Form Approved
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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 via multiple efforts from subject matter experts and stakeholders, including state, tribal, local, and territorial (STLT) public health agencies. These efforts include conducting an online survey distributed to 50 state, 3000 local, 5 territorial and 2 freely associated state healthdepartments and 12 tribal epidemiology centers to assess current approaches, capacity, and best practices for addressing community concerns about excess cancer. A companion effort aimed at better understanding the perspective of community members and advocacy groups is also planned as part of the overall effort to revise the 2013 CDC/CSTE Guidelines.

We are also conducting approximately 10 focus groups with representatives from state and territorial public health agencies in order to collect more detailed and nuanced information than is possible with a survey. The goals of the focus groups are to 1) better understand how state and territorial public health agencies respond to and address community concerns about excess cancer and the environment and 2) gather input on updated guidelines and other federal support.

We recognize that STLT public health agencies use different terms when describing "suspected cancer clusters." For the purposes of this focus group, 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).

This focus group discussion should take approximately 90 minutes. Aggregate information gathered during focus groups may be included in the updated Guidelines document and/or published separately. CDC/ATSDR will only release information in aggregate form. This will ensure that no individual or agency is identifiable. If at any time you are uncomfortable with my questions, you can choose not to answer. Your participation in this focus group is completely voluntary. If you have any questions or would like to provide additional input into the Guidelines update, please contact CDC/ATSDR at CCGuidelines@cdc.gov

Besides the focus group facilitator, one or more persons working on this project will be listening and taking notes about the discussion. We will record the focus groups discussion to ensure that we capture all the information that is provided. By participating in this focus group discussion, you are agreeing to be recorded. Is there anyone who would like to withdraw their participation at this time?

[If yes] Thank you. You are free to disconnect from the discussion at this time.

[If no] Okay, we will proceed with the discussion.

SECTION 1: RESPONSE TO INQUIRIES ABOUT EXCESS CANCER

We would like to understand how your public health agency manages and responds to inquiries about excess cancer.

1) First, please tell us how your agency responds to the initial phone or email inquiries about excess cancer possibly related to environmental hazards.
   a) Who receives and responds to the initial inquiry?

      PROBE: What is the job title and program/department of the person or team of persons?

      PROBE: What relevant training and experience does the person or team of persons have?

   b) What information is elicited from the inquirer during the initial communication?

      PROBE: Are there standard forms or templates used to collect information?

      PROBE: What efforts are made to understand the comprehensive basis of the inquirer's concern (e.g. are there environmental concerns in the community that they believe might be impacting health?)?

   c) What information is provided to the inquirer during the initial communication?

      PROBE: Are there standard forms/templates or educational materials used to share information?

2) Next, please tell us what actions are typically taken by your agency after receiving and responding to the initial inquiry.
   a) Who is regularly involved in reviewing, triaging, and addressing inquiries about excess cancer?

      PROBE: Does your agency have a designated team or workgroup? Who are the members of that team and what disciplines and programs/departments do they represent?

      PROBE: Are there other disciplines or programs/departments that should be involved?

   b) When does your agency evaluate cancer data? What is typically done? Who does it?

      PROBE: Under what circumstances does your agency evaluate or analyze cancer data (e.g., calculate a standardized incidence ratio)?

      PROBE: Does your agency routinely look at cancer rates in the community/area of concern?

   c) When does your agency review environmental data? What is typically done? Who does it?

      PROBE: Under what circumstances does your agency review environmental data?

      PROBE: What kinds of environmental data are readily available for review?

      PROBE: If environmental data are not readily available, when and how are they collected? How are they evaluated relative to the inquiry (e.g. drinking water consumer confidence reports, EPA data)?

   d) What, if any, other actions are routinely taken by your agency when addressing inquiries about excess cancer?

3) Next, please tell us when and how your agency closes an inquiry (i.e., when the response is concluded).

   PROBE: Under what circumstances does your agency decide to close an inquiry?

PROBE: What steps or activities are taken (a) within the agency and/or (b) with community members when it is time to close an inquiry?

PROBE: Examples of activities could include generate and share a report summarizing actions and outcome, conduct a follow-up telephone call and/or email with the inquirer, hold community meetings.

4) Please describe what your agency considers to be a satisfactory outcome to an inquiry about excess cancer?

PROBE: Does this differ from what the inquirer or community considers to be a satisfactory outcome? If so, how?

5) What approaches do you feel work best for communicating with the public about potential cancer clusters (or concerns about excess cancer possibly associated with an environmental hazard)?

PROBE: Examples of communication approaches include developing communication products for the web or printed materials (such as written reports or briefs), social media posts, community meetings, or establishing a Community Advisory Panel.

a) Are certain communication approaches best suited for different stages of the response? If so, please describe what works best for specific stages.

b) What communication approaches have you found to be less effective? Why?

SECTION 2: FEDERAL SUPPORT & UPDATED GUIDELINES

We'd like to end the focus group discussion by hearing more about how the federal government can better support your agency and by receiving your input on the updated guidelines.

6) Under what circumstances has your agency requested assistance from CDC or ATSDR related to inquiries about excess cancer?

a) How has federal support been helpful to your agency? Has this type of federal support resulted in difficulties in your efforts to respond to inquiries?

b) How can CDC/ATSDR support be improved to best support your agency's efforts to respond to inquiries?

7) What aspects of the 2013 CDC/CSTE Guidelines would your agency like to see retained in the Updated Guidelines? Why?

8) What would your agency like to see changed, added, or improved upon in the Updated Guidelines? Why?

9) Is there anything else you would like to share with CDC/ATSDR that has not been discussed today?

Thank you for your time and valuable input. If you have any questions or would like to provide additional input into the Guidelines update, please feel free to contact us at CCGuidelines@cdc.gov