

Results from a State and Territorial Survey about
Updating the 2013 CDC Guidelines for Investigating Cancer Clusters

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Executive Summary

In federal fiscal (FY) year 2019, Congress appropriated funding for the Centers for Disease Control and Prevention (CDC)/Agency for Toxic Substances and Disease Registry (ATSDR) to update the 2013 Guidelines “[Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists](#)” (hereafter referred to as 2013 Guidelines). To update the 2013 Guidelines, CDC sought input from the public; conducted literature reviews and an environmental media scan; held subject matter expert discussions; and gathered information from state, tribal, local, and territorial (STLT) public health agencies. This report summarizes results from a survey of STLT public health agencies.

In November 2020, following approval for information collection on October 20, 2020 (OMB Control No. 0920-0879), CDC/ATSDR sent STLT public health agencies a survey asking about strengths and weaknesses of the 2013 Guidelines, suggested revisions to the 2013 Guidelines, and facilitators and barriers for effectively addressing cancer cluster inquiries. All 50 states, the District of Columbia, and 2 U.S. territories completed the survey for a state response rate of 100% and overall response rate of 90%.

The primary findings from the survey are included in this report. Results reflect many strengths and areas for improvement for consideration when updating the 2013 Guidelines. Primary findings include the following:

- States/territories receive an average of nine cancer cluster inquiries per year.
- Approximately half (47%) of survey respondents reported that they routinely do proactive evaluations of cancer data; however, only one respondent suggested this approach should be used to identify unusual patterns of cancer.
- Most respondents agree with CDC’s current definition of a cancer cluster, although some suggestions were made for enhancing the language to address etiological factors and provide different terms to describe “cancer clusters”.
- Most respondents were neutral regarding whether the 4 steps in the 2013 Guidelines need to be revised. Those that reported whether the steps in the 2013 Guidelines should or should not be revised were almost equal. Of those that suggested the steps should be revised suggested either eliminating steps 3 and 4 (unless resources become available) or expanding the number of steps to provide more details.
- Almost 90% of respondents reported that it would be helpful if CDC/ATSDR expanded the scope of the 2013 Guidelines to more broadly focus on cancer and environmental hazards versus cancer clusters alone.
- Survey respondents reported that investigations were more successful when they involved collaboration with other government entities and/or academic or medical partners. Regarding federal assistance, respondents wanted the ability to contact subject matter experts who could provide technical assistance in all aspects of a local cancer investigation.
- Survey respondents reported that addressing staffing and data limitations would be of great value. Additional tools and templates such as decision trees clearly outlining the Guidelines’ process, the development of protocols and standard operating procedures, and providing education to community members would assist with investigations.

These findings along with other inputs will contribute directly to the updates to the 2013 Guidelines.

Background

In 2013, the Centers for Disease Control and Prevention (CDC) along with the Council of State and Territorial Epidemiologists (CSTE) published guidelines for "[Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists](#)" (2013 Guidelines). In 2016, President Barack Obama signed the Frank Lautenberg Chemical Safety for the 21st Century Act into law, which included a provision for "Trevor's Law." In 2019, Congress appropriated funds as part of Trevor's Law to CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) to update the 2013 Guidelines.

In an effort to update the 2013 Guidelines, CDC and ATSDR gathered a variety of inputs: feedback from community advocates and the general public; literature reviews and an environmental media scan; subject matter expert discussions; and input from state, tribal, local, and territorial (STLT) partners. One of the ways CDC gathered STLT input was through a survey to STLT public health agencies.

On November 4, 2020, CDC/ATSDR distributed a survey to all 65 members of the Council of State and Territorial Epidemiologists (CSTE); State Environmental Health Directors (SEHD) of the Association of State and Territorial Health Officials (ASTHO); and the U.S. Indian Health Service's Tribal Epidemiology Centers (TEC) representing all 50 state health agencies, the District of Columbia, 8 U.S. territories, and federally recognized tribes.

The goals of the survey were to:

- understand the current capacity to respond to inquiries about excess cancer;
- identify the strengths and weaknesses of the 2013 Guidelines (as well as suggested revisions); and
- determine the resource needs (e.g., technical assistance) that STLT health officials might have when conducting investigations associated with local cancer concerns.

Methods

Survey Instrument

A core group of CDC/ATSDR staff working to update the 2013 Guidelines developed the survey with input from a CDC/ATSDR Internal Steering Committee, which was established to provide input to the work associated with updating the 2013 Guidelines. The final survey instrument considered information garnered from a review of previous surveys administered to STLT public health agencies involved with cancer investigation activities, review of the literature, and discussion with subject matter experts (SMEs). Five public health professionals pilot tested the survey, and their feedback was used to refine questions, ensure accurate programming and skip patterns, and establish the estimated time required

Historic Timeline

- **1990:** CDC published Guidelines for Investigating Clusters of Health Events, which focused on chronic diseases, injuries, and birth defects.
- **2013:** CDC/ATSDR revised the guidelines to focus on cancer clusters and published the revised version in the [Morbidity and Mortality Weekly Report](#).
- **2016:** President Barack Obama signed into law the Frank Lautenberg Chemical Safety for the 21st Century Act. Section 21—Trevor's Law—called for periodic updates to guidelines for investigating potential cancer clusters.
- **2018:** In late 2018, Congress provides funds (as part of Trevor's Law) to CDC/ATSDR to update the 2013 Guidelines.
- **2019:** NCEH/ATSDR establishes a core team to collaborate with a CDC-wide steering committee and other subject matter experts on the updates. The team establishes a plan to gather a variety of inputs.
- **2020:** CDC/ATSDR conducted a survey of STLT health officials.

to complete the survey. On October 20, 2020, the Office of Management and Budget (OMB) provided Paperwork Reduction Act (PRA) approval (OMB Control No. 0920-0879) for the survey.

Pre-Distribution

CDC/ATSDR coordinated with several non-profit organizations that represent STLT health officials, including ASTHO/SEHD, CSTE, the National Association of County and City Health Officials (NACCHO), and the U.S. Indian Health Service's Tribal Epidemiology Centers (TEC) to disseminate information about the survey prior to survey launch.

CDC/ATSDR presented information about the survey and the mission of updating the 2013 Guidelines at forums/meetings to ASTHO/SEHD, CSTE, NACCHO, and the National Environmental Health Association (NEHA). [Note: NACCHO did not send the survey to their members because of competing priorities; in particular, they did not want to overburden members given they had recently distributed another non-related survey to their members. In addition, a majority of their members represent local public health agencies, and NACCHO revealed that most of their members would rely on their state counterparts to lead cancer cluster investigations.]

Distribution

CDC/ATSDR emailed a survey invitation letter to all potential respondents, which included a unique link to complete the Research Electronic Data Capture (REDCap) survey. Respondents were asked to complete the assessment within 4 weeks and were given the option to complete the assessment in multiple sessions, if necessary. Reminder emails encouraging participation in the electronic survey were distributed 2 weeks after the initial email. CDC/ATSDR worked with partner organizations to distribute additional reminders.

CDC/ATSDR requested that each public health agency submit one survey per jurisdiction (i.e., state, territory). The survey included a unique code so that multiple people within a jurisdiction could complete the survey together, if needed.

Due to competing priorities associated with the COVID-19 response and the holiday season, CDC/ATSDR extended the data collection period for 3 months through the end of February 2021 to provide the opportunity for agencies to respond. CDC/ATSDR placed follow up calls and sent emails to STLT officials in non-responding states in January and February 2021 to increase the response rate.

Analysis

CDC/ATSDR reviewed respondent data in REDCap and created a summary report to show the frequency and counts of responses for each survey question. CDC/ATSDR exported final data to an Excel spreadsheet and stored on a protected shared drive with access limited to authorized staff. Data were checked for quality and completeness and analyzed using Microsoft Excel and Stata 15.0 (College Station, TX).

Descriptive statistics summarized responses to multiple-choice questions. Qualitative analyses summarized responses to open-ended questions. Responses to open-ended questions were manually coded and an inductive coding process was used to identify themes and subcategories. This process included an initial review of responses to identify potential themes, followed by another review to assign codes to the data. Responses were reviewed by two reviewers to ensure that all emerging themes and subcategories had been identified and coded. Themes included the use of key words and categories discussed in responses. Prevalent themes in each question were identified by calculating the total count for each individual code. Cross-tabulations evaluated information across survey questions.

Results

Agency Information

All 50 states and Washington D.C. completed the survey (100% state response rate) and 2 out of 8 territories completed the survey (25% response rate), for a total response rate of 90%. The primary respondents submitting the survey included epidemiologists (66%), cancer registry staff (34%), and environmental health specialists/toxicologists (15%).

STLT public health agencies were asked about current resources and support through the CDC's National Environmental Public Health Tracking Program (Tracking Program) and ATSDR's Partnership to Promote Local Efforts to Reduce Environmental Exposure (APPLETREE) programs.

Twenty-five states reported having a tracking program. Of these, the team that responds to cancer inquiries at the state is:

- part of the same program as staff in the tracking program (32%, n=8); or
- a separate program that coordinates with the tracking program (42%, n=11).

Twenty-eight states are funded by ATSDR under the APPLETREE program. Of these, the team that responds to cancer inquiries at the state is:

- the same staff as the APPLETREE program staff (25%, n=7); or
- a separate program that coordinates with the APPLETREE program (46%, n=13).

Respondents identified the number of staff members generally involved in responding to inquiries about excess cancer on a routine basis. A majority of respondents (66%, n=35) indicated that they had between 1-3 people routinely responding to excess cancer inquiries while 27% (n=13) reported having between 4-10 people.

Respondents for agencies with 4-10 people assigned to respond to inquiries were primarily states with tracking or APPLETREE programs (85%).

Staff/Personnel

Most (85%, n=45) respondents reported having a trained geospatial analyst who is available to assist with addressing inquiries about excess cancer. The number of personnel and percentage of time dedicated to cancer cluster inquiries varies greatly by state. Some indicated that they did not have dedicated personnel for this topic or did not know if they had dedicated personnel (n=5). Others reported having a team of five or more personnel who worked on cancer cluster inquiries (n=10). A majority of staff time was apportioned to less than 10% of their full-time responsibilities. Two respondents reported that they do not have any personnel responsible for responding to inquiries routinely and two reported not knowing how many personnel are involved.

Role of Tracking Programs in Cancer Cluster Investigations*

- Help to provide or display cancer registry data
- Assist with analyzing data
- Provide GIS support

**As reported by STLT partners.*

Role of APPLETREE Programs in Cancer Cluster Investigations*

- Provide and assess environmental data
- Coordinate with other health agency staff
- Often help with communications to the public, particularly if an environmental contaminant is under investigation

**As reported by STLT partners.*

Cancer Activities

Respondents reported the number of times, over the past 7 years, their agency received one or more inquiries about excess cancer. All respondents reported that their agency did receive one or more inquiry about excess cancer (Figure 1). Many respondents (64%) reported that their agency has a tracking system in place to record or log inquiries about excess cancer.

Highlight

On average, agencies received around nine inquiries (range 1–62) about excess cancer in 2019.

Figure 1. Estimated number of cancer inquiries per year reported by agencies.

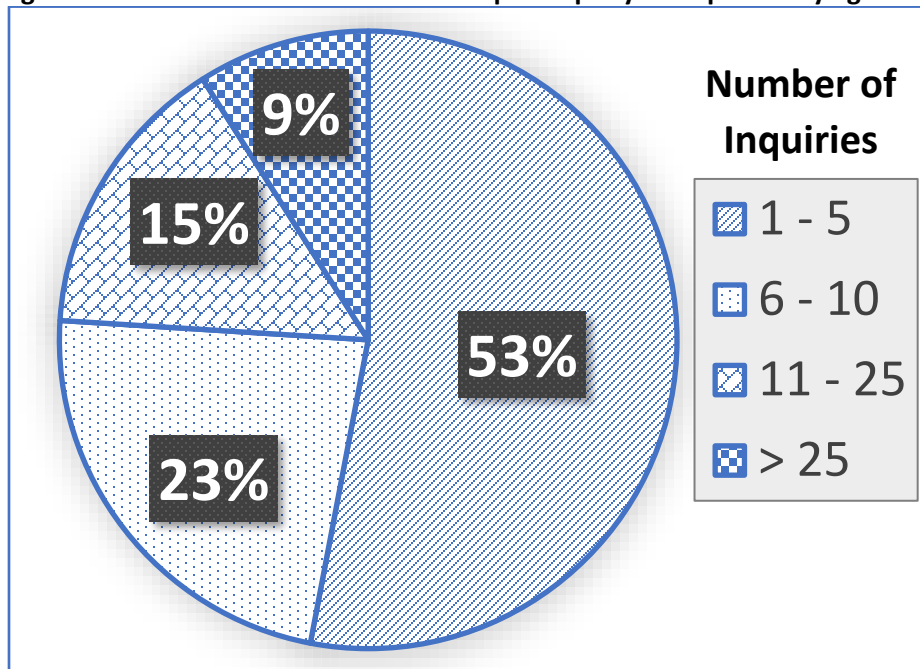
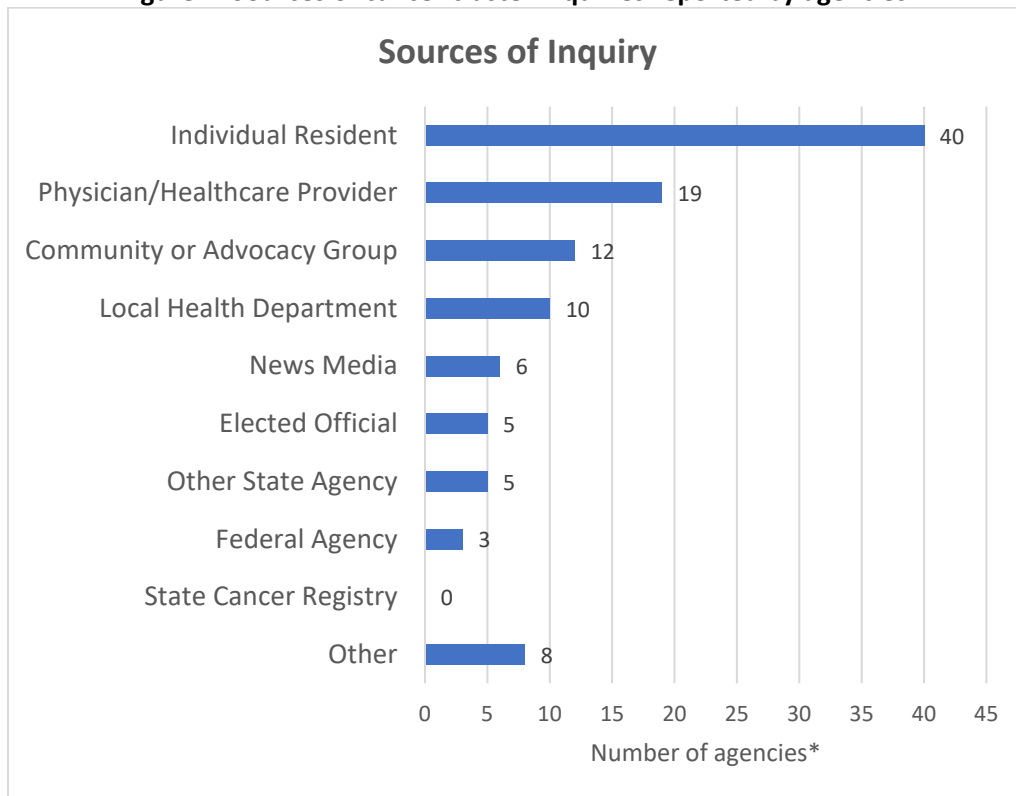


Figure 1 shows the estimated number of cancer inquiries per year reported by agencies. 53% of agencies reported 1-5 inquiries per year; 23% reported 6-10 inquiries per year; 15% reported 11-25 inquiries per year; and 9% reported more than 25 inquiries per year.

Figure 2 shows the sources of cancer inquiries reported to agencies. The majority of respondents reported inquiries are received from individual residents (75%); 36% reported inquiries received from physicians and healthcare providers and 23% reported inquiries received from community advocacy groups. For the year 2019, reports to agencies from individual residents ranged from 1–31, with an average of 7 inquiries that year.

Figure 2. Sources of cancer cluster inquiries reported by agencies.



*Agencies could report more than one source of inquiry.

Figure 2 shows the sources of cancer cluster inquiries reported by agencies.

- 40 agencies reported receiving inquiries from individual residents;
- 19 agencies reported receiving inquiries from physicians or healthcare providers;
- 12 agencies reported receiving inquiries from community or advocacy groups;
- 10 agencies reported receiving inquiries from local health department;
- 6 agencies reported receiving inquiries from news media;
- 5 agencies reported receiving inquiries from elected officials;
- 5 agencies reported receiving inquiries from other state agencies;
- 3 agencies reported receiving inquiries from federal agencies;
- 0 agencies reported receiving inquiries from state cancer registries; and,
- 8 agencies reported receiving inquiries from other sources not listed

Table 1 shows the frequency with which agencies carry out cancer investigation-related activities. Of note:

- A majority of respondents almost always respond to inquiries and provide education to the inquirer. Fourteen respondents reported that they conducted follow-up activities for inquiries from previous years.
- Twenty-five agencies (47%) routinely look proactively for geographic areas with elevated cancer rates.

Highlight

Approximately half (47%) of survey respondents reported that they routinely do proactive evaluations of cancer data; however, only one respondent suggested this approach is/should be used to identify unusual patterns.

Table 1. Frequency with which agency carries out cancer investigation related activities*[¶].

	Almost Never <5%	Rarely 5-25%	Sometimes 26-50%	Often 51-90%	Almost Always >90%
Respond to inquiries			2	2	48
Provide education	1		2	8	41
Contact State HD		1		9	
Analyze Cancer Registry Data	2	6	13	7	23
Collect Information on Cases/Exposures	8	18	8	6	11
Case Control Study	40	8	2		
Review Environmental Data	6	7	19	12	6
Environmental Sampling	29	12	3		1
Contact Fed Agency	22	20	4	2	4
Contact NGO	26	13	5	5	3
Create Communication	17	15	11	3	4
Release News/Media	29	13	4	2	2
Hold Community meetings	18	22	7	2	2
Community Advisory Panel	35	13	2		1
Written Report	11	20	13	2	5
Follow up Activities	14	35	4		

* Colors on the table show a hot/cold map by frequency of response. Higher number of responses are indicated in red or dark red while lower number of responses are indicated in blue or dark blue.

- Items with 1-6 responses are shown in dark blue
- Items with 7-12 responses are shown in light blue
- Items with 13-18 responses are shown in grey
- Items with 19-24 responses are shown in light red
- Items with 25 or more responses are shown in dark red

[¶]Rows did not sum to 53 due to non-response on select questions.

GIS use in cancer investigations

Thirty-three agencies (62%) use geospatial software and methods when addressing inquiries about excess cancer. Of those who do not use geospatial software (n=17; 32%), the most common reason for not using it is that they do not receive many inquiries (n=7). Only one respondent reported not using geospatial methods because they are not part of the 2013 Guidelines, and one reported that the software was too expensive. Two respondents reported that geospatial analyses are not necessary or that they only use statistical analyses for addressing cancer cluster inquiries. One respondent reported currently being in the process of geocoding their cancer registry data.

Best Practices

Respondents provided their thoughts on the best practices for assessing and investigating potential cancer clusters. Table 2 summarizes key topics identified from respondents. Many respondents suggested comparing rates of cancer (n=12) or looking at observed versus expected case counts (n=12). Others mentioned the importance of communication (n=8), education (n=4), and community engagement (n=4). Only a few recommended epidemiologic investigations (n=6) or using GIS as best practices (n=3). Several mentioned that they use the 2013 Guidelines as a best practice (n=5). Additionally, some respondents cited the importance of engaging or consulting with an environmental health expert or environmental regulatory agency (n=5), to help identify and explore environmental concerns.

Table 2. Categorized recommendations on best practices for assessing and investigating potential cancer clusters.

Category	Count*
Compare rates	12
Observed vs expected	12
Consistent methodology	8
Communication	8
Data collection/management	6
Epidemiologic investigation	6
2013 Guidelines	5
Environmental consultation	5
Community engagement	4
Provide education	4
Geographic information systems	3
Other [¶]	8

*The count is the number of agencies who provided an answer related to the category.

[¶]Other responses did not fall into one of the other common themes identified as categories.

Guidelines and Protocols

Nearly all respondents (95%) reported being very familiar or somewhat familiar with the 2013 Guidelines. Only one respondent reported never having heard of the 2013 Guidelines. Table 3 shows the stratification of respondents' familiarity with the 2013 Guidelines and the perceived usefulness of the 2013 Guidelines. Most of the respondents who are familiar with the 2013 Guidelines found them extremely (16%), very (42%), or moderately (36%) useful.

Table 3. Public health agency familiarity with the 2013 Guidelines and usefulness.

		If very or somewhat familiar, Usefulness of 2013 Guidelines					
Is your public health agency familiar with the 2013 CDC/CSTE Guidelines for "Investigating Suspected Cancer Clusters and Responding to Community Concerns"?	Response Count (%)	Extremely Useful	Very Useful	Moderately useful	Slightly useful	Not Useful at all	Don't Know
Very familiar with the Guidelines	28 (53%)	7 (25%)	9 (32%)	11 (39%)	1 (4%)	0 (0%)	0 (0%)
Somewhat familiar with the Guidelines	22 (42%)	1 (5%)	12 (55%)	7 (32%)	2 (9%)	0 (0%)	0 (0%)
Have heard of the Guidelines, but have not read them	2 (4%)	---	---	---	---	---	---
Have NOT heard of the Guidelines	1 (2%)	---	---	---	---	---	---
Don't Know	0 (0%)	---	---	---	---	---	---

* Survey question 8-9

Many respondents reported that their agency (n=34, 64%) has their own protocol for addressing inquiries about excess cancer. Of those who have their own protocols, only 5 (15%) use the 2013 Guidelines without modification, while 25 (74%) use the 2013 Guidelines with some modification (Table 4). Only one agency has a protocol that is not consistent with the 2013 Guidelines. Five agencies (9%) have formally evaluated their agency’s approach to addressing inquiries about excess cancer.

Table 4. Current agency protocols for addressing excess cancer inquiries.

Does your public health agency have a written protocol for addressing inquiries about excess cancer?	If yes, is your public health agency's protocol consistent with the 2013 CDC/CSTE Guidelines?				
	Response Count (%)	Yes, without modification	Yes, with some modification	No, our agency protocol is not consistent	Don't Know
Yes	34 (64%)	5 (15%)	25 (74%)	1 (3%)	3 (9%)
No	19 (36%)	--	--	--	--
Don't Know	0 (0%)	--	--	--	--

* Question 10-12

Updates to Guidelines

“Cluster”

When addressing community concerns about elevated cancer rates, slightly less than half (46%) of respondents reported not using the term “cluster”. Those that do not use the term “cluster” provided alternative terms, summarized in Table 5. The terms “elevated”, “excess”, “greater than expected” and “concern” most often replaced “cluster”.

Table 5. Terms suggested as alternates to “cluster”.

Key Word	Count
Concern	9
Elevated/Excess/Greater than expected	8
Inquiry/Investigation	5
Incidence	2
Pattern	2
Other	2

Definition of Cancer Cluster

Respondents were asked if they thought the definition of a cancer cluster should be revised. Most respondents indicated there was not a need to revise the current definition (64%), with a third of respondents (34%) indicating that the definition should be revised. Respondents that suggested the definition should be revised were asked to provide suggestions for revisions. Suggested revisions included the following primary themes (Appendix Table A.1):

- **Add information on the specific cancer type within the definition.** Some respondents stated the definition should include only one type of cancer or etiologically similar cancers.
- **Add or remove mention of statistical significance.** Some respondents wanted no mention of statistical significance within the definition, adding that the definition should not rely alone on statistical significance to confirm a cluster. Justifications included that the expected number may not be known and that the current definition does not consider biological significance or other confounders, which can be contributing factors. Conversely, other agencies suggested to keep statistical significance in the definition, but to clarify and include more information in the definition such as biological significance or confounders.
- **Address environmental concern or cancer etiology.** Some respondents stated the definition could be clarified by including mention of potential etiology or associations between the specific cancer type and known environmental contaminants. Respondents suggested clarifying the limitations of determining environmental contributors.

Highlight

Most respondents agree with CDC's current definition of a cancer cluster, although some suggestions were made for enhancing the language to address etiological factors and provide different terms to describe "cancer clusters".

Revision of Four-Step Approach

When agencies were asked if the four-step approach within the 2013 Guidelines should be revised, many respondents (42%) reported feeling neutral, meaning neither in support nor against revising the four-step approach. For the remainder, 14 agencies indicated that the approach should not be revised, and 12 agencies indicated it should be revised.

Among agencies that indicated that the four-step approach should be revised (23%), several provided suggestions for revisions (Table A.2):

- **Exclude steps three and four.** Some agencies lack the capacity to perform epidemiological studies. Additional funding or resources (i.e., technical support) are needed to complete steps three and four.
- **Include more details for steps three and four.** Include ways to communicate findings with the community, the use of a decision tree to move through steps, rubrics for interpreting standardized incidence ratios (SIR), and the inclusion of residential history and review of risk factors.

Highlight

Most respondents were neutral regarding whether the four-step approach in the 2013 Guidelines need to be revised. Suggested revisions centered on eliminating steps three and four (unless resources become available) or expanding the number of steps to provide more details.

Expanded Scope

Respondents were asked about how helpful it would be to expand the scope of the 2013 Guidelines to address community concerns more broadly about cancer and environmental hazards. A majority of respondents indicated that it would be very helpful (62%) to make this update, while 26% indicated that it would be somewhat helpful.

Highlight

Almost 90% of respondents reported that it would be helpful if CDC/ATSDR expanded the scope of the 2013 Guidelines to more broadly focus on cancer and environmental hazards versus cancer clusters alone.

Communications

Cancer Cluster Communications Toolkit

Respondents were asked about their familiarity with the Cancer Cluster Guidelines Communication Toolkit. Only 17% reported being very familiar (n=9) and 36% reported being somewhat familiar (n=19) with the Communications Toolkit. Fourteen agencies (26%) had heard of the Communications Toolkit but had not read it. A higher percentage of agencies were not familiar with the Communications Toolkit (n=25; 47%) compared to the overall Cancer Cluster Guidelines document (n=3; 6%).

Resources

Approximately half of respondents (45%, n=24) reported that their agencies have a written protocol for how to communicate with the public regarding potential cancer clusters. Of note:

- 71% of respondents have their communications plan as part of their agency's protocol for addressing inquiries about excess cancer.
- 29% of respondents have a separate document specific to cancer cluster communications.
- 26% of respondents have a health communicator trained specifically on how to address inquiries about excess cancer.

Several respondents suggested key resources that would be helpful for communications (Table A.3), including:

- fact sheets that address and explain the challenges and limitations of investigations (analysis and results), cancer data, causality and epidemiological studies type, the effect of lifestyle factors, and SIR calculation;
- recommended language and/or a template for communicating to the public and the media;
- educational resources;
- resources on the different risk factors that should be considered;
- staff with experience and expertise in communicating with the public (cancer epidemiologist, health educator, public health nurse); and
- trainings for staff in communications and in risk communications.

Best Practices

Respondents were asked to suggest best practices for communicating with the public about potential cancer clusters (Table 6). Respondents primarily suggested educating the public about cancer, risk factors for cancer, and about the definition of a cluster. Several suggested providing education and

outreach materials to the inquirers. Multiple respondents stressed the importance of plain language and clear communications, a prompt response, a consistent message, as well as being transparent throughout the inquiry and investigation process. Finally, many agencies discussed the importance of listening to the constituent or inquirer and trying to meet in-person or discuss via phone when possible.

Table 6. Categories described for best practices communicating with the public about potential cancer clusters.

Category	Count*
Education	21
Plain language	13
Listen	10
Transparency	8
In-person communication	8
Prompt response	5
Consistent message	4
Open house/Forum/Town Hall	3
Follow 2013 Guidelines	2
Other [¶]	13

*The count is the number of agencies who provided an answer related to the category.

[¶]Other responses did not fall into one of the other common themes identified as categories.

Multiple additional suggestions were given that did not match the key terms categorized in Table 6 including:

- refer to the Cardinal Rules of Risk Communication;
- bring oncologists to the discussion;
- couple education with screening initiatives in a community;
- use open-house formats with local officials and strong moderators; and
- provide website updates on progress of the investigation.

Facilitators, Barriers, and Resources Needed for Addressing Inquiries

Facilitators

The survey asked respondents to describe the top three facilitators to effectively addressing cancer cluster inquiries. Table 7 displays the most common facilitators identified as well as some specific suggestions within each category. The most frequent facilitators cited were related to collaborations (n=26), tools/resources (n=22), personnel (n=20), and data (n=13).

Collaborations with other agencies and institutions contributed greatly to addressing inquiries effectively. Collaborations include partnerships with:

- academic institutions;
- cancer registries;
- other local and state agencies;
- federal agencies (technical assistance, APPLETREE program, ATSDR); and
- interagency support.

These collaborations enabled better response to inquiries by providing aid and expertise in areas that some agencies do not have the resources such as epidemiological/geospatial analysis, health communications, and exposure assessment.

Respondents also identified specific tools or resources, trained personnel in communications and geospatial analysis, and the availability of complete cancer data as facilitators that allowed them to effectively address inquiries. The 2013 Guidelines and tools offered by CDC/ATSDR were among some of the resources mentioned that were helpful to agencies. Having pre-existing documents such as internal protocols and standard operating procedures (SOPs) that included clear guidance on communications throughout the investigation process, how to use specific software, and GIS resources for geocoding and spatial analysis were beneficial. Multiple respondents also mentioned the importance of engaging and working with the community throughout the entire process (n=5).

Highlight

Survey respondents reported that investigations were more successful when they involved collaboration with other government entities and/or academic or medical partners.

Table 7. Top facilitators that effectively assist with addressing cancer cluster inquiries.

Category	Count*	Suggestions
Collaborations	26	Academic partners
		ATSDR and APPLETREE
		Cancer registry
		Environmental Health units
		Local clinicians
		Local officials
Tools and Resources	22	Analysis tools and software
		CDC guidance
		Protocols in place
		Standard templates
		GIS resources
		Communications toolkit
		Structured policy
Personnel	20	Communications experts
		Experienced staff
		Geospatial expertise
		Multi-disciplinary teams
		Team members in the same Division
Data	13	Standard and functional data system for cancer cases
		Good cancer data
		Timely and available data
Community	5	Direct conversation with inquirers
		Provide background information
		Engage community in the investigation
		Working with community groups

*The count is the number of agencies who provided an answer related to the category.

Barriers

Respondents were asked to describe the top three barriers to effectively addressing cancer cluster inquiries (Appendix Table A.4). The most frequent barriers that agencies faced included:

- **Limited staffing.** Respondents reported having a limited number of staff, appropriately trained personnel, staff time and capacity to address inquiries and lack of expertise in cancer, environmental hazards, communications, or geospatial methods.
- **Lack of sufficient data.** The primary barrier mentioned concerned the timeliness of cancer data from the cancer registry and the lack of information on specific risk factors within the data. Other barriers included challenges with population data, trouble with geocoding, and lack of residential history data. Small case numbers also impacted analyses, investigations, and results.
- **Challenges conducting an investigation.** Respondents identified barriers with the investigation process including the time it takes to conduct an investigation, the framework to conduct an epidemiological study, the ability to identify exposures, and the inability to uncover causes/meaningful correlates.
- **Communications.** Respondents discussed challenges communicating statistics and cancer risk, identifying exposures or causative agents, and managing expectations with the community members. Challenges also exist due to government mistrust and the public's understanding of cancer inquiry investigations. Respondents highlighted the need to identify more effective methods to communicate findings and explain limitations of data.

Highlight

Survey respondents reported that addressing staffing and data limitations would be of great value. Additional tools and templates such as decision trees clearly outlining the Guidelines' process, the development of protocols and standard operating procedures, and providing education to community members would assist with investigations.

Resources and Federal Assistance

Respondents were asked to describe scientific or technical resources that would improve their agency's ability to effectively address inquiries about excess cancer. They were also asked to describe what type of federal government assistance they would find most useful (Appendix Table A.5). The most frequent resources described included tools or guidance on implementing the guidelines. Tools include:

- Statistical guidance specifically centered around the small numbers of cases and populations.
- Guidance on specific threshold values for interpreting the SIR with different population sizes.
- A webpage with scientific and technical resources.
- Templates to create better tracking systems.
- Summary documents on specific cancers.
- A collection of scientific literature of known and suspected environmental causes of cancer.
- Access to software to help perform analyses.

Regarding what type of federal assistance would be most useful, the most common responses are displayed in Appendix Table A.6. Several respondents would like assistance with developing standard operating procedures. Some requested assistance with record keeping and communications with communities. Many also expressed the need for technical assistance and access to experts who can assist in all aspects of a cancer cluster investigation. Similarly, several respondents described the need for federal funding and training. Training programs could include specific workshops on risk communication or full-day trainings on all aspects of cancer cluster investigations.

Highlight

Regarding Federal assistance, respondents wanted the ability to contact subject matter experts who could provide technical assistance in all aspects of a local cancer investigation.

Summary

The findings from this survey reflect many strengths and areas for improvement in the 2013 Guidelines. A summary of the survey responses is included below:

- States/territories receive an average of nine cancer cluster inquiries per year.
- Approximately half of survey respondents reported that they routinely do proactive evaluations of cancer data; however, only one respondent suggested this approach should be used to identify unusual patterns of cancer.
- Most respondents agree with CDC's current definition of a cancer cluster, although some suggestions were made for enhancing the language to address etiological factors and provide different terms to describe "cancer clusters."
- Most respondents were neutral regarding whether the four steps in the 2013 Guidelines need to be revised. Those that reported whether the steps in the 2013 Guidelines should or should not be revised were almost equal. Of those that suggested the steps should be revised suggested either eliminating steps three and four (unless resources become available) or expanding the number of steps to provide more details.
- Almost 90% of respondents reported that it would be helpful if CDC/ATSDR expanded the scope of the 2013 Guidelines to focus more broadly on cancer and environmental hazards versus cancer clusters alone.
- Survey respondents reported that investigations were more successful when they involved collaboration with other government entities and/or academic or medical partners. Regarding Federal assistance, respondents wanted the ability to contact subject matter experts who could provide technical assistance in all aspects of a local cancer investigation.
- Survey respondents reported that addressing staffing and data limitations would be of great value. Additional tools and templates such as decision trees clearly outlining the Guidelines' process, the development of protocols and standard operating procedures, and providing education to community members would assist with investigations.

Appendix

Table A.1. Respondent suggestions on how the definition of a cancer cluster should be revised.

Category	Count*	Summary
Cancer Type	9	Suggestion to expand on "cancer cases" in the definition, making it more specific to one type of cancer and allowing for the inclusion of rare cancers.
Statistical Significance	9	Some states suggested to revising the definition to not include statistical significance or not relying alone on statistical significance to confirm a cluster, since the expected number may not be known. The current definition does not consider biological significance or other confounders which can be contributing factors. Other states alternatively suggested to keep statistical significance but to clarify and include more information in the definition. The definition should consider that other factors can play a role in statistical significance and the use of multi-level modeling. Many respondents also suggested clarification on the meaning of "greater than expected".
Etiology	6	Etiology should be clarified in the definition such as including that cancer cases should be potentially related to a known environmental contaminant and addressing the limitations of determining environmental contributors. The current definition implies to the community that a shared etiology already exists.
Term Perception	6	The term "cancer clusters" can be a confusing term to the community since environmental cause is automatically assumed before an investigation have even been conducted. The term has also been known to invoke emotions such as fear due to this assumption.
Considerations	4	The term "cancer clusters" can be a confusing term to the community in what it means. For this reason, additional factors to be considered in the definition include confounders such as disparities in cancer rates and exposure, and risk factors. Another consideration, involved changing the scope of the guidelines to evaluating patterns of cancers.
Definition Suggestions	4	Alternative definitions provided by respondents
Comparison Group	1	Suggestion to include a comparison group in the definition

*The count is the number of agencies who provided an answer related to the category.

Table A.2. Respondent suggestions on how the four-step approach should be revised.

Category	Count	Summary
Need for Technical support and/or Funds	5	More funding and technical assistance for states to be able to collect more robust and conduct epidemiological studies.
Communications	5	Suggested including more guidance within the steps for communicating with the community throughout the process, such as using a pre-assessment tool and how to communicate the findings in step 2 (setting realistic expectations for the health department).
Expand on Steps	5	Suggestion to expand the current steps in the guidelines. Examples include the reviewing available information on risk factors and expanding on steps 3 and 4. Also including tools such as a decision tree for moving through the steps.
Exclude Steps	4	Suggested the focus should be on only steps 1 and 2 since these states rarely moved to the latter steps or lacked the capacity to complete them.
SIR Interpretation	3	Suggestions to consider other steps in evaluating the geographic distribution besides SIR only. Also, the use of a rubric to assist with interpreting the strength of SIR.
Spatial Analysis	2	Suggestion to consider and include the use of spatial statistics and software specific programs
Residential	2	Agencies noted the importance of using and including residential history in investigations.
Example	1	Example of approach/steps used in respondent's agency
Additional Considerations	1	Suggest separating childhood and adult cancers.

Table A.3 Respondent suggestions for communication resource needs.

Category	Count*	Example
Resources	15	<ul style="list-style-type: none"> • Expand info on CDC Webpage including case study examples, communications guidance, and community education resources. • Risk communication training • Resources to help address environmental justice • Funding
Recommended Language/Template	11	<ul style="list-style-type: none"> • Communications tools and templates • Fact sheets explaining different aspects of a cancer cluster investigation • Visuals/infographics • Social media messaging
Staffing	6	<ul style="list-style-type: none"> • Cancer epidemiologist, communications specialist, health educator
Training	4	
Tools	6	<ul style="list-style-type: none"> • Communication plans or protocols
Other	3	<ul style="list-style-type: none"> • Census tract level data on CDC Environmental Tracking Portal
Tools	2	

*The count is the number of agencies who provided an answer related to the category.

Table A.4. Top barriers to conducting investigations into excess cancer inquiries.

Categories	Count*	Examples
Staffing	42	<ul style="list-style-type: none"> • Expertise in cancer, communications, geospatial analysis, environment • Limited staff, time, and resources
Data Limitations	35	<ul style="list-style-type: none"> • Access to data • Limitations to data • Small case counts • Population data limitations
Public Perceptions	15	<ul style="list-style-type: none"> • Distrust • Understanding
Investigation Process	8	<ul style="list-style-type: none"> • Defining analytical area • Length of time for an investigation • Identifying exposures
Communications	5	

*The count is the number of agencies who provided an answer related to the category.

Table A.5. Suggested resources that would improve the agency’s ability to effectively address cancer cluster inquiries.

Category	Count*	Examples
Tools/Scientific Resources	11	<ul style="list-style-type: none"> • Analysis tools to calculate SIRs and other statistics to be consistent nationally • Central literature repository • GIS at census tract • More details about steps during initial inquiry and assessment phase • National tracking system
Statistical guidance	10	<ul style="list-style-type: none"> • For small numbers and populations
Better data	6	<ul style="list-style-type: none"> • Population data at the census tract level
Training for staff	6	<ul style="list-style-type: none"> • GIS training • Cancer cluster training • Risk assessment
Additional staff	3	<ul style="list-style-type: none"> • Environmental epidemiologist • GIS staff
Proactively assess rates	1	

*The count is the number of agencies who provided an answer related to the category.

Table A.6. Types of Federal assistance that would be most useful for addressing inquiries about excess cancer.

Category	Count*	Examples
Methods	14	<ul style="list-style-type: none"> • Assistance with drafting a full SOP • Communications
Technical assistance	11	<ul style="list-style-type: none"> • From CDC, ATSDR, and NIOSH
Funding	8	
Training	7	
Other	2	<ul style="list-style-type: none"> • Importance of census data
Additional staff	1	

*The count is the number of agencies who provided an answer related to the category.