

# Adequacy of State Capacity to Address Noncommunicable Disease Clusters in the Era of Environmental Public Health Tracking

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As defined by the Centers for Disease Control and Prevention (CDC), a disease cluster is “an unusual aggregation, real or perceived, of health events that are grouped together in time and space and that is reported to a public health department.”<sup>1</sup> Clusters of infectious disease have long been identified through reportable disease registries, allowing early detection of emerging diseases and establishment of prevention strategies.<sup>2</sup> With its beginnings in the mid-19th century, when John Snow identified cholera contamination in the London drinking water supply, public health tracking has served as an early warning to prevent the spread of infectious disease.<sup>3,4</sup>

Public health response to chronic diseases has been more limited, primarily focusing only on cancer end points. This is largely because sparse data exist to assess hazards and exposure, track chronic diseases, and integrate the information.<sup>5</sup> In 2000, the Pew Environmental Health Commission addressed the environmental public health capacity and found that our nation lacks basic information to document and identify possible links between environmental hazards and chronic disease.<sup>6</sup> The commission recommended establishment of a national environmental public health tracking network to track diseases and exposures, provide an early warning system for critical environmental public health threats, establish federal investigative response capability, and build links between community health and research.

In 2002, the CDC established the National Environmental Public Health Tracking Program to expand collection, analysis, and interpretation of tracking data on environmental hazards, exposure to environmental hazards, and health effects potentially related to environmental exposures.<sup>7,8</sup> This expansion of environmental public health data offers opportunities to identify populations at risk and respond to chronic disease outbreaks, clusters, and emerging disease.<sup>6</sup> Public health

**Objectives.** We sought to assess the capacity of state public health agencies to address noncommunicable disease clusters (NCCs) and to develop recommendations to enhance agencies’ NCC response capacity.

**Methods.** We conducted an inventory of state public health agency Web sites and administered a Web-based survey of state health agency personnel to examine NCC capacity with respect to responsibility and authority, scope, protocols, trends in NCC investigations, and desired assistance.

**Results.** Twenty-six of the state agency Web sites listed an NCC contact, and 12 mentioned a cluster response team. Thirty-seven states completed the Web-based survey, all addressed cancer clusters, and 30 also responded to other NCCs, such as multiple sclerosis, amyotrophic lateral sclerosis, and autism.

**Conclusions.** NCCs are of key concern to communities, and all of the survey respondents indicated that citizen reports were an impetus for investigations; yet, state-level capacity to address NCCs was inconsistent and disjointed. State agency personnel were committed to responding to NCC inquiries but were hampered by lack of personnel, resources, and prescribed protocols, as well as inadequate interagency communication. We offer recommendations to address these challenges. (*Am J Public Health.* 2007;97:S163–S169. doi:10.2105/AJPH.2006.096453)

agencies will need to be prepared to address public concerns regarding suspected clusters of noncommunicable diseases.

Limited information is available on the number of noncommunicable disease cluster (NCC) investigations that are conducted each year; however, more than 1000 requests are made by citizens to state public health agencies for investigations of suspected cancer clusters alone, not accounting for noncancer end points.<sup>9–11</sup>

In 2002, the Council of State and Territorial Epidemiologists (CSTE) evaluated chronic disease epidemiology capacity in state health departments.<sup>12</sup> The CSTE’s findings indicated that many states lack chronic disease epidemiologists and statisticians, clerical support, and access to medical libraries. In 2003, the CDC examined approaches of public health agencies in responding to reports of cancer clusters. The CDC found limitations in current scientific methods, lack of appropriate or insufficient staff, poor data quality, lack of educational materials, and difficulties in establishing appropriate comparison populations.<sup>13</sup>

We sought to build on these efforts by evaluating the state-level public health agency capacity to conduct NCC investigations. Our analysis included a review of responsibility and authority for addressing NCC investigations, scope of clusters work conducted by state agencies, protocols used, and an effort to identify trends in cluster studies. We also sought to identify the needs of state public health agencies to enhance capacity in NCC investigations.

## METHODS

A 2-phased qualitative and quantitative study was conducted that included an inventory of state public health agency Web sites (phase I), and a Web-based survey of state agency personnel (phase II). This design enabled a comprehensive assessment of state agency NCC capacity and provided a concurrent review of state agencies’ Web-based communication approach. The investigation evaluated responsibility and authority for addressing NCC investigations, scope of clusters work conducted by state agencies, established

protocols, trends in cluster investigations, and state needs. This research did not seek to identify specific protocols, data, or methodology necessary to conduct cluster investigations, because this has been addressed previously.<sup>14–33</sup> The survey included a broad array of activities in which states participate to address NCCs, without limiting the scope to extensive epidemiological and environmental evaluations. The project was approved by the Johns Hopkins Committee on Human Research.

### Phase I

Phase I, conducted January to August 2004, included an inventory of each state public health agency Web site to identify available information on state cluster programs. A predefined list of the following 19 search terms was used to ensure consistent review of each Web site: *Alzheimer's, asthma, ATSDR* (Agency for Toxic Substances and Disease Registry), *autism, birth defects, cancer cluster, cancer registry, disease clusters, environmental disease surveillance, epidemiology, health assessments, health consultations, lead poisoning, multiple sclerosis, occupational lung disease, pesticide poisoning, reportable diseases, surveillance, and tumor registry.*

### Phase II

**Survey Instrument.** Phase II was conducted to verify and expand on phase I results. Survey Monkey (Portland, OR), an online survey tool, was used to create the survey questionnaire for distribution.<sup>34</sup> The survey was pilot tested by representatives of CDC, CSTE, and by state epidemiologists before implementation in June to August 2005.

**Survey Implementation.** E-mail requests for completion of the survey were sent to state epidemiologists and directors of chronic disease, environmental health, and cancer divisions as listed on the CSTE Web site,<sup>35</sup> as well as any individuals who were identified in phase I as having a leadership role in state clusters programs. All 122 of the identified individuals were asked to complete the survey and review our phase I findings for their respective state. The majority of individuals were employed by state public health agencies, although a few represented state cancer registries or private entities, such as health plans or hospitals.

**TABLE 1—Summary of Contact Information From the Web Site Inventory (Phase I) and Web-Based Survey (Phase II)**

Variable	Web Site Inventory (n = 50 Web Sites Reviewed)	Web-Based Survey <sup>a</sup> (n = 37 States)
No. of states responding	NA	37 states
No. of respondents	NA	57 respondents (representing 37 states)
No. of states in which the survey was completed by an individual self-identified as the contact person for addressing NCCs	NA	33 <sup>b</sup>
No. of states with an identified contact person or division/branch to address NCCs	26	37 <sup>c</sup>
No. of states with a cluster response team	12	NA

*Note.* NA = not applicable; NCC = noncommunicable disease cluster.

<sup>a</sup> Responding states included: Alabama, Alaska, Arizona, California, Florida, Georgia, Idaho, Indiana, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, Wisconsin, West Virginia, and Wyoming.

<sup>b</sup> A state was counted as having the Web-based survey completed by the contact person if at least 1 of the state's respondents self-identified herself or himself as the contact. In some states with multiple respondents, more than 1 respondent identified herself or himself as a contact person for addressing NCCs.

<sup>c</sup> Four states indicated that their survey response was not completed by the contact person, and each provided information for another agency or individual who could be contacted regarding NCC investigations.

**Data Compilation and Analysis.** Responses were summarized with respect to responsibility and authority; scope of cluster investigations; reporting, response, and communication protocols; trends in cluster investigations; and state needs. Where multiple respondents from the same state submitted completed surveys, responses were aggregated to derive a composite view of that state's NCC program.

## RESULTS

During phase I, all 50 US state health agency Web sites were comprehensively reviewed for any mention of NCC programs. In phase II, 57 respondents representing 37 states completed the survey resulting in a 74% response rate from the 50 states. The following sections describe results of both study phases.

### Responsibility and Authority

There was an overall lack of consistency across states in NCC personnel, training, and agency responsibility. There was no consistent identifiable job title or agency division with responsibility and authority for addressing suspected NCC clusters across the 50 states. Of the 37 states responding, surveys

from 33 states were completed by individuals self-identified as contacts for addressing NCCs in their state. The respondents' job titles and responsibilities varied widely and included state epidemiologists, directors of state health departments, environmental and medical epidemiologists, state health commissioners, cancer registry directors and coordinators, and public health managers. Table 1 presents further information on survey respondents.

Training and expertise of the individuals responsible for addressing suspected NCCs varied widely from physicians to nurses and epidemiologists and statisticians to environmental health specialists. The training of individuals varied from professional degrees in medicine (MDs) and public health (PhDs and DrPHs), including statisticians and epidemiologists, to master- and bachelor-level program coordinators.

Not all professionals who addressed suspected NCCs worked in traditional public health agencies. Many of those with responsibility for addressing suspected disease clusters were not employees of state public health agencies, but represented environmental regulatory agencies, cancer registries, universities,

and private organizations with affiliations to state public health agencies.

Findings from the phase I Web site inventory provided additional information regarding the responsibility for NCC investigations.

Twenty-six states listed a contact person or division or branch assigned to address NCCs on their Web sites. Nine of these states listed a contact only for addressing cancer clusters, and 2 gave no indication of the diseases addressed by their program.

States lacked dedicated personnel to address suspected NCCs. Only 12 states indicated on their Web site that they had a dedicated cluster response team that was appropriately staffed and had the necessary expertise to address suspected disease clusters.

The federal agency role in NCC investigations was not well defined and was inconsistent across states. ATSDR has worked with all 50 states to conduct health consultations and assessments at sites with suspected contamination<sup>36</sup>; however, these assessments did not always include cluster evaluations. Eighteen state Web sites listed the Environmental Protection Agency and 19 listed the CDC as collaborators on health assessments and consultations, whereas 1 state each listed the Occupational Safety and Health Administration, National Institute for Occupational Safety and Health, and National Institutes of Health as collaborators. In the majority of states, it was not possible to discern the role of federal agencies in actual disease cluster investigations.

### Scope

Few states defined the term *clusters*, yet all respondents received requests for cluster investigations on a very broad range of diseases. Based on the phase I Web site inventory, only 14 states defined NCCs—generally as “the occurrence of greater numbers of the same type of disease than expected within a period of time and within a geographic area.” Many of the states defined NCCs only for cancer clusters and did not indicate that clusters of other chronic diseases may also occur.

Phase I and II results indicated that 38 states investigate suspected cancer clusters, and 30 states also investigate other disease end points. The remaining 12 states did not

respond to the survey and did not have information on their Web sites to indicate the existence of any NCC program.

Requests for NCC investigations have been made for a very broad range of diseases. State public health agencies received requests to conduct NCC investigations on diseases including cancer, birth defects, lead poisoning, occupational lung disease, occupational pesticide poisoning, asthma, multiple sclerosis, and autism, among others. Figure 1 presents the number of states that have reported receiving cluster investigation requests for given diseases from 2000 to 2004.

The impetus for conducting the investigations came largely from public requests. Although most states lacked adequate records to identify how an NCC investigation was initiated, respondents indicated that disease cluster investigations were initiated often or occasionally by citizen reports (37 states), politician requests (33 states), and news articles or media reports (30 states), tracking data (28 states), and physician or health care provider reports (17 states). Other factors leading to initiation of disease cluster investigations included requests from federal agencies (i.e., ATSDR, CDC, Environmental Protection Agency, and Occupational Safety and Health Administration), public requests to assess effects of environmental hazards (i.e., dump sites), assistance requests from state and local environmental agencies, reports of poisonings (e.g., lead and occupational exposures), and requests by community organizations.

There was no systematic method of record keeping. There was wide variation among states in both the collection of NCC data and its storage format, which ranged from electronic records that link geographic, health, and demographic information to hand-written logs of public calls.

Respondents from 32 states indicated that they kept records of NCC investigations, whereas 5 states indicated that no records were kept. A number of states indicated that other state agencies (e.g., labor and environmental quality) may also track NCC investigations but that there was limited or no coordination between agencies.

Most of the requested NCC investigations were for cancer. Figure 2 presents common cancer sites in which states reported receiving

requests or conducted investigations from 2000 to 2004. The most common tumor sites for which NCC investigations were conducted included the brain, breast, lung, and liver along with leukemia or lymphomas.

### Established Protocols

The majority of states did not have protocols in place for addressing NCCs. Despite the availability of published guidance documents for the conduct of NCC investigations from CDC, ATSDR, and the National Cancer Institute, the majority of states did not have any protocols in place.<sup>1,14–16,37</sup> Only 13 states indicated having protocols for reporting of suspected NCCs to the state health agency. Sixteen states had established protocols for responding to suspected disease clusters. Only 8 states indicated that they had established policies for communicating with the public regarding suspected disease clusters.

Despite the increasingly common use of the Internet as a source of information for the public, NCC information on state public health agency Web sites was extremely limited. The phase I Web site inventory revealed a paucity of information on state Web sites with only 6 states having extensive information on NCCs and 26 states with minimal information. In the phase II state personnel survey, only 17 states reported having a Web site for reporting NCC information.

### Trends

Given the lack of systematic record keeping, it was not possible to identify specific trends in cluster investigations or the number of state NCC investigations conducted each year. In phase I, only 1 state listed the number of cluster investigations conducted from 1998 to 2003. In the phase II survey, incomplete and inconsistent data were provided by survey respondents of the number of investigations conducted from 2000 to 2004. Moreover, when estimates were reported, the numbers varied widely by year and by end point, ranging from 0 to 40 for suspected cancer clusters and from 0 to 76 for other suspected NCCs. In addition, several states indicated that investigations were conducted but did not estimate the number. Given these responses, it was not possible to discern any meaningful trends in the data.

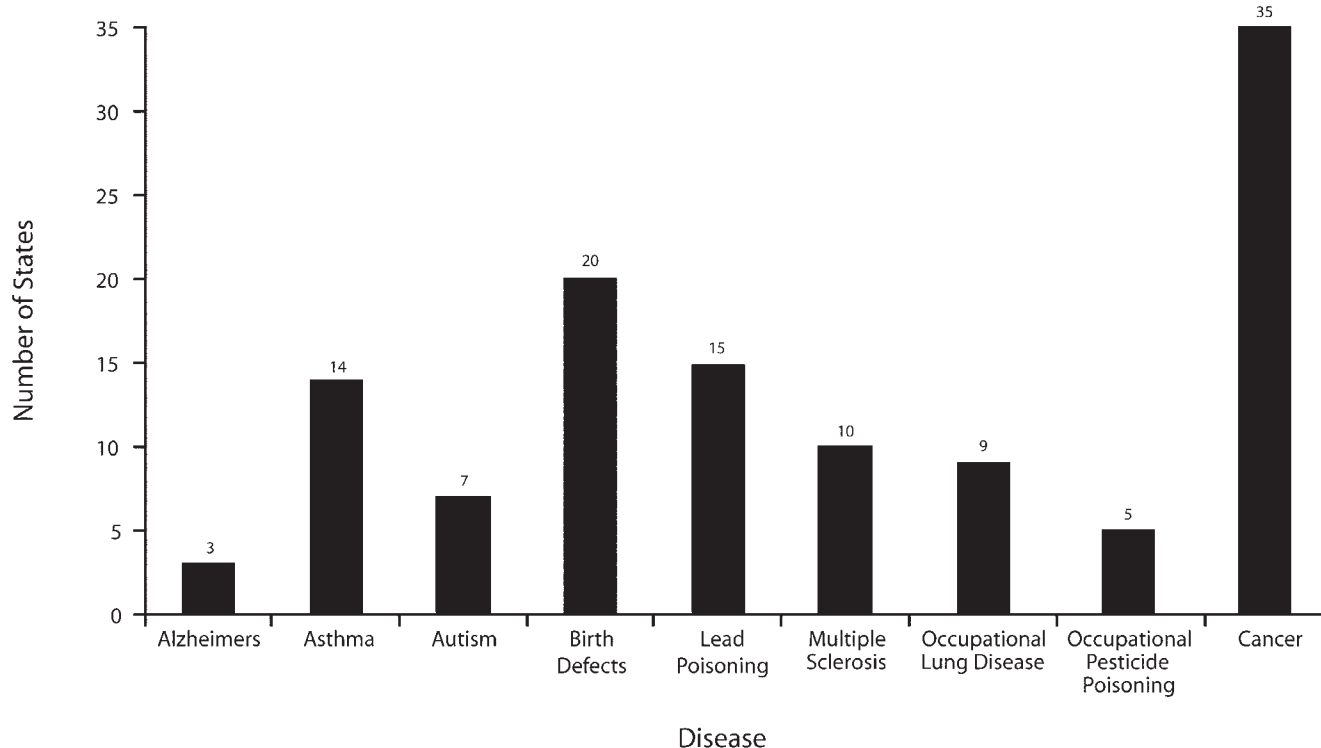


FIGURE 1—Number of states (N = 37) reporting requests received for cluster investigations from 2000 to 2004, by disease.

### State Needs

A model approach to NCCs, strengthened programs, and enhanced scientific capacity were identified as needs. Findings from the phase II survey indicated a broad range of needs, including development of policies and protocols for NCC requests (requested by 27% of responding states), the conduct and management of NCC cluster investigations (35%), and the determination of when no further investigation of a suspected NCC was required (11%). Forty-one percent of respondents desired staff training regarding identification of disease clusters, methods for small area analyses, statistical techniques for cluster investigations, and the use of analytic and statistical software tools. Respondents from 2 states suggested that national advisory panels be convened to develop recommendations on how states should address NCCs. One respondent also suggested that educational materials are needed to inform the public about disease cluster investigations, including their challenges and limitations. Table 2 summarizes

responses of the agency personnel with regard to needs to enhance NCC capacity.

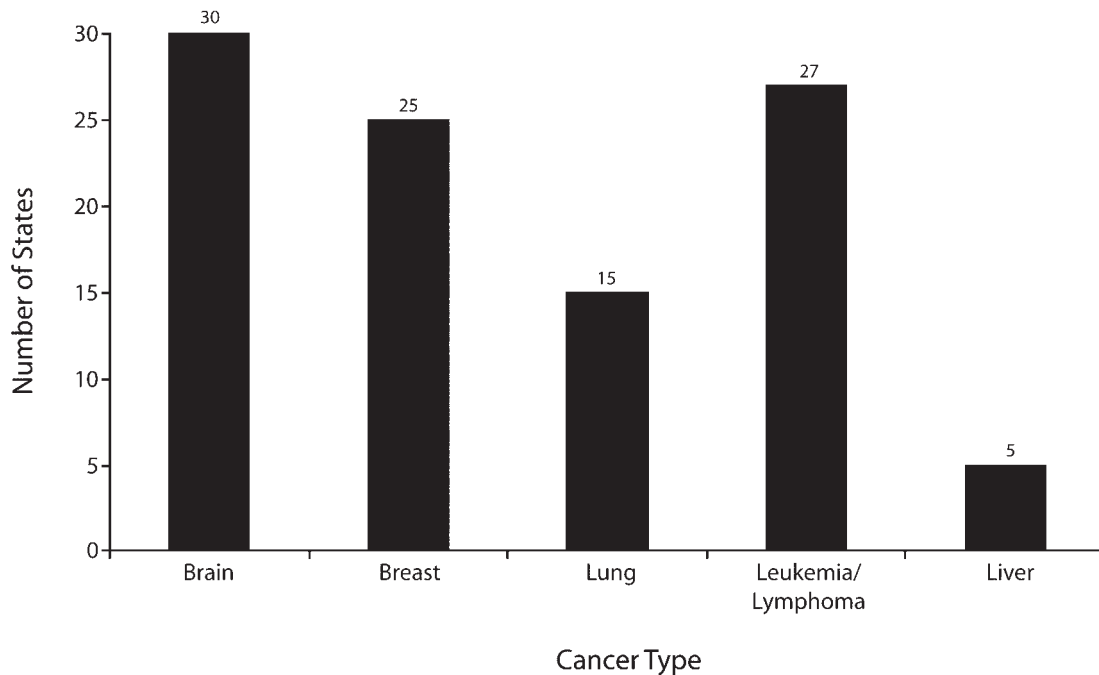
### DISCUSSION

Identifying potential disease clusters and responding to community inquiries pose challenges to state public health agencies, which are often tasked with addressing these issues. Scientific challenges to disease cluster investigations are substantial and include lack of statistical power because of the small numbers of cases, difficulties in determining biological plausibility, challenges because of disease latency, and limited understanding of the effects of chronic low-level exposures to environmental contaminants.<sup>20</sup> Often, NCC investigations are highly visible, politically charged, resource intensive, and may take many years to complete.<sup>21</sup>

As community level environmental public health tracking data improve and we begin proactive use of the data, it is anticipated that greater numbers of expected cases of specific

diseases within a population during a defined space and time will be identified. Such findings will bring new requests and expectations to evaluate perceived clusters of disease. Public health agencies will need to be prepared to respond and address questions regarding potential environmental etiology. The goals of this project were to develop a profile of the state public health agency capacity to address NCCs and to identify strategies to enhance response capacity.

Our investigation revealed that most states did not have a standardized definition for the term *clusters*, indicating a lack of focus and inadequate attention placed on addressing NCCs. However, nearly half of the survey respondents indicated a desire to expand programs and receive greater support for NCC programs. In addition, we found a critical need to develop the capacity to conduct NCC investigations on a broad range of diseases. There was a wide range of capability for states to address disease clusters, with the large majority lacking sufficient personnel,



**FIGURE 2—Number of states (N = 37) reporting at least 1 request received or investigation conducted for potential cancer clusters from 2000 to 2004, by cancer type.**

resources, expertise, and prescribed protocols. Those states with well-developed cluster programs generally focused only on cancer end points.

All of the states indicated that community concerns were the major impetus for conducting investigations, reflecting a high level of public health concern. State health department personnel also indicated a desire for assistance to adequately respond to these requests.

### Strengths

Chief among the strengths of this study was the 2-phased design that allowed efficient collection of qualitative and quantitative information concerning a range of issues associated with NCC programs in each of the 50 states. The review of state Web sites followed by a more focused survey permitted a consistent and comprehensive review of each state's program. In addition, allowing multiple survey respondents from a given state provided an improved picture of the breadth of NCC programs, particularly in jurisdictions where public health responsibilities were divided among multiple agencies.

### Limitations

However, as with all survey-based studies, there were limitations with the study design. Data collection for the phase I Web site inventory occurred from January to August 2004, whereas data collected from the phase II agency personnel survey occurred during the summer of 2005. Although this lag was necessary to allow identification of data gaps in the phase I inventory and to help our researchers structure questions for the phase II survey, this schedule prevented direct comparison of phase I and II results. In addition, direct comparison was limited by the more focused nature of the phase II survey. The survey format was specifically designed to avoid redundancy with phase I and to create a survey that could be efficiently and easily completed by the respondents. This approach allowed for the timely collection of complementary data.

Multiple attempts were made to identify the correct individuals through Web site contact information, direct requests to health department personnel, and by referencing the CSTE contact lists.<sup>35</sup> However, it is possible

that the survey did not reach the appropriate personnel in each state. Specifically with respect to the 13 states that did not respond to the survey, we may not have identified the correct contact individual. This would result in our undercounting NCC programs across the 50 states.

We recognize that local level public health agencies and community members are often key participants in NCC investigations. Because of time and resource constraints, this study focused on overall state capacity and did not address local agencies or community members. Local agency and community input on NCC investigations is critical to the implementation of recommendations presented in this article.

The National Environmental Public Health Tracking Program offers the opportunity to provide proactive and early detection of increased rates of disease, even when specific hypotheses regarding etiology have not been identified.<sup>14</sup> Tracking may identify potential clusters and allow for early identification, investigation, and prevention efforts.<sup>21</sup> However, our findings indicate that the current

**TABLE 2—Needs Identified by Agency Personnel to Improve State Noncommunicable Disease Cluster (NCC) Capacity**

Establish a Model Approach

- Develop standard protocols for all facets of NCC investigations
- Issue guidance that explains how the protocols are implemented
- Develop materials to help the public better understand NCC challenges
- Form a federal advisory group to assist with difficult cluster requests
- Issue national policy statements to better inform the public about environment and disease links

Strengthen NCC Programs

- Encourage interagency/intra-agency collaboration to address NCC issues or challenges
- Provide technical assistance and training
- Increase staffing and budgets

Build NCC Scientific Capacity

- Build and maintain a national database of NCC investigations
- Improve tracking systems for noncommunicable diseases
- Develop more robust statistical methods for assessing potential clusters
- Improve tools, such as geographic information systems, to effectively support NCC analysis and response

Note. Needs were compiled from the Web-based survey.

national capacity for NCC response is disjointed and inconsistent. Because there is no consistency in the responding organization or in the training of individuals charged with NCC response, the next steps must provide flexibility and adaptability in various settings. The following recommendations are offered to provide guidance to the CDC and ATSDR in their support of state public health agency cluster programs. We also believe that there are opportunities for other organizations (i.e., the National Disease Cluster Alliance) to act on these recommendations to address the critical need to enhance the NCC capacity at the state level, as described subsequently.

A model approach should be established for NCCs to be adapted by states by developing standard cluster definitions and adapting

existing documents to establish standardized protocols for the following: (1) reporting of suspected NCC clusters, (2) responding to public concerns, (3) identifying when NCC investigations are not warranted, (4) improving interagency communication; (5) communicating NCC investigation results to the public, and (6) tracking requests and conduct of NCC investigations to identify trends at local, state, and national levels.

NCC programs should be strengthened by (1) defining roles and responsibilities for agency personnel in addressing NCCs, (2) expanding NCC technical assistance and training opportunities to include training on the use and application of geographic information systems, and (3) broadening NCC programs to address a wide range of chronic diseases that have potential environmental etiology.

NCC scientific capacity should be built by (1) building a national database of NCC investigations, (2) improving tracking systems for noncommunicable diseases, and (3) developing technical tools and methods to improve the science of NCC investigations.

NCCs often present daunting public health challenges. As indicated by our research findings, although a desire exists among state personnel to adequately respond to NCCs, many agencies are unable to garner the resources, personnel, and technical tools to adequately respond to NCCs. However, as the tracking of disease end points improves, public concern and questions will continue to grow. Improved tracking provides the opportunity to identify populations at risk and respond to outbreaks, clusters, and emerging disease. However, we must provide our state public health agencies with the adequate capacity—resources, tools, and training—to detect and, ultimately, prevent NCC disease clusters. ■

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### Contributors

N.S. Juzych, B. Resnick, and T.A. Burke originated the study and supervised all aspects of its implementation. N.S. Juzych, R. Streeter, and J. Herbstman participated in the development of the survey instrument, oversaw data management, and led data analysis. N.S. Juzych led the writing. J. Zablotzky assisted with the survey implementation and writing. M. Fox provided guidance on study approach and, along with the other authors, helped to interpret findings and review drafts of the article.

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### Human Participant Protection

The Johns Hopkins Bloomberg School of Public Health institutional review board approved the study protocol.

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