




Cancer Cluster Guidelines



Now open for public comment: [Draft CDC Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns](#) . Comments will be accepted until July 25.


CDC develops guidance for state, tribal, local, and territorial health departments on how to respond to cancer cluster concerns. The current guidelines, "[Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists](#)," were published in MMWR in September 2013.

In fall 2018, CDC/ATSDR began working to update existing guidelines in accordance with the Trevor's Law provision within the [Frank R. Lautenberg Chemical Safety for the 21st Century Act](#)  . The updates will ensure that state, tribal, local, and territorial public health agencies and other stakeholders have access to information about current scientific tools and approaches to assess and respond to potential cancer clusters in communities.

CDC is following a stepwise approach in updating the guidelines, including,

1. Soliciting input from subject matter experts, state, tribal, local, and territorial public health agencies, the public, and other collaborators.
2. Reviewing the latest scientific literature on related topics, including epidemiology of clusters, cancer genomics, geospatial analysis, and risk communication.
3. Developing a draft of the updated guidelines.
4. Finalizing guidance.

Activities so far have included:

- Establishing an internal steering committee of experts from across CDC to oversee and carry out the process.
- Seeking public input via a [Federal Register notice](#)  announcing the planned update of the guidelines. CDC/ATSDR received comments from individuals, academic institutions, and community groups. CDC continues to accept comments throughout the process via email at CCGuidelines@cdc.gov.
- Convening an external expert panel of scientists representing various disciplines. Experts provided input to ensure that proposed revisions to the guidelines represent best practices.
- Conducting a comprehensive literature review on topics related to cancer cluster investigations. The review examined recent findings in the fields of cluster epidemiology, cancer genomics, geospatial analysis, statistics, and risk communication to inform the update.
- Administering an [online survey](#) to state, territorial, local, and tribal (STLT) health departments about how public health agencies respond to community concerns about unusual patterns of cancer. This survey was completed by all 50 states, the District of Columbia, and two U.S. territories (Guam and Puerto Rico).
- Conducting focus groups with STLT health officials to guide the update and the development of accompanying tools, templates and other materials for health agencies to use to help implement the guidelines.
- Holding a meeting with collaborators, including non-government researchers, community members, and advocacy groups, in April 2021 to gather feedback about concerns associated with current guidelines.
- Conducting focus groups with community members and advocates to hear suggestions for how to improve communication and community engagement activities related to the guidelines, as well as other suggestions on improving cancer cluster investigations from individuals.

Challenges include the availability of subject matter experts at the federal, state, local, tribal, territorial, and community levels—many of whom are responding to the COVID-19 pandemic. Despite this challenge, updating the guidelines remains an agency priority, and the work is ongoing.

The updated guidelines are projected to be released in 2022. The web site will be updated if this projection changes.

Questions & Answers

Why is CDC doing this now?

In 2016, the Frank Lautenberg Chemical Safety for the 21st Century Act was enacted, which included a provision called “Trevor’s Law” that addresses cancer clusters. The Act calls for periodically updating guidelines for investigating potential cancer clusters. In FY 2019, Congress appropriated \$1M to CDC/NCEH to update the current guidelines.

The updates will ensure that state, tribal, local, and territorial public health agencies and other stakeholders have access to information about current scientific tools and approaches to assess and respond to potential cancer clusters in communities.

What will change?

Current (2013) guidelines provide government public health officials with a four-step process in responding to and investigating potential cancer clusters, and outline how to seek federal technical assistance if needed.


The process of updating the guidelines will include reviewing any scientific and technological advances in cancer cluster investigations to see if and how they can be incorporated.

We don’t know yet how the guidelines will change.

Will CDC be more involved in ongoing or new state investigations?

States will retain the primary role in responding to community concerns about cancer. The guidelines update will ensure that public health agencies have the most recent scientific tools to address community concerns. CDC/ATSDR will continue to provide technical assistance to states as requested.

How can I provide input?

CDC released a Federal Register Notice to solicit input from the public, including individuals, community groups, and scientific and medical professionals. The notice was open from May 15, 2019 through July 15, 2019. You can access the notice [here](#) . CDC continues to accept comments from the public via e-mail at CCGuidelines@cdc.gov.

How long will this take?

The process began in late 2018. Time is needed to gather information from a number of experts and collaborators, including time for approval of survey and focus group plans. Challenges include the availability of subject matter experts at the federal, state, local, and community levels—many of whom have been responding to the COVID-19 pandemic. Despite this challenge, updating the guidelines remains an agency priority and the work is ongoing. We aim to publish the new guidelines in 2022. You can stay informed by visiting this web site.

Related Materials

- **New:** [Results from a State and Territorial Survey about Updating the 2013 CDC Guidelines for Investigating Cancer Clusters](#)

Contact Us: CCGuidelines@cdc.gov

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