ILLINOIS STATE CANCER INCIDENCE REVIEW AND UPDATE
1986-2013

OVERVIEW

This is the 23rd release of the annual Illinois state cancer statistics report. This report presented Illinois' cancer incidence for 1986 through 2013 for all races combined, whites, blacks, and Asian/other races and for 1990 through 2013 for Hispanics (any race), non-Hispanics (any race), non-Hispanic whites, and non-Hispanic blacks. Pediatric cancer incidence statistics on Illinois children for 1986 through 2013 are included in a separate section. At the time this report was written, cancer mortality data were unavailable.

They will be presented later in a separate report. To be consistent with national guidelines, all rates in this report were created using both the intercensal and Vintage 2014 population estimates and age-adjusted to the 2000 U.S. standard million population.

Cancer group definitions for major and minor sites are those established by the Surveillance Epidemiology and End Results (SEER) program of the National Cancer Institute (NCI) and are used by the North American Association of Central Cancer Registries (NAACCR) and the United States Cancer Statistics (USCS) of the U.S Centers for Disease Control and Prevention (CDC). These standardized classification schemes allow direct comparisons of Illinois cancer statistics with international, national, and state publications.[1-5]

In this report, incidence data were tabulated for each major or minor cancer site for four race groups and four ethnicity/race groups. Counts, age-adjusted rates, standard errors and 95 percent confidence intervals for rates are displayed for the combined 1986-2013 time period as well as for individual years. For cancers occurring in both genders, separate tables were presented for both males and females. Pediatric cancer incidence rates were calculated and presented for all races, both sexes, and by the two age groups: 0-14 and 0-19 years.

INCIDENCE HIGHLIGHTS

- A total of 1,610,534 cases of invasive cancer among Illinois residents were reported to the Illinois State Cancer Registry (ISCR) from 1986 through 2013, including 64,959 new cases reported in 2013. The overall race distribution for cases in 2013 was 82.5 percent white, 13.5 percent black, 2.7 percent Asian/other races and 1.3 percent unknown race.

- For the ethnicity/race categories, a total of 1,431,606 cases of invasive cancer among Illinois residents were reported to ISCR from 1990 through 2013. The ethnicity/race distribution for cases diagnosed in 2013 was 6.4 percent Hispanics (any race) and 93.6 percent non-Hispanics (any race); among non-Hispanic cases, non-Hispanic whites accounted for 81.8 percent and non-Hispanic blacks 14.3 percent.

- Black males had the highest overall age-adjusted invasive cancer incidence rates of all major race/gender groups. In general, males and females of Asian/other races in Illinois had substantially lower cancer incidence rates than their white or black counterparts.

- Breast cancer was the most commonly diagnosed cancer among Illinois females, accounting for 29.7 percent of 796,602 invasive cancer diagnoses in women during 1986-2013. The predominance of breast cancer among females persists for all major race and ethnicity groups.

- The incidence of female breast cancer diagnosed in the *in situ* stage increased steadily for every race and ethnicity group across 1986-1999 with an annual percent increase of 8.2 percent, but slowed around 2000 among whites and Asian/other races, and in 2004 among blacks. The annual percent change between 2000 and 2013 was a 1.6 percent increase for all races. These trends suggested that screening, mammography usage, and earlier detection of breast cancer among Illinois women may have plateaued.

- For Illinois males, prostate cancer was the most frequently diagnosed invasive cancer, accounting for 26.8 percent of 813,932 new cancer diagnoses in men during 1986-2013. Black males had the highest prostate cancer incidence rates among all race groups, approximately 61 percent higher than those observed for white males and over three times those observed for males of Asian/other races in 2013.

- A total of 15,751 new cases of cancer were diagnosed during 1986-2013 among Illinois children aged 0 to 19 years. The three most common diagnostic sites for childhood cancer in Illinois were, in descending order, leukemia, central nervous system and lymphoma.

TECHNICAL NOTES

Cancer Incidence

Cancer incidence data are from the Illinois Department of Public Health, Illinois State Cancer Registry (ISCR), the only source of population-based cancer incidence data for the state. Identification of cancer cases in the ISCR is dependent upon reporting by hospitals, free-standing clinics, radiation treatment facilities, laboratories and physician offices, as mandated by state law. All newly diagnosed cancer cases among Illinois residents are reported to ISCR by these reporting sources. In addition, ISCR has agreements with other central registries to submit Illinois cancer data that are identified outside of the state. These registries include Arkansas, California, Florida,

Indiana, Iowa, Kentucky, Michigan, Mississippi (through August of 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 standards of quality.[6] Between 1986 and 2013, 5.7 percent of ISCR cases were reported from out-of-state agencies and organizations.

A death certificate clearance process has been employed since August 1993. The process involves following cancer cases, identified only through a death certificate, back to the facility or physician that treated them for their cancer. These efforts help to identify the cases not reported to ISCR. Between 1986 and 2013, 1.6 percent of reported cases were identified from death certificates alone.

The preparation and release of data used for this report is dependent on the completion of annual reporting by Illinois facilities. Although case reporting is mandated within six months of diagnosis, it has been the ISCR policy to keep database files open for late reporting of cases and to allow for a 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 2015.

Data Use Agreement

By using the data contained in this report, you signify your agreement to comply with the following statutorily based requirements.

The Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/12) provides that data collected by the Illinois State Cancer Registry be made available to the public; however, the identification or contact of individuals is prohibited.

In an effort to exclude identifying information on individual patients, the data (e.g., age, race, 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.

These data are provided as a public service for the purpose of statistical reporting and analysis only. There should be no attempt to learn the identity of any person included in these data. If the identity of any person is discovered inadvertently, no disclosure or other use of the identity will be made.

Uses of these data do not constitute an endorsement of the user's opinion or conclusions by the Department and none should be inferred.

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 of Illinois for all races, whites,

Blacks, and Asian/other races from 1986 through 2013, and for Hispanics, non-Hispanics, non-Hispanic white, and non-Hispanic black for 1990 through 2013 were obtained from both the intercensal and Vintage 2014 bridged-race post censal population estimates. Population estimates by age, sex, race, and Hispanic origin were produced by the United States Bureau of Census Population Estimates Program (http://www.census.gov/popest/index.html), in collaboration with the National Center for Health Statistics, and with support from the National Cancer Institute (NCI) through an interagency agreement. The population estimates incorporate intercensal (for 2000-2009) and Vintage 2014 (for 2010-2013) bridged single-race estimates are derived from the original multiple race categories in the 2000 and 2010 Censuses (as specified in the 1997 Office of Management and Budget standards for the collection of data on race and ethnicity https://www.whitehouse.gov/omb/inforeg_statpolicy/). The bridged single-race estimates and a description of the methodology used to develop them appear on the National Center for Health Statistics website (http://www.cdc.gov/nchs/nvss/bridged_race.htm).

The intercensal estimates provide an adjustment of previous population estimates based on the actual 2010 census results (http://www.census.gov/popest/methodology/2000-2010_Intercensal_Estimates_Methodology.pdf).[7,8] Previous estimates utilized prior to the availability of the 2010 census data were prone to increased error as the time from the actual 2000 census increased. At the national level, estimates using both the 2000 census and the 2010 census are not very different from the previous estimates. However, there are more significant differences at the state and county levels that may result in changes to cancer incidence rates when one compares this report to earlier versions. Changes in rates also could be attributable to the addition of cases reported late.

Definitions

Cancer Site Coding for Incidence Data: All cases diagnosed during 1986 through 2013 were reported with *The International Classification of Diseases for Oncology* version 3 (ICD-O-3) codes.[9] Cancer sites in this report were grouped according to site group definitions established by the SEER program of the National Cancer Institute (NCI)[5] and also are used by the North American Association of Central Cancer Registries (NAACCR). These standardized classification schemes allow direct comparisons of Illinois data with international, national and other state publications.[3-5] The ISCR cancer site groups used in this report are listed in Appendix B.

Beginning with the 1986-2002 report and continuing through this year's report, both Kaposi sarcoma and mesothelioma were classified as separate site groups. This change has a slight impact on cancer incidence rates for a few specific cancers when compared with the previous site grouping method.

When comparing this report to the ones published before the 1986-2002 report, it should be noted that several cancers that previously were not coded as malignant in

ICD-O-2 (used in diagnoses prior to 2001) are coded as malignant in ICD-O-3 (beginning with 2001 diagnoses). For example, Myelodysplastic syndrome (MDS) and chronic myeloproliferative disease (CMPD) are considered malignant cancers in ICD-O-3, so are papillary ependymomas and papillary meningiomas which, according to ICD-O-3, are included in the "brain and other nervous system" and "all sites" categories. Some endometrial tumors also are classified as malignant in ICD-O-3. Conversely, some low malignant potential tumors of the ovary and pilocytic astrocytomas are no longer coded as malignant in ICD-O-3. Overall, these changes would have a slight impact on incidence of a specific cancer site; however, it might result in a noticeable increase in cancer incidence rates for "all sites" or for "all other sites."

The ICD-O-3 recode, with an adjustment for WHO 2008 hematopoietic histologies, was first used in the 1986-2010 report and continues to be used in subsequent reports. SEER-NCI recommends that this site recode scheme (Site Recode ICD-O-3/WHO 2008) be used 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 this report containing cases diagnosed in 2010 or later will use the SEER Site Recode
ICD-O-3/WHO 2008.

Counts and rates were calculated only for invasive cancers with the exception of carcinoma *in situ* occurring in the urinary bladder. Counts and rates for carcinoma *in situ* of the breast are displayed separately in tables, but were not included in the calculation of counts or incidence rates for all sites combined.

Pediatric Cancer Groups: Tumors diagnosed in children are classified using SEER site/histology recode based on the *International Classification of Childhood Cancer, Third Edition* (ICCC-3)[10] and ICD-O-3. The main classification table of SEER recode scheme used in the present report was listed in Appendix C.

Rate Calculation: The SEER*Stat® software package,[11] developed by the Information Management Services Inc. for NCI, was used to calculate both incidence and mortality rates. Rates are expressed per 100,000 population with the exception of pediatric cancer incidence rates, which are expressed per 1 million population. Age-adjustment of rates was calculated by the direct method adjusting to the 2000 U.S. standard million population. Rates are rounded to the nearest 10th 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 percent level using Tiwari method.[12] Algorithms used for the calculation of standard errors and 95 percent confidence intervals are displayed in Appendix D.

Race-specific Rates: The race-specific categories in this report are all races combined, whites, blacks and Asian/other races. Cases reported as unknown race were included in the "all races" category, but not in any race-specific group.

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 was linked to the Indian Health Service (IHS), which provides medical services to an estimated 55 percent of the American Indian/Alaska Native population.[13] 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, blacks, or Asian/other races due to the relatively small number of cases affected.

Through the utilization of the NAACCR Asian Pacific Islander Identification Algorithm (NAPIIA), improvements have been, and will continue to be made in classifying cancer incidence cases as Asian or Pacific Islander. Through the use of birthplace and first, last, and maiden name fields, NAPIIA assigns a more specific race group to cases identified as Asian NOS, Pacific Islander NOS, other, and unknown.[14]

Since 1991 the ISCR has included the race category "Other Unspecified" in an aggregate group that contained "Asian and Other Races." Beginning with the 2010 data year the "Other Unspecified" race group will not be included in the aggregate "Asian and Other Races" aggregate group used in the report. Cases identified as a race of "Other Unspecified" will continue to be included in the "All Races" grouping. This was done in an effort to maintain comparability to other state and national reporting sources.

Ethnicity/Race Rates: Hispanic ethnicity was derived according to the NAACCR Hispanic identification algorithm (NHIA).[15] NHIA is a generally reliable method to enhance the ethnic identification of the Latino population in the United States.[16] Ethnic categories are reported as Hispanic (any race), non-Hispanic (any race), non-Hispanic whites and non-Hispanic blacks. In order to be consistent with national and other state reports, cases reported as "unknown" ethnicity are included in the non-Hispanic group.

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 each year to the NAACCR *Call for Data* and for NAACCR registry certification. Based on the certification criteria shown in the following table,[2] ISCR has been awarded gold certification for all diagnosis years from 1996 through 2012.

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

Constantly updating registry data is a standard operation in ISCR. As of November 2015, ISCR quality control data for each diagnosis year are as follow:

Year	Completeness (NAACCR Method)[a] (% As of 11-15)	Pass EDITS (%)	DCO[b] (%)	Unresolved Duplicate[c] (%)	Missing Data Fields			
					Sex (%)	Age (%)	County (%)	Race (%)
1986	88	~	~	~	0.0	0.0	0.0	0.2
1987	90	~	~	~	0.0	0.0	0.0	0.2
1988	87	~	~	0.04	0.0	0.0	0.0	0.3
1989	88	~	~	0.04	0.0	0.0	0.0	0.2
1990	89	100	~	0.04	0.0	0.0	0.0	0.2
1991	88	100	~	0.04	0.0	0.0	0.0	0.6
1992	91	100	~	0.04	0.0	0.0	0.0	0.3
1993	92	100	2.2	0.04	0.0	0.0	0.0	0.2
1994	97	100	6.1	0.06	0.0	0.0	0.0	0.3
1995	99	100	2.7	0.03	0.0	0.0	0.0	0.4
1996	100	100	1.8	0.02	0.0	0.0	0.0	0.5
1997	100	100	1.8	0.09	0.0	0.0	0.0	0.6
1998	100	100	1.5	0.03	0.0	0.0	0.0	0.9
1999	100	100	1.8	0.02	0.0	0.0	0.0	0.9
2000	100	100	2.4	0.03	0.0	0.0	0.0	1.0
2001	100	100	2.4	0.00	0.0	0.0	0.0	0.9
2002	100	100	2.6	0.00	0.0	0.0	0.0	1.1
2003	100	100	1.5	0.02	0.0	0.0	0.0	1.2
2004	100	100	1.7	0.01	0.0	0.0	0.0	1.1
2005	100	100	1.9	0.00	0.0	0.0	0.0	1.3
2006	100	100	2.0	0.00	0.0	0.0	0.0	1.0
2007	100	100	1.2	0.00	0.0	0.0	0.0	1.1
2008	100	100	1.7	0.07	0.0	0.0	0.0	1.2
2009	100	100	1.6	0.03	0.0	0.0	0.0	1.4
2010	100	100	1.8	0.03	0.0	0.0	0.0	1.4
2011	100	100	1.8	0.00	0.0	0.0	0.0	1.6
2012	100	100	0.9	0.02	0.0	0.0	0.0	1.5
2013	100	100	1.0	0.02	0.0	0.0	0.0	1.3

~ 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. DCO follow back not started until end of 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 years and across sex and race groups in cancer incidence and/or mortality may be real, reflecting 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 not be significant, but instead may be the result of random fluctuations and other factors related to the estimation process. Any conclusions should be made only after carefully considering the following factors that influence 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 cancer incidence rates. It should be noted that, because years prior to 1994 are less than 95 percent complete (see above table), some rates for those years, especially for all sites combined, would be underestimates of 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 or lack precision. Population data for 1990, 2000 and 2010, 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 rather 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 or 2010 (see notes under "Population Estimates").

- The 95 percent 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 95 percent 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.[17]

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