# Statistics for Action Guide to State Cancer Profiles

## DRAFT

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# 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 action.
- want evidence to get decision-makers to pay attention.

Making a connection between cancer cases and the environment is tricky. Staff from departments of public health are asked to look at places where cancer rates seem high. Their job is to see (1) if there is a cancer cluster—a higher than expected rate, and (2) if there is a common cause. See page 11 for challenges to making an argument about links between cancer and the environment.

In 2006, according to the United States Cancer Statistics:
- 1,370,095 new cancer cases were diagnosed in the United States
- 559,880 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 people

Over a million new cancer cases in the United States in 2006 alone leads people to wonder if the cause is something in the air or water.

*But in order to be able to really evaluate ... one needs to look at pathways. So let's go back to how one is exposed and perhaps affected by something ... that could cause ... a health issue. The exposure pathways usually for DEP cleanup are your soils, or water, and drinking water. ... Air deposition was something that people in the neighborhood wanted us as a citizens' group to take on. The reason for that is that when Dow Chemical was doing their research they [the scientists} vented chemicals out the building through the fume hood devices that have vents at the top of the roof. And Dow did have a number of those. So people thought, "Well for 25 years they were venting gases out through the roof and where did those gases go?" Well, in general the flow of air, if you think about how air usually flows in our area, very often the breezes go from the water from east to west. So it was not so surprising that some people would say, "There should be some way to determine a path. There should be some way to evaluate what went up in the air for all of those years." It turns out the state's Department of Environmental Protection for cleanup has a policy and a set of regulations and also standards for evaluating exposure by water and they also have something similar for soil, but DEP really didn't have anything on the books for dealing with historic exposure by air. And when you're 25 years later, where do you go to look for the air? Obviously the air has dissipated. It's a question of deposition. Well, how do you go about evaluating that? Do you start tearing apart the trees?*

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# Terms You May Run Across

## Raw numbers

Are simply a count. The raw number of 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.

## Crude rate

Describes frequency. A crude rate compares the raw numbers to the number of people in the population under consideration. So 100 cases in a town of 25,000 is a crude rate. The crude rate does not take into account factors that may influence the rate.

## Age-adjusted rate

Counts the number of cases compared to the population *and* adjusts the numbers to take age into account. Since older people are more likely to get ill, a county with a higher percentage of older residents will almost always have a much higher crude death rate than a county with a higher percentage of people under 50. Age-adjusted death rates balance out age for the populations being compared. An age-adjusted rate is more reliable for comparisons than a crude rate.

*Example*: The longer people live, the higher their chance of getting cancer is. In County 1, nearly half the residents are retirees. In the next county over, the population is mostly parents raising young children. The raw number of people who die from cancer in County 1 will be higher. The crude rate will likely show a higher cancer death rate in the county with retirees, but if researchers adjust for age as a factor, the cancer rate may be the same.

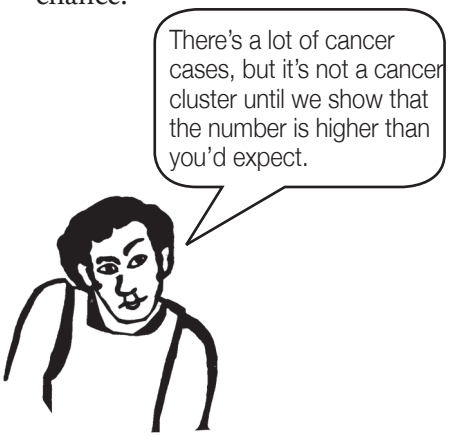
## Cancer burden

Has more than one meaning. In some cases the term refers to anyone affected by cancer, including cancer patients and their families, since they all carry a burden in emotional, physical, and financial cost. However, in the State Cancer Profiles and in this text, cancer burden means the total numbers of people who

- have cancer,
- who had cancer and are in remission, and
- who had cancer and died from it.

## 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 is higher than what you would expect to occur by chance.




## Cancer risk

Is a rate describing the frequency with which cancer is expected to strike. You may see cancer risk stated, for example, as 1 in 100,000, meaning 1 case in 100,000 individuals.

## Confidence interval

Tells us how certain the researchers are that a statistic will hold true. When it is hard to pinpoint an exact number, the researchers list a range. A confidence interval of 95% means that 95% of the time, the statistic will fall within the range they have given. In other words, if they did the same survey 100 times, 95 times they would get a number in the stated range. Note that 5% of the time, an error or an unusual event could push the number out of the given range.

## 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 cancer cases that are diagnosed and reported to the state's cancer registry.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## Cancer Gets Personal

Concern over cancer rates can spark action in a community. People may begin gathering data by keeping logs or taking a survey. They might make their own maps to show cases and possible causes. They may even request that the Department of Health look into cases in the area.

*I keep hearing cancer stories about people who live in this area. 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.*

Concerns and questions can become the basis for designing a health study.

# Using the State Cancer Profiles

On a computer with Internet access, you can take a look at cancer statistics. Start with the State Cancer Profiles, a web site that has assembled data from all over the country. You can use information on this web site 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.

**Community Member Checklist**

- ☐ Start with the State Cancer Profiles, a web site that has assembled data from all over the country.
- ☐ Visit: http://statecancerprofiles.cancer.gov/index.html

The State Cancer Profiles web site brings together data collected by clinics, hospitals, and insurers.

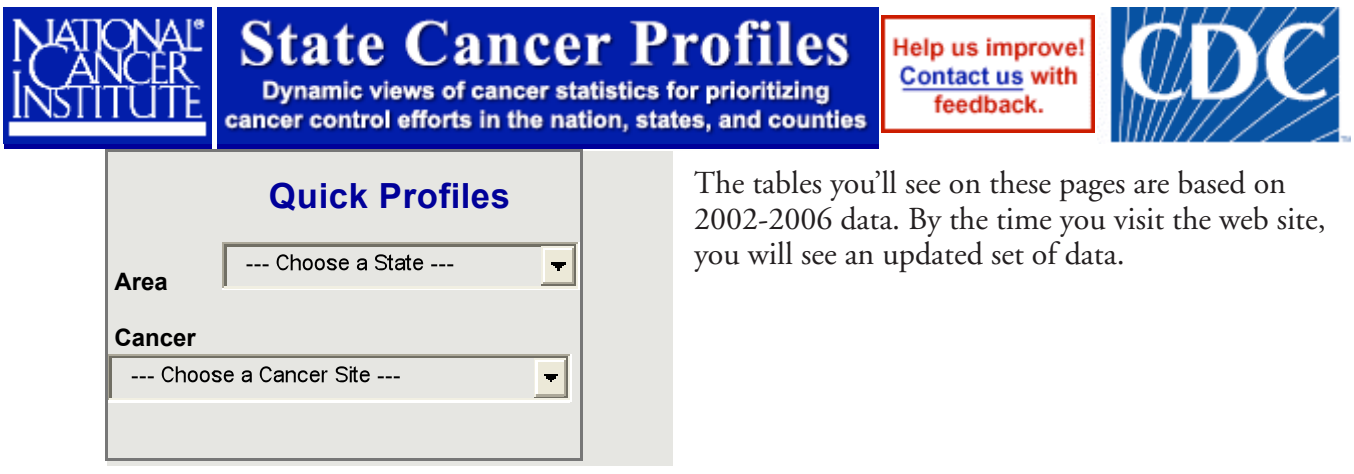
**Possibilities**

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

**Limitations of the data and presentation**

- × The data are available for periods of time up to two years ago.
- × 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.




The tables you'll see on these pages are based on 2002-2006 data. By the time you visit the web site, you will see an updated set of data.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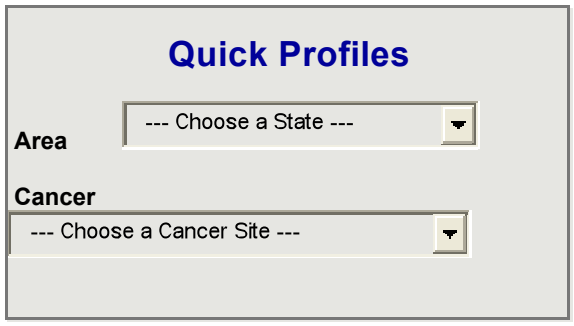
## Creating a Quick Profile for Tennessee Counties

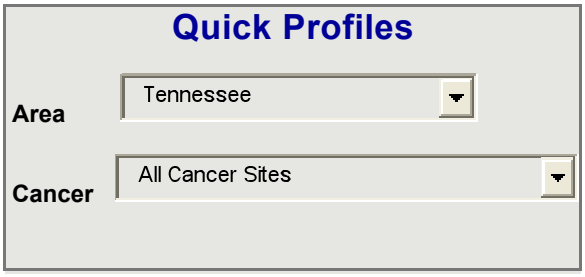
To get a statistical overview of cancer in your state, you can go to the Quick Profiles section.



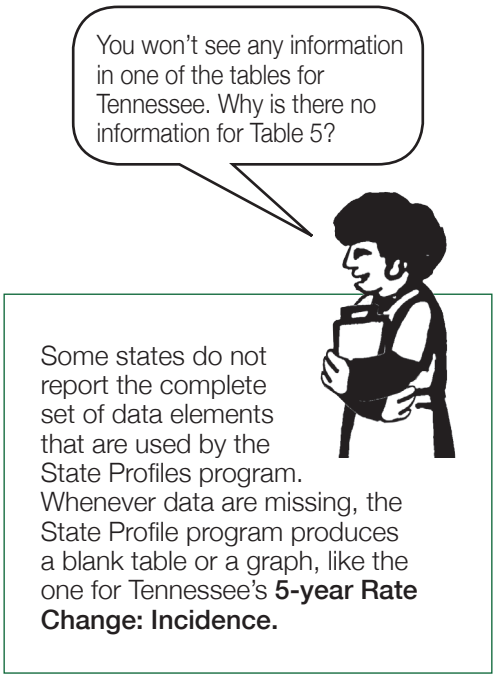

1. Select the State: Tennessee.

2. Select the type of Cancer you want.

Looking at all cancers in all counties will provide an overview of the cancer rates in Tennessee.




3. Click on the Generate profile button located under the drop-down boxes and you will soon see a set of tables and graphs containing the data you selected. This can take a minute or more. If possible, print them and spread them out.




Some states do not report the complete set of data elements that are used by the State Profiles program. Whenever data are missing, the State Profile program produces a blank table or a graph, like the one for Tennessee's **5-year Rate Change: Incidence.**

## Comparing Trends

The table called **Death Rate Report for Tennessee by County, death years through 2006** includes all cancer types, for all races and both sexes in Tennessee. An excerpt from that table is shown below.

Take a look: The middle column shows the death rate per 100,000. Tennessee rates are between 207 and 211 deaths from cancer per 100,000. In the United States overall, the rate was 186 or 187 deaths per 100,000. So Tennessee residents carry a heavier cancer burden compared with the rest of the United States. State 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.

**Death Rate Report for Tennessee by County, through 2006 All Cancer Sites, All Races, Both Sexes, All Ages**

| County | Annual Death Rate over rate period deaths per 100,000 (95% Confidence Interval) | Average Deaths per Year over rate period |
|---|---|---|
| Tennessee (State) | 208.8 (207.2, 210.5) | 12,753 |
| United States | 186.9 (186.7, 187.1) | 557,443 |
| Perry County | 276.7 (231.3, 329.1) | 27 |
| Overton County | 266.8 (238.5, 297.7) | 66 |
| Lake County | 261.5 (213.7, 317.2) | 21 |
| Marion County | 258.2 (233.1, 285.4) | 80 |
| Grainger County | 257.8 (228.8, 289.5) | 60 |
| Polk County | 255.2 (223.7, 290.1) | 48 |
| Claiborne County | 245.1 (222.1, 270.0) | 84 |
| Lewis County | 241.8 (204.7, 283.8) | 31 |
| Trousdale County | 241.6 (196.6, 294.1) | 21 |
| Decatur County | 239.9 (206.7, 277.4) | 38 |

Look at the third column. You'll see that the average number of deaths per year by county are all under 100, but they vary from a low of 21 to a high of 84. In Lewis County the average death rate for cancer was 31, and in Trousdale County the average was 21. Since 31 is about one-third higher than 21, these raw numbers make it look as if the cancer burden in Lewis County is greater than in Trousdale County.

Now, look down the second column, which uses statistical calculations of age-adjusted rate per 100,000 residents. When you compare rates that take into account the age distribution in the two counties, the rates are almost the same, 241.8 and 241.6 cancer deaths per 100,000 residents.

The range is spread out. On average 21 people died in Trousdale County, but that number could have fallen between 196 and 294 per 100,000 people—a range of nearly 100 cases. This indicates that the number of deaths varied from year to year and that the population is not very large. The larger the population, the narrower the range. So for all of Tennessee or all of the United States, the range is under 10 cases, not 100 cases.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Now focus on the table called **Death Rate/ Trend Comparison by State/County, death years through 2006, Tennessee versus United States.** This table includes all cancer types, 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 Priority 1? Why do you think so?

**Death Rate/Trend Comparison by State/County, death years through 2006 Tennessee versus United States All Races, Both Sexes**

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

From the data, you can see that:

- The death rate for Lung and Bronchus cancer for females is rising in Tennessee, and is higher than the U.S. rate. This cancer is labeled Priority 1 for two reasons: (1) the rate is increasing, that is, there are more deaths each year, and (2) the rate is already higher than the U.S. rate.
- Brain cancer death rates are stable in Tennessee, but the rate is higher than the U.S. rate. Because the rates are stable, this cancer is considered less of a priority in Tennessee, compared to Lung and Bronchus cancer in females.
- Although higher than the U.S. rate, the following cancer death rates are falling in Tennessee: Lung and Bronchus (Males), Oral Cavity and Pharynx (Males), Prostate (Males).

What types of cancer are increasing at rates similar to the U.S. rates?

The Esophagus (Males), Liver and Bile Duct (Males), Melanoma of the Skin (Males), and Pancreas (Females).

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

Bladder (Males), Esophagus (Females), Leukemia (Males and Females), Melanoma of the Skin (Females), Ovary (Females), and Thyroid (Females).

The cancer types that are still increasing must be a priority for public health. States may use the data to make decisions about funding. For example, lung cancer is increasing. It is listed as a higher priority than breast cancer. Someone might argue that the state should spend less money to promote mammography screening and more money on anti-smoking 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. Also, cancer of specific types occurs less often than other health problems like diabetes.

Because researchers can't base reliable statistics on one or two years of data with small numbers like 3 in 100,000,000, the standard practice is to look at cancer cases and deaths 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, it looks as if the childhood leukemia death rate 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.

In order to build an argument that cancer rates are high in a certain county, you will need to have numbers equal to or greater than 16 for a five-year period, or an average number of deaths per year of at least 4. Remember, the larger the numbers, the more stable the comparisons will be, and the narrower the ranges.

Two graphs generated by the State Cancer Profiles follow. The first is a 5-year trend graph, and the second graph displays cancer cases for 36 years. Look to the left of zero for cancer types where the death rate is going down. The rate is negative; the numbers are falling. The higher the number, the faster the decrease in number of deaths. Use the chart to find out which cancer rates are changing the fastest and which ones are staying close to the same.


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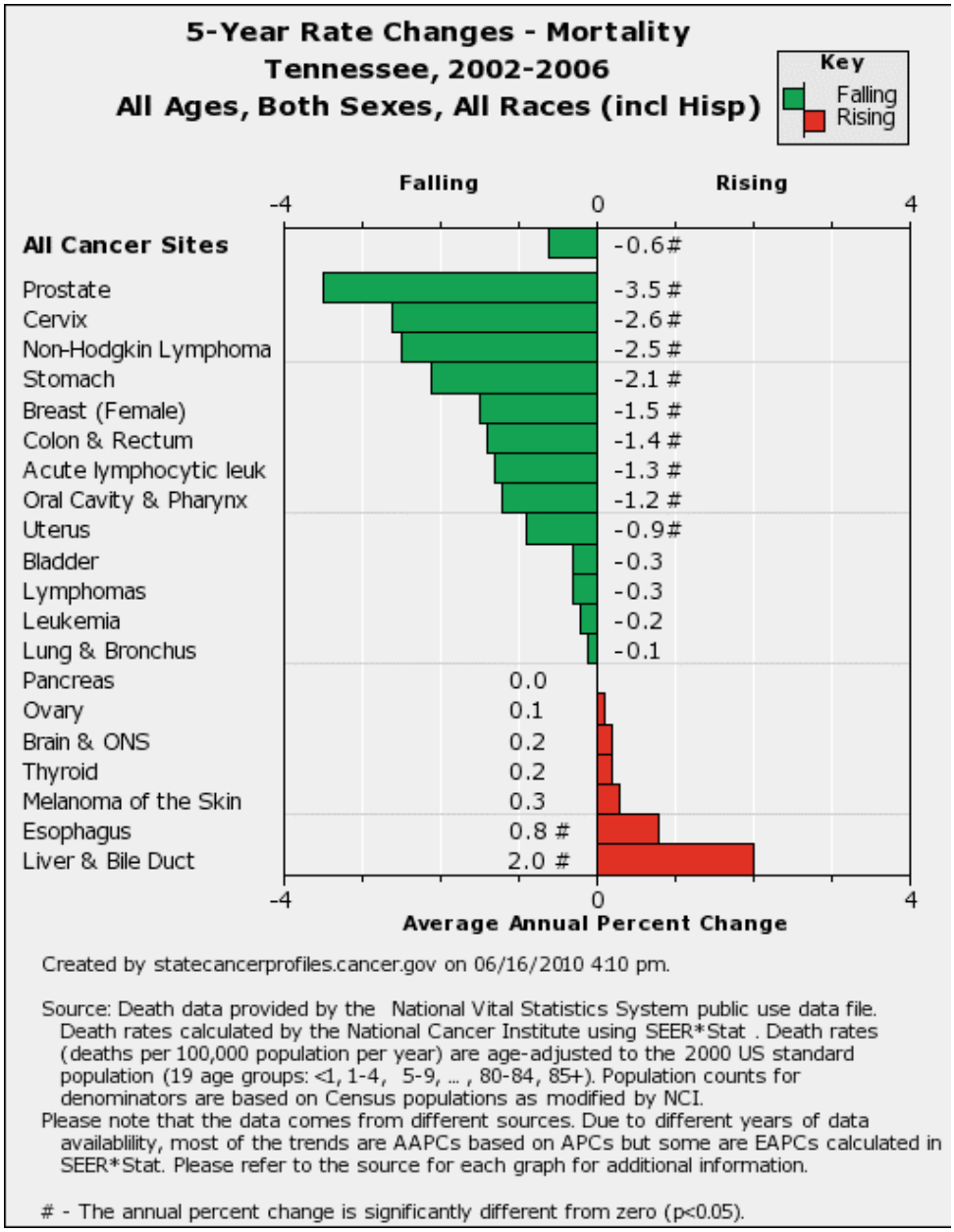
A line graph of historical trends shows when death rates peaked. Check the graph to see when deaths from cancer peaked and when they stayed about the same. On the graph below, you can compare the trend in Tennessee to the trend nationwide. Were the trends the same for white and black residents?

From the first graph, **5-Year Rate Changes-Mortality**, you probably noticed that in Tennessee over the period 2002-2006, the overall cancer death rate fell. It fell for 14 of 20 types of cancer, with the biggest drop for prostate cancer deaths, a 3.5 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 percent rise.

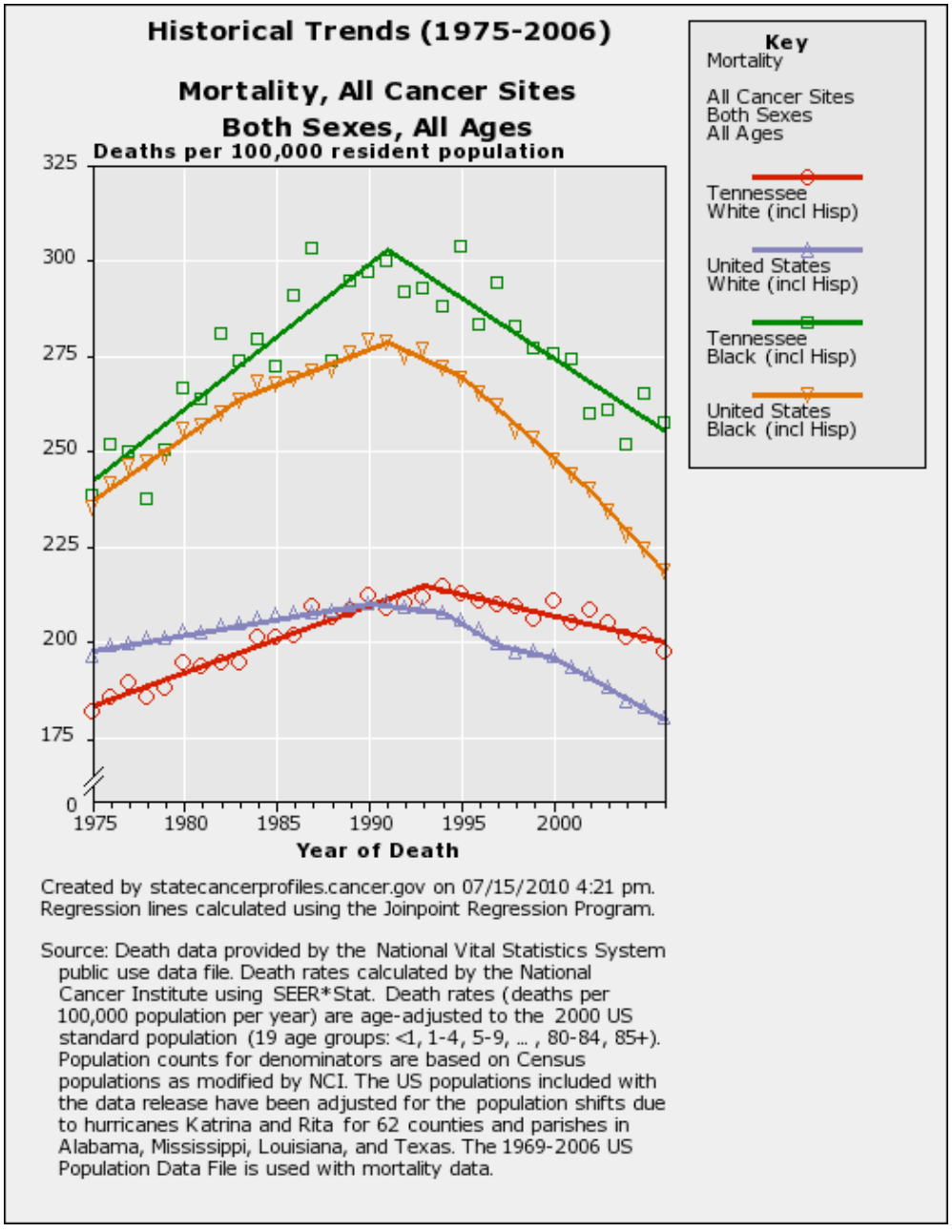


What does the second graph, **Historical Trends, 1975-2006**, tell us? Three trends jump out:

(1) Cancer trends for the United States and Tennessee rose from 1975 through the early 1990s.

(2) After the mid-1990s, cancer rates began to fall.

(3) In Tennessee, the rise in cancer deaths was faster and higher than in the United States, and it took longer for the deaths to slow and finally begin to drop in Tennessee.





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# Cancer and Environmental Exposures

**It is not easy to prove a connection between toxins in the environment and cancer. As you look for patterns in the 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.

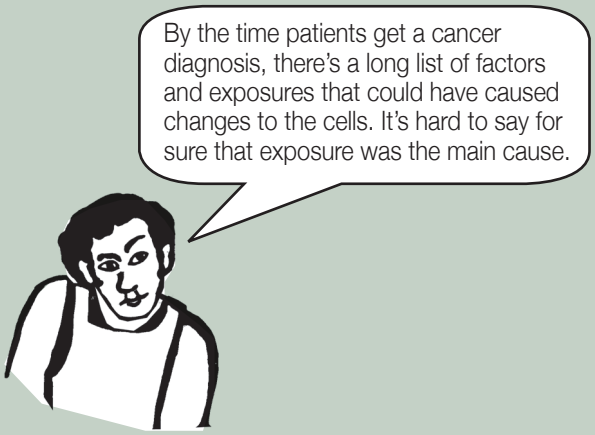
Health professionals examine each cancer case. They count cases by the primary (original) cancer even if the cancer has metastasized (spread to other organs). Scientists consider *only* the primary cancer when they investigate a possible cancer cluster.

Epidemiologists look at the research to find out if the suspected exposure has the potential to cause the reported cancer. Every cancer type has a different set of suspected causes.

**Cancer develops slowly**
It may take many years before a person notices symptoms and gets a diagnosis. 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.

Because cancer develops slowly the incidence rate in a given year might not reflect all the people who are going to be affected by cancer. It is difficult to say that all the cases are counted when symptoms and a diagnosis may come about later. Furthermore, it is difficult to know who "got" cancer, at what point. Without a time stamp, it becomes difficult to connect exposures that are not constant.

**Cancer is not the result of a single cause**
Cancer develops because of an interaction. Most people who are exposed to a chemical that is linked to cancer do not develop cancer. A person's age, underlying health factors (such as a family history of cancer), behaviors (such as smoking or working in an environment with a lot of fine dust, such as that from stone-sanding), and amount of exposure all affect whether a person develops cancer.




**Research on lab animals has shown that many contaminants can 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 harmful health effects of chemicals depend on the dose, strength of the chemical compound, and length of exposure.

Some chemicals in the environment may cause the development of abnormal cells (altering the DNA), which can lead to cancer. However, it is difficult to prove that a certain chemical causes cancer in humans. Proof would require a lot of data gathered over time. Further, to prove the toxicity of a chemical, we have to show that an illness is caused by that chemical alone and not another factor, such as a different chemical that is also present in the environment. Studies on toxicity can be conducted on lab animals, but not on people.

**Documenting a cancer cluster from an environmental cause means showing that more than the expected number of cancer cases occurs in a particular location**
One in three people will have cancer in their lifetimes. To identify a cluster, epidemiologists must identify the time period of concern and the

population at risk. They then calculate the expected number of cases and compare that number with the observed number of cases.

Epidemiologists must also determine if the cancer cases could have occurred by chance. They often test for "statistical significance," which is a mathematical measure of the difference between groups. The difference is said to be statistically significant if it is greater than what would be expected to happen by chance alone. In common practice, a statistically significant finding means that the probability that the observed number of cases could have happened by chance alone is 5 percent or less. For instance, if we examine the number of cancer cases in 100 neighborhoods, and cancer cases are occurring by chance alone, we should expect to find about five neighborhoods with a statistically significant rise in the number of cancer cases. In other words, some amount of clustering within the same family or neighborhood may occur simply by chance.

Epidemiologists must also consider that a confirmed cancer cluster may not be the result of any single, external cause. It could be the result of chance, an error in the calculation of the expected number of cancer cases, or differences in the case definition between observed and expected cases. Moreover, because people move from place to place, it can be difficult for epidemiologists to identify previous exposures, and to find the medical records that confirm the kind of cancer a person had—or if it was cancer.



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## Resources

- Add to the data from the Cancer Registry by calling by requesting annual or special topic reports from 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