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Report to the Chairman, Subcommittee on Public Health, Committee on Health, Education, Labor, and Pensions, U.S. Senate

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EMERGING INFECTIOUS DISEASES

Consensus on Needed Laboratory Capacity Could Strengthen Surveillance

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The Honorable Bill Frist
Chairman, Subcommittee on Public Health
Committee on Health, Education, Labor, and Pensions
United States Senate

Dear Mr. Chairman:

The spread of infectious diseases is a public health problem once thought to be largely under control. However, outbreaks over the last decade illustrate that infectious diseases remain a serious public health threat. For example, in 1993, more than 400,000 people became ill from a city's drinking water contaminated with *Cryptosporidium parvum*—a common parasite resistant to chlorination and other water treatment measures. Over 4,000 people were hospitalized, and 55 died. In 1996, drinking apple juice contaminated with a virulent strain of *E. coli* bacteria made more than 60 people seriously ill and caused the death of one person. And in 1998, 26 children became ill from playing in a swimming pool contaminated by a virulent strain of *E. coli*. Four of the children developed a serious complication that affects the blood and kidneys.

The resurgence of some infectious diseases is particularly alarming because previously effective forms of control are breaking down. For example, some pathogens (disease-causing organisms) have become resistant to antibiotics used to bring them under control or have developed strains that no longer respond to the antibiotics.

Monitoring infectious diseases—identifying diseases and their sources—is critical for determining control and prevention efforts. Public health officials refer to this activity as surveillance—the ongoing collection, analysis, and interpretation of disease-related data to plan, implement, and evaluate public health actions. Many public health experts have raised concerns about the adequacy of the nation's infectious diseases surveillance network, especially for those diseases considered to be emerging—that is, ones more prevalent now than 20 years ago or ones that show signs of becoming more prevalent in the near future.

In light of these concerns, you asked us to examine the nation's surveillance network and to focus on the contribution of laboratories, since new technology gives them an increasingly important role in identifying pathogens and the sources of outbreaks. Specifically, you

asked us to (1) determine the extent to which states conduct public health surveillance and laboratory testing of selected emerging infectious diseases, (2) identify the problems state public health officials face in gathering and using laboratory-related data in the surveillance of emerging infectious diseases, and (3) describe the assistance that the Department of Health and Human Services' (HHS) Centers for Disease Control and Prevention (CDC) provides to states for laboratory-related surveillance and the value of this assistance to state officials.

To provide information on the contribution of laboratories to the surveillance network, we surveyed the directors of all state public health laboratories and infectious diseases epidemiology[1] programs that report disease-related information directly to CDC, including officials in all 50 states, 5 territories, the District of Columbia, and New York City.[2] We also conducted case studies in Kentucky, New York, and Oregon; spoke with additional state and local public health officials around the country; and interviewed CDC officials. We focused our work on six specific emerging infectious diseases or pathogens: tuberculosis, Shiga-like toxin-producing *E. coli* (including *E. coli* O157:H7),[3] pertussis, *Cryptosporidium parvum*, hepatitis C virus, and penicillin-resistant *Streptococcus pneumoniae*. Our methodology is described in more detail in appendix I, the results from our surveys are in appendixes II and III, and details on the six diseases are in appendix IV. Our work was conducted from December 1997 through December 1998 in accordance with generally accepted government auditing standards.

Results in Brief

Surveillance and testing for important emerging infectious diseases are not comprehensive in all states, leaving gaps in the nation's infectious diseases surveillance network. Our survey found that most states conduct surveillance of five of the six emerging infectious diseases we asked about, and state public health laboratories conduct tests to support state surveillance of four of the six. However, over half of the state laboratories do not conduct tests for surveillance of hepatitis C and penicillin-resistant *S. pneumoniae*. Many state epidemiologists believe that their infectious diseases surveillance programs should expand, and they frequently cited a need to gather more information on antibiotic-resistant diseases. Just over

[1]Epidemiology is the study of the distribution and causes of disease or injury in a population.

[2]Throughout this report, we refer to this group collectively as "states."

[3]Shiga-like toxin-producing *E. coli* belong to a group of virulent *E. coli* that can produce severe intestinal bleeding. Throughout this report, we will refer to the group by the name of its most well-known member, *E. coli* O157:H7.

half of the state public health laboratories have access to advanced molecular technology, which many experts believe could be valuable to all states' diseases surveillance efforts. Furthermore, few states require the routine submission of specimens or isolated quantities of a pathogen from patients with certain diseases for testing in state laboratories—a step CDC has urged them to adopt to improve the quality of surveillance information.

Many state laboratory directors and epidemiologists reported that inadequate staffing and information-sharing problems hinder their ability to generate and use laboratory data to conduct infectious diseases surveillance. For example, they believe that the number of laboratory staff to perform tests and the number of epidemiology staff who can analyze data and translate surveillance information into disease prevention and control activities are insufficient. They also cited a need for training to ensure that their staffs have the skills to take advantage of technological advances in laboratory methods, information-sharing systems, or both. Participants in the surveillance network, particularly at the local level, often lack basic computer hardware or integrated systems to allow them to rapidly share information. State officials also expressed concerns about CDC's many separate data reporting systems, which result in duplication of effort and drain scarce staff resources. Although many state officials told us that they did not have sufficient staffing and technology resources, public health officials have not agreed on a consensus definition of the minimum capabilities that state and local health departments need to conduct infectious diseases surveillance. This lack of consensus makes it difficult to assess resource needs. We are recommending that the Director of CDC lead an effort to help federal, state, and local public health officials create consensus on the core capacities needed at each level of government.

CDC provides state and local health departments with a wide range of technical, financial, and staff resources to help maintain or improve their ability to detect and respond to emerging infectious disease threats. Most state laboratory directors and epidemiologists placed high value on CDC's testing and consulting services, training, and grant funding and said these services were critical to their ability to use laboratory data to detect and monitor emerging infections. However, they identified a number of ways in which these services could be improved. Specifically, most state officials said CDC needs to better integrate its data systems and help states build systems that link them with local and private surveillance partners. Many state officials would also like CDC to provide more hands-on training

experience. State officials also pointed out that obtaining assistance with problems that cut across programmatic boundaries could be improved if CDC's departments that focus on specific diseases communicated better with one another.

Background

Emerging infectious diseases pose a growing health threat to people in this country and around the world. The causes of this increase are complex and often difficult to anticipate. For example, increased development, deforestation, and other environmental changes have brought people into contact with animals or insects that harbor diseases only rarely encountered before. Not all emerging infections are unfamiliar diseases, however. Some pathogens have developed resistance to the antibiotics that brought them under control just a generation ago. Moreover, the threefold increase in international travel during the past 20 years and greater importation of fresh foods across national borders allow infectious diseases to spread rapidly. As these diseases travel, they interact with growing numbers of people who have weakened immunity, such as transplant recipients, elderly persons, patients treated with radiation, and those infected with HIV/AIDS.

With the introduction of antibiotics in the 1940s and the development of vaccines for diseases like polio, there was widespread optimism that infectious diseases could be eliminated completely. As a result, public health officials shifted some monitoring efforts to other health problems, such as chronic diseases. By 1986, CDC had discontinued surveillance of drug-resistance trends in tuberculosis. The resurgence of tuberculosis and the appearance of HIV/AIDS thus caught the nation's public health system off guard.

Today, infectious diseases account for considerable health care costs and lost productivity. In the United States, an estimated one-fourth of all doctor visits are for infectious diseases. Foodborne illnesses, some of which were unrecognized 20 years ago, are estimated to cause up to 33 million cases and 9,000 deaths annually and to cost as much as $22 billion a year. The number of pathogens resistant to one or more previously effective antibiotics is increasing rapidly, adding to health care costs and threatening to return the nation to the pre-antibiotic era. Antibiotic resistance limits effective treatment options, with potentially fatal results. Resistant infections that people acquire during hospitalizations are estimated to cost as much as $4 billion and cause 19,000 deaths a year.

Surveillance Is the Primary Public Health Tool to Detect and Monitor Infections

Surveillance is public health officials' most important tool for detecting and monitoring both existing and emerging infectious diseases. Without an adequate surveillance system, local, state, and federal officials cannot know the true scope of existing health problems and may not recognize new diseases until many people have been affected. They rely on surveillance data to focus their staff and dollar resources on preventing and controlling the diseases that most threaten populations within their jurisdictions. Health officials also use surveillance data to monitor and evaluate the effectiveness of prevention and control programs.

Passive and Active Surveillance

Because known diseases can become emerging infections by changing in unanticipated ways, the methods for detecting emerging infections are the same ones used to monitor infectious diseases generally. These methods can be characterized as passive or active.

When using passive surveillance methods, public health officials notify laboratory and hospital staff, physicians, and other relevant sources about disease data they should report. These sources in turn must take the initiative to provide data to the health department, where officials analyze and interpret the information as it comes in.

Under active surveillance, public health officials contact people directly to gather data. For example, state or local health department staff could call commercial laboratories each week to ask if any tests conducted for cryptosporidiosis yielded positive results. Active surveillance produces more complete information than passive surveillance, but it takes more time and costs more.

Infectious diseases surveillance in the United States depends largely on passive methods of collecting disease reports and laboratory test results. Consequently, the surveillance network relies on the participation of health care providers, private laboratories, and state and local health departments across the nation.

Surveillance Depends on Participation by Many

States have principal responsibility for protecting the public's health and, therefore, take the lead role in conducting surveillance. Each state decides for itself which diseases will be reported to its health department, where reports should be submitted, and which information it will then pass on to CDC.

The surveillance process usually begins when a person with a reportable disease seeks care. To help determine the cause of the patient's illness, a

physician may rely on a laboratory test, which could be performed in the physician's own office, a hospital, an independent clinical laboratory, or a public health laboratory. State and local health departments that provide clinical services also generate laboratory test results for infectious diseases surveillance.

Local health departments are often the first to receive the reports of infectious diseases generated by physicians, hospitals, and others. Health department staff collect these reports, check them for completeness, contact health care professionals to obtain missing information or clarify unclear responses, and forward them to state health agencies. Staff resources devoted to disease reporting vary with the overall size and mission of the health department. Since nearly half of local health agencies have jurisdiction over a population of fewer than 25,000, many cannot support a large, specialized staff to work on disease reporting.

In state health departments, epidemiologists analyze data collected through the disease reporting network, decide when and how to supplement passive reporting with active surveillance methods, conduct outbreak and other disease investigations, and design and evaluate disease prevention and control efforts. They also transmit state data to CDC, providing routine reporting on selected diseases. Many state epidemiologists and laboratory directors provide the medical community with information obtained through surveillance, such as rates of disease incidence and prevailing patterns of antimicrobial resistance.

Federal participation in the infectious diseases surveillance network focuses on CDC activities—particularly those of the National Center for Infectious Diseases (NCID), which operates CDC's infectious diseases laboratories. CDC analyzes the data furnished by states to (1) monitor national health trends, (2) formulate and implement prevention strategies, and (3) evaluate state and federal disease prevention efforts. CDC routinely provides public health officials, medical personnel, and others information on disease trends and analyses of outbreaks. Through NCID and other units—such as the National Immunization Program and the National Center for HIV, Sexually Transmitted Diseases, and Tuberculosis Prevention (NCHSTP)—CDC offers an array of scientific and financial support for state infectious diseases surveillance, prevention, and control programs. NCID officials said that most of their 1,100 staff and $186 million budget in fiscal year 1998 were devoted to assisting state infectious diseases efforts. For example, CDC provides testing services and consultation not available at the state level; training on infectious diseases

and laboratory topics, such as testing methods and outbreak investigations; and grants to help states conduct diseases surveillance.[4] The Epidemiology Program Office provides training and technical assistance related to software for disease reporting and oversees data integration efforts.

Laboratories Play an Essential Role in Surveillance of Emerging Infectious Diseases

Public health and private laboratories are a vital part of the surveillance network because only laboratory results can definitively identify pathogens. In addition, they often are an essential complement to a physician's clinical impressions. According to public health officials, the nation's 158,000 laboratories are consistent sources of passively reported information for infectious diseases surveillance.[5] Independent commercial and hospital laboratories may also share with public health agencies information gathered through their private surveillance efforts, such as studies of patterns of antibiotic resistance or the spread of diseases within a hospital.

Every state has at least one state public health laboratory to support its infectious diseases surveillance activities and other public health programs. Some states operate one or more regional laboratories to serve different parts of the state. In five states—Iowa, Nebraska, Nevada, Ohio, and Wisconsin—academic institutions, such as university medical schools, provide public health laboratory testing. State laboratories conduct testing for routine surveillance or as part of special clinical or epidemiologic studies. These laboratories provide diagnostic tests for rare or unusual pathogens that are not always available in commercial laboratories or tests for more common pathogens that use new technology still needing controlled evaluation. State public health laboratories provide specialized testing for low-incidence, high-risk diseases, such as tuberculosis and botulism. Testing they provide during an outbreak contributes greatly to tracing the spread of the outbreak, identifying the source, and developing appropriate control measures. Epidemiologists rely on state public health laboratories to document trends and identify events that may indicate an emerging problem. Many state laboratories also provide licensing and quality assurance oversight of commercial laboratories.

[4]The grants discussed in this report are cooperative agreements in which CDC helps direct and monitor funded activities.

[5]U.S. laboratories include about 90,000 laboratories in physicians' offices; 5,800 independent clinical laboratories; 9,000 hospital laboratories; and 53,000 other laboratories, such as those in state and local health departments, nursing homes, and other health care facilities. In 1993, about 60 percent of the nation's approximately 3,000 local health departments provided at least some laboratory services, often for a limited number of diseases.

State public health laboratories are increasingly able to use new advanced molecular technology to identify pathogens at the molecular level. Often, these tests provide information that is used not to diagnose and treat individual patients but to tell epidemiologists whether cases of illness are caused by the same strain of pathogen—information that is not available from clinical records or other conventional epidemiologic methods. Public health officials have already used this type of laboratory information to identify the movement of diseases through a community in ways that would not have been possible 5 years ago. For example, staff in Minnesota's laboratory use a molecular technology called pulsed field gel electrophoresis (PFGE) to test "isolates" (isolated quantities of a pathogen) of *E. coli* O157:H7 that laboratories in the state must submit. From 1994 to 1995, the resulting DNA fingerprint patterns identified 10 outbreaks—almost half of which would not have been identified by traditional surveillance methods. Using the laboratory results, epidemiologists were able to find the sources of contamination and eliminate them, thus preventing additional infections.

CDC laboratories provide highly specialized tests not always available in state public health or commercial laboratories and assist states with testing during outbreaks. The staff at CDC's laboratories also have a broad range of expertise identifying pathogens. These laboratories help diagnose life-threatening, unusual, or exotic infectious diseases; provide information on cases of infectious diseases for which satisfactory tests are not widely or commercially available; and confirm public or private laboratory test results that were atypical or difficult to interpret. According to NCID officials, CDC laboratories provide testing services and consultations on conducting tests or interpreting results to every state. CDC also conducts research to develop improved diagnostic methods and trains state laboratory staff to use them.

Not All States Conduct Surveillance and Testing for Important Emerging Infections

While state surveillance and laboratory testing programs are extensive, not all include every significant emerging infectious disease, leaving gaps in the nation's surveillance network. Each state decides which diseases it includes in its surveillance program and which diseases it routinely reports to CDC. Many state epidemiologists believe their surveillance programs need to add or focus more attention on important infectious diseases, including hepatitis C and antibiotic-resistant diseases. Our survey found that almost all states conduct surveillance of *E. coli* O157:H7, tuberculosis, pertussis, and hepatitis C, but fewer collect information on cryptosporidiosis and penicillin-resistant *S. pneumoniae*. State public

health laboratories commonly perform tests to support state surveillance programs for *E. coli* O157:H7, tuberculosis, pertussis, and cryptosporidiosis. Most, however, do not test for hepatitis C and penicillin-resistant *S. pneumoniae*. Slightly more than half the state laboratories use PFGE, which state and CDC officials believe could be valuable to most or all states' diseases surveillance efforts. Few states have followed CDC's suggestion to improve surveillance by requiring medical providers and laboratories to routinely submit specimens for testing in state public health laboratories.

States Determine Which Diseases Are Under National and State Surveillance

Each year, the Council of State and Territorial Epidemiologists (CSTE), in consultation with CDC, reviews the list of infectious diseases that are "nationally notifiable"—that is, important enough for the nation as a whole to merit routine reporting to CDC. The list currently includes 52 infectious diseases.[6] States are under no obligation to adopt the nationally notifiable diseases for their own surveillance programs, and state reporting to CDC is voluntary. A 1997 CSTE survey of state health departments found that 87 percent of states included at least 80 percent of the 52 nationally notifiable diseases in their surveillance programs, and about one-third of states included over 90 percent.[7] Lists of state reportable diseases vary considerably, partly because of differences in the extent to which diseases occur in different regions of the country.[8]

Surveillance of Some Diseases Is Not Widespread

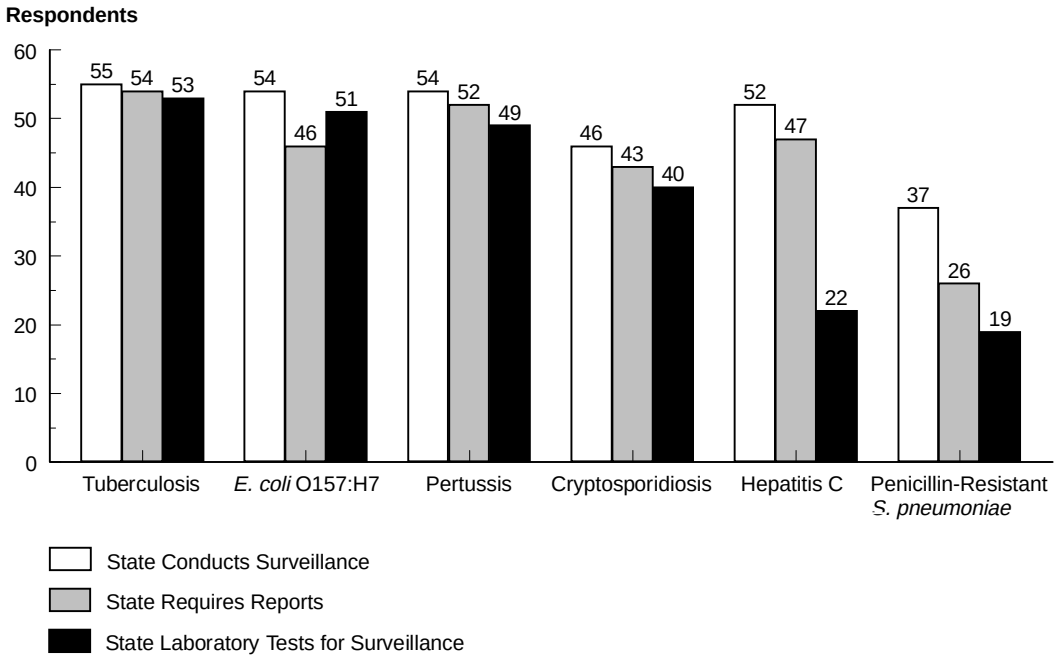
Of the six diseases covered by our survey, nearly all the states include at least four in their diseases surveillance—most commonly tuberculosis, *E. coli* O157:H7, pertussis, and hepatitis C. A slightly smaller number of states include cryptosporidiosis in their surveillance programs. Penicillin-resistant *S. pneumoniae* was covered least often, with about two-thirds of the states including it. For all of the diseases except penicillin-resistant *S. pneumoniae*, most states require health care providers, laboratories, and others to submit disease reports to public health officials. These reports contain information such as demographic characteristics of the ill person, the date disease symptoms appeared, and the suspected or confirmed diagnosis. (See fig. 1.)

[6]State and CDC officials periodically revise the list of nationally notifiable diseases.

[7]Survey results did not include information from the District of Columbia and three of the territories.

[8]States also request or require reporting of diseases of local importance that are not on the list of nationally notifiable diseases. The 1997 survey revealed that a total of 74 other infectious diseases were each included in the surveillance program of at least one state.

Figure 1: State Surveillance of Selected Emerging Infections: Diseases Included, Reporting Requirements, and State Public Health Laboratory Testing



Note: State surveillance and reporting requirement data include 55 states; state laboratory testing data include 54 states that provided complete data.

Over three-quarters (44) of the responding epidemiologists told us that their surveillance programs either leave out or do not focus sufficient attention on important infectious diseases. Antibiotic-resistant diseases, including penicillin-resistant *S. pneumoniae*, and hepatitis C were among the diseases they cited most often as deserving greater attention.[9]

[9]The epidemiologist in one state reported taking steps to add hepatitis C and penicillin-resistant *S. pneumoniae* to the state's list of reportable diseases. Another state epidemiologist reported adding hepatitis C to the list of reportable diseases, and a third reported adding penicillin-resistant *S. pneumoniae*.

State Public Health Laboratory Testing Does Not Always Accompany Surveillance

State laboratory testing to support state surveillance of the six emerging infections in our survey varies across the nation. Testing is most common for four of the six: tuberculosis, *E. coli* O157:H7, pertussis, and cryptosporidiosis (see fig. 1). In 43 of the 54 state responses we analyzed,[10] the state public health laboratory conducts testing for four or more of the diseases included in its state's surveillance program.[11] Testing to support state surveillance of hepatitis C and penicillin-resistant *S. pneumoniae* occurs in fewer than half of the states.

State and CDC officials believe that most, and possibly all, states should have PFGE technology, which can be used to study many diseases and greatly improves the ability to detect outbreaks. However, for the diseases we asked about in our survey, state public health laboratories are less likely to use advanced molecular technology than more conventional techniques. For example, slightly more than half the state laboratories reported using PFGE technology to support state surveillance efforts. Twenty-nine of the 54 laboratory directors responding to our survey reported using PFGE to support *E. coli* O157:H7 surveillance, and nine of these laboratories also use it for pertussis surveillance.

If a state laboratory provided testing in support of state-level surveillance of a specific disease, we asked directors to assess the adequacy of their testing equipment for that disease. Laboratory directors' views about the adequacy of the testing equipment they use varied somewhat by disease but were generally positive. Eighty percent or more of the laboratory directors rated their equipment as generally or very adequate for four diseases—tuberculosis, *E. coli* O157:H7, cryptosporidiosis, and hepatitis C. Percentages were slightly lower for pertussis (69 percent) and penicillin-resistant *S. pneumoniae* (68 percent).[12]

[10]To study the full range of state surveillance, reporting, and testing efforts for the conditions we asked about, we paired the responses of laboratory directors and epidemiologists by state. For these data, we analyzed only the responses of the 54 pairs of epidemiologists and laboratory directors who provided complete information. We excluded the two states where only the laboratory director responded and the one state where the laboratory director did not provide complete information on surveillance testing.

[11]The 11 other state laboratories conduct tests for one or more of these six infectious diseases. In some cases, the laboratory tests three or fewer of the diseases as part of the state's surveillance efforts; in others, the laboratory tests on behalf of other public or private laboratories.

[12]These results exclude laboratories that do not provide surveillance-related testing for the specific disease.

State epidemiologists' views about the adequacy of the testing information provided by state laboratories vary considerably by disease.[13] More than 94 percent rated their state laboratory as very or generally adequate to provide testing information for tuberculosis and *E. coli* O157:H7. More than 70 percent said their state laboratory is generally or very adequate for generating information on pertussis and cryptosporidiosis. In contrast, only about one-third of epidemiologists said the information generated by their state laboratory for hepatitis C (32 percent) and penicillin-resistant *S. pneumoniae* (37 percent) is generally or very adequate.

We also found that many states do not require other public and private laboratories or medical providers to submit to the state public health laboratory specimens or isolates from persons with certain diseases. CDC has urged states to consider developing such laws because gathering specimens from across the state helps ensure that the state's surveillance data include a diverse sample of the state's population. Such action by states also contributes to more comprehensive national data. In all, 29 states require specimens for one or more of the six diseases in our survey: 5 states require specimens for four diseases, 4 states require specimens for three diseases, 9 states for two, and 11 for one disease.[14] Specimens of tuberculosis and *E. coli* O157:H7 are required most frequently.

Officials Report That Staffing Constraints and Weak Information Sharing Impede Surveillance of Emerging Infections

As part of our survey and field interviews, we asked state officials to identify the problems they considered most significant in conducting surveillance of emerging infectious diseases. The problems they cited fall principally into two categories: staffing and information sharing. State epidemiologists reported that staffing constraints prevent them from undertaking surveillance of diseases they consider important. Laboratory directors told us they do not always have enough staff to conduct tests needed for surveillance; furthermore, their staff need training to remain current with technological advances. Epidemiologists and laboratory officials both said that public health officials often lack either basic computer equipment or integrated data systems that would allow them to rapidly share surveillance-related information with public and private partners.

[13]If testing by the state laboratory was part of state-level surveillance of a specific disease, we asked state epidemiologists to assess the state laboratory's adequacy in generating the data needed for surveillance.

[14]Twenty-two states require no specimens but ask for voluntary submission of specimens for one or more of the six diseases, usually for special studies rather than routinely. Three states neither require nor ask that specimens of these diseases be sent to their state public health laboratory.

Staffing and Training Limitations Affect Ability to Expand Laboratories' Role

Public health officials reported that the nation's infectious diseases surveillance system is basically sound but could improve its ability to detect emerging threats. Most state officials believe they need to expand their infectious diseases surveillance programs. However, both state laboratory directors and epidemiologists said that such expansion has been constrained by staffing and training limitations. Most of the 44 epidemiologists who reported that they need to expand coverage of important infectious diseases said insufficient staff and funding resources prevent them from taking this action. Some noted that they need more and better trained staff just to do a better job on diseases already included in their programs.

We found considerable variability among states in laboratory and epidemiology staffing per 1 million population. In total, we found that during fiscal year 1997, states devoted a median of 8 staff years per 1 million population to laboratory testing of infectious diseases. Laboratory staff year medians for individual types of testing ranged from 0.4 for foodborne pathogens to 2.4 for all other infectious diseases not specifically listed in table 1. The median for total epidemiology staff years per 1 million population was 14; the range was from 0.1 for foodborne pathogens to 5 for HIV/AIDS. (See table 1.)

Table 1: State Public Health Laboratory and Epidemiology Staff Years Per 1 Million Population in Fiscal Year 1997

	Laboratory staff years		Epidemiology staff years	
Disease or condition	**Median**	**Range**	**Median**	**Range**
Tuberculosis	1.2	0-21	1.8	0-45
HIV/AIDS[a]	1	0.2-33	5.1	0-193
Sexually transmitted diseases	1.4	0.1-50	3.3	0-72
Foodborne diseases	0.4	0-17	0.1	0-33
Other emerging infectious diseases	0.7	0-14	0.2	0-33
All other infectious diseases	2.4	0-16	3.2	0-50
Total staff years devoted to infectious diseases programs	8.1	1.3-89	14	2.1-321

[a]HIV/AIDS was excluded from the "other emerging infectious diseases" category.

The majority of state laboratory directors indicated that their staffing resources are generally adequate to generate test results for the diseases in our study.[15] For each of the four diseases that state laboratories most

[15]This represents the views of laboratory directors whose staff conduct tests to support surveillance of at least one of the diseases we asked about.

commonly support, more than 75 percent of directors rated their staff as generally or very adequate to perform the tests.[16] Among the smaller number of state laboratories that conduct tests to support surveillance of hepatitis C and penicillin-resistant *S. pneumoniae*, a smaller percentage of laboratory directors considered their staff resources at least adequate (68 percent and 58 percent, respectively).

Some state laboratory and epidemiology officials told us that staffing constraints prevent them from making full use of testing capacity. For example, the laboratory director in a state that had acquired PFGE technology cited lack of staff time as one reason for not routinely using PFGE in surveillance of *E. coli* O157:H7. As a result, he said, the incidence of *E. coli* O157:H7 in his state is probably understated. If resources were available, he would also like laboratory staff to test pertussis specimens collected during a recent outbreak to determine whether the increase in reported cases was a true outbreak or the result of increased awareness—and reporting—of the disease following the death of a child. Thirty-six state laboratory directors reported having vacancies during the past year and said the vacancies had negatively affected their laboratory's ability to support their state's infectious diseases surveillance activities. Nine rated the impact as great or significant. Administrative and financial constraints, such as hiring freezes or budget reductions, were most often responsible for the vacancies.

Laboratory officials noted that advances in scientific knowledge and the proliferation of molecular testing methods have created a need for training to update the skills of current staff. They reported that such training is often either unavailable or inaccessible because of funding or administrative constraints. For example, several state officials said that in reducing costs, training budgets are often cut first. In other states, staff are subject to per capita limits on training or travel expenses. Therefore, if CDC or another source provided additional funding, these funds could not be used.

Lack of Equipment and Cumbersome Systems Hinder Information Sharing

For health crises that need an immediate response—as when a serious and highly contagious disease appears in a school or among restaurant staff—rapid sharing of surveillance information is critical. Public health officials told us, however, that many state and local health departments do not have the basic equipment to efficiently share information across the

[16]The specific percentages for the four diseases are *E. coli* O157:H7 (82 percent), tuberculosis (75 percent), pertussis (78 percent), and cryptosporidiosis (77 percent).

surveillance network. Computers and other equipment, such as answering or fax machines, that can shorten the process of sharing surveillance information from weeks to a day or less are not always available.

Our survey responses indicate that state laboratory directors use electronic communication systems much less often than state epidemiologists use them. Although about three-quarters of responding state laboratory directors use electronic systems to communicate within their laboratories, they do not frequently use electronic systems to communicate with others. Almost 40 percent of laboratory directors reported using computerized systems to little or no extent for receiving surveillance-related data, and 21 percent use them very little for transmitting data. While state epidemiologists use electronic systems more than laboratory directors, they also use them less commonly to receive information (42 percent) than to report it (62 percent).

One reason for the limited use of electronic systems may be the lack of equipment. A 1996 CDC survey found that, on average, about 20 percent of staff in most state health agencies did not have access to desktop computers that were adequate for sharing information rapidly. Forty percent of local health officials responding to a 1996 survey conducted by the National Association of City and County Health Officials said they lacked such equipment.[17] State and local health officials most often attributed the lack of computer equipment and integrated data processing and management systems to insufficient funding.

The absence of equipment means some tasks that could be automated must be done by hand—and in some cases must be done by hand even after data have already been processed in electronic form. For example, representatives from two large, multistate private clinical laboratories told us that data stored electronically in their information systems had to be converted to paper so that it could be reported to local health departments. In one state we visited, a local health department mails data stored on disk to the state health agency because it lacks the equipment to transfer the data electronically.

Even with adequate computer equipment, the difficulty of creating integrated information systems can be formidable. Not only does technology change rapidly, but public health data are currently stored in thousands of places, including the record and information systems of

[17]Questionnaires were mailed to a random sample of 800 health officials in local health agencies; 384 responded.

public health agencies and health care institutions, individual case files, and data files of surveys and surveillance systems. These data are in isolated locations that have differing hardware and software structures and considerable variation in how the data are coded, particularly for laboratory test results.

CDC operates over 100 data systems to monitor over 200 health events, such as specific infectious diseases. Many of these systems collect data from state surveillance programs. This patchwork of data systems arose, in part, to meet CDC and state needs for more detailed information for particular diseases than was usually reported. For example, while information collected to determine incidence rates of many nationally notifiable diseases consists of minimal geographic and demographic data, the information collected to determine incidence rates of tuberculosis includes information on personal behavior, the presence of other diseases, and stays in institutional settings, as well as geographic and demographic data. The additional information collected on tuberculosis also helps guide prevention and control strategies.

Public health officials told us that the multitude of databases and data systems, software, and reporting mechanisms burdens staff at state and local health agencies and leads to duplication of effort when staff must enter the same data into multiple systems that do not communicate with one another. Furthermore, the lack of integrated data management systems can hinder laboratory and epidemiologic efforts to control outbreaks. For example, in 1993 the lack of integrated systems impeded efforts to control the hantavirus outbreak in the Southwest. Data were locked into separate databases that could not be analyzed or merged with others, requiring public health investigators to analyze individual paper printouts.

Other Concerns May Also Affect Use of Laboratory Data

State officials also raised concerns about a lack of complete data for surveillance and the increased reliance on fees to fund state laboratories, which they believe undermine their infectious diseases surveillance efforts.

Completeness of Data

Public health officials and experts acknowledge that, even when states require reporting, the completeness of data reported varies by disease and type of provider. As might be expected, reporting of severe and life-threatening diseases is more complete than reporting of mild diseases. However, when mild diseases are not reported, outbreaks affecting a large

number of people may go unnoticed until deaths occur among people at higher than normal risk. In addition, reporting by practitioners in frequent contact with infectious diseases, such as family practitioners, is more complete than reporting by those who are not, such as surgeons. Although surveillance need not be complete to be useful, underreporting can adversely affect public health efforts by leading to erroneous conclusions about trends in incidence, risk factors for contracting a disease, appropriate prevention and control measures, and treatment effectiveness.

Completeness of reporting is a concern for the surveillance of illnesses that can produce mild symptoms, such as diarrheal illnesses, which include many foodborne and waterborne conditions. Reported cases of some illnesses represent the tip of the iceberg, at best. A recent CDC-sponsored study estimated that 340 million annual episodes of acute diarrheal illness occurred in the United States, but only 7 percent of people who were ill sought treatment. The study further estimated that physicians requested laboratory testing of a stool culture for 22 percent of those patients who sought treatment, which produced about 6 million test results that could be reported.[18] In cases of mild diarrheal illness, physicians may not request laboratory tests to identify the pathogen because patients with these diseases can get better without treatment or effective treatments do not exist.

Public health officials expressed varying views about how managed care growth and the consolidation of the laboratory industry might affect the completeness of surveillance data. Some public health officials and physicians believe that managed care—with its emphasis on controlling costs—could lead doctors to order fewer diagnostic tests, particularly those not needed for treatment decisions. Also, to the extent that managed care organizations less frequently use specialists, results from specialized tests they employ would not be generated. Concerns about laboratory consolidation—particularly when specimens are shipped to central testing facilities in other states—stem from fears that out-of-state testing centers will not report test results needed for surveillance, possibly because they might not be aware of state reporting requirements regarding what information should be reported and where to direct it. In two states we visited, representatives of large multistate independent laboratories said their policy is to report test results in accordance with state requirements. One representative provided us with documentation showing the various reporting requirements of states in one region served by the laboratory.

[18]H. Herikstad and others,"Population-Based Estimates of the Burden of Diarrheal Illness: FoodNet 1996-1997" (Atlanta, Ga.: International Conference on Emerging Infectious Diseases, 1998).

Each of these laboratories is participating in electronic laboratory reporting pilot programs in different states.

Other CDC and state public health officials believe that managed care organizations and concentrated ownership of laboratories could provide information that is potentially more consistent, complete, and reliable than what public health officials now routinely obtain through passive reporting. They argue that because information on a large number of patients is concentrated in a small number of organizations, the number of contacts for active surveillance projects is smaller and more manageable and information can be analyzed from large databases. Moreover, they add, these organizations are likely to collect and store laboratory data electronically, which could speed disease reporting.

Our survey asked epidemiologists whether they or other agencies in their states had evaluated the impacts of managed care and laboratory consolidation on surveillance data; we could identify no systematic evaluations on this issue. Similarly, researchers who conducted a survey for HHS did not find data that address concerns about the impact of managed care.[19]

Increased Reliance on Fees to Fund State Laboratories

Another concern state officials frequently mentioned is an increasing reliance on fees to fund the operations of state public health laboratories. Over 30 laboratory directors responding to our survey said their budgets were partly supported by fees for genetic screening and tests for regulatory and licensure programs. State officials told us that an imbalance of fees in relation to appropriated funding shifts the focus of laboratory operations away from testing services beneficial to the entire community and toward services that can be successfully marketed—a shift that they believe could jeopardize fulfilling their public health mission. One state laboratory director said that over the past 15 years, state funding has declined by more than half and fees are expected to cover the difference. He believes that if the laboratory loses contracts for genetic or blood lead-level testing, he will have to reduce other testing, such as for sexually transmitted diseases or CDC's influenza surveillance.

[19]Public Health Laboratories and Health System Change, The Lewin Group, Oct. 6, 1997.

No Public Health Consensus Defines Core Capacities Needed for Surveillance System

Although many state officials are concerned about their staffing and technology resources, public health officials have not developed a consensus definition of the minimum capabilities that state and local health departments need to conduct infectious diseases surveillance. For example, according to CDC and state health officials, there are no standards for the types of tests state public health laboratories should be able to perform; nor are there widely accepted standards for the epidemiological capabilities state public health departments need. Public health officials have identified a number of elements that might be included in a consensus definition, such as the number and qualifications of laboratory and epidemiology staff; the pathogens that each state laboratory should be able to identify and, where relevant, test for antibiotic resistance; specialized laboratory and epidemiology capability that should be available regionally; laboratory and information-sharing technology each state should have; and support services that CDC should provide.

Recognizing this lack of guidance, CSTE, the Association of Public Health Laboratories (APHL), and CDC have begun collaborating to define the staff and equipment components of a national surveillance system for infectious diseases and other conditions. Their work is to include agreements about the laboratory and epidemiology resources needed to conduct surveillance, diseases that should be under surveillance, and the information systems needed to share surveillance data. One goal of reaching this consensus would be to give state and local health agencies the basis for setting priorities for their surveillance efforts and determining the resources needed to implement them.

CDC Services Are Wide-Ranging and Generally Perceived as Valuable

CDC provides state and local health departments with a wide range of technical, financial, and staff resources to help maintain or improve their ability to detect and respond to disease threats. Many state laboratory directors and epidemiologists said this assistance has been essential to their ability to conduct infectious diseases surveillance and to take advantage of new laboratory technology. However, a small number of laboratory directors and epidemiologists believe CDC's assistance has not added much to their ability to conduct surveillance of emerging infections, and many state officials indicated that further improvements are needed, particularly in the area of information-sharing systems.

Services Include Both Technical and Financial Assistance

CDC's various units, particularly NCID, provide an array of technical and financial support for state infectious diseases surveillance programs. In general, this support falls into the following six areas: testing and consulting, training, grant assistance, funding for regional laboratories, staffing assistance, and information-sharing systems.

- Laboratory testing and consultation. CDC staff and laboratories support state infectious diseases surveillance efforts with technical assistance and testing services that may not be available at the state level. CDC staff provide consultation services on such matters as epidemiological methods and analysis, laboratory techniques, and interpretation of laboratory results. Almost all of the state laboratory directors and epidemiologists responding to our survey said they use CDC's laboratory testing services and frequently consult with CDC staff.
- Training. CDC provides public health and medical personnel with training on a wide range of topics. The training is offered through such means as interactive audio- or video-conferences, computer-assisted instruction, seminars, and hands-on workshops. Since 1989, CDC has offered laboratory training through a collaboration with APHL. An APHL and CDC assessment identified the need for training on current advances in food microbiology, fungal and viral infections, rabies, tuberculosis, and new and emerging pathogens. To meet these needs, CDC developed a series of courses incorporating hands-on experience, offered in various locations around the country. State laboratory directors and epidemiologists indicated they use CDC training extensively, and most said they participated in CDC-sponsored training in 1997.
- Grant programs. CDC's various grant and staffing assistance programs provide at least some support to the infectious diseases surveillance programs of all states. In fiscal year 1998, NCID distributed $31.2 million of its $185.7 million budget to state and local health agencies for infectious diseases programs. NCID supports three major grant programs that aid state surveillance programs for emerging infectious diseases (see table 2).[20] Together these three grant programs provided about $20 million to state and local health departments in fiscal year 1997.

[20]CDC's NCHSTP provides grants that aid state surveillance of HIV/AIDS, sexually transmitted diseases, and tuberculosis.

Table 2: NCID's Grant Assistance for State Infectious Diseases Programs During Fiscal Year 1997

Program description	FY 1997 funding	1997 recipients
Tuberculosis grants		
Helps state laboratories improve their testing ability to support state tuberculosis surveillance and elimination efforts.	$9.6 million, with awards ranging from $8,000 to $1.3 million	All 50 states, Los Angeles, and New York City
Emerging Infections Program (EIP) grants		
Helps states improve their surveillance of emerging infections and produce information of national significance. States have used funds for active surveillance of drug-resistant infections, foodborne and waterborne diseases, and vaccine-preventable conditions; to conduct applied research on epidemiologic and laboratory methods; and to implement prevention projects. CDC began EIP with funding for programs in four states.	$5.8 million, with annual awards ranging from $645,000 to $1.2 million	California, Connecticut, Georgia, Maryland, Minnesota, New York, Oregon (CDC intends to add 3 states by 2000, bringing the total to 10.)
Epidemiology and Laboratory Capacity (ELC) grants		
Helps states and large local health departments strengthen and enhance their basic capacity for surveillance of and response to infectious diseases. Funds allow states to implement new technology, upgrade information systems, hire and train staff, and purchase office and laboratory equipment. Projects include building electronic reporting systems; using molecular laboratory methods in outbreak investigations; and enhancing surveillance of hepatitis C, diarrheal illnesses, and other conditions. CDC awarded ELC grants initially to 10 states.	$4.3 million, with awards ranging from $128,000 to $379,000	California, Colorado, Florida, Georgia, Hawaii, Illinois, Kansas, Louisiana, Maine, Massachusetts, Michigan, New Jersey, New York, New York City, Ohio, Pennsylvania, Tennessee, Utah, Vermont, Washington, West Virginia, Wisconsin (CDC added 8 states in 1998 and plans to involve all 50 state health departments as well as many territorial and large local health departments by 2002.)

EIP and ELC grants, designed to strengthen and enhance state surveillance abilities, are components of CDC's overall plan to address emerging infectious diseases.[21]

- Funding for regional laboratory networks. To help with both state-specific and nationwide control and prevention efforts, CDC has sponsored development of regional laboratory networks that give states access to molecular testing services that may not be available in their own state laboratory. The two main laboratory networks are PulseNet, which currently focuses on *E. coli* O157:H7, and the Tuberculosis Genotyping Network (see table 3).

[21]Centers for Disease Control and Prevention, Preventing Emerging Infectious Diseases: A Strategy for the 21st Century (Atlanta, Ga.: Department of Health and Human Services, Sept. 1998).

Table 3: CDC-Sponsored Regional Laboratory Networks

Description	Laboratories participating	Notable results
PulseNet		
EIP and ELC funding helped build PulseNet, a laboratory network that uses PFGE to study *E. coli* O157:H7. *Salmonella typhimurium* and other non-typhoidal *Salmonella* were recently added to the organisms under study; more will be added in the future. Participating laboratories are electronically linked to rapidly share PFGE patterns of foodborne pathogens for comparison.	In 1998, the network included 4 state public health laboratories that provide testing to nearby states, 20 public health laboratories that test specimens from within their borders, and U.S. Department of Agriculture (USDA) and Food and Drug Administration laboratories that test food products.	In 1997, Colorado's public health laboratory, using PFGE to develop DNA fingerprints of *E. coli* O157:H7 isolates submitted from laboratories in the state, found identical fingerprint patterns in samples from 13 different patients. Subsequent testing at a USDA laboratory matched the fingerprints with those of *E. coli* O157:H7 isolates recovered from ground beef taken from packages used by two of the patients. State officials concluded the cases were linked to the meat, which had been distributed nationally. The manufacturer, in cooperation with federal officials, removed 25 million pounds of potentially contaminated ground beef from U.S. markets.
Tuberculosis Genotyping Network		
This network of enhanced tuberculosis surveillance uses restriction fragment length polymorphism—a DNA fingerprint technology—to trace the spread of specific strains of the disease. The laboratories also help states investigate outbreaks and identify instances of laboratory contamination that resulted in false diagnoses.	CDC selected seven regional laboratories in April 1996. In 1997, CDC gave these laboratories a total of over $900,000.	CDC and participating laboratories established a national database of tuberculosis fingerprints. Patterns in the database showed that drug-resistant strains first found in New York City have spread to other parts of the country. The fingerprints also showed that tuberculosis can be transmitted during brief contact among people who do not work or live together, an important discovery that led to improved treatment and control programs.

- Staffing assistance. CDC provides a small number of staff resources to assist state infectious diseases programs through 2-year Epidemic Intelligence Service (EIS) placements and fellowships in state or local health departments or laboratories. About one-fourth of the 60 to 80 EIS participants selected each year work in state and local health departments. Additionally, by February 1998, CDC had trained 18 laboratory fellows to work in state, local, and federal public health laboratories through its Emerging Infectious Diseases Laboratory Fellow Program, a collaborative effort with APHL; CDC plans to make 9 emerging diseases laboratory fellowships available through APHL and the CDC Foundation.[22] One goal of the fellowships is to strengthen the relationship of public health

[22]The CDC Foundation is a nonprofit corporation established under the authority of the Preventive Health Amendments of 1992 (42 U.S.C. section 280 d-11) to support CDC's mission.

laboratories to infectious diseases and drug-resistance surveillance, prevention, and control efforts.

- Information sharing. Over the past several decades, CDC has developed and made available to states several general and disease-specific information management and reporting programs. Virtually all states use two of these programs to report data on some infectious diseases to CDC—the Public Health Laboratory Information System (PHLIS) and the National Electronic Telecommunications System for Surveillance (NETSS). PHLIS is used primarily by laboratories; NETSS is used primarily by epidemiology programs.

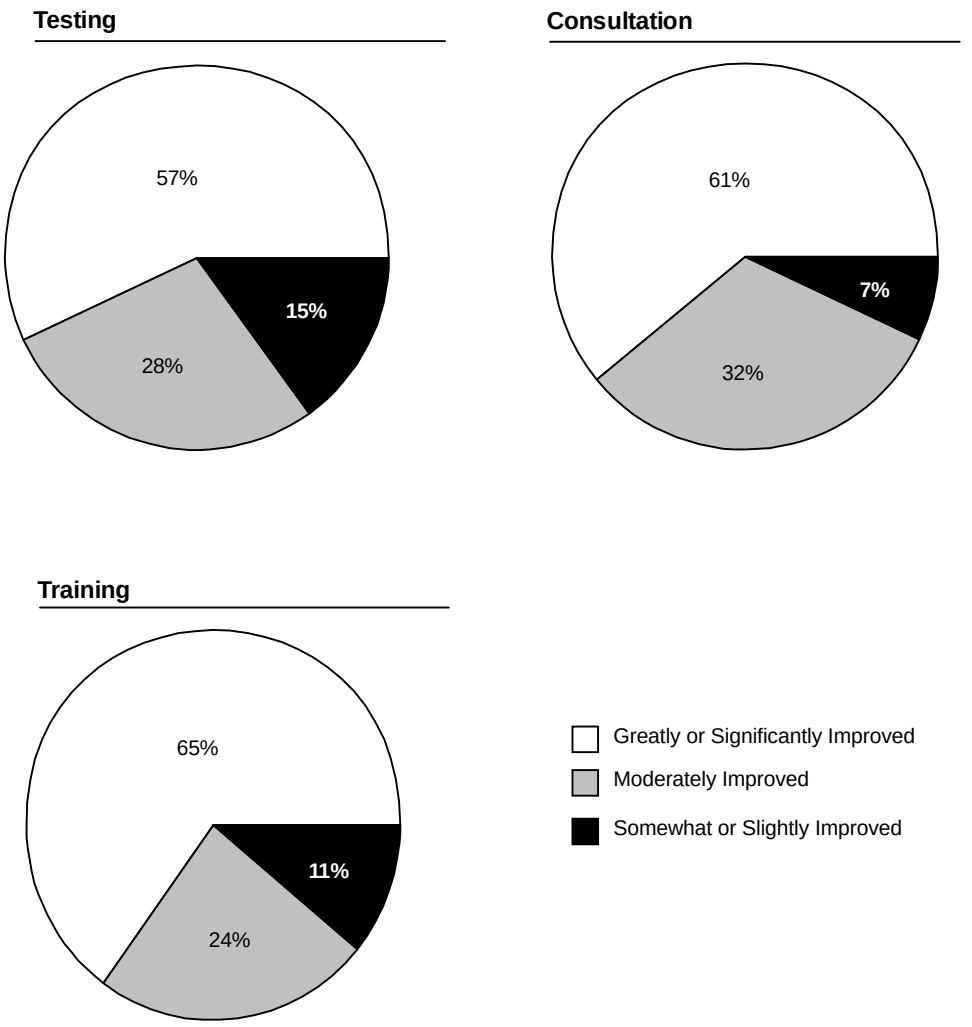
State Officials Value CDC's Assistance but See a Need for Improvement in Information-Sharing Systems

Our surveys showed that overall state laboratory directors and epidemiologists highly value the support CDC provides for their surveillance efforts. Usage and satisfaction levels were highest in the areas of testing and consultation, training, and grant support. The area most often identified as needing improvement was the development of information-sharing systems.

Laboratory Testing, Consultation, and Training Assistance Are Viewed as Critical

Many state laboratory directors and epidemiologists told us that CDC's testing, consultation, and training services are critical to their surveillance efforts. In all three areas of assistance, more than half of those responding to our survey indicated that the services greatly or significantly improved their state's ability to conduct surveillance (see fig. 2). According to officials who spoke with us, CDC's testing for unusual or exotic pathogens and the ability to consult with experienced CDC staff are important, particularly for investigating cases of unusual diseases. However, about 15 percent of survey respondents said CDC's testing services made only modest improvements in their state's surveillance capacity.

Figure 2: Views of State Laboratory Directors and Epidemiologists on Extent CDC's Testing, Consultation, and Training Improved Emerging Infectious Diseases Surveillance Ability



Over 70 percent of epidemiologists responding to our survey said that knowledgeable staff at CDC are easy to locate when they need assistance, but many noted that help with matters involving more than one CDC unit is very difficult to obtain. Many state officials who spoke with us thought that this problem arose because staff in different units do not seem to communicate well with each other. One official described CDC's units as separate towers that do not interact.

A number of state officials commented that CDC provides tests and consultation very promptly when people are at risk—for example during outbreaks of life-threatening diseases—but less quickly in other circumstances. To provide more timely consultation, CDC has developed an on-line image-sharing ability that allows CDC staff and health professionals in remote locations to view an organism under a microscope at the same time. In one state, staff at CDC and a surgeon in another state used this capacity during an operation to identify a parasite as the cause of the patient's eye problem, allowing the surgeon to rule out cancer as a diagnosis and eliminating the need to remove the patient's eye.

Some state officials and survey respondents said that in less urgent circumstances, CDC's test results were often not returned quickly enough to be useful to physicians or, in some cases, to epidemiologists. For example, state officials have waited up to a year for CDC to return test results on unusual organisms, making it difficult—if not impossible—to recognize any subsequent encounters with these organisms. Some of these officials suggested that competing priorities at CDC often prevented the timely return of test results in the absence of immediate need.

Training is another CDC service that state officials believe is important. As figure 2 shows, the percentage of respondents indicating that training greatly or significantly improved their ability to conduct surveillance of emerging infections was even higher than for testing and consultation. Participant evaluations of recent courses offered in collaboration with APHL were generally consistent with our survey results. These evaluations indicated that the courses provided information the participants needed on the most current technologies available. However, about 11 percent of our survey respondents did not believe that the training they received appreciably improved their surveillance ability.[23]

Although state officials generally valued the training CDC provides, they also said more training is needed, especially hands-on, skill-based training in new laboratory techniques. Laboratory officials in particular said that the use of distance learning through audio- or video-conferences—as opposed to hands-on workshops in CDC laboratories—diminished opportunities to develop close collaboration between state and CDC laboratory staff. According to CDC officials, the use of distance learning became desirable when downsizing of staff in state public health

[23]The officials who considered the benefits from training moderate consisted of 29 percent of responding laboratory directors and 19 percent of epidemiologists. The 11 percent who felt the benefits were minimal represented 15 percent of responding epidemiologists and 6 percent of laboratory directors.

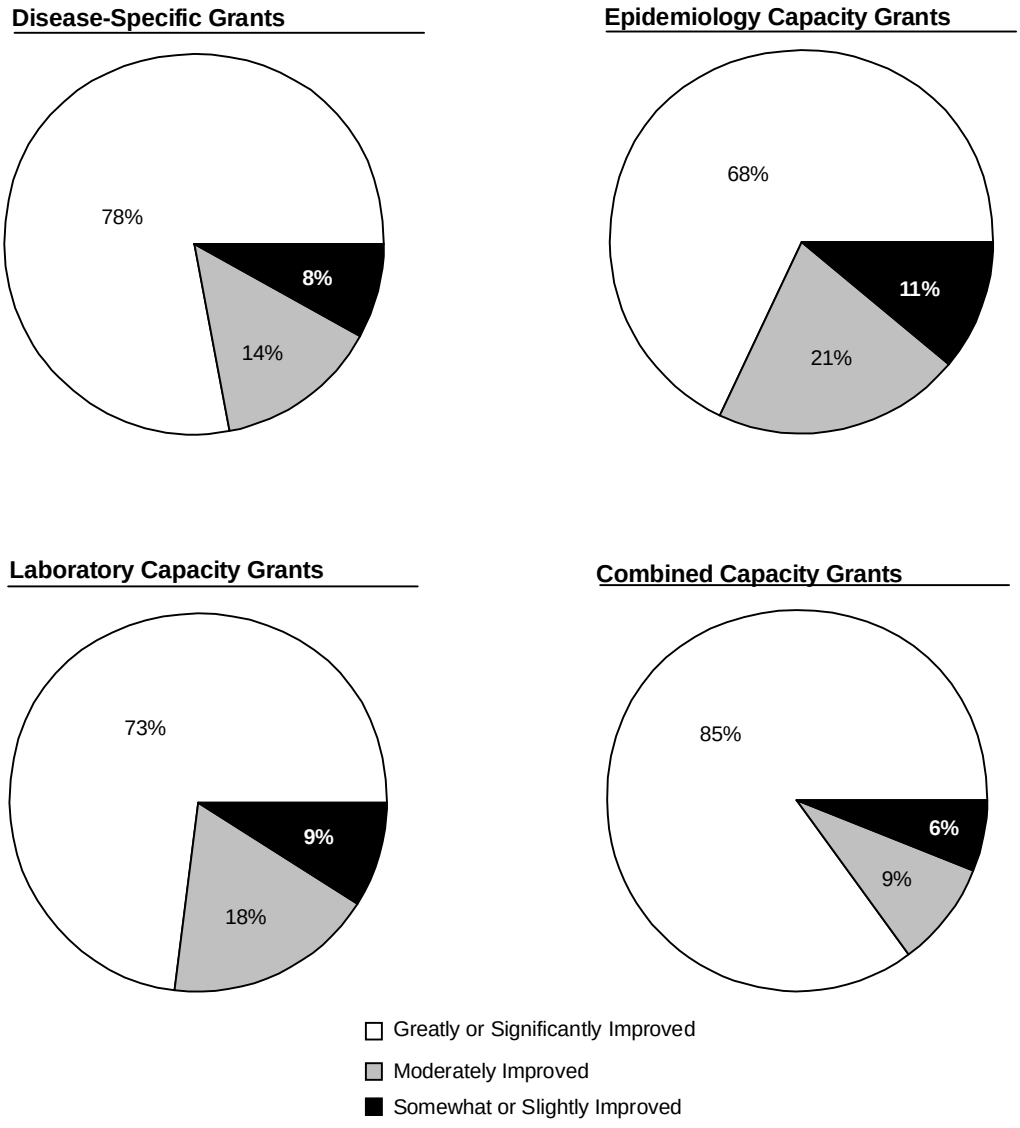
laboratories and the costs of sending staff to Atlanta led to declining attendance at courses at CDC headquarters. State officials also cited a need for training and technical assistance in information-sharing systems.

Most Respondents See Substantial Value in Grant Assistance Programs

Most state officials responding to our survey reported that funding through CDC's disease-specific grants and epidemiology and laboratory capacity grants had made great or significant improvements in their ability to conduct surveillance for emerging infectious diseases (see fig. 3).[24] Over 70 percent of responding laboratory directors and 80 percent of responding epidemiologists—comprising more than three-quarters of all survey respondents—said disease-specific funding had greatly or significantly enhanced their state's capacity to conduct infectious diseases surveillance. With one exception, epidemiology, laboratory, and combined capacity grants were similarly valued, with at least 68 percent of recipients saying the enhancement was great or significant. Laboratory directors reported benefitting more from grants specifically directed to laboratory or combined laboratory and epidemiology capacity than from grants specifically designed to enhance epidemiology capacity.

[24]More states received disease-specific grant funding than epidemiology, laboratory, or combined capacity building grants.

Figure 3: Views of State Laboratory Directors and Epidemiologists on Extent CDC's Funding Assistance Improved Efforts to Use Laboratory Data in Emerging Infectious Diseases Surveillance



Note: Sixty-five officials provided views on disease-specific grants, 28 provided views on epidemiology capacity grants, 34 on laboratory capacity, and 33 on combined capacity.

Officials cited several examples in which CDC assistance was instrumental in helping states improve their surveillance and laboratory testing efforts for high-priority conditions, such as antibiotic-resistant diseases.

- After state laboratories began receiving funds from CDC's tuberculosis grant program, they markedly improved their ability to rapidly identify the disease and indicate which, if any, antibiotics could be used effectively in treatment. State laboratory officials attributed this improvement to the funding and training they received from CDC.
- In addition to supporting such core activities as active surveillance of antibiotic-resistant conditions, four states use EIP funds to conduct active surveillance of unexplained deaths and severe illnesses in previously healthy people under age 50—a potentially critical source of information to detect new or newly emerging diseases. This project will also provide information on known infectious diseases that health care professionals are not recognizing in their patients. The epidemiologist in one of these states said that although reporting of such cases had been required for a long time, efforts to improve the completeness of the reporting and analyze the data began only after the state received CDC funds.

Our survey provided one other possible indication of the effect of CDC's assistance on state surveillance and testing for antibiotic-resistant conditions. In comparison to its funding for tuberculosis, which goes to programs in all states and selected localities, CDC funds active surveillance and testing for penicillin-resistant *S. pneumoniae* in only eight states. This pattern of funding parallels the pattern of testing reported by our survey respondents. Of the 54 states that reported conducting surveillance for tuberculosis, 49 have laboratories that test for antibiotic-resistance. In contrast, of the 37 states that reported conducting surveillance for penicillin-resistant *S. pneumoniae*, only about half have laboratories that provide testing support. Moreover, while all but one of the states require health care providers to submit tuberculosis reports to public health officials, fewer than half require reporting of penicillin-resistant *S. pneumoniae*.[25]

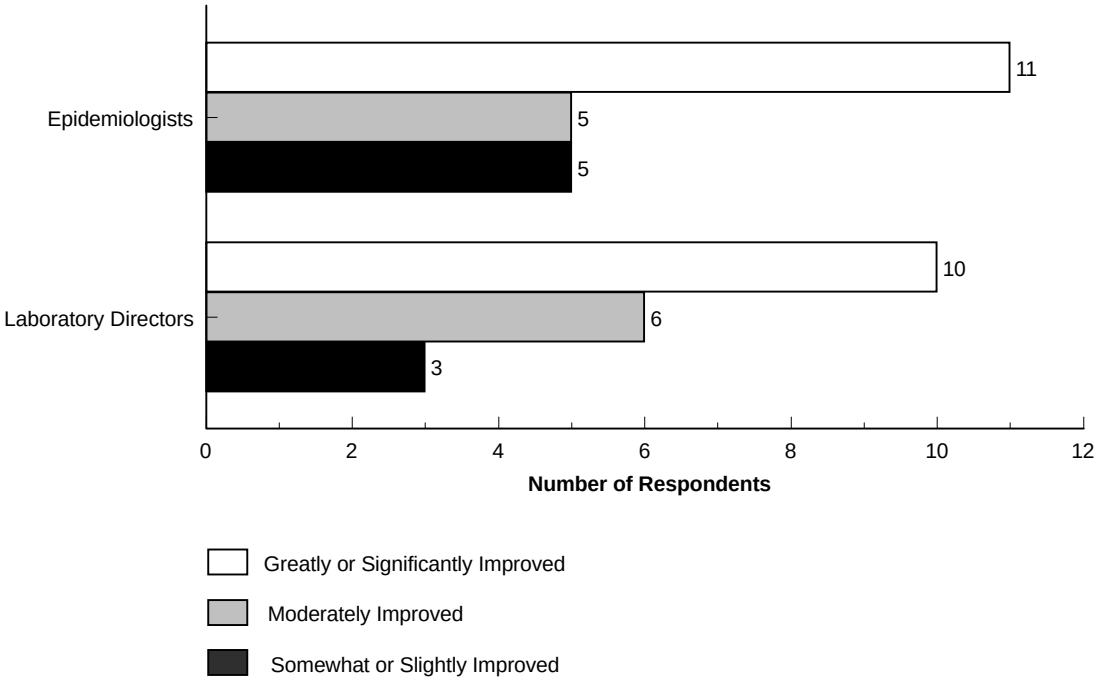
Regional Laboratory Networks Seen as Valuable, but Fewer Than Half of States Use Them

Although CDC-sponsored regional laboratory networks are intended to expand states' access to advanced testing services, our survey responses indicate that only about half of the states have used these laboratories during the past 3 years. Among those state officials who did use the networks, views on their usefulness are generally favorable, although

[25]In the 55 states where epidemiologists responded to our survey regarding their surveillance programs for the conditions we asked about, only 54 laboratory directors provided complete information on their testing to support state surveillance.

networks were not valued as highly as other types of assistance (see fig. 4). Of the 19 laboratory directors who used the services of regional laboratories, 10 reported great improvement in their surveillance capacity as a result, 6 reported moderate improvement, and the remaining 3 said improvement was minimal. Of the 21 epidemiologists who used regional laboratory services, 11 reported the services made great improvement, 5 said the improvement was moderate, and 5 said the improvement was slight.

Figure 4: Views of State Laboratory Directors and Epidemiologists on Extent CDC's Regional Laboratories Improved Emerging Infectious Diseases Surveillance Ability



Note: Officials are from 29 states.

Mixed Views on Staffing Assistance

Almost two-thirds of the 33 epidemiologists and about half of the 13 laboratory directors who had hosted CDC field placements reported that their staff had greatly or significantly improved their program's capacity to conduct surveillance. State officials we spoke with generally highly praised field placement programs because participants—who might

continue their careers in federal or state government—gained hands-on experience working in state programs. An epidemiologist commented that these placements, which spanned most of the past 20 years, had been invaluable as they provided staff to supplement his state's surveillance program. One state official, however, said that the benefits of such placements are limited because it takes almost 2 years of training for new staff to effectively assist in state programs.

Information-Sharing Systems Seen as Area Needing Considerable Improvement

According to officials who spoke with us, CDC's information-sharing systems have limited flexibility for adapting to state program needs—one reason many states have developed their own information management systems to capture more or different data, they said. State and federal officials told us that NETSS and PHLIS often cannot share data for reporting or analysis with each other or with state- or other CDC-developed systems. CDC officials responsible for these programs said that the most recent versions can share data more readily with other systems but that the lack of training in how to use the programs and high staff turnover at state agencies may limit the number of state staff and officials able to use the full range of program capabilities.

NETSS supports the collection and management of information such as patient demographics and residence, the suspected or confirmed diagnosis, and the date of disease onset. PHLIS contains more definitive information on the pathogen provided by the laboratory test. Both programs also offer optional disease-specific reporting modules states may use to gather additional data. When epidemiologists cannot electronically merge data from different sources, they must manually match the records to analyze disease trends and determine the relevant risk factors needed for effective prevention and control efforts. Sharing data between systems also identifies multiple records on the same case and can help epidemiologists take steps to improve reporting.

Epidemiologists responding to our survey rated NETSS more highly for flexibility and overall helpfulness than laboratory directors rated PHLIS. About half (48 percent) of responding epidemiologists said NETSS was highly flexible for meeting their needs while only one-quarter (27 percent) of laboratory directors said the same for PHLIS.[26] Fifty-eight percent of epidemiologists said NETSS greatly helped them conduct surveillance, while 22 percent said it was moderately helpful and the remaining 20 percent said it was minimally helpful. In contrast, 76 percent of laboratory

[26]Twenty-four percent of epidemiologists said NETSS was not very flexible, while 57 percent of laboratory directors said PHLIS had little flexibility. The remaining 28 percent of epidemiologists and 16 percent of laboratory directors said the programs were moderately flexible.

directors said PHLIS was of little help, 13 percent said it was very helpful, and 11 percent said it was moderately helpful.

Many epidemiologists and laboratory directors thought the system they use does not share data well with other systems. About two-thirds of the laboratory directors who use PHLIS and one-quarter of the epidemiologists who use NETSS said the systems have little to no ability to share data. Many officials we spoke with complained about a substantial drain on scarce staff time to enter and reconcile data into multiple systems, such as their own system plus one or more CDC-developed systems. One large local health department has one person working full time to enter and reconcile data for a single disease.

As some of CDC's disease-specific electronic reporting and information management systems become outdated and need to be replaced, CDC has responded to state and local requests for greater integration of reporting systems and for flexibility in the use of grant funds to build information systems. In late 1995, CDC established the Health Information and Surveillance System (HISS) Board to formulate and enact policy for integrating public health information and surveillance systems. Subcommittees of the HISS Board bring together federal and state public health officials to focus on issues such as data standards and coding schemes, legislation for data security, assessing hardware and software used by states, and identifying gaps in CDC databases.[27] As of August 1998, the HISS Board or its subcommittees had identified barriers to implementing effective laboratory reporting standards and some solutions, established mechanisms to assess information needs and gaps in state and local data systems, and begun to assess ways to integrate NETSS and PHLIS.

CDC provides some training and technical assistance related to NETSS and PHLIS, although state officials we interviewed said such training and assistance are in short supply. Responses to our survey suggest that CDC's training for these two systems was less widely used and less highly valued than its technical assistance. Nearly all respondents used CDC's technical assistance for these two programs, while two-thirds of laboratory directors and 82 percent of epidemiologists used the training. Almost half of the

[27]Integrating data systems also requires agreement on policy issues, such as access, sharing, and confidentiality of data. Our work did not address these issues. A recent federal mandate requiring the use of uniform standards when medical records are shared electronically has begun to intensify efforts to reach these types of agreements. Section 262 of the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) provided for electronic data exchange standardization for certain administrative and financial transactions, while protecting the security and confidentiality of transmitted data. HHS, through its Data Council, is responsible for establishing data and privacy standards. CDC is a member of the Data Council.

epidemiologists and 40 percent of the laboratory directors found the technical assistance highly valuable, but less than 30 percent of either group found the training highly valuable. Staff at two local health departments told us that no training was offered to them by state or CDC staff and the wait for technical assistance could last a month or more. State and local officials appreciated the help CDC offered but said CDC had few staff or other resources devoted to helping them use these reporting systems.

CDC and the states have made progress in developing more efficient information-sharing systems through one of CDC's grant programs. The Information Network for Public Health Officials (INPHO) is designed to foster communication between public and private partners, make information more accessible, and allow for rapid and secure exchange of data. By 1997, 14 states had begun INPHO projects. Some had combined these funds with other CDC grant moneys to build statewide networks linking state and local health departments and, in some cases, private laboratories. In New York, state officials developed a network that will link all local health agencies with the state health department and over 4,500 health care facilities and diagnostic laboratories. The network provides electronic mail service and access to surveillance data collected by the state. In Washington, systems for submitting information electronically reduced passive reporting time from 35 days to 1 day and gave local authorities access to health data for analysis.[28]

In addition to funding specific projects through INPHO grants, in April 1998 CDC adopted a policy that allows states to submit proposals to use disease grant funds to build integrated information systems. As of November, no states had submitted proposals, although several indicated they planned to do so. This initiative involves no new funding but allows states to use money from existing grants in more flexible ways.

While state officials were supportive of additional CDC efforts in this area, they also recognized that progress in developing effective networks could be affected by the actions—or lack of action—of others in the surveillance network. For example, officials in some states said autonomous local health departments may elect not to adopt or link with state-developed systems, thereby continuing some level of fragmentation among data systems regardless of efforts undertaken by CDC or others.

[28]J. Davies and D. B. Jernigan, "Development and Evaluation of Electronic Laboratory-Based Reporting for Infectious Diseases Surveillance" (Atlanta, Ga.: International Conference on Emerging Infectious Diseases, 1998).

Conclusions

Public health officials agree that the importance of infectious diseases surveillance cannot be overemphasized. The nation's surveillance network is considered the first line of defense in detecting and identifying emerging infectious diseases and providing essential information for developing and assessing prevention and control efforts. Laboratories play an increasingly vital role in infectious diseases surveillance, as advances in technology continually enhance the specificity of laboratory data and give public health officials new techniques for monitoring emerging infections.

Public health officials who spoke with us said that the nation's surveillance system is essentially sound but in need of improvement. They point to outbreaks rapidly identified and contained as visible indications of the system's strength. Our survey results tend to support this view: surveillance of five of the six emerging infectious diseases we asked about is widespread among states, and surveillance of four of the six is supported by testing in state public health laboratories. Officials also view CDC's support as essential and are generally very satisfied with both the types and levels of assistance CDC provides.

However, our survey also revealed gaps in the infectious diseases surveillance network. Just over half of the state public health laboratories have access to molecular technology that many experts believe all states could use, and few states require the routine submission of specimens to their state laboratories for testing—a step urged by CDC. In addition, many state epidemiologists believe their surveillance programs do not sufficiently study all infectious diseases they consider important, including antibiotic-resistant conditions and hepatitis C.

Both laboratory directors and epidemiologists expressed concerns about the staffing and technology resources they have for surveillance and information sharing. They were particularly frustrated by the lack of integrated information systems within CDC and the lack of integrated systems linking them with other public and private surveillance partners. CDC's continued commitment to integrating its own data systems and to helping states and localities build integrated electronic data and communication systems could give state and local public health agencies vital assistance in carrying out their infectious diseases surveillance and reporting responsibilities.

The lack of a consensus definition of what constitutes an adequate infectious diseases surveillance system may contribute to some of the shortcomings in the surveillance network. For example, state public health

officials assert that they lack sufficient trained epidemiologic and laboratory staff to adequately study infectious diseases, as well as sufficient resources to take full advantage of advances in laboratory and information-sharing technology. Without agreement on the basic surveillance capabilities state and local health departments should have, however, it is difficult for policymakers to assess the adequacy of existing resources or to identify what new resources are needed to carry out state and local surveillance responsibilities. Moreover, public health officials make decisions about how to spend federal dollars to enhance state surveillance activities without such criteria to evaluate where investments are needed most.

Recommendation to the Director of CDC

To improve the nation's public health surveillance of infectious diseases and help ensure adequate public protection, we recommend that the Director of CDC lead an effort to help federal, state, and local public health officials create consensus on the core capacities needed at each level of government. The consensus should address such matters as the number and qualifications of laboratory and epidemiologic staff, laboratory and information technology, and CDC's support of the nation's infectious diseases surveillance system.

Agency Comments

CDC officials reviewed a draft of this report. They generally concurred with our findings and recommendation and provided technical or clarifying comments, which we incorporated as appropriate. Specifically, CDC agreed that a clearer definition of the needed core epidemiologic and laboratory capacities at the federal, state, and local levels would be useful and that integrated surveillance systems are important to comprehensive prevention programs. CDC noted that it is working with other HHS agencies to address these critical areas.

We also provided the draft report to APHL and CSTE. APHL officials said the report was comprehensive and articulated the gaps in the current diseases surveillance system well. They also provided technical comments, which we incorporated as appropriate. CSTE officials did not provide comments.

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from the date of this letter. At that time, we will send copies to the Secretary of HHS, the Director of CDC, the directors of the state epidemiology programs and

public health laboratories included in our survey, and other interested parties. We will make copies available to others upon request.

If you or your staff have any questions, please contact me or Helene Toiv, Assistant Director, at (202) 512-7119. Other major contributors are included in appendix V.

Sincerely yours,

Bernice Steinhardt
Director
Health Services Quality and
Public Health Issues

Contents

Abbreviations

APHL	Association of Public Health Laboratories
CDC	Centers for Disease Control and Prevention
CSTE	Council of State and Territorial Epidemiologists
EIP	Emerging Infections Program
EIS	Epidemic Intelligence Service
ELC	Epidemiology and Laboratory Capacity Program
HHS	Department of Health and Human Services
HISS	Health Information and Surveillance System
HUS	hemolytic uremic syndrome
INPHO	Information Network for Public Health Officials
NCHSTP	National Center for HIV, Sexually Transmitted Diseases, and Tuberculosis Prevention
NCID	National Center for Infectious Diseases
NETSS	National Electronic Telecommunications System for Surveillance
PFGE	pulsed field gel electrophoresis
PHLIS	Public Health Laboratory Information System
TTP	thrombotic thromobocytopenic purpura
USDA	U.S. Department of Agriculture

Objectives, Scope, and Methodology

The Chairman of the Subcommittee on Public Health of the Senate Committee on Health, Education, Labor, and Pensions asked us to study the nation's public health surveillance of emerging infectious diseases, focusing on the contribution of laboratories. This report discusses (1) the extent to which states conduct public health surveillance and laboratory testing of selected emerging infectious diseases, (2) the problems state public health officials face in gathering and using laboratory-related data in the surveillance of emerging infectious diseases, and (3) the assistance CDC provides to states for laboratory-related surveillance and the extent to which state officials consider it valuable.

Scope of Our Study

Although laboratories are only one part of the surveillance network, they merit attention because newly developed laboratory technology is an increasingly important means to more quickly identify pathogens and the source of outbreaks. We could describe laboratories' contributions in more detail only by focusing on a small sample of diseases because the specific contribution of laboratory testing to surveillance varies with each disease. Due to the lack of a consensus definition of the types of public health laboratory testing that should occur and the lack of explicit, widely accepted standards to assess epidemiologic capacity, we were not able to assess the overall adequacy of the nation's emerging infectious diseases surveillance efforts.

We selected—with the assistance of officials from CDC, APHL, CSTE, and the American Society for Microbiology—a sample of six bacterial, viral, and parasitic pathogens that can be identified using laboratory tests and pose nationwide health threats (see table I.1). Our sample includes diseases transmitted by food and water as well as ones that had previously been controlled by the use of antibiotics and vaccines. These diseases affected up to 1.5 million people in the United States in 1996 and caused an unknown number of deaths.

Table I.1: Emerging Infectious Diseases Covered in Our Review

Disease or pathogen	Public health threat
Tuberculosis	The appearance of strains resistant to one or more commonly used antibiotics threatens U.S. efforts to control the spread of tuberculosis.
Shiga-like toxin-producing *E. coli*, including *E. coli* O157:H7	This deadly—often foodborne—group of *E. coli* first appeared in 1982. No effective treatment exists and infection can result in death or long-term disability.
Pertussis (whooping cough)	Pertussis is one of the nation's most commonly reported vaccine-preventable childhood diseases. Incidence is increasing despite high rates of immunization.
Cryptosporidium parvum (Cryptosporidiosis)	This parasite is frequently found in the nation's surface and treated water supplies and the risks of low-level exposure from its presence are unknown. The disease it causes has no effective treatment.
Hepatitis C virus	Identified only in 1988, hepatitis C is a leading cause of chronic liver disease and is the nation's most common bloodborne infection. Chronic liver disease related to hepatitis C is also the most frequent indication for liver transplantation.
Penicillin-resistant *Streptococcus pneumoniae*	*S. pneumoniae*, a leading cause of death and illness, is rapidly becoming resistant to penicillin, with resistance rates as high as 30 percent of cases in some areas.

These six emerging infectious diseases or pathogens are described in more detail in appendix IV.

Survey Development and Distribution

To gather nationwide data on state public health surveillance efforts for the sample of six emerging infections, we surveyed the directors of all state public health laboratories and infectious diseases epidemiology programs that report disease-related information directly to CDC. These include programs in each of the 50 states, the District of Columbia, New York City, and 5 U.S. territories (American Samoa, the Commonwealth of the Northern Mariana Islands, Guam, Puerto Rico, and the Virgin Islands).

To develop questions used in our surveys, we reviewed documentation on surveillance and emerging infectious diseases prepared by CDC, professional organizations representing state public health laboratorians and epidemiologists, professional laboratorians, and public health experts. We also spoke with officials and representatives from each of these groups. We worked with officials from professional organizations of public and private laboratories and CDC to judgmentally select a sample of six emerging infections with nationwide significance and to identify appropriate laboratory tests used to generate data for state public health surveillance efforts.

We pretested our surveys in person with both laboratory directors and epidemiologists in each of four states and asked knowledgeable people at

CDC and in the laboratory and public health fields to review the instruments. We refined the questionnaire in response to their comments to help ensure that potential respondents could provide the information requested and that our questions were fair, relevant, answerable with readily available information, and relatively free of design flaws that could introduce bias or error into our study results.

We mailed 57 questionnaires to laboratory directors in April 1998 and 57 questionnaires to epidemiologists in May 1998. We sent at least one follow-up mailing and conducted telephone follow-ups to nonrespondents. We ended data collection in July 1998. At that time, we had received responses from all 57 laboratory directors and from 55 epidemiologists, for response rates of 100 percent and 97 percent, respectively.

Survey Analysis

In preparing for our analysis, we reviewed and edited the completed questionnaires and checked the data for consistency. We tested the validity of the respondents' answers and comments by comparing them with data we gathered through interviews with public health experts and other public health officials in a total of 30 states and with documentation obtained at CDC and in case study states.

We combined responses from epidemiologists and laboratory directors, by state, to analyze for each of our six specific diseases the extent to which state public health laboratories supported state surveillance efforts and the views of epidemiologists and laboratory directors on the adequacy of testing equipment, staff, and the resulting surveillance information. To analyze the extent to which state public health laboratories supported state surveillance efforts, we selected only those states that met the following conditions: for each disease, (1) the state public health laboratory director indicated the laboratory performed tests that generated results used in state surveillance and (2) state epidemiologists indicated that the state conducted surveillance. Using these criteria, we analyzed responses from 54 states.

Case Study Work

We also conducted on-site work at CDC and in three states—New York, Kentucky, and Oregon. These three states were selected as a nonrandom judgmental sample representing diverse geographic areas and public health surveillance programs. In the three states, we interviewed state and local public health officials as well as other interested groups, including representatives from hospitals, large private clinical laboratories, managed

care organizations, and medical associations. At CDC, we interviewed officials responsible for infectious diseases surveillance and laboratories, information systems development, and support services for states. We interviewed officials and obtained documentation to determine how these various programs were organized and how they interacted with other public health and private parties to obtain, analyze, and share disease-related data for surveillance. In addition, we reviewed the general literature on public health surveillance and emerging infectious diseases and interviewed officials from organizations representing state public health laboratory directors, state epidemiologists, state and local public health officials, laboratory professionals, and public health experts.

Our work was conducted from December 1997 through December 1998 in accordance with generally accepted government auditing standards.

Laboratory Directors' Survey Results

U.S. General Accounting Office

Survey of State Public Health Laboratory Directors

Introduction

At the request of the U.S. Senate Labor and Human Resources Subcommittee on Public Health and Safety, the U.S. General Accounting Office is conducting a study on the role laboratories play in the surveillance of emerging infectious diseases (EID). Epidemiologic surveillance of these diseases, a grave threat to the nation's health, increasingly relies on information generated by public health and private clinical laboratories.

As part of our study, we are surveying state public health laboratory directors and state epidemiologists in all 55 states and territories, the District of Columbia, and New York City. The enclosed questionnaire for state public health laboratory directors should take about 40 minutes to complete. Most of the questions can be answered quickly and easily by checking boxes. A few questions, however, may require a little additional time to answer because you may need to consult your laboratory records.

Instructions

We realize that terms may be defined differently by different people. For the purposes of this study, please use the following definitions:

--**A state public health laboratory** is a laboratory, usually state owned or operated or both, that provides support for the state's public health programs. Its services are directed at preventing and controlling disease, improving the community's health, and offering disease assessments to the epidemiologist and disease control personnel.

--**Surveillance** is the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know.

--**Emerging infectious diseases** are infectious diseases whose incidence in humans has increased within the past two decades or threatens to increase in the near future. These can be new or previously unrecognized infectious diseases, reemerging diseases, or infectious diseases that have developed resistance to previously effective antimicrobial drugs.

This questionnaire should be completed by the person or persons most familiar with your state laboratory activities. Please provide the name, title, and telephone number of the person mainly responsible for completing the questionnaire so that we may consult with him or her if necessary.

Name of person to call: _____

Title: _____

Telephone number: ( ) _____

If you have any questions about this questionnaire, please call Cheryl Williams at (503) 235-8451 or Susan Lawes at (202) 512-6848.

Please return the completed questionnaire within 10 days of receipt. In the event the envelope is misplaced, please send your questionnaire to

Susan Lawes
U.S. General Accounting Office
HEHS/HSQ&PH
441 G Street, N.W.
Washington, D.C. 20548

The responses of the questionnaire will be incorporated in our final report and a copy will be sent to you once it is issued.

Note: ***All 57 laboratory directors returned the questionnaire; however, some did not respond to all the questions. The "N" for each question is the number of respondents who answered that question.***

Background

1. Consider all the public health laboratories operating in your state. In addition to all the state-operated public health laboratories in the state, how many cities and counties operate their own public health laboratories? ***(Enter number. If none, enter "0." If all public health laboratories are state owned or operated, check the box in number 4.)***

	Range	Median
1. Cities that operate public health laboratories (N=31)	0 - 30	1
2. Counties that operate public health laboratories (N=32)	0 - 95	4
3. Health districts that operate public health laboratories (N=23)	0 - 17	1

4. State owns or operates all public health laboratories (N =19)

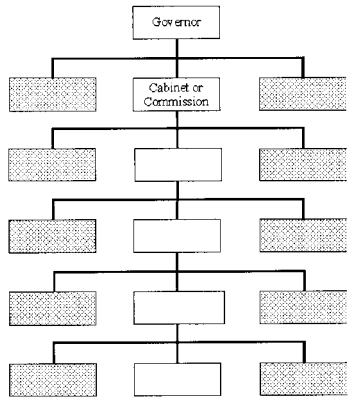
State Public Health Laboratory

2. We are interested in learning where your state public health laboratory is located in your state's governmental organization. Do you have an organizational chart that shows the level at which your state public health laboratory is located? ***(Check one)***

   1. Yes --> Please provide a copy of your organizational chart with the specific location of the laboratory indicated.

   2. No --> Pictured below are various levels of a state governmental hierarchy in descending order. Please indicate the level that most closely resembles where your state public health laboratory is located by checking the appropriate box. ***(Check the appropriate box (1-5) that represents the level closest to the location of your laboratory in your state government.)***

(N=54)



1. ☐ Level 1.
2. ☐ Level 2. (5)
3. ☐ Level 3. (29)
4. ☐ Level 4. (14)
5. ☐ Level 5. (4)
6. Other (2)

3. Do your state laws specifically state that a state public health laboratory must exist? ***(Check one)*** (N=56)

   1. 32 Yes
   2. 23 No
   3. 1 No, but special program

4. Listed below are various areas for which a state public laboratory might have testing responsibility. Indicate each area for which your state public health laboratory has testing responsibility. ***(Check all that apply)***

   1. 56 Infectious diseases
   2. 56 HIV/AIDS
   3. 55 Tuberculosis
   4. 57 Sexually transmitted diseases
   5. 50 Immunology
   6. 38 Clinical chemistry
   7. 12 Pathology
   8. 18 Occupational health and safety
   9. 29 Toxicology
   10. Environmental microbiology
       (1) 48 Water (potable)
       (2) 32 Dairy products
       (3) 46 Food and beverage
       (4) 11 Other
   11. 46 Environmental chemistry
   12. Other ***(Please specify)*** _____
       2 Hematology/Immunology
       1 Pathology
       1 Consumer
       2 Other

Computerized Systems

The following series of questions focuses on your state public health laboratory's use of computerized systems, **including e-mail, bulletin boards, or computer networks**, for both transmitting and receiving surveillance-related information.

5. Does your state public health laboratory have, in addition to any CDC systems you might use, its own internal communication system (including e-mail, bulletin boards, or computer networks) for transmitting and receiving surveillance-related information? ***(Check one)*** (N=57)

   1. 43 Yes
   2. 14 No

6. Consider all the surveillance-related information, including test results and data analysis, that you transmit to and receive from others. To what extent, if at all, does your state public health laboratory use computerized systems (including e-mail, bulletin boards, and computer networks)?

	Extent your laboratory uses computer system *(Check one for each statement)*				
	Very great extent	Great extent	Moderate extent	Some extent	Little or no extent
1. To transmit information electronically to others. (N=57)	7	5	17	16	12
2. To receive information electronically from others. (N=57)	4	3	14	14	22

7. Now consider your use of PHLIS (Public Health Laboratory Information System). To what extent, if at all, have you found the Centers for Disease Control and Prevention's (CDC) technical assistance and training for **PHLIS** helpful? ***(If you have not used CDC for technical assistance or training, check the appropriate box below.)***

	Extent CDC technical assistance and training for **PHLIS** have been helpful *(Check one for each)*				
	Very helpful	Moderately helpful	Somewhat helpful	Of little or no help	Have not used
1. CDC technical assistance (N=53)	21	12	16	4	3
2. CDC training (N=57)	11	7	12	7	19

8. How flexible, if at all, are the PHLIS modules in meeting your state program needs? ***(Check one)*** (N=56)

1. 3 Very flexible
2. 10 Generally flexible
3. 8 Moderately flexible
4. 10 Somewhat flexible
5. 18 Little or no flexibility
6. 6 Don't know
7. 1 Not Applicable

9. To what extent, if any, does PHLIS allow you to share data with another computer system, avoiding having to enter the data twice? ***(Check one)*** (N=55)

   1. __2__ Very great extent
   2. __4__ Great extent
   3. __5__ Moderate extent
   4. __7__ Some extent
   5. __32__ Little or no extent
   6. __5__ Don't know

10. CDC asks (and funds) state programs to use specific software and information management systems. Overall, how helpful, if at all, has PHLIS been to you in contributing to your state's surveillance efforts and reporting to CDC?

	Extent PHLIS has been helpful ***(Check one for each)***				
	Very helpful	Moderately helpful	Somewhat helpful	Of little or no help	Don't Know
1. Your state surveillance efforts (N=54)	6	5	16	20	7
2. Reporting to CDC (N=54)	27	11	12	2	2

Laboratory Workload

11. Listed below are various activities that laboratory staff might perform. Indicate about what proportion of your state public health laboratory's total staff time was devoted to each activity during state fiscal year (SFY) 1997. ***(Enter percentage. If none, enter "0.")***

Activity	Percentage of total staff time devoted to activity in SFY 1997	
	Range	Median
1. Laboratory testing (N=57)	25-100%	80
2. Applied research (developing or evaluating new laboratory methods) (N=57)	0-20%	5
3. Assisting with case or outbreak investigations (activities other than laboratory testing) (N=57)	0-15%	3
4. Regulation (implementing CLIA, operating exempt state programs) (N=57)	0-30%	2
5. Proficiency testing of other laboratories (N=57)	0-10%	1
6. Training and laboratory improvement programs (N=57)	0-15%	5
7. Other ***(Specify)*** _____ (N=56)	0-35%	0
Total	**100 %**	

12. About what percentage of your total staff time in SFY 1997 was devoted to testing that generates results for your state's infectious disease surveillance? (N=54)

Range	Median
8-100%	40%

Staffing

13. Consider the total staff of your state public health laboratory and the testing activities they perform. For SFY 1997, how many full-time-equivalents (FTE) in your laboratory were devoted to testing? ***(Enter number. If none, enter "0." If your laboratory's responsibilities do not include surveillance of the disease or pathogen, please check the appropriate box.)***

	Total number of FTE's in SFY 1997 [1]	
	Range	Median
1. Tuberculosis testing (N=56)	0-50	4
2. HIV/AIDS testing (N=56)	0-56	2
3. STD testing (N=56)	.50-60	4
4. Food-borne pathogen testing (N=56)	10-13	1
5. Other EID testing (N=52)	10-25	2
6. All other infectious disease testing (N=50)	0-82	6

14. During the current or past SFY, has your state public health laboratory had any staff vacancies that negatively affected the ability of your state laboratory to provide information needed for surveillance of emerging infectious diseases? ***(Check one)*** (N=57)

1. 36 Yes --> ***Continue***
2. 21 No --> ***Go to question 17***

15. In your opinion, to what extent, if any, have the vacancies hindered your state laboratory's efforts to provide information needed for surveillance of emerging infectious diseases? ***(Check one)*** (N=36)

1. 4 Significantly hindered
2. 5 Greatly hindered
3. 20 Moderately hindered
4. 7 Somewhat hindered
5. 0 No effect
6. 0 Don't know

[1]For this analysis we combined the responses of New York City and the State of New York.

16. About what proportion of all these staff vacancies is attributable to *(Enter percentage)*

		Percentage of vacancies	
		Range	Median
1.	lack of qualified applicants? (N=35)	0-100	0
2.	administrative or financial constraints, such as a hiring freeze or insufficient funding? (N=36)	0-100	75
3.	other? *(Please specify)* (N=34)	0-60	0

_____

Funding

17. For each source of funding listed below, enter the amount of funds in your state laboratory's budget for SFY 1997. *(If no funds were budgeted from the source, enter "0.")*

	Source	SFY 1997 [1]	
		Range	Median
1.	Federal (N=52)	$ 0-6,600,000	$ 666,000
2.	State appropriations (N=52)	$ 0-12,100,000	$ 2,900,000
3.	Other sources *(Please specify)* (N=52)	$ 0-14,400,000	$ 1,200,000
4.	Total budgeted funds (N=32)	$ 150,000-30,800,000	$ 5,900,000

18. Approximately what percentage of your total budgeted funds were devoted to infectious disease surveillance? (N=52)

Range	Median
5-100%	35%

Selected Emerging Infectious Diseases

The following series of questions focuses on the submission of specimens and isolates and specific types of tests that produce information useful in the surveillance of six specific EIDs: Shiga-like toxin producing *Escherichia coli,* including *E. coli* O157; tuberculosis; pertussis; drug-resistant (penicillin) streptococcal pneumonia; cryptosporidium; and hepatitis C.

19. Consider your state's policy on the collection of specimens and isolates. For each disease or pathogen listed below, indicate your state's policy for health care professionals submitting specimens or isolates.

Disease (Pathogen)	State's policy on health care professionals submitting specimens and isolates *(Check all that apply for each disease)*			
	Required to submit routinely	Asked to submit only for specific surveillance project	Neither required nor asked	Ask routinely
1. Shiga-like toxin-producing *E. coli* (N=55)	20	26	6	3
2. Tuberculosis (*Mycobacterium tuberculosis)* (N=56)	27	19	9	1
3. Pertussis (*Bordetella pertussis)* (N=55)	12	25	15	3
4. Drug-resistant (penicillin) streptococcal pneumonia (*Streptococcus pneumoniae)* (N=55)	8	19	26	2
5. Cryptosporidium (*Cryptosporidium parvum)* (N=55)	6	23	24	2
6. Hepatitis C (hepatitis C virus) (N=54)	2	9	41	2

20. Now consider the types of tests your laboratory conducts for these six diseases (pathogen). Does your state public health laboratory perform tests that generate results used in your state's surveillance of **Shiga-like toxin-producing *E. coli*?** ***(Check one)*** (N=56)

    1. 54 Yes --> Please indicate each method your laboratory uses. ***(Check all that apply)***

        1. 51 Culture using differential media
        2. 48 Agglutination tests
        3. 29 PFGE (pulsed field gel electrophoresis)
        4. 0 Phage typing
        5. 17 Other
        6. 0 Don't know

    2. 2 No

21. Does your state public health laboratory perform tests that generate results used in your state's surveillance of **tuberculosis**? ***(Check one)*** (N=56)

    1. 54 Yes --> Please indicate each method your laboratory uses. ***(Check all that apply)***

        1. 29 Direct specimen nucleic acid amplification
        2. 50 Fluorescent microscopy
        3. 52 Broth culture
        4. 49 Species ID using DNA probes or HPLC (high performance liquid chromatography) or both
        5. 50 Susceptility testings ***(indicate number of drugs)***_____
        6. 9 RFLP (restriction fragment length polymorphism)
        7. 7 Other
        8. 0 Don't know

    2. 2 No

22. Does your state public health laboratory perform tests that generate results used in your state's surveillance of **pertussis**? (N=56)

    1. 50 Yes --> Please indicate each method your laboratory uses. ***(Check all that apply)***

        1. 40 Direct flourescent antibody
        2. 45 Culture
        3. 33 Species ID using biochemical tests.
        4. 7 Serology
        5. 9 PFGE (pulsed field gel electophoresis)
        6. 7 PCR (polymerase chain reaction)
        7. 3 Other
        8. 0 Don't know

    2. 6 No

23. Does your state public health laboratory perform tests that generate results used in your state's surveillance of drug-resistant streptococcal pnuemonia? ***(Check one)*** (N=56)

    1. 28 Yes --> Please indicate each method your laboratory uses. ***(Check all that at apply)***

        1. 8 Direct detection
        2. 22 Biochemical tests
        3. 6 Quellung reaction
        4. 1 Nucleic acid probes for culture ID
        5. 19 Susceptibility testing ***(indicate number of drugs)***_____
        6. 4 Other
        7. 0 Don't know

    2. 28 No

24. Does your state public health laboratory perform tests on human specimens that generate results used in the state's surveillance of **cryptosporidium**? ***(Check One)*** (N=57)

    1. 48 Yes --> Please indicate each method your laboratory uses. ***(Check all that apply)***
        1. 45 Concertration of specimen
        2. 41 Specialized strains, such as carbol fuchsin
        3. 22 IF (immuno-flourescence)
        4. 9 EIA (enzyme immunoassay)
        5. 0 Other
        6. 0 Don't know
    2. 9 No

25. Does your state public health laboratory perform tests that generate results used in your state's surveillance of **hepatitis C**? ***(Check one)*** (N=57)

    1. 25 Yes --> Please indicate each method your laboratory uses. ***(Check all that apply)***
        1. 23 EIA antibody test
        2. 5 Immunoblot assay
        3. 3 Reverse transcriptase polymerase chain reaction (RT-PCR)
        4. 2 Other
        5. 0 Don't know
    2. 32 No

26. Does your state public health laboratory routinely conduct any of the specific tests mentioned in the preceding questions on selected emerging infectious diseases for other public or private laborarories, including laboratories in other statess? ***(Check one)*** ***(N=57)***

    1. 48 Yes --> ***Continue***
    2. 9 No ***--> Go to question 28***

27. Indicate each disease for which your laboratory conducts tests for other laboratories. ***(Check all that apply)*** (N=48)

    1. 41 Shiga-like toxin producing *E. coli*
    2. 44 Tuberculosis
    3. 37 Pertussis
    4. 22 Drug-resistant (penicillin) streptococcal pneumonia
    5. 39 Cryptosporidium
    6. 14 Hepatitis C
    7. 32 Other infectious diseases ***(Please specify)***

       _____

28. For each disease listed below, how adequate or inadequate are your state public health laboratory's equipment and staffing resources for performing the types of tests needed for your state's EID surveillance efforts? ***(If your state does not conduct surveillance for a disease or pathogen, check "no surveillance.")***

Disease (Pathogen)	Adequacy of laboratory equipment and staffing resources for testing *(Check one for each disease)*					
	Very adequate	Generally adequate	Neither adequate nor inadequate	Generally inadequate	Very inadequate	No Surveillance
1. Shiga-like toxin producing *E. coli*						
(1) equipment (N=55)	16	30	2	4	0	3
(2) staffing (N=55)	13	31	4	3	1	3
2. Tuberculosis (*Mycobacterium tuberculosis)*						
(1) equipment (N=56)	26	22	3	4	0	1
(2) staffing (N=53)	21	20	7	5	0	0
3. Pertussis (*Bordetella pertussis)*						
(1) equipment (N=55)	15	20	6	6	3	5
(2) staffing (N=54)	14	28	5	1	2	4
4. Drug-resistant (penicillin) streptococcal pneumonia (*Streptococcus pneumoniae)*						
(1) equipment (N=54)	6	15	4	3	1	25
(2) staffing (N=54)	7	14	6	2	1	24
5. Cryptosporidium--human specimens (*Cryptosporidium parvum)*						
(1) equipment (N=56)	17	24	5	1	0	9
(2) staffing (N=55)	12	26	6	2	1	8
6. Hepatitis C (hepatitis C virus)						
(1) equipment (N=54)	6	13	2	1	3	29
(2) staffing (N=54)	3	13	2	5	3	28

29. Does your state public health laboratory currently have any ongoing research **related to emerging infectious diseases** that is funded by organizations other than CDC? ***(Check one)*** (N=57)

1. 10 Yes --> Please list the titles of these ongoing research projects (list up to four titles only)
   1. _____
   2. _____
   3. _____
   4. _____
2. 47 No

Relationships With CDC and the State Health Agency

CDC

30. Listed below are various types of CDC funding that your state public health laboratory might have received. ***Indicate in***

Part A: Whether or not your state public health laboratory received each type of CDC funding during the past 3 years.

Part B: If you answered **"yes"** in **Part A**, to what extent, if any, has CDC's funding improved your laboratory's capacity for surveillance of emerging infections?

Funding	**Part A** Received funding during the past 3 years? ***(Check one)*** Yes	No		**Part B** Improved your laboratory's capacity for EID surveillance ***(Check one for each type of funding)*** Signif-icantly improved	Greatly improved	Moderately improved	Somewhat improved	Little or no improve-ment
1. Epidemiology capacity (e.g., EIP) (N=51)	16	35	**If yes->**	4	6	4	2	0
2. Laboratory capacity (e.g., Molecular Surveillance Project) (N=50)	20	30	**If yes->**	8	6	4	1	0
3. Combined capacity (e.g., ELC) (N=47)	13	34	**If yes->**	6	6	1	0	0
4. Disease specific (N=50)	38	12	**If yes->**	18	10	6	2	2
5. Other ***(Specify)*** (N=10) _____	6	4	**If yes->**	1	2	2	1	0

31. Listed below are various types of CDC assistance your state public health laboratory might have received that may or may not be associated with CDC funding. ***Indicate in***

Part A: Whether or not your state public health laboratory received each type of CDC assistance during the past 3 years.

Part B: If you answered **"yes"** in **Part A**, to what extent, if any, has CDC's assistance improved your laboratory's capacity for surveillance of emerging infections?

CDC assistance	**Part A** Received assistance during the past 3 years? ***(Check one)*** Yes	No		**Part B** Improved your laboratory's capacity for EID surveillance ***(Check one for each type of assistance)*** Signif-icantly improved	Greatly improved	Moderately improved	Somewhat improved	Little or no improve-ment
1. Advanced testing by CDC laboratories (N=54)	50	4	**If yes->**	9	18	14	4	5
2. Support for national databases of test results (N=52)	31	21	**If yes->**	3	12	5	8	3
3. Support for regional laboratory networks (N=52)	19	33	**If yes->**	5	5	6	1	2
4. New software for analysis of test results (e.g., SODA) (N=51)	5	46	**If yes->**	2	1	2	0	0
5. Consultations with skilled laboratory staff (N=55)	52	3	**If yes->**	9	19	19	4	1
6. Field placements (e.g., EIS officers) (N=50)	13	37	**If yes->**	3	4	5	1	0
7. Relevant training or experience for existing staff (N=56)	48	8	**If yes->**	12	19	14	3	0
8. Other ***(Specify)*** (N=8) _____	5	3	**If yes->**	2	2	0	1	0

32. Now consider all the assistance, including assistance related to work on emerging infectious diseases, your state public health laboratory has received from CDC during the past year. Overall, to what extent, if any, has the assistance your laboratory received from CDC during the past year had the following attributes?

Attribute	Extent to which CDC assistance had the attribute during the past year *(Check one for each attribute)*					
	Very great extent	Great extent	Moderate extent	Some extent	Little or no extent	Does not apply
1. Establishes good working environment during outbreaks because CDC field staff understand lead role of state health agency (N=55)	3	17	9	8	7	11
2. Provides opportunities to initiate more complex studies (N=54)	6	8	13	14	8	5
3. Provides new technologies or the seed money to acquire them (N=54)	8	15	10	10	7	4
4. Provides software for entering and managing data (N=54)	2	2	11	7	24	8
5. Provides new software for analysis (N=51)	1	1	2	4	23	20
6. Other *(Specify)* _____ (N=3)	0	1	0	0	0	2

State Health Agency

33. When state health agency officials develop strategies for surveillance of emerging infectious diseases, how often, if at all, do they consult laboratory staff regarding the participation of your state laboratory? *(Check one)* (N=55)

1. 21 Very often
2. 15 Often
3. 15 Sometimes
4. 4 Rarely
5. 0 Never

34. Briefly explain your response to question 33. (N=47)

_____

_____

_____

35. Now consider times when state health agency officials develop CDC grant proposals related to surveillance of emerging infectious diseases. How often, if at all, do they consult laboratory staff regarding the participation of your state laboratory? ***(Check one)*** (N=56)

    1. 17 Very often
    2. 13 Often
    3. 17 Sometimes
    4. 8 Rarely
    5. 0 Never
    6. 1 Does not apply

36. Briefly explain your response to question 35. (N=43)

    _____

    _____

    _____

37. If you have any additional comments about the role of your state public health laboratory in the surveillance of emerging infectious diseases or your working relationship with CDC, please write them in the space provided below. (N=33)

    33 respondents provided comments
    24 respondents did not provide comments

Thank you for participating in this study.

108351

Epidemiologists' Survey Results

U.S. General Accounting Office

Survey of State Public Health Epidemiologists

Introduction

At the request of the U.S. Senate Labor and Human Resources Subcommittee on Public Health and Safety, the U.S. General Accounting Office is conducting a study on the role laboratories play in the surveillance of emerging infectious diseases (EID). Epidemiologic surveillance of these diseases, which pose a grave threat to the nation's health, increasingly relies on information generated by public health and private clinical laboratories.

As part of our study, we are surveying state epidemiologists and public health laboratory directors in all 55 states and territories, the District of Columbia, and New York City. The enclosed questionnaire for state epidemiologists should take about 45 minutes to complete. Most of the questions can be answered quickly and easily by checking boxes. A few questions, however, may require a little additional time to answer because you may need to consult your epidemiology office records.

Instructions

We realize that terms may be defined differently by different people. For the purposes of this study, please use the following definitions:

-- **A state public health laboratory** is a laboratory, usually state owned or operated or both, that provides support for the state's public health programs. Its services are directed at preventing and controlling disease, improving the community's health, and offering disease assessments to the epidemiologist and disease control personnel.

-- **Surveillance** is the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know.

-- **Emerging infectious diseases** are those infectious diseases whose incidence in humans has increased within the past two decades or threatens to increase in the near future.

These can be new or previously unrecognized infectious diseases, reemerging diseases, or infectious diseases that have developed resistance to previously effective antimicrobial drugs.

This questionnaire should be completed by the person or persons most familiar with your state's emerging infectious disease surveillance and related laboratory activities. Please provide the name, title, and telephone number of the person mainly responsible for completing the questionnaire so that we may consult with him or her if necessary.

Name of person to call: _____

Title: _____

Telephone number: ( ) _____

If you have any questions about this questionnaire, please call Cheryl Williams at (503) 235-8451 or Susan Lawes at (202) 512-6848.

Please return the completed questionnaire within 10 days of receipt. In the event the envelope is misplaced, please send your questionnaire to

Susan Lawes
U.S. General Accounting Office
HEHS/HSQ&PH
441 G Street, N.W.
Washington, D.C. 20548

The responses of the questionnaire will be incorporated in our final report and a copy will be sent to you once it is issued. Thank you for your help.

55 epidemiologists returned the questionnaire; however, some did not respond to all the questions. The "N" for each question is the number of respondents who answered that question.

Infectious Disease Unit Background

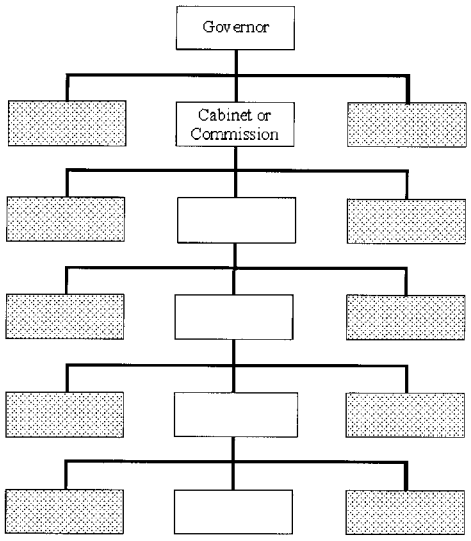
1. We are interested in learning where your state infectious disease epidemiologist is located in your state's governmental organization. Do you have an organizational chart that shows the level at which your state infectious disease epidemiologist is located? ***(Check one)***

   1. Yes --> Please provide a copy of your organizational chart with the specific location of the epidemiologist indicated.

   2. No --> Pictured below are various levels of a state governmental hierarchy in descending order. Please indicate the level that most closely resembles where your state infectious disease epidemiologist is located by checking the appropriate box. ***(Check the appropriate box (1-5) that represents the level closest to the location of the state epidemiologist in your state government.)***

(N=48)

1. ☐ Level 1. (3)
2. ☐ Level 2. (22)
3. ☐ Level 3. (17)
4. ☐ Level 4. (6)
5. ☐ Level 5.



2. Listed below are various areas for which a state infectious disease epidemiology unit may have surveillance responsibility. Indicate whether your state infectious disease epidemiology unit or another unit in your state has surveillance responsibility for each area. ***(If your state does not conduct surveillance of an area, please check the appropriate column.)***
(N=55)

Area	Unit with responsibility for surveillance *(Check all that apply for each area)*		
	Your state infectious disease epidemiology unit	Another unit in the state	State does not conduct surveillance in this area
1. HIV/AIDS	39	20	0
2. Tuberculosis	40	18	0
3. Sexually transmitted diseases (STD)	39	19	0
4. Vaccine preventable diseases	47	12	0
5. Other infectious diseases	54	3	0
6. Environmental health	17	39	2
7. Food safety and handling	10	44	3
8. Accidents and preventable injuries	12	41	3
9. Occupational health and safety	8	37	11
10. Chronic diseases	16	40	2
11. Other *(Specify)*_____	6	6	0

Computerized Systems

The following series of questions focuses on your state infectious disease unit's use of computerized systems, **including e-mail, bulletin boards, or computer networks**, for both transmitting and receiving surveillance-related information.

3. Listed below are two CDC reporting systems that you might use to collect, transmit, and receive data needed for public health surveillance. How helpful, if at all, have you found CDC's technical assistance and training for each reporting system? ***(If you do not use the system, check the appropriate box below.)***

CDC system	Extent technical assistance and training have been helpful *(Check one for each system)*				
	Very helpful	Moderately helpful	Somewhat helpful	Of little or no help	Don't use
1. **PHLIS** (Public Health Laboratory Information System) (1) CDC technical assistance (N=53)	9	11	12	1	20
(2) CDC training (N=51)	5	10	9	5	22
2. **NETSS** (National Electronic Telecommunications System for Surveillance) (1) CDC technical assistance (N=55)	24	22	6	0	3
(2) CDC training (N=55)	12	19	9	5	10

4. For each CDC reporting system listed below, how flexible, if at all, were its modules in meeting your state program needs? ***(If you do not use the system, check the appropriate box below.)***

CDC system	Flexibility of the system's modules in meeting your state program needs *(Check one for each system)*					
	Very flexible	Generally flexible	Moderately flexible	Somewhat flexible	Little or no flexibility	Don't use
1. PHLIS (N=52)	2	4	5	11	10	20
2. NETSS (N=55)	12	12	14	9	3	5

5. To what extent, if any, does each CDC reporting system listed below allow you to share data with another computer system you use so you avoid entering the data twice? ***(If you do not use the system, check the appropriate box below.)***

CDC system	Extent system allows sharing of data with another system *(Check one for each system)*					
	Very great extent	Great extent	Moderate extent	Some extent	Little or no extent	Don't use
1. PHLIS (N=52)	1	5	3	8	20	15
2. NETSS (N=55)	3	15	9	10	13	5

6. Overall, how helpful, if at all, has each CDC reporting system listed below been to you in conducting your state's surveillance efforts? ***(If you do not use the system, check the appropriate box below.)***

CDC system	Extent CDC system has been helpful *(Check one for each system)*					
	Very helpful	Moderately helpful	Somewhat helpful	Of little or no help	Don't know	Don't use
1. PHLIS (N=52)	4	8	10	15	2	13
2. NETSS (N=55)	29	11	6	4	0	5

7. Consider all the surveillance-related information, including test results and data analysis, that you transmit to and receive from others. To what extent, if at all, do you use computerized systems (including e-mail, bulletin boards, and networks)?

	Extent you use computer systems *(Check one for each statement)*				
	Very great extent	Great extent	Moderate extent	Some extent	Little or no extent
1. To transmit information electronically to others. (N=55)	18	16	9	10	2
2. To receive information electronically from others. (N=55)	13	10	16	10	6

Required Reporting

8. Are any health professionals (hospitals, physicians, laboratories) required by state law or regulation to send disease reports or information to your state infectious disease epidemiology office, either directly or through local health departments? *(Check one)* (N=55)

   1. 55 Yes --> ***Continue***

   2. 0 No --> ***Go to question 12***

9. During the past 5 years, has your state studied or taken any actions to improve the submission of required information by health care providers and professionals? *(Check one)* (N=55)

   1. 50 Yes --> ***Continue***

   2. 5 No --> ***Go to question 11***

10. Listed below are various barriers that explain why health care providers and professionals, such as laboratories and physicians, may not provide required information. Indicate which barriers, if any, your state has identified or addressed. *(Check all that apply)* (N=50)

    1. 44 Health care providers and professionals don't understand the need for disease information to monitor public health.

    2. 47 Health care providers and professionals do not fully understand their reporting obligations.

    3. 46 Health care providers and professionals believe someone else, such as the testing laboratory, will do it.

    4. 37 Health care providers and professionals are concerned about confidentiality of patient information.

    5. 18 Health care providers and professionals receive no reimbursement for reporting.

    6. 29 Health care providers and professionals do not routinely request laboratory confirmation of diagnosis.

    7. 14 Reporting forms are complicated, confusing, or not available.

    8. 15 Facsimile (fax) or twenty-four-hour telephone reporting is not available either at the state epidemiology office or local health departments.

    9. 26 The available computerized system links for reporting to the state epidemiology office or local health departments are too few or inadequate.

    10. 13 Other *(Please specify)*_____

11. In recent studies, some public health officials have stated that managed care and hospital and laboratory consolidation have affected the generation and submission of required information. Has any agency in your state evaluated the effect of each on the extent to which health providers and professionals, such as physicians and laboratories, generate and submit information specified in your state reporting requirements?

	Any agency in your state evaluated the effect? *(Check one for each)*			
	Yes	No	Don't know	Does not apply
1. Managed care				
(1) generate information (N=53)	3	38	9	3
(2) submit information (N=50)	5	37	6	2
2. Hospital consolidation				
(1) generate information (N=53)	0	43	7	3
(2) submit information (N=50)	0	41	6	3
3. Laboratory consolidation				
(1) generate information (N=54)	5	37	9	3
(2) submit information (N=49)	7	31	8	3
4. Other *(Specify)* _____				
(1) generate information (N=14)	0	9	3	2
(2) submit information (N=12)	0	8	3	1

Staffing for the infectious disease unit

12. Now consider the total number of staff in your state infectious disease programs. For each program listed below, indicate the number of full-time-equivalents (FTE) devoted to it during state fiscal year (SFY) 1997. ***(Enter number. If none, enter "0.")***

		Total FTE's devoted to program in SFY 1997[1]	
		Range	Median
1. Tuberculosis program	N=54	0-788	5.2
2. HIV/AIDS program	N=53	0-432	12
3. STD program	N=54	0-337	9.5
4. Foodborne pathogen program	N=54	0- 39	.25
5. Other EID programs	N=53	0- 39	1
6. All other infectious diseases programs	N=54	0-713	7.1

13. Of all the staff in your infectious disease programs, about what percentage of their time was devoted to surveillance in SFY 1997?[1] (N=51)

Range	Median
0-75%	25 %

[1]For this analysis we combined the responses of New York City and the State of New York.

Funding for the infectious disease unit

14. Consider the total funding you receive for your infectious disease programs, including funds you pass on to local health departments. For each program listed below, indicate the amount budgeted for it during SFY 1997. ***(Enter number. If none, enter "0.")***

		Funds budgeted [1]	
		Range	Median
1. Tuberculosis program	(N=54)	$ 0-53,596,000	$ 898,735
2. HIV/AIDS program	(N=54)	$ 0-185,258,000	$ 3,338,117
3. STD program	(N=54)	$ 0-16,226,000	$ 898,060
4. Foodborne pathogen program	(N=54)	$ 0-3,293,086	$ 0
5. Other EID program	(N=54)	$ 0-3,293,086	$ 142,605
6. All other infectious disease programs	(N=54)	$ 0-43,500,000	$ 730,250

15. Approximately what percentage of your SFY 1997 total budgeted funds for infectious disease programs was devoted to surveillance? [1] (N=50)

Range	Median
0-80%	10%

16. Did your SFY 1997 budget for infectious diseases include amounts for the operation of your state public health laboratory? ***(Check one)***[1] (N=51)

1. 26 Yes --> About what percentage of your budget funding was allocated to the state laboratory? [1]
   (N=23) % Range 1-50% Median 7%
2. 25 No

Emerging Infectious Diseases Surveillance

The following series of questions focuses on your surveillance of infectious diseases that you believe may be emerging disease threats. The questions begin with general information about your surveillance.

General Information

17. Does your state conduct surveillance for any of the following? ***(Check all that apply)*** (N=55)

1. 50 Any cluster of illnesses
2. 45 Any unusual case
3. 21 Any unexplained deaths
4. 4 None of the above

18. Are there types of EID surveillance that your state currently does not conduct but that you think it should? ***(Check one)*** (N=54)

    1. 44 Yes --> Please specify _____

    2. 10 No --> ***Go to question 20***

19. Please describe below why your state is not conducting surveillance of conditions you think it should be. (N=43)

    _____

    _____

    _____

20. Consider all the EID surveillance you conduct. To what extent, if at all, does your surveillance for EIDs use laboratory-generated data, such as test results and analysis? ***(Check one)*** (N=55)

    1. 31 Very great extent

    2. 14 Great extent

    3. 4 Moderate extent

    4. 4 Some extent

    5. 2 Little or no extent

21. Do you currently have any ongoing research **related to EIDs** that is funded by sources other than CDC? ***(Check one)*** (N=55)

    1. 14 Yes --> Please list the titles of these ongoing research projects (list up to four titles only)
       1. _____
       2. _____
       3. _____
       4. _____

    2. 41 No

Surveillance of Selected Emerging Infectious Diseases

The following series of questions focuses on the submission of disease reports or other disease-related information for six specific EIDs--Shiga-like toxin-producing *E. coli,* including *E. coli* O157; tuberculosis; pertussis; drug-resistant (penicillin) streptococcal pneumonia; cryptosporidium; and hepatitis C--and on specific sources of laboratory information useful in the surveillance of each.

22. Consider your state's policy on the submission of reports and information to the state infectious disease epidemiology unit. For each disease or pathogen listed below, indicate your state's policy for health care professionals submitting reports and information, either directly or through local health departments.

Disease (Pathogen)		State's policy on health care professionals submitting reports and information *(Check all that apply for each disease)*		
		Required to submit routinely	Asked to submit only for specific surveillance project	Neither required nor asked
1. Shiga-like toxin-producing *E. coli*	(N=53)	46	3	3
32. Tuberculosis (*Mycobacterium tuberculosis)*	(N=55)	54	0	1
13. Pertussis (*Bordetella pertussis)*	(N=54)	52	1	1
4. Drug-resistant (penicillin) streptococcal pneumonia (*Streptococcus pneumoniae)*	(N=53)	26	12	15
5. Cryptosporidium (*Cryptosporidium parvum)*	(N=54)	43	3	7
6. Hepatitis C (hepatitis C virus)	(N=54)	47	3	4

23. Listed below are various sources of laboratory data that might provide you with data for your surveillance of emerging infectious diseases. How important, if at all, is each source to your surveillance of **Shiga-like toxin-producing *E. coli*?**

_1_ ***Check this box if your state does not conduct surveillance for Shiga-like toxin-producing E coli.***

(N=54) Source	Importance of source of data for surveillance of **Shiga-like toxin-producing *E. coli* (Check one for each source)**				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	40	11	1	0	1
2. Local health departments or laboratories	15	11	6	2	11
3. Hospital laboratory	29	23	1	1	0
4. Private laboratory (e.g., independent or commercial)	27	15	11	0	0
5. CDC laboratory	10	10	10	11	12
6. Other *(Specify)* _____	2	0	0	0	2

24. How important, if at all, is each source to your surveillance of **tuberculosis** *(Mycobacterium tuberculosis)*?

__0__ ***Check this box if your state does not conduct surveillance for tuberculosis.***

(N=55)

Source	Importance of source of data for surveillance of **tuberculosis** *(Check one for each source)*				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	51	1	1	1	0
2. Local health departments or laboratories	26	4	5	1	11
3. Hospital laboratory	31	16	6	2	0
4. Private laboratory (e.g., independent or commercial)	28	14	9	3	1
5. CDC laboratory	13	11	7	8	15
6. Other ***(Specify)*** _____	2	4	1	1	2

25. How important, if at all, is each source to your surveillance of **pertussis** *(Bordetella pertussis)*?

__1__ ***Check this box if your state does not conduct surveillance for pertussis.***

(N=54)

Source	Importance of source of data for surveillance of **pertussis** *(Check one for each source)*				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	39	6	4	1	3
2. Local health departments or laboratories	20	9	4	3	12
3. Hospital laboratory	25	18	7	3	1
4. Private laboratory (e.g., independent or commercial)	25	16	9	4	0
5. CDC laboratory	8	7	6	9	21
6. Other ***(Specify)*** _____	0	0	1	0	2

26. How important, if at all, is each source to your surveillance of **drug-resistant** *(penicillin)* **streptococcal pneumonia** *(Streptococcus pneumoniae)*?

18 ***Check this box if your state does not conduct surveillance for drug-resistant streptococcal pneumonia.***

(N=37)

Source	Importance of source of data for surveillance of **drug-resistant streptococcal pneumonia** *(Check one for each source)*				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	11	1	11	3	11
2. Local health departments or laboratories	6	3	1	2	19
3. Hospital laboratory	30	6	1	0	0
4. Private laboratory (e.g., independent or commercial)	23	9	2	3	0
5. CDC laboratory	4	2	5	2	23
6. Other *(Specify)* _____	2	1	0	0	1

27. How important, if at all, is each source to your surveillance of human specimens for **cryptosporidium** *(Cryptosporidium parvum)*?

9 ***Check this box if your state does not conduct surveillance for cryptosporidium.***

(N=46)

Source	Importance of source of data for surveillance of cryptosporidium *(Check one for each source)*				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	23	14	3	1	4
2. Local health departments or laboratories	9	6	4	5	16
3. Hospital laboratory	27	11	5	2	1
4. Private laboratory (e.g., independent or commercial)	25	13	6	2	0
5. CDC laboratory	5	2	4	8	26
6. Other *(Specify)* _____	0	0	0	0	2

28. How important, if at all, is each source to your surveillance of **hepatitis C** *(hepatitis C virus)*?

3 ***Check this box if your state does not conduct surveillance for hepatitis C.***

(N=52) Source	Importance of source of data for surveillance of **hepatitis C** *(Check one for each source)*				
	Essential	Very important	Moderately important	Somewhat important	Of little or no importance
1. My state public health laboratory	6	4	3	4	30
2. Local health departments or laboratories	9	4	3	5	22
3. Hospital laboratory	28	15	4	1	3
4. Private laboratory (e.g., independent or commercial)	31	15	4	0	2
5. CDC laboratory	5	0	2	8	22
6. Other *(Specify)* _____	2	3	1	3	3

29. In your opinion, how adequate or inadequate is your state public health laboratory for generating the types of data you need for your surveillance for each disease listed below?

Disease (Pathogen)	Adequacy of your state public health laboratory in generating data you need for surveillance *(Check one for each disease or pathogen)*						
	Very adequate	Generally adequate	Neither adequate or inadequate	Generally inadequate	Very inadequate	Don't know	Does not apply
1. Shiga-like toxin producing *E. coli* (N=54)	27	14	4	4	1	0	4
2. Tuberculosis (*Mycobacterium tuberculosis)* (N=55)	38	13	0	1	0	0	3
3. Pertussis (*Bordetella pertussis*) (N=54)	27	13	5	1	2	1	5
4. Drug-resistant (penicillin) streptococcal pneumonia (*Streptococcus pneumoniae*) (N=55)	8	4	7	9	8	0	19
5. Cryptosporidium (*Cryptosporidium parvum)* (N=55)	18	15	5	3	4	1	9
6. Hepatitis C (hepatitis C virus) (N=55)	5	7	3	2	15	1	22

Relationships with CDC and the State Public Health Laboratory

30. Listed below are various types of CDC funding that your state health department or state public health laboratory might have received. ***Indicate in***

Part A: Whether or not your state health department or public health laboratory received each type of CDC funding during the past 3 years.

Part B: If you answered **"yes"** in **Part A**, to what extent, if any, has CDC's funding improved your efforts in using laboratory data to conduct surveillance of emerging infections.

Funding	**Part A** Received funding during the past 3 years? ***(Check one)***			**Part B** Improved your efforts in using laboratory data in EID surveillance ***(Check one for each type of funding)***				
	Yes	No		Signif-icantly improved	Greatly improved	Moderately improved	Somewhat improved	Little or no im-provement
1. Epidemiology capacity (e.g., EIP) (N=51)	12	39	**If yes->**	7	2	2	1	0
2. Laboratory capacity (e.g., Molecular Surveillance Project) (N=51)	16	35	**If yes->**	8	3	2	2	0
3. Combined capacity (e.g., ELC) (N=53)	20	33	**If yes->**	11	5	2	1	1
4. Disease specific (N=48)	28	20	**If yes->**	14	9	3	1	0
5. Other ***(Specify)*** _____ (N=15)	4	11	**If yes->**	1	2	0	0	1

31. Listed below are various types of CDC assistance your state health department or state public health laboratory might have received that may or may not be associated with CDC funding. ***Indicate in***

Part A: Whether or not your state health department or public health laboratory received each type of CDC assistance during the past 3 years.

Part B: If you answered **"yes"** in **Part A**, to what extent, if any, has CDC's assistance improved your efforts in using laboratory data to conduct surveillance of emerging infections.

CDC assistance	**Part A** Received assistance during the past 3 years? *(Check one)* Yes	No		**Part B** Improved your efforts in using laboratory data in EID surveillance *(Check one for each type of assistance)* Signif-icantly improved	Greatly improved	Moderately improved	Somewhat improved	Little or no im-provement
1. Advanced testing by CDC laboratories (N=55)	49	6	If yes->	15	14	13	4	2
2. Support for national databases of test result (N=52)	17	35	If yes->	2	6	8	1	0
3. Support for regional laboratory networks (N=53)	21	32	If yes->	5	6	5	4	1
4. New software for analysis of test results (e.g., SODA) (N=50)	8	42	If yes->	0	1	4	2	1
5. Consultations with skilled laboratory staff (N=55)	50	5	If yes->	13	19	13	0	2
6. Field placements (e.g., EIS officers) (N=54)	33	21	If yes->	12	9	4	4	4
7. Relevant training or experience for existing staff (N=54)	48	6	If yes->	9	22	9	4	3
8. Other *(Specify)* _____ (N=7)	3	4	If yes->	1	2	0	0	0

32. Now consider your experiences in working with CDC during the past year. To what extent, if any, would each of the following statements describe those experiences?

Statement	Extent statement describes your experiences during the past year *(Check one for each statement)*					
	Very great extent	Great extent	Moderate extent	Some extent	Little or no extent	Does not apply
1. Staff with relevant knowledge are easy to locate (N=55)	17	23	10	5	0	0
2. Programmatic boundaries in CDC are easily crossed for issues that involve more than one Center (N=54)	5	8	15	13	10	3
3. Other *(Specify)* _____ (N=7)	4	0	1	0	0	2

33. When you develop strategies for surveillance of emerging infectious diseases, how often, if at all, do you consult state public health laboratory staff regarding the participation of the state laboratory? *(Check one)* (N=55)

1. 49 Very often
2. 3 Often
3. 1 Sometimes
4. 2 Rarely
5. 0 Never

34. Briefly explain your response to question 33. (N=49)

35. Now consider times when you develop CDC grant proposals related to surveillance of emerging infectious diseases. How often, if at all, do you consult state public health laboratory staff regarding the participation of the state laboratory? ***(Check one)*** (N=55)

    1. 46 Very often
    2. 4 Often
    3. 1 Sometimes
    4. 0 Rarely
    5. 1 Never
    6. 3 Does not apply

36. Briefly explain your response to question 35. (N=46)

37. If you have any additional comments about the role of your state epidemiology office or state public health laboratory in the surveillance of emerging infectious diseases or your working relationship with CDC, please write them in the space provided below. (N=24)

    24 respondents provided comments
    31 respondents did not provide comments

Thank you for participating in this study.

108351

Six Emerging Infectious Diseases

Given the multitude of infectious diseases and varying state surveillance programs, we consulted experts to select a sample of emerging disease threats of nationwide significance. These six conditions are described in greater detail below.

Shiga-Like Toxin-Producing *E. Coli*, Including *E. Coli* O157:H7

The Pathogen and Disease

E. coli are normal bacterial inhabitants of the intestines of most animals, including humans, where they suppress the growth of harmful bacteria and synthesize vitamins. For reasons not completely understood, a minority of strains cause illness in humans. Shiga-like toxin-producing *E. coli* are one of five recognized classes of *E. coli* that cause gastroenteritis in humans. The group derives its name from producing potent toxins, closely related to those produced by *Shigella dysenteriae*, which cause severe damage to the lining of the intestine. *E. coli* O157:H7, first identified as a human pathogen in 1982, causes severe abdominal cramping and diarrhea that can become heavily bloody. Although people usually get well without treatment, the illness can be fatal.

E. coli O157:H7 is easily killed by heat used in pasteurization and cooking. However, it can live in acid environments. The amount of bacteria needed to cause illness is thought to be low.

Complications

Three to 5 percent of victims develop hemolytic uremic syndrome (HUS), which is characterized by kidney failure and anemia. Some elderly victims develop thrombotic thromobocytopenic purpura (TTP), consisting of HUS plus fever and neurologic symptoms. Approximately 1 percent of HUS victims die, though many more develop long-term complications. Death rates from TTP can be as high as 50 percent.

Transmission

The disease is often associated with consumption of undercooked ground beef, but sources of contamination are diverse. Recent outbreaks of *E. coli* O157:H7 have been linked to consumption of contaminated apple juice and

cider, raw vegetables such as lettuce, raw milk, and processed foods such as salami. Illness can also be caused by ingesting contaminated water at recreational sites such as swimming pools or spread from child to child in day care settings.

Costs and Prevalence

For *E. coli* O157:H7, the estimated annual cost in the United States from the acute and long-term effects of illness and from lost productivity is $302 to $726 million, most of which is due to lost productivity. The number of reported cases fluctuates seasonally, peaking in June though September. Northern states report more cases than southern states. In the Pacific Northwest, *E. coli* O157:H7 may be second only to *Salmonella* as a cause of bacterial diarrhea. The true prevalence is unknown and the disease has only recently been added to the list of nationally notifiable diseases. CDC received reports of over 2,741 cases from 47 states in 1996.

Despite the high visibility of *E. coli* O157:H7 due to recent outbreaks, clinicians often do not consider it when diagnosing patients or collect appropriate specimens. Although laboratory testing to detect *E. coli* O157:H7 is relatively straightforward and inexpensive, a recent study showed that at the end of 1994 only about half of the clinical laboratories in the United States were screening stool samples for it.

Tuberculosis

The Pathogen and Disease

Tuberculosis, caused by *Mycobacterium tuberculosis*, was the leading cause of death from infectious diseases in the United States at the turn of the century; it remained the second leading cause of death until the development of antibiotics in the 1950s. Worldwide, about one-third of all people are infected. Tuberculosis kills over 2.9 million people a year—making it a leading cause of death. Tuberculosis of the lungs destroys lung tissue and, if left untreated, half of victims die within 2 years. The risk of contracting the disease is highest in the first year after infection and then drops sharply, although reactivation can occur years later. Only about 10 percent of healthy people infected with the pathogen develop clinical disease. Tuberculosis is difficult to treat, requiring a 6-month regimen of multiple antibiotics to effect a cure and prevent the emergence of antibiotic-resistant strains. When health care is adequate and compliance with treatment is maintained, cure rates should exceed

90 percent, even in those whose immune systems have been compromised by HIV/AIDS.

Complications

The emergence of strains resistant to one or more antibiotics puts not only tuberculosis patients at risk, but also health care workers, social workers, and any other people in frequent contact with them. For cases of multidrug-resistant tuberculosis, fatality rates can exceed 80 percent for immuno-compromised and 50 percent for previously healthy individuals. Multidrug-resistant cases are extraordinarily difficult to treat, and most patients do not respond to therapy.

Transmission

Tuberculosis is spread primarily by the respiratory route from patients with active disease. Shouting, sneezing, and coughing can easily spread the pathogens in the environment. The risk of transmission varies with the length of exposure, degree of crowding and ventilation, virulence of the strain, and health of the person exposed.

Costs and Prevalence

From the 1950s through the early 1980s, the incidence of tuberculosis declined in the United States, then began to increase in 1988, reaching a peak in 1992. The HIV/AIDS epidemic, immigration from countries with high rates of tuberculosis, and outbreaks in facilities such as correctional institutions and nursing homes have contributed to the resurgence. Treatment costs for an individual with multidrug-resistant tuberculosis can be as much as $150,000, 10 times the cost of treating a nonresistant case. In 1996, 54 states reported 21,337 cases to CDC.

Pertussis

The Pathogen and Disease

Pertussis, caused by the bacterium *Bordetella pertussis*, is characterized by uncontrollable spells of coughing in which one cough follows another too quickly to allow a breath in between. An intake of breath that produces a high-pitched “whooping” sound follows each coughing spell, hence the name whooping cough. The illness lasts about 2 weeks and responds to antibiotic therapy. In the early to mid-1900s, pertussis was a common childhood disease and a leading cause of death among children in

the United States. Today, pertussis is one of the nation's most commonly reported childhood vaccine-preventable diseases.

Complications

Complications associated with pertussis may be severe, especially among infants. Secondary bacterial pneumonia causes most pertussis-related deaths. Other complications include seizures, encephalopathy, and ear infections. About 1 percent of affected infants died in 1993. The risk of complications is highest among infants and under-vaccinated preschool aged children. In 1994, a strain resistant to the antibiotic preferred for treatment appeared in the United States.

Transmission

Immunity to pertussis can decrease with age. Consequently, young adults and adolescents who contract the disease can be an important source in transmitting it to unimmunized infants. Pertussis among adults and adolescents is often not diagnosed by physicians—despite the presence of a persistent cough—because they do not expect to see the disease in this age group. Pertussis is endemic in the United States.

Incidence

Pertussis incidence is cyclical, with peaks every 3 to 4 years. Incidence has decreased from 150 cases per 100,000 population prior to 1940 to about 1.2 cases per 100,000 by 1991. In 1996, 7,796 cases were reported to CDC, an estimated 10 percent of the true number. Although the total number of reported cases remains well below the annual number reported during the pre-vaccine era, the total number of cases has increased steadily in each peak year since 1977. The reasons for the increase in reported cases are unclear but appear unrelated to decreased vaccination rates or reduced vaccine efficacy. Because few pertussis specimens are tested for resistance, the prevalence of antibiotic-resistant strains is unknown.

Penicillin-Resistant *Streptococcus Pneumoniae*

The Pathogen and Disease

Worldwide, *S. pneumoniae* infections are among the leading causes of illness and death for young children, individuals with underlying medical conditions, and elderly people. *S. pneumoniae* is the most common cause

of bacterial pneumonia and is implicated in infections of the ears, sinuses, lungs, abdominal cavity, bloodstream, and tissues that envelop the brain and spinal column. A vaccine that controls the 23 most common strains has been available since the 1980s, but it is largely underutilized. In the past, *S. pneumoniae* uniformly responded to treatment with penicillin, allowing physicians to treat even severely ill patients without testing for antibiotic resistance. During the 1990s, however, resistance to penicillin spread rapidly in the United States, and strains resistant to multiple antibiotics account for a small, but growing, proportion of cases.

Complications

Case fatality rates—which vary by age, type of infection, and underlying medical condition—can be as high as 40 percent among some high-risk patients, despite appropriate antibiotic therapy.

Transmission

Transmission occurs through contact with infected saliva.

Prevalence

In the United States, *S. pneumoniae* causes up to 3,000 cases of meningitis, 135,000 cases of hospitalized pneumonia, and as many as 7 million ear infections each year. Resistance to penicillin varies widely by region and age group but accounts for 30 percent of cases in some communities. The prevalence of resistance for most areas of the United States is unknown, possibly because the condition was not nationally reportable until 1996. Limited knowledge of local patterns of resistance and the lack of a rapid diagnostic test often result in therapy that uses either unnecessary or overly broad antibiotics, thereby contributing to the development of resistant strains.

Cryptosporidiosis

The Pathogen and Disease

Cryptosporidiosis, caused by the parasite *Cryptosporidium parvum*, can affect human intestinal and, rarely, respiratory tracts. The disease has long been known to veterinarians but was first recognized as a human pathogen in 1976. The intestinal disease is generally characterized by severe watery diarrhea and can include abdominal cramps, nausea, vomiting, and low-grade fever. Most healthy individuals recover after 7 to 10 days. Infection of the respiratory tract is associated with coughing and a low-grade fever, often accompanied by severe intestinal distress. Unlike

many bacterial infections, the infective dose of cryptosporidiosis is thought to be small, perhaps as few as 10 organisms, each about half the size of a red blood cell. An infected person or animal can shed millions of organisms per milliliter of feces. Once in the environment, the organisms can remain infective for many months. No safe and effective treatment for cryptosporidiosis has been identified.

Complications

Among persons with weakened immune systems, the disease can lead to dehydration and death.

Transmission

The infectious stage of the parasite is passed in the feces of infected humans and animals. Infection can be transmitted from person to person, from animal to person, through ingesting contaminated food or water, or through contact with fecally contaminated environmental surfaces.

Prevalence

The parasite is common among herd animals and is present in virtually all the surface—and much of the treated—waters of the United States. The parasite, small enough to slip through most water filters, is resistant to chlorine treatment. The public health risk of contracting the disease from tap water is unknown. Tests on body fluids indicate as many as 80 percent of the United States population have had cryptosporidiosis. Throughout the world, the organism has been found wherever it was sought. In 1996, 42 states reported 2,426 cases to CDC.

Hepatitis C Virus

The Pathogen and Disease

The virus that causes hepatitis C was discovered in 1988 and is the major cause of chronic liver disease worldwide. Since 1990, molecular-based laboratory tests have allowed detection of specific antibodies in the blood of infected people. Prior to 1990, diagnosis of hepatitis C was made by excluding both hepatitis A and hepatitis B. The incubation period for acute hepatitis C averages 6 to 7 weeks. Typically, adults and children with acute hepatitis C are either asymptomatic or have a mild clinical illness. More severe symptoms of hepatitis C are similar to those of other types of viral hepatitis and include anorexia, nausea, vomiting, and jaundice. Most patients do not achieve a sustained response to treatment.

Complications

At least 85 percent of persons infected with hepatitis C develop persistent infection. Chronic disease develops in 60 to 70 percent of infected individuals, and up to 20 percent may develop cirrhosis over a 30-year period. Hepatitis C is a leading cause of chronic liver disease in the United State and a major reason for liver transplants. An estimated 8,000 to 10,000 people die annually from hepatitis C and its related chronic disease.

Transmission

Hepatitis C is most efficiently transmitted through large or repeated contact through the skin with infected blood. Intravenous drug use is the most common risk factor for acquiring hepatitis C. Currently, transfusion-associated hepatitis rarely occurs due to donor screening policies instituted at blood banks and to routine testing of blood donors for evidence of infection.

Costs and Prevalence

In the United States, the annual number of newly acquired acute hepatitis C infections has ranged from an estimated 180,000 cases in 1984 to an estimated 28,000 in 1995. The prevalence of hepatitis C in the general population is about 1.8 percent, which corresponds to approximately 3.9 million people with chronic infection. Hepatitis C and related chronic diseases cost about $600 million annually (in 1991 dollars).

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