Recommendations for Updating CDC/CSTE Cancer Cluster Investigation Guidelines

In 2021, ASTHO convened a workgroup of public health experts to assess the 2013 CDC/CSTE Cancer Cluster Investigation Guidelines for updates and revisions. The group had expertise in epidemiology, toxicology, surveillance systems, and communication. Members of the workgroup were quite familiar with such investigations and how to use the Guidelines, and represented geographically diverse local, state, tribal, and non-profit public health organizations. Further, they supported ongoing application of the 2013 Cancer Cluster Guidelines and recommended three key steps for improvement.

Improve access to historical cancer cluster investigation reports from ATSDR and local/state health departments.

Published and unpublished reports of cancer cluster investigations conducted by local and state agencies are public records but currently exist in a patchwork of databases. A searchable database would enable investigators to gain insight drawn from a national database and advance research on possible linkages between environmental hazards and different cancer types.

This recommendation for a tool to identify previous cancer cluster investigations described in published and unpublished reports is a novel concept. There is a need for further discussion to understand feasibility and requirements for the development, management, and operation of such a database. Important details on how this tool could be developed without placing an impractical burden on existing state public health officials have yet to be determined.

Expand guidance to address health equity challenges in cancer cluster investigations and environmental justice concerns for non-cancer endpoints.

Expanding language to consider environmental justice issues in cancer cluster investigations is vital. As such, there should be a health equity perspective provided in the guidelines when discussing community engagement and the need to acknowledge systemic challenges or historical trauma that may contribute to distrust in government authorities.

Further, it is important to consider that environmental exposures linked to higher morbidity and mortality are not limited to cancer outcomes. For example, certain exposures from pesticides, air pollution, radon, and asbestos are considered carcinogenic while also being associated with symptoms of asthma. It is important to acknowledge the environmental justice concerns for exposures that are associated with both cancer and non-cancer endpoints. Given communities’ concerns about these exposures, it would be beneficial to include guidance for incorporating non-cancer cases—that are associated with similar environmental exposures (e.g., asthma)—into cancer cluster investigations.

These recommendations are consistent with public health initiatives of the past decade. The expertise and capacity to support the implementation of these recommendations exists at CDC with support from its partner organizations, including ASTHO.
Include tools and guidance on communicating about cancer cluster investigations and statistical concepts with the public.

Local and state health departments, along with cancer registries, are at the forefront of investigating suspected cancer clusters in a community and responding to questions from the public. While social media platforms are a powerful tool for communicating with the public, they can also be a conduit of misinformation or exaggeration. Cancer cluster investigations can be emotionally charged, so there should be instructions on how to carefully use and review social media for ongoing or recently completed investigations.

Guidance on how social media can be leveraged to educate communities about what cancer clusters entail, the purpose of assessments, and assessment limitations would help local and state health departments. Stock PowerPoint presentations that explain cancer clusters would be useful at community meetings whenever health communicators are trying to explain cancer clusters using plain language.

Maps are well-recognized as an effective means of presenting and communicating health data such as cancer incidence and mortality rates. It is critical to develop guidance on how Geographic Information Systems (GIS) can be used to advance cancer cluster investigations. Applying a spatial lens allows users to identify location-based patterns and trends related to risk factors, health outcomes, and population health. Many states have CDC-funded environmental public health tracking (EPHT) programs that maintain public-facing data portals. Leveraging state EPHT programs to develop tools, applications, and products can better educate communities about cancer clusters and their associated metrics.

Conclusion

Cancer cluster investigations are an important function of public health agencies. ASTHO’s workgroup members recognize that it is inherently difficult to investigate cancer clusters with complex etiology and long latency periods. As such, the workgroup supports the continued use of the existing guidelines with several key recommendations for assisting state public health officials to address community concerns about perceived cancer clusters. CDC/CSTE released the 2022 draft guidelines for public comment earlier this year and will likely issue the final guidelines in the coming months.

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