

Introduction

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

Section 1: Agency Information

1. Which type of public health agency are you representing?

State

Territory

City or County (local)

Tribe or Tribal Epidemiology Center

Other Specify: _____

Don't know

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)

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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 your agency as it relates to addressing inquiries about excess cancer?

- Epidemiologist
- Environmental health specialist/toxicologist
- Cancer registry staff
- Statistician
- Communications staff
- Other Specify: _____
- Don't know

5. [Screening question] 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

If No: "What agency or organization do you refer inquiries to?"

If Don't know: "Is there someone else in your agency who would be better suited to complete this survey? If so, please forward this to the appropriate individual."

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

- Yes
- No
- Don't know

7. If Q6="Yes": 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

Section 2: 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

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- 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 Q10="Yes": If you are willing to share a copy of your agency's protocol with CDC/ATSDR, please upload it here.

12. If Q10="Yes": 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. If Q13="No": 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."

Should the cancer cluster definition be revised in the updated guidelines?

- Yes, the definition should be revised
- No, the definition should remain the same
- Neutral
- Don't know; I'm not familiar with the cancer cluster definition

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16. If Q15="Yes": How should the cancer cluster definition 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. If Q17="Yes": 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

Section 3: 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.)

_____ number of inquiries about excess cancer in 2019

- Don't know (we do not track this, and I can't estimate)

22. The number provided above is:

- Actual/measured
- Estimated

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23. When considering all the inquiries your agency received in 2019, please tell us how many inquiries came from each of the sources below. (Please note that the total number should add up to the response provided in Q21.)

Source of inquiry	Number of inquiries in 2019
Individual resident	
Community or advocacy group	
Physician or healthcare provider	
Local health department	
State cancer registry	
Other state agency	
Federal agency	
Elected official	
News media	
Other: _____	

24. When considering all the inquiries your agency received in 2019, please tell us how often your agency carried out the following activities by checking one of the boxes for each activity.

ACTIVITY	Always or Almost Always (>90%)	Often (60-90%)	Sometimes (40-60%)	Rarely (10-40%)	Never or Almost Never (<10%)	NA
Respond to email/phone inquiry						
Provide education during initial email/phone contact						
Contact state health department (if applicable)						
Analyze cancer registry data to determine whether there is an elevated rate of cancer in the community of concern (e.g., calculate an SIR)						
Collect additional information about cases, such as potential exposures and risk factors (e.g., conduct case series study or case reports)						
Conduct a case-control study						
Review environmental data						
Conduct environmental sampling						
Contact federal agency for technical assistance						
Contact non-governmental organization (e.g. academia, local medical community, clinician, Pediatric Environmental Health Specialty						

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Units/PEHSU) for assistance						
Create public communication product (e.g. web, printed materials, social media)						
Release information through news media						
Hold community meeting(s)						
Establish a Community Advisory Panel						
Prepare written report for public dissemination						
Other activity not listed above (specify): _____						

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. If Q25="Yes": In 2019, how many inquiries from previous years did your agency conduct follow-up activities for?

_____ number of previous inquiries with follow-up activities in 2019

- Don't know (we do not track this, and I can't estimate)

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 them here.

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 Q28="No": Why not? [check all that apply]

- 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 _____

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

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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. If Q31="Yes": 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. If Q31="Yes": How does the Environmental Public Health Tracking program contribute to your agency's ability to respond to inquiries about excess cancer?

A Tracking program exists, but does not contribute to this work

Don't know

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. If Q34="Yes": 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. If Q34="Yes": How does the APPLETREE program contribute to your agency's ability to respond to inquiries about excess cancer?

An APPLETREE program exists, but does not contribute to this work

Attachment A – Assessment: Word Version

Don't know

Section 4: 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 Q37="Yes": If you are willing to share a copy of your agency's protocol with CDC, please upload it here.

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.

Don't know/Not applicable

Section 5: 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)

Don't know

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43. For each person involved in responding to inquiries about excess cancer, please tell us the estimated percent time spent addressing these inquiries in the past year, job title or discipline, and agency/department/organization.

	% time (note: 100% is equal to 40 hrs/wk)	Job Title or Discipline (e.g., epidemiologist, health communicator, statistician, environment health scientist, GIS analyst)	Agency, Department, or Organization (e.g., health department, cancer registry, environmental protection agency)
Individual 1			
Individual 2			
Individual 3			
Individual 4			
Individual 5			
Individual 6			

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

Section 6: Barriers, Facilitators, and Needed Resources

46. What are the top 3 barriers (i.e., factors that limit or restrict) to effectively addressing inquiries about excess cancer?

- 1) _____
 - 2) _____
 - 3) _____
- Don't know

47. What are the top 3 facilitators (i.e., factors that promote or help) for effectively addressing inquiries about excess cancer?

- 1) _____
 - 2) _____
 - 3) _____
- Don't know

48. What communication resources would improve your agency's ability to effectively address inquiries about excess cancer?

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Don't know

49. What scientific or technical resources would improve your agency's ability to effectively address inquiries about excess cancer?

Don't know

50. What type of Federal assistance would your public health agency find most useful?

Don't know

Section 7: Best Practices and Recommendations for Updated Guidelines

51. Has your 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 Q51="Yes": 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?

Don't know

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

Don't know

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

Don't know/Not applicable

Attachment A - Assessment: Word Version

This is the end of our assessment. Thank you for participating. If you have any additional comments or questions, please email us at CCGuidelines@cdc.gov.