: \$17.9 billion.
- Indirect costs associated with lost productivity due to premature death: \$110.2 billion.

These costs are likely to increase because of the anticipated growth and aging of the U.S. population.

There are effective primary and secondary prevention measures that could substantially reduce the number of new cancer cases and

prevent many cancer-related deaths. To reduce the nation's cancer burden, we must reduce behavioral and environmental exposures that increase cancer risk, and we must ensure that high-quality screening services and evidence-based treatments are available and accessible, particularly to medically underserved populations.^{8,9}

Cancer registries collect 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).^{10,11} Cancer data are reported to metropolitan-area, regional, and statewide cancer registries from a variety of medical facilities, including hospitals, physicians' offices, radiation facilities, freestanding surgical centers, and pathology laboratories. Cancer death data are recorded on death certificates that are sent to state vital statistics offices. Death certificates contain information regarding primary cancer site and morphology as well as demographic information on the decedent.

Information derived from population-based central cancer registries and from death certificates is critical to guide effective geographic area- or population-specific cancer prevention and control programs that focus on preventing behaviors that put people at increased risk for cancer (e.g., smoking) and on reducing environmental risk factors (e.g., occupational exposure to known carcinogens). This information is also essential for deciding which geographic areas should have cancer screening programs and for making long-term plans for adequate diagnostic and treatment services. Local data can provide incentives for community involvement and ownership of the cancer issues. Pooled data at the national, regional, state, and sub-state levels will help federal and state public health officials establish, prioritize, and monitor national public health surveillance initiatives and track progress toward the national goals and objectives set forth in *Healthy People 2010*,¹² which contains a set of health objectives for the nation for the first decade of the 21st century. For more information on *Healthy People 2010*, visit <http://www.healthypeople.gov/document>.

Federal Programs

Surveillance, Epidemiology, and End Results (SEER) Program

In 1971, Congress passed the National Cancer Act that mandated NCI to collect, analyze, and disseminate data useful to prevent, diagnose, and treat cancer.¹³ This mandate led to the establishment of the SEER Program.¹⁴ For more than 30 years, NCI's SEER Program has provided statistics regarding cancer incidence, survival, and mortality in the United States; monitored cancer incidence trends in geographic and demographic population groups; provided information on trends in extent of disease at diagnosis, therapy, and patient survival; promoted studies measuring progress in cancer control and etiology; provided specialty training in epidemiology, biostatistics, surveillance research, and tumor registry methodology, operations, and management; and developed new statistical methods, models, and software for analyzing and presenting national and small-area statistics.

The SEER Program currently collects and publishes cancer incidence and survival data from 14 population-based cancer registries and 3 supplemental registries covering approximately 26% of the U.S. population (Appendix B). SEER registries provide complete coverage for metropolitan regions and special populations whose data are reported to their respective state registries: the Alaska Native registry covers 16% of the state population; Arizona Indians, 5%; Greater Bay Area (San Francisco-Oakland and San Jose-Monterey), 19%; Los Angeles County, 28%; the remainder of California, 53%; Atlanta and rural Georgia, 37%; metropolitan Detroit, 41%; and Seattle-Puget Sound, 69%. In addition, since 2001, NCI funding for Kentucky, Louisiana, New Jersey, and the remainder of California has provided resources for these registries to meet the requirements of the SEER Program regarding completeness of case ascertainment, follow-up, timeliness, and data quality metrics. Information on more than 3 million *in situ* and invasive cancer cases is included in the SEER database, and approximately 170,000 new cases are added each

year within SEER coverage areas. (See <http://seer.cancer.gov/registries> for the first diagnosis year for which data were reported to NCI for each SEER area.) The mortality data reported by SEER are provided by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC). A public-use data set is issued each year by the SEER Program for additional analyses.

For more information on the SEER Program, visit <http://seer.cancer.gov>.

National Program of Cancer Registries (NPCR)

Recognizing the need for more complete local, state, regional, and national cancer incidence data, Congress established NPCR in 1992 by enacting the Cancer Registries Amendment Act, Public Law 102-515; the program was reauthorized in 1998.¹⁵ Congress mandated CDC to provide funds to state and territorial health departments (or their authorized agencies) at a ratio of \$3:\$1 to match state support for the central cancer registry. As of 2006, CDC funds a total of 49 registries: 45 states, the District of Columbia, and 3 territories (Appendix B).

NPCR registries cover 96% of the U.S. population. NPCR has the state and national capacity to monitor the cancer burden; identify cancer incidence variation for racial and ethnic populations and for regions within a state, among states, and among regions; provide data for research; provide guidance for health resource allocation; respond to public concerns and inquiries about cancer; improve planning for future health care needs; and evaluate cancer prevention and control activities.¹⁶

In January 2001, NPCR registries began annually reporting their incidence data to CDC from the first diagnosis year for which a state or territorial cancer registry collected data with the assistance of NPCR funds (<http://apps.nccd.cdc.gov/cancercontacts/npcr/contacts.asp>). Data from the special population cancer registries or

the SEER metropolitan-area cancer registries operating in Alaska, Arizona, California, Georgia, Michigan, and Washington are reported to their respective NPCR state cancer registry for inclusion in the state's incidence data and are transmitted to CDC as part of the state's annual data submission. In January 2006, CDC received information on more than 10 million invasive cancer cases diagnosed during 1995–2003, and more than 1 million new invasive cancer cases are added each year. In addition to the *United States Cancer Statistics (USCS)* series, NPCR disseminates (1) a public-use data set of precalculated cancer incidence rates on CDC WONDER (<http://wonder.cdc.gov>), (2) state cancer burden data fact sheets intended for lay audiences, (3) a U.S. county cancer incidence data set of rates and counts for major cancer sites for selected counties, and (4) an expanded *USCS* data set of age-adjusted rates, crude rates, and case counts.

For more information on NPCR, visit <http://www.cdc.gov/cancer/npcr>.

National Vital Statistics System (NVSS)

The nation's vital statistics are available from NVSS, which is maintained by CDC's NCHS. These vital statistics are provided through state-operated registration systems and are based on vital records filed in state vital statistics offices. The recording of vital events is the responsibility of the individual states and independent registration areas (e.g., District of Columbia, New York City, territories) in which the event occurs. Legal responsibility for the registration of vital events rests with the individual states. Through its Vital Statistics Cooperative Program, NCHS cooperates with state vital statistics offices to develop and recommend standard forms for data collection and model procedures to ensure uniform registration of the events monitored by 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. 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. Monthly provisional data on vital statistics are available for the United States and each state.

A public-use data set is issued each year by NCHS for additional analyses.

For more information on NCHS and its NVSS, visit <http://www.cdc.gov/nchs>.

Collaborating Partner

North American Association of Central Cancer Registries (NAACCR)

Both federally funded registry programs (i.e., the SEER Program and NPCR) work closely with NAACCR to promote cancer incidence surveillance in the United States and Canada. Established in 1987, NAACCR is an organization of population-based cancer registries, governmental agencies, professional associations, and private groups in North America interested in cancer surveillance and dedicated to NAACCR's mission. Its mission is to reduce the burden of cancer in North America by developing and promoting cancer registration standards; providing education and training; certifying population-based cancer registries; evaluating and publishing data; and promoting the use of cancer surveillance data and systems for cancer control, epidemiologic research, public health programs, and patient care. All state and metropolitan-area registries participating in NPCR and SEER, as well as all provincial and territorial registries in Canada, are members of NAACCR. A public online query system, CINA+ (Cancer in North America Plus) Online, is updated annually with the most recent 5 years of incidence data (see <http://www.naacrr.org/cinap>). Starting with the 1995 diagnosis year, the incidence data file is updated annually for qualified researchers. For more information about this file, contact the NAACCR office (<http://www.naacrr.org>).

In 1992, NAACCR began annual reviews of member registries' data for completeness, accuracy, and timeliness. In 1997, this process was formalized into a certification program, whereby registries report their data in December and NAACCR evaluates the data using standard, objective measures. Registries that meet the highest standards for data quality are recognized through certification.¹⁷⁻¹⁹

In 1997, when NAACCR evaluated 1995 incidence data, 9 NPCR registries and all 10 SEER registries were certified. Nine years later, when NAACCR evaluated the 2003 incidence in 2005, 37 NPCR registries, 4 NPCR/SEER registries, and 9 SEER registries were certified. (Data from San Francisco-Oakland and San Jose-Monterey are combined and evaluated as the Greater Bay Area.)

For more information on NAACCR, visit <http://www.naacr.org>.

Data Sources

Incidence Data

Data from the registries participating in NPCR were reported to CDC as of January 31, 2006. Data from registries in the SEER Program were reported to NCI as of November 1, 2005, and made available through the SEER Program public-use data file released in April 2006 (<http://seer.cancer.gov/publicdata>). For this report, data from California, Kentucky, Louisiana, and New Jersey (states that are supported by both NPCR and SEER) are presented as reported to CDC as of January 31, 2006.

The primary source of cancer incidence data is medical records. Staff at health care facilities abstract cancer incidence data from patients' medical records, enter the data into the facility's own cancer registry, if it has one, and then send the data to the regional or state registry. Both NPCR and SEER registries collect data using uniform data items and codes as documented by NAACCR. This uniformity ensures that data items collected by the two federal programs are comparable.^{11,20} Information on primary site and histology was coded according to the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3)²¹ and categorized according to the revised SEER recodes dated January 27, 2003, which define standard groupings of primary cancer sites (http://seer.cancer.gov/siterecode/icdo3_d01272003).

NPCR and SEER cancer registries consider as reportable all incident cases with a behavior code

of 2 (*in situ*, noninvasive) or 3 (invasive, primary site only) in ICD-O-3, with the exception of *in situ* cancer of the cervix. Basal and squamous cell carcinomas of the skin are also excluded, with the exception of those on the skin of the genital organs.²¹ Several cancers are coded as malignant in ICD-O-3 (beginning with 2001 diagnoses) that were not previously coded as malignant in ICD-O-2.²¹

Myelodysplastic syndromes (MDS) including refractory anemias (histology codes 9980, 9982–9984, 9989) are now considered malignant in ICD-O-3. Chronic myeloproliferative diseases (CMPDs) including polycythemia vera and thrombocythemias (histology codes 9950, 9960–9962) are also now considered malignant in ICD-O-3.²¹ MDS and CMPD arise in the bone marrow. MDS is characterized by abnormal growth of blood cells in the bone marrow and is a clonal disease, meaning a large population of exactly alike abnormal cells arise from a single abnormal cell.²² CMPD is the overproduction of blood cells by the bone marrow; polycythemia vera is the production of too many red blood cells and thrombocythemia is the production of too many platelets.²² CMPDs sometimes become acute leukemia, in which too many abnormal white blood cells are made.²² In this report, these cancers are included in the “Miscellaneous” and “All Sites” categories.

Papillary ependymomas (9393) and papillary meningiomas (9538)—cancers that occur in the central nervous system²²—are also newly classified as malignant according to ICD-O-3. In this report, these cancers are included in the “Brain and Central Nervous System” and “All Sites” categories. Although these cancers were newly classified as malignant beginning with 2001 diagnoses, *USCS* reports published in 2004²³ and 2005²⁴ did not include them in order to be consistent with other cancer statistics reports and publications.^{3,4,25}

Some endometrial tumors (8931) are also newly classified as malignant in ICD-O-3. These cancers were reported in *USCS* reports published in 2004²³ and 2005²⁴ and are still included in the “Corpus and Uterus, Not Otherwise Specified (NOS)” and “All Sites” categories.

For consistency with *USCS* reports published in 2004²³ and 2005,²⁴ and other reports that do not include these cancers,^{3,4,25} an additional row of data is presented in Tables 1.1.1.1M and 1.1.1.1F with the heading “All Sites (excl. newly classified as malignant)” and in Tables 2.1.1.1.M and 2.1.1.1.F with the heading “United States (excl. newly classified as malignant).” These rows exclude all the newly malignant histology codes described above and listed as follows: 8931, 9393, 9538, 9950, 9960–9962, 9980, 9982–9984, 9989.²¹ Footnotes describing these rows are provided in these tables.

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 ovarian cancer incidence rate calculations included in tables and figures. A footnote is provided where appropriate to remind readers of this exclusion. Pilocytic astrocytomas (9421) are also not coded as malignant in ICD-O-3; however, these cancers are included in this report.

This report also contains data for two rare cancers: Kaposi sarcoma (KS) and mesothelioma. KS is a cancer of connective tissue such as cartilage, bone, fat, muscle, and blood vessels. Since the vast majority of 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 in this report. Mesothelioma is a cancer that generally occurs in the chest, abdominal region, and areas surrounding the heart. It is typically associated with exposure to asbestos. Because KS and mesothelioma are considered separate cancers for this report, they were removed from counts of other primary cancer sites.

In situ bladder cancers were recoded to invasive bladder cases because the information needed to distinguish between *in situ* and invasive bladder cases is not always available or reliable. Case counts and rates for invasive cancers are included in this report. This report also includes counts and rates for *in situ* breast cancer cases among women; these

are reported separately and are not included in counts or rates for the “All Sites” category. Case counts and rates for leukemias were calculated for acute and chronic lymphocytic leukemia, acute and chronic myeloid leukemia, and other leukemias, which include other myeloid/monocytic leukemias. Nonreportable 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. Counts of cases used in this report are available at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”).

Mortality Data

Cancer mortality statistics in this report are based on information from all death certificates filed in the 50 states and the District of Columbia and processed by NVSS at NCHS for deaths that occurred in 2003 and were reported as of February 28, 2005. The U.S. Standard Certificate of Death, which is used as a model by the states, was revised in 2003.²⁶ This report includes data for five areas (California, Idaho, Montana, New York City, and New York State), which implemented the 2003 revision of the U.S. Standard Certificate of Death in 2003. The remaining 46 states and the District of Columbia collected and reported death data in 2003 based on the 1989 revision of the U.S. Standard Certificate of Death.²⁶⁻²⁹

The cancer mortality data were compiled in accordance with World Health Organization (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)*. Starting with deaths that occurred in 1999, the United States began using the Tenth Revision of this classification (ICD-10).³⁰

Rules for coding cause(s) of death may sometimes require modification when evidence suggests that such modifications will improve the quality of cause-of-death data. Prior to 1999, such modifications were made only when a new revision of the ICD was implemented. A process for

updating the ICD was introduced with ICD-10 that allows for mid-revision changes. Minor changes may be implemented every year, while major changes may be implemented every 3 years (e.g., 2003 data year). Updates to the ICD for 2003 do not have a significant impact on the data presented in this report.

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 this report were coded by procedures outlined in annual issues of the NCHS Instruction Manuals.^{31,32}

Tabulations of cause-of-death statistics are based solely on the underlying cause of death. The underlying cause 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.”³⁰ 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 directly reflected in the underlying cause of death. This information is captured in NCHS multiple cause-of-death statistics.³³⁻³⁵

Since 1968, NCHS has computerized the coding of the underlying cause of death in accordance with WHO rules. In this system, called “Automated Classification of Medical Entities” (ACME),³⁶ multiple cause-of-death codes serve as inputs to the computer software that selects the underlying cause of death. In addition, NCHS has developed two computer systems as inputs to ACME. Beginning with 1990 data, the Mortality Medical Indexing, Classification, and Retrieval (MICAR) system^{37,38} has been applied to automate coding of multiple causes of death. Then, beginning with data year 1993, SuperMICAR, an enhancement of the MICAR system, was applied to allow for literal entry of the multiple cause-of-death text as reported by medical certifiers in the states. Records that cannot be automatically processed by MICAR or SuperMICAR are manually multiple-cause coded and then further processed through ACME. For 2003 mortality statistics, all of the

nation’s death records were multiple-cause coded using SuperMICAR.

For consistency with the cancer incidence data, cancer sites in mortality data were grouped according to the revised SEER recodes dated January 27, 2003. 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, differences occur in mortality and incidence coding. For example, there are several codes for mesothelioma in ICD-10 (depending on the primary site). However, one code in ICD-O-3 captures all the primary sites that mesothelioma affects. SEER recodes for cancer mortality are at http://seer.cancer.gov/codrecode/1969+_d09172004/index.html.

All states and the District of Columbia submitted part or all of their 2003 mortality data in electronic data files to NCHS. All states provided precoded cause-of-death data to NCHS except Illinois and West Virginia.³⁹ For 2003, all states submitted precoded demographic data (e.g., sex and race of the deceased) for all deaths. 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. Deaths among overseas armed forces personnel are not included.

One index of the quality of reporting causes of death is the proportion of death certificates coded to ICD-10 codes R00–R99 (i.e., symptoms, signs, and abnormal clinical and laboratory findings not elsewhere classified). Although deaths occur for which the underlying causes are impossible to determine, the proportion classified as R00–R99 indicates the care and consideration given to the cause-of-death statement by the medical certifier. This proportion also may be used as a rough measure of the specificity of the medical diagnoses made by the certifier in various areas. In 2003, the percentage of all reported deaths in the United States assigned to symptoms, signs, and abnormal clinical and laboratory findings not elsewhere classified was 1.28%, which was slightly higher than in 2002 (1.23%) but lower than in 2000 (1.33%) and 2001 (1.34%).³⁹ In general, from 1990 through 1999, the percentage of deaths from this cause for all ages combined was fairly stable

(1.08%–1.18%). In addition, causes of death are more likely to be misclassified for populations other than white as symptoms, signs, and abnormal clinical and laboratory findings not elsewhere classified, and this misclassification may affect comparisons of cause-specific death data.⁴⁰

Population Denominator Data

The population estimates for the denominators of incidence and death rates presented in this report are race-specific (all races, whites, blacks, Asians/Pacific Islanders, and American Indians/Alaska Natives), Hispanic-specific, and sex-specific county population estimates aggregated to the state or metropolitan-area level. The county population estimates that are incorporated into NCI's SEER* Stat software (<http://www.seer.cancer.gov/seerstat>) to calculate cancer incidence and death rates are available at <http://www.seer.cancer.gov/popdata>. The SEER* Stat population estimates are a slight modification of the annual time series of July 1 county population estimates (by age, sex, race, and Hispanic origin) produced by the Population Estimates Program of the U.S. Bureau of the Census (Census Bureau) with support from NCI through an interagency agreement. The Census Bureau's population estimates and documentation of the procedures used to develop them are available at <http://www.census.gov/popest/counties>. The estimates used in this report are postcensal estimates for 2003 (based on the 2000 census) that include bridged single-race estimates derived from the multiple-race categories through collaboration between the Census Bureau and CDC's NCHS. For more information on the 2000 bridged population estimates, see <http://www.cdc.gov/nchs/about/major/dvs/popbridge/popbridge.htm>.

Documentation regarding modifications made by NCI to Census Bureau estimates is available at <http://www.seer.cancer.gov/popdata>. Briefly, the modification affects only population estimates for Hawaii and is based on information from the Epidemiology Program of the Hawaii Cancer Research Center. The modified population estimates were obtained by SEER using survey data collected by the Hawaii Department of Health to address concerns that the Native Hawaiian population had been undercounted in previous

censuses. The “Hawaii-adjustment” to Census Bureau estimates has the net result of reducing the estimated white population and increasing the estimated Asian/Pacific Islander population in the state. Census Bureau estimates for the total population, black population, and American Indian and Alaska Native populations in Hawaii are unaffected.

Registry Eligibility Criteria

Cancer incidence data included in this report are from statewide or metropolitan-area cancer registries that have high-quality cancer incidence data for 2003 as demonstrated by meeting the following data quality criteria for all cancer sites combined:

- *Case ascertainment is 90% or more complete.* The registry data include at least 90% of the expected, unduplicated cases where the expected cases are estimated by using methods developed by NAACCR.^{18,19,25,41} Because some cancer patients receive diagnostic or treatment services at more than one reporting facility, cancer registries perform a procedure known as “unduplication” to ensure that each cancer case is counted only once.⁴²
- *No more than 5% of cases are ascertained solely on the basis of a death certificate.* 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,”⁴²⁻⁴⁴ is another measure of the completeness of case ascertainment.
- *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 set of single-field, interfield, and interrecord computerized edits.* Computerized edits are

computer programs that test the validity and logic of data components. For example, if (a) a patient received a diagnosis of cancer in 1999, (b) the patient's age was reported as 80 years, and (c) the patient's year of birth was reported as 1942, a computerized edit could, without human intervention, identify these components as incompatible. The computerized edits applied to the data in this report were designed by the SEER Program for use by SEER registries. During the 1990s, these edits were expanded and incorporated into NAACCR standards (<http://www.naacr.org>) and into the EDITS software designed and maintained by CDC (<http://www.cdc.gov/cancer/npcr/tools/edits>).

Complete state- and metropolitan-area-specific measures for the data quality criteria are available (Appendix C). Registry data that were not eligible for inclusion in this report are shaded.

Populations Covered by This Report

Incidence data on more than 1.2 million invasive cancer cases (including approximately 12,000 cases among children younger than 20 years) diagnosed during 2003 and reported by 47 state cancer registries (38 NPCR, 4 NPCR/SEER, and 5 SEER), the District of Columbia (NPCR), and 6 SEER metropolitan areas (Atlanta, Detroit, Los Angeles, San Francisco-Oakland, San Jose-Monterey, and Seattle-Puget Sound) are included in this report. In total, the NPCR and SEER cancer registries whose data are included in this report cover 96% of the U.S. population (Figure 1) (96% of the white, 97% of the black, 98% of the Asian/Pacific Islander, 89% of the American Indian/Alaska Native, and 96% of the Hispanic populations).

Mortality data on 556,890 deaths in 2003 from malignant neoplasms (i.e., cancers) as recorded in the National Vital Statistics System from the 50 states and the District of Columbia are included in this report; therefore, with regard to mortality

data, 100% of the U.S. population is covered.³⁹ In 2003, malignant neoplasms caused 23% of the total deaths and were overall the second leading cause of death in the United States.³⁹ In Alaska, Maine, Minnesota, Oregon, and Washington State, age-adjusted death rates in 2003 indicated that cancer was the leading cause of death.³⁹

Statistical Methods

Age-Adjusted Incidence and Death Rates

The occurrence of many cancers increases with age, as does cancer mortality. The age distribution of a population (i.e., the number of people in particular age groups) 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 from one geographic area to another are not due to differences in the age distribution of the populations being compared.

The standard population used to age-adjust the rates in this report is the 2000 U.S. standard population, in accordance with a 1998 U.S. Department of Health and Human Services recommendation.^{45,46} The 2000 U.S. standard population is based on the proportion of the 2000 population in specific age groups (younger than 1 year, 1–4 years, 5–9 years, 10–14 years, 15–19 years, . . . 85 years or older). The proportions of the 2000 population in these age groups serve as weights for calculating age-adjusted incidence or death rates. However, NCHS uses a different set of age groups in its age-adjustment of death rates. Therefore the cancer death rates in this report may differ slightly from those published by NCHS. 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 between geographic areas or among populations being compared. They do, however, provide the basis for adjusting for differences in the age distributions across groups defined by sex, race, 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. For the 5-year age groups, the single years of age populations are summed to form the 5-year age groups. For more information, visit http://seer.cancer.gov/stdpopulations/single_age.html. These standard weights are used to compute age-adjusted incidence and death rates by the method of direct standardization as implemented in NCI's SEER*Stat software (<http://www.seer.cancer.gov/seerstat>) and are described as follows:⁴⁷

If N_j is the number of incident cases diagnosed in 2003 or the number of cancer deaths in 2003 in age category j , and P_j is the population size at risk in age category j , then the incidence or death rate R_j in age category j is defined as

$$R_j = N_j/P_j$$

If w_j is the 2000 U.S. standard population weight for age category j , then the age-adjusted (directly standardized) incidence or death rate R_{adj} is computed as

$$R_{adj} = R_j w_j R_j \times 100,000$$

Note from the multiplier in the above formula that incidence or death rates are expressed as cases or deaths per 100,000 persons. For childhood cancers coded according to ICC-3, the multiplier in the formula is 1,000,000 because the childhood cancer rates are expressed per million persons.

Crude and Age-Specific Incidence and Death Rates

Crude and age-specific rates are available at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”).

The crude and age-specific incidence rates equal the total number of new cancer cases diagnosed in 2003 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 (ICCC-3 groupings of childhood cancers).

The crude and age-specific death rates equal the total number of cancer deaths in 2003 in the population category of interest, divided by the at-risk population for that category, and multiplied by 100,000.

Confidence Intervals

Confidence intervals reflect the range of variation in estimates of cancer rates. The width of a confidence interval depends on the amount of variability in the data. Sources of variability include the underlying occurrence of cancer as well as uncertainty about when 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 large numbers, and the confidence interval will 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 the rate. Under these circumstances, the confidence interval will be wide to indicate uncertainty or instability in the cancer rate.

To estimate the extent of this uncertainty, a statistical framework is applied.⁴⁸ The standard model used for rates for vital statistics is the Poisson process,⁴⁹ which assigns more uncertainty to rare events relative to the size of the rate than it does to common events. The population risk profile is positioned to influence the underlying Poisson process from which rates arise, and only a single realization of that process is observed.

Parameters are estimated for the underlying disease process. For this report, we estimated a single parameter to represent the 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.

For this report, we used confidence intervals that are expected to include the true underlying rate 95% of the time. Confidence intervals in this report were computed by using SEER*Stat Version 6.2 software (<http://www.seer.cancer.gov/seerstat>) and are based on the gamma method.⁵⁰ These gamma intervals are approximations to exact Poisson confidence intervals. The gamma method performs better than other methods, especially for small incidence rates or for populations with age distributions that differ from the standard age distribution. 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, as discussed in “Interpreting the Data,” the confidence intervals do not account for systematic (i.e., nonrandom) biases in the incidence rates.

Users of this report who want to know if the differences between the rates of various groups are statistically significant might check whether the confidence intervals overlap. However, we discourage the use of overlapping confidence intervals to test for statistically significant differences between two rates because the practice more frequently fails to detect significant differences than does standard hypothesis testing.⁵¹

Another consideration when comparing differences between rates is their public health importance. For some rates in this report, 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.

Suppression of Rates and Counts at the State, Regional, Division, and National Levels

When the numbers of cases (incidence) or deaths (mortality) used to compute rates are small, those rates tend to have poor reliability.⁴⁹ Therefore, to discourage misinterpretation or misuse of rates or counts that are unstable because case or death counts are small, these rates and counts are not

shown (cell suppression) in tables and figures if the case or death counts are less than 16. A count of less than about 16 results in a standard error of the rate that is approximately 25% or more as large as the rate itself. Similarly, a case count of less than approximately 16 results in the width of the 95% confidence interval around the rate 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.

Another important reason for using a cell suppression threshold value is to protect the confidentiality of patients whose data are included in a report by reducing or eliminating the risk of identity disclosure.^{52,53} 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 patient confidentiality given the low level of geographic and clinical detail provided in the report.⁵⁴

Because the incidence and death rates shown in the state-, sex-, and race-specific bar graphs in Figures 3.1.M1 through 3.58.F2 are presented in rank order, we applied a data suppression criterion in addition to the threshold value of 16 cases. In these figures, incidence rates are not ranked or shown for any sex-specific population groups of less than 50,000 people.

U.S. Census Regions and Divisions

Rates for U.S. Census regions and divisions were calculated by aggregating data reported from the states in each region and division. Only data from state registries that met the criteria for inclusion in this report (see “Registry Eligibility Criteria”) were included in calculations of incidence rates for U.S. Census regions and divisions. There is a potential for bias in the incidence rates for Census regions and divisions where data for some states were excluded. We estimated cancer rates for Census regions or divisions with ineligible cancer registries by assuming that the incidence-to-mortality ratio in the portion of the region or division that is covered by eligible registries is

the same as the incidence-to-mortality ratio in the portion that is not covered by eligible cancer registries (Appendix D). The age-adjusted incidence rates for U.S. Census regions and divisions are reported only if (1) at least 80% of the population for the Census region or division is covered by cancer registries that meet the criteria for inclusion in this report and (2) the 95% confidence intervals around the observed age-adjusted region or division incidence rates based on data from eligible registries for each of six major cancer sites (prostate, female breast, male colorectal, female colorectal, male lung and bronchus, female lung and bronchus) included the estimate of the region or division rate calculated using the methods described in Appendix D.

On the basis of these analyses, we present in this report the observed age-adjusted incidence rates for all U.S. Census regions and divisions with the exception of the South region, East South Central division, and the Mountain division of the West region. The estimate of rates based on the methods described in Appendix D are not presented but are used for determining the exclusion of observed age-adjusted rates for Census regions and divisions.

Case counts for U.S. Census regions and divisions are available at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”) if all state cancer registries in the region or division met the criteria for inclusion in this report, unless the count for exactly one state in the region or division is suppressed due to a count of less than 16.

Total United States

Cancer incidence rates for the United States are aggregate rates based on more than 1 million cancer cases reported from central cancer registries in 47 states, including 6 metropolitan areas, and the District of Columbia. The same statistical criteria that were applied to rates and counts for U.S. Census regions and divisions were also applied to the rates for the entire United States (see “U.S. Census Regions and Divisions” and Appendix D). The cancer rates for the entire United States met these criteria and are the best estimates of the U.S. cancer burden available that are based on observed data. The observed cancer rates are for 96% of the U.S. population covered by eligible cancer registries.

Case counts for the U.S. incidence rates for all ages combined are available at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”). The U.S. case counts are provided only to allow readers to verify the crude rates (available at <http://www.cdc.gov/uscs> [see “*United States Cancer Statistics on the Web*”]) by recalculation. The U.S. counts and U.S. cancer incidence rates in this report pertain to the 96% of the U.S. population covered by eligible cancer registries.

Interpreting the Data

Age-adjusted rates are presented in this report. Crude and age-specific rates have also been calculated and can be found at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”). Crude rates are helpful in determining burden and specific needs for services for a given population, compared with another population, regardless of size. Crude rates are influenced by the underlying age distribution of the state’s population. Even if two states have the same age-adjusted rates, the state with the relatively older population (as demonstrated by having a higher median age) will have higher crude rates because incidence or death rates for most cancers increase with increasing age. Ideally, crude, age-adjusted, and age-specific rates are all used to plan for population-based cancer prevention and control interventions.⁴⁶

Incidence Data

Published age-adjusted cancer incidence rates for diagnosis years before 1999 were calculated by using the 1970 U.S. standard population; for mortality data, the 1940 standard population was used. Beginning with the publication of data for the 1999 diagnosis year, cancer incidence rates were age-adjusted to the 2000 U.S. standard population. This change conforms to U.S. Department of Health and Human Services policy for reporting death and disease rates.^{45,46} This policy was motivated by a need to standardize age-adjustment procedures across government agencies.⁴⁵ The change to the 2000 U.S. standard updated the calculation of age-adjusted rates to more closely reflect the current age distribution of the U.S. population and the current burden of cancer. Because of the aging of the U.S. population, the

2000 U.S. standard population gives more weight to older age categories than did the 1940 and 1970 standard populations.^{5,46}

Because cancer incidence increases with age, the change to the 2000 U.S. standard population resulted in higher incidence rates for most cancers. The data published here should not be compared with cancer incidence rates adjusted to different standard populations.

Incidence rates are also influenced by the choice of population denominators used in calculating the rates. Because some state health departments use customized state population projections when calculating incidence rates, the rates published in this report may differ slightly from those published by individual states.

The new population estimates based on the 2000 census improve the accuracy of cancer incidence rates (see “Population Denominator Data”). Previously reported overall cancer rates, when recalculated with the new denominators, do not appear to change appreciably (Dr. Francis P. Boscoe, New York State Cancer Registry, and Dr. Barry Miller, NCI, personal communication, July 2003). However, rates for geographic areas with small populations and for specific racial or ethnic populations appear to be affected to a greater degree and should be interpreted with caution.⁵⁵ Furthermore, since corrections to the population denominators extrapolated from the 1990 census were larger in the late 1990s than earlier in the decade, rates calculated for the late 1990s may be subject to more change than rates calculated for the early 1990s. We published *United States Cancer Statistics: 1999 Incidence* using extrapolated 1999 population estimates based on the 1990 census, with the expectation that the 1999 incidence rates would be revised when the intercensal (i.e., based on both the 1990 census and the 2000 census) race-specific population estimates for 1999 became available.⁵⁶ The incidence rates published in *United States Cancer Statistics: 1999 Incidence* have been revised to incorporate the modified 1999 population denominators and are available at <http://www.cdc.gov/uscs> (see “*United States Cancer Statistics on the Web*”).

Statistical bias can arise if, within a region, division, or country, the sub-area for which data are available has rates that are substantially different from the rates in the sub-area for which data are not available. Because of bias, rates for a U.S. Census region or division, or the country, may not meet statistical criteria for inclusion in this report. It is possible to have some statistical bias even if the percentage of coverage is high and large numbers of cases are recorded. Where coverage is less than 100%, merely increasing the percentage of the population covered may not reduce statistical bias unless the covered population is similar to the uncovered population in terms of cancer rates or proportions. The U.S. counts and rates in this report pertain to the 96% of the U.S. population covered by eligible cancer registries. The 4% of the population that is not covered by eligible cancer registries may have different cancer rates than does the 96% that is covered, so reported observed cancer rates may not be representative of the entire United States. Of note, however, the 95% confidence intervals around the observed rates for the six specific major cancer sites (prostate, female breast, male colorectal, female colorectal, male lung and bronchus, and female lung and bronchus) contain the rates for the entire United States that were estimated using the method described in Appendix D for those same sites. Furthermore, the estimated rates for the entire United States and the observed rates for the same sites that are published in this report did not differ by more than 0.4%. This observation provides strong support that the reported rates are representative of those for the entire United States.

Data quality is routinely evaluated by NPCR and the SEER Program.^{57,58} Some evaluation activities are conducted intermittently to find missing cases or to identify errors in the data. Although the cancer registries whose data are included in this report meet data quality criteria for all invasive sites combined, the completeness and quality of site-specific data may vary. 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, and from one primary cancer site to another.

Completeness and accuracy of the site-specific data may also be affected by the time interval allowed for reporting data to the two federal programs. For this report of 2003 data, the NPCR and SEER time interval for reporting data differed by 3 months. NPCR allowed an interval of 25 months after the close of the diagnosis year (data submission by January 31, 2006), and SEER allowed a shorter interval of 22 months after the close of the diagnosis year (data submission by November 1, 2005).

Delays in reporting cancer cases can affect timely and accurate calculation of cancer incidence rates.⁵⁷ Cases are reported continuously to state and metropolitan-area cancer registries in accordance with statutory and contractual reporting requirements. After the initial submission of the most recent year's data to the federal funding agency, cancer registries continue to revise and update their data on the basis of new information received. Therefore, some cancer cases for the 2003 diagnosis year will likely have been reported to state and metropolitan-area cancer registries after these registries submitted their 2003 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 in this publication. Reporting delays appear to be more common for cancers that are usually diagnosed and treated in nonhospital settings such as physician offices (e.g., early-stage prostate and breast cancer, melanoma of the skin). NCI routinely models SEER reporting patterns and estimates that the delay-adjusted 2003 incidence rate for all sites combined is about 4% higher than the observed 2003 age-adjusted incidence rate. Delay adjustments for 2003 SEER age-adjusted rates vary: melanoma is 7%, prostate cancer is 4%, and breast cancer is 3% (Dr. Brenda K. Edwards, NCI, personal communication, September 2006). Updates to observed data and reported cancer rates are due to improvements in the registry database gained through additional knowledge that only comes with increased time and effort (Dr. Brenda K. Edwards, NCI, personal communication, September 2006). Methods to adjust incidence rates for reporting delay were not applied to the data in this report.⁵⁹

Each year, not only do state cancer registries submit data for a new diagnosis year to CDC or

NCI, but they also submit an updated version of previous years' data. Federal agencies in turn update their cancer incidence statistics with each data submission and document the states' data submission date whenever the data are published. These continual updates by state and federal agencies illustrate the dynamic nature of cancer surveillance and the attention to detail that is characteristic of cancer registries. Each year when *USCS* is published, we publish updates to previous years' data at <http://www.cdc.gov/uscs> (see "*United States Cancer Statistics on the Web*"). Users of cancer incidence data published by federal agencies should be mindful of the data submission date for all data used in their comparisons. See "*United States Cancer Statistics on the Web*" for more information.

Geographic variation in cancer incidence rates may be the result of regional differences in the exposure of the population to known or unknown risk factors.⁶⁰⁻⁶³ Differences may arise because of differences in sociodemographic population characteristics (e.g., age, race and ethnicity, geographic region, urban or rural residence), screening use, health-related behaviors (e.g., behaviors related to tobacco use, diet, physical activity), exposure to cancer-causing agents, or registry operations factors (e.g., completeness, timeliness, specificity in coding cancer sites). Cancer researchers are investigating variability associated with known factors that 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.

Mortality Data

The cancer mortality statistics in this report 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.⁶⁴ Autopsy studies of mortality data coded according to the eighth or ninth revision of ICD (ICD-8A or ICD-9) indicate that, when neoplasms (i.e., cancers) are an underlying cause of death, the sensitivity of death certificates was 87%–93%, and their predictive value positive was 85%–96%.⁶⁴⁻⁶⁶

However, these studies are limited by selection bias, and currently less than 10% of deaths in the United States are autopsied.⁶⁷ 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 underlying cause of death can be determined from the death certificate. Available studies show that 78%–85% of malignant neoplasms coded as an underlying cause of death on death certificates agreed with the clinical cancer diagnosis in medical records under ICD-8A or ICD-9,⁶⁸⁻⁷⁰ with a range of 69% for larynx cancer to 98% for prostate cancer under ICD-9. These results underscore the need to further monitor the accuracy of cancer mortality data overall and by anatomic site.

Some cancer patients may die with cancer (rather than die of it) as an underlying cause of death. Comparing the original cancer diagnosis in the medical record with those cancers later coded as an underlying cause of death on death certificates is a way of measuring if a person died with cancer rather than of it. Findings from an 11-year study under ICD-9 showed that about 83% of malignant neoplasms recorded on the medical record in ICD for oncology were also coded as an underlying cause of death from death certificates;⁷⁰ this percentage ranged from 72% for larynx cancer to 97% for myeloma. This SEER study suggests that misattribution bias (i.e., the mistaken assignment of cancer as the underlying cause of death because the decedent received a diagnosis of cancer) affects how cancer is recorded on death certificates.⁷¹

In collaboration with the Social Security Administration and the National Association for Public Health Statistics and Information Systems, NCHS is developing a Model Vital Event Re-Engineered System to improve the accuracy and timeliness of vital statistics disseminated through NVSS. Under the system, standard certificates for births and deaths will be revised, and state data systems will be re-engineered to better accommodate revisions, special studies or projects, and linkage with other health promotion programs. With regard to mortality statistics, handbooks have been revised for professionals who complete death certificates.⁷² (Also see “Data Sources, Mortality Data”).

Race and Ethnicity in Cancer Data

The NAACCR Race and Ethnicity Identifier Assessment Project confirmed the importance of publishing cancer rates by race and ethnicity.⁷³ In cancer incidence, race and ethnicity information is abstracted from medical records and then grouped into race and ethnicity categories.²⁰ Although state registries across the country use standardized data items and codes for both race and ethnicity (i.e., Hispanic origin), 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.⁷³ Thus, some inconsistency is expected in this information.

In cancer mortality, race and Hispanic origin are reported 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.³⁹ Inconsistencies in the collection and coding of data on race and Hispanic origin and their effect on mortality statistics have been described previously.⁷⁴ The net effect of misclassification is an underestimation of deaths and death rates for races other than white or black. In addition, under-coverage of minority populations in the census and resultant population estimates introduce biases into death rates by race.⁷⁴⁻⁷⁶ For the white population, published death rates are overstated by an estimated 1% and for the black population by 5%, resulting principally from undercounts of these populations in the census.

In this report, cancer incidence and mortality data are presented for all races combined and by race (whites, blacks, Asians/Pacific Islanders, and American Indians/Alaska Natives) and ethnicity (Hispanics). Data for Asians/Pacific Islanders and American Indians/Alaska Natives are presented only for the nation and for states with a population of at least 50,000 per sex because of concerns regarding the relatively small sizes of these populations in some states (see Figures 3.1.M1–3.58.F2). Race-specific incidence counts and rates are based on Race1 (NAACCR data element 160),²⁰ Race2 (NAACCR data element 161),²⁰ and IHS Link (NAACCR data element 192).²⁰ If Race1 is white and Race2 is a specified race other than white, then the value from Race2 is used. After

this check, if race is still white, unknown, or other non-specified race and there is a positive IHS Link, then the race is set to American Indian/Alaska Native.

Asians/Pacific Islanders

Data for Asians/Pacific Islanders were included for the first time in *United States Cancer Statistics: 2000 Incidence*.⁷⁷ The Asian/Pacific Islander population in the United States is approximately 12.4 million or 4.3% of the 2003 U.S. population, substantially smaller than the white or black populations.⁷⁸ The Asian/Pacific Islander population is concentrated in several states: California, Hawaii, Illinois, New Jersey, New York, Texas, and Washington.^{79,80}

Grouping Asians and Pacific Islanders into one racial population can mask differences in subpopulations. The U.S. Asian/Pacific Islander population is not a homogeneous group. Rather, it comprises many subpopulations that differ in language, culture, and length of residence in the United States.^{78,81} The three largest Asian subpopulations in the United States are Chinese, Filipino, and Asian Indian.⁸⁰ Although state cancer registries have designated codes for race that allow them to document the occurrence of cancer in 23 different Asian/Pacific Islander subpopulations,²⁰ the subpopulations are grouped into a single Asian/Pacific Islander race group in this report because of small numbers and concerns regarding the possible misclassification of race for Asian/Pacific Islander subpopulations.

Studies show that a person self-reported as Asian/Pacific Islander in a census or survey was sometimes reported as white on the death certificate.^{82,83} Death rates are understated for Asians/Pacific Islanders by approximately 11%.⁷⁴ Studies are under way to examine the misclassification of race for Asian/Pacific Islander subpopulations and the underreporting of Asian/Pacific Islander race in cancer incidence data (Dr. Holly L. Howe, NAACCR, personal communication, August 2005).

Hispanics

Data for Hispanics were included for the first time in *United States Cancer Statistics: 2001 Incidence and*

Mortality.²³ The Office of Management and Budget defines Hispanics (or Latinos) as persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.⁸⁴ Hispanics have one of the highest growth rates among minority groups in the United States with approximately 39.9 million in the 2003 U.S. population, similar in size to the U.S. black population.^{78,85,86} The three largest Hispanic subpopulations living in the United States are Mexicans, Puerto Ricans, and Cubans. States with 1 million or more Hispanics include Arizona, California, Florida, Illinois, New Jersey, New York, and Texas.⁸⁵

NAACCR convened an expert panel to develop a best practices approach to improving Hispanic identification and is addressing Hispanic origin misclassification in central cancer registries. All NPCR and some SEER registries assigned Hispanic ethnicity through the standardized use of the NAACCR Hispanic Identification Algorithm (NHIA).⁸⁷ NHIA uses a combination of NAACCR variables to directly or indirectly classify cancer cases as Hispanic for analytic purposes. Cases reported as having Spanish/Hispanic origin (as indicated by NAACCR data element 190 with values 1–6)²⁰ are directly identified as Hispanic in the dataset. Cases reported as non-Spanish/non-Hispanic, Spanish surname only, or unknown whether Spanish (NAACCR data element 190 with a value of 0, 7, or 9)²⁰ are evaluated for possible Hispanic ethnicity through indirect identification. The ultimate goal of the algorithm is to classify these cases as Hispanic or non-Hispanic on the basis of an evaluation of the strength of the birthplace, race, and/or surname associations with Hispanic ethnicity. After applying NHIA, cases not classified as Hispanic are classified as non-Hispanic, leaving no cases with unknown Hispanic status. More detailed information on the algorithm is available at <http://www.naacr.org>.⁸⁸

In this report, NHIA-classified case counts and incidence rates for Hispanics are presented for 35 NPCR, 3 NPCR/SEER, and 9 SEER registries. The following NPCR registries have opted not to present state-specific, NHIA-classified Hispanic counts and rates: Florida, Illinois, Kentucky, Pennsylvania, South Carolina, and Wisconsin (male colorectal cancer rates only). The counts

and rates for Hawaii and metropolitan Seattle-Puget Sound are not presented since NHIA was not completed by these registries. Some registries may have a small percentage of Hispanics in their states. Quality reviews of NHIA and the data elements that make up NHIA, including but not limited to Hispanic ethnicity, race, birthplace, surname, and maiden name for women, have been conducted.⁸⁹ National rates include data from registries that opted not to present state-specific, NHIA-classified Hispanic counts and incidence rates. Preliminary data analyses showed that exclusion of these registry data did not appreciably change the overall incidence rates.

Death counts and rates for Hispanics 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.

The National Longitudinal Mortality Study examined the reliability of Hispanic origin and reported a 89.7% record-by-record agreement and a net underreporting of Hispanic origin on death certificates by 7% compared with self-reports on the surveys.⁷⁴ Death rates for the Hispanic-origin population are also affected by under-coverage of this population group in the census and the resultant population estimates; the estimated net correction, taking into account both sources of bias, is 1.6%.⁷⁶

American Indians/Alaska Natives

Data for American Indians/Alaska Natives were included for the first time in *United States Cancer Statistics: 2002 Incidence and Mortality*.²⁴ More than 560 American Indian tribes are recognized by individual states and the federal government.^{90,91} The American Indian/Alaska Native population in the United States is approximately 2.8 million or 1.0% of the 2003 U.S. population, substantially smaller than the white or black populations and smaller than the Asian/Pacific Islander population.⁷⁸ The American Indian/Alaska Native population is concentrated in several states: Alaska, Arizona, California, New Mexico, New York, North Carolina, Oklahoma, Texas, and Washington.⁷⁸

Previous studies have found racial misclassification to contribute to lower death rates and lower cancer incidence rates among the American Indian/Alaska Native population. Based on a comparison of race reported on death certificates during 1979–1989 with nine Current Population Survey files for the years 1973–1985 from the National Longitudinal Mortality Study conducted by the U.S. Bureau of the Census, record-by-record agreement was only 57% for American Indians.⁷⁴ When the net agreement of counts by race was examined between the two sources, almost 40% more persons were reported as American Indian/Alaska Native in the Current Population Survey files than on the death certificates.⁷⁴ For cancer incidence rates among this population, the range of underestimation is similar. Studies that estimate misclassification among American Indians/Alaska Natives using cancer registry data report these rates are underreported by 40%–57%, depending on the region of the country.^{91–93}

Studies measuring racial misclassification with cancer registry data have linked cases with Indian Health Service (IHS) administrative records.^{91–93} IHS provides medical services to American Indians/Alaska Natives who are members of federally recognized tribes, estimated to be approximately 55% of the American Indian/Alaska Native population (Dr. David Espey, IHS, personal communication, July 2005). IHS coverage of these populations varies by region, does not include American Indians/Alaska Natives who are members of non-federally recognized tribes, and underrepresents those who live in certain urban areas. However, American Indians/Alaska Natives who live outside of service counties may continue to receive IHS services or may have received services before moving. To address American Indian/Alaska Native misclassification in cancer registry data, in 2004, all NPCR and 15 SEER registries linked to the IHS administrative records database for cases diagnosed during 1995–2002 and 1988–2002, respectively. Results of the linkage were captured in a new data element, IHS Link (NAACCR data element 192),²⁰ that was sent back to state cancer registries. The results of this linkage led to the decision that NPCR registries will continue to link with IHS annually if they contribute 90% of all new American Indian/Alaska Native cases. Also, state registries

with more than 0.8% of the total cases will continue to link with IHS annually. The remainder of NPCR registries will link every 5 years, or sooner if required. Therefore, in 2005, 24 NPCR registries (22 NPCR-only supported, including the SEER metropolitan registries in WA and MI, plus 2 NPCR/SEER-supported [CA, NJ] registries) linked with IHS. SEER registries provide complete coverage for special populations whose data are reported to their respective state registries: Alaska Natives, 16% and Arizona Indians, 5%. In 2005, the SEER registries did not link with IHS.

California opted not to present state-specific American Indian/Alaska Native case counts, incidence rates, death counts, and death rates.

National death counts and rates consist of data obtained from all 50 states and the District of Columbia. American Indian/Alaska Native race for these data is obtained from information on the death certificate.

United States Cancer Statistics on the Web

The USCS Web site (<http://www.cdc.gov/uscs>) is a comprehensive source of 2003 incidence and mortality data. All the tables and figures in this report are available on the site.

In addition to the data published in this report, the following data presentation for all years (1999, 2000, 2001, 2002, 2003, and 2001–2003) are only available on the Web:

- Cancer incidence and death rates for 2001–2003.

Combining years of data adds stability to the rates and allows for less suppression of smaller cancer sites or smaller race populations. The population coverage for incidence data for these combined years is 90% of the U.S. population. The methods for calculating rates and their confidence intervals, as well as the suppression of data at the state, regional, division, and national levels, are the same for single year and combined years of data. See “Statistical Methods” for more information

- Childhood cancer incidence rates according to the third edition of the *International Classification of Childhood Cancer* (ICCC-3).

ICCC-3 was published in 2005⁹⁴ and categorized according to the SEER recodes (<http://seer.cancer.gov/iccc/seericcc.html>). According to ICC-3, childhood cancers are categorized into 12 main groups classified primarily by morphology. A new grouping was created in ICC-3 for refractory anemia, myelodysplastic syndrome, and other myeloproliferative diseases, in order to be consistent with changes in ICD-O-3. These cancers represent 3%–9% of the hematologic malignancies in children.

- Childhood cancer incidence and death rates by the SEER site recodes.

The incidence data are presented in this format to make them comparable with other published mortality data. This format allows the incidence data for childhood cancers to be categorized into 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.

- Detailed malignant brain and central nervous system cancer incidence data.

The Benign Brain Tumor Cancer Registries Amendment Act changed NPCR’s definition of reportable tumors to include benign central nervous system (CNS) tumors. Subsequently, in addition to NPCR, both SEER and the Commission on Cancer (CoC) agreed to require reporting of nonmalignant brain tumors, beginning with cases diagnosed on or after January 1, 2004. A table of CNS tumors categorized by histology groupings is presented and includes malignant incident cases only. These groupings were agreed upon by a consensus conference at the Society for Neuro-Oncology annual meeting in 2000.⁹⁵ In 2007, cases for nonmalignant brain tumors will be added, and an increase in rates will be seen in the following histology groups and subgroups: (groups) tumors

of the cranial and spinal nerves; tumors of the sellar region and (subgroups) unique astrocytoma variants and for neuronal/glial, neuronal; meningioma; and hemangioma.

- Crude incidence and death rates for Tables 1 and 2.
- Age-specific incidence and death rates for 27 cancer sites that are listed in the “Cancer Incidence and Mortality by U.S. Census Region and Division, State, and Metropolitan-area” section.
- New case (incident) and death counts.
- Population data.
- Cancer incidence and death rates for men and women combined.
- State rankings of incidence and mortality for selected major cancers.
- State versus national comparisons of incidence and death rates for the most common cancers.

Previously published data based on 1999–2002 cancer cases as reported to CDC as of January 31, 2006, and as reported to NCI as of November 1, 2005, and made available through the SEER Program public use file (see “Interpreting the Data: Incidence Data”) have been updated. All updated data are coded and classified according to current standards (i.e., ICD-O-3 and 2000 U.S. standard population) in order to be comparable across diagnosis years. The population coverage for incidence rates is as follows:

- 1999 incidence: 90% of the U.S. population
- 2000 incidence: 91% of the U.S. population
- 2001 incidence: 92% of the U.S. population
- 2002 incidence: 92% of the U.S. population

All data presented on the Web version can be downloaded for use in other applications. A portable document file (PDF) that mirrors this report is also available for download.

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Criteria for Reporting Age-Adjusted Cancer Incidence Rates for U.S. Census Regions and Divisions

The annual age-adjusted cancer incidence rates for some U.S. Census regions and divisions are not available because the data from the cancer registries of some states in those regions or divisions do not meet the eligibility criteria for inclusion in this report. In contrast, the annual age-adjusted cancer death rates are available for all states in every Census region or division. However, the age-adjusted incidence rate for Census regions or divisions in which the data of less than 100% of the cancer registries meet eligibility criteria can be estimated by assuming the following: the incidence-to-mortality ratio for states *without* eligible cancer registry data in that Census region or division equals the incidence-to-mortality ratio for states *with* eligible cancer registry data in that Census region or division.

Let

M_1 = age-adjusted death rate in states with eligible cancer registries

M_0 = age-adjusted death rate in states without eligible cancer registries

I_1 = age-adjusted incidence rate in states with eligible cancer registries

I_0 = age-adjusted incidence rate in states without eligible cancer registries (incidence data are not available)

P_1 = proportion of the population in the Census region or division that resides in states with eligible cancer registries

$$R = \frac{M_0}{M_1}$$

\hat{I}_{total} = age-adjusted incidence rate for the entire Census region or division where “eligible” refers to the state and metropolitan-area cancer registries that meet this report’s data quality criteria for all invasive cancer sites combined.

Since we are assuming that

$$\frac{I_1}{M_1} = \frac{I_0}{M_0},$$

the estimate of the age-adjusted incidence rate for states without eligible cancer registries is

$$I_0 = I_1 \left(\frac{M_0}{M_1} \right) = I_1 R.$$

Thus, an estimate of the age-adjusted incidence rate for 100% of the Census region or division is computed as the following weighted average:

$$\begin{aligned} \hat{I}_{total} &= P_1 I_1 + (1 - P_1) I_0 = P_1 I_1 + (1 - P_1) I_1 R \\ &= I_1 [P_1 + (1 - P_1) R]. \end{aligned}$$

As an example, consider invasive female breast cancer in a hypothetical Census region with seven states. Incidence data for five states that cover 86.3% of the population ($P_1 = 0.863$) are eligible for inclusion in the calculation of the regional incidence rate; data for two states are not eligible. The female breast cancer death rate for the five eligible states is

$$M_1 = \frac{27.3}{10^5},$$

and the rate for the two ineligible states is

$$M_0 = \frac{27.7}{10^5}.$$

The age-adjusted incidence rate for states with eligible cancer registries is

$$I_1 = \frac{145.1}{10^5}.$$

The age-adjusted incidence rate for female invasive breast cancer in the entire Census region (i.e., corrected for the data not available from the ineligible registries) is

$$\hat{I}_{total} = \frac{145.1}{10^5} * [0.863 + 0.137 \left(\frac{27.7}{27.3} \right)] = \frac{145.39}{10^5}.$$

The underlying assumptions for this method are that the age-adjusted death rates for states with and without eligible cancer registries are accurate and that the incidence-to-mortality ratio for states without eligible cancer registries in that Census region or division equals the incidence-to-mortality ratio for states with eligible cancer registries in that Census region or division.

For each Census region or division in which less than 100% of the registries provided data eligible for this report, we used the above-described method to estimate the age-adjusted incidence rates (\hat{I}_{total}) for the six major cancer sex-site groups: breast (female only), prostate, male and female colorectal, and male and female lung and bronchus. If the estimate of the age-adjusted incidence

rate for each of the six cancer sites for that Census region or division falls within the confidence interval of the observed age-adjusted incidence rate for states with eligible cancer registries, then the observed age-adjusted incidence rates for *all* cancer sites are published. If one or more of the six estimates of age-adjusted incidence rates falls outside the confidence interval, then the observed age-adjusted cancer incidence rates are not reported for that U.S. Census region or division.

We emphasize, however, that all cancer incidence rates in this report (1) are based exclusively on data obtained from states with eligible cancer registries and (2) are not the estimates of the age-adjusted incidence rates calculated using the methods described in this appendix.