



# Indiana State Department of Health

## **Questions and Answers about Suspected Cancer Clusters**

October 2017

Eric J. Holcomb, *Governor*

Suzanne Crouch, *Lt. Governor*

Kristina Box, M.D., *State Health Commissioner*

## Questions and Answers about Suspected Cancer Clusters

Often, concerns about cancer clusters begin when people notice that several relatives, friends, neighbors or coworkers have been diagnosed with cancer. The Indiana State Department of Health (ISDH) takes every suspected cancer cluster seriously.

The ISDH cancer inquiry process is a collaboration between the ISDH Cancer Control Section, the ISDH Environmental Public Health Division, and other state and federal partners. The cancer inquiry process follows the [guidelines from the Centers for Disease Control and Prevention \(CDC\) and Council of State and Territorial Epidemiologists \(CSTE\)](#). Indiana residents should know that, while ISDH uses the same basic framework for investigations, each inquiry is slightly different, based on the type of cancer, number of cases involved, environmental concerns, and other factors.

This document provides a brief overview of cancer, cancer clusters, and the inquiry process.

### Cancer in Indiana

Cancer is not one disease. The term cancer refers to a group of more than 100 diseases that share some basic characteristics. Cancer is the result of an uncontrolled growth and spread of abnormal cells in the body. The cancer facts listed below can help a person better understand the nature of cancer.

#### ***Cancer is very common.***

Cancer is the second leading cause of death in Indiana and the United States. Approximately 2.4 million Indiana residents, or two in five people now living in Indiana, will eventually develop cancer. According to the Indiana State Cancer Registry, 31,067 Indiana residents were diagnosed with cancer, and 13,496 Indiana residents died as a result of cancer, during 2015 alone. Breast, colorectal, lung, and prostate cancers are the most commonly diagnosed cancers in Indiana. Known lifestyle factors that increase cancer risk include smoking, obesity, and lack of physical activity. Anyone can get cancer at any age; however, middle-aged and older people are most likely to develop cancer.

#### ***Cancer causes are still not well understood.***

The term “cancer” refers to a group of more than 100 diseases that share some basic characteristics. Cancer is the result of uncontrolled growth and spread of abnormal cells in the body. Different types of cancer usually have different causes or risk factors. Although scientists have made progress in understanding and treating cancer, there is still a lot that is not known about what causes cancer, and why some people get cancer and others do not. The newest research shows that the causes of cancer may have to do with the complex relationship between a person’s genetics, lifestyle, and exposures.

#### ***Is cancer caused by toxins in the environment?***

Carcinogens are chemicals that cause cancer. Exposure to these chemicals at work, in neighborhoods, or within communities only account for a relatively small percentage of cancer deaths. According to the American Cancer Society (ACS), an estimated 4 percent of cancer deaths are related to occupational exposures and 2 percent from carcinogens in the environment.

#### ***Lifestyle factors may account for a large number of cancers.***

Lifestyle factors are habits that can increase cancer risk such as smoking, being overweight, and not getting enough exercise. Lifestyle factors often cluster in communities, as people tend to adopt the same habits and diet as their family, friends, and neighbors. In the [ACS’s Cancer Facts and Figures 2017 report](#), approximately 32 percent of cancer deaths in the United States will be caused by cigarette smoking during 2017, not including second-hand smoke. In addition, being

overweight and obese are associated with increased risk of 13 types of cancer. These cancers account for about 40 percent of all cancers diagnosed in the United States in 2014, according to the latest [Vital Signs](#) report by the CDC.

***The risk of developing cancer increases with age and varies based upon other factors, such as gender.***

Age is the most important risk factor for developing cancer. About 87 percent of all cancers in the United States are diagnosed among people age 50 years or older.<sup>1</sup> Therefore, a community of older adults is expected to have more cancer cases than a community of younger people, or a community with a range of age groups.

***Cancers diagnosed today are usually related to events that happened many years ago.***

Although childhood cancers are an obvious exception, people may develop cancer a long time after being exposed to a cancer-causing agent. This “latency period” can be years or even decades. This makes identifying when a person might have been exposed to a particular carcinogen very difficult. The cancer may have been caused by something that happened somewhere else, a long time ago. For adult cancers, unless people have remained in the same geographic area or type of work for many, many years, cancers caused by something in the place where they now live and work are unlikely.

## **What is a Cancer Cluster?**

A cancer cluster is defined by the CDC, the National Cancer Institute, and other public health institutions as “a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time.”

***How commonly are cancer clusters reported, and how often do they occur?***

State and local health agencies receive approximately 1,000 inquiries per year regarding suspected cancer clusters. According to a [2004 study](#), most reported situations do not fit the scientific definition of a cancer cluster. In a small number of situations (between 5 and 15 percent), formal testing confirms that the number of cases of a specific cancer in a community exceeds the expected number. However, in the majority of these cases, science is unable to identify any specific hazards causing the cancer.

***Cancer clusters can occur by chance.***

For some cancer types, and some geographic areas, a small number of cases may be enough to change an area’s cancer rate from below average to above average. These increases may be real; however, these additional cases may simply be the result of variations that occur randomly or by chance, and not due to a single cause.

***Trevor’s Law***

On June 22, 2016, Trevor’s Law was enacted. This federal law addresses the investigation of potential cancer clusters by requiring the Secretary of the United States Department of Health and Human Services (HHS) to develop criteria for the designation of cancer clusters, as well as develop, publish, and periodically update guidelines for the investigation of potential cancer clusters. In addition, the law requires that HHS provide assistance to state and local health departments. The ISDH’s current [guidelines](#) for responding to inquiries related to suspected cancer clusters align with the 2013 [guidelines](#) from the CDC and the CSTE. These guidelines have not changed since the passage of Trevor’s Law. The ISDH will continue to monitor for new guidance or changes in resources provided by federal partners.

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<sup>1</sup>American Cancer Society. Cancer Facts and Figures 2017. Atlanta: American Cancer Society; 2017. Available online at [cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2017.html](http://cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2017.html).

## Suspected Cancer Clusters in Indiana

Typically, people concerned about a suspected cancer cluster report it to either their local health department, or directly to the ISDH. All suspected cancer cluster inquiries are directed to the ISDH Cancer Control Section. When looking at a suspected cancer cluster, the ISDH Cancer Control Section will ask for the following information:

- The type(s) and number of cancers involved,
- Any suspected environmental exposure(s),
- The area and time period in which the cases occurred, and
- Information (such as name, age, contact information, and cancer type) for each person thought to be affected.

According to [CDC guidelines](#), some factors may point out that there is not a need to do a formal investigation. These include:

- Cancer cases among family members who are blood relatives (especially cancers known to be strongly genetically linked)
- Different types of cancers not known to be related to one another
- A few cases of very common cancers, particularly when the people involved are of the usual age and sex for those cancers (for example, breast cancer in women over the age of 50)

In Indiana, a suspected cancer cluster investigation is started when the ISDH receives an inquiry from a concerned citizen, community, local health department, or other outside source, such as a legislator or nonprofit organization. The initial investigation includes reviewing and analyzing cancer data and gathering environmental information to determine whether a greater than expected number of cases exist, or if there is an environmental exposure of concern.

### Conclusion

The complex nature of cancer makes it difficult to identify, interpret and address cancer clusters. Cancer is a term used to describe more than 100 different diseases that share a similar characteristic: uncontrollable growth and division of the body's cells. Each type of cancer has its own risk factors and causes. This is why true cancer clusters very rarely involve more than one type of cancer. In most cases, identified cancer clusters must have one of the following characteristics:

- There are several cases of a rare type of cancer.
- There are greater-than-expected numbers of a more common type of cancer.
- It is a type of cancer that is not usually seen in a certain group of people (e.g. children getting a cancer usually seen in adults).

Confirmation of a cancer cluster does not mean that there is a known cause or hazard. A confirmed cancer cluster could be the result of chance (random events with no known cause), miscalculation of the expected number of cancer cases, differences in the case definition between observed cases (actual number of cases) and expected cases (the rate that cancer normally occurs), known causes of cancer (for example, high smoking rates), and unknown cause(s) of cancer. Follow-up investigations can be done but can take years to complete, and the results are typically inconclusive (i.e., usually, no cause is found).

The ISDH takes every report of a suspected cancer cluster seriously. And, while the steps are similar, each investigation is slightly different, based on the type of cancer, number of cases involved and other factors.

If you are concerned about a suspected cancer cluster, contact the ISDH online at [www.in.gov/isdh/23556.htm](http://www.in.gov/isdh/23556.htm), or at 317-234-2945.