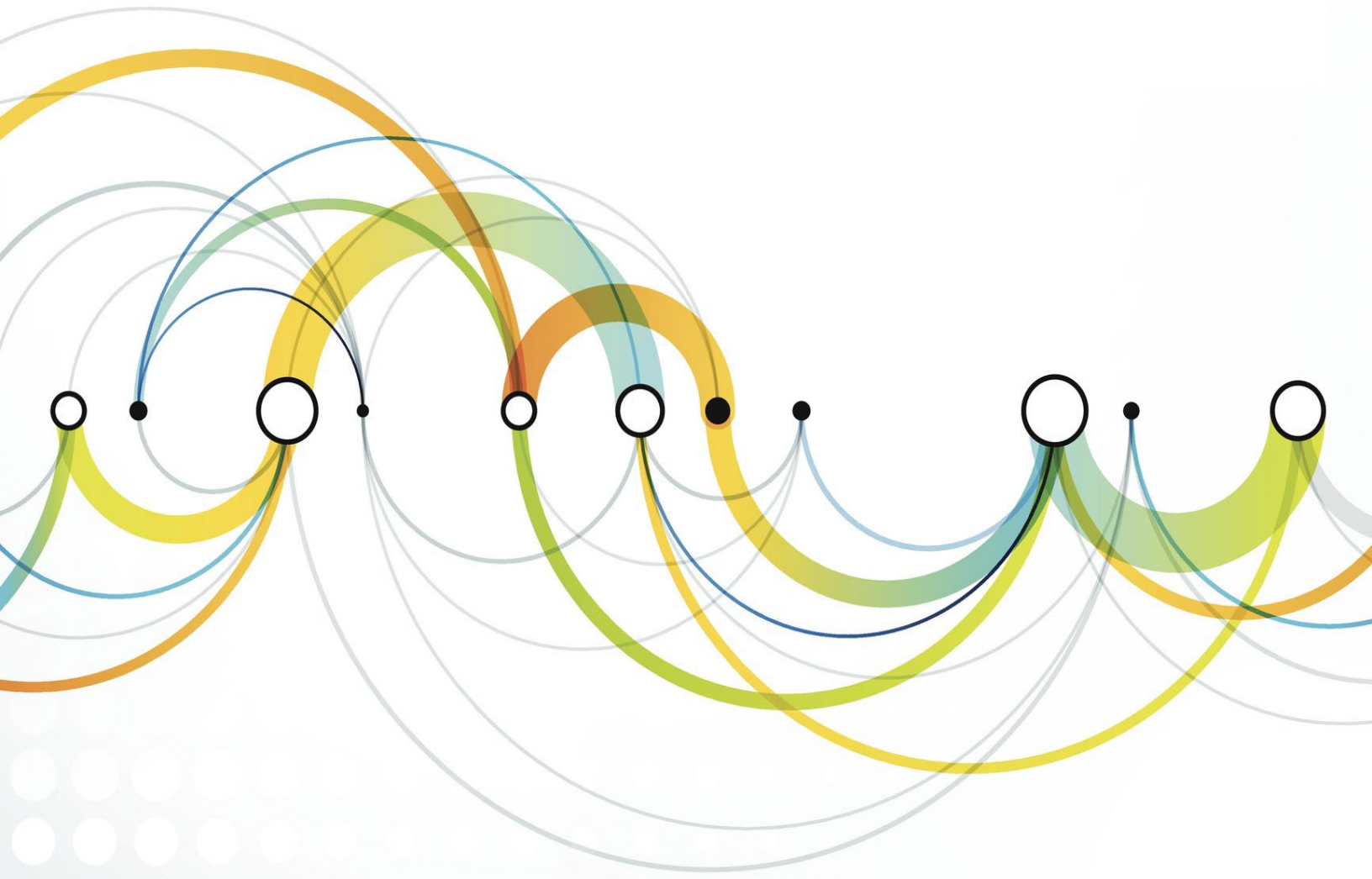
U.S. Cancer Statistics Public Use Database Technical Documentation

U.S. and Puerto Rico Data
November, 2019 Submission
Diagnosis Years 2005–2017



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

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U.S. Cancer Statistics Public Use Databases

Researchers can access and analyze high-quality population-based cancer incidence data on the *entire* United States population.

De-identified cancer incidence data reported to CDC's National Program of Cancer Registries (NPCR) and the National Cancer Institute's (NCI's) Surveillance, Epidemiology, and End Results (SEER) Program are available to researchers for free in public use databases that can be analyzed using software developed by NCI's SEER Program.

Cancer surveillance data from CDC and NCI are combined to become U.S. Cancer Statistics, the official source for federal cancer data. U.S. Cancer Statistics public use databases include cancer incidence and population data for all 50 states, the District of Columbia, and Puerto Rico, providing information on more than 28 million cancer cases.

Documentation for U.S. and Puerto Rico Data (2005–2017)

U.S. Cancer Statistics Public Use Database

Two United States Cancer Statistics public use databases are available for researchers: the U.S. and Puerto Rico (2005–2017) database, described in this section, and the U.S. (2001–2017) database.

The U.S. and Puerto Rico (2005–2017) database—

- Does not include race and ethnicity variables.
- Includes Puerto Rico data.
- The population denominators are sex-specific, are from the 2010 U.S. Census, and are not available by race or ethnicity.

Population Coverage by Diagnosis Year

For cases diagnosed from 2005 through 2017, 100% of the population is covered for all 50 states, the District of Columbia, and Puerto Rico.

Puerto Rico's 2017 incidence counts are restricted to the first six months of reported data (January to June 2017). Data from July to December 2017 are excluded to account for the population shift that occurred due to Hurricane Maria. The population denominators were adjusted by dividing the U.S. Bureau of the Census's July 1, 2017 (vintage 2018) Puerto Rico population estimate in half.

Suggested Citations

Please use these standard citations for tables and figures when presented in presentations or publications.

For population coverage: Data are from population-based registries that participate in CDC's National Program of Cancer Registries and/or NCI's Surveillance, Epidemiology, and End Results Program and meet high-quality data criteria. These registries cover approximately [XX]% of the U.S. population.

For age-adjusted rates: Rates are per 100,000 persons and are age-adjusted to the 2000 U.S. standard population (19 age groups – Census P25–1130).

For the database: National Program of Cancer Registries and Surveillance, Epidemiology, and End Results SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer Statistics 2005–2017 Public Use Research Database, 2019 submission (2005–2017), United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2020. Accessed at www.cdc.gov/cancer/uscs/public-use.

Cautionary Notes for U.S. and Puerto Rico Data

U.S. Cancer Statistics Public Use Database

Before using the U.S. and Puerto Rico (2005–2017) data, analysts should read and understand the following information. If you have questions, please contact CDC at uscsdata@cdc.gov.

Case Inclusions and Exclusions

NPCR- and SEER-supported cancer registries report all incident cases coded as *in situ* (non-malignant), invasive (malignant; primary site only), and non-malignant (including borderline and benign) central nervous system tumors according to the *International Classification of Diseases for Oncology, Third Edition* (ICD-O-3), with the following exceptions—

- *In situ* cancers of the cervix are not reported.
- Basal and squamous cell carcinomas of the skin are not reported, except when these occur on the skin of the genital organs.
- *In situ* cancers of the urinary bladder are re-coded as invasive behavior because the information needed to distinguish between *in situ* and invasive bladder cancers is not always available or reliable. Stage for these cases remains coded as *in situ.*[1]

Additionally, in these public use databases—

- Cancer cases that were identified only through death certificate or autopsy reports have been excluded.
- Cases with an unknown age or with sex other than male or female have been excluded from the database. The frequency counts will not change based on whether *Known Age* or *Male or Female Sex* is checked on the SEER*Stat Selection tab.
- *Malignant Behavior* is a default selection for this database, as this restriction is used by CDC's NPCR and NCI's SEER Program for generating most official cancer statistics. Malignant behavior is defined by the variable *Behavior Code ICD-O-3*. This database includes *in situ* and nonmalignant central nervous system (CNS) cases. These nonmalignant cases can be analyzed by unselecting the *Malignant Behavior* check box on the SEER*Stat Selection tab.

Suppression Rules[2] [3]

Suppressing Fewer Than 16 Cases

The suppression rule is fewer than 16 cases for the time period based on rate stability. This suppression rule is enforced automatically in these databases.

When the number of cases used to compute the incidence rates are small, those rates tend to have poor reliability. Therefore, to discourage misinterpretation and misuse of counts, rates, and trends that are unstable because of the small number of cases, these statistics are not shown in tables and figures if the counts are fewer than 16 for the time period. A count of fewer than about 16 in a numerator results in a standard error of the rate that is about 25% or more as large as the rate itself. Equivalently, a count of fewer than about 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 close to the observed population age distribution.

Another important reason for employing 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. The cell suppression threshold value of 16 is recommended to protect patient confidentiality given the low level of geographic and clinical detail provided.

Complementary Cell Suppression

Complementary cell suppression is necessary to prevent users from subtracting to find suppressed counts. This practice should be employed when any suppression occurs in the data presentation. In addition, when information from other cells, tables, or figures can be used to determine a suppressed cell, at least one other cell must also be suppressed. When analyzing data at the state or regional levels, counts for national and regional data must be suppressed if a single state in a region or division is suppressed. Rates, confidence intervals (CIs), and populations can be shown at the national and regional levels. Rates, confidence intervals (CIs), and populations can be shown at the national and regional levels. This suppression should occur when a single or multiple years of data are being presented.

Case-Level Data

As a further mechanism to protect data confidentiality and due to data sharing agreements with some states, the case listing function in SEER*Stat has been disabled for these databases.

Benign Central Nervous System (CNS) Tumors

Cancer registries began collecting information on nonmalignant brain and other central nervous system tumors with cases diagnosed in 2004. 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 other central nervous system tumors with a behavior code of 0 (benign) or 1 (borderline), in addition to *in situ* and malignant tumors. Data for nonmalignant brain and other nervous system tumors were available from all registries contributing to this report.

Primary Site Variables[4–8]

Beginning in diagnosis year 2010, some of the lymphoma and leukemia ICD-O-3 codes were updated based on changes from the World Health Organization. The appropriate site recode variables to include these updates are *Site recode ICD-O-3/WHO 2008* for all ages and *International Classification of Childhood Cancer (ICCC) site recode ICD-O-3/WHO 2008* and *ICCC site rec extended ICD-O-3/WHO 2008* for the childhood cancer recodes.

Consider reviewing the variable *Site recode ICD-O-3/WHO 2008* before using the directly coded primary site. See more information on the SEER primary site recodes.

Stage

A merged variable, *Merged Summary Stage,* has been created to span three time periods when two different staging schemes were used. The coding logic for this merged variable is—

- For NPCR-registries—
  - If a case was diagnosed between 2005 and 2015, stage at diagnosis is recorded using the *Derived SEER Summary Stage 2000* variable value.
  - If a case was diagnosed in 2016 or 2017, stage at diagnosis is recorded using the *SEER Summary Stage 2000* variable value.
- For SEER-only registries (Connecticut, Hawaii, Iowa, and New Mexico)—
  - If a case was diagnosed between 2005 and 2015, stage at diagnosis is recorded using the *Derived SEER Summary Stage 2000* variable value.
  - If a case was diagnosed in 2016 and 2017, the best available data from either *Derived SEER Summary Stage 2000* or *SEER Summary Stage 2000* is used.

Reporting Delay[9]

NPCR and SEER registries annually submit all eligible years of data to CDC and NCI, respectively. As a result, cases submitted in previous years may be deleted, and new cases diagnosed in previous years may be added. The addition of new cases is called a *reporting delay.* This reporting delay may cause an appearance of

decreasing trends. For example, reporting of melanoma cases diagnosed in an outpatient facility may be delayed. As a result, the trend in incident melanoma cases might superficially appear to have dropped in the most recent year.

References

[1]Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA (eds). *SEER Summary Staging Manual – 2000: Codes and Coding Instructions.* National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001.

[2]Federal Committee on Statistical Methodology. *Report on Statistical Disclosure Limitations Methodology (Statistical Working Paper 22).pdf* Washington, DC: Office of Management and Budget; 2005.

[3]Doyle P, Lane JI, Theeuwes JM, Zayatz LM. *Confidentiality, Disclosure, and Data Access: Theory and Practical Applications for Statistical Agencies.* Amsterdam: Elsevier Science; 2001.

[4]Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin D, et al., editors. *International Classification of Diseases for Oncology, Third Edition.* Geneva: World Health Organization; 2000.

[5]*International Classification of Diseases for Oncology, Third Edition, First Revision.* Geneva: World Health Organization, 2013.

[6]Ruhl J, Adamo M, Dickie L. (January 2015). *Hematopoietic and Lymphoid Neoplasm Coding Manual.pdf* National Cancer Institute, Bethesda, MD.

[7]Surveillance, Epidemiology, and End Results Program. *2007 Multiple Primary and Histology Coding Rules.* Bethesda, MD: US Department of Health and Human Services, National Cancer Institute; Revised August 24, 2012; Accessed January 25, 2017.

[8]Surveillance, Epidemiology, and End Results Program. Hematopoietic and Lymphoid Neoplasm Database. Bethesda, MD: US Department of Health and Human Services, National Cancer Institute; 2016.

[9]Clegg LX, Feuer EJ, Midthune DN, Fay MP, Hankey BF. Impact of reporting delay and reporting error on cancer incidence rates and trends. *Journal of the National Cancer Institute* 2002;94(20):1537–1545.

U.S. and Puerto Rico Data (2005–2017) Analyses Checklist

U.S. Cancer Statistics Public Use Database

- If a user-defined **primary site variable** was created (rather than using the *Site recode ICD-O-3/WHO 2008* variable)—
  - Did you exclude leukemias and lymphomas (9590–9992)?
  - Did you consider excluding Kaposi sarcoma (9140) and mesothelioma (9050–9055)?

  For more information, see Primary Site Variables.
- If your analysis includes **histology,** and if appropriate for the cancer site, did you use the *Diagnostic Confirmation* variable to specify the analysis be limited to *Microscopically confirmed* cases?
- If you are analyzing **sex-specific cancers** (such as prostate cancer or female breast cancer), did you limit the analysis to the appropriate sex to get the correct population denominator?
- When reporting **rates,** have you included the label “per 100,000 persons,” “per 100,000 women,” or “per 100,000 men”?
- Have you included **citations** for the—
  - Percentage of United States population coverage provided by the database?
  - NPCR and SEER Incidence – U.S. Cancer Statistics 2005–2017 Public Use Research Database?

U.S. and Puerto Rico Data Variables

U.S. Cancer Statistics Public Use Database

The following variables are available in the U.S. Cancer Statistics Public Use Database, U.S. and Puerto Rico data (2005–2017). They are listed by SEER*Stat category. Click on the variable name for more information, including the source, description, and considerations for use.

Age at Diagnosis

- Age recode with <1 year olds

Race, Sex, Year of Diagnosis, Registry, County

- Sex
- Year of diagnosis
- Address at diagnosis – state
- Program

Site and Morphology

- Primary site – labeled
- Histologic type ICD-O-3 (International Classification of Diseases for Oncology, Third Edition)
- Behavior code ICD-O-3
- Grade
- Diagnostic confirmation
- ICD-O-3 histology/behavior, labeled
- Site recode ICD-O-3/Word Health Organization (WHO) 2008
- International Classification of Childhood Cancer (ICCC) site recode ICD-O-3/WHO 2008
- ICCC site recode extended ICD-O-3/WHO 2008
- Adolescent and young adult (AYA) site recode/WHO 2008
- Lymphoma subtype recode/WHO 2008

Stage – Local, Regional, Distant (LRD) [Summary and Historic]

- Merged summary stage

Therapy

- RX summary – surgery primary site
  Restricted to female breast only and diagnosis years ≥2003

Extent of Disease – Collaborative Stage (CS)

- CS site-specific factor 1
  Restricted to two groups—
  - Female breast (Estrogen Receptor Assay)
  - Brain and other nervous system and diagnosis years ≥2011 (WHO Grade Classification)
- CS site-specific factor 2 (Progesterone Receptor Assay)
  Restricted to female breast only

- CS site-specific factor 15 (HER-2 Summary Results)
  Restricted to female breast only and diagnosis years ≥2010
- Laterality

Multiple Primary Fields

- Sequence number – central

Dates

- Year of birth
- Month of diagnosis

Other

- Type of reporting source

Merged System-Supplied

- Alcohol-related cancers
- Human papillomavirus (HPV)-related cancers
- Obesity-related cancers
- Physical inactivity-related cancers
- Tobacco-related cancers