

2019 STLT Public Health Agency Cancer Cluster Response

Form Approved

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The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) are updating "Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologist" (hereafter referred to as the 2013 CDC/CSTE Guidelines; <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>). To help inform the update, CDC/ATSDR is gathering input from subject matter experts and stakeholders, including state, tribal, local, and territorial (STLT) public health agencies.

We recognize that STLT public health agencies use different terms when describing "suspected cancer clusters." For the purposes of this survey, the term "inquiries about excess cancer" refers to inquiries about excess or elevated cancer cases in a particular geographic area possibly linked with an environmental hazard (this includes, but is not limited to, suspected cancer clusters). The goal of this survey is to gather input from STLT public health agencies about how they address community concerns about excess cancer, available and needed resources, and barriers, facilitators, and best practices for effectively responding to community concerns.

The survey, which may take approximately 30 minutes to complete, is intended to be completed by an individual who is familiar with the agency's process for responding to inquiries about excess cancer. Participation is voluntary and responses to all questions will be kept secure to the fullest extent allowed by law. Aggregate information gathered from this survey may be included in the updated Guidelines document and/or published separately. CDC/ATSDR will only release information in aggregate form and will ensure that no individual or public health agency is identifiable.

Thank you in advance for your participation. We kindly request that you complete this assessment by INSERT DATE. If you have any questions or would like to provide additional input into the Guidelines update, please contact us at CCGuidelines@cdc.gov

CDC estimates the average public reporting burden for this collection of information as 30 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0879)

Agency Information

1 Which type of jurisdiction is your public health agency affiliated with?

- Federal
- State
- Territory
- City or County (Local)
- Tribe or Tribal Epidemiology Center
- Other

If other, please type in type of jurisdiction

2 What is the name of your agency? (do not abbreviate)

3 What is your title? (do not abbreviate)

4 What is your role within the agency as it relates to addressing inquiries about excess cancer?

- Epidemiologist
- Environmental health specialist/toxicologist
- Cancer registry staff
- Statistician
- Communications staff
- Other
- Don't Know

If other, please specify what role is

5 Is your public health agency responsible for responding to inquiries about excess cancer?

- Yes, my agency responds to inquires when they are received
- No, my agency refers inquiries to another agency or organization (e.g., state health department)
- Don't know

What agency or organization do you refer inquiries to?

Is there someone else in your agency who would be better suited to complete this survey?

- Yes. If so please, forward this to the appropriate individual.
 No

6 Over the past 7 years, has your public health agency recieved one or more inquiries about excess cancer?

- Yes
 No
 Don't Know

7 About how many inquiries about excess cancer does your public health agency receive each year?

- 1-5
 6-10
 11-25
 >26
 Don't Know

Guidelines and Protocols

- 8 Is your public health agency familiar with the 2013 CDC/CSTE Guidelines for "Investigating Suspected Cancer Clusters and Responding to Community Concerns"?
- Very familiar with the Guidelines
 - Somewhat familiar with the Guidelines
 - Have heard of the Guidelines, but have not read them
 - Have NOT heard of the Guidelines
 - Don't Know
-
- 9 Please rate the usefulness of the 2013 CDC/CSTE Guidelines
- Extremely useful
 - Very useful
 - Moderately useful
 - Slightly useful
 - Not at all useful
 - Don't know
-
- 10 Does your public health agency have a written protocol for addressing inquiries about excess cancer?
- Yes
 - No
 - Don't Know
-
- 11 If you are willing to share a copy of your agency's protocol with CDC, please upload here.
-
- 12 Is your public health agency's protocol consistent with the 2013 CDC/CSTE Guidelines?
- Yes, our agency uses the 2013 Guidelines without modification
 - Yes, our agency protocol is consistent with the 2013 Guidelines with some modification
 - No, our agency protocol is not consistent with the 2013 CDC/CSTE Guidelines
 - Don't Know
-
- 13 Does your public health agency use the term "cluster" when addressing community concerns about elevated cancer rates in a specific geographic area?
- Yes
 - No
 - Don't Know
-
- 14 What term(s) does your agency use?
-
- 15 The 2013 CDC/CSTE Guidelines define a cancer cluster 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."
Do you think this definition of a cancer cluster should be revised in the updated guidelines?
- Yes, the definition should be revised
 - No, the definition should remain the same
 - Don't Know, I'm not familiar with the cancer cluster definition
-
- 16 How should the definition of cancer clusters be revised?

-
- 17 The 2013 CDC/CSTE Guidelines recommend a four-step approach to addressing cancer cluster inquiries. Should the four-step approach be revised in the updated guidelines?
- Yes, the four-step approach should be revised
 - No, the four-step approach should remain the same
 - Neutral
 - Don't Know, I'm not familiar with the approach in the Guidelines
-

18 How should the approach be revised?

- 19 How helpful would it be to your public health agency if CDC/ATSDR broadened the scope of the updated guidelines to more broadly address community concerns about “cancer and environmental hazards” rather than focusing on “suspected cancer clusters”?
- Very helpful
 - Somewhat helpful
 - Not helpful
 - Don't Know

Public Health Agency Response Activities

20 Does your public health agency have a tracking system in place to record or log inquiries about excess cancer?

- Yes
 No
 Don't Know

21 How many inquiries about excess cancer did your public health agency receive in 2019?
 (Please use data from your agency's tracking system, if one exists. Otherwise, please estimate the number of inquiries received.)

 (Please indicate if not known or if not tracked and unable to estimate)

22 The number provided above is:

- Actual/measure
 Estimated

23 When considering all the inquiries your agency received in 2019, please select the source(s) of these inquiries.

(Check all that apply)

- Individual Resident
 Community or Advocacy Group
 Physician/Health Care Provider
 Local Health Department
 State Cancer Registry
 Other State Agency
 Federal Agency
 Elected Official
 News Media
 Other

 Individual Resident: Number of inquiries?

 (Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

 Community or Advocacy Group: Number of inquiries?

 (Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

 Physician/Health Care Provider: Number of inquiries?

 (Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

 Local Health Department: Number of inquiries?

 (Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

State Cancer Registry: Number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

Other State Agency: Number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

Federal Agency: Number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

Elected Official: Number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

News Media: Number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

Other: Name source(s) and provide number of inquiries?

(Please note that the total numbers for all sources checked should add up to the response provided in Question 21)

24. When considering all the inquiries your agency received in 2019, please tell us how often did your agency carry out the following activities.

	Never or Almost Never (>10%)	Rarely (10-40%)	Sometimes (40-60%)	Often (60-90%)	Always or Almost Always (90-100%)	Not Applicable
Respond to email/phone inquiry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide education during initial email/phone contact	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact state health department (if applicable)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Analyze cancer registry data to determine whether there is an elevated rate of cancer in the community of concern (e.g., calculate an SIR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collect additional information about cases, such as potential exposures and risk factors (e.g., conduct case series study or case reports)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conduct a case-control study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Review environmental data	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conduct environmental sampling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact federal agency for technical assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contact non-governmental organization, (e.g. academia, local medical community, clinician, Pediatric Environmental Health Specialty Units/PEHSU) for assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Create public communication product (e.g. web, printed materials, social media)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Release information through news media	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hold community meeting(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establish a Community Advisory Panel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prepare written report for public dissemination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If any, please list other activities not listed above that your agency may conduct:

(Additionally please indicate how often each activity is conducted using the scale in the previous question)

-
- 25 Does your agency routinely conduct follow-up activities on previous inquiries (e.g., follow-up communication, recalculate cancer statistics on a recurring basis, etc.)?
- Yes
 No
 Don't Know
-

- 26 In 2019, how many inquiries from previous years did your agency conduct follow-up activities for?

(Indicate if not known, or not tracked)

- 27 To more fully understand your agency's approach, CDC/ATSDR would like to review example reports or documents that highlight how your agency responds to inquiries about excess cancer. If you are willing to share any documents, please upload.
-

- 28 Does your public health agency use geospatial software and methods when addressing inquiries about excess cancer (for example, to assess whether there is an elevated number of cancer cases in a particular location and time)?
- Yes
 No
 Don't Know
-

- 29 If no, why not?

- Geospatial methods are not part of the 2013 CDC/CSTE Guidelines
 Do not have trained staff
 Software too expensive
 Do not receive many inquiries
 Other
-

If other, please write in here.

- 30 Does your public health agency analyze cancer incidence data on a routine basis to proactively look for geographic areas with elevated cancer rates?
- Yes
 No
 Don't Know
-

- 31 Does your jurisdiction have a CDC-funded Environmental Public Health Tracking program? For more information see: <http://ephtracking.cdc.gov/showHome.action>
- Yes
 No
 Don't know

32 Does the program/team that responds to inquiries about excess cancer (and conducts investigations into excess cancer) coordinate with the CDC-funded Environmental Public Health Tracking program?

- Yes, they are part of the same program
 Yes, the programs coordinate but they are separate programs
 No
 Don't know
-

33 How does the Environmental Public Health Tracking program contribute to your agency's ability to respond to inquiries about excess cancer?

(If a tracking program exists but does not contribute to this work, please indicate so in box)

34 Does your jurisdiction have an ATSDR-funded APPLETREE (ATSDR's Partnership to Promote Localized Efforts to Reduce Environmental Exposure) program? For more information see: <https://www.atsdr.cdc.gov/states/index.html>

- Yes
 No
 Don't Know
-

35 Does the program/team that responds to inquiries about excess cancer (and conducts investigations into excess cancer) coordinate with the ATSDR-funded APPLETREE program?

- Yes, they are part of the same program
 Yes, the programs coordinate but they are separate programs
 No
 Don't Know
-

36 How does the APPLETREE program contribute to your agency's ability to respond to inquiries about excess cancer?

(if program exists, but does not contribute please indicate so in box)

Communication with the Public

- 37 Does your public health agency have a written protocol for how to communicate with the public regarding potential cancer clusters?
- Yes, as a separate document specific to cancer cluster communications
 - Yes, as part of the agency's protocol for addressing inquiries about excess cancer
 - No
 - Don't know

- 38 If you are willing to share a copy of your agency's protocol with CDC, please upload here.

(This refers to the protocol in Question 37)

- 39 Is your public health agency familiar with the Cancer Cluster Communication Toolkit developed by CDC and the National Public Health Information Center? (available at: <https://www.nphic.org/toolkits/cancer-cluster>)
- Very familiar with the Communications Toolkit
 - Somewhat familiar with the Communications Toolkit
 - Have heard of the Communications Toolkit, but have not read it (or am not familiar with it)
 - Have NOT heard of the Communications Toolkit
 - Don't know

- 40 Please rate the usefulness of the Communications Toolkit.

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not at all useful
- Don't know

- 41 CDC/ATSDR is interested in receiving input on the current and updated guidelines from community members and advocacy groups. Please provide the name of individuals or advocacy groups that you believe might be helpful in obtaining such input.

(If none, please respond N/A)

Personnel

- 42 Approximately how many people in your public health agency are involved in responding to inquiries about excess cancer on a routine basis? (Number of people)

(If not known, please write in "Don't Know")

- 43 For each person involved in responding to inquiries about excess cancer, please provide the following information:
Estimates percent time spent addressing these inquires in the past year (note that 100% is equal to 40 hrs/wk) Job Title or Discipline (e.g., Epidemiologist, Health Communicator, Statistician, Environmental Health Scientist, GIS analyst) Agency/Department/Organization (e.g., Health Department, Cancer Registry, Environmental Protection) (Provide information for EACH person. Example: Individual 1, Individual 2, etc.)

-
- 44 Does your public health agency have health communicators trained specifically on how to address inquiries about excess cancer?

- Yes
 No
 Don't Know
-

- 45 Does your public health agency have personnel trained in geospatial analysis who are available to assist with addressing inquiries about excess cancer?

- Yes
 No
 Don't Know

Barriers, Facilitators, and Needed Resources

- 46 What are the top 3 barriers (i.e., factors that limit or restrict) for effectively addressing inquiries about excess cancer?
(If not known, please write in "Don't Know")
-
- 47 What are the top 3 facilitators (i.e., factors that promote or help) for effectively addressing inquiries about excess cancer?
(If not known, please write in "Don't Know")
-
- 48 What communication resources would improve your agency's ability to effectively address inquiries about excess cancer?
(If not known, please write in "Don't Know")
-
- 49 What scientific or technical resources would improve your agency's ability to effectively address inquiries about excess cancer?
(If not known, please write in "Don't Know")
-
- 50 What type of Federal governmental assistance would your public health agency find most useful?
(If not known, please write in "Don't Know")

Best Practices and Recommendations for Updated Guidelines

51 Has your public health agency ever formally evaluated any aspect (e.g., risk communication and education) of your agency's approach to addressing inquiries about excess cancer?

- Yes
 No
 Don't Know
-

52 If you are willing to share the finding of your evaluation, please upload here.

53 What are best practices for communicating with the public about inquiries about excess cancer?

(If not known, please write in "Don't Know")

54 What are best practices for assessing and investigating inquiries about excess cancer?

(If not known, please write in "Don't Know")

55 Please use this space to provide any additional information or comments you would like to share with CDC/ATSDR.