

Defining the Cancer Burden for Cancer Control: Changing Data into Information

Presented by

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Topics to be covered

- **What is Cancer Control?**
- **What are the measures of cancer burden?**
- **What are the major sources of data that can be used to describe the burden of cancer?**
- **What are some limitations associated with using these major data sources?**
- **Some specific limitations associated with using central cancer registry data for cancer control.**
- **What are the major cancer control sites?**
- **What is the logic model for using these major sources of data to define the burden of cancer?**
- **How can sources of data be combined to give a better picture of the burden of cancer for the major cancer control sites in specific geographic areas?**

What is “Cancer Control”?

The NCI's Division of Cancer Prevention and Control (DCPC) has defined **cancer control** as

“The reduction of cancer incidence, morbidity, and mortality through an orderly sequence from research on interventions and their impact in defined populations to the broad systematic application of the research results.”

What is “Cancer Control”?

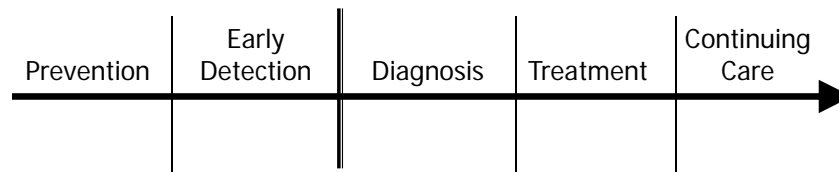
The CDC defines **Comprehensive Cancer Control** as

“An integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention (**primary prevention**), early detection (**secondary prevention**), treatment, rehabilitation, and palliation.”

What is “Cancer Control”?

The use of proven prevention, early detection, treatment, and continuing care intervention strategies to reduce cancer incidence, morbidity and mortality in defined populations.

Phases of Cancer Control

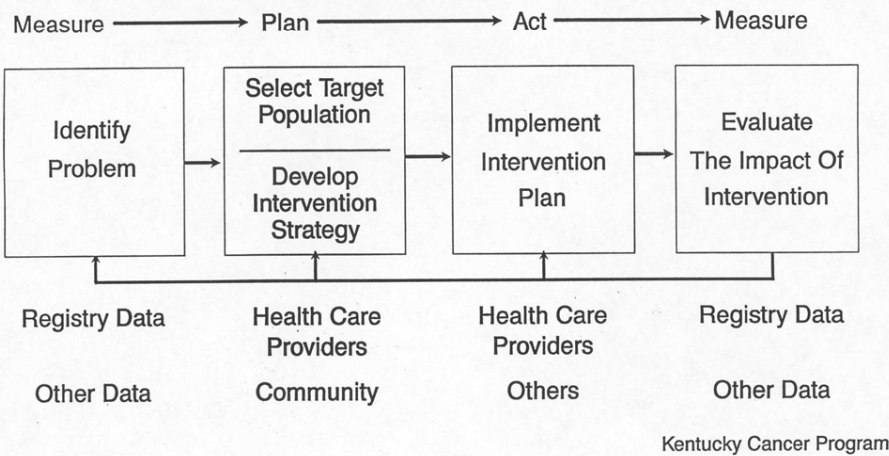


Data and Cancer Control

What is striking about the definition of cancer control are its implications for the use of **data** at all phases of the cancer control continuum. Muir, et al. have said that “**data** are an essential part of any rational program of cancer control”. In fact, it is difficult to imagine any effective cancer control efforts that do not rely on some type of **data** collection and analysis. In essence, **data** represent the eyes of our cancer control program. Without these eyes, it would not be possible to see our cancer control problems and it would not be possible to see the impact of our cancer control activities.

Model for Cancer Control

(Cancer control can be defined as "activities designed to reduce morbidity and mortality from cancer")



What are the basic measures used to describe the burden of cancer?

- Counts (Frequency)
- Demographic Characteristics
- Risk Factors
- Rates
 - Incidence
 - Mortality
 - Prevalence
 - Survival

All descriptive measures must be grounded by person, time and place.

Incidence Rate

**Number of new cases of disease
occurring in a defined population
during a specified period of time**

_____ X 100,000

**The number of people living
in the defined population
During the specified period of time**

Mortality Rate

Number of people dying
in a defined population
during a specified period of time

$$\frac{\text{Number of people dying in a defined population during a specified period of time}}{\text{The number of people living in the defined population during the specified period of time}} \times 100,000$$

The number of people living
in the defined population
during the specified period of time

Period Prevalence Rate

Number of cases of disease
present in a defined population
during a specified time period

$$\frac{\text{Number of cases of disease present in a defined population during a specified time period}}{\text{The number of people living in the defined population during the specified time period}} \times 100,000$$

The number of people living in the
defined population
during the specified time period

Survival Rate

- Crude or Observed Survival
- Cause Specific or Adjusted Survival
- Relative Survival

Describing the cancer incidence and mortality in Saskatchewan

- The 2007 estimated female breast cancer incidence rate in Saskatchewan was 98 per 100,000 population.
- The 2007 estimated female breast cancer mortality rate in Saskatchewan was 22 per 100,000 population.

Age Standardized using the 1991 Canadian population

Source: 2007 Cancer Statistics, Canadian Cancer Society

- Are these good rates?
- Are these bad rates?
- How can you tell?

Answer: You must compare these rates with the rates from some other population.

What are the common sources of data that can be used for cancer control and Cancer Control Research ?

- Demographic data (Census U.S. and Canada)
- Risk factor data (BRFSS, Canadian Health Risk Survey)
- Incidence data (NAACCR, SEER, NPCR, Statistics Canada)
- Mortality data (NCHS, Statistics Canada)

Demographic (Census) data

- Covers the entire population
- Provides details on important factors that influence the burden of cancer in a population
- Is only done once every 10 years in the U.S. and every 5 years in Canada.
- Is difficult to determine the number of people in a population by race and ethnicity.

Behavioral Risk Factor Surveillance System

- Largest telephone survey in the world
- Tracks many important health risks
- Complex sample design
- Difficult to generalize the information to small populations

Canadian Risk Factor Data

- **Survey data that can be generalized to whole populations.**
- **Tracks many important health risks in whole populations**
- **Complex sample design**
- **Difficult to generalize the information to small populations**

Incidence Data

- Closer in time to causal events
- Represents both occurrence and risk of getting disease
- Difficult to get all of the cases
- Complex coding rules
- Screening effect

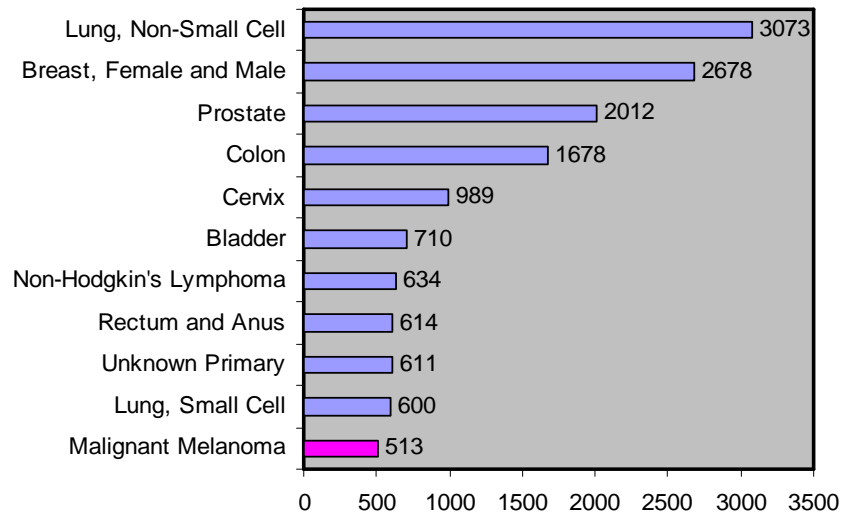
Mortality Data

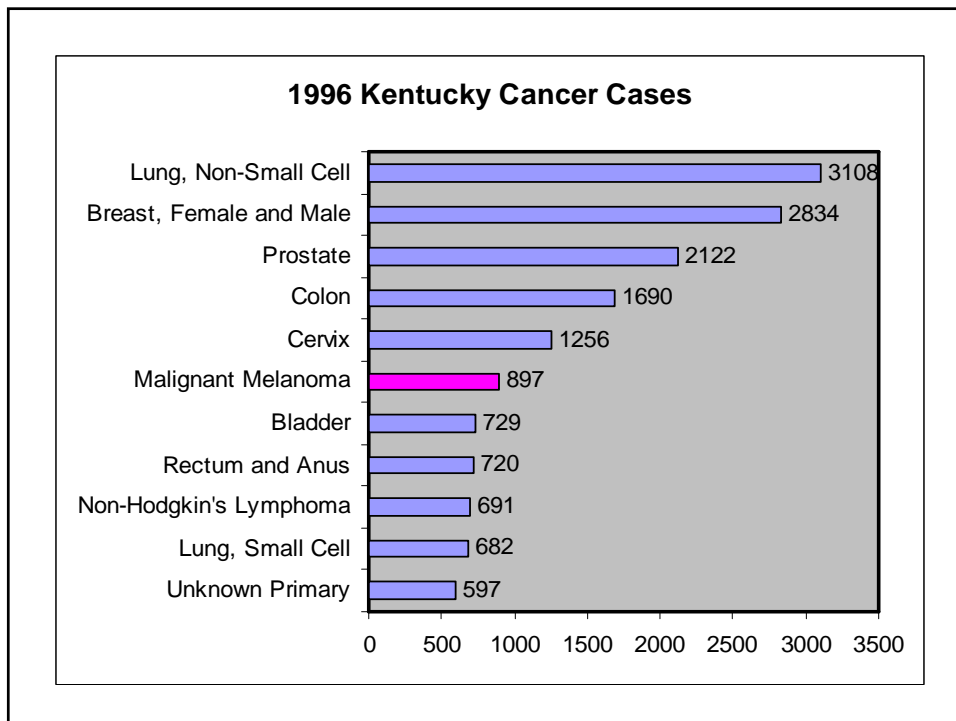
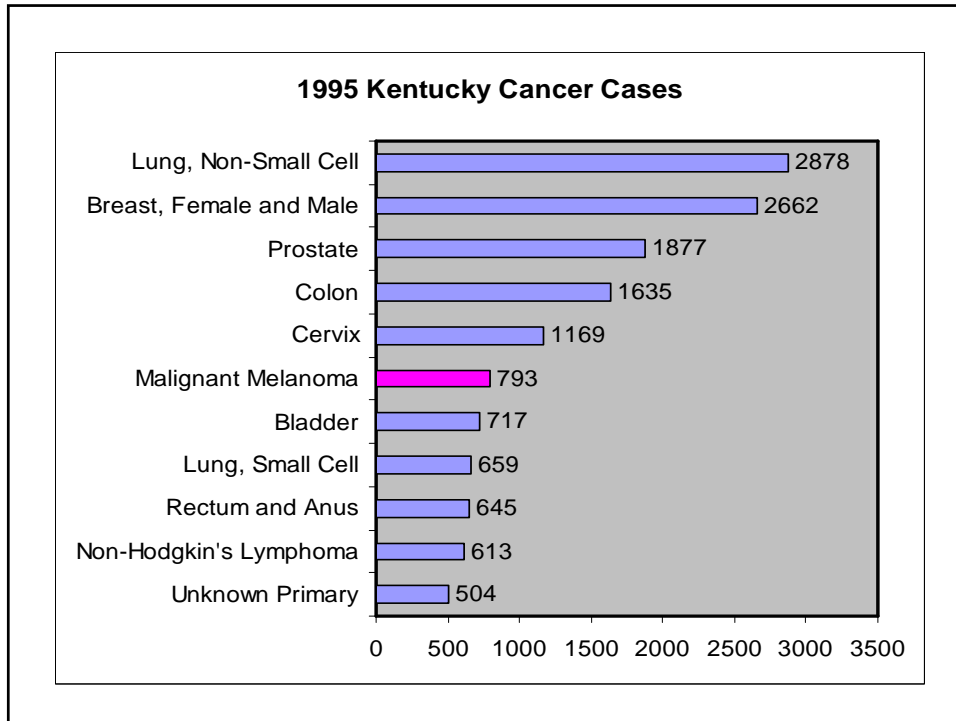
- Very complete data
- Represents the ultimate negative health outcome
- Far away in time from causal factors
- Care must be taken to use consolidated death records

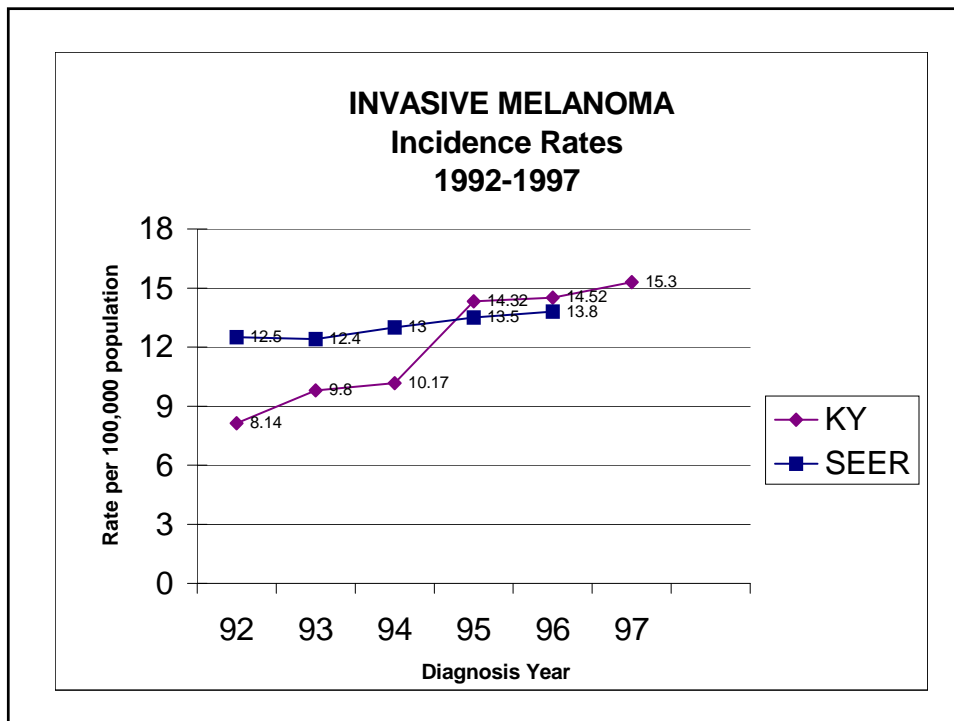
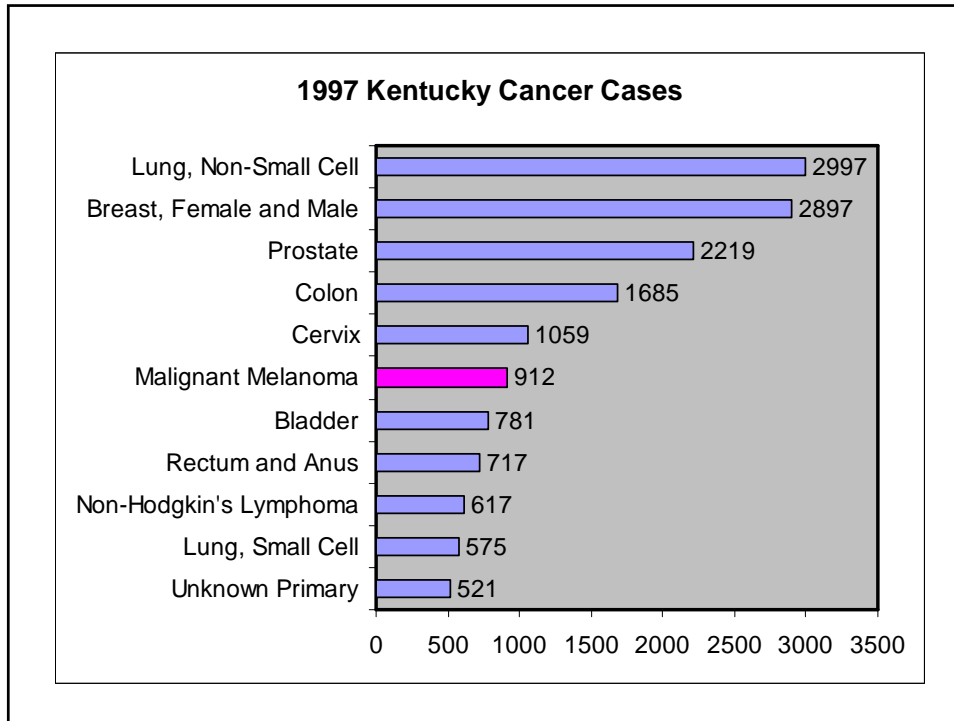
Limitations Associated with Using Central Cancer Registry Data for Cancer Prevention and Control

- The screening effect
- Difficulties associated with the occurrence of cancer in very small populations
- Difficulties associated with determining the true population at risk
- The nature and complexities of the diseases classified together as cancer
- The different roles of population scientists and cancer control advocates

1994 Kentucky Cancer Cases







Difficulties associated with the occurrence of cancer in very small populations

- The difference between “counts” (frequency) and “rates” (Risk).
- Community A: Population 1 million, Count = 1000 cases
Crude Rate = $1000/1,000,000 \times 100,000 = 100$ per 100,000 Pop.
- Community B: Population 100,000, Count = 100 cases
Crude Rate = $100/100,000 \times 100,000 = 100$ per 100,000 Pop.
- Community C: Population 1000, Count = 2 cases
Crude Rate = $2/1000 \times 100,000 = 200$ per 100,000 Pop.

Difficulties associated with the occurrence of cancer in very small populations (Cont.)

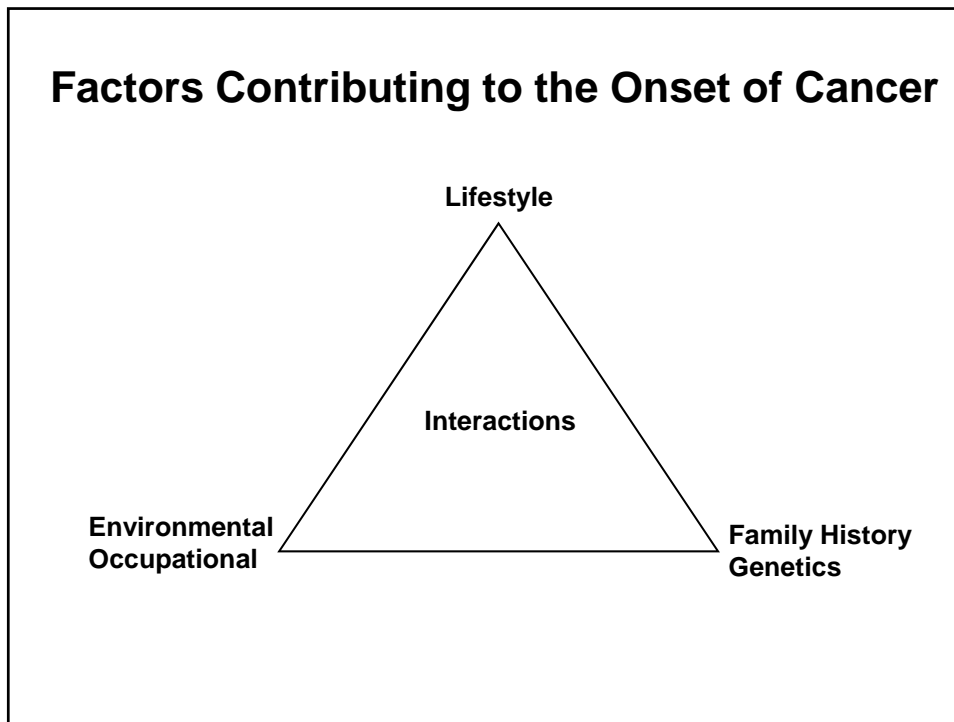
- Cancer rates are considered to be unstable when case counts are less than 15.
- Sentinel surveillance techniques can be used when communities have small populations and low case counts.
- Working with population scientists, communities should be able to determine if the frequency of cancer is normal (endemic) or abnormal (epidemic).

Difficulties associated with determining the true population at risk

- **It is not possible to calculate the rate (risk) of cancer in a community or special population unless the number of people living in the population is known.**
- **The number of people in many special population groups is not known because this information is not available from the U.S. Census Bureau or another source.**
- **Cancer incidence rates can not be calculated without knowing both the population at risk (the denominator) and the number new cases occurring (the numerator).**

The nature and complexities of the diseases classified together as cancer

- **Difficulties associated with communicating scientific information to people who do not understand science.**
- **Cancer is not one disease. Rather, cancer is a term for a large number of diseases that we classify together.**
- **Each cancer has a different set of factor that contribute to its' onset.**
- **Most cancers are not caused by a single factor.**



Components Contributing to the Onset of Cancer

Lifestyle Factors	(68%)
Occupational and Environmental Exposures	(18%)
Genetics and Family History	(13%)

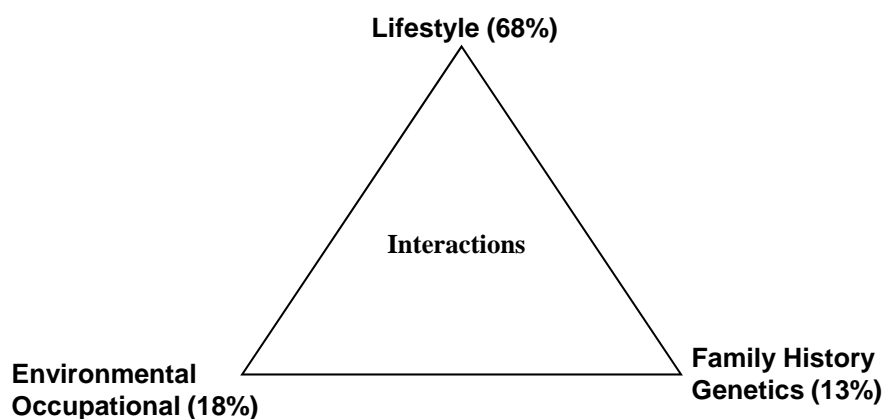
Source: Harvard Report on Cancer Prevention, *Cancer Causes & Control*, Vol. 7, Supplement 1, Nov. 1996

The preceding information is for all cancers combined.

It is important to note that the relative contribution of environmental, genetic, and behavioral factors will be different for each specific type of cancer and in each individual.

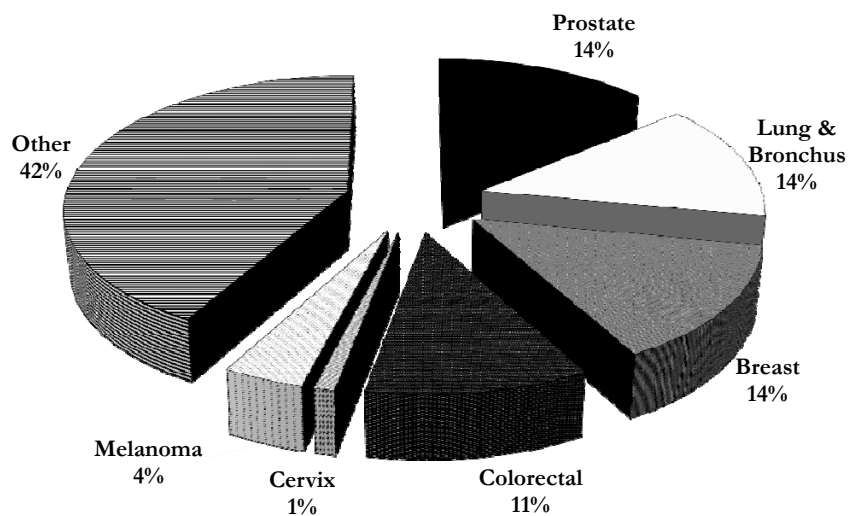
It is also important to note that the interaction between environmental, genetic, and behavioral factors may significantly increase the risk of cancer.

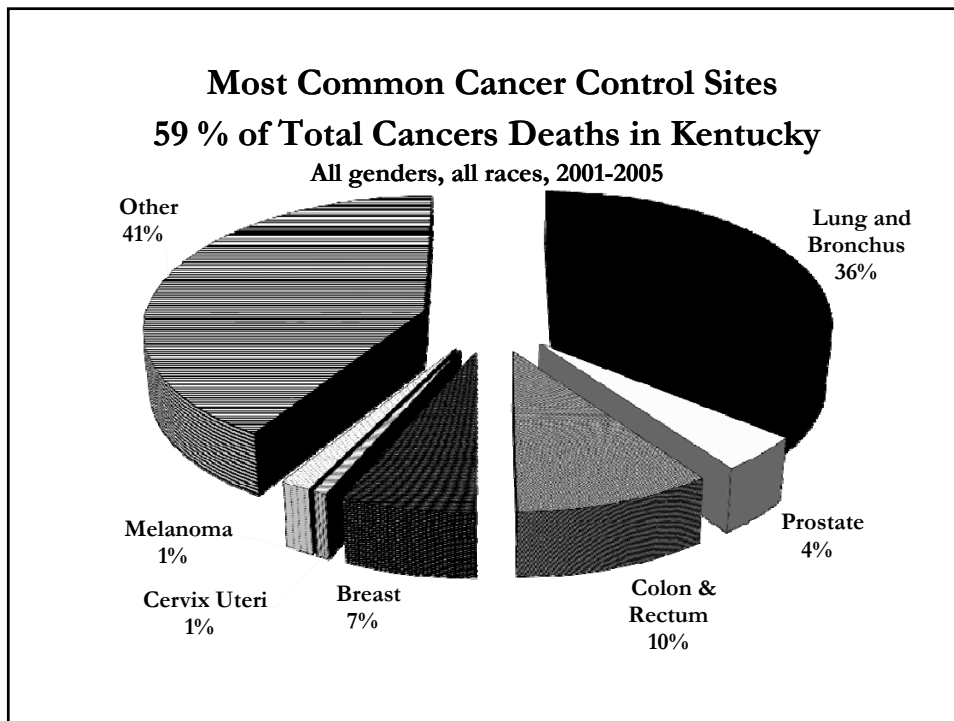
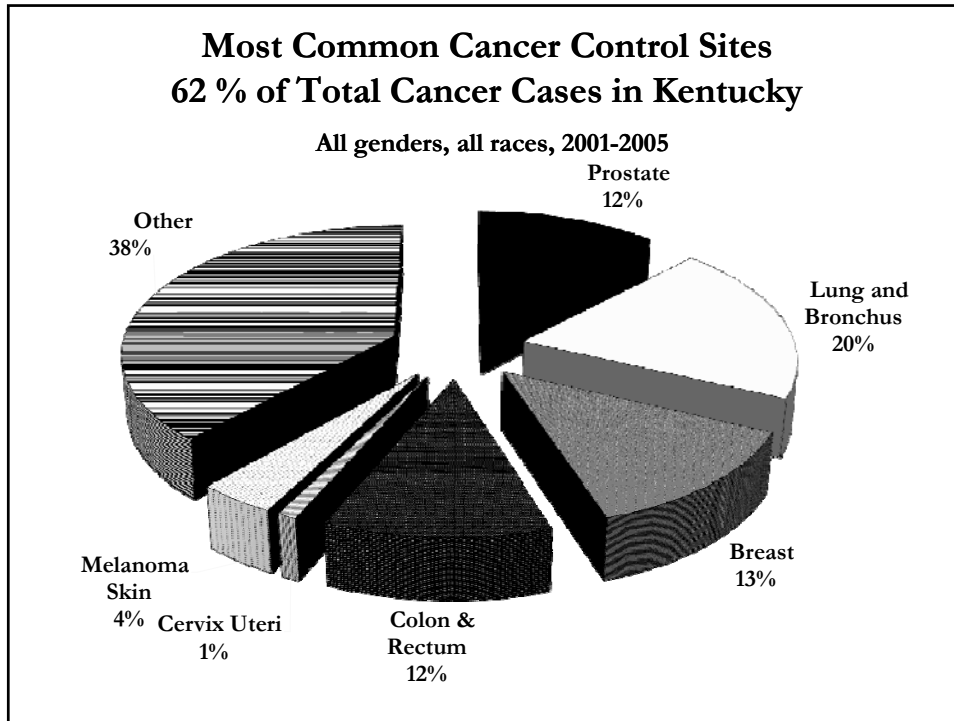
Factors Contributing to the Onset of Cancer

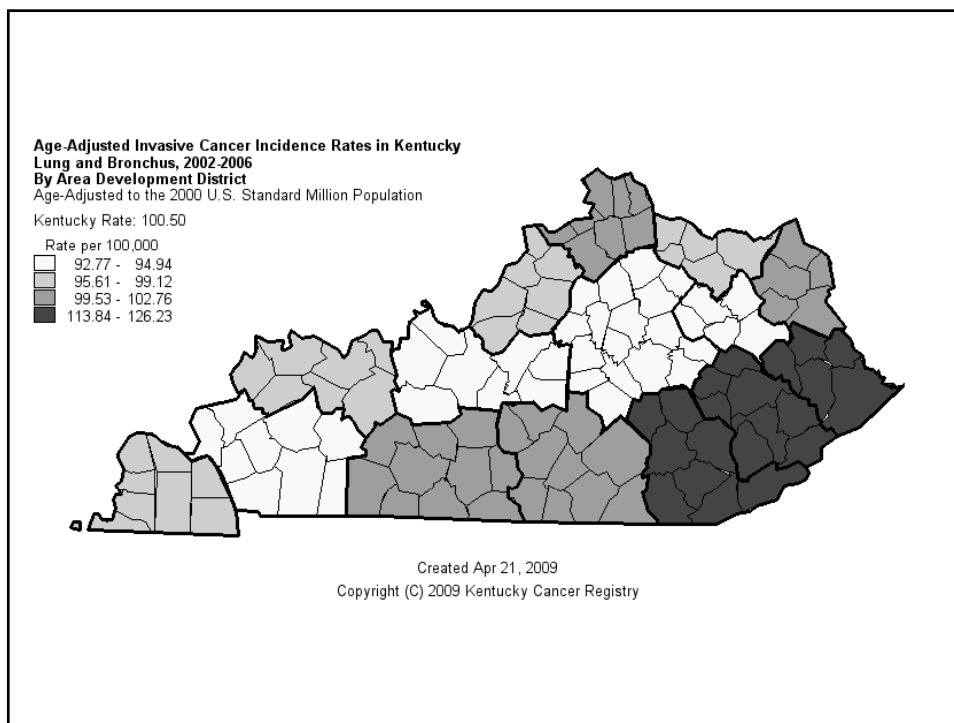
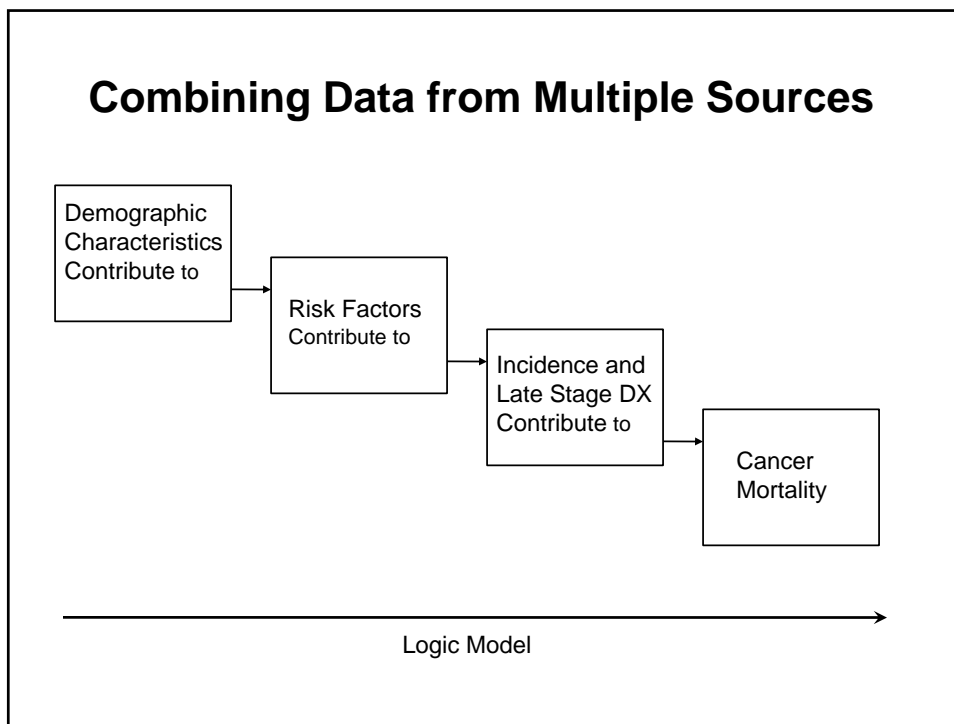


What are the major cancer control sites?

**Most Common Cancer Control Sites
58 % of Total Cancer Cases in the U.S.**



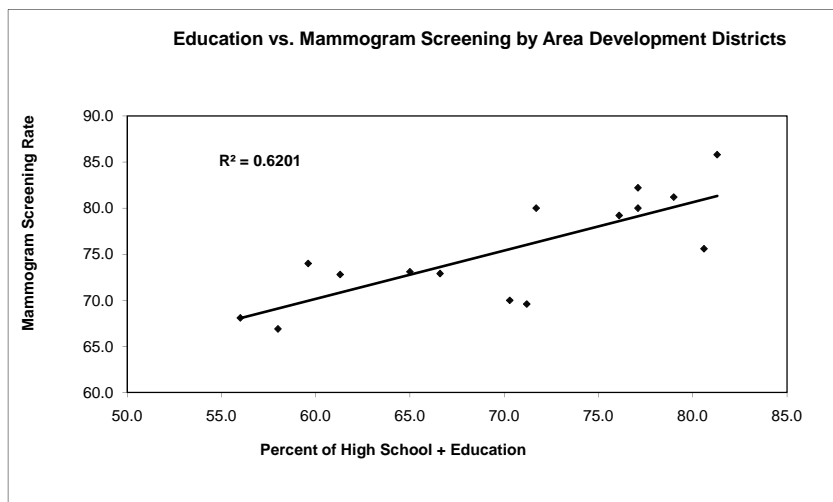




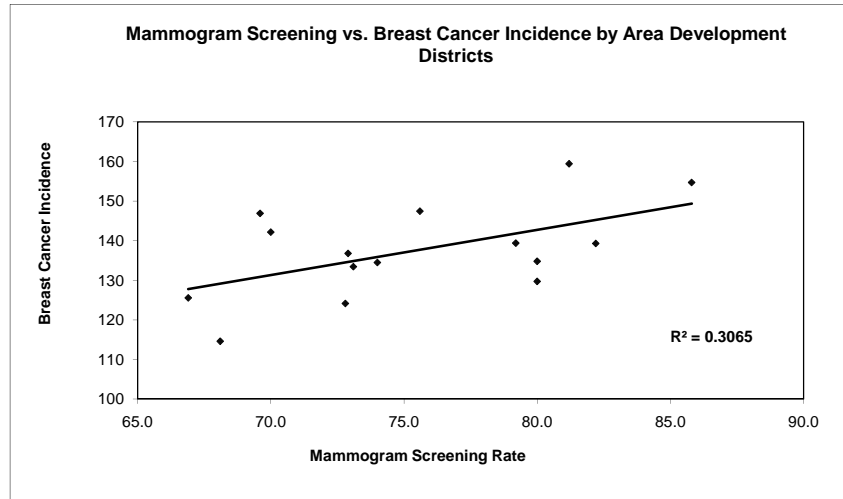
2001-2005 Breast Cancer by Area Development District in KY

Area Development District	Under Poverty Level (%)	High School + Education (%)	Mammography Screening Rate (%)	Age-Adjusted Incidence		Late Stage Incidence (%)	Age-Adjusted Mortality	
				N	Adj. Rate		N	Adj. Rate
US	12.4	90.4	79.4	161654	157.0	29.4	206597	25.0
KENTUCKY	15.8	74.1	78.1	16708	143.86	30.2	3054	25.53
BARREN RIVER	16.7	70.3	70.0	1034	142.16	30.0	202	26.4
BIG SANDY	27.9	59.6	74.0	618	134.49	33.9	152	32.98
BLUEGRASS	13.1	79.0	81.2	2989	159.43	26.8	477	25.21
BUFFALO TRACE	19.6	66.6	72.9	223	136.79	37.0	49	27.6
CUMBERLAND VALLEY	29.1	58.0	66.9	844	125.54	34.9	197	28.31
FIVCO	18.8	71.2	69.6	622	146.91	26.1	108	24.86
GATEWAY	21.2	65.0	73.1	278	133.44	29.4	47	21.95
GREEN RIVER	13.7	77.1	80.0	804	129.71	27.3	167	25.81
KENTUCKY RIVER	31.0	56.0	68.1	394	114.59	36.9	79	22.53
KIPDA	11.5	81.3	85.8	3975	154.71	30.2	694	26.21
LAKE CUMBERLAND	23.0	61.3	72.8	747	124.15	34.0	153	24
LINCOLN TRAIL	12.9	76.1	79.2	919	139.39	28.8	144	21.7
NORTHERN KENTUCKY	9.0	80.6	75.6	1551	147.46	31.3	297	28.27
PENNYRILE	15.9	71.7	80.0	837	134.79	30.8	170	26.31
PURCHASE	15.0	77.1	82.2	873	139.28	27.8	118	17.08

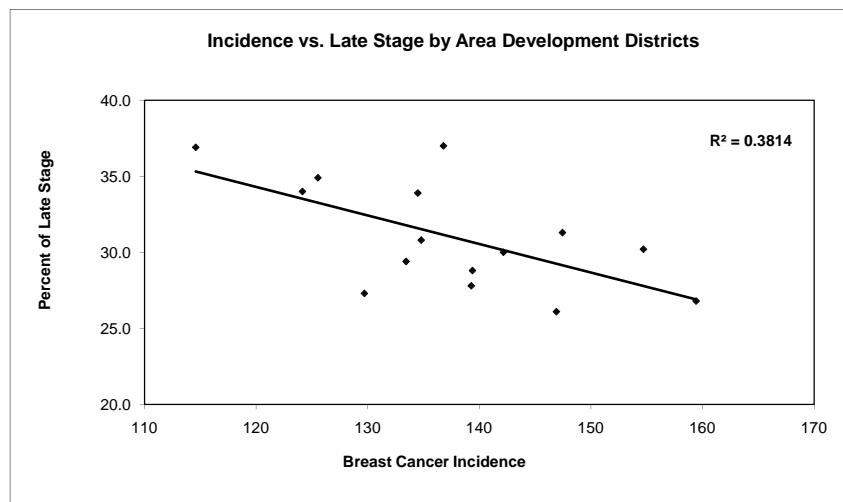
Female Breast Cancer, 2001-2005



Female Breast Cancer, 2001-2005



Female Breast Cancer, 2001-2005

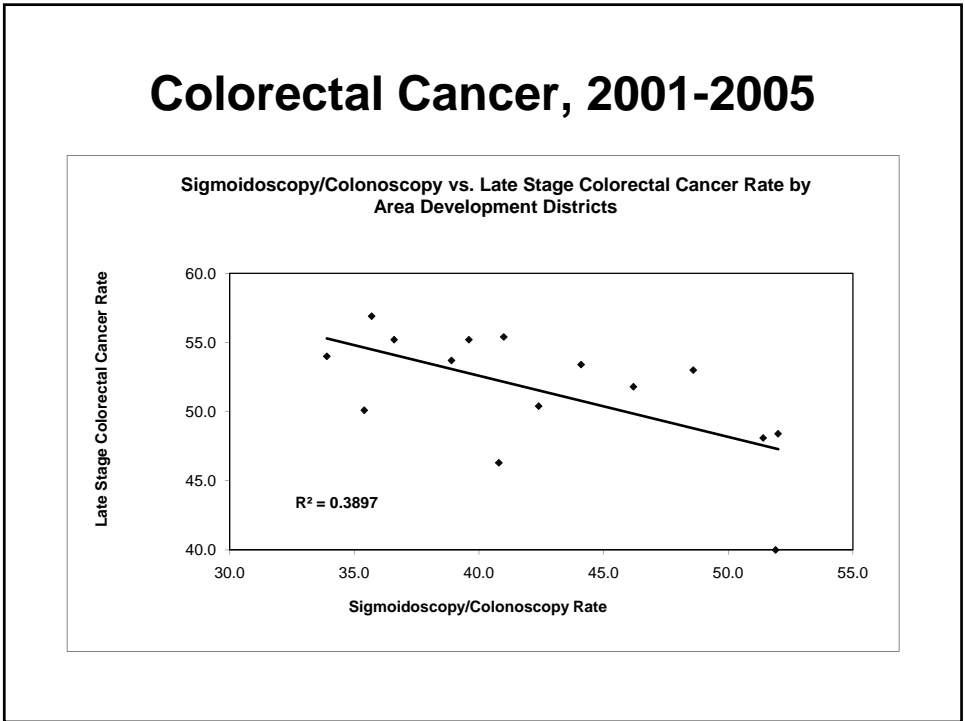
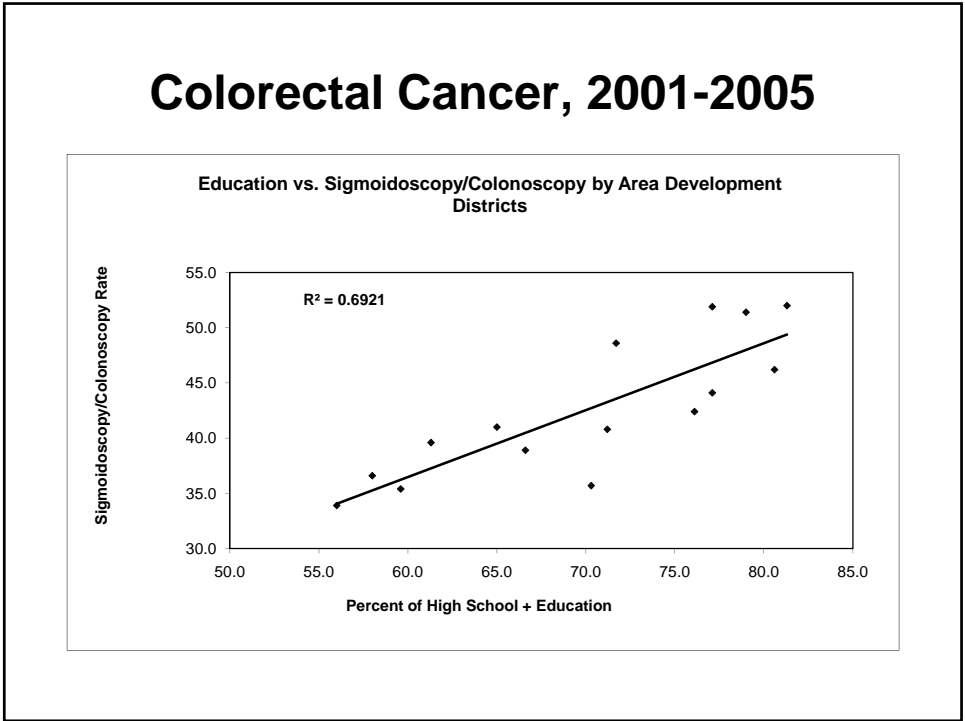


2001-2005 Female Breast Cancer by Area Development District Rank Sum

Area Development District	High School Ed. +		Mammography		Age-Adjusted Incidence		Late Stage Incidence		Overall Rank
	%	Rank	%	Rank	Rate	Rank	%	Rank	
KENTUCKY RIVER	56.0	1	68.1	2	114.59	1	36.9	2	6
CUMBERLAND VALLEY	58.0	2	66.9	1	125.54	3	34.9	3	9
LAKE CUMBERLAND	61.3	4	72.8	5	124.15	2	34.0	4	15
BUFFALO TRACE	66.6	6	72.9	6	136.79	8	37.0	1	21
BIG SANDY	59.6	3	74.0	8	134.49	6	33.9	5	22
GATEWAY	65.0	5	73.1	7	133.44	5	29.4	10	27
BARREN RIVER	70.3	7	70.0	4	142.16	11	30.0	9	31
PENNYRILE	71.7	9	80.0	12	134.79	7	30.8	7	35
FIVCO	71.2	8	69.6	3	146.91	12	26.1	15	38
GREEN RIVER	77.1	12	80.0	11	129.71	4	27.3	13	40
LINCOLN TRAIL	76.1	10	79.2	10	139.39	10	28.8	11	41
NORTHERN KENTUCKY	80.6	14	75.6	9	147.46	13	31.3	6	42
PURCHASE	77.1	11	82.2	14	139.28	9	27.8	12	46
KIPDA	81.3	15	85.8	15	154.71	14	30.2	8	52
BLUEGRASS	79.0	13	81.2	13	159.43	15	26.8	14	55

2001-2005 Colorectal Cancer by Area Development District in KY

Area Development District	Under Poverty Level (%)	High School + Education (%)	Rate of Sigmoidoscopy & Colonoscopy (%)	Age-Adjusted Incidence		Late Stage Incidence (%)	Age-Adjusted Mortality	
				N	Adj. Rate		N	Adj. Rate
US	12.4	80.4	48.1	96073	51.8	54.9	275779	18.8
KENTUCKY	15.8	74.1	45.6	13496	63.87	50.3	4579	21.95
BARREN RIVER	16.7	70.3	35.7	736	54.23	56.9	265	19.7
BIG SANDY	27.9	59.6	35.4	589	71.97	50.1	168	21.21
BLUEGRASS	13.1	79.0	51.4	2085	62.54	48.1	674	20.64
BUFFALO TRACE	19.6	66.6	38.9	210	67.36	53.7	76	24.52
CUMBERLAND VALLEY	29.1	58.0	36.6	772	61.93	55.2	270	22.04
FIVCO	18.8	71.2	40.8	585	74.09	46.3	178	22.88
GATEWAY	21.2	65.0	41.0	257	64.97	55.4	78	19.94
GREEN RIVER	13.7	77.1	44.1	661	57.14	53.4	229	19.93
KENTUCKY RIVER	31.0	56.0	33.9	420	68.09	54.0	156	26.05
KIPDA	11.5	81.3	52.0	2980	65.37	48.4	1067	23.74
LAKE CUMBERLAND	23.0	61.3	39.6	703	61.11	55.2	232	19.98
LINCOLN TRAIL	12.9	76.1	42.4	804	67.39	50.4	274	23.59
NORTHERN KENTUCKY	9.0	80.6	46.2	1233	67.85	51.8	429	24.17
PENNYRILE	15.9	71.7	48.6	668	57.88	53.0	232	19.74
PURCHASE	15.0	77.1	51.9	793	65.34	40.0	251	20.13



2001-2005 Colorectal Cancer by Area Development District Rank Sum

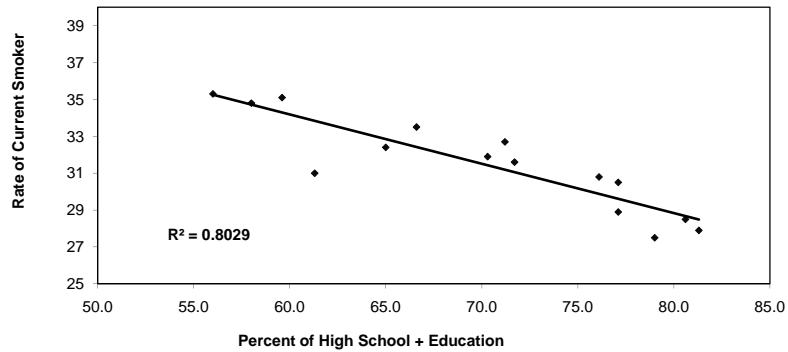
Area Development District	High School Ed. +		Had Sigmoidoscopy or Colonoscopy		Late Stage Incidence		Overall Rank
	%	Rank	%	Rank	%	Rank	
KENTUCKY RIVER	56	1	33.9	1	54	5	7
CUMBERLAND VALLEY	58	2	36.6	4	55.2	4	10
BARREN RIVER	70.3	7	35.7	3	56.9	1	11
LAKE CUMBERLAND	61.3	4	39.6	6	55.2	3	13
GATEWAY	65	5	41	8	55.4	2	15
BIG SANDY	59.6	3	35.4	2	50.1	11	16
BUFFALO TRACE	66.6	6	38.9	5	53.7	6	17
FIVCO	71.2	8	40.8	7	46.3	14	29
GREEN RIVER	77.1	12	44.1	10	53.4	7	29
LINCOLN TRAIL	76.1	10	42.4	9	50.4	10	29
PENNYRILE	71.7	9	48.6	12	53	8	29
NORTHERN KENTUCKY	80.6	14	46.2	11	51.8	9	34
BLUEGRASS	79	13	51.4	13	48.1	13	39
PURCHASE	77.1	11	51.9	14	40	15	40
KIPDA	81.3	15	52	15	48.4	12	42

2001-2005 Lung Cancer by Area Development District in KY

Area Development District	Under Poverty Level (%)	High School + Education (%)	Current Smoker (%)	Age-Adjusted Incidence		Late Stage Incidence (%)	Age-Adjusted Mortality	
				N	Adj. Rate		N	Adj. Rate
US	12.4	80.4	23.1	107922	59	82.5	788812	54.1
KENTUCKY	15.8	74.1	30.1	21568	101.3	80.6	16701	78.89
BARREN RIVER	16.7	70.3	31.9	1358	99.24	78.2	1106	81.13
BIG SANDY	27.9	59.6	35.1	1031	123.57	81.1	794	96.3
BLUEGRASS	13.1	79.0	27.5	3192	95.88	80.9	2479	75.2
BUFFALO TRACE	19.6	66.6	33.5	314	100.6	83.2	239	76.85
CUMBERLAND VALLEY	29.1	58.0	34.8	1444	114.5	79.4	1135	90.48
FIVCO	18.8	71.2	32.7	846	104.83	81.6	674	84.21
GATEWAY	21.2	65.0	32.4	382	95.81	83.6	295	74.45
GREEN RIVER	13.7	77.1	30.5	1146	99.1	80.1	924	79.93
KENTUCKY RIVER	31.0	56.0	35.3	843	131.7	85.4	698	110.95
KIPDA	11.5	81.3	27.9	4575	100.17	80.2	3445	75.8
LAKE CUMBERLAND	23.0	61.3	31	1221	103.48	77.4	946	80.06
LINCOLN TRAIL	12.9	76.1	30.8	1101	90.99	79.4	798	67.18
NORTHERN KENTUCKY	9.0	80.6	28.5	1883	102.17	81.6	1444	79.04
PENNYRILE	15.9	71.7	31.6	1132	97.39	82.1	892	76.45
PURCHASE	15.0	77.1	28.9	1100	91.12	82.5	832	68.3

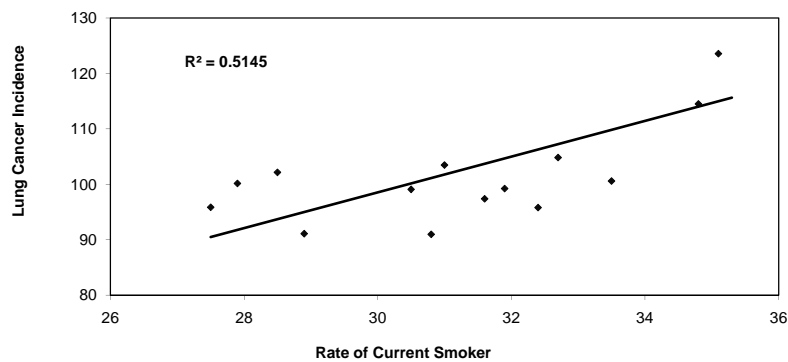
Lung Cancer, 2001-2005

Education vs. Current Smoker by Area Development Districts

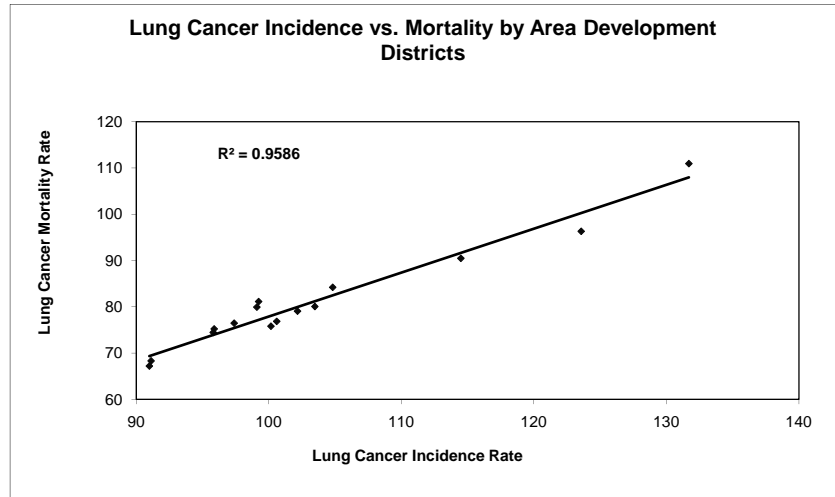


Lung Cancer, 2001-2005

Current Smoker vs. Lung Cancer Incidence by Area Development Districts



Lung Cancer, 2001-2005



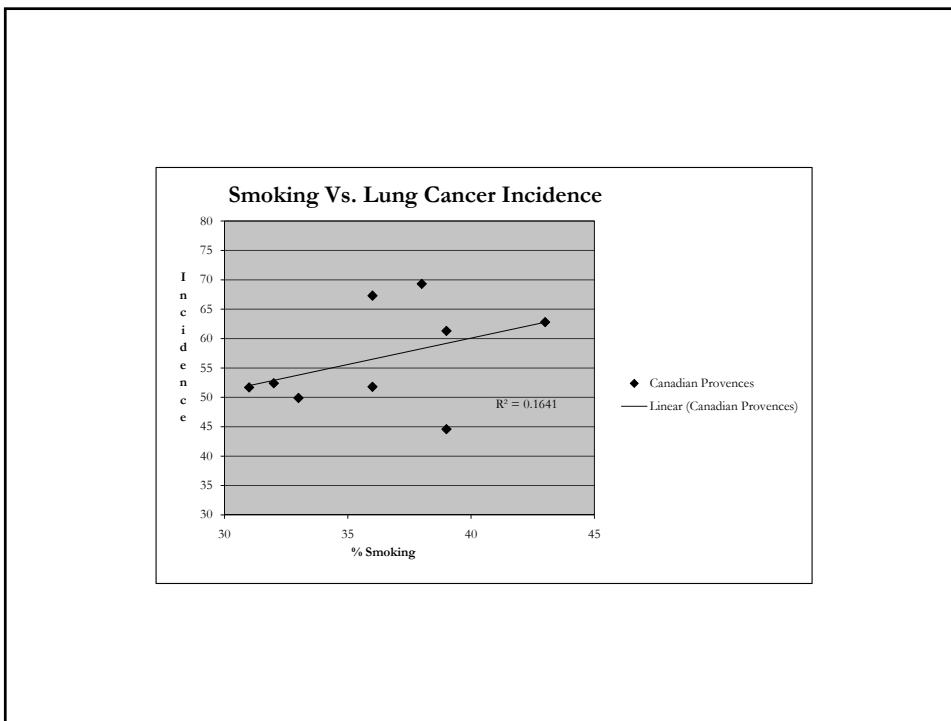
2001-2005 Lung Cancer by Area Development District Rank Sum

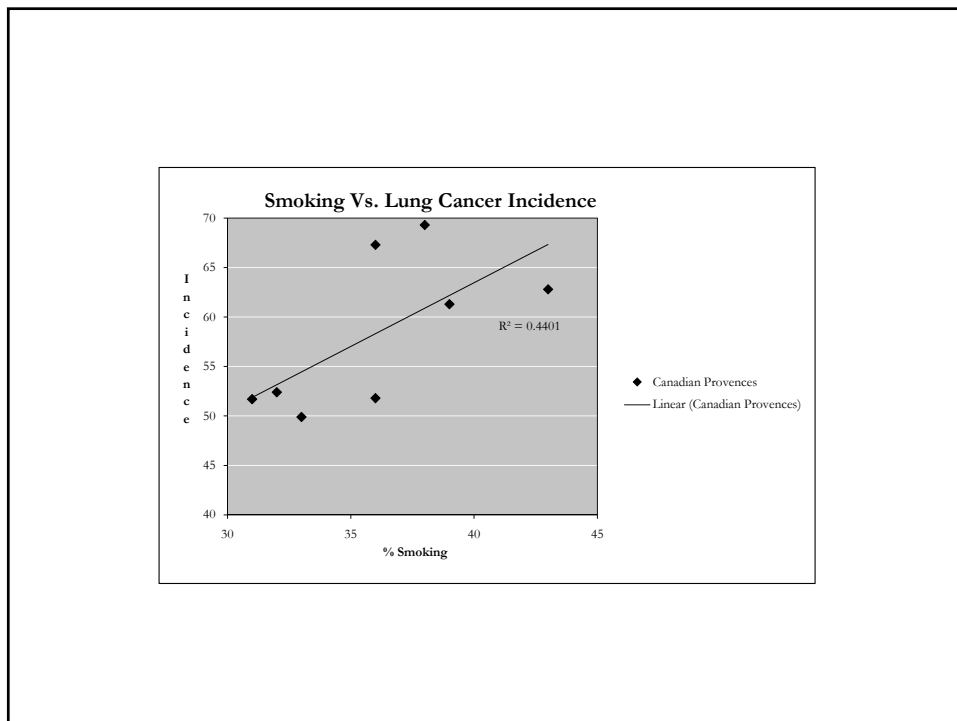
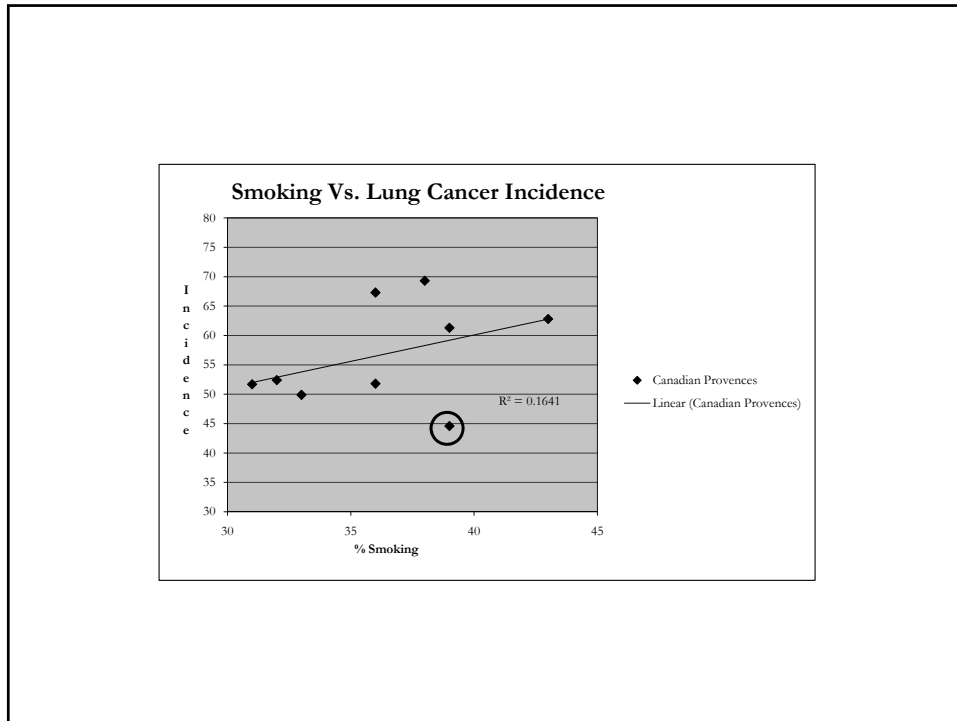
Area Development District	High School Ed. +		Current Smoker		Age-Adjusted Incidence		Age Adjusted Mortality		Overall Rank
	%	Rank	%	Rank	Rate	Rank	Rate	Rank	
KENTUCKY RIVER	56.0	1	35.3	1	131.7	1	110.95	1	4
BIG SANDY	59.6	3	35.1	2	123.57	2	96.3	2	9
CUMBERLAND VALLEY	58.0	2	34.8	3	114.5	3	90.48	3	11
FIVCO	71.2	8	32.7	5	104.83	4	84.21	4	21
LAKE CUMBERLAND	61.3	4	31	9	103.48	5	80.06	5	23
BUFFALO TRACE	66.6	6	33.5	4	100.6	7	76.85	7	24
BARREN RIVER	70.3	7	31.9	7	99.24	9	81.13	9	32
GATEWAY	65.0	5	32.4	6	95.81	13	74.45	13	37
NORTHERN KENTUCKY	80.6	14	28.5	13	102.17	6	79.04	6	39
PENNYRILE	71.7	9	31.6	8	97.39	11	76.45	11	39
GREEN RIVER	77.1	11	30.5	11	99.1	10	79.93	10	42
KIPDA	81.3	15	27.9	14	100.17	8	75.8	8	45
LINCOLN TRAIL	76.1	10	30.8	10	90.99	15	67.18	15	50
BLUEGRASS	79.0	13	27.5	15	95.88	12	75.2	12	52
PURCHASE	77.1	12	28.9	12	91.12	14	68.3	14	52

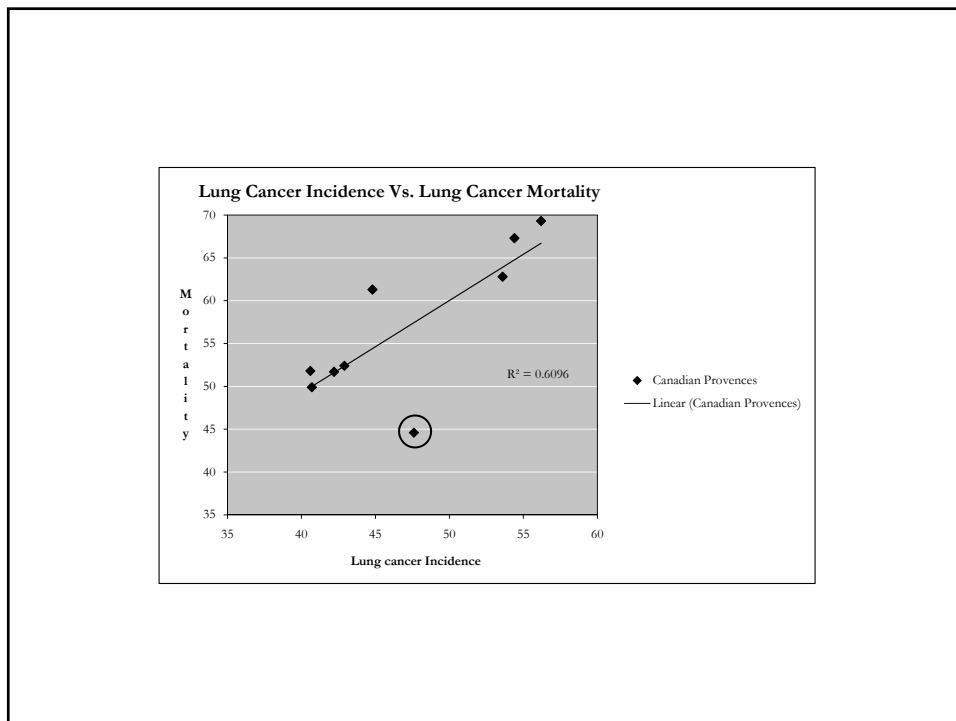
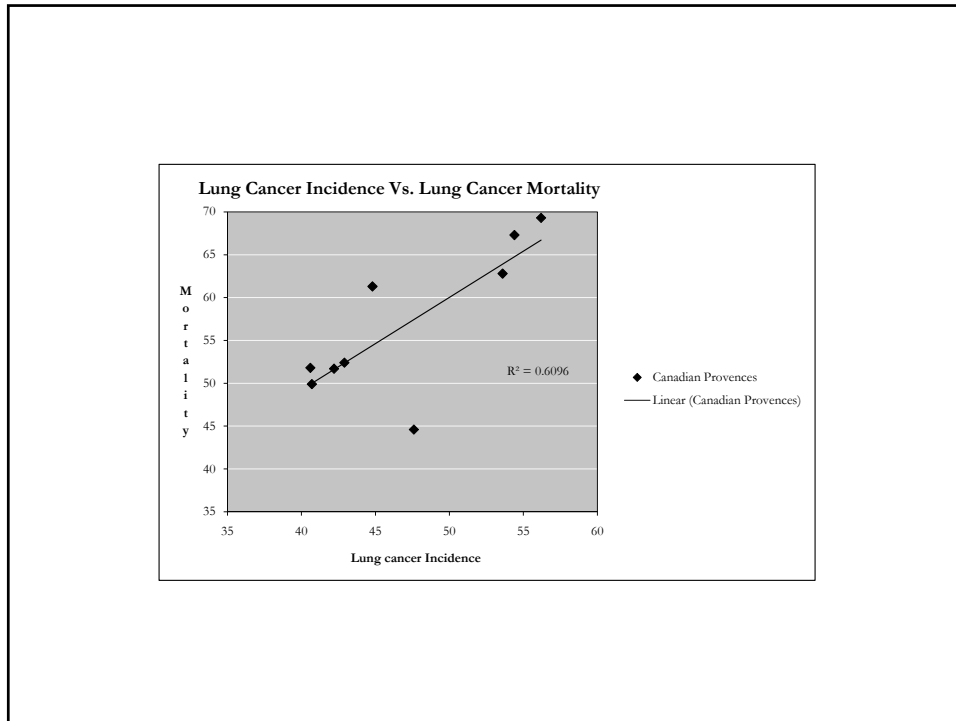
Province	Lung Incidence	Incidence Rank	Lung Mortality	Mortality Rank	Current Smoker (1985)	Smoking rank	Overall Rank
Canada	53.4		44.1		35		
Nova Scotia	69.3		56.2		38		
Prince Edward Island	62.8		53.6		43		
New Brunswick	67.3		54.4		36		
Manitoba	61.3		44.8		39		
Newfoundland	44.6		47.6		39		
Ontario	52.4		42.9		32		
Alberta	51.8		40.6		36		
British Columbia	49.9		40.7		33		
Saskatchewan	51.7		42.2		31		

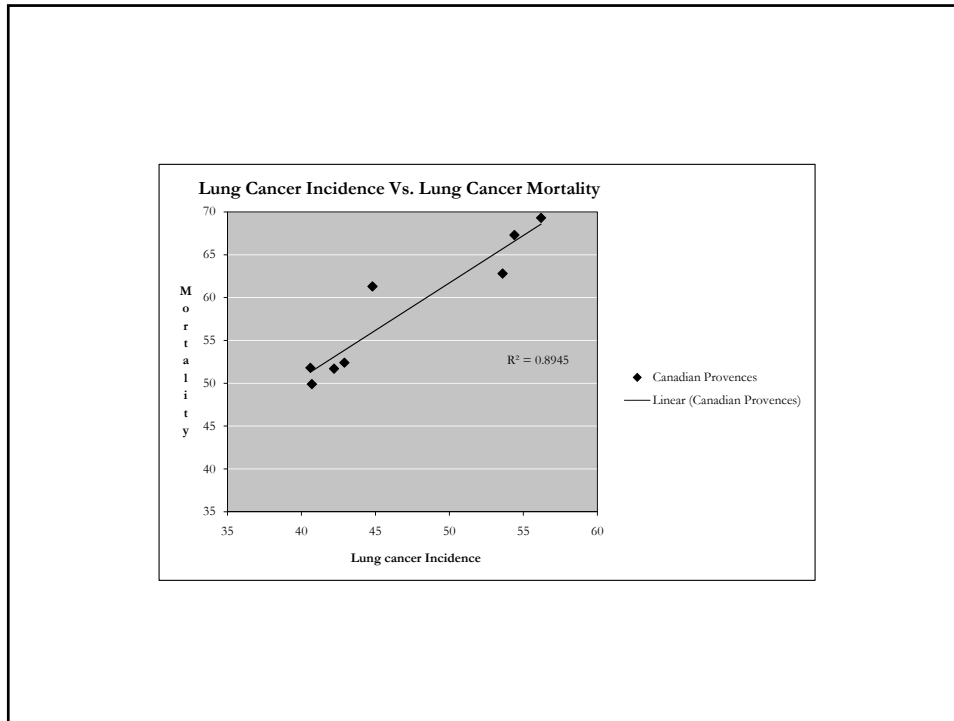
Province	Lung Incidence	Incidence Rank	Lung Mortality	Mortality Rank	Current Smoker (1985)	Smoking rank	Overall Rank
Canada	53.4		44.1		35		
Nova Scotia	69.3	1	56.2	1	38	4	6
Prince Edward Island	62.8	3	53.6	3	43	1	7
New Brunswick	67.3	2	54.4	2	36	5	9
Manitoba	61.3	4	44.8	5	39	3	12
Newfoundland	44.6	9	47.6	4	39	2	15
Ontario	52.4	5	42.9	6	32	8	19
Alberta	51.8	6	40.6	9	36	6	21
British Columbia	49.9	8	40.7	8	33	7	23
Saskatchewan	51.7	7	42.2	7	31	9	23

Province	Lung Incidence	Incidence Rank	Lung Mortality	Mortality Rank	Current Smoker (1985)	Smoking rank	Overall Rank
Canada	53.4		44.1		35		
Nova Scotia	69.3	1	56.2	1	38	4	6
Prince Edward Island	62.8	3	53.6	3	43	1	7
New Brunswick	67.3	2	54.4	2	36	5	9
Manitoba	61.3	4	44.8	5	39	3	12
Newfoundland	44.6	9	47.6	4	39	2	15
Ontario	52.4	5	42.9	6	32	8	19
Alberta	51.8	6	40.6	9	36	6	21
British Columbia	49.9	8	40.7	8	33	7	23
Saskatchewan	51.7	7	42.2	7	31	9	23



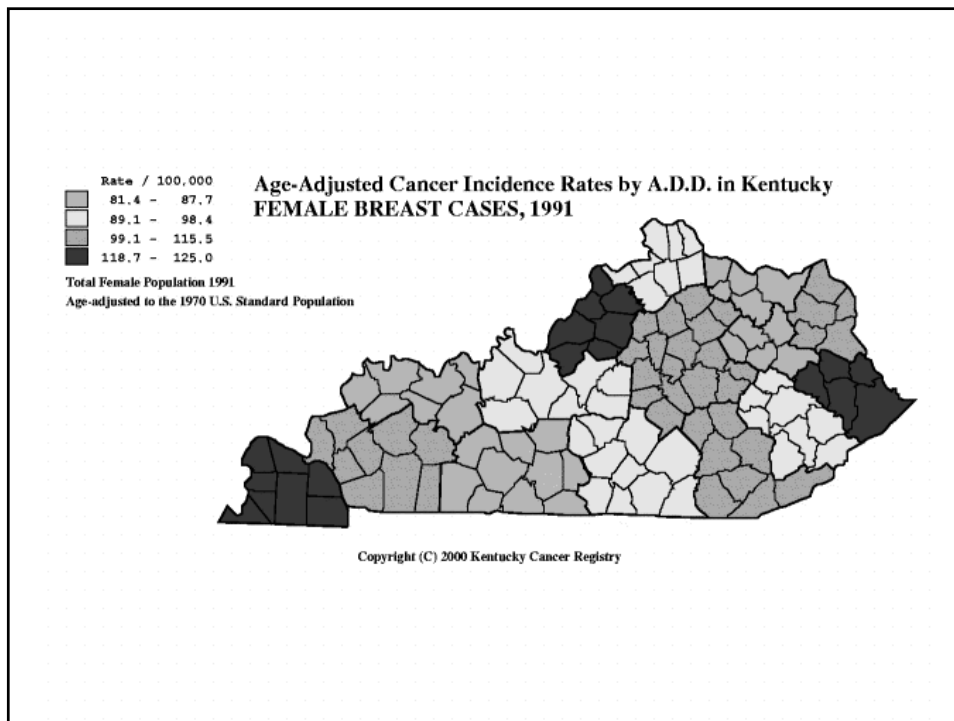
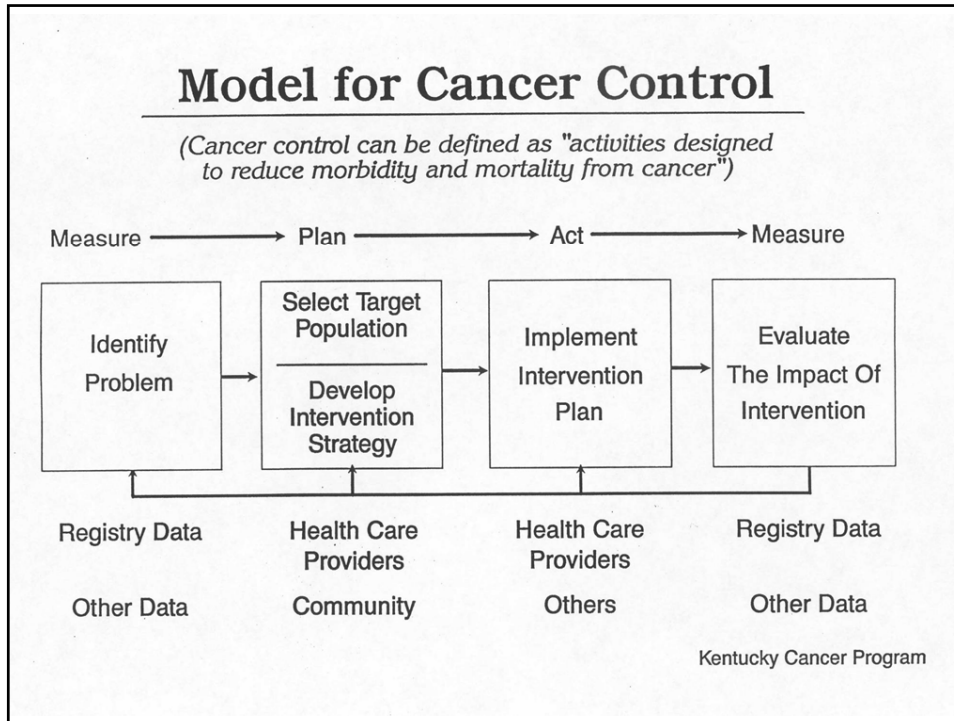


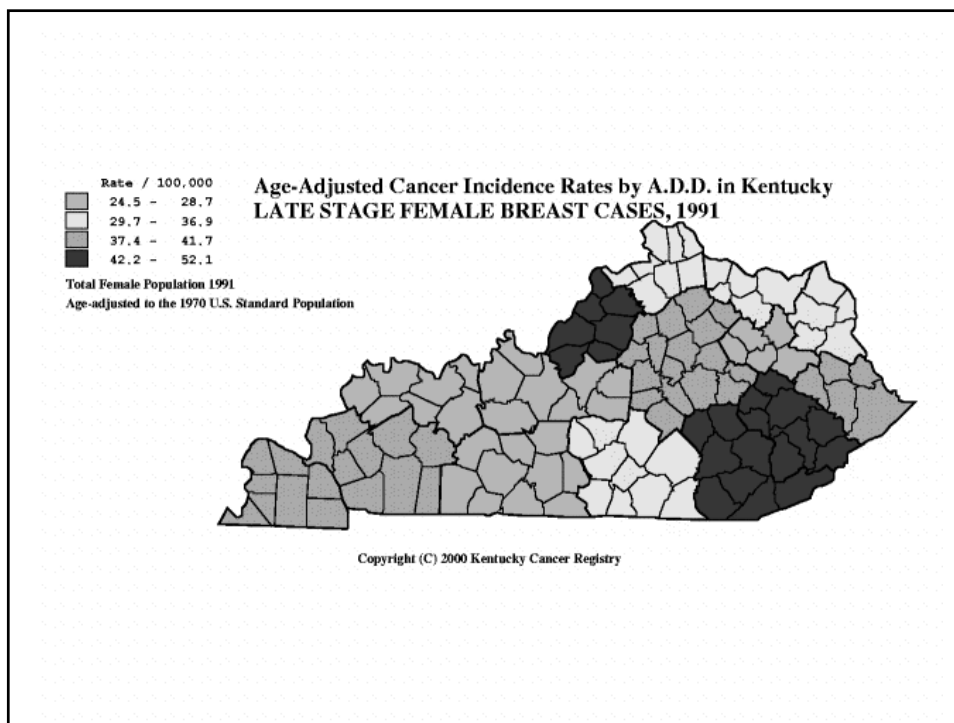
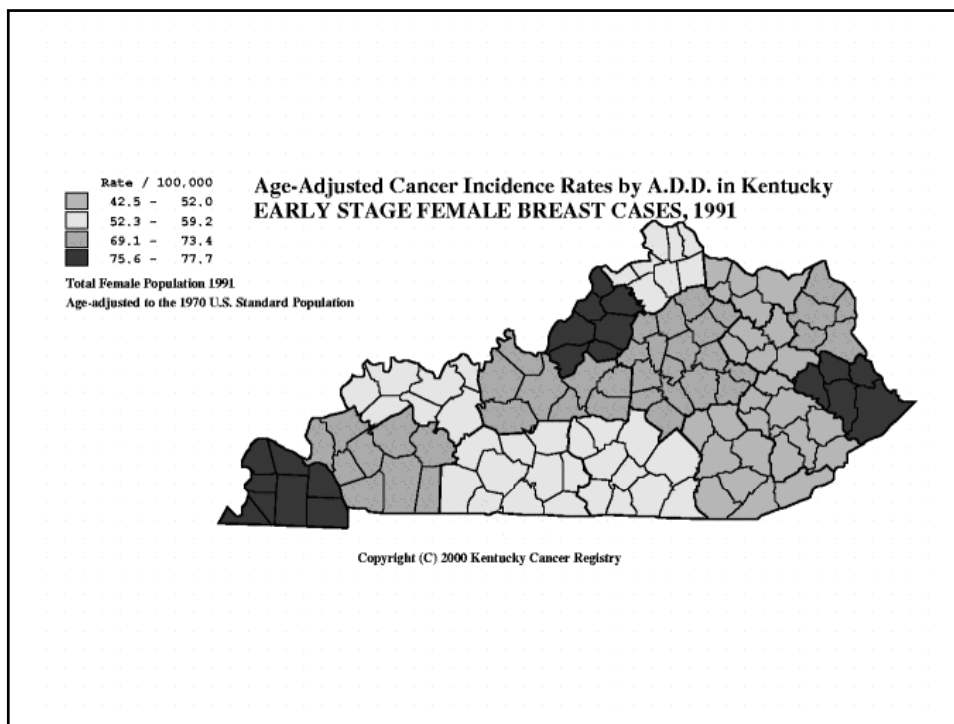


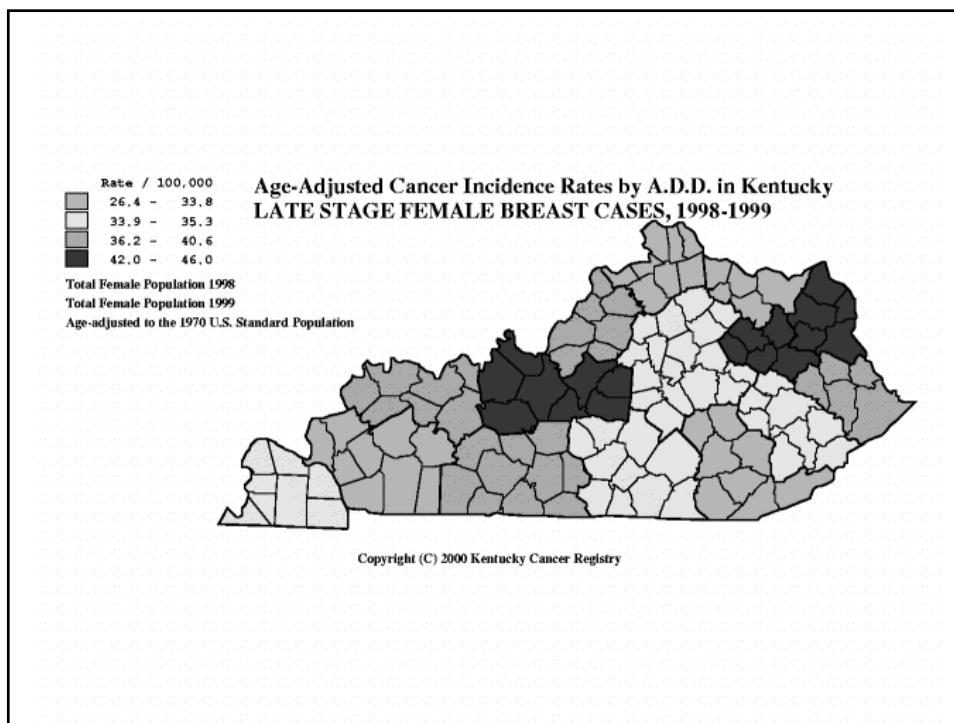
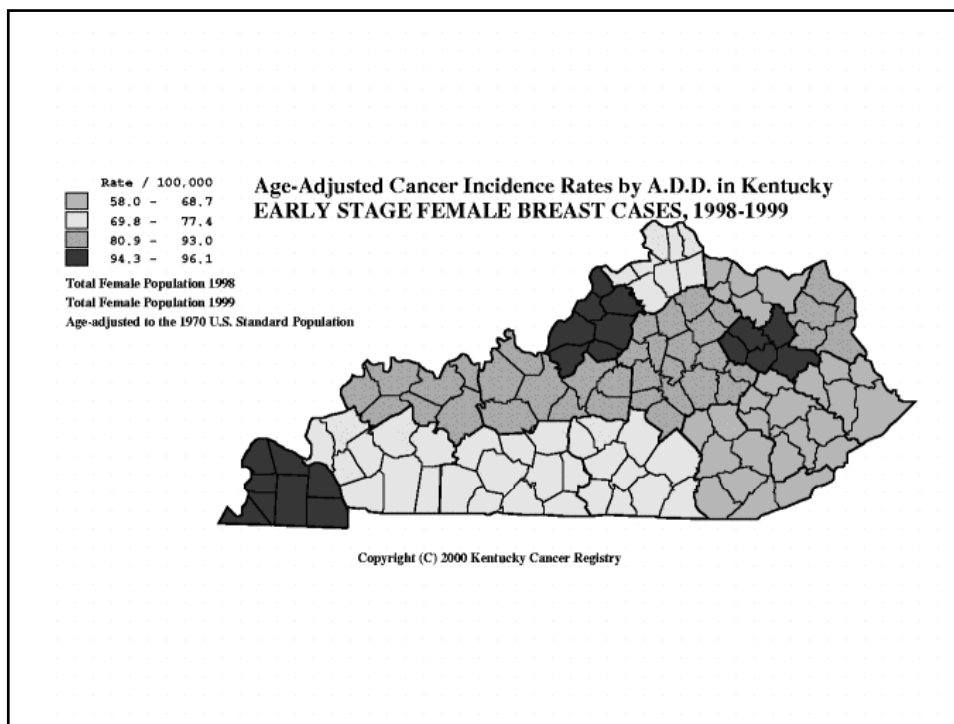


An example of using the data for cancer control

**Breast Cancer
(Secondary Prevention)**







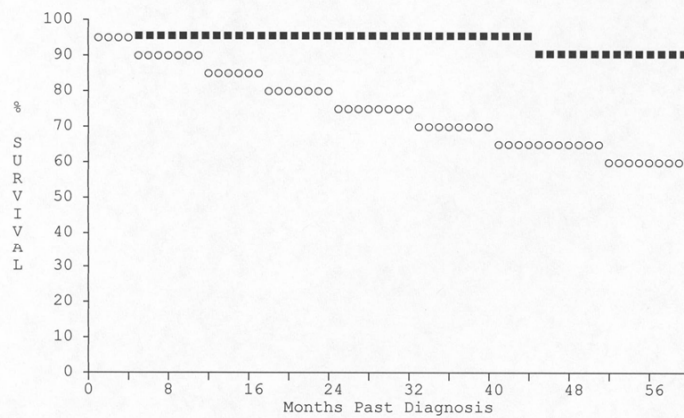
Number and (Percent) of Kentucky Female Breast Cancer Cases
By Stage at Diagnosis
(1991 through 1996)

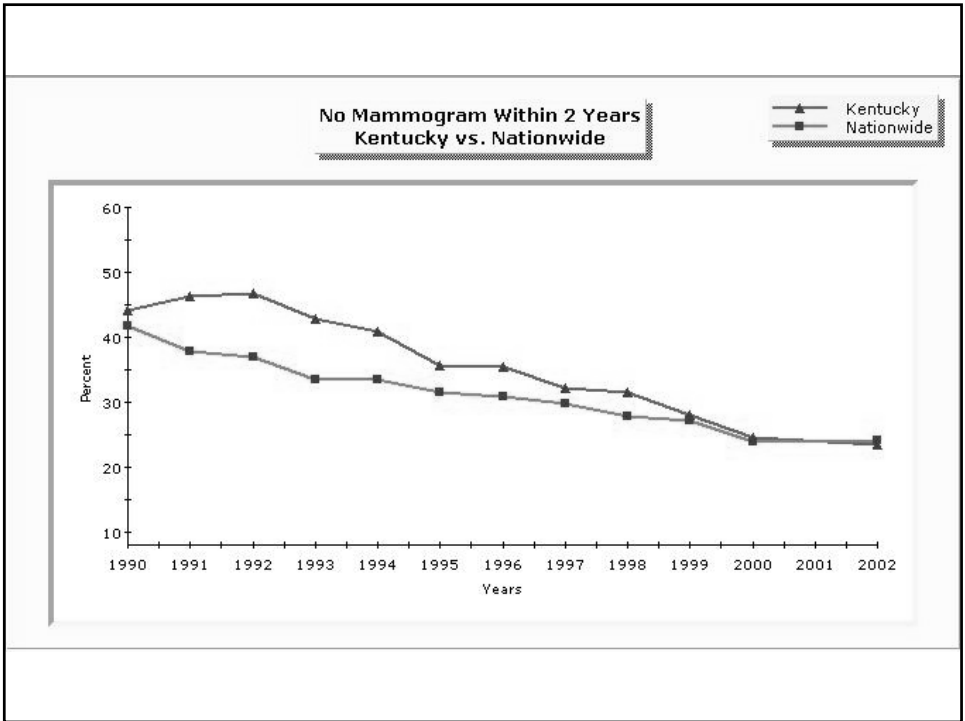
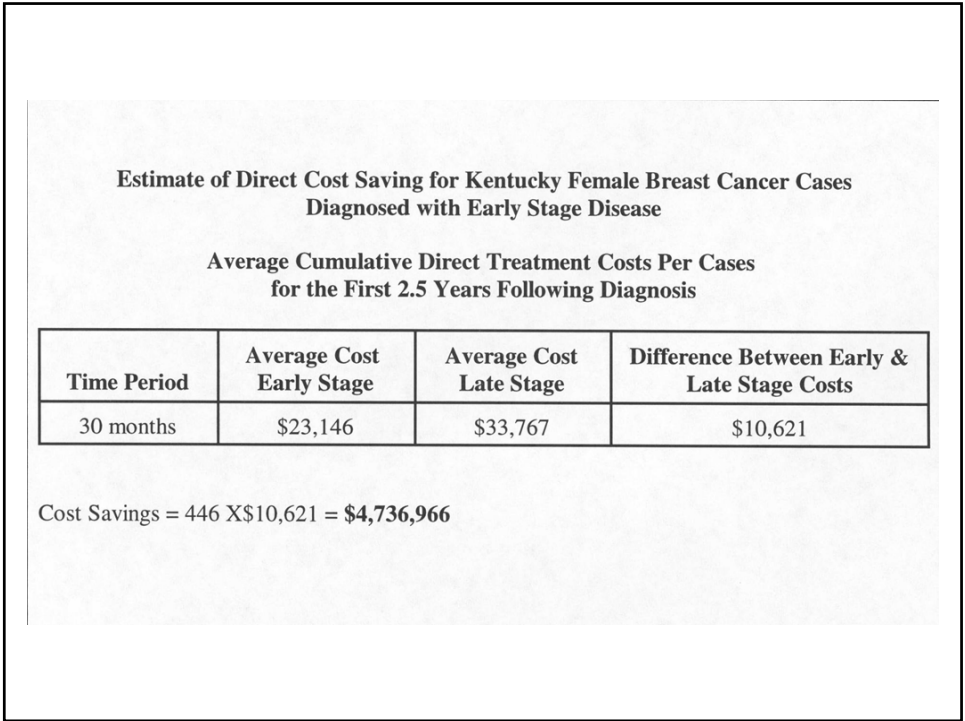
Year	Stage		Total	Change in Early Stage Cases (Δei)	Significance
	Early	Late			
1991	1584 (64.9%)	856 (35.1%)	2440		
1992	1608 (66.9%)	795 (33.1%)	2403	+48	NS
1993	1680 (68.1%)	787 (31.9%)	2467	+79	*
1994	1792 (67.3%)	870 (32.7%)	2662	+64	*
1995	1896 (69.9%)	817 (30.1%)	2713	+135	**
1996	1909 (69.3%)	847 (30.7%)	2756	+120	**
	$\sum \Delta ei$			446	

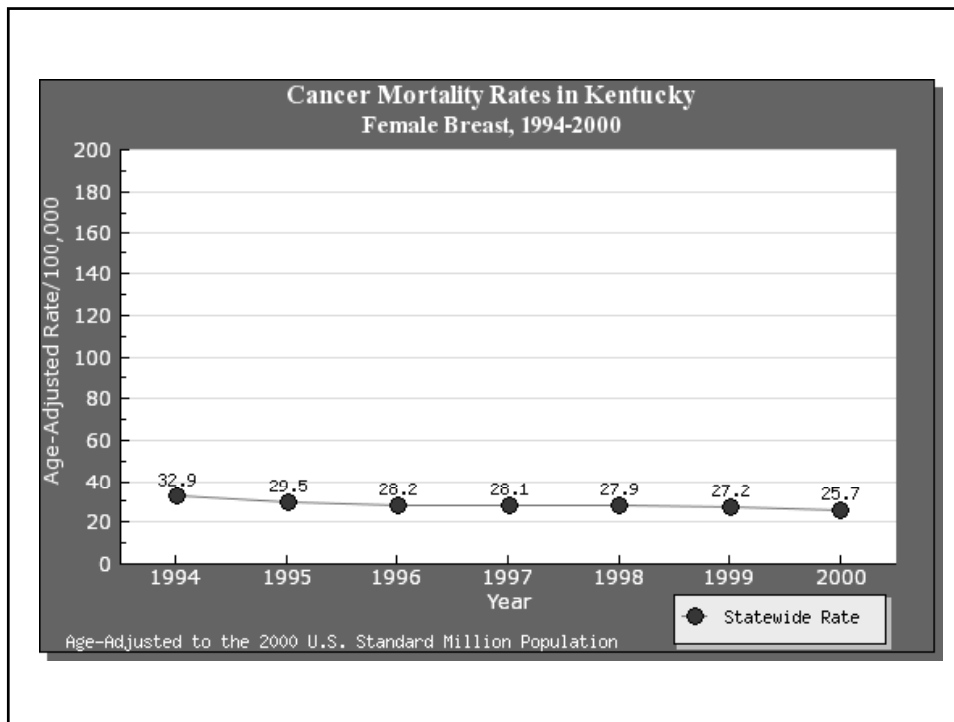
NS = Not Significant, * = P<.05, ** = P<.01
Early Stage = SEER Summary Stages In Situ and Local
Late Stage = SEER Summary Stages Regional and Distant

FIVE YEAR SURVIVAL FOR KENTUCKY FEMALE BREAST CANCER CASES
BY STAGE AT DIAGNOSIS
(1991 THROUGH 1996)

(■)=EARLY STAGE (SEER SUMMARY STAGES IN SITU AND LOCAL)
(○)=LATE STAGE (SEER SUMMARY STAGES REGIONAL AND DISTANT)







Questions & Answers