INCIDENCE DATA TECHNICAL NOTES

DATA USE AGREEMENT

By using these data, you signify your agreement to comply with the Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/12). Data collected by the Illinois State Cancer Registry (ISCR) are made available to the public; however, identifying or contacting individuals is prohibited.

To exclude identifying information on individual patients, these data (e.g., age, race, Hispanic ethnicity, year of diagnosis, and type of cancer) have been aggregated into categories within individual records, the number of which depends on the size of the geographic area.

IDPH provides these data to the public solely for statistical reporting and analysis. Users must not attempt to identify any individual represented in the data. If an identity is discovered inadvertently, the user must not disclose or use that information in any way. IDPH does not endorse any interpretations, opinions, or conclusion drawn from these data, and none should be inferred.

DATA SOURCES

Cancer Incidence Data: The Illinois State Cancer Registry (ISCR) within the Illinois Department of Public Health (IDPH), routinely collects all cancer data used in this report. ISCR is the state's only population-based source of cancer incidence data. State law requires hospitals, free-standing clinics, radiation treatment facilities, laboratories, and physician offices to report every newly diagnosed cancer case among Illinois residents to ISCR. In addition, ISCR has agreements with other central registries to exchange Illinois cancer cases identified outside of the state. These registries include Arkansas, California, Florida, Indiana, Iowa, Kentucky, Michigan, Mississippi (through August 2004), Missouri, North Carolina, Washington, Wisconsin, Wyoming (through February 2008), and the Mayo Clinic in Minnesota (through October 2005).

Completeness of out-of-state reporting depends upon the years of operation of these other central registries, the extent of their identification of out-of-state residents, and their quality standards.[1] For data used in this publication, approximately 6% of ISCR cases were reported from out-of-state central registries.

A death certificate clearance process has been employed since August 1993. The process involves follow back of cancer deaths to identify the cases not reported to ISCR. Between 2019 and 2023, 1% of reported cases were identified from death certificate clearance.

The preparation and release of data used for this report depends on the completion of annual reporting by Illinois facilities. Although case reporting is mandated within six months of diagnosis, the ISCR policy has been to keep database files open for late reporting of cases and to allow for the two- to four-year lag in case identification of Illinois residents from other state central cancer registries. This practice is consistent with data published nationally. For this report, the database files reflect the status of ISCR as of November 2025.

Population Estimates: The population estimates of the sex- and race-specific, as well as sex- and ethnicity/race-specific groups in five-year age categories, were used as denominators in the formulation of rates. These population estimates for Illinois cover all races categorized as Whites, Blacks, and Asian and all other races from 1986 through 2023. They also include estimates for Hispanics, non-Hispanics, non-Hispanic White, and non-Hispanic Black from 1990 through 2023. The estimates were

obtained from both the intercensal files and the Vintage[a] 2020 bridged-race postcensal population estimate files. Woods & Poole Economics, Inc. calculated the Vintage 2024 population estimates for the National Cancer Institute (NCI). The estimates include intercensal data for 2000-2009 from the U.S. Census Bureau and for 2010-2019 from Woods & Poole. The Vintage 2024 estimates for 2020-2023 use bridged-race estimates derived from the multiple-race categories in the 2000, 2010, and 2020 censuses and based on the 1997 Office of Management and Budget standards for race and ethnicity data collection. The bridged single-race estimates, and a description of the methodology used to develop them are available on the National Center for Health Statistics website.[b]

Woods & Poole Economics used methods that are similar to the U.S. Census Bureau expected methods[c] for its population estimates between 2000–2010 and 2010–2020. Earlier estimates, created before the 2010 Census, became less accurate over time. At the national level, the updated estimates are very close to the older numbers. However, at the state and county levels, the differences are larger and may change some cancer incidence rates compared with earlier reports. Some changes may also come from cases that were reported late.

DEFINITIONS

Cancer Site Coding for Incidence Data: Although the anatomic site and morphology for cancer cases diagnosed before 2001 were coded using the *International Classification of Diseases for Oncology* version 2 (ICD-O-2)[2] and for cancer cases diagnosed in 2001 through 2009, version 3 (ICD-O-3),[3] all ICD-O-2 coded cases were converted to version 3 codes. The ISCR Web-based query data utilizes the ICD-O-3 recode with adjustment for WHO 2008 hematopoietic. SEER-NCI recommends using this site recode scheme (Site Recode ICD-O-3/WHO 2008) for any data containing cases diagnosed in 2010 or later years. In the interests of comparability to other national, state, and registry-specific data, subsequent versions of the Web-based query data containing cases diagnosed in 2010 or later will use the SEER Site Recode ICD-O-3/WHO 2008. For a complete listing, see Appendix B of the annual state report (see Illinois State Cancer Incidence Review and Update).

Data at the county level in this application are aggregated into 24 major site groups and at the ZIP code level into 11 site groups. These standardized classification schemes allow directly comparing Illinois data with international, national, and state publications.

Several definitional changes occurred in some histologies and behaviors in ICD-O-3 that affected the inclusion and exclusion of reportable cancers diagnosed beginning in 2001. These changes may affect the comparability of data between rates before 2001 and 2001 or later. The changes predominantly affected leukemias, lymphomas, and ovarian cancer. Several cancers that previously were not coded as malignant in ICD-O-2 are coded as malignant in ICD-O-3. For example, Myelodysplastic syndrome (MDS) and chronic myeloproliferative disease (CMPD) are considered malignant cancers in ICD-O-3, as are papillary ependymomas and papillary meningiomas, which, according to ICD-O-3, are included in the "Brain and Nervous System" and "All Cancers Combined" categories. Some endometrial tumors are also classified as malignant in ICD-O-3. Conversely, some low malignant potential tumors of the

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[a] "Vintage denotes an entire time series created with a consistent population starting point and methodology. The release of a new vintage of estimates supersedes any previous series and incorporates the most up-to-date input data and methodological improvements." (Methodology for the United State Population Estimates: Vintage 2023)

[b] http://www.cdc.gov/nchs/nvss/bridged_race.htm. For more information on the modifications to county population categorized for each decade, visit https://seer.cancer.gov/popdata/modifications.html.

[c] The U.S. Census Bureau's 2000-2010 and 2010-2020 intercensal estimates methodology are published at https://www2.census.gov/programs-surveys/popest/technical-documentation/methodology/intercensal/; U.S. County Population Data 1969-2023 - SEER Population Data

ovary and pilocytic astrocytoma are no longer coded as malignant in ICD-O-3. Because of how cancers are grouped in this report, these changes would have a slight or little impact on the incidence of a specific cancer site; however, it might result in a noticeable increase in cancer incidence rates for "All Cancers Combined."

In addition, both Kaposi sarcoma and mesothelioma are classified as separate site groups within the SEER recode. This change slightly impacts cancer incidence rates for a few specific cancers, compared to using the previous site grouping method.

Counts and rates were calculated for invasive cancers only, except *in situ* bladder cancer. Although counts and rates for breast cancer *in situ* are displayed in a separate table, these cases were not included in any counts or rates of all sites combined incidence.

Confidentiality of the incidence data is maintained by aggregating data within individual records into categories, the number of which depends on the size of the geographic area. Individual year of diagnosis is available for the Illinois data files, however, for the county, ZIP code, Cook County, and stage files, the diagnosis year is a five-year aggregate (1999-2003, 2004-2008, 2009-2013 [this and prior groups are not available for the Cook County file]), 2014-2018, and 2019-2023).

Incidence Rates: The SEER*Stat® software package,[4] developed by the Information Management Services Inc. for NCI, calculated incidence rates. Rates are expressed per 100,000 population. Age-adjustment of rates was calculated using the direct method, adjusting to the 2000 U.S. standard million population. Rates are rounded to the nearest $10^{th,}$ and very small rates (e.g., 0.04) are shown as 0.0. They are presented with the lower and upper confidence intervals computed at the 95% level using the Tiwari method.[5] Algorithms used for calculating standard errors and 95% confidence intervals are displayed in Appendix D of the state incidence report (see Illinois State Cancer Incidence Review and Update).

Percent Distribution by Stage at Diagnosis: The distribution of incident cancer within counties is expressed as percentage localized, regional, distant, and unstaged for cancers of the oral cavity and pharynx (both sexes), colon and rectum (both sexes), lung cancer (both sexes), melanoma and the skin (both sexes), invasive cervix, and prostate. Female breast cancer incidence data are displayed with in situ stage, in addition to localized, regional, distant, and unstaged stage categories. Data by race are available for 15 counties (Champaign, Cook, DuPage, Kane, Kankakee, Lake, Macon, Madison, Peoria, Rock Island, Sangamon, St. Clair, Vermilion, Will, and Winnebago) that have sufficiently large Black populations to allow meaningful statistics for racial subgroups.

Race-specific Rates: At the state level, the race-specific categories include "White," "Black," and "Asian/Other Races." The "Asian/Other Races" category includes Asian-Americans, Pacific Islanders, American Indians, Alaskan Natives, and all other races. Cases reported as of unknown race were included in the "All Races" category, but not in any race-specific group. At the county level, race-specific data are available for Whites and Blacks in 15 counties (Champaign, Cook, DuPage, Kane, Kankakee, Lake, Macon, Madison, Peoria, Rock Island, Sangamon, St. Clair, Vermilion, Will, and Winnebago). These same race groupings are available on the Cook County-specific file. No race-specific data are available at the ZIP code level.

To improve the identification and surveillance of American Indians and Alaska Natives diagnosed with cancer and to be consistent with the national data, cancer incidence data since 1995 were linked to the Indian Health Service (IHS), which provides medical services to an estimated 55% of the American Indian/Alaska Native population.[6] If a race code in the ISCR database is White, Black, other, or

unknown and the IHS link is positive, then the race code is re-categorized to American Indian/Alaskan Native; otherwise, the race code stays unchanged. This practice has minimal impact on the incidence rates for Whites or Blacks due to the small number of cases affected.

Ethnicity/Race Rates: For the incidence data at the state level, Hispanic ethnicity was derived according to the North American Association of Central Cancer Registries (NAACCR) Hispanic identification algorithm (NHIA).[7] NHIA is a generally reliable method to enhance the ethnic identification of the Latino population in the United States.[8] In consistency with national or state data, categories are reported as "Hispanic (any race)," "Non-Hispanic (any race)," "Non-Hispanic White," and "Non-Hispanic Black." Cases that meet certain criteria around race and birthplace, and who are also identified as non-Hispanic, Hispanic not otherwise specified, Spanish surname only, and unknown ethnicity, are examined. Through the use of race, birthplace, last name, first name, and maiden name, NHIA assigns a more specific and sometimes different ethnicity to these cases.

QUALITY CONTROL

Ongoing quality control procedures are integral in assuring high-quality cancer incidence data. In addition to these activities, in 1997, NAACCR developed a certification process that reviews registry data for completeness, accuracy, and timeliness of reporting (starting with cases diagnosed in 1995). Since then, ISCR has submitted data yearly to the NAACCR *Call for Data* and NAACCR registry certification. Based on the certification criteria in the following table,[9] ISCR has been awarded gold certification for all diagnosis years from 1996 through 2023.

Completeness (NAACCR Method)	Pass Edits	DCO	Timeliness	Unresolved Duplicate	Missing Data Fields				Certification Status
					Sex	Age	County	Race	
≥ 90%	≥ 97%	≤ 5%	Within 23 months	≤ 2/1000	≤ 3%	≤ 3%	≤ 3%	≤ 5%	SILVER
≥ 95%	100%	≤ 3%	Within 23 months	≤ 1/1000	≤ 2%	≤ 2%	≤ 2%	≤ 3%	GOLD

DCO – Death Certificate Only

Constantly updating registry data is a standard operation in ISCR. As of November 2024, ISCR quality control data for each diagnosis year are as follows:

Year	Completeness (NAACCR Method)[a] (% As of 11-24)	Pass Edits (%)	DCO[b] (%)	Unresolved Duplicate[c] (per 1000)	Missing Data Fields			
					Sex (%)	Age (%)	County (%)	Race (%)
1986	88	~	~	~	0.0	0.0	0.0	0.1
1987	90	~	~	~	0.0	0.0	0.0	0.1
1988	87	~	~	0.4	0.0	0.0	0.0	0.2
1989	88	~	~	0.4	0.0	0.0	0.0	0.2
1990	89	100	~	0.4	0.0	0.0	0.0	0.2
1991	88	100	~	0.4	0.0	0.0	0.0	0.3
1992	91	100	~	0.4	0.0	0.0	0.0	0.1
1993	92	100	2.2	0.4	0.0	0.0	0.0	0.2
1994	97	100	6.1	0.6	0.0	0.0	0.0	0.2
1995	99	100	2.6	0.3	0.0	0.0	0.0	0.2
1996	100	100	1.8	0.2	0.0	0.0	0.0	0.3
1997	100	100	1.8	0.9	0.0	0.0	0.0	0.4
1998	100	100	1.5	0.3	0.0	0.0	0.0	0.5
1999	100	100	1.8	0.2	0.0	0.0	0.0	0.4
2000	100	100	2.3	0.3	0.0	0.0	0.0	0.5
2001	100	100	2.4	0.0	0.0	0.0	0.0	0.4
2002	100	100	2.6	0.0	0.0	0.0	0.0	0.5
2003	100	100	1.5	0.2	0.0	0.0	0.0	0.6
2004	100	100	1.7	0.1	0.0	0.0	0.0	0.5
2005	100	100	1.9	0.0	0.0	0.0	0.0	0.7
2006	100	100	1.9	0.0	0.0	0.0	0.0	0.4
2007	100	100	1.1	0.0	0.0	0.0	0.0	0.5
2008	100	100	1.6	0.7	0.0	0.0	0.0	0.5
2009	100	100	1.6	0.3	0.0	0.0	0.0	0.6
2010	100	100	1.8	0.3	0.0	0.0	0.0	0.5
2011	100	100	1.8	0.0	0.0	0.0	0.0	0.6
2012	100	100	0.8	0.2	0.0	0.0	0.0	0.5
2013	100	100	0.9	0.2	0.0	0.0	0.0	0.3
2014	100	100	2.0	0.2	0.0	0.0	0.0	0.4
2015	100	100	2.1	0.9	0.0	0.0	0.0	0.5
2016	100	100	1.9	0.9	0.0	0.0	0.0	0.4
2017	100	100	1.9	0.6	0.0	0.0	0.0	0.3
2018	100	100	1.3	0.7	0.0	0.0	0.0	0.5
2019	100	100	0.9	0.2	0.0	0.0	0.0	0.6
2020	100	100	1.2	0.2	0.0	0.0	0.0	0.9
2021	100	100	1.1	0.0	0.0	0.0	0.0	1.1
2022	100	100	0.9	0.0	0.0	0.0	0.0	1.3
2023	100	100	1.1	0.0	0.0	0.0	0.0	1.6

~ not applicable

a. For data prior to 1995, the NAACCR's completeness estimating algorithm (version 1) was used. For data on or after 1995, the NAACCR's completeness estimating algorithm (version 2) was used.

b. Death Certificate Only (DCO) follow-back not started until the end of the 1993 reporting year.

c. NAACCR's duplicate protocol was run for each year at the time of data submission for registry certification.

DATA INTERPRETATION

Observed variations and differences over the years and across sex and race groups in cancer incidence may reflect modifications in the risk factor status of the population or the consequence of participation in screening and early detection programs. Such changes or differences, however, may instead result from random fluctuations and other factors related to the estimation process. Any conclusions should be made only after carefully considering the following factors influencing annual incidence rates. Random fluctuations in annual rates are usual and may be substantial, especially for rates based on small numbers of incidence counts (i.e., less than 16).

Differences in registry database completeness and data quality will influence the magnitude of estimated cancer incidence rates. It should be noted that, because years before 1994 are less than 95% complete (see above table), some rates for those years, especially for all sites combined, would underestimate the "true" rates for the Illinois population. The rates presented here have not been adjusted for completeness differences across the database.

Population estimates used for denominators may be inaccurate. The population data for 1990, 2000, 2010, and 2020, the years of the U.S. decennial census, are the most accurate for all age-, race-, ethnicity-, and sex-specific categories and would, therefore, produce the most accurate incidence and mortality rates. Those for other years are not based on actual population counts, but instead on interpolation or extrapolation of estimates based on demographic characteristics of the population. Incidence rates based on these population estimates would be expected to be less accurate than those for 1990, 2000, 2010, or 2020.

The 95% confidence intervals are included with reported rates to help put the rate in perspective and to facilitate rate comparisons over years and across sex, race, and ethnicity/race groups. Observed differences may not be statistically significant. The range between the lower confidence interval and the upper confidence interval defines, with a 95% probability, where the "true" rate may fall. The comparison of two sets of confidence intervals is approximately equivalent to statistical significance tests for differences between two rates and is more conservative than the standard significance test when the null hypothesis is true.[10]

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Suggested citation for Incidence Data

Reference the source of these data in any published document as follows: Illinois Department of Public Health, Illinois State Cancer Registry, data as of November 2025.

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If you have questions about these data, contact the Illinois State Cancer Registry at DPH.ISCRinquiries@illinois.gov.

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