

Statistics for Action Guide to State Cancer Profiles: Understanding Cancer Statistics for Community Action

Table of Contents

ntroduction	1
Why Investigate Cancer Rates	2
Ferms You May Run Across	3
ssues To Think About When Using Cancer Data	5
Using the State Cancer Profiles	.10
Cancer and Environmental Exposures	. 20
Resources	



Contributors

Joan Gancarski Molly Jacobs Martha Merson Kathryn Edmunds Valerie Martin

Acknowledaments

Prepared in collaboration with Toxics Action Center, Blue Ridge Environmental Defense League, Little Village Environmental Justice Organization, Operation Green Leaves, Pesticide Watch, Alternatives for Community & Environment, New England Literacy Resource Center, Mary Jane Schmitt, Ethan Contini-Field, Sara Lacy, Sherry Soares, and Richard Clapp, Professor Emeritus, Boston University School of Public Health..

With thanks to Statistics for Action advisors Beth Bingman, AppalShop, Inc.; Steve Dickens, River Network; Andrew Friedmann, Mass Department of Environmental Protection; Alexander Goldowsky, The EcoTarium; Marlene Kliman, TERC; Jim Luker, Green Seal Environmental; Madeleine Kangsen Scammell, Boston University School of Public Health, Dept. of Environmental Health; and Molly Jacobs, University of Massachusetts Lowell, Lowell Center for Sustainable Production.





© 2014 TERC. This material is based on work at TERC funded in part and supported by the National Science Foundation under Grant No. 0812954. Any opinions, findings, and conclusions or recommendations expressed in this material are those of the authors and do not necessarily reflect the views of the National Science Foundation.





SfA Guide to State Cancer Profiles

Introduction to this Guide

WHAT'S HERE

This how-to guide to the State Cancer Profiles is for you if you

- are concerned about cancer rates in your area;
- want to make the best case possible for a formal study;
- want numbers to get decision-makers to pay attention.

Most people want to know about cancer in their community—their street or neighborhood. Finding out the cancer rate for a street won't be easy. To get some sense of the cancer rates in your local area, this guide explains two options: 1) the information to assemble and provide to state health department staff so they can help; and 2) how to interpret the meaning of data that are available.

In 2010, according to the statistics from the U.S. National Cancer Institute

• 1,447,277 new cancer cases were diagnosed in the US

• 574,738 cancer deaths occurred in the United States

New Cancer Case	(Incidence) Rates	Death Rates	
Area	Rate*	Area	Rate
United States	461.8	United States	181.1
* per 100,000 pe	ople		

This whole guide is related to a type of health study called Studies of Outcomes. A First Look at Health Studies¹, reviews many types of health studies, including outcome studies, which can answer questions such as, "Does our county have a higher than expected rate of childhood leukemia?" An outcome study relies on already collected data to provide a picture of health trends or health status in a community. I keep hearing stories about people who live in this area who have cancer. In May, my son's basketball coach died from liver cancer. In February, the woman who delivers the mail stopped. She was diagnosed with colon cancer, and the treatments made her tired all the time. Now I hear that a man down the road has bladder cancer, and he just buried his wife who had leukemia.

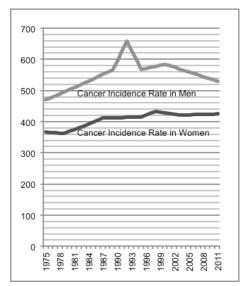
It seems like something in the environment could be causing these health problems.



¹(see: http://sfa.terc.edu/materials/pdfs/a_first_look_at_health_studies. pdf)

Today, 1 in 2 men, and 1 in 3 women are at risk of being diagnosed with cancer in the United States. While overall mortality rates have declined in recent years, cancer incidence for many types of cancer, for example non-Hodgkin's lymphoma, has risen dramatically since the mid 1970s. With rising rates of some types of cancer, many people wonder if there is something in the air or water.

Making a connection between cancer cases and the environment is complicated. In past cases, law firms on both sides have spent millions of dollars. See page 19 for obstacles to proving links between cancer and the environment. Read on to understand better why and how to use cancer data collected and maintained by state and national cancer registries.



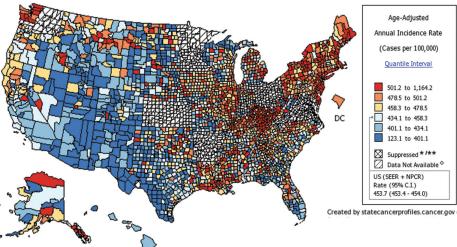
Source: Surveillance Epidemiology & End Results Program, Delayed-Adjusted, Age-Adjusted Cancer Incidence Rates, 1975-2011

WHY INVESTIGATE CANCER RATES?

Spending time with data can help provide an overall picture of the problem. You can identify how much cancer is occurring

- of a specific type or types,
- in a specific area,
- over a specific time period.

You can learn if people of specific ages or races/ethnicities seem to be more affected than others. These observations about trends are useful. From them we generate hypotheses to explain trends. Such observations can motivate and guide an official health study or environmental investigation. Incidence Rates for United States by County, 2006-2010 All Cancer Sites, All Races (includes Hispanic), All Ages



TERMS YOU MAY RUN ACROSS

Age-adjusted rate

Counts the number of cases compared to the population and adjusts the numbers to take age into account. Since the risk of cancer increases with age, a county with a majority of older residents will almost always have a much higher crude rate for cancer incidence or death rate from cancer than a county with a higher percentage of people under 50. Age-adjusted rates balance out age for the populations being compared so that age is not a reason for differences in the cancer rates between populations. Use an age-adjusted rate to identify questions and concerns about trends.

Cancer burden

Is inclusive of several terms and reflects the burden that cancer has on both individuals and society. Cancer burden often includes the economic cost anyone affected by cancer carries, including cancer patients and their families, since there is an emotional, physical, and financial cost. Cancer burden can also include the term, cancer prevalence. Cancer prevalence is defined as the total number of people who have the disease. This includes people recently diagnosed and people who are in remission, since cancer is a chronic illness. Some uses of the term cancer burden may include people who died of cancer; however cancer deaths or rates of *cancer mortality* the total number of people who died from the disease over a specific period of time

are statistics that are typically collected by state offices of vital statistics.

Cancer cluster

Is the term used when the number of cancer cases in a specified area (for example, a stretch of houses by a river or a few neighborhood blocks) is significantly greater than the expected number of cases. "Significantly greater" is the term used by researchers to mean that the number of cases observed is higher than what would be expected based on statewide rates after ruling out chance to a reasonable degree.

Cancer risk

Is the likelihood of developing cancer. You may see cancer risk stated, for example, as 1 in 100,000, meaning 1 case in 100,000 individuals in a given year.

Cancer risk factors

Cancer risk factors are those exposures that increase an individual's cancer risk. Cancer risk factors are tied to specific types of cancer, because clinically cancer is over a hundred diseases. For example, risk factors for lung cancer are different from risk factors for brain cancer. Pollutants in air, water or soil are one category of cancer risk factors. Other common cancer risk factors include smoking, and lifestyle factors (e.g., diet, alcoholic beverages, lack of physical exercise).

Census tract

Is a small a geographic region defined for the purpose of taking the U.S. census, which counts the number of people. Health officials will often define the population where there are concerns about cancer using census tracts. A number of census blocks comprise a census tract and can be used to define the specific population of concern, especially when a particular census tract is quite large and inclusive of people not affected by the environmental exposure of concern.

Confidence intervals

In addition to p-values, confidence intervals are also used to show the range of results that are consistent with the 95% probability. This is also called the statistical variation. In other words, if researchers did the same survey 100 times, 95 times they would get a number in the stated range. Confidence intervals are helpful in revealing how precise the result is. The wider the confidence interval, the greater the statistical variability around the result, the less precise the result. Narrower confidence intervals have less statistical variability around the result and are therefore more precise. Note that there is only one true value, and that the confidence interval defines the range where it's most likely to be.







Crude rate

Describes frequency. A crude rate compares the raw numbers of cases of cancer to the number of people in the population under consideration. So 100 cancer cases in a town of 25,000 is a crude rate.

Epidemiologist

Is a person who studies the distribution of disease in human populations. Epidemiologists look at factors such as age, gender, and occupation to find patterns in disease rates. They can also look at locations and time periods as factors affecting illness and death rates.

Incidence rate

Is the number of new cancer cases that are diagnosed and reported to a state's cancer registry in a given year divided by the population of males and females in the state. Incidence is a measure of "new cases" of a particular disease.

Raw numbers

Are simply a count. The raw number of cancer cases in a county may be 100. But you cannot make generalizations or comparisons from a raw number because information that might affect those numbers is missing such as how many people live in the county.

Statistical significance

Tells us how certain the researchers are that study results or study estimates will hold true. For cancer rates, comparisons between groups (for example a comparison of rates between your community and the state-wide rate) are often made. Differences between groups are said to be "statistically significant" or "statistically significantly different" when chance can be ruled out as an explanation. It is conventional practice to state that the results are statistically significant if there is less than or equal to a 5% probability that chance alone can explain for the difference between groups. This is called a p-value (probability value) statistic. If the probability (the p-value) is less than 1%, the evidence is even stronger that the observed difference is true and not due to chance alone. Results that are not statistically significant imply that chance cannot be ruled out as the explanation for the difference between groups.

There's a lot of cancer cases, but it's not a cancer cluster until we show that the number is higher than you'd expect.



ISSUES TO THINK ABOUT WHEN USING CANCER DATA

Cancer Clusters

Public concern about cancer clusters usually (but not always) starts when people observe many people with cancer in their neighborhood or in their workplace. The Centers for Disease Control and Prevention (CDC) defines a cancer cluster as: a higher than expected number of cancer cases that occurs within a group of people, in a specific geographic area, over a defined period of time.

Cancer data are collected through state cancer registries and vital record offices. Staff collect data on every cancer diagnosis and every cancer death. Unfortunately, county data is simply too wide to answer a question about a cancer cluster that occurs each year. Cancer data are now publicly available in all 50 states. Yet very few states provide the publicly available cancer data by zip code, city or by census tract. They want to protect individuals' confidentiality. For cancer cluster investigations, often a census tract (or even better, a collection census blocks) may be the most accurate way to spot an area of concern. Two states provide the public routinely with census tract-level cancer data: Delaware and Massachusetts. However, for the vast majority of other states, county data is the smallest geographic area that the public has access to cancer data.

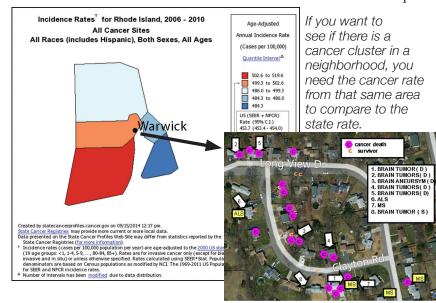
This guide shows you how to use data from the State Cancer Profiles to get the statewide or county rate. Outside of Massachusetts and Delaware, you will need health department officials to investigate your concerns. Consult the checklist; gather the information that your health department staff will want. After they review your request, they will decide to take further steps or not.

When Health Department officials evaluate neighborhood cancer data

If your concerns raise a red flag for health department staff, they will query the state's cancer registry data. They then identify the number of incident cases of cancer during the time period of concern and in the population of concern (again, likely the census tract for your street or community). Health department officials compare the observed number of cases to the number expected based on the statewide experience.

Observed Cases/Expected Cases

If there are more observed incident cancer cases than expected, cancer incidence in your community is elevated. However, health officials also determine if the higher number of observed cases versus expected cases could have occurred by chance. This requires testing for "statistical significance,"



which is a mathematical measure of the difference between groups. The difference is said to be statistically significantly different if there is less than a 5% chance that the difference is the result of random fluctuations in the observed number of cancer cases. Without a statistically significant finding, health officials usually state that the "apparent cluster was likely due to chance." Yet what a nonstatistically significant result actually means is that chance cannot be ruled out as a competing explanation for the elevation of cancer incidence in the community.





Expressing Concerns

In 1998, the Massachusetts Department of Public Health received a call from Kevin Kane, a lifelong resident of Ashland, Massachusetts. Kevin told health department officials that the year before, at age 25, he was diagnosed with a rare cancer called soft tissue sarcoma. He also knew of other boys from his graduating high school class that had the same rare cancer. Kevin was concerned that their cancers were caused from exposure to toxics at the Nyanza chemical waste site as all boys played there during their youth.

The Health Department was very familiar with Nyanza. Nyanza manufactured chemical dyes for the textile industry from 1965 until 1978 when it went bankrupt and closed the facility. In 1983, the US Environmental Protection Agency placed Nyanza on its National Priorities list declaring it a Superfund site because the company and its predecessors that operated on the site as far back as 1917 dumped toxic waste into unlined pits and into multiple wetlands and ponds in the area.



Nyanza Color & Chemical Co. Trade Ad American Dyestuff Reporter 1957

CHECKLIST

This is the information you need in hand to most effectively start a conversation about a cancer cluster with your health department. Find out and make a list of:

- ✓ What types of cancers are affecting your community. Note which type or types are your biggest concern;
- ✓ What age the individuals were when they were diagnosed;
- ✓ When the affected individuals were diagnosed with cancer.

Health department officials will review cancer incidence statistics for the geographic area of concern (likely at the census tract level) and compare these rates to what would be expected based on the statewide experience. Yet this evaluation takes staff time and resources and may not even occur if the patterns you describe are not unusual. So what is unusual? If you find:

- Cancer affecting mainly children or young adults. Childhood cancer is rare. It's even more rare if multiple children have the same type.
- The same type of cancer strikes again and again. Each cancer type is treated as its own disease with its own set of risk factors. If many people in your community have the same type of cancer, that suggests that a common risk factor may be at work.
- A rare type of cancer shows up (that is, cancer with a low rate of incidence). Some types of cancer are common, such as breast cancer or prostate cancer. Health department staff will be more willing to look further into less common types. Using the State Cancer Profiles in the following section, you can learn how rare or not rare a type of cancer is. In other words, you will query the incidence rate for specific types of cancer.



6



PLANNING

The Nyanza contamination was well documented I in environmental surveys of the site. Because the waste site was not fenced in, for several years, kids routinely played in the area. To their parent's dismay kids often returned home with their socks dyed purple from playing in the wetlands.

The health department was struck by:

- the high number of rare cancers among young men
- a clear exposure pathway to toxics at a hazardous waste site
- the men diagnosed with these rare cancers had exposures as children to carcinogens early in life
- the timing of exposures corresponded to the latency period for cancers (i.e., exposures occurred at least 10-15 years prior to diagnosis)

The site of the Nyanza Plant in Ashland. Mass., which left deadly contamination in the surrounding environs.



As a result of Kevin's call, the health department queried cancer statistics for the town of Ashland. Using data available, they found that among those less than 40 years old at the time of diagnosis, there was a statistically significant elevation in cancer in Ashland compared to what would be expected based on the state average for the same age group. Specifically, there was a 2-fold elevation in men and 4-fold elevation in women. Very soon after, the health department launched a study that took nearly a decade to complete and found what Kevin had presumed long before: children who played in contaminated water at the site had a higher risk of being diagnosed with a rare cancer compared to those that did not experience such exposures.

Final study at: http://www.mass.gov/eohhs/gov/departments/ dph/programs/environmental-health/investigations/ashlandnyanza/ashland-nyanza-health-study-final-report.html



Review your list:

 \checkmark Note names and dates when individuals were diagnosed during a similar time period.

Count: Were most of the individuals with cancer diagnosed around the same year or two? Within the last 1-5 years? Health department officials consider 'when' as well as 'how many' before directing resources to a study.

Look into the source of contamination. List:

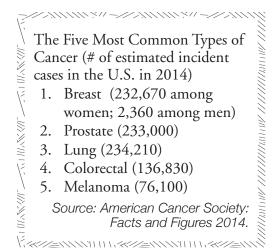
- \checkmark The environmental pollution source or sources of concern
- The history of this source of toxic contamination in your community
- \checkmark When, where, and how people had the opportunity to be exposed (e.g., ate fish, breathed fumes)

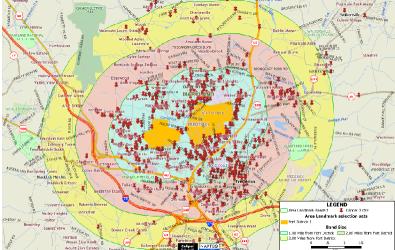
Name	Age	Cancer type	Year díagnosed	Notes
James	67	Prostate	2010	Worked at asphalt plant 1980-1985
Ana	59	Bladder	2010	Líved near asphault plant 1992-2002
Mary	52	Breast	2004	Moved to the area ín 2004
Ríley	62	Bladder	2010	Taught ín local HS 1998-2012

Health department officials will want to know details about the environmental contamination or pollution source that you are concerned about. Be ready to describe the type of industry or source of pollution and the history of contamination. If the source of environmental pollution is recent, such as a manufacturing plant that began operations five years ago, it is likely too soon for this pollution source to cause cancer in the community over the last five

years. Health department officials need to answer whether the source of concern: (a) could have exposed people and (b) has been around along enough for cancer to develop. See *Cancer and Environmental Exposures*, p. 20, for a discussion about cancer latency periods. If the information you provide suggests further research is needed, health officials will conduct their own review of available environmental pollution data for your community.

Remember: A cancer cluster is a surprisingly large number of cases in a specific location, within a defined period of time. The more you can show a number of cases with the same diagnosis, around the same period of time with an environmental exposure that has some tie to a specific type of cancer, the stronger your argument for attention and resources.





Cancer cluster map, Fort Detrick, MD

Using Cancer Morality vs. Cancer Incidence Data to Understand Cancer Occurrence

The next section shows you how to use data from the State Cancer Profiles, which include state- and county-level cancer incidence and mortality rates. If the goal is to understand how much cancer there is, and what specific types of cancer have occurred in a given area, cancer incidence rates are the best measure. Cancer incidence rates are a measure of disease occurrence-how much cancer occurred in a given year. Mortality data are not as useful for cancers such as breast, prostate, colon, and thyroid cancers. These cancers have low mortality rates, meaning people survive the cancer and live. Mortality data would be misleading, leaving out all the people who have it but are still alive. Mortality data are helpful in understanding trends for cancers with short survival periods, such as pancreatic, liver, lung and some types of brain cancer.



Using the State Cancer Profiles

On a computer with Internet access, you can take a look at cancer statistics. Start with the National Cancer Institute's State Cancer Profiles, a web site that has assembled cancer data from all over the country. You can use information on this website as evidence to make a point about a particular cancer type, geographic location, or type of cancer sufferer (gender, age, race). If you are hoping to capture the attention of decision-makers, the data here may support your calls for needed action.



The State Cancer Profiles website brings together data collected by state cancer registries, which in turn collect data from clinics, hospitals, other medical care facilities, and vital statistics offices.

- ✓ Make comparisons between states.
- \checkmark Make comparisons between one state and the national rate.
- \checkmark Find rates for all types of cancer.
- ✓ Find rates for one type of cancer.
- \checkmark Find rates by gender, age, and race.
- \checkmark Choose to see data in tables, graphs, and maps.

Limitations of the data and presentation

- × The data are available for periods of time back to 2002.
- × The cancer registry does not track causes or suspected causes.
- × The site does not provide data on cases and trends for areas smaller than a county.

The steps below are one way to walk through the cancer numbers for a state. We chose Tennessee as an example. We suggest that you read through the following text before trying out the web site yourself.

State Cancer Prof Help us improve! Contact us with Dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, states, and counties

	Quick Profiles	
Area	Choose a State	•
Cancer		
Choo	se a Cancer Site	-

The tables you'll see on these pages are based on 2002-2006 data. By the time you visit the website, you will see an updated set of data.

feedback.

This guide was updated in 2014 when 2010 cancer data was the most recent data available. In general, there is a 4-year time lag, i.e., data on cancer deaths or diagnoses that occurred in 2014 will likely not be available until 2018.





Creating a Quick Profile for Tennessee Counties

To create a quick profile of tables and graphs for the counties, go to the Quick Profiles section.

	Quick Profiles	
Area	Choose a State	-
Cancer Choos	e a Cancer Site	-
		_

- 1. Select the State: Tennessee.
- 2. Select the type of Cancer you want.

First, let's start by looking at all cancers and in all counties in Tennessee. These data will provide an overview of the cancer burden in Tennessee.

	Quick Profiles	
Area	Tennessee	
Cancer	All Cancer Sites	-

3. Click on the Generate profile button located under the drop down boxes.

Once you hit the Generate Profile button, the page will be replaced with a set of tables and graphs containing the data you selected.

You can look at them online, but if you can, print them and spread them out.



COMPARING TRENDS

Let's see take a look at the second table generated called Death Rate/Trend Comparison by State/ County, death years through 2010, Tennessee Counties versus United States. This table includes all cancer sites, for all races and both sexes in Tennessee.

Check the labels and cancer types in each part of the chart to find out for what types of cancer the death rates are increasing, staying stable, or decreasing compared to rates in the United States overall. *What types of cancer are labeled at Priority 1? Why do you think so?*

	Above US Rate	Similar to US Rate	Below US Rate
	Priority 1: rising [↑] and above [↑]	Priority 2: rising [†] and similar =	Priority 3: rising [↑] and below ↓
Rising Trend	Melanoma of the Skin (Males)	Esophagus (Males) Liver & Bile Duct (Females) Liver & Bile Duct (Males)	[none]
	Priority 4: stable -> and above	Priority 6: stable -> and similar	Priority 7: stable \rightarrow and below \downarrow
Stable Trend	Leukemia (Males) Lung & Bronchus (Females)	Bladder (Females) Bladder (Males) Brain & ONS (Females) Childhood (Ages <20, All Sites) (Females) Kidney & Renal Pelvis (Females) Ovary (Females) Pancreas (Females) Pancreas (Males) Thyroid (Females) Thyroid (Males)	Esophagus (Females) Uterus (Females)
	Priority 5: falling 🕹 and above 🕇	Priority 8: falling \downarrow and similar =	Priority 9: falling $ ightarrow$ and below $ ightarrow$
Falling Trend	Colon & Rectum (Females) Lung & Bronchus (Males) Oral Cavity & Pharynx (Males)	Brain & ONS (Males) Breast (Females) Cervix (Females) Childhood (Ages <15, All Sites) (Males) Childhood (Ages <20, All Sites) (Males) Colon & Rectum (Males) Kidney & Renal Pelvis (Males) Leukemia (Females) Melanoma of the Skin (Females) Non-Hodgkin Lymphoma (Females) Non-Hodgkin Lymphoma (Males) Oral Cavity & Pharynx (Females) Prostate (Males) Stomach (Females)	[none]

Death Rate/Trend Comparison by State/County, death years through 2010 Tennessee versus United States All Races, Both Sexes





From the data, you can see that:

- The death rate for melanoma of the skin in males is rising in Tennessee, and is higher than the U.S. rate. This cancer rate is labeled Priority 1 for two reasons: (1) the rate is increasing, that is, there are more deaths each year (note: how this increasing trend is determined is a bit more complicated and beyond the scope of this guide), and (2) the rate is higher than the U.S. rate.
- Death rates for leukemia among men and lung and bronchus among females are stable in Tennessee, but the rate is above the U.S. rate. Because the rates are stable, this cancer is considered less of a priority in Tennessee, compared to melanoma of the skin in males.
- Although higher than the U.S. rate, the following cancer death rates are falling in Tennessee: colon & rectum (females), lung and bronchus (males), oral cavity & pharynx (males).

What types of cancer are increasing at rates similar to the US rates?

• The esophagus (males), liver & bile duct (males and females).

The chart also shows that some types of cancer rates are stable, similar to the U.S. rates:

• bladder (females), bladder (males), brain & ONS (females), childhood (ages <20, all sites, females), kidney & renal pelvis (females), ovary (females), pancreas (females), pancreas (males), thyroid (females), thyroid (males).

Increasing cancer death rates are often used to prioritize limited public health resources. States may use the data to make decisions about funding and program support. For example melanoma death rates in Tennessee men is increasing. It is listed as a higher priority than breast cancer. Someone might argue that the state should spend more money on skin cancer awareness programs.

It is important to note that sometimes data are not available because they have been "suppressed." If there are fewer than sixteen cases over a five-year period for a given region, the information will not

be included in the tables or graphs. This protects cancer victims' confidentiality in places where the population is small, increasing the chances that the individual could be identified.

Because researchers can't base reliable statistics one or two years of data with small numbers like 3 in 100,00,000, the standard practice is to look at cancer cases and death in five-year blocks of time or longer.

Consider how very small numbers can be misleading. If there is one death from childhood leukemia in 2008 and three deaths from childhood leukemia in 2009 (where only 1 was expected based on the state rate), it looks as if the childhood leukemia death rate just jumped 200% in one year. That could be a trend, but it could be chance. You could make a better judgment if you had more cases or more years to look at.

Two graphs generated by the State Cancer Profiles follow. The first graph displays historical trends in cancer mortality since 1975 and the second displays a 5-year trend graph for 20 different cancer types.

A line graph of historical trends show when death rates peaked. Check the graph to see when deaths from cancer peaked and when they stayed about the same. On the graph below you can compare the trend in Tennessee to the trend nationwide. Were the trends the same for white and black residents?

Four trends jump out:

- (1) Cancer mortality trends for the U.S. and Tennessee rose from 1975 through the early 1990s.
- (2) After the mid-1990s, cancer death rates began to fall.
- (3) In Tennessee, the rise in cancer deaths was faster and higher than in the U.S., and it took longer for the deaths to slow and finally begin to drop in Tennessee.
- (4) Blacks (including Hispanics) are dying from cancer at higher rates than for White in Tennessee and at higher rates than Blacks (including Hispanics) nationwide.

© 2014 TERC • Statistics for Action sfa.terc.edu



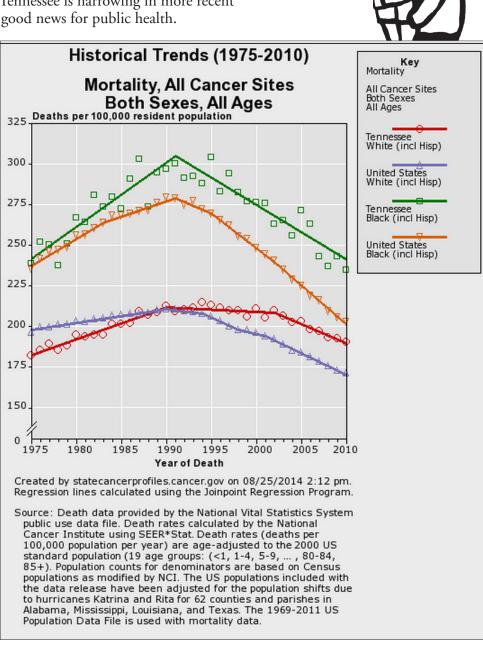
Data about the state

about local trends?

are interesting, but what



This last trend is particularly worrisome and is a red flag for the public health and medical community to increase and prioritize health care services, including cancer screening efforts within Black (including Hispanics) populations in Tennessee. Notice however, that the difference in mortality rates among Blacks (including Hispanics) and Whites in Tennessee is narrowing in more recent years, which is good news for public health.

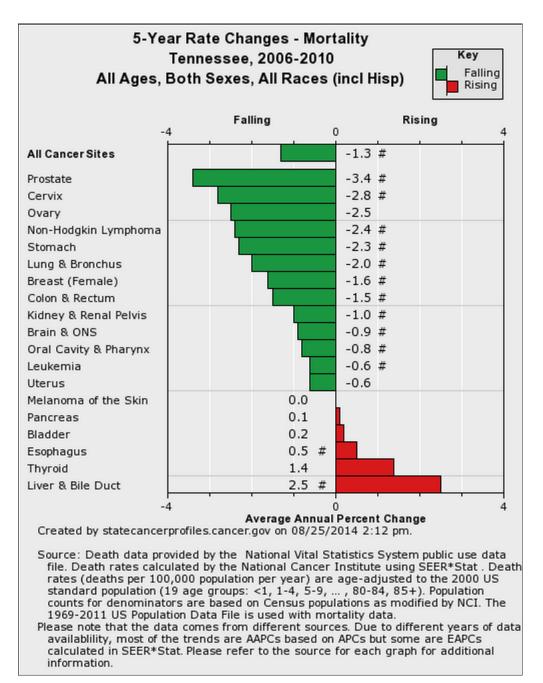






For the graph, 5-Year Rate Changes-Mortality, look to the left of zero for cancer types where the death rate is going down. The rate is negative; the numbers are falling (bars on the chart are colored green). Where the rate is positive; the numbers are climbing (bars on the chart are colored red). The higher the number, the faster the decrease in numbers of deaths. Use the chart to find out which cancer rates are changing the fastest and which ones are staying close to the same.

You probably noticed that in Tennessee over the period 2006-2010, the overall cancer death rate fell. It fell for 13 of 20 types of cancer with the biggest drop for prostate cancer deaths, a 3.4 percent average annual percentage decline. For one cancer (pancreas), the rate stayed the same. For six types of cancer, the rate rose. The rate of deaths from liver and bile duct cancer increased the most, with an average annual 2.5 percent rise.



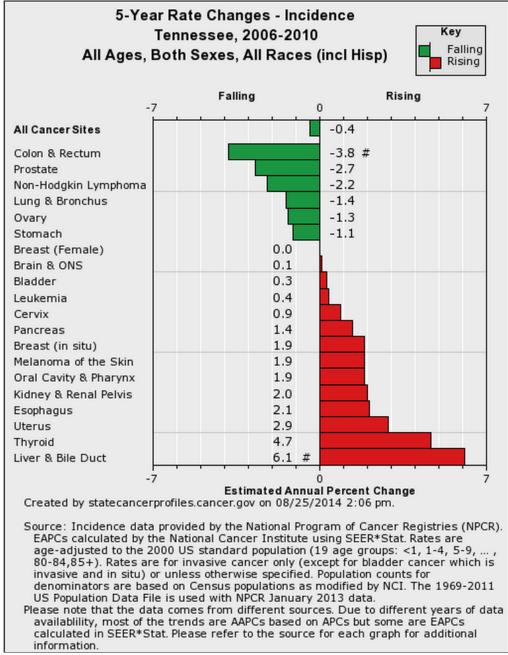


Now look at a similar looking graph, but it focuses now on cancer incidence: **5-Year Rate Changes – Incidence Tennessee, 2006-2010.** As before, the incidence rate for cancer types that decreased are shown in green, whereas the incidence rate for cancer types that increased are shown in red.

What do you notice about the cancer incidence rates that are increasing, versus the cancer mortality rates that are increasing the earlier graph?

One difference that is striking between the two graphs is that the incidence rate for the majority of cancer types increased over the last 5 years, whereas the mortality rate for a minority of cancer types increased during the same time period. While it is great news that the incidence of several types of cancer are decreasing, the majority are on the rise. This is cause for concern.

Yet why then is the incidence rate for all cancer sites declining? We can't answer this question simply by looking at the graph, but cancer epidemiologists agree that the decline in overall cancer incidence is being driven primarily by reductions in lung cancer incidence in men.





The table called Death Rate/Trend Comparison by Cancer, death years through 2010 Tennessee Counties versus United States, includes all cancer sites, for all races and both sexes in Tennessee. An excerpt from that table is shown below.

Take a look: The middle column shows the cancer death rate per 100,000. Tennessee's cancer mortality rate is 199.1 per 100,000. This means that among 100,000 people living in Tennessee, 200 individuals died of cancer during the period 2006-2010. The 95% confidence interval is 197.5 – 200.6, a very narrow interval around 199, which shows this cancer mortality rate have minimal statistical variation and is very precise. In the U.S. overall, the rate was 176 per 100,000. So Tennessee residents carry a heavier cancer burden compared with the rest of the United States. NCI State Cancer Profiles make it possible to look at this cancer burden by county. Let's focus on 10 of the 95 counties in Tennessee and three of the columns of data from the table on the web site.

Now, look down the second column, which calculates a confidence interval around the ageadjusted mortality rate. When rates are "ageadjusted", the calculations take into account difference in the age distribution across the various counties. This allows you to directly compare a rate in one county to another. Which county has a lower cancer mortality rate? When you look at the confidence intervals associated with the rates of the various counties, do you see that the intervals are much wider than for the cancer mortality rate for Tennessee as a whole? This is because county populations are smaller—the smaller the population, the greater the statistical variation or the less precise the estimate.

County	Annual Death Rate over rate period deaths per 100,000 (95% Confidence Interval)	Average Deaths per Year over rate period
Tennessee (State)	199.1 (197.5, 200.6)	13,290
United States	176.4 (176.2, 176.6)	566,112
Lake County	246.2 (201.8, 298.0)	22
Smith County	245.3 (215.7, 277.9)	51
Fentress County	243.7 (214.8, 275.8)	55
Benton County	243.0 (215.5, 273.5)	59
Scott County	242.7 (215.1, 272.9)	58
Macon County	239.0 (211.7, 268.9)	57
Sequatchie County	236.8 (203.3, 274.4)	37
Hickman County	233.1 (207.4, 261.0)	62
Lauderdale County	230.2 (205.3, 257.2)	64
Gibson County	229.7 (213.2, 247.2)	64

Look at the third column. You'll see that the average number of deaths per year (between the years 2006) and 2010) by county varies from a low of 22 to a high of 64. In Lake County, the average death rate for cancer was 22, and in Gibson County the average was 64. Since 64 is about two-thirds higher than 22, these raw numbers correspond to a higher cancer morality rate also in Gibson County compared to Lake County.

If you lived in anyone of these 10 counties, could you say that people in your county were dying from cancer at *higher rates than the state rate?* Yes. Every one of the cancer mortality rates in these counties are higher than 199.



To better understand cancer incidence rates for specific types of cancer in a particular county, you need to go back to the home page and start again. Go back to the home page of the State Cancer Profiles and under the heading, Comparison Tables, click on Incidence Rates. You will get a screen that looks like the following:

Let us keep using Tennessee as our example and look further into the patterns of cancer incidence for cancer of the kidney and renal pelvis for all races and both sexes as noted above.

I NATIONAI® ANCER INSTITUTE		State Cancer Profiles Dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, states, and counties
Profiles Home >	Incidence Rates Report	
Area:	Tennessee Counties	About This Table
Cancer:	Kidney & Renal Pelvis	Quick Reference Guide
Race/Ethn:	All Races (includes Hispanic)	tutorial
Sex:	Both Sexes	Data Use Restrictions
		Generate Table

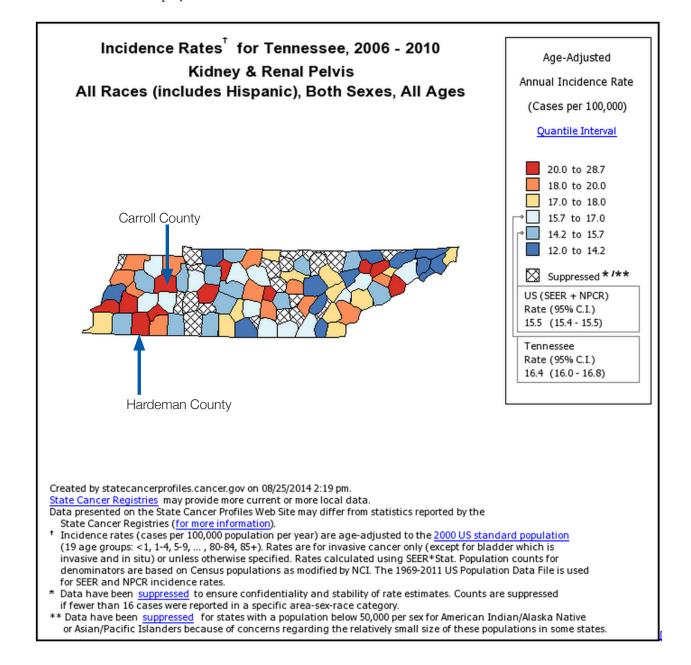
When you click on "Generate Table," the following table appears, Incidence Rate Report for Tennessee County. This table displays the incidence rate for cancers of the kidney and renal pelvis over 2006-2010. It includes the incidence rate in Tennessee overall, in the US overall, and by county. Which counties have incidence rates above the state rate? You can tell by looking at the rates just as you did for the mortality rates earlier. And you can visualize it better, if you click on the "make map" icon (see arrow).

Incidence Rate Report for Tennessee by County				Export Data
All Races (includes Hispanic), Both Sexes, Kidney & Renal Pelvis, All Ages Sorted by Rate				<u>il Interpret</u>
County	Annual Incidence Rate ¹ over rate period (95% Confidence Interval)	Average Annual Count		Printable View
Δ	▼	∇	Rate Period	
Tennessee ⁶	16.4 (16.0, 16.8)	1,123	2006-2010	
US (SEER+NPCR) ¹	15.5 (15.4, 15.5)	50,142 §	2006-2010	
Grainger County ⁶	28.7 (20.1, 40.0)	8	2006-2010	1
Hardeman County ⁶	25.9 (18.5, 35.4)	8	2006-2010	
Carroll County ⁶	25.7 (18.5, 35.0)	9	2006-2010	
Cheatham County ⁶	22.6 (16.3, 30.6)	9	2006-2010	
Hickman County ⁶	22.5 (15.1, 32.3)	6	2006-2010	1



Cancer incidence rates for kidney and renal pelvis are color-coded. Look at Carroll County and Hardeman County, are both colored red as their incidence rates, 25.7 per 100,000 and 25.9 per 100,000, are among the highest in the state and higher than the state rate overall of 16.4 per 100,000. So in these counties, kidney cancer is elevated compared to the state rate. Notice also the counties with hash-marks. These counties had 3 or fewer cases so for confidentiality reasons, the incidence rates are not displayed.

If you lived in either Carroll or Hardeman counties and your concerns focused on too much kidney cancer in your community, you can use these cancer statistics to help justify your concern and ask for deeper examination of the cancer statistics for your community, specifically.





CANCER AND ENVIRONMENTAL EXPOSURES

It is not easy to prove a connection between toxins in the environment and cancer. The previous sections of this guide focus on just one part of the story, cancer rates. Yet making a connection with cancer rates and environmental exposures is more involved and could take years to investigate. As you look for patterns in the cancer data, remember:

Medical professionals view cancer as many diseases, not one. The medical community recognizes lung cancer, breast cancer, and prostate cancer as different diseases. If the disease is not named for its main location, it may be named for the cells affected. For example, melanoma involves cells that contain the skin pigment called melanin. Health professionals examine each cancer case. They count cases by the primary (original) cancer even if the cancer has metastasized (spread to other organs). Scientists consider only the primary cancer when they investigate a possible cancer cluster.

Every type of cancer has a different set of suspected causes (risk factors). For example, smoking is a risk factor for lung cancer and bladder cancer, but not for thyroid cancer. Drinking water that contains high levels of arsenic is a risk factor for skin cancer and bladder cancer, but not prostate cancer. To make a case for linking environmental pollutants with cancer in your community, health department staff will look for evidence linking contaminants and certain types of cancers in published studies.

Cancer is not the result of a single cause. Cancer is known as a multi-factorial disease—several factors are required to ultimately cause cancer. Not everyone who smokes get lung cancer, although smoking is a known cause of the disease.

By the time patients get a cancer diagnosis, there's a long list of factors and exposures that could have caused changes to the cells. It's hard to say for sure which specific exposure was the main cause. **Cancer develops slowly.** It may take many years before a person notices symptoms and gets a diagnosis. Latency is the term used to describe the time period when a person was exposed to a causal agent and when the disease is diagnosed. Latency periods for most cancers are 10-20 years, although some childhood cancers are less than 1 year. Cancer is a disease with many steps. The first step involves changes to the genetic code (DNA) of a cell. Normally, the body can repair or replace damaged sections of DNA, and the cell recovers. If the cell reproduces while the DNA is damaged, more abnormal cells can result. Additional time leads to more changes that are the result of the malignant tumor.

Research has shown that contaminants can cause or may cause cancer, but this does not offer proof of an environmental cause for a cancer cluster. Environmental pollution by chemicals in drinking water, air, food, and in the workplace may contribute to cancer. The evidence we have is primarily based on research using lab animals and from studies in the workplace (where many people are exposed to the same chemicals). We have few community-based studies. It is difficult to prove that a certain chemical causes cancer, especially when the concern is based on exposure to environmental contamination. Other factors such as changing residences, smoking, or diet complicate the picture. Finding evidence that a specific chemical is a known cause of cancer usually takes years of research.

However, even when it is clear that a chemical can cause cancer, to prove a cause, one has to document exposure. Exposure has several components including, when a person was exposed (i.e. in utero, as a young child, during puberty, as an adult), the dose (or amount), and length of time. Depending on the type of chemical, some of these aspects of exposure matter more than others. With cancer, latency (as described above) is a key issue. For example: did the person spend time in the area when there was a spill or some other exposure occurred? Some of the details will come out early





on. Some will need additional investigation or an investigation led by someone with an official appointment. A health department-led survey will gather these kinds of data.

When clustering of cancer cases in a community is confirmed, further research is needed to assess whether suspected environmental pollutant(s) could be increasing cancer rates. This type of assessment is an exposure-outcome relationship health study (see Health Studies Guide: Is A Health Study The Answer *For Your Community?* at http://www.busrp.org/hsg and SfA: First Look at Health Studies at http://sfa. terc.edu/materials/pdfs/a_first_look_at_health_ studies.pdf). A "reference" population—a population that is similar to the community of concern, except for the environmental contamination-will allow for comparison, to see if the risk of cancer is in fact higher with exposure to environmental pollution in the community.





Resources

You can request additional data, such as annual or special topic reports, to augment data from the Cancer Registry. Call your state health department.

You can find a list of the National Program of Cancer Registries (CDC/ U.S. Center for Disease Control and Prevention) at: http://apps.nccd.cdc. gov/cancercontacts/npcr/contacts.asp

It includes dynamic views of statistics on cancer incidence (newly diagnosed cases) for prioritizing cancer control efforts

For a workshop introducing health studies. see: http://sfa.terc.edu/materials/pdfs/a_first_look_at_ health_studies.pdf.

If you are wondering whether some form of environmental health investigation or health study may be necessary in your community, Health Studies Guide: Is A Health Study The Answer For Your Community? from Boston University Superfund Research Program may help. Find it at http://www. busrp.org/hsg.

