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Cancer Clusters

What is a cancer cluster?

Possible cancer clusters tend to get a lot of attention in the news and other forms of media. About 1,000 suspected cancer clusters are reported to state health departments each year. But just what is a cancer cluster?

People may become concerned that there's a cancer cluster in their community if they believe there is a higher than normal number of cancers in the area. Often there's a concern that the cancers might be caused by some type of carcinogen (cancer-causing agent) in the environment.

Scientists have a specific definition of a cancer cluster. The US Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) define a cancer cluster as **a greater-than-expected number of cancer cases that occurs within a group of people in a defined geographic area over a specific period of time**. Each part of this definition is important.

A greater-than-expected number of cancer cases...

To see if there is a greater number of cancers than expected, the number of cases seen needs to be compared to what would typically be seen in a similar group of people – such as a group with the same age, gender, and ethnicity.

The type(s) of cancer seen is also important. The cancers should either be all of the same type or types of cancer that are known to have the same cause.

Cancer is a group of more than 100 different diseases. Each type of cancer has its own risk factors and causes. True cancer clusters rarely involve more than one type of cancer. For it to be considered a true cluster, it usually must have one of the following

characteristics:

- There is a larger than expected number of a specific type of cancer (or types of cancer that are known to have a common cause).
- There are several cases of a rare type of cancer.
- The cancers are a type that is not usually seen in a certain group of people (for example, children getting a cancer usually seen in adults).

If the excess cancer cases include many different types of cancer over a period of many years, it's not likely to be a true cancer cluster, or to be caused by a single environmental factor or exposure.

That occurs within a group of people...

Cancer doesn't affect all groups of people equally. For example, it's rare in children, and becomes more common as people age. Some types of cancer are more common in men than in women (and vice versa), and some are more common in certain racial or ethnic groups, or in people with other shared characteristics (such as a history of tobacco use). These factors need to be taken into account when determining if there are more than the expected number of cancers in a group of people.

In a defined geographic area...

The boundaries of the area in which to include cancer cases needs to be defined carefully. Moving the boundaries (for example, to make the area larger or smaller) might make it look more or less likely that a cancer cluster exists.

Over a specific period of time

The number of cancer cases needs to be looked at over a specific time period when determining if there are more than the expected number of cases.

The time period is also important when looking for the possible causes of a cluster. For example, there are exceptions, but for most cancers linked to environmental causes, there's often a delay of many years (even decades) between the time of exposure and when the cancer first appears. Because of this, it might be important to see if the people affected by the cancer shared some common exposure in the past (and not necessarily the present). The longer ago this was, the harder this might be to determine.

Collections of cancers that don't meet all parts of this definition are much less likely to

be true cancer clusters.

Note that **the definition of a cancer cluster does not include anything about the cancers all having a common cause**. It might turn out that a cluster does have a common cause once it's investigated, but more often it turns out that no common cause can be found. This is discussed in more detail later on.

Some important points to consider

When considering if a cancer cluster might exist, it's important to keep in mind that cancer is common. Well over a million new cancers are diagnosed every year in the United States alone, and nearly 4 out of 10 people in the United States will develop cancer during their lifetimes. So, it's not uncommon for several people in a relatively small area to develop cancer around the same time.

Even if the excess number of cases reported in a cancer cluster looks significant based on statistics, it doesn't necessarily mean that the cancers are caused by something unique to that area. Some clustering of cancer cases happens by chance, but people tend to notice and report situations where rates seem to be above average.

If the excess cases of cancer don't seem to be random, they might need to be looked at more closely to find out if they might have a common cause. Studying cancer clusters allows scientists to identify areas of increased cancer risk, as well as to try to figure out what is causing the increase in risk. For example, studying clusters of [malignant mesothelioma](#)¹ led to the discovery of the link between [asbestos exposure](#)² and this rare cancer.

For most well-documented cancer clusters that have been found to be caused by a shared exposure, the exposure took place in the workplace, rather than in the communities where people lived. Workplace exposures may be more likely to cause cancer because the level of exposure can be higher and might last longer than in other settings. Workplace exposures can also be easier to identify because the group of exposed people is better defined and easier to trace as compared to groups in the community. This is why the links between cancer and many cancer-causing agents (carcinogens) are often first found in studies of workers. Of course, it's also possible for cancer clusters to occur in communities as well.

How are cancer clusters reported?

People concerned about a possible cancer cluster can report it to a local or state health department. Procedures vary by state, but most health departments will first ask for

information, such as:

- The type(s) and number of cancers involved
- Any suspected exposure(s) that might cause cancer
- The area and time period in which the cases occurred
- Specific information about each person thought to be affected
- Specific information about the cancers themselves

How are cancer clusters investigated?

When a cancer cluster is reported, the health department will first review the initial information provided. Based on this, most suspected clusters can be determined **not** to be true clusters, and no further investigation is needed. According to guidelines from the CDC, some factors that do not support the need for further investigation include:

- Cancer cases within family members who are blood relatives (especially cancers known to be strongly genetically linked)
- Different types of cancers that are not known to be related to one another
- A few cases of very common cancers, particularly when the people affected are of the usual age and sex for those cancers
- Cancers among people who didn't live in the same area at the time an exposure would have to had taken place to cause that cancer

If the health department feels that the potential cluster should be studied further, they will collect more information. They'll need to make sure that the cases are cancer and that they know the specific diagnosis. For example, there are several types of leukemia, and it's important to know which type each person has. They also may want to see if there are specific cancer risk factors that affected people have in common. To do this, they might contact patients or relatives or look at medical records. The health department will look at the number of cases in the affected area and those nearby to see if there are really more cases than expected. Scientists in the health department might also look at reports in the medical literature to see if other clusters like this have been noted in the past.

If needed, the state or local health department might ask federal agencies for help with the investigation. The CDC is the agency most often involved in cancer cluster investigations. Other agencies, such as the Environmental Protection Agency (EPA) and the National Institute of Environmental and Health Sciences (NIEHS), may also help investigate.

A more in-depth investigation might include getting more thorough medical histories from affected people, as well as testing blood or other body fluid samples from both affected and non-affected people. It might also include collecting and testing samples from the environment (air, soil, drinking water, etc.), especially if there is concern about a specific type of exposure as a possible cause.

Suspected cancer clusters can cause a great deal of concern and confusion in a community. It's very important that government agencies keep members of the community informed from the start of and throughout the investigation. This should include giving people a realistic idea of what may or may not be found.

What are the possible outcomes of a cluster investigation?

There are 3 main possible outcomes from a cancer cluster investigation:

- In most cases, an investigation will show that the suspected cluster is not a true cancer cluster.
- Less often, an investigation finds a true cancer cluster, but no cause can be found.
- Rarely, an investigation finds a cancer cluster where the cause can be determined.

To help illustrate this point, in a scientific review of over 500 cancer cluster investigations done over 20 years, only about 1 in 8 found a true increase in cancer rates, and in only one case was a clear cause for the increase found.

It might not be a cancer cluster.

In many cases, investigators can determine that a “cluster” of cancers isn't a true cluster. For example, the number of cases might not really be higher than expected once other factors that could explain the increase (such as people's age, gender, and tobacco use) are taken into account. Or the types of cancer might not be related to each other.

It might be a cancer cluster, and its cause is found.

Sometimes a true cancer cluster can be confirmed, and its cause is identified. At that point, steps can be taken to address it. Unfortunately, this is not a common outcome of cancer cluster investigations.

It might be a cancer cluster, but no cause can be identified.

Even if statistics show that it may be a true cluster, it's important to know that it's very rare that a cause is found. There can be several reasons for this. For example:

Random patterns can form a cluster: Even if the number of cases in an area is higher than expected, it still might not be caused by a single factor or exposure. More cancer cases in the United States are expected in large population centers or in places where the population tends to be older. But even so, for the most part, cancer cases in the United States are spread randomly across the country.

As with any random pattern, there will be more cases than expected in some spots, and fewer cases than expected in others. The areas with more cases than expected are more likely to be noticed. But many of these will be due to the "bull's-eye effect" (which is something like drawing a target on the wall after the darts have been thrown). Suppose you took a map of the United States and started drawing random circles of different sizes in different locations. You would find that some of the circles would contain more cancers than expected, and some would have fewer. Some of the circles with more cases might be clusters that have a single cause, but most would be due to chance.

Random patterns are the most common reason for a cancer cluster with no identified cause.

It can be very hard to figure out which of many exposures might be the cause:

With rare exceptions, scientists don't have a way of telling what trigger (if any) may have caused cancer in any one person, whether it's part of a cluster or not. Humans aren't like lab animals – their environments aren't strictly controlled. People are exposed to countless natural and man-made substances during their lifetimes, and to make this even more complex, these can interact with each other.

Think about how hard it would be to test for everything you've been exposed to, even if you knew where to start. Investigators might have a few clear leads or starting points for common exposures among affected people, but they need to look at all the possibilities. Finding the one exposure that could be the cause can be like looking for a needle in a haystack.

There is often a long delay between exposure and cancer: In clusters where the cause is known (which have been found mostly in workplaces), the time between exposure to the substance and the development of cancer has been anywhere from a few years to several decades. Exposures are very unlikely to cause cancers right away. And again, it's not easy to study people and their environments.

Suppose a group of people live in a community that has a higher than expected number

of cases of a certain type of cancer. If there is a potential cause, investigators first have to figure out when these people were exposed to it. Was it a single event or has it been ongoing? Was it 5 years ago? 10? 20? And what did the people with cancer have in common during that time? Added to this, some people will have moved into the community, while others may have moved away. Should the cases of people who moved into town in recent years be included? And can the people who moved away be found?

The boundaries of the cluster area can be hard to define: Defining the geographic cluster area is not always as clear-cut as one might think it would be. Just how big should the “bull’s eye” be? Should it include only the local neighborhood where most of the cases were found? Or should it also include the larger community, or even nearby communities? These areas may have cases that may or may not be related to the others.

Not everyone who is exposed is likely to develop cancer: To make things even more tricky, some people might be more or less likely to get cancer after being exposed to something, based on their genes. It’s unlikely that everyone exposed will develop cancer. At the same time, there may be people who were not exposed who develop the same cancer by chance.

Even after investigating, questions often remain

Scientists do their best to piece together the puzzle when there is a cancer cluster, but more times than not, they don’t find a likely cause. This doesn’t always mean that there isn’t one; it may just be that one can’t be found with the methods available at the time.

In many cases there might not be a common cause for the cancers, but it can be hard for everyone to feel sure of that. This might not be a satisfactory answer for the people in a community being affected, but it is often the case.

What should I do if I suspect a cancer cluster?

Concerns about cancer clusters most often come up in schools, workplaces, and in certain areas of a community. If you are concerned about a possible cancer cluster, contact your local or state health department. If you don’t know who to call in your area, the CDC has a list of web links to local and state contacts at [.cdc.gov/nceh/clusters/statelocal.htm](https://www.cdc.gov/nceh/clusters/statelocal.htm).³ (Also see the Additional resources section.)

Some of your concerns might be relieved during the initial phone call. If not, the health department will probably look into doing a brief investigation and then, if needed, will do

a more complete review of the situation. For more complex or urgent situations, the health department might also call in experts from the CDC or other federal agencies to help do a more in-depth investigation.

The investigators might be able to figure out with a fair amount of certainty that there is no true cluster, or that there is a true cluster and it's probably caused by a certain exposure. But in many cases, even when it seems there is a cluster, a single cause can't be found.

Suspected cancer clusters can be very distressing for those affected by them. Some people might be comforted if an investigation finds no clear cause for a cluster, but others might find it worrisome or frustrating. Even though thorough investigations of potential cancer clusters often don't give clear-cut answers, it's important that communities keep reporting suspected cancer clusters, and that health organizations respond to these concerns.

Additional resources

Along with the American Cancer Society, other sources of information and support include:

Centers for Disease Control and Prevention (CDC) Toll-free number: 1-800-232-4636 Home page: www.cdc.gov⁴ Cancer cluster information: www.cdc.gov/nceh/clusters/default.htm⁵ Links to state and local health departments: www.cdc.gov/nceh/clusters/statelocal.htm⁶

National Cancer Institute (NCI) Toll-free number: 1-800-4-CANCER (1-800-422-6237) Home page: www.cancer.gov⁷ Cancer Clusters Fact Sheet: www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet⁸

National Institute for Occupational Safety and Health (NIOSH) Cancer Clusters: www.cdc.gov/niosh/topics/cancer/clusters.html⁹

Hyperlinks

1. www.cancer.org/cancer/malignant-mesothelioma.html
2. www.cancer.org/cancer/cancer-causes/asbestos.html
3. www.cdc.gov/nceh/clusters/statelocal.htm
4. <http://www.cdc.gov/>
5. www.cdc.gov/nceh/clusters/default.htm

6. www.cdc.gov/nceh/clusters/statelocal.htm
7. <http://www.cancer.gov/>
8. www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet
9. www.cdc.gov/niosh/topics/cancer/clusters.html

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