

Cancer in Downstate Illinois, 1990-2009 Incidence, Mortality, Disparities, Care Encounters and Survival

Epidemiologic Report Series 14:02

September 2013



Cancer in Downstate Illinois, 1990-2009

Incidence, Mortality, Disparities, Care Encounters and Survival



A Joint Report of the Illinois Department of Public Health's Division of Epidemiologic Studies and the Southern Illinois University School of Medicine Simmons Cancer Institute Springfield, Illinois

September 2013

Prepared by

Kyle Garner, M.P.H. Cancer Epidemiologist Division of Epidemiologic Studies Illinois Department of Public Health

Tiefu Shen, Ph.D., M.D. Division Chief Division of Epidemiologic Studies Illinois Department of Public Health

David Steward, M.D., M.P.H. Associate Dean of Community Health and Service Southern Illinois University School of Medicine Simmons Cancer Institute

Acknowledgements

This report would not have been possible without the diligent work of the Illinois State Cancer Registry staff, the personnel at the reporting facilities that diagnose or treat cancer patients throughout Illinois, and the staff members at other state central cancer registries with data exchange agreements.

This publication was supported, in part, by Cooperative Agreement Number 1U58DP003883-01 from the U.S. Centers for Disease Control and Prevention (CDC) National Cancer Prevention and Control Program. The contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

Suggested citation

Garner K, Shen T, Steward D. Cancer in Downstate Illinois, 1990-2009. Epidemiologic Report Series 14:02. Springfield, Ill.: Illinois Department of Public Health, September 2013.

Copyright information

All material in this report is in the public domain and may be reproduced or copied without permission; citation as to source, however, is appreciated.

The Illinois Department of Public Health, Illinois State Cancer Registry (ISCR), makes the cancer incidence data available as a public service. Use of these data does not constitute an endorsement of the user's opinion or conclusions by the Department and none should be inferred.

Cancer in Downstate Illinois, 1990-2009 Incidence, Mortality, Disparities, Care Encounters and Survival

Introduction and Demographic Background

This report is intended to present descriptive data concerning the cancer burden in central and southern Illinois commonly referred to as downstate Illinois. Map 1, below, shows specifically what 73 counties this report includes in the downstate area. Technical notes regarding the data sources and data quality control activities for Illinois State Cancer Registry data can be found in the appendix of this report.

Illinois is the fifth most populous state in the union and mimics the racial ethnic makeup of the nation as a whole.¹ As with many large states, Illinois' population is heavily concentrated in and around large cities (i.e. the northeast corner of the state in the greater Chicago metro area (Map 1). The downstate portion of Illinois is dotted with small and medium urban areas with large expanses of rural areas.





Demographically the upstate and downstate regions of Illinois display similar proportions of impoverished individuals as well as adults with less than a high school education. Downstate Illinois is much less densely populated and contains markedly smaller proportions of minorities compared to upstate (Table 1).

Cancer Incidence in Downstate Illinois

Overall, Illinois' cancer incidence rates are slightly higher than national rates for both men and women (Chart 1). Between 2005 and 2009, cancer was the second leading cause of death in Illinois next to heart disease. This held true for both downstate and upstate populations. In 2009, downstate Illinois had 17,611 new malignant cancer cases diagnosed. Downstate Illinois cancer incidence had essentially remained flat during the latest 10 years² (The average annual percent change (APC) in the incidence rate for downstate Illinois was +0.1 percent per year.), while upstate cancer incidence had trended downward. From 2003 forward downstate cancer incidence rates were consistently higher than that of upstate Illinois (Chart 2).

Male Incidence:

The five cancers with the highest incidence rates for downstate males were shown in Chart 3. Prostate cancer had the highest incidence rate, which steadily increased from 1995 to 2002 and then began to decline and end the time period at roughly the same rate with which it began the period. Kidney and renal pelvis, as well as urinary bladder incidence remained steady throughout the time period. Lung and bronchial and colorectal cancer showed a slight reduction in incidence during this time. These five cancer sites accounted for 65 percent of all cancer cases diagnosed in downstate Illinois during 2009.

Table 1. 2009 Population Estimates								
	Illinois	Upstate	Downstate					
Population ¹	12,910,409	9,872,007	3,038,402					
Population Per	231.1	595.3	78.0					
Square Mile ¹								
No. of Counties	102	29	73					
Non-Hispanic								
White ¹	64.6%	58.1%	85.8%					
Non-Hispanic								
Black ¹	14.5%	16.2%	9.0%					
Hispanic ¹	15.2%	19.2%	2.3%					
<100% FPL* ²	12.4%	11.9%	14.3%					
<200% FPL ²	28.6%	27.6%	32.1					
<hs ed<sup="">2</hs>	14.3%	14.7%	12.7%					
HS ed / GED** ²	28.1%	26.2%	34.0%					
Bachelors ²	18.6%	19.9%	14.3%					
¹ U.S. Census Bureau Population Estimates 2009, Vintage 2009								
² American Community Survey 2009								
*FPL=Federal Poverty Level								
**GED=General Educational Development Test								







Examination of 2009 cancer incidence data by cancer site and geographies reveals differences in site specific incidence between downstate and upstate geographies. Specifically, significantly higher rates of lung and bronchus, colorectal, kidney and melanoma of the skin were seen in downstate males. On the other hand, a slightly higher rate of prostate cancer incidence was observed in upstate males (Chart 4).



Female Incidence:

Invasive breast cancer incidence declined slightly between 1995 and 2009, while lung and bronchial cancer incidence increased in downstate Illinois females. Cancer incidence of the colon and rectum, corpus and uterus, and non-Hodgkin lymphoma remained fairly constant during this time period. These five sites represented 64 percent of all cancer cases in downstate females diagnosed during 2009 (Chart 5).





Downstate women have significantly increased rates of both lung and bronchial, and skin cancer incidence when compared to upstate females (Chart 6).

Cancer Mortality in Downstate Illinois

On average, between 2005 and 2009, downstate Illinois had 6,981 cancer deaths per year. This was roughly 23 percent of the total number of deaths for the state during this time period. Cancer mortality rates for each gender have declined over the years. However, Illinois males, specifically downstate males, have not experienced decreases in mortality rates like the United States, Illinois, or upstate Illinois (Chart 7). Downstate males had significantly higher cancer mortality rates compared to upstate males during the 1999 through 2001, 2002 through 2004, and 2004 through 2008 time periods.



As with cancer incidence, downstate males experienced significantly higher rates of death due to lung and bronchial cancer when compared to their upstate counterparts (81.7 per 100,000 and 64.8 per 100,000 respectively, Chart 8). Prostate cancer mortality also was significantly higher in downstate despite a lower, albeit insignificant, incidence rate.



Female cancer mortality trended down slightly during the time period, but as with males, downstate female mortality did not realize the same decreases as the United States, Illinois, or upstate Illinois (Chart 9).



The rates of death due to lung and bronchial cancers were higher in downstate females when compared to upstate (45.1 per 100,000 compared to 41.0 per 100,000, Chart 10), which are similar to what was seen in males. Compared to upstate females, downstate females had a significantly higher mortality due to lung and bronchial cancer, while upstate females had significantly higher rates of mortality due to invasive breast and pancreatic cancers.



Cancer Disparities within Downstate Illinois

Gender: In general, males have a higher rate of both cancer incidence (Chart 1) and mortality (Charts 7 and 8) throughout Illinois when compared to females. Within Illinois males, increased incidence and mortality rates for lung and bronchial cancer appear in downstate males.

Geography: Maps 2 and 3 below display the cancer incidence and mortality rates for all cancers.



in men and women combined. In Map 2 one can see that a large group of counties in central Illinois has some of the highest cancer incidence rates compared to other counties. Also, counties in the southern tip of the state are a mixture of both high and low incidence rates. County mortality rates, shown in Map 3, do not appear to follow the same pattern as the incidence rates; however, some of the highest county mortality rates are found in the southern tip of the state. Several counties throughout downstate Illinois have both relativly high cancer incidence and mortality rates (e.g.

Mason, Christian, Vermillion, Macon, Montgomery, St. Clair, Marion, and Franklin).

Race / Ethnicity: Downstate male incidence, when examined by race and ethnicity, displays a persistent disparity between non-Hispanic black males and both non-Hispanic white and Hispanic males. Hispanic males began the time period with similar rates as their non-Hispanic white counterparts but their rates



quickly dropped between 2003 and 2008; below that of non-Hispanic white and non-Hispanic black males (Chart 11). This disparity also was observed for upstate Illinois.

Compared to their male counterparts in downstate Illinois, females appear to experience less variation after 2000 as shown in Chart 12. The incidence rate for downstate Hispanic females displayed considerable variability due to the small population and small number of cases. Nonetheless, the rate for Hispanic females seemed to be very close to that of non-Hispanic black



and non-Hispanic white women.

Lung and bronchus: Lung and bronchus cancer is a major cancer that contributes to cancer incidence and mortality rates, and it seems to be driving the higher cancer incidence and mortality in downstate Illinois (Chart 13, 14). In males, downstate non-Hispanic blacks had the highest incidence rates both



within and between geographies and racial/ethnic subgroups. Downstate non-Hispanic white and black men had significantly higher rates (p<= 0.05) than their upstate counterparts. Downstate

Hispanics seemed to have higher rates when compared to upstate Hispanics but the difference was not statistically significant. Females displayed lower rates of lung and bronchial cancer incidence across racial ethnic subgroups and geographies when compared to males. However, among females, non-Hispanic black women experienced higher rates of lung and bronchial cancer no matter the



geography. Non-Hispanic blacks of both genders displayed higher rates of mortality in downstate Illinois than elsewhere (Chart 14).

Cancer Related Health Behaviors

Screening is effective in the early detection of several common types of cancer. Cancer sites such as cervical, breast, colorectal, skin, and oral have proven screening tests that can aid in the early identification of malignant tumors in those sites. In addition to detecting cancer early, screening for

cervical and colorectal cancers also can lead to the detection and removal of precancerous abnormalities, thus preventing cancer altogether. Existing data from Illinois Behavioral Risk Factor Surveillance System (BRFSS, Table 2) suggest that several of the screening tests for breast and colorectal cancer are employed regularly by Illinoisans with little variation by geography. Noteworthy from the BRFSS was that the rates of smoking, both current and former, were higher in downstate Illinois versus upstate. The higher smoking rate was consistent with the finding of higher lung cancer incidence seen in downstate.

	Percent	Percent	Percent
BRFFS Survey Question	Downstate	Upstate	Illinois
	2007-2009	2007-2009	2008
HAD MAMMOGRAM (women 40 and older)			
Yes	92.0	91.7	91.2
No	8.0	8.3	8.8
LAST MAMMOGRAM (women 40 and older)			
<= 1 year	67.3	66.5	64.5
> 1 year	32.7	33.5	35.5
EVER HAD A PAP SMEAR			
Yes	93.3	95.4	93.7
No	6.7	4.6	6.3
HOW LONG SINCE YOUR LAST PAP SMEAR			
Within the past year (1 to 12 months ago)	58.4	65.0	77.5
More than one Year (13 months +)	41.5	35.0	22.5
AGE 50+: HAD COLON/ SIGMOIDOSCOPY			
Yes	62.1	60.4	58.8
No	37.9	39.6	41.2
HAD HOME BLOOD STOOL TEST (AGES 50+)			
Yes	41.2	40.3	37.9
No	58.8	59.7	62.1
SMOKING			
Current Smoker	22.6	17.3	18.8
Former Smoker	24.3	21.6	23.0
Non-smoker	53.1	61.1	58.2
LAST SMOKED REGULARLY			
Less than five years ago	23.5	21.9	23.0
Greater than five years ago	76.5	78.1	77.0
WEIGHT			
Underweight/normal	30.9	36.9	36.1
Overweight	40.5	37.4	37.2
Obese	29.1	26.5	26.8
Source: Illinois Department of Public Health, Illinois Behavioral	Risk Factor Survei	llance System	

Table 2: Behavioral Risk Factor Surveillance System

In downstate Illinois, roughly 45 percent of cancers are diagnosed in the local or early stages of the disease and 46 percent are discovered in the regional or distant stages with the remainder having

unknown stage at diagnosis. This distribution was seen in upstate as well (Table 3). Racial differences in cancer stage persisted across geographies: Non-Hispanic black males had slightly higher percentages of distant stage cancer at diagnosis (Chart 15). Non-Hispanic black females had higher percentages of both distant and regional stage cancers at diagnosis (Chart 16).

Table 3: Illinois Malignant Cancers by Stage and Geography,2005-2009								
	Percent Localized	Percent Regional	Percent Distant	Percent Unknown				
Downstate	45.6	21.7	25.1	7.6				
Upstate	45.9	21.8	24.8	7.6				
Illinois	45.8	21.7	24.9	7.6				

Source: Illinois State Cancer Registry, data as of November 2011





Downstate Cancer Care Encounters

For this report a cancer care encounter is defined as any cancer diagnosis and cancer directed treatment reported to the ISCR by facilities that are mandated to report such events. These facilities include hospitals, free standing clinics, radiation treatment facilities, laboratories, and physician's offices. Another source of information is the Illinois resident death file. While not a facility per se, death certificates do provide missing cases that were not reported by the types of facilities mentioned above. Cancer care encounters could occur more than once on the same patient because the patient could see multiple health providers and, under the ISCR reporting rules, all these encounters are reported by different providers supplying information at different stages of diagnosis and treatment. From the perspective of cancer care, linking the patient's address and the provider's location may provide information about where the cancer care encounter occurred. In this analysis, these care encounters were examined by downstate versus upstate.

Table 4 below summarizes cancer care encounters for both downstate and upstate geographies in 2009. As expected, the majority of cancer care encounters were between downstate residents and downstate care providers, and the same was true for upstate cancer care encounters. However, it is noted that the proportion of downstate resident/downstate facilities cancer encounters (79.7 percent) was much lower than that of upstate (94.5 percent). Downstate Illinois facilities had 798 cancer encounters in their facilities by upstate residents or 1.3 percent of the total for upstate. Downstate residents visited upstate facilities 607 times for some type of cancer care accounting for 2.6 percent of

the downstate total. The difference between upstate and downstate facilities also can be seen in the number of cancer care encounters occurring outside of the state. Downstate residents left Illinois 4,234 times to seek cancer care outside of the state. This number represents 18.3 percent of the cancer events occurring to downstate Illinois residents. In contrast, upstate residents left Illinois 1,242 times for cancer care which accounted for only 2.1 percent of upstate resident cancer care encounters.

Table 4: Illinois Cancer Events by Resident Location and Facility - 2009									
Resident Region	Total Resident Cancer	Downstate FacilityUpstate FacilityEEncounter (percentEncountersC		Death Certi Only Encour	ficate nters	Out of State Facility			
	Encounters	of Total)						Encoun	ters
Downstate	23,164	18,468	(79.7)	607	(2.6)	375	(1.6)	4,234	(18.3)
Upstate	59,705	798	(1.3)	56,445	(94.5)	997	(1.7)	1,242	(2.1)
Source: Illinois State Cancer Registry, data as of November 2011									

Map 4 depicts the movement of Illinois residents when seeking cancer care at Illinois facilities by noting the number of cancer care events occurring out of state, upstate, as well as upstate residents coming into downstate facilities.

Cancer Survival

A cancer survival rate measures the proportion of patients alive at some point subsequent to the diagnosis of their cancer. It is represented as the probability of a group of patients "surviving" a specified amount of time (e.g. two years, five years). Unlike incidence or mortality statistics where the total population is included in the denominator, only diagnosed patients are included in the survival calculations. This report examined five year cause-specific survival. Cause-specific survival was utilized because of its ability to compare the geographies and racial-ethnic groups that are a focus of this report.

Table 5 displays the five-year survival percentage for individuals older than 19 years of age who were diagnosed between 2000 and 2004. The downstate Illinois region displayed lower five-year survival percentages for all cancers when compared to the upstate region. Downstate lung and bronchus survival rates were significantly lower than those of upstate and appeared to drive the overall difference since other sites did not display much variability between upstate and downstate. Survival percentages for female breast cancer were higher downstate

Examination of five-year survival by stage (Table 6) shows that cancers diagnosed earlier are associated with a greater percentage of cases surviving past five years. However, the downstate region, while following the pattern of higher survival percentages in early staged tumors, still has consistently lower percentages compared to the upstate region.



	Male and	Female	Ma	le	Female				
	N	%	N	%	Ν	%			
All Sites	245,557	63.0	125,384	62.6	120,173	63.5			
Downstate	68,715	62.0	35,854	61.2	32,861	62.9			
Upstate	176,842	63.4	89,530	63.1	87,312	63.8			
Colon and Rectum	28,564	63.1	14,298	63.4	14,266	62.9			
Downstate	8,537	63.4	4,231	62.7	4,306	64.1			
Upstate	20,027	63.0	10,067	63.7	9,960	62.4			
Lung and Bronchus	33,938	18.3	18,702	15.6	15,236	21.4			
Downstate	10,452	17.2	6,014	14.5	4,438	20.7			
Upstate	23,486	18.7	12,688	16.1	10,798	21.7			
Breast					36,327	85.6			
Downstate					9,646	86.6			
Upstate					26,681	85.3			
Prostate			38,677	90.5					
Downstate			10,958	90.5					
Upstate			27,719	90.4					
Source: Illinois State Cancer Registry, data as of November 2011									

Table 5: Cause-Specific Five-Year Survival for Illinois Residents Older Than 19 Years of Age by

 Geography and Gender, 2000-2004

Table 6: Cause-Specific Five-Year Survival for Illinois Residents Older Than 19 Years of Age by Cancer									
Stage and Geography, 2000-2004									
Illinois Upstate Downstate									
	N	%	Ν	%	N	%			
Localized	107,629	87.3	77,429	87.5	30,200	86.9			
Regional	56,257	59.4	40,926	59.9	15,331	57.9			
Distant	54,958	24.6	39,745	24.9	15,213	22.7			
Unknown	22,181	39.5	15,603	39.5	6,578	37.5			
Source: Illinois State Cancer Registry, data as of November 2011									

Conclusion

This report was developed to provide a general description of the state of cancer in downstate Illinois residents. Compared to upstate Illinois, the overall cancer incidence in downstate was higher and the incidence trend has not shown the same decline experienced by upstate. Lung cancer seems to be driving this cancer pattern with its incidence rate higher downstate in both males and females. Cancer mortality in both genders declined less than upstate over time, and lung cancer again showed higher rates among downstate's male and female populations. A few other cancer sites (breast and prostate cancer, for example) had lower mortality in downstate, probably reflecting downstate's racial composition. In downstate, non-Hispanic blacks had the highest cancer incidence and mortality rates among all other racial and ethnic groups, and lung cancer rates among non-Hispanic black's were even higher than those of upstate non-Hispanic blacks. With the high level of lung cancer dominating the downstate cancer pattern, it was no surprise that the smoking rate among adults also was higher in downstate.

More cancer care encounters of downstate residents, proportionally, seemed to occur in upstate facilities than the other way around, and more downstate cancer patients seemed to go outside the state to seek cancer care than upstate patients.

Five-year cancer survival rates were consistently lower in downstate than upstate for all sites combined and for lung, breast, prostate, and colorectal cancer, with lung cancer showing the largest difference. These downstate versus upstate differences persisted across the various stages of cancer as well.

APPENDIX

TECHNICAL NOTES

DATA SOURCES

Cancer Incidence Data: 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. Newly diagnosed cancer cases among Illinois residents are reported to ISCR by the health care facilities where the cancer is diagnosed and treated. Central cancer registries and facilities in other states also report data to ISCR on Illinois residents diagnosed and treated for cancer in their states. ISCR has agreements with the following central cancer registries to exchange cancer data: Arkansas, California, Florida, Indiana, Iowa, Kentucky, Michigan, Minnesota (Mayo Clinic, through October 2005), Mississippi, Missouri, Mississippi (through 2004), North Carolina, Washington, Wisconsin, and Wyoming (through February 2008).

Most out-of-state cases come from Florida, Indiana, Iowa, Kentucky, Minnesota, Missouri and Wisconsin. 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.⁴ Three states did not report all cancer cases among Illinois residents diagnosed in 2009. This had little impact on the overall cancer incidence rate for Illinois but the rates among some rural counties along the border of Illinois may be affected.

Additionally, a death certificate clearance process has been employed since August 1993. The process involves active follow back of cancer deaths in an effort to identify the cases that are not reported to ISCR.

The preparation and release of these data are 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 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 November 2011.

Cancer Mortality Data: The SEER (Surveillance Epidemiology and End Results) program of NCI (National Cancer Institute) was the source of information on cancer mortality for 1990 through 2009 by race and ethnicity. The underlying cause of death was provided by the National Center for Health Statistics. Data presented are as of April 2012.

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 that were used as denominators for rate calculations in these data. These population estimates of Illinois and Illinois counties for all races, whites, blacks and Asian/other races from 1986 through 2009 and for Hispanics and non-Hispanics for 1990 through 2009, were obtained from the SEER program based on United States Bureau of Census population estimates.⁵

CODINGS

Cancer Site Coding for Incidence Data: All cases diagnosed during 1986 through 2009 were reported with *The International Classification of Diseases for Oncology* version 3 (ICD-O-3) codes.⁶ Cancer sites in this report were grouped according to site group definitions established by the SEER program of the National Cancer Institute (NCI)⁷ 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 state publications.⁷⁻¹⁰

This report classified both Kaposi sarcoma and mesothelioma as separate site groups. Compared to using the previous site grouping method, this change has a slight impact on cancer incidence rates for a few specific cancers. 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 cancer 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." Although the anatomic site and morphology for cancer cases diagnosed prior to 2001 were coded using the International Classification of Diseases for Oncology version 2 (ICD-O-2)¹¹ and for cancer cases diagnosed in 2001 through 2009 the version 3 (ICD-O-3).⁶ all ICD-O-2 coded cases were converted to version 3 codes and grouped according to the site group definitions established by the SEER program of NCI and also used by NAACCR and CDC.

Counts and rates were calculated only for invasive cancers with the exception of carcinoma *in situ* occurring in the urinary bladder.

Cancer Site Coding for Mortality Data: Underlying cause of death was coded using the *International Classification of Diseases* (ICD-9)¹² for all deaths for years 1986 through 1998 and the *International Classification of Diseases* (ICD-10)¹³ for all deaths for year 1999 and later. In the present data, the SEER mortality recode scheme based on ICD-9 and ICD-10 was used to classify cancer deaths by site.

Because of many changes in ICD-10 as compared to ICD-9, discontinuities in trends for many causes of death, including cancer, may arise. According to a study, compared to using ICD-9 coding, overall, approximately 0.7 percent more deaths are assigned to cancer when ICD-10 is used, leading to a higher mortality rate for all cancers combined.¹⁴ But this pattern does not hold for specific cancer sites, whose rates may be higher or lower using ICD-10. These discontinuities are relatively small, and the changes in mortality rates across the years of the ICD-9/ICD-10 boundary are still interpretable, especially for major cancer sites.¹⁵

Calculation of Rates: The SEER*Stat® software package,¹⁶ 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. 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 tenth 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.¹⁷

Five-year Cause-Specific Survival: Cause-specific survival is a net survival measure representing survival of a specified cause of death in the absence of other causes of death. Estimates are calculated by specifying the cause of death which, for this report, was death due to malignant cancer. Individuals who die of causes other than the one specified are considered to be censored.¹⁸ This requires a cause-of-death variable that accurately captures all causes related to the specific cause. The ISCR utilizes SEER algorithms to process causes of death from death certificates in order to identify a single, disease specific, underlying cause of death. In some cases, attribution of a single cause of death may be difficult and misattribution may occur. For example, a death may be attributed to the site of metastasis instead of the primary site.¹⁹

To capture deaths related to the specific cancer but not coded as such, cause-specific death classification is defined by taking into account causes of deaths in conjunction with tumor sequence (i.e., only one tumor or the first of subsequent tumors), site of the original cancer diagnosis, and comorbidities (e.g., AIDS and/or site-related diseases).²⁰ To learn more on this topic visit: <u>http://seer.cancer.gov/causespecific/</u>.

The ISCR engages in passive follow-up of cancer cases, meaning that cancer cases are linked to Illinois death certificates to ascertain death information. Recent research has shown that in comparison to active follow-up, passive follow-up displays small differences in survival statistics, but complete ascertainment of the cause of death should generally be sufficient for survival analysis.²¹

Ethnicity/Race Rates

In this report, the race-specific categories include non-Hispanic whites and non-Hispanic blacks. For the incidence data displayed in this report, Hispanic ethnicity was derived according to the NAACCR Hispanic identification algorithm (NHIA).²² NHIA is a generally reliable method to enhance the ethnic identification of the Latino population in the United States.²² Cases that meet certain criteria around race and birthplace, and who also are 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.

For mortality, Hispanic ethnicity was used as defined in the database. Because there were a considerably large number of cancer deaths with unknown Hispanic ethnicity in the mortality database, the mortality rates calculated for Hispanics may be underestimated.

QUALITY CONTROL

Ongoing quality control procedures are integral components of ISCR operations that assure 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, ²³ ISCR has been awarded gold certification for all diagnosis years from 1996 through 2009.

Completeness					Missing Data Fields				Certification Status
(NAACCR Method)	Pass EDITS	DCO	Timeliness	Unresolved Duplicate	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

REFERENCES

- United States Census Bureau, Website: <u>http://2010.census.gov/2010census/popmap/</u> Accessed on 01/10/2012.
- North American Association of Central Cancer Registries. WebSite: <u>http://www.naaccr.org/LinkClick.aspx?fileticket=tdgCsNGrZMI%3d&tabid=93&mid=433</u> Accessed on 01/10/2012.
- 3. Smith RA, Cokkinides V, Brawley OW, Cancer Screening in the U.S., 2009: A Review of Current American Cancer Society Screening Guidelines and Issues in Cancer Screening, CA Cancer J Clin. 2009;59(1):27-41.
- 4. Lehnherr M and Havener LA. Assessment of Interstate Exchange of Cancer Data, 1986-1998. *ISCR Quality Control Series 02:1.* Springfield, Ill.: Illinois Department of Public Health, January 2002.
- Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Populations - Total U.S. (1969-2009) and (1990-2009), Katrina/Rita Adjustment - Linked To County Attributes - Total U.S., 1969-2009 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released November 2010.
- 6. Fritz A, Percy C, Jack A, et al (eds). *International Classification of Diseases for Oncology*. Third edition. Geneva: World Health Organization, 2000.
- 7. Howlander N, Noone AM, Krapcho M, et al (eds). SEER Cancer Statistics Review, 1975-2009 (Vintage 2009 Populations), National Cancer Institute. Bethesda, Md., http://seer.cancer.gov/csr/1975_2009/, based on November 2011 SEER data submission, posted to the SEER website, 2012.
- 8. Copeland G, Lake A, Firth R, et al (eds). Cancer in North America: 2005-2009. *Volume One: Combined Cancer Incidence for the United States, Canada, and North America*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2012.
- 9. Copeland G, Lake A, Firth R, et al (eds). Cancer in North America: 2005-2009. *Volume Two: Registry-specific Cancer Incidence in the United States and Canada*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. June 2012.
- 10. Copeland G, Lake A, Firth R, et al (eds). *Cancer in North America, 2005-2009. Volume Three: Registry-specific Cancer Mortality in the United States and Canada.* Springfield, Ill.: North American Association of Central Cancer Registries, Inc., June 2012.
- 11. Percy C, Van Holten V, and Muir C (eds). *International Classification of Diseases for Oncology*. second edition. Geneva: World Health Organization, 1990.
- 12. World Health Organization. *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death*, based on the recommendations of the Ninth Revision Conference, 1975. Geneva: World Health Organization, 1977.

- 13. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems*. 10th revision. Geneva: World Health Organization, 1992.
- 14. Anderson RN, Minino AM, Hoyert DL, Rosenberg HM. Comparability of cause of death between ICD-9 and ICD-10: Preliminary estimates. National Vital Statistics Reports 2001;49:1-32.
- 15. Copeland G, Lake A, Firth R, et al (eds). *Cancer in North America, 2003-2007. Volume Three: Registry-specific Cancer Mortality in the United States and Canada*. Springfield, IL: North American Association of Central Cancer Registries, Inc., May 2010.
- 16. Surveillance Research Program, National Cancer Institute SEER*State software (seer.cancer.gov/seerstat) Version 7.0.4, April 11, 2011.
- 17. Tiwari RC, Clegg LX, Zou Z. Efficient interval estimation for age-adjusted cancer rates. *Stat Methods Med Res* 2006 Dec;15(6):547-69.
- 18. Marubini E, Valsecchi MG. Analysing Survival Data from Clinical Trials and Observational Studies. England: John Wiley & Sons; 1995, pp 331-61.
- 19. Percy C, Stanek E, Gloeckler L. Accuracy of cancer death certificates and its effect on cancer mortality statistics. *Am J Public Health* 1981;71: 3242-3250.
- 20. Howlader N, Ries LAG, Mariotto AB, Reichman ME, Ruhl J, Cronin KA. Improved estimates of cancer-specific survival rates from population-based data. *J Natl Cancer Inst* 2010;102:1-15.
- 21. Johnson J, Weir HK, Daixin Y, Xiaoling N. The Impact of Patient Follow-up on Population-based Survival Rates. *Journal of Registry Management* 2010;37(3):86-103.
- 22. NAACCR Expert Panel in Hispanic Identification. *Report of the Expert Panel on Hispanic Identification 2003*. Springfield, Ill.: North American Association of Central Cancer Registries, October 2003.
- 23. Hofferkamp, J (Ed). *Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis, Management, Security and Confidentiality of Data*. Springfield (IL): North American Association of Central Cancer Registries, August 2008.