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COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

REVIEW OF THE 2013 CDC/CSTE CANCER CLUSTER INVESTIGATION GUIDELINES

Evaluation of Facilitators and Barriers to Implementation and Identification of Resources to Implement Updated Guidelines

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Acknowledgments

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Executive Summary

In 2010, the Council on State and Territorial Epidemiologists (CSTE) collaborated with the Centers for Disease Control and Prevention (CDC) to convene a workgroup of experts from state, tribal, local, and territorial (STLT) health departments to revise the then current 1990 "Guidelines for Investigating Clusters of Health Events."[1] To do so, CSTE conducted an assessment with state and territorial epidemiologists to better understand the resources needed to investigate cancer cluster concerns. The workgroup utilized the findings of the assessment and a literature review to inform the development of the 2013 Guidelines, "Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists"[2].

Presently, CDC is working to update the 2013 Guidelines in accordance with Trevor's Law, which is included in the Frank R. Lautenberg Chemical Safety for the 21st Century Act[3]. Updating the 2013 Guidelines will provide STLT health departments with the most current information on investigation tools and approaches for assessing and responding to potential cancer clusters (CDC, 2019).

In 2021, CSTE, in collaboration with the CDC National Center for Environmental Health (NCEH) and the Agency for Toxic Substances and Disease Registry (ATSDR), convened a workgroup to 1) assess facilitators and barriers to implementing the 2013 Guidelines and 2) determine what, if any tools, trainings, or non-financial resources would assist STLT health departments in implementing the updated guidelines. The workgroup was composed of staff from STLT health departments recruited because of their experience in conducting suspected cancer cluster investigations. To accomplish its work, the workgroup held three virtual, video conference meetings on April 15, 2021, May 20, 2021, and June 25, 2021.

During the initial workgroup meeting, workgroup members identified numerous opportunities to update the 2013 Guidelines, including facilitators and barriers to implementation in STLT health departments. These fell into two main topic areas: methodologic issues and communication challenges. As a result, the second and third workgroup meetings concentrated on methodologic issues and communication concerns, respectively.

The workgroup's recommendations for the cancer cluster guidelines update include:

1. Providing guidance on the minimum threshold (or a suggested range) of cases needed to assure reliability and allow for the reporting of observed and expected numbers of cancer cases and Standardized Incidence Ratios (SIRs). It would be helpful if the update provided more robust guidance on the interpretation of SIRs.
2. Including more information on ways to approach study areas that are population-based. Techniques for sparsely populated areas are needed, such as minimum case counts needed to perform an investigation or qualitative methods of assessing patterns of concern.
3. Providing more robust guidance on formal methods for selecting comparison groups based on propensity scores, peer counties based on work being done by the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, to better standardize the methods that STLT health departments use for reference population selection.
4. Providing guidance on ways to handle migration and including suggestions and/or best practices for effectively communicating with stakeholders making inquiries about the amount of outward migration that would need to occur to cause null findings where an excess of cancer truly exists.

5. Continuing to use the term “cancer cluster” in the update but devoting a section to explain concerns with the use of the term as part of a broader discussion in the background of the complex, multifactorial causes of cancer. Additionally, the update could use terms such as “assessments of incidence or occurrence of cancer” to expand the focus to address issues of unusual patterns that may not meet statistical definitions of a cluster.
6. Creating or incorporating a decision tree or other visualization to help depict how 1) most inquiries are likely to not merit proceeding to later steps and 2) to establish the criteria that should be considered especially when deciding to proceed from step to step (e.g., Step 1 to Step 2, Step 2 to Step 3). STLT health department staff should be engaged in the development, pilot testing, and implementation of the decision tree prior to finalization. The criteria established for the decision tree should be cognizant of diminished STLT health department staff resources, but still driven by evidence, and the realities of whether data and methods are available to confirm a cancer cluster, should it exist.
7. Devoting a section of the update to better set expectations for constituents who submit inquiries. This should include information on the inherent limitations of suspected cancer cluster investigations. Additionally, the section should explain that an inquiry not proceeding to a later step in the process does not indicate a failure on the part of an STLT health department nor a poor outcome—rather, there is a lack of evidence supporting additional investigation. In circumstances where an environmental concern exists, communication resources, and recommended actions on addressing the environmental concern should be provided.
8. Providing guidance that jurisdictions may want to cautiously proceed when calculating SIRs and performing assessments unless clear criteria are met to merit proceeding to the Step 2 assessment phase.

The workgroup’s recommendations for the development of the tools, trainings, and/or non-financial resources for use by STLT health department staff supporting suspected cancer cluster investigations include:

9. Slide sets that could be used to cover introductory material with constituents, including but not limited to, information on the causes of cancer, the process and methods for performing suspected cancer cluster investigations, potential findings of investigations, and cancer cluster investigation limitations. The slide sets should be in plain language to allow for use at public meetings and engaging in initial conversations with inquiring parties.
10. A series of videos that could be made publicly available (through YouTube or another video service) that explain suspected cancer cluster investigations. These could include testimonials from community groups that have worked closely with their state health departments, highlighting their productive relationship and satisfaction with investigation outcome.
11. A reference website that could be used to identify the known causes for each cancer type based upon the latest peer-reviewed literature. In tandem, there should be a commitment to updating the reference website on a regular basis to assure STLT health departments and their constituents that this information is credible, up-to-date, and well maintained.
12. Reevaluating the 2013 Communications Toolkit to determine if it should be updated and/or incorporated into the update.

When performing investigations, these materials are often independently created by states—developing these tools would both standardize cancer cluster investigation risk communication nationally and optimize STLT health department staff time to have these resources readily available.

The workgroup's additional policy recommendations include:

13. Expanding the activities in the National Program of Cancer Registries and/or the National Comprehensive Cancer Control Program to include proactive analyses of cancer incidence in small geographic areas as an allowable or featured activity or providing special grants to states to pursue this effort.
14. Creating an independent, scientific advisory group to review and validate STLT health department decisions about whether investigations merit proceeding from step to step (e.g., Step 1 to Step 2, Step 2 to Step 3). An independent group of experts could give constituents more confidence that decisions are appropriate and allow STLT health departments to defend decisions that are made. While an individual state may not have enough investigations to warrant maintaining a panel, there may be enough investigations nationally per year to support one.

STLT health department staff engaged in suspected cancer cluster investigations are dedicated public health professionals who work to determine whether communities in their jurisdiction are experiencing excess rates of cancer and, if so, seek to learn the potential contributing causes. All efforts are in hopes of creating and maintaining mitigation strategies for areas experiencing excess rates of cancer in the hopes of fewer people being diagnosed with cancer in the future. The work of performing suspected cancer cluster investigations is nearly always controversial and often underappreciated. CSTE and workgroup members are grateful to CDC/ATSDR for obtaining the STLT health department staff input in the process of improving the 2013 Guidelines to better support cancer cluster activities.

Background

In 2010, the Council of State and Territorial Epidemiologists (CSTE) collaborated with the Centers for Disease Control and Prevention (CDC) to convene a workgroup of experts from state, tribal, local, and territorial (STLT) health departments to revise the then current 1990 "Guidelines for Investigating Clusters of Health Events."[1] To do so, CSTE conducted an assessment with state and territorial epidemiologists to assess the needs of public health professionals when responding to cancer cluster concerns. The workgroup utilized the assessment findings and an extensive literature review to inform development of the 2013 Guidelines, "Investigating Suspected Cancer Clusters and Responding to Community Concerns: Guidelines from CDC and the Council of State and Territorial Epidemiologists"[2].

Following the 2019 enactment of the Trevor's Law legislation within the Frank R. Lautenberg Chemical Safety for the 21st Century Act[3], the CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) started a multifaceted process to update the 2013 Guidelines as required in the legislation. Updating the 2013 Guidelines will provide STLT health departments the most current information on investigation tools and approaches for assessing and responding to potential cancer clusters.

CSTE, the professional home for applied public health epidemiologists, received funding through its 2020 CDC/CSTE Cooperative Agreement to gather stakeholder perspectives on the 2013 Guidelines. In collaboration with the CDC's National Center for Environmental Health (NCEH) and ATSDR, they convened a workgroup to 1) assess facilitators and barriers to implementing the 2013 Guidelines and 2) determine what, if any tools, trainings, or non-financial resources would assist STLT health departments in implementing the updated guidelines.

CSTE's assessment is summarized in this report. The assessment was conducted by convening a workgroup of selected STLT epidemiologists with expertise in cancer cluster investigations. A consultant guided the workgroup's discussions to identify issues with the 2013 Guidelines and make recommendations for updates. The report includes findings and recommendations related to methodological and communications issues—it also includes examples from participating state workgroup members to illustrate points.

Workgroup

In 2021, CSTE convened a workgroup of 11 STLT health department staff with experience conducting suspected cancer cluster investigations. The workgroup members were charged with reviewing the 2013 Guidelines to identify, assess, and determine:

1. Needed changes, adjustments, or clarifications;
2. Facilitators and barriers to implementing the 2013 Guidelines; and
3. Any tools, trainings, or non-financial resources that would assist STLT health departments in implementing the updated guidelines.

To accomplish its work, the workgroup held three virtual, video conference meetings on April 15, 2021, May 20, 2021, and June 25, 2021.

During the initial workgroup meeting, workgroup members identified numerous opportunities to update the 2013 Guidelines, including facilitators and barriers to implementation in state health departments.

These fell into two main topic areas: methodologic issues and communication challenges. As a result, the second and third workgroup meetings focused on methodologic issues communication concerns, respectively.

Note: a separate workgroup supported by the Association of State and Territorial Health Officials (ASTHO) conducted similar work—to provide feedback to CDC/ATSDR on the effort to revise the 2013 Guidelines—but with a different viewpoint that mirrors their mission and member expertise. CSTE's workgroup focused on the scientific methods and epidemiologic aspects, and ASTHO's workgroup (comprised of environmental health program directors) focused on the broader environmental health perspective.

Findings and Recommendations

For each recommendation section, the issue is outlined, current approaches from STLT workgroup members are reviewed, and workgroup discussions and recommendations are described.

Recommendations for the Cancer Cluster Guidelines Update

Standardized Incidence Ratios (SIRs)

Standardized Incidence Ratios, or SIRs, indicate the size of the difference between the observed and expected number of cancer cases. Workgroup members discussed that SIRs are currently used by most represented states when performing cancer incidence investigations to estimate the likelihood that an excess of cancer cases exists in the study population relative to the comparison group. Statistical significance, judged by the width of the confidence intervals and whether they include 1 or the p-value, indicates whether a result could have occurred by chance. Minimum case counts are an additional way to ensure reliability of the estimate, since even when statistically significant, a SIR that is based on small numbers is less reliable. Minimum case counts may also be used to ensure confidentiality.

New York State (NYS) reports the observed and expected numbers of cases and sample sizes for a specific study population and time period. Michigan (MI) and North Carolina (NC) only interpret SIRs calculated for their investigations if the 95% confidence intervals do not include 1. For minimum case counts, Texas (TX) suppresses the data if the observed number of cases is less than or equal to 5. If the suppression criteria are met, TX reports the expected number of cases, the SIR, and 95% confidence interval. NC does not calculate SIRs for case counts less than 5. MI does not have a minimum threshold number of observed cases for calculating SIRs. MI and TX report the observed and expected number of cancer cases if there are 6 or more cases.

MI uses the following scale to assist in interpreting the magnitude of the SIRs[4]. It should be noted that while values further from 1.0 are more likely to indicate evidence of an increased cancer incidence, it is possible for an SIR of 1.1 to be strongly statistically significant should it be based on large numbers. Similarly, an SIR of 3.0 based on small numbers may not indicate as significant of findings.

SIRs	Interpretation
<0.4	Strong evidence of decreased cancer incidence
0.4 – 0.7	Moderate evidence of decreased cancer incidence

0.7 – 0.9	Weak evidence of decreased cancer incidence
0.9 – 1.2	No evidence of a difference in cancer incidence
1.2 – 1.5	Weak evidence of increased cancer incidence
1.5 – 3.0	Moderate evidence of increased cancer incidence
>3.0	Strong evidence of increased cancer incidence

The 2013 Guidelines lack standards on both 1) the interpretation of SIRs to determine whether an excess of cancer exists and 2) for the minimum threshold needed to assure reliability of calculated SIRs. The interpretation and reliability of SIRs are important in determining whether a true excess of cases of cancer exists and whether investigations warrant proceeding to the next iterative step of the guidelines.

The workgroup recommends that the update provide guidance on the minimum threshold (or a suggested range) of cases needed to assure reliability and allow for the reporting of observed and expected numbers of cancer cases and SIRs as well as more robust guidance on the interpretation of SIRs.

Geographic Areas with Sparse Data

Workgroup members discussed how states, regardless of population size, frequently encounter situations where investigations involve study areas with small case numbers. Small numbers of cases can occur even in densely populated areas (e.g., rare cancers, childhood cancers, or cancers are confined to a specific residential building). It is difficult to assess whether there is a true excess of cancers in such study area(s) without either calculating ratios that are highly unstable or compromising privacy. Responding to cancer cluster inquiries in which an investigation is not possible due to a sparsely populated study area is often met with strong negative reactions.

When there are small numbers of cases in a study area, NY uses a qualitative approach that looks at patterns of cancer case data, which includes reviewing the distribution of cancer cases by age at diagnosis, types of cancers diagnosed, and years of diagnosis to determine whether any unusual patterns exist that warrant further review. TX includes suppression criteria in their algorithm such that cases drop out of the assessment if there is not an adequate population size in the geographic area of study. All represented states mentioned struggling with requests to perform analyses at the zip code level, which is typically not a population-based geographic area—they also noted the need to convince study requesters of the need for population-based study areas (e.g., Census estimates) in their place. Similarly, the workgroup discussed how states commonly receive requests to conduct studies associated with school districts and how they would benefit from guidance on population data selection for such analyses.

The workgroup recommends that the update include guidance on methods for analyses on population-based study areas. This should include techniques for sparsely populated areas, such as minimum case counts needed to perform an investigation or advice on qualitative methods for assessing patterns of concern.

Comparison Groups

The workgroup discussed challenges in selection of an appropriate reference or comparison populations when performing cancer incidence investigations. The expected number of cases that occurs in a study

population is calculated by applying comparison group age-specific cancer rates to the study population age-specific counts. The choice of comparison group is critical and can impact SIRs. If a comparison group is selected that is not reflective of the study population's demographics or other characteristics, the resulting SIR could spuriously appear to suggest that an excess of cancer cases does or does not exist.

Each represented state noted having a preferred comparison groups that they use in cancer incidence investigations. NYS looks at sociodemographic characteristics of the study area to help determine if they will use their standard comparison group or an alternative option. MI compares a few options including the remainder of a county or other geographic area after removing the study population. NC typically uses the entire state population as its comparison group. Some states commented that they also adjust for sex and race/ethnicity. Propensity scores are increasingly being used in observational cancer studies for treatment effect estimation and could be applied here.[5] Alternatively, NCI could establish peer counties for each jurisdiction in the United States based upon demographic characteristics and other factors such as cancer incidence patterns.

The workgroup recommends that the update provide more guidance on formal methods for selecting comparison groups for study populations based on alternatives such as propensity scores, or peer counties based on work being done by the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program[6], to better standardize the methods that STLT health departments use for reference population selection.

Migration

The workgroup also discussed how states often struggle to identify and explain the impact of migration on their investigations. Community representatives making inquiries often perceive normal migration out of a study area as a source of bias that can cause cancer cases to be missed or undercounted. Residents often think that tracking down those who have moved away will result in stronger effects, while it generally results in weaker effects. However, the healthy migrant effect (i.e., healthier individuals are more likely to migrate for a variety of reasons) means that the bias is toward the null[7]. Additionally, each state experiences different concerns with migration. For example, states in warmer regions have inward migration, and states in colder regions have outward migration. Such migration can be seasonal, making it even more complicated to address. Additionally, states are challenged with migration associated with studies concerning children attending a school—some proportion of the population always migrates away from childhood communities. For cancers with longer latency periods, this is especially difficult to address.

There was a consensus among workgroup members that methodologic strategies for dealing with migration are lacking. TX includes statements in their reports regarding the fact that they do not account for migration in their studies. The workgroup discussed that states could attempt to calculate the number of cancer cases that would need to migrate out of a study area to result in flawed findings—this would be especially useful if not enough time has elapsed to account for the latent period for a specific type of cancer. However, in the end, workgroup members believe that migration is both a communication challenge and a methodologic issue. Additionally, it is resource intensive to track down cases that have migrated out of a study area.

The workgroup recommends that the update provide guidance on ways to handle migration and include suggestions and/or best practices on effectively communicating with inquiring stakeholders about the amount of outward migration that would need to occur to cause null findings where an excess of cancer truly existed.

Terminology Used in Describing Work

The workgroup discussed the appropriateness of continuing to refer to investigations as "cancer clusters." The term can imply an excess of cancers that are clustered together in an area before a formal analysis is completed. The term can also foster the notion that confirmed excess rates of cancer have a single, environmental etiology when cancer causation is complicated and almost always multifactorial.

Comparably, injury control professionals have sought to change the use of the term "accidents" to "unintentional injuries" to educate the public that many injuries can be prevented. However, both the general public and public health professionals commonly use the term "accidents" when referring to such injuries and efforts to redirect stakeholders to change terminology has been generally unsuccessful. The workgroup noted the same to be true for the term "cancer clusters"—both the lay and public health communities use the term "cancer cluster" when referring to cancer incidence investigations and efforts to change this vernacular may prove challenging.

The workgroup recommends that the update continue to use the term "cancer cluster" but with a section explaining concerns with the use of the term as part of the background's broader discussion on the complex, multifactorial causes of cancer. Additionally, the update could use terms, such as "assessments of incidence or occurrence of cancer" to expand the focus to address issues of unusual patterns that may not meet statistical definitions of a cluster.

Communicating Decisions Related to Stepwise Framework of Investigations

The 2013 Guidelines lay out a stepwise approach for STLT health departments to use when performing suspected cancer cluster investigations. These steps include:

1. Initial contact and response to an inquiry
2. Assessment to determine whether a statistically significant excess of cancers exists in the study area
3. Determination of the feasibility of conducting an epidemiologic study of an association between an excess of cancers and environmental or other causes
4. Epidemiologic investigation

While described in the 2013 Guidelines, stakeholders and requesters likely do not realize that there are rarely investigations that warrant proceeding to Steps 3 and 4. In fact, most inquiries do not meet the relevant criteria to even proceed to a formal assessment and analysis of cancer registry and other data (Step 2). One review by Goodman et al.[8] found that of 576 cancer cluster investigations over 20 years, only 72 of the perceived clusters had a confirmed increase in cancer, and only 3 of the 72 clusters were linked to a possible exposure. Yet, the current framework often leaves STLT health departments in a defensive posture with community advocates when faced with the prospect of explaining why an investigation does not proceed to Step 2. Moreover, due to lack of time, money, environmental sampling instrumentation, and staff, few STLT jurisdictions can conduct such epidemiologic studies without the assistance of a partnership with external researchers.

The workgroup recommends several additions to be incorporated into the update to help address concerns related to communicating with stakeholders about the stepwise framework of cancer cluster investigations. See below:

- Creating and incorporating a decision tree or other visualization to help 1) depict how most inquiries are likely to not merit proceeding to later steps and 2) establish the criteria that should be considered, especially when deciding to proceed from step to step (e.g., Step 1 to Step 2, and Step 2 to Step 3). STLT health department staff should be engaged in the development, pilot testing, and implementation of the decision tree. The criteria established for the decision tree should be cognizant of diminished STLT health department staff resources but still driven by the evidence, and the realities of whether data and methods are available to confirm the existence of an excess of cancer cases, should one exist.
- Devoting a section to better set expectations for constituents who submit inquiries. This should include information on the inherent limitations of suspected cancer cluster investigations. Additionally, the section should explain that an inquiry not proceeding to a later step in the process does not indicate a failure on the part of an STLT health department nor a poor outcome—rather, there is a lack of evidence supporting additional investigation. In circumstances where an environmental concern exists, communication resources and recommended actions on addressing the environmental concern should be provided.
- Providing guidance that jurisdictions may want to cautiously proceed when calculating SIRs and performing assessments unless clear criteria are met to merit proceeding to the Step 2 assessment phase. Experience with past investigations has shown that expectations become heightened once SIRs are calculated and assessments are conducted because they imply a potential excess of cancer cases in the study area.

Recommendations for Cancer Cluster Resource Development

Risk Communication Support

The workgroup discussed opportunities for STLT health department staff engaged in suspected cancer cluster investigations to receive additional training, support, and/or materials to better communicate with stakeholders on the issues related to cancer risk, cancer causation, and limitations of cancer cluster investigations. Communications with communities that have the expectation that there is a single environmental etiology for the perceived cancer cluster are particularly challenging. Health department staff could use assistance when communicating with communities about the factors that impact rates of cancer outside of environmental exposure, such as demographics, genetics, and health behaviors (e.g., diet, tobacco use, alcohol use, physical activity, obesity). The workgroup recognized that while the 2013 Guidelines had a companion 2013 Communications Toolkit that was developed by the CDC and the National Public Health Information Coalition, they were unaware how widely it had been disseminated and/or used.

Additionally, STLT health department staff could use training on how to best engage stakeholders in the earliest phases of inquiries to establish rapport and explain the investigation process. Many times, STLT health departments are presented with community-collected data that may not be valid and/or reliable (e.g., self-reported cancer cases, cases identified from social media) or that contains personally identifiable information. Guidance is also needed on how to communicate with stakeholders on the importance of validating self-reported cases as part of cancer cluster investigations.

The workgroup recommends that the update include appendices of risk communication materials compiled and/or developed for use by STLT staff. See below for more details.

- Slide sets that could be used to cover introductory material with constituents, including but not limited to, information on the causes of cancer, the process and methods for performing suspected cancer cluster investigations, potential findings of investigations, and cancer cluster investigation limitations. These slide sets should be in plain language to allow for use at public meetings and engaging in initial conversations with parties making inquiries.
- A series of videos that could be made publicly available (through YouTube or another video service) that explain suspected cancer cluster investigations. These could include testimonials from community groups who worked closely with their state health departments highlighting their productive relationship and satisfaction with the investigation outcome.
- A reference website that could be used to identify the known causes for each cancer type based upon the latest peer-reviewed literature. In tandem, there should be a commitment to update the reference website on a regular basis to assure STLT health departments and their constituents that this information is credible, up-to-date, and well-maintained.
- Reevaluating the 2013 Communications Toolkit to determine if it should be updated and/or incorporated into the update.

When performing investigations, these materials are often independently created by states—it would both standardize cancer cluster investigation risk communication nationally and optimize STLT health department staff time to have these resources readily available.

The workgroup also recommends that the 2013 Communications Toolkit be reevaluated to determine if it should be updated and/or incorporated into the update.

Recommendations for Cancer Cluster Policy

Proactive vs. Reactive Initiation of Investigations

The 2013 and 1990 Guidelines are structured based on the expectation that STLT health departments use a workflow whereby they complete suspected cancer cluster investigations in response to community concerns. The workgroup discussed the pros and cons of performing analyses proactively as opposed to continuing to work reactively in response to a complaint or community concern. While responsive to those making inquiries, it is reactive and can be influenced by the media and perceptions of communities (rather than based on data)—it can also result in investigations being prioritized by the vocality of community representatives as opposed to the level of evidence. Modern cancer registries have timely, complete, and quality data. Additionally, sophisticated geospatial methods can be used proactively to analyze cancer rates in small geographic areas and identify jurisdictions that appear to have excess rates of cancers relative to peer counties. Workgroup members are especially interested in learning about new methods in geospatial temporal analyses, including any new statistical measures to augment the use of SIRs.

NYS is required under legislation to proactively conduct analyses of cancer incidence in small areas across the state and, as a result, releases maps of cancer incidence in small geographic areas.

The workgroup concluded that while states are interested in being more proactive with cancer cluster analyses, there are concerns that STLT health departments lack adequate staff resources to support this

approach. In the absence of more dedicated federal grant funding to support suspected cancer cluster investigations, states should be cautious about engaging in proactive analyses without first ensuring they have the staff resources to complete investigations in a timely manner once they have been started. It may be best to have staff continue to focus on responding to community concerns and overseeing incidence investigations.

The workgroup recommends expanding the activities in the National Program of Cancer Registries and/or the National Comprehensive Cancer Control Program to include proactive analyses of cancer incidence in small geographic areas as an allowable or featured activity or providing special grants to states to pursue this effort.

Advisory Group

Aligning with the recommendations regarding concerns related to communicating with stakeholders about the stepwise framework of cancer cluster investigations, the workgroup discussed the opportunity to convene an independent, scientific advisory group to review and validate decisions about whether an investigation merits proceeding from step to step (e.g., Step 1 to Step 2 and Step 2 to Step 3). An independent group of experts could give constituents more confidence that decisions are appropriate and allow for STLT health departments to defend decisions that are made. While an individual state may not have enough investigations to warrant maintaining a panel, there may be enough investigations nationally per year to support one.

The workgroup recommends convening an independent, scientific advisory group to review and validate stepwise decisions regarding investigation (e.g., moving from Step 1 to Step 2, Step 2 to Step 3).

Conclusion

STLT health department staff engaged in suspected cancer cluster investigations are dedicated public health professionals who work to determine whether communities in their jurisdiction are experiencing excess rates of cancer and, if so, seek to learn the potential contributing causes in the hopes that fewer people being diagnosed with cancer in the future. The work of performing suspected cancer cluster investigations is nearly always controversial and is often underappreciated. CSTE and the Workgroup are grateful to CDC/ATSDR for obtaining the input of STLT health department staff about ways to improve the 2013 Guidelines to better support their work in this important field.

References

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