State Capacity to Address Non-Communicable Disease Clusters

Johns Hopkins Center for Excellence in Environmental Public Health Tracking

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Definition and Purpose

Non-Communicable Disease Cluster Investigations

includes the range of responses that state agencies may conduct in response to a report of a non-communicable disease cluster

Purpose of our study:

To develop a profile of the state public health agency capacity to address non-communicable disease clusters
Who has the responsibility and authority for addressing non-communicable disease clusters?

How does the agency define a disease cluster?
Where do requests for investigations come from?
For which disease endpoints?

Does the agency have a protocol for:
The report of clusters?
- Cluster response?
- Communication of results?

Are there identifiable patterns in the:
- # of requests?
- # of responses?
- Disease endpoints?
Methods: Two Phases

Phase I: Web Inventory
Jan. to Aug. 2004

- Inventory of state public health agency web sites
- 17 search terms were used to review each website

Phase II: Web-based Survey
July to Aug. 2005

- Web-based survey of state health agency personnel
- Link was sent to state epidemiologists, directors of chronic disease, environmental health, and cancer divisions as listed on the CSTE web site
Results

Phase I: Web Inventory

- 50 states comprehensively reviewed
- 26 states with cluster programs
- 32 states conducting cancer cluster investigations
- 25 states conducting cluster investigations other than cancer

Phase II: Web-based Survey

- 57 respondents from 37 states
- 74% response rate (37 of 50 states)
- 100% of respondents conduct cancer cluster investigations
- 81% (30 of 37 states) conduct cluster investigations other than cancer
• Across states, there was no consistent identifiable individual or agency division responsible for addressing disease cluster reports

• Training and expertise of the individuals responsible for addressing suspected disease clusters varies widely

• Not all professionals who address suspected disease clusters work in traditional public health agencies

• States largely lack the dedicated personnel to address suspected or reported disease clusters
Where do reports of non-communicable disease clusters come from?
How many states reported conducting investigations in past 5 years?

- Alzheimer's: 3
- Asthma: 14
- Autism: 7
- Birth Defects: 20
- Lead Poisoning: 15
- Multiple Sclerosis: 10
- Occupational Lung Disease: 9
- Occupational Pesticide Poisoning: 5
- Cancer: 35
Results: Protocols & Trends

Protocols:

- 15 states have protocols for reporting suspected non-communicable disease clusters to the state health agency
- 16 states have protocols for responding to suspected disease clusters
- 8 states have protocols for communicating with the public regarding suspected disease clusters

Trends:

After both phase I and phase II, it was not possible to identify any specific trends in cluster investigations
Overall Conclusions

There is a broad diversity of expertise and preparedness to address disease clusters, with the majority of states lacking sufficient resources, expertise, and prescribed protocols.

Recommendations

1. Develop Cohesive National Approach to Disease Clusters
2. Strengthen disease cluster Programs
3. Advance Scientific Methods
Develop a Cohesive National Approach to Disease Clusters

- Develop standard cluster definitions
- Establish standardized protocols for:
  - Reporting of suspected disease clusters;
  - Responding to public concerns;
  - Identifying when cluster investigations are not warranted;
  - Establishing inter-agency communication procedures; communicating disease cluster investigation results to the public; and
  - Tracking requests and conduct of disease cluster investigations to identify trends at local, state, and national levels.
Strengthen Disease Cluster Programs

- Establish defined roles and responsibilities for agency personnel to address potential NCC;
- Expand disease cluster technical assistance and training opportunities; and
- Broaden disease cluster programs to address a wide range of diseases that have potential environmental etiology.
Advance Disease Cluster Scientific Capacity

- Improve methods in exposure assessment to advance the science of cluster investigations and improve the understanding of the role of environment in NCC;
- Expand the use of biomonitoring to detect, and expand our understanding of, human exposures to chemicals in the environment; and;
- Utilize the tools of geographic and spatial analysis to address methodological barriers inherent in small data sets.
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