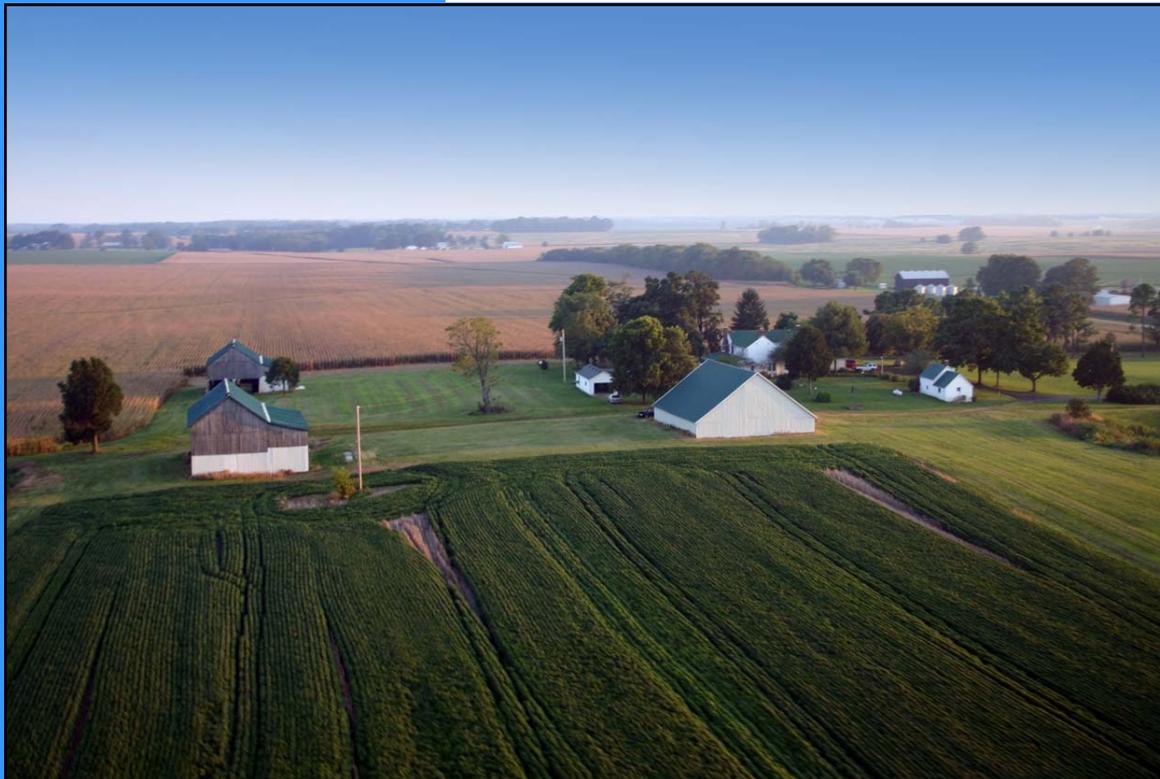


Kentucky Cancer Registry

December 2008

Annual Report

Cancer Incidence and Mortality in Kentucky, 2001-2005



*Includes a Special Report:
Colorectal Cancer in Kentucky*

ACKNOWLEDGEMENTS

The population-based cancer rates contained in this report were made possible by the Kentucky General Assembly. Legislation was passed in April, 1990 that formally established the Kentucky Cancer Registry as the population-based central cancer registry for the Commonwealth. This legislation mandated reporting of all cancer cases to the Registry.

The full and active participation of all acute care hospitals in Kentucky is gratefully acknowledged. The hospitals, their medical staffs, tumor registrars, and health information personnel are essential to the process of completely and accurately reporting cancer cases. The participation of non-hospital facilities such as freestanding treatment centers, private pathology labs, and physician offices is also greatly appreciated. These facilities

are required by law (KRS 214.556) to report all cancer cases diagnosed or treated at their facilities. Their participation ensures complete and accurate reporting of all cases occurring in Kentucky.

In 1994, the Kentucky Cancer Registry was awarded funding from the Centers for Disease Control and Prevention through the National Program for Cancer Registries to institute a formal quality assurance program to improve the completeness and accuracy of reporting. In 2001, The Kentucky Cancer Registry was awarded additional funding from the National Cancer Institute's Surveillance, Epidemiology and End Results Program (SEER) to improve follow-up information and expand quality assurance activities. These resources have made it possible for the

Registry to gain recognition as a complete, accurate, and timely population-based cancer registry.

Finally, special recognition is given to the staff of the Kentucky Cancer Registry. These outstanding individuals have developed and maintained state-of-the-art computer programs for entering, editing, and analyzing information on cancer in Kentucky. The Kentucky Cancer Registry staff have also developed training programs and have provided ongoing support to all of the reporting facilities throughout the state. These same individuals are actively involved in activities at both national and international levels. The Kentucky Cancer Registry could not succeed without the thoughtful and consistent efforts of these individuals.

TECHNICAL NOTES

Data for this report were obtained from the Kentucky Cancer Registry. The KCR has retained case records of each cancer seen at any of the Kentucky acute care hospitals as well as all freestanding outpatient diagnostic and treatment facilities since January 1, 1995. Information pertaining to each new case of cancer was abstracted by a hospital based tumor registrar or by a KCR regional abstractor. All of these individuals have received formal training for cancer case abstracting in the KCR format. Case finding systems designed to identify each new case of cancer have been implemented at each hospital. The abstracting of data conforms to the guidelines established by the American College of Surgeons for cancer registries, and by the Surveillance, Epidemiology, and End Results Program of the National Cancer Institute.

Since some patients are seen at different hospitals for the same diagnosis of cancer, KCR uses well-established and tested procedures to ensure that a case is entered and counted only once in the registry.

Only new primary cases of cancer diagnosed in Kentucky residents during 2001 to 2005 were included in calculating the incidence rates presented in this report. The population figures used to calculate age-specific and age-adjusted cancer incidence rates were provided by the SEER Program: U.S. Population Data 1969-2005, Release date March 3, 2008.

Five-year rates are calculated by adding together the number of cases occurring over a five-year

period. This sum is then divided by the sum of the population estimates for each year.

All of the cancer incidence rates for Kentucky have been age-adjusted by the direct method using the 2000 U.S. standard million population. The 2000 standard million population was chosen for age-adjustment in order to make these data comparable to national statistics, which have been published using this standard since 2002.

All of the cases included in the Kentucky Cancer Registry are classified according to the International Classification of Disease for Oncology (ICD-O), third edition.

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LIMITATIONS AND ISSUES TO CONSIDER

Completeness of Case Ascertainment

The degree to which all of the new cases of cancer in Kentucky are identified and reported to KCR is called case completeness. It can be estimated by comparing the actual cancer incidence rate for a given year to the expected incidence rate for that same year. The expected cancer incidence rate can be calculated by applying the age-, sex-, and race-specific five-year SEER age-adjusted incidence to the U.S. mortality rate ratios to the cancer mortality rate for the state. This method was adopted by the North American Association of Central Cancer Registries (NAACCR) as the standard for determining completeness of case ascertainment. Using the NAACCR method for estimating completeness, KCR has ranged between 101.75% and 106.84% complete for the years 2001 through 2005. Registries that have an estimate of completeness greater than 95% are considered to meet the highest standards.

Case finding audits to determine where cases are missing have also been conducted annually since 1995. These audits have helped to identify some areas of under-reporting. The number of missed cases for the years 2001 through 2005 is estimated to be very small and is not expected to alter the rates presented in this report significantly.

Unstable Rates in Small Populations

When 15 or fewer cases of cancer occur in the population, the rates are considered to be unstable and caution should be used when interpreting these rates. A single case of cancer in a county with a small population can cause the rate of cancer in that county to be very high relative to other counties in the state. For example, one case of cancer in a county with a population of 5,000 will result in a rate of cancer that is roughly twice as high as the rate of cancer in a county with a population of 10,000 that also reports only one case. Care should be taken in interpreting the data contained in this report and on the web site, particularly at the county level or in racial groups where the number of people in the population may be relatively small.

Crude Rates Versus Age-Adjusted Rates

Finally, when comparing differences in the rates of cancer among counties or Area Development Districts (ADDs), it is preferable to use the age-adjusted rates. The process of age-adjustment removes the differences in the cancer incidence rates that are due to differences in the age structures of the populations being compared. In other words, if one county has a large proportion of older people and another county has a small proportion of older people, the county with more elderly people will have higher crude incidence rates. Age-adjustment removes this effect and allows for comparison of rates among different counties or ADDs. The rates presented in this report have been age-adjusted to the year 2000 population standard and should not be compared with any rates age-adjusted to a different population standard. The 2000 population standard is currently used by all central cancer registries in the U.S. for age-adjustment.

INTRODUCTION

The cancer incidence and mortality rates included in this report cover the five-year period 2001 through 2005. All of the incidence rates presented have been calculated from invasive cancers with two exceptions. Urinary bladder and breast cancer incidence rates include both *in situ* and invasive cancers. The incidence rates for all sites include the *in situ* urinary bladder cases but not the *in situ* breast cancer cases. These reporting features are consistent with those used by other central cancer registries throughout North America.

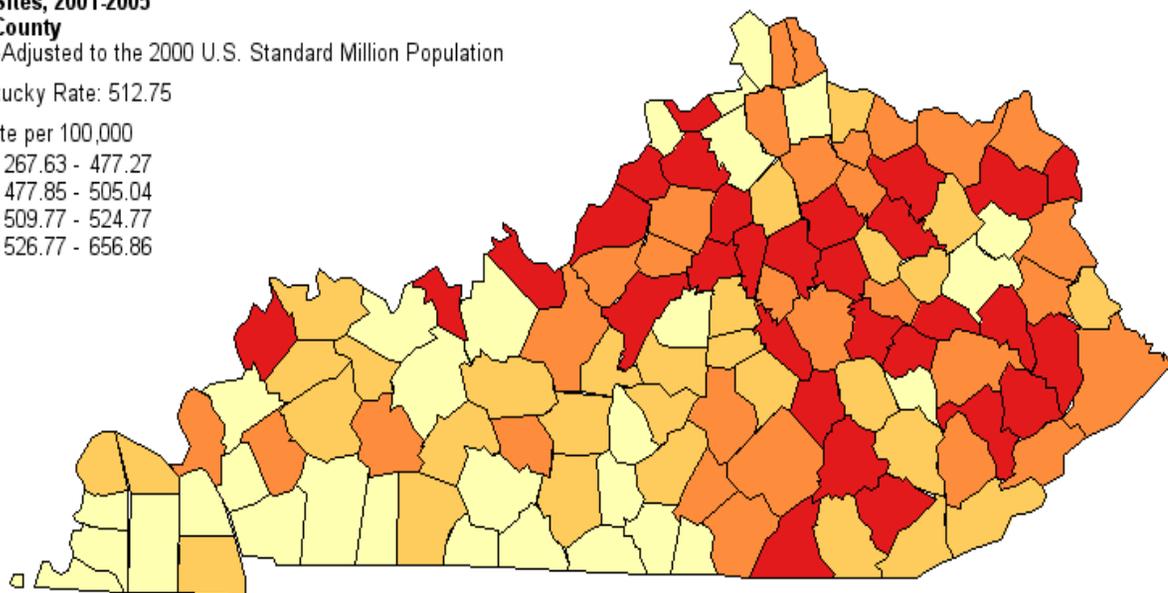
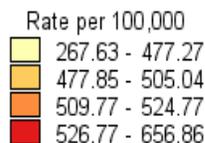
This report is divided into four sections. The first section contains a brief overview of cancer incidence and mortality rates in Kentucky as compared to the nation. The second section describes the burden of colorectal cancer in Kentucky as well as geographic variations in colorectal cancer incidence and mortality within the state. The third section of the report provides an overview of the Kentucky Cancer Registry's interactive web site. The final section of the report highlights research projects conducted in 2007 and 2008 that utilize data from the Kentucky Cancer Registry.

Age-Adjusted Invasive Cancer Incidence Rates in Kentucky All Sites, 2001-2005

By County

Age-Adjusted to the 2000 U.S. Standard Million Population

Kentucky Rate: 512.75



Created Nov 21, 2008

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CANCER INCIDENCE IN KENTUCKY, 2001-2005

SITE	Overall			Male			Female		
	Cases	KY*	US**	Cases	KY*	US**	Cases	KY*	US**
All Sites	108913	512.8	458.6	56497	612.5	537.2	52416	447.1	404.8
Oral Cavity & Pharynx	2501	11.6	10.2	1780	18.3	15.0	721	6.1	6.2
Stomach	1245	5.9	8.3	780	8.5	11.6	465	3.8	5.8
Colon & Rectum	12520	59.3	49.2	6330	70.3	57.3	6190	51.4	42.9
Liver & Intrahepatic Bile Duct	921	4.3	6.7	624	6.6	10.1	297	2.5	3.7
Pancreas	2301	10.9	11.4	1142	12.6	12.8	1159	9.8	10.2
Lung & Bronchus	21555	101.2	59.0	12513	136.2	73.1	9042	76.2	48.7
Melanoma of the Skin	4375	20.6	18.3	2394	25.0	23.2	1981	17.7	15.0
Breast (Female)	16708	143.9	157.0	~	~	~	16708	143.9	157.0
Cervix Uteri (Female only)	1084	9.9	8.1	~	~	~	1084	9.9	8.1
Corpus Uteri (Female only)	2586	22.2	23.3	~	~	~	2586	22.2	23.3
Ovary (Female only)	14358	12.3	13.3	~	~	~	1435	12.3	13.3
Prostate (Male only)	13380	144.4	164.7	13380	144.4	164.7	~	~	~
Testis (Male only)	505	4.9	5.4	505	4.9	5.4	~	~	~
Urinary Bladder	4525	21.5	20.4	3342	38.1	36.0	1183	9.8	9.0
Kidney & Renal Pelvis	3363	15.8	12.5	2049	21.5	17.3	1314	11.2	8.7
Brain & Other Nervous System	1403	6.7	6.3	757	7.7	7.4	646	5.8	5.4
Thyroid	1782	8.5	9.2	407	4.1	4.7	1375	12.7	13.5
Hodgkins Disease	614	3.0	2.7	345	3.5	3.0	269	2.5	2.4
Non-Hodgkins Lymphoma	4072	19.3	19.7	2065	22.4	23.8	2007	16.6	16.4
Leukemias	2683	12.9	12.3	1498	16.7	16.0	1185	10.1	9.5

*Source: Kentucky Cancer Registry. Rates are age-adjusted & are per 100,000. **Source: SEER 13 Registries. Rates are age-adjusted & are per 100,000

Rates in red represent KY rates that are higher than the U.S. rates.

*The American Cancer Society estimates that there will be **23,270 Kentuckians** diagnosed with cancer in 2008.*

The age-adjusted incidence rate for all cancer sites in Kentucky is 11.8% higher than the estimated age-adjusted incidence rate for all cancer sites in the United States. Kentuckians have significantly higher rates of both lung and colon cancers as compared to the U.S. The incidence rates for prostate, lung, and colorectal cancers are highest for males in Kentucky while the rates of breast, lung, and colorectal cancers are highest for women.

CANCER MORTALITY IN KENTUCKY, 2001-2005

SITE	Overall			Male			Female		
	Deaths	KY*	US**	Deaths	KY*	US**	Deaths	KY*	US**
All Sites	46574	221.5	189.8	24901	285.1	234.4	21673	179.6	159.9
Oral Cavity & Pharynx	614	2.9	2.6	431	4.6	4.0	183	1.5	1.5
Stomach	737	3.5	4.1	443	5.0	5.7	294	2.4	2.9
Colon & Rectum	4579	22.0	18.8	2252	26.6	22.7	2327	18.8	15.9
Liver & Intrahepatic Bile Duct	1041	5.0	5.0	627	7.0	7.3	414	3.4	3.1
Pancreas	2196	10.5	10.6	1078	12.0	12.2	1118	9.2	9.3
Lung & Bronchus	16701	78.9	54.1	10025	111.4	72.0	6676	55.9	41.0
Melanoma of the Skin	707	3.3	2.7	457	4.9	3.9	250	2.1	1.7
Breast (Female)	3054	25.5	25.0	~	~	~	3054	25.5	25.0
Cervix Uteri (Female only)	318	2.8	2.5	~	~	~	318	2.8	2.5
Corpus Uteri (Female only)	189	1.9	1.9	~	~	~	189	1.6	1.9
Ovary (Female only)	1037	8.7	8.8	~	~	~	1037	8.7	8.8
Prostate (Male only)	1979	26.6	26.7	1979	26.6	26.7	~	~	~
Testis (Male only)	14	0.1***	0.3	14	0.1***	0.3	~	~	~
Urinary Bladder	923	4.4	4.3	616	7.6	7.5	307	2.4	2.3
Kidney & Renal Pelvis	997	4.7	4.2	625	7.0	6.0	372	3.1	2.7
Brain & Other Nervous System	975	4.6	4.4	529	5.5	5.4	446	3.9	3.6
Thyroid	111	0.5	0.5	47	0.5	0.5	64	0.5	0.5
Hodgkins Disease	114	0.5	0.4	72	0.8	0.5	42	0.4	0.4
Non-Hodgkins Lymphoma	1580	7.6	7.3	831	9.7	9.3	749	6.1	5.9
Leukemias	1575	7.6	7.4	873	10.3	9.9	702	5.8	5.6

*Source: Kentucky Cancer Registry. Rates are age-adjusted & are per 100,000. **Source: SEER 13 Registries. Rates are age-adjusted & are per 100,000

***Counts <15 are too few to calculate a stable age-adjusted rate. Rates in red represent KY rates that are higher than the U.S. rates.

Approximately 9,500 Kentuckians will die from cancer in 2008.

The mortality rate for cancer in Kentucky is significantly higher than the cancer mortality rate of the nation. Cancers of the lung & bronchus and of the colon & rectum have the highest mortality rates for men and women combined. The leading rates of cancer-related mortality for men in Kentucky are lung, prostate, and colorectal cancers. Women in Kentucky have the highest rates of cancer-related mortality from lung, breast, and colorectal cancers.

SPECIAL REPORT: COLORECTAL CANCER IN KENTUCKY, 2001-2005

Colorectal cancer (CRC) is the third most commonly occurring cancer in both men and women and accounts for 9% of all cancer deaths in the United States. The American Cancer Society estimates that there will be 148,810 new cases of CRC in the United States in 2008, and 49,960 deaths due to this disease. Colorectal cancer in Kentucky poses a significant health concern as both incidence and mortality rates are higher in Kentucky than in the United States. Regional variations in colorectal cancer also exist within Kentucky.

Characteristics of Colorectal Cancer Cases in Kentucky

There were 12,520 cases of invasive colorectal cancer diagnosed in Kentucky during 2001-2005. Of those, 6330 were men (50.6%) and 6190 were women (49.4%); and 11,625 (92.9%) were White, 830 were Black (6.6%), and 65 (0.5%) were of unknown race. In addition, 1155 were less than 50 years of age (9.2%), 5403 were between 50 and 70 years of age (43.2%), and 5962 were 70 years of age or older (47.6%). Table I summarizes the population distributions by gender, race, age, tobacco use, and geographic region of residence.

KENTUCKY VERSUS THE UNITED STATES

Incidence and Mortality

According to the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results program (SEER), the estimated age-adjusted incidence rate of colorectal cancer for men and women in the United States was 49.2 per 100,000 persons during 2001-2005, while the age-adjusted mortality rate was 18.8 per 100,000 during the same time. In Kentucky, colorectal cancer incidence and mortality rates are notably higher than the estimated rates for the nation. The age-adjusted incidence rate for men and women living in Kentucky during 2001-2005 was 59.3 per 100,000 and the age-adjusted mortality rate was 22.0 per 100,000 persons. These rates are 20.5% and 17.0% higher than the national rates for incidence and mortality, respectively.

Gender and Race Differences

Gender and race differences in colorectal cancer incidence and mortality rates have also been identified. The rate of colorectal cancer incidence in the United States during 2001-2005 was significantly higher for men (57.3 per 100,000 men) than for women (42.9 per 100,000 women). Similarly the age-adjusted mortality rate was higher in men than in women during the same time period (22.7 per 100,000 men versus 15.9 per 100,000 women).

Data from the SEER program shows that Blacks in the U.S. have higher age-adjusted incidence and mortality rates than Whites. During 2001-2005, the incidence of colorectal cancer in Blacks (60.3 per 100,000 Blacks) was 24.3% higher than Whites (48.5 per 100,000 Whites).

Table I. Colorectal Cancer, 2001-2005

	Frequency	Percent
Gender		
Male	6330	50.6%
Female	6190	49.4%
Race		
White	11625	92.9%
Black	830	6.6%
Other	65	0.5%
Age		
<50	1155	9.2%
50-70	5403	43.2%
>70	5962	47.6%
Geographic Region		
Urban	6756	54.0%
Rural	5764	46.0%
Appalachian Region		
Appalachia	3734	29.8%
Non-Appalachia	8786	70.2%

Furthermore, Blacks in the United States have notably higher mortality rates due to CRC than Whites (26.1 per 100,000 Blacks compared to 18.3 per 100,000 Whites).

The rates of colorectal cancer by gender and race in Kentucky are higher than those for the U.S. The age-adjusted incidence rate for all men in Kentucky during 2001-2005 was 70.3 per 100,000 men which represents a 22.7% higher rate than the national estimate for men. The incidence of colorectal cancer in women in Kentucky is lower than that of men in Kentucky, but is 19.8% higher than the rate for women in the nation. Mortality rates for men and women in Kentucky are 17.2% and 18.2% higher than the U.S. mortality rates for men and women, respectively.

Table 2. Colorectal Cancer Incidence and Mortality by Race & Gender, 2001-2005

	Incidence*				Mortality*			
	Men		Women		Men		Women	
	U.S.**	KY	U.S.**	KY	U.S.**	KY	U.S.**	KY
Race								
All	57.3	70.3	42.9	51.4	22.7	26.6	15.9	18.8
Black	70.1	81.3	53.9	65.5	31.8	33.2	22.4	30.1
White	56.5	69.8	42.0	50.6	22.1	26.2	15.3	18.2

*Rates are per 100,000 **SEER*Stat SEER 13 registries

Rates in red represent KY rates that are higher than the U.S. rates.

Colorectal cancer incidence rates in Kentucky also vary by race. During 2001-2005, Blacks in Kentucky had an age-adjusted incidence rate of 71.7 per 100,000, which represented an 18.9% higher rate than Blacks in the U.S. (60.3 per 100,000). Likewise, White Kentuckians experienced a 21.0% higher age-adjusted incidence rate than Whites in the United States. Like the rates in the U.S., Blacks have a higher mortality rate than Whites, but the rates in Kentucky are markedly higher than those of the nation. Age-adjusted mortality rates for Blacks and Whites in Kentucky are 19.2 and 17.5% higher than the U.S. rates, respectively. See Table 2.

Table 3. Colorectal Cancer by Stage at Diagnosis, 2001-2005

	Early Stage		Late Stage	
	U.S.*	KY**	U.S.*	KY**
Sex				
Male	42.7%	50.5%	57.3%	49.5%
Female	41.4%	48.8%	58.6%	51.2%
Race				
Black	37.5%	45.7%	62.5%	54.3%
White	42.7%	49.4%	57.3%	50.6%

*SEER*Stat SEER 13 Registries **Kentucky Cancer Registry

Of the Blacks in Kentucky diagnosed with CRC in 2001-2005, 54.3% were diagnosed in late stage. In contrast, 50.1% of Whites in Kentucky were diagnosed with late stage CRC during the same time period. See Table 3.

Despite increased screening efforts aimed at identifying colorectal cancer in early stage, the percentage of colorectal cancers in the United States diagnosed in late stage remains high. Early stage is defined as *in situ* and localized stages, while late stage is defined as regional and distant stages using the SEER Summary Stage. Of all new colorectal cancer cases diagnosed in the U.S. during 2001-2005 (excluding unknown and undefined cancer stages), 57.9% were classified as late stage. Kentucky has a lower percentage of new CRC cases diagnosed in late stage (50.3%) than the U.S. Men in Kentucky had a lower percentage of cases diagnosed in late stage than women in Kentucky (49.5% and 51.2%, respectively). Of the Blacks in Kentucky diagnosed with CRC in 2001-2005, 54.3% were diagnosed in late stage. In contrast, 50.1% of Whites in Kentucky were diagnosed with late stage CRC during the same time period. See Table 3.

Screening

Current guidelines set forth by the American Cancer Society suggest that all adults 50 years of age and older should participate in regular screening for colorectal cancer. For more information on screening guidelines and the types of screening methods available, please refer to the American Cancer Society web site at www.cancer.org.

The prevalence of colorectal cancer screening in the United States is low. According to the 2004 Behavioral Risk Factor Surveillance System (BRFSS), 26.5% of adults 50 years of age and older have had a fecal occult blood test (FOBT) in the last two years, while 53.5% of adults claimed to have ever had a sigmoidoscopy or colonoscopy. Slightly more male than female adults 50 years of age and older reported ever having had a sigmoidoscopy or colonoscopy (53.8% and 53.3%, respectively).

In Kentucky, rates of screening are lower than the national CRC screening rates. Of Kentucky adults 50 years of age and older, 24.0% reported having had a FOBT test within the last two years. Only 47.2% of Kentucky adults reported having ever had a sigmoidoscopy or colonoscopy. In addition, more adult women than men in Kentucky claimed to have ever had a sigmoidoscopy or colonoscopy (49.7% and 44.2%, respectively).

GEOGRAPHIC VARIATIONS WITHIN KENTUCKY

Appalachia versus Non-Appalachia

Of the 120 counties in Kentucky, 51 are designated as Appalachian by the Appalachian Regional Commission. The age-adjusted incidence rate of CRC in Appalachian Kentucky was 61.0 per 100,000 persons during 2001-2005, while the rate for Non-Appalachian Kentucky was slightly lower at 58.6 per 100,000 persons during the same time. Colorectal cancer mortality rates in Appalachian Kentucky (22.2 per 100,000 persons) are similar to the mortality rates of Non-Appalachian Kentucky (21.9 per 100,000 persons) and the entire state (22.0 per 100,000). Of the 3734 colorectal cancer cases in Appalachian Kentucky, 52.0% were diagnosed in late stage. A lower percentage (49.6%) of the 8786 cases of CRC in Non-Appalachian Kentucky were diagnosed in late stage during 2001-2005.

The incidence rate of CRC for women in Appalachian Kentucky (54.4 per 100,000) was higher than that of women in Non-Appalachian Kentucky (50.2 per 100,000). Conversely, the CRC incidence rate for men in Non-Appalachian Kentucky (70.4 per 100,000) was higher than that of men in Appalachian Kentucky (69.9 per 100,000). Women in Appalachian Kentucky had a slightly

Table 4. Colorectal Cancer Incidence and Mortality by Appalachian Region, 2001-2005

	Incidence*			Mortality*		
	KY**	Appalachian KY**	Non-Appalachian KY**	KY**	Appalachian KY**	Non-Appalachian KY**
Gender						
Male	70.3	69.9	70.4	26.6	26.5	26.6
Female	51.4	54.4	50.2	18.8	19.0	18.7

*All rates are per 100,000 **Source: Kentucky Cancer Registry

Rates in red represent KY rates that are higher than the U.S. rates.

higher mortality rate (19.0 per 100,000) than Non-Appalachian women (18.7 per 100,000). Men in Appalachian and Non-Appalachian Kentucky had similar mortality rates (26.5 per 100,000 versus 26.6 per 100,000, respectively). See Table 4.

Urban versus Rural

Differences in colorectal cancer rates also exist between urban and rural areas of Kentucky. Beale codes are utilized to categorize areas of Kentucky as urban or rural based on the definition of metropolitan and non-metropolitan counties set forth by the Office of Management and Budget (OMB).

The age-adjusted incidence rate of CRC in urban Kentucky (59.8 per 100,000) was slightly higher than rural Kentucky (58.9 per 100,000). Urban men, women, Blacks, and Whites have higher incidence rates than their rural counterparts. The percentage of late stage diagnoses of colorectal cancer was slightly lower in urban Kentucky (49.9%) as compared to rural Kentucky (50.8%). Table 5 details the regional variations in late stage diagnoses of CRC in Kentucky.

The CRC mortality rate in urban Kentucky is higher than that of rural Kentucky (22.4 per 100,000 and 21.5 per 100,000, respectively). Men in urban Kentucky have a higher rate of mortality (27.3 per 100,000) than men in rural Kentucky (25.7 per 100,000). In addition, urban Blacks in Kentucky have a higher mortality rate than rural Blacks in Kentucky while urban and rural Whites in Kentucky have very similar rates of mortality. See Table 5.

Table 5. Late Stage Diagnosis of Colorectal Cancer, 2001-2005

	Incidence*			Mortality*		
	KY**	Urban**	Rural**	KY**	Urban**	Rural
Gender						
Male	70.3	71.4	69.2	26.6	27.3	25.7
Female	51.4	51.6	51.3	18.8	19.1	18.5
Race						
Black	71.7	72.3	69.2	31.1	31.4	30.4
White	58.7	58.8	58.6	21.5	21.7	21.3

*All rates are per 100,000 **Source: Kentucky Cancer Registry

CONCLUSION

In conclusion, the burden of colorectal cancer in Kentucky is significant. Although screening methods for colorectal cancer are available, rates of screening for the disease in Kentucky fall below national screening rates. Variations in incidence and mortality rates within the state suggest that collaborative efforts aimed at more aggressive screening practices are needed in certain populations and regions of the state in order to decrease morbidity and mortality from colorectal cancer.

For more information on colorectal cancer in Kentucky, visit our web site:

www.kcr.uky.edu

THE KCR WEB SITE: PUBLIC ACCESS TO CANCER INCIDENCE AND MORTALITY RATES

www.kcr.uky.edu

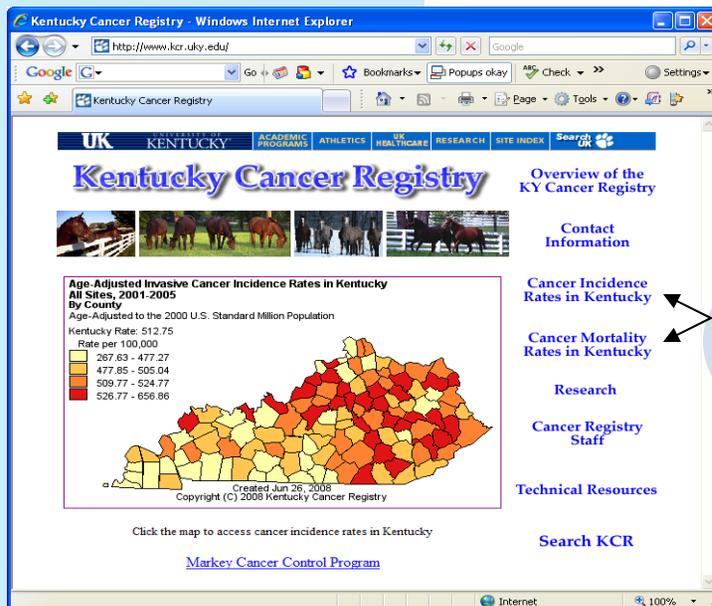
The Kentucky Cancer Registry web site was created to provide the public with user-friendly access to cancer data in Kentucky. Cancer incidence data reported by KCR were first available from the World Wide Web in January 1995. In 2002, the web site was updated to provide the public with both cancer incidence and cancer mortality data.

The web site is a resource that both public and private agencies can use to understand the distribution of cancer throughout Kentucky. Information provided on the web site is also useful for planning and targeting appropriate cancer control and intervention strategies as well as for the allocation of health care resources. In addition, the information presented at the county and Area Development District (ADD) levels can be used to provide insight for developing appropriate programs regarding cancer prevention, screening, diagnosis, and management.

Navigating the KCR Web Site

The KCR web site address is www.kcr.uky.edu. Cancer incidence and mortality rates can be accessed by clicking on the incidence and mortality icons on the right side of the homepage. Figure 1 displays the KCR homepage.

Figure 1. KCR web site homepage.

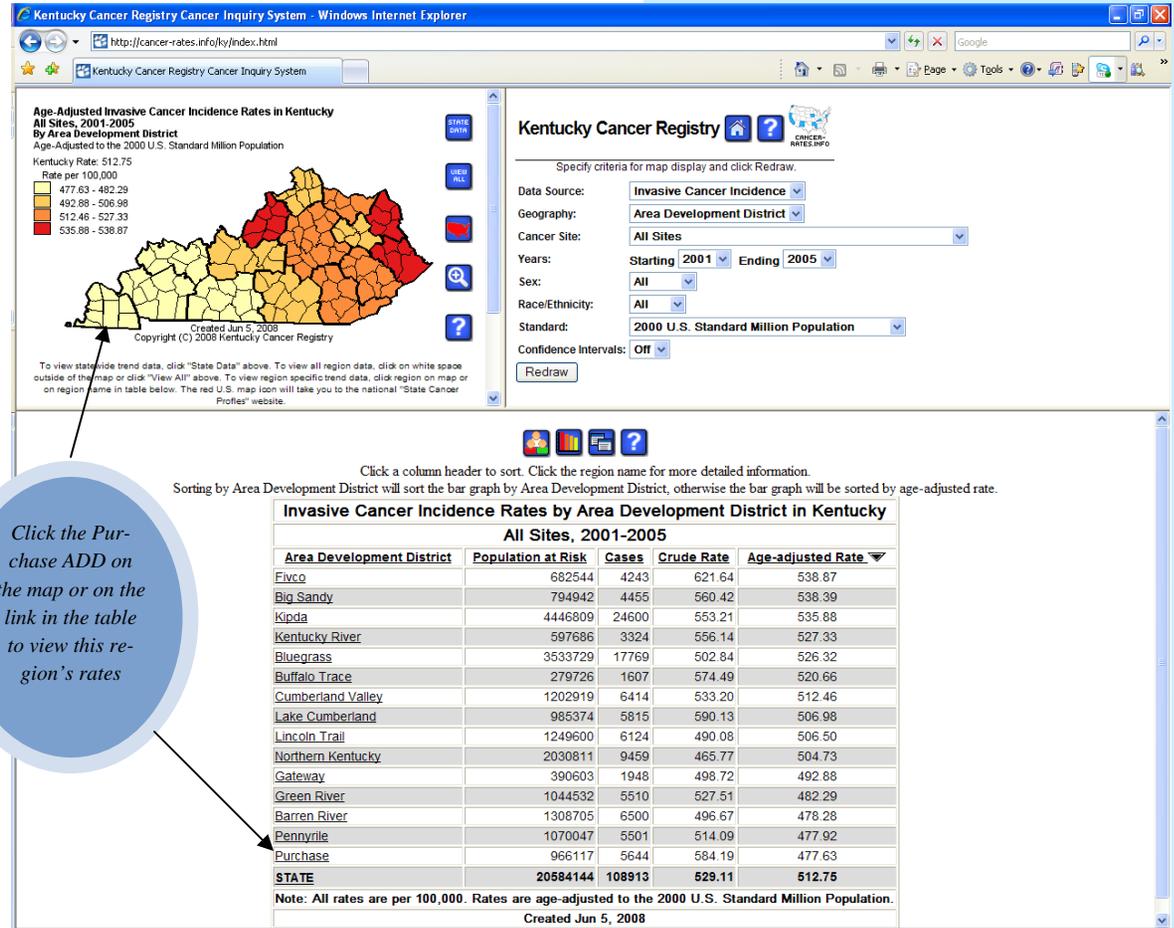


Left-clicking on either the incidence or mortality icon will split the screen into a map of Kentucky on the left and selection criteria on the right. The web site enables users to specify display criteria for both incidence and mortality data. Each of the criteria have convenient drop-down lists that include the data available. The user can select specific cancer sites and years (1995 through 2005) for data as well as the sex and race of the population. A standard reference population may be selected in addition to how the data are displayed geographically. The age-adjusted rates can be mapped by county, Area Development District (ADD), Appalachian region, or urban/rural regions. The at-risk population, case counts, crude rates, age-adjusted

Rates, and 95% confidence intervals can be obtained for the entire state and are also available by ADD, county, Appalachian region, and urban/rural region. Once the specific criteria are chosen, left click on the “Redraw” icon and the map will reconfigure to display the requested rate(s) along with a third screen that displays the regional rates that correspond with the criteria selected for the geographic region. Figure 2 displays all site, invasive cancer incidence by ADD from 2001-2005.

There are two ways in which the user can view specific regional rates. First, the user can move the cursor over the interactive map and left click the mouse on the desired county, ADD, Appalachian, or urban/rural region or the user can left click the name of the region that appears in the table below the map (see Figure 2). Once the desired area is selected, a table appears at the bottom of the screen that includes the population at risk, the total number of cases, crude rate, age-adjusted rate, and the statewide age-adjusted rate for each year these rates were requested. See Figure 3.

Figure 2. All site, invasive cancer incidence by ADD



Click the Purchase ADD on the map or on the link in the table to view this region's rates

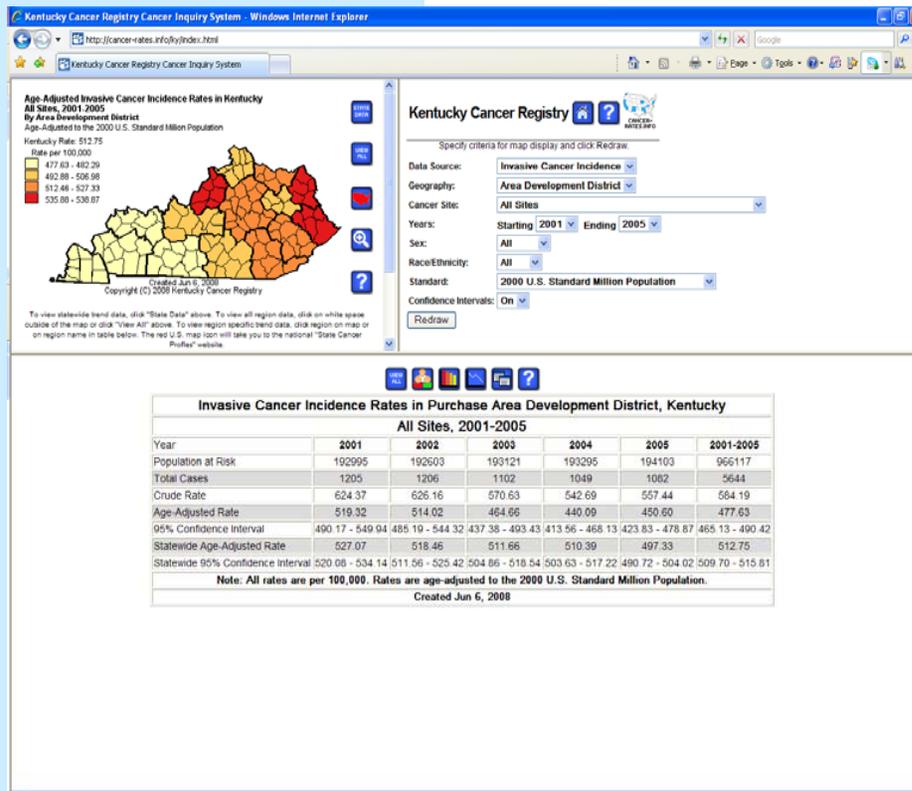
Interpreting the Data in the Table

Population at Risk: This number represents the total number of residents who were at risk for the cancer type, gender, and race that was specified. Not all residents are at risk for all cancers. For example, males are not at risk for cervical cancer and females are not at risk for prostate cancer. The population is defined by either the U.S. census or the inter-censal estimate of the population living in each geographic region for each year of data. The population at risk is the sum of the populations at risk for each year of data selected.

Total Cases: The cases are the total number of cancer cases occurring during the selected year(s). It is important to note that the cases are not the number of persons with cancer, as persons may have multiple cases of cancer.

Deaths: Deaths are the number of people who died from a specified cancer during the selected year(s).

Figure 3. Case counts and rates by ADD



Crude Rate: This number represents the number of cases or deaths per 100,000 population at risk for the selected years.

Age-Adjusted Rate: Age-adjustment is used in order to compare cancer incidence and mortality rates across different states or regions. The process of age-adjustment removes differences in the cancer incidence or mortality rates that are due to differences in the age structures of the populations being compared and allows for comparison of rates between different counties or regions.

95% Confidence Interval: When this feature is turned on, the upper and lower bound 95% confidence intervals are displayed for the age-adjusted rates.

Special Note: In order to protect patient confidentiality, case counts and age-adjusted rates are suppressed when the total number of cases is 5 or fewer. Also, rates with fewer than 15 cases are considered unstable and are designated by the *** symbol.

Interpreting the Maps

The age-adjusted incidence and mortality rates are mapped by ADD, county, Appalachian region, or urban/rural regions. Maps displaying incidence rates by ADDs and counties are color-coded from yellow to red, while the mortality rates are color-coded from yellow to blue. Each shade represents a quartile, or one-fourth, of the range of incidence and mortality rates, respectively. The ADDs and counties with the lowest rates are shaded the lightest while the areas with the highest rates are shaded the darkest. Maps displaying incidence and mortality rates by Appalachian region and urban/rural region are shaded in two separate colors to represent the two regions. For both incidence and mortality rates, the lighter shade corresponds to the lower rate while the darker shade represents the higher rate.

There are 5 icons that appear to the right of the shaded map. The following details the function of each icon:



This icon displays the statewide incidence or mortality rates for the type of cancer selected. Rates are presented for each year specified and all years combined.



This icon allows the user to view the rates for all of the regions in the specific criteria selected (county, ADD, urban/rural, Appalachian regions).



This icon redirects the user to the State Cancer Profiles web site sponsored by the National Cancer Institute (NCI) and the Centers for Disease Control and Prevention (CDC). The web site has specific incidence and mortality data for all sites of cancer in Kentucky as well as the 49 other states and the District of Columbia.



This icon enlarges the map image and allows the user to copy the map into another document. The user can choose color or grayscale.



This icon directs the user to the help topics page.

Bar Graphs and Trend Charts

Bar graphs, trend charts, and age-specific rate charts that display cancer incidence or mortality data are also available on the web site. There are six icons that appear above the table. These icons allow the user to obtain graphs and charts. The following details the function of each icon:



This icon allows the user to view the rates for all of the regions in the specific criteria selected (county, ADD, urban/rural, Appalachian regions).



This icon produces a table that displays the total number of residents who were at risk for the cancer site selected and the year(s) selected. When the sex and race are specified, the table will display the populations according to the selected sex and race.



This icon generates a bar graph of the cancer incidence or mortality rates for all regions in the selected geography.



This icon produces a trend line of the incidence or mortality rates for the years selected. The trend line is useful in making comparisons of incidence or mortality over time. Figure 4 displays the trend line for female breast cancer in Kentucky from 1995 to 2005.

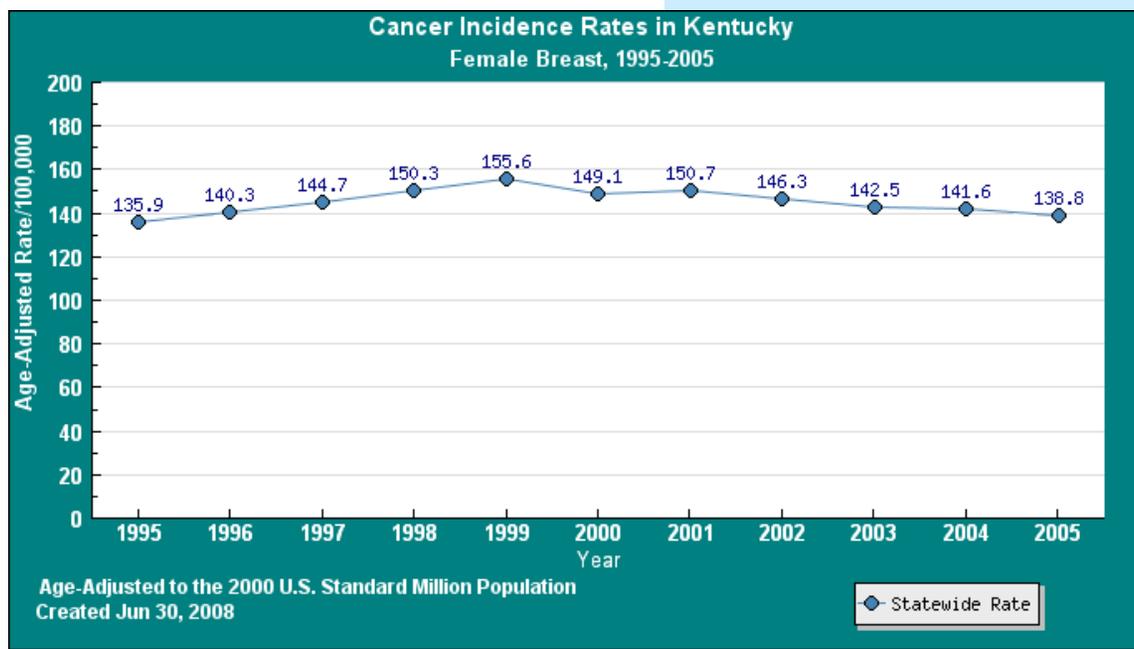


This icon displays cancer incidence or mortality for the most recent five-year period for all cancer sites in a specified region.



This icon directs the user to the help topics page.

Figure 4. Female breast cancer incidence rate trend line, 1995-2005



2007-2008 RESEARCH USING KCR DATA

The Kentucky Cancer Registry recognizes four categories, levels, or types of data that can be released for cancer surveillance and research purposes. Investigators who wish to use data from the registry for research purposes must complete an application for review by the KCR review panel. All applications include a detailed description of the proposed research study and assurances of maintaining confidentiality of sensitive data. Level two through four studies must also include documentation of approval by an appropriately constituted institutional review board (IRB) or human subjects review committee.

During 2007-2008, the Kentucky Cancer Registry received a number of requests to use registry data for research purposes. These population-based research studies are aimed at understanding, preventing, and treating cancer. Each of the following projects was conducted by or done in collaboration with the Kentucky Cancer Registry. The researchers and their projects are highlighted below.

For more information on how to request data from the registry please go to our web site: www.kcr.uky.edu.

Level I Projects

A level I project is a report of data stratified by non-confidential data fields such as case counts by race, sex, or county of residence. The following research utilized KCR data and qualified as a level I data request:

Norton Healthcare Quality Report

Principal Investigator: Li Li, MS, Senior Clinical Information Analyst, Norton Healthcare, Louisville, KY

Five-year survival rates by stage at diagnosis for years 1998 to 2000 are requested for prostate, colon, rectum, lung, female breast, cervix, melanoma, kidney, and bladder cancers. The censored life tables are used for Norton Healthcare's quality healthcare report that is available on their institution's web site.

Norton Healthcare: Examining Disparities in Cancer

Principal Investigator: Tina Hembree, MPH, Program Coordinator, Norton Cancer Institute, Prevention and Early Detection, Louisville, KY

The purpose of the study is to determine if there are differences in cancer incidence and mortality between African-Americans, Hispanics/Latinos, and Caucasians in Norton Cancer Institute's target areas that include Jefferson and Shelby counties. The cancers being examined are female breast, colon, prostate, lung, and cervix.

Evaluation of a Local Pilot Cancer Control Program

Principal Investigator: Brittney Thomas, BA, MPH candidate, University of Kentucky, College of Public Health, Lexington, KY

A pilot program aimed at increasing breast and cervical cancer screening rates is evaluated. Data on early and late stage female breast and cervix cancer incidence pre- and post-intervention is requested for the intervention/target counties in Kentucky and the control/compare counties in Kentucky.

Level 2 Projects

Level 2 projects are data files containing individual, record-level data with no personal identifiers. The files will not contain name, street address, phone number, social security number, date of birth, any reporting facility, or physicians involved in the patient's care. The files may contain zip code and county of residence. The following are projects that contain level 2 data:

Prostate Cancer Treatment Efficacy

Principal Investigator: David Clark, MPH, DrPH candidate, University of Kentucky, College of Public Health, Lexington, KY

This project utilizes Kentucky Cancer Registry data related to cases of prostate cancer diagnosed in Kentucky between 1995 and 2005. The study seeks to determine prostate cancer treatment efficacy through examination of the survival for those who were treated for prostate cancer and those who received no treatment.

Disparities in Stage at Diagnosis Among Adults with Oral Cancer in Kentucky

Principal Investigator: Juan F. Yepes, DDS, MD, MPH Candidate, University of Kentucky, College of Dentistry, Lexington, KY

The main objective of the study is to determine if there are gender, race, or geographic disparities in rates of incidence and mortality, and in the distribution of stage at diagnosis of oral cancers (including lip, tongue, gum, and floor of the mouth) diagnosed in Kentucky between 1995 and 2004.

Disparities in Access to Screening Mammography in the Rural South

Principal Investigator: Linda Elting, DrPH, MD Anderson Cancer Center, Health Services Research, Houston, TX

The intent of the study is to examine the impact of access to an in-county mammography facility on mammography screening rates and stage of breast cancer at diagnosis in counties in the South. The researchers also aim to determine whether lack of access amounts for part of the disparity in stage of breast cancer at diagnosis among racial and ethnic minority women.

Radon, Tobacco Smoke, and Lung Cancer in Kentucky

Principal Investigator: Gwendolyn Hayes, MS, ARNP, PhD/MPH candidate, University of Kentucky, College of Nursing, Lexington, KY

The purpose of the study is to describe the relationship between lung cancer incidence by zip code, adult smoking rates, and residential radon levels by utilizing Geographical Information System (GIS) software. The results of the study will be used to target high-risk geographic areas for public health education and screening interventions.

Development of Breast Cancer Recurrence Prediction Model Using Machine Learning Algorithm

Principal Investigator: Sujin Kim, PhD, University of Kentucky, School of Library and Information Science, Lexington, KY

The purpose of the study is to employ various machine learning approaches in order to determine the best prediction model for female breast cancer recurrence and survival. Existing tools such as Weka, Clementine, and SAS systems will be used to determine which data mining algorithms are best suited to support the breast cancer data collected at the Kentucky Cancer Registry.

Geographic Disparities in Gynecologic Cancer Incidence and Mortality in Kentucky

Principal Investigator: Mary Gordinear, MD, University of Louisville, James G. Brown Cancer Center, Louisville, KY

Co-Investigator: Carol Hanchette, PhD, University of Louisville, Department of Geography and Geosciences, Louisville, KY

The aim of the study is to examine geographic disparities in gynecologic (cervix, endometrium, and ovary) cancer incidence and mortality in Kentucky. In particular, potential survival differences between women treated in areas with access to a gynecologic oncologist and those treated in areas without one will be explored. Furthermore, the researchers intend to identify areas with geographic clustering of high cancer rates and examine these areas within the context of neighborhood-level and county-level socioeconomic and access-to-care indicators.

Patterns of Cancer Care in Kentucky

Principal Investigator: Ramesh Gupta, PhD, University of Louisville, School of Medicine, Louisville, KY

Co-Investigator: Frank Groves, MD, MPH, University of Louisville, School of Public Health and Information Sciences

The purpose of the study is to estimate the proportion of newly-diagnosed cases of breast, cervix, colorectal, lung, and prostate cancers in Kentucky between 1995 and 2004 that wait more than 28 days to begin their first course of treatment after initial diagnosis of cancer. Gender, race, and regional differences will be examined.

Level 3 Projects

A level 3 data request includes files containing individual, record-level data with personal identifiers, to be used for purposes of record linkage, either electronic or manual, but not direct patient contact. Once the record linkage is complete, the personal identifiers are removed from the data set. The following are projects that utilize data that was linked with the Kentucky Cancer Registry database:

The Black Women's Health Study

Principal Investigator: Lynn Rosenberg, ScD, Boston University, Boston, MA

The Black Women's Health Study (BWHS) is a large, prospective follow-up study of African-American women from across the United States. The aims of the study include prospective analyses of the influence of body size, physical activity, diet, alcohol consumption, oral-contraceptive use, hair relaxer use, cigarette smoking, and psychosocial factors on the incidence of breast cancer in black women.

Health Effects of Occupational Exposures in Paducah Gaseous Diffusion Plant Workers

Principal Investigator: David J. Tollerud, MD, MPH, University of Louisville, School of Public Health and Information Sciences, Louisville, KY

Co-Investigator: Gail Brion, PhD, University of Kentucky, College of Public Health, Lexington, KY

The main objective of the research is a comprehensive occupational health study of workers at the Paducah Gaseous Diffusion Plant, a producer of enriched uranium for use by commercial reactors or as feed material for other plants that further enrich uranium. The plant is located in western Kentucky, approximately ten miles west of the city of Paducah. This aspect of the study aims at identifying cancer cases within a cohort of workers at the plant in an attempt to evaluate the impact of historical occupational exposures on worker morbidity and mortality.

Smoking and Cervical Cancer Survival

Principal Investigator: Ann Coker, PhD, University of Kentucky, Department of Obstetrics and Gynecology, Lexington, KY

The purpose of the study is to determine the role of smoking on stage of disease detection, treatment received, and survival among a cohort of Kentucky women diagnosed with cervical cancer between 1995 and 2004.

Adjuvant Treatment Decision Making for Lung Cancer

Principal Investigator: Jamie L. Studts, PhD, University of Kentucky, College of Medicine, Department of Behavioral Science, Lexington, KY

The primary objective is to examine the effects of different methods of communicating quantitative estimates of treatment benefit on adjuvant chemotherapy decisions among individuals diagnosed with non small cell lung cancer (NSCLC) in Kentucky. The secondary aim of the research is to examine sociodemographic, psychological, social, and health factors which influence adjuvant chemotherapy decisions among individuals diagnosed with NSCLC.

Level 4 Projects

A level 4 project is a request for files containing individual, record-level data with personal identifiers, to be used for research purposes involving direct patient or family contact. The following projects require direct patient contact and qualify as level 4 research projects:

Insulin-like Growth Factors, Diet and Risk of Colon Cancer: A Population-Based Case-Control Study

Principal Investigator: Li Li, MD, PhD, Case Western Reserve University, Cleveland, OH

Co-Investigator: Thomas C. Tucker, PhD, MPH, Markey Cancer Control Program, Kentucky Cancer Registry, Lexington, KY

Researchers are studying factors that may increase an individual's chance of getting colon cancer. The study will try to identify biomarkers, such as insulin-like growth factors, and genes as well as environmental factors that may cause colon cancer. Information about lifestyle and health, including diet, will be examined. The study will compare biomarkers, genes, and information about lifestyle and health between unrelated individuals with colon cancer and individuals without colon cancer.

Differences in Quality of Life Between Rural and Urban Dwelling Cancer Survivors

Principal Investigator: Michael Andrykowski, PhD, University of Kentucky, Department of Behavioral Science, Lexington, KY

The purpose of the study is to provide information regarding the nature, prevalence, and magnitude of disparities in quality of life (QOL) outcomes, particularly mental health outcomes, between rural and urban cancer survivors in Kentucky. Additionally, the study aims to provide information regarding possible sources of differences in QOL outcomes, particularly mental health outcomes, between rural and urban cancer survivors. Specifically, the study will assess and compare differences in regard to dispositional characteristics (e.g., optimism), social environment (e.g., social support, social constraint, social network), and awareness, access, and utilization of both formal and informal mental health care services.

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