United States Government Accountability Office

GAO

Report to the Chairman, Permanent Subcommittee on Investigations, Committee on Governmental Affairs, U.S. Senate

September 2004

EMERGING INFECTIOUS DISEASES

Review of State and Federal Disease Surveillance Efforts

GAO-04-877

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Highlights

Highlights of GAO-04-877, a report to the Chairman, Permanent Subcommittee on Investigations, Committee on Governmental Affairs, U.S. Senate

Why GAO Did This Study

The threat posed by infectious diseases has grown. New diseases, unknown in the United States just a decade ago, such as West Nile virus and severe acute respiratory syndrome (SARS), have emerged. To detect cases of infectious diseases, especially before they develop into widespread outbreaks, local, state, and federal public health officials as well as international organizations conduct disease surveillance. Disease surveillance is the process of reporting, collecting, analyzing, and exchanging information related to cases of infectious diseases.

In this report GAO was asked to examine disease surveillance efforts in the United States. Specifically, GAO described (1) how state and federal public health officials conduct surveillance for infectious diseases and (2) initiatives intended to enhance disease surveillance.

GAO reviewed documents, such as policy manuals and reports related to disease surveillance, and interviewed officials from selected federal departments and agencies, including the Departments of Defense (DOD), Agriculture (USDA), and Homeland Security (DHS) as well as the Food and Drug Administration (FDA), and the Centers for Disease Control and Prevention (CDC). GAO conducted structured interviews of state public health officials from 11 states.

www.gao.gov/cgi-bin/getrpt?GAO-04-877.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Majorie Kanof at (202) 512-7119.

What GAO Found

Surveillance for infectious diseases in the United States comprises a variety of efforts at the state and federal levels. At the state level, state health departments collect and analyze data on cases of infectious diseases. These data are required to be reported by health care providers and others to the state. State public health departments verify reported cases of diseases, monitor disease incidence, identify possible outbreaks within their state, and report this information to CDC. At the federal level, agencies and departments collect and analyze disease surveillance data and maintain disease surveillance systems. For example, CDC uses the reports of diseases from the states to monitor national health trends, formulate and implement prevention strategies, and evaluate state and federal disease prevention efforts. FDA analyzes information on outbreaks of infectious diseases that originate from foods that the agency regulates. Some federal agencies and departments also fund and operate their own disease surveillance systems and laboratory networks and have several means of sharing surveillance information with local, state, and international public health partners.

State and federal public health officials have implemented a number of initiatives intended to enhance disease surveillance, but challenges remain. For example, officials have implemented and expanded syndromic surveillance systems, which monitor the frequency and distribution of health-related symptoms among people within a specific geographic area. Although syndromic surveillance systems are used by federal agencies and departments and in all of the states whose officials GAO interviewed, concerns have been raised about this approach to surveillance. Specifically, syndromic surveillance systems are relatively costly to maintain compared to other types of surveillance and are still largely untested. Public health officials are also implementing initiatives designed to enhance public health communications and disease reporting. For example, CDC is working to increase the number of participants using its public health communication systems. In addition, state public health departments and CDC are implementing an initiative designed to make electronic disease reporting more timely, accurate, and complete. However, the implementation of this initiative is incomplete. Finally, federal public health officials have enhanced federal coordination on disease surveillance and expanded training programs for epidemiologists and other public health experts.

In commenting on a draft of this report, the Department of Health and Human Services (HHS) said the report captures many important issues in surveillance. HHS also provided suggestions to clarify the discussion.

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Abbreviations

AIDS	acquired immunodeficiency syndrome
BSE	bovine spongiform encephalopathy
CDC	Centers for Disease Control and Prevention
CSTE	Council of State and Territorial Epidemiologists
DHS	Department of Homeland Security
DOD	Department of Defense
EIP	Emerging Infections Program
EIS	Epidemic Intelligence Service
ELC	Epidemiology and Laboratory Capacity
eLEXNET	Electronic Laboratory Exchange Network
Epi-X	Epidemic Information Exchange
ESSENCE	Electronic Surveillance System for the Early Notification of Community-based Epidemics
FDA	Food and Drug Administration
FELTP	Field Epidemiology and Laboratory Training Program

FETP	Field Epidemiology Training Program
FoodNet	Foodborne Disease Active Surveillance Network
GAS	group A streptococcus
GOARN	Global Outbreak Alert and Response Network
GPHIN	Global Public Health Intelligence Network
HAN	Health Alert Network
HIV	human immunodeficiency virus
HHS	Department of Health and Human Services
IDSA-EIN	Infectious Diseases Society of America Emerging Infections Network
IEIP	International Emerging Infections Program
IOM	Institute of Medicine
LRN	Laboratory Response Network
NAHRS	National Animal Health Reporting System
NBS	NEDSS-Base system
NEDSS	National Electronic Disease Surveillance System
NETSS	National Electronic Telecommunications System for Surveillance
NRDM	National Retail Data Monitor
NVSL	National Veterinary Services Laboratories
PHIN	Public Health Information Network
RODS	Real-time Outbreak and Disease Surveillance
SARS	severe acute respiratory syndrome
STD	sexually transmitted disease
STD*MIS	Sexually Transmitted Disease Management Information System
STELLAR	Systematic Tracking of Elevated Lead Levels & Remediation
STSS	streptococcal toxic shock syndrome
USAMRIID	U.S. Army Medical Research Institute of Infectious Diseases
USDA	U.S. Department of Agriculture
vCJD	variant Creutzfeldt-Jakob disease
WHO	World Health Organization

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United States Government Accountability Office
Washington, DC 20548

September 30, 2004

The Honorable Norm Coleman
Chairman
Permanent Subcommittee on Investigations
Committee on Governmental Affairs
United States Senate

Dear Mr. Chairman:

Infectious diseases account for millions of deaths every year. Although the great majority of these deaths occur in developing countries, infectious diseases are not confined by international borders and therefore present a substantial threat to populations in all parts of the world, including the United States. In recent years, the threat posed by infectious diseases has grown. New diseases, unknown in the United States just a decade ago, such as West Nile virus and severe acute respiratory syndrome (SARS), have emerged, and known infectious diseases once considered in decline have reappeared with increased frequency. Furthermore, there is always the potential for an infectious disease to develop into a widespread outbreak—which could have significant consequences. The Centers for Disease Control and Prevention (CDC) estimates that if an influenza pandemic[1] were to occur in the United States, it could cause an estimated 314,000 to 734,000 hospitalizations and 89,000 to 207,000 deaths, with associated costs ranging from $71 to $167 billion.[2] In addition to naturally occurring infectious disease outbreaks, there is also the threat posed by the deployment of infectious disease pathogens[3] as weapons of war or instruments of terror.

To detect cases of infectious diseases, especially before they develop into widespread outbreaks, local, state, and federal public health officials as

[1]Pandemics are worldwide epidemics. Influenza pandemics can have successive "waves" of disease and last for up to 3 years. Three pandemics occurred in the 20th century: the "Spanish Flu" of 1918 which killed at least 20 million people worldwide; the "Asian flu" of 1957; and the "Hong Kong flu" of 1968.

[2]See Centers for Disease Control and Prevention, *Fiscal Year 2005 Justification of Estimates for Appropriations Committees*, 172.

[3]Pathogens are bacteria, viruses, parasites, or fungi that have the capability to cause disease in humans.

well as international organizations conduct disease surveillance. Disease surveillance is the process of reporting, collecting, analyzing, and exchanging information related to cases of infectious diseases. Disease surveillance provides national and international public health authorities with information for planning and managing efforts to control these diseases. In the mid-1990s, public health experts in the United States and abroad determined that infectious disease surveillance was inadequate worldwide, and both the World Health Assembly and the President of the United States called for concerted action to develop effective disease surveillance and response capabilities.[4] In 2003, the Institute of Medicine (IOM) of the National Academies published a report that acknowledged that the United States has taken some important steps over the past decade to improve its disease surveillance and response capabilities, but also emphasized the need for continued action.[5]

You asked us to examine disease surveillance efforts in the United States. Specifically, we describe (1) how state and federal public health officials conduct surveillance for infectious diseases and (2) initiatives intended to enhance disease surveillance.

To describe how state and federal public health officials conduct disease surveillance, we reviewed reports, state policy manuals, journal articles, and various documents related to disease surveillance. We conducted structured interviews of state public health officials from 11 states; interviewed representatives from professional associations representing state and local public health officials, such as the Association of State and Territorial Health Officials; and interviewed officials from selected federal agencies and departments—CDC, the Department of Defense (DOD), the Food and Drug Administration (FDA), the U.S. Department of Agriculture (USDA), and the Department of Homeland Security (DHS). To identify initiatives intended to enhance disease surveillance, we reviewed and

[4]See World Health Assembly Resolution 48.13m, Communicable Disease Prevention and Control: New Emerging and Re-Emerging Infectious Diseases (Geneva, Switzerland: May 12, 1995); *Emerging Infections: Microbial Threats to Health in the United States*, Institute of Medicine (Washington, D.C.: 1992); *Infectious Disease—A Global Health Threat*, Report of the National Science and Technology Council, Committee on International Science, Engineering, and Technology, Working Group on Emerging and Re-emerging Infectious Diseases (Washington, D.C.: Sept. 1995); and Presidential Decision Directive, Addressing the Threat of Emerging Infectious Diseases (PDD, NSTC-7: June 1996).

[5]Institute of Medicine, *Microbial Threats to Health: Emergence, Detection and Response* (Washington, D.C.: 2003).

analyzed documents, such as journal articles on states' innovative approaches to enhancing disease surveillance. We also interviewed state public health officials from the 11 states about their assessment of enhancements and continuing weaknesses in disease surveillance efforts. We also reviewed and analyzed related federal documents, such as policy directives and annual reports, and we interviewed relevant federal health officials. We focused our review of initiatives intended to enhance surveillance on those currently under way or implemented since 2001. Appendix I contains more details about our scope and methodology. We conducted our work from October 2003 through July 2004 in accordance with generally accepted government auditing standards.

Results in Brief

Surveillance for infectious diseases in the United States comprises a variety of efforts at the state and federal levels. At the state level, state health departments collect and analyze data on cases of infectious diseases. These data are required to be reported by health care providers and others to the state. The diseases that must be reported vary by state. State public health departments verify reported cases of diseases, monitor disease incidence, identify possible outbreaks within their state, and report this information to CDC. At the federal level, agencies and departments collect and analyze disease surveillance data and maintain disease surveillance systems. For example, CDC uses the reports of diseases from the states to monitor national health trends, formulate and implement prevention strategies, and evaluate state and federal disease prevention efforts. FDA analyzes information on outbreaks of infectious diseases that originate from foods that the agency regulates. Some federal agencies and departments also conduct disease surveillance using disease surveillance systems that they operate or fund. For example, DOD has a syndromic surveillance system called the Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE). ESSENCE and other syndromic surveillance systems gather data on patient symptoms looking for anomalous increases in the frequency of these symptoms that may indicate the presence of an infectious disease outbreak. CDC, FDA, USDA, and DOD also support networks of laboratories that test specimens and develop diagnostic tests for identifying infectious diseases and biological or chemical agents. As part of their role in national disease surveillance efforts, some federal agencies and departments also share information with local, state, and international partners through different means such as from public Web sites or secure Web-based communication systems. Finally, some federal agencies and departments provide training, technical assistance, and funding to support state and international disease surveillance efforts.

State and federal public health officials have implemented a number of initiatives intended to enhance disease surveillance, but challenges remain. For example, officials have implemented and expanded syndromic surveillance systems, such as the Real-time Outbreak and Disease Surveillance (RODS) system. RODS is used by officials from four of the state health departments we interviewed and automatically gathers data on patient symptoms from hospital emergency room visits. Although syndromic surveillance systems are used by federal agencies and departments and by all of the states we interviewed, concerns have been raised about this approach to surveillance. Specifically, syndromic surveillance systems are relatively costly to maintain compared to other types of disease surveillance and are still largely untested. Public health officials have also implemented initiatives designed to enhance public health communications and disease reporting. For example, CDC is working to increase the number of participants using its public health communication systems. In addition, state public health departments and CDC have taken steps intended to enhance the information technology used for disease reporting. CDC introduced the National Electronic Disease Surveillance System (NEDSS), which is designed to make electronic disease reporting more timely, accurate, and complete, in part, by consolidating the 60-100 different systems used by state health departments to report disease data to CDC. However, initiatives designed to enhance public health communications and disease reporting are incomplete. Finally, federal public health officials have enhanced federal coordination on disease surveillance and expanded training programs for epidemiologists and other public health experts.

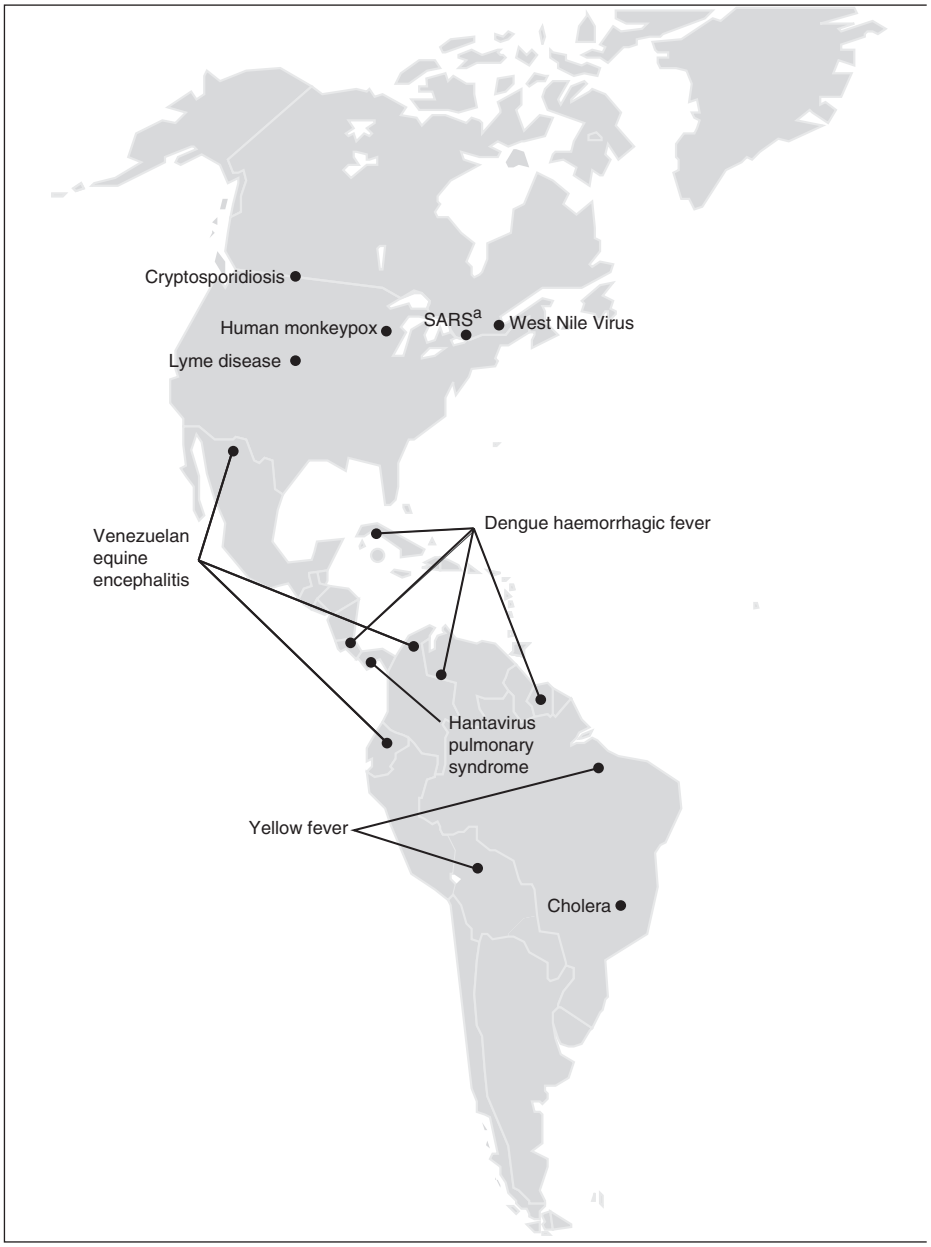
In commenting on a draft of this report, the Department of Health and Human Services (HHS) said the report captures many important issues in surveillance. HHS also provided suggestions to clarify the discussion or incorporate additional information. HHS's comments are reprinted in appendix IV. In providing oral comments on a draft of this report, DOD said it concurred and did not have any substantive comments. USDA said it had no comments on the draft report. HHS and USDA provided technical comments that we incorporated where appropriate.

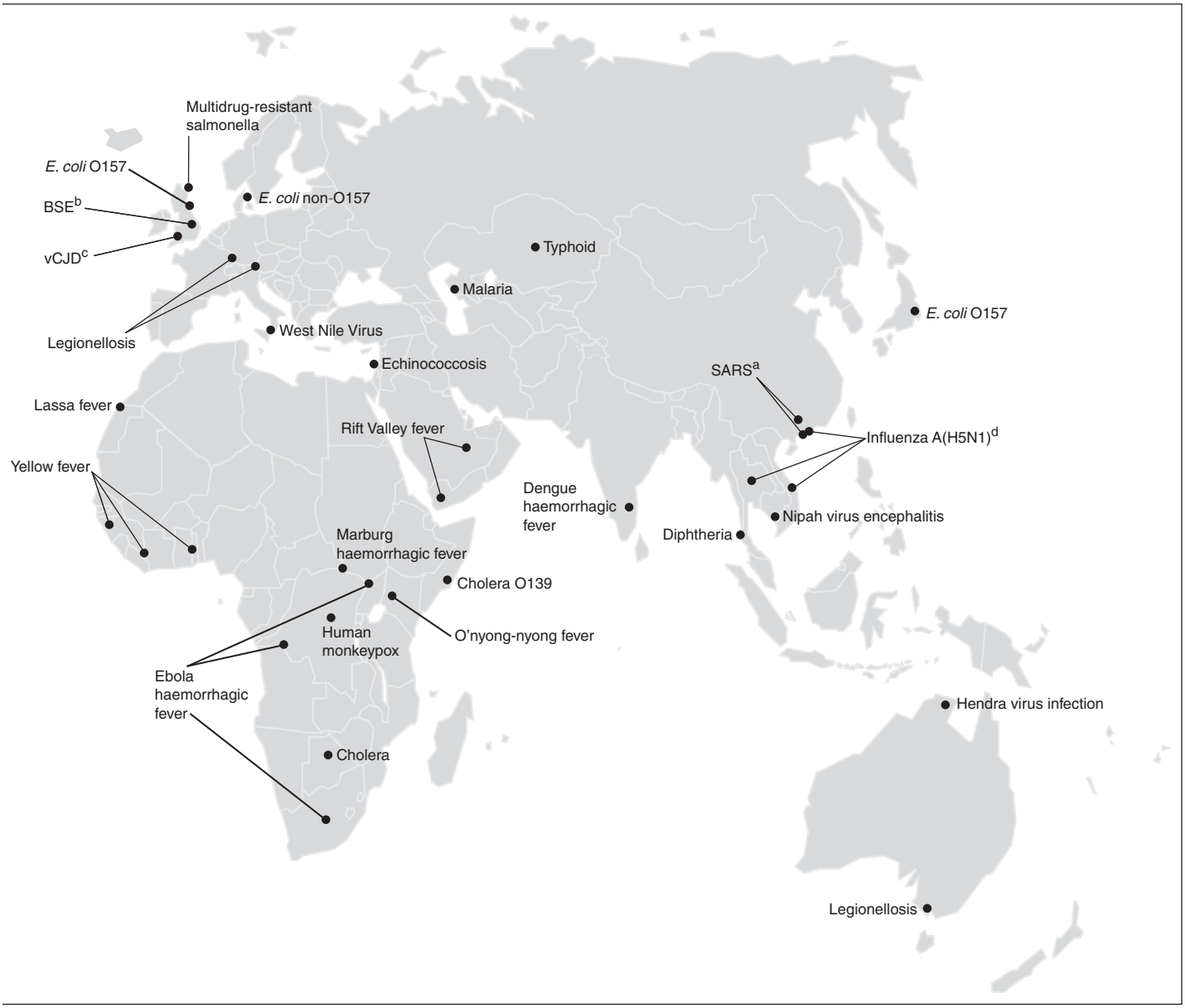
Background

IOM defines an emerging infectious disease as either a newly recognized, clinically distinct infectious disease or a known infectious disease whose reported incidence is increasing in a given place or among a specific population. More than 36 newly emerging infectious diseases were identified between 1973 and 2003, and new emerging infectious diseases continue to be identified. Figure 1 provides information on selected

emerging infectious diseases compiled by the World Health Organization (WHO) and CDC.

Figure 1: Selected Emerging Infectious Diseases, 1996-2004





Source: World Health Organization and Centers for Disease Control and Prevention.

[a]SARS refers to severe acute respiratory syndrome.

[b]BSE refers to bovine spongiform encephalopathy, also called mad cow disease.

[c]vCJD refers to variant Creutzfeldt-Jakob disease.

[d]Influenza A (H5N1) is also called avian influenza.

According to CDC, nearly 70 percent of emerging infectious disease episodes during the past 10 years have been zoonotic diseases, which are diseases transmitted from animals to humans. The West Nile virus, which was first diagnosed in the United States in 1999, is an example of a zoonotic disease. The West Nile virus can cause encephalitis, or inflammation of the brain. Mosquitoes become infected with West Nile virus when they feed on infected birds, and infected mosquitoes transmit the virus to humans and animals by biting them. Other zoonotic diseases include SARS, avian influenza, human monkeypox, and variant Creutzfeldt-Jakob disease (vCJD), which scientists believe is linked to eating beef from cattle infected with bovine spongiform encephalopathy (BSE) and is also called mad cow disease. Surveillance for zoonotic diseases requires collaboration between animal and human disease specialists.[6]

Disease surveillance provides information for action against infectious disease threats. Basic infectious disease surveillance activities include detecting and reporting cases of disease, analyzing and confirming this information to identify possible outbreaks or longer-term trends, and applying the information to inform public health decision-making. When effective, surveillance can facilitate (1) timely action to control outbreaks, (2) informed allocation of resources to meet changing disease conditions and other public health threats, and (3) adjustment of disease control programs to make them more effective.

Responsibilities for Disease Surveillance

In the United States, responsibility for disease surveillance is shared—involving health care providers;[7] more than 3,000 local health departments

[6]The initial outbreak of the West Nile virus in the United States in 1999 demonstrated this need. An infectious disease specialist first reported two cases of an unusual neurological disease, which she initially suspected to be botulism, to the New York City Department of Health. Further investigation and tests suggested that her patients had a type of viral encephalitis that might have been transmitted by an insect. The Department of Health subsequently consulted with experts at CDC and an entomologist from the American Museum of Natural History in New York and initially misdiagnosed the disease as St. Louis encephalitis. More than a month after the initial outbreak, the disease was correctly diagnosed as West Nile virus when it was discovered that a biologist at the New York State Department of Environmental Conservation and a veterinary pathologist at the Bronx Zoo had found several dead birds that had died of viral encephalitis.

[7]For this report, the term "health care providers" includes all health care professionals, such as physicians and nurses, as well as health care institutions, such as hospitals and clinics.

including county, city, and tribal health departments; 59 state and territorial health departments; more than 180,000 public and private laboratories; and public health officials from four federal departments. Although state health departments have primary responsibility for disease surveillance in the United States, health care providers, local health departments, and certain federal departments and agencies share this responsibility. In addition, the United States is a member of WHO, which is responsible for coordinating international disease surveillance and response efforts.

Health Care Providers

Health care providers are responsible for the medical diagnosis and treatment of their individual patients, and they also have a responsibility to protect public health—a responsibility that includes helping to identify and prevent the spread of infectious diseases. Because health care providers are typically the first health officials to encounter cases of infectious diseases—and have the opportunity to diagnose them—these professionals play an important role in disease surveillance. Generally, state laws or regulations require health care providers to report confirmed or suspected cases of notifiable diseases to their local and/or state health department. A notifiable disease is an infectious disease for which regular, frequent, and timely information on individual cases is considered necessary for the prevention and control of the disease. States publish a list of the diseases they consider notifiable and therefore subject to reporting requirements. According to IOM, most states also require health care providers to report any unusual illnesses or deaths—especially those for which a cause cannot be readily established.[8]

State and Local Health Departments

States, through the use of their state and local health departments, have principal responsibility for protecting the public's health and therefore take the lead in conducting disease surveillance and supporting response efforts. Generally, local health departments are responsible for conducting initial investigations into reports of infectious diseases. They employ epidemiologists,[9] physicians, nurses, and other professionals. Local health

[8]The requirement to report the clinically anomalous is particularly important for the detection of emerging infectious diseases, many of which may be unfamiliar to health care providers.

[9]Epidemiologists are specialists who study how diseases are distributed and transmitted in populations and the factors that influence or determine this distribution and transmission. Epidemiologists at state health departments are often responsible for analyzing data collected through disease reporting systems, conducting outbreak investigations, and designing and evaluating disease prevention and control efforts.

departments are also responsible for sharing information they obtain from providers or other sources with their state department of health. State health departments are responsible for collecting surveillance information from across their state, coordinating investigations and response efforts, and voluntarily sharing surveillance data with CDC and others.

Federal Agencies and Departments

Several federal agencies and departments are involved in disease surveillance. For example,

- CDC, an agency in HHS, is charged with protecting the nation's public health by directing efforts to prevent and control diseases and responding to public health emergencies. It has primary responsibility for conducting national disease surveillance and developing epidemiological and laboratory tools to enhance disease surveillance. CDC also provides an array of technical and financial support for state infectious disease surveillance efforts.

- FDA, which is also a part of HHS, is responsible for protecting the public health by ensuring that domestic and imported food products (except meat, poultry, and certain processed egg products) are safe and properly labeled. It is also responsible for ensuring that all drugs and feeds used in animals are safe, effective, and properly labeled and produce no health hazards when used in animals that produce foods for humans. FDA enforces food safety laws by inspecting food production establishments and warehouses and collecting and analyzing food samples for microbial contamination that could lead to foodborne illnesses.

- USDA is responsible for protecting and improving the health and marketability of animals and animal products in the United States by preventing, controlling, and eliminating animal diseases. USDA is also responsible for regulating veterinary vaccines and other similar products. USDA undertakes disease surveillance and response activities to protect U.S. livestock, ensure the safety of international trade, and contribute to the national zoonotic disease surveillance effort. In addition, USDA is responsible for ensuring that meat, poultry, eggs, and certain processed egg products are safe and properly labeled and packaged. USDA establishes quality standards and conducts inspections of processing facilities in order to safeguard certain animal food products against infectious diseases that pose a risk to humans.

- DOD, while primarily responsible for the health and protection of its service members, contributes to global disease surveillance, training, research, and response to emerging infectious disease threats.

- DHS's mission involves, among other things, protecting the United States against terrorist attacks. One activity undertaken by DHS is to coordinate the surveillance activities of federal agencies and departments related to national security.[10]

World Health Organization

While national governments have primary responsibility for disease surveillance and response within their country, WHO plays a central role in coordinating international surveillance and response efforts. An agency of the United Nations, WHO administers the International Health Regulations, which outline WHO's role and the responsibility of member states in preventing the global spread of infectious diseases. Adopted in 1951 and last modified in 1981, the International Health Regulations require, among other things, that WHO member states report the incidence of three diseases within their borders—cholera, plague, and yellow fever. There are currently proposed revisions to these regulations that will expand the scope of reporting beyond the current three diseases to include all events potentially constituting a public health emergency of international concern.[11] WHO is the agency that serves as the focal point for international information on these diseases as well as others, and the agency also helps marshal resources from member states to control outbreaks within individual countries or regions. In addition, WHO works with national governments to improve their surveillance capacities through—for example—assessing and redesigning national surveillance strategies, offering training in epidemiologic and laboratory techniques, and emphasizing more efficient communication systems.

[10]DHS officials told us it is only beginning these efforts and therefore its roles and responsibilities for the coordination of surveillance activities related to national security are still evolving.

[11]Efforts to revise the International Health Regulations began in 1995, and the revised regulations are scheduled to be ready for submission to the World Health Assembly, the governing body of WHO, in May 2005. As part of the revision process, WHO is considering criteria to determine whether an outbreak is serious, unexpected, and likely to spread internationally. Furthermore, the draft regulations would broaden the definition of a reportable disease to include significant illness caused by biological, chemical, or radionuclear sources.

Disease Surveillance Comprises a Variety of Efforts at the State and Federal Levels

Disease surveillance comprises a variety of efforts at the state and federal levels. At the state level, state health departments collect and analyze data on notifiable diseases submitted by health care providers and others, although the diseases considered notifiable and the requirements for reporting them vary by state. State-run laboratories conduct testing of samples for clinical diagnosis and participate in special clinical or epidemiologic studies. State public health departments verify cases of notifiable diseases, monitor disease incidence, and identify possible outbreaks within their state. At the federal level, agencies and departments collect and analyze surveillance data gathered from the states and from international sources. Some federal agencies and departments also support their own national surveillance systems and laboratory networks and have several means of sharing surveillance information with local, state, and international public health partners. Finally, some federal agencies and departments support state and international surveillance efforts by providing training and technical expertise.

States Collect and Report Data on Notifiable Diseases, Although the Diseases Considered Notifiable and the Reporting Requirements Vary by State

To conduct disease surveillance at the state level, state public health officials collect reports on cases of notifiable diseases from health care providers and others. Both the diseases considered notifiable and the requirements for reporting them vary by state. Most states have their list of notifiable diseases approximate a national list of notifiable diseases maintained and revised by the Council of State and Territorial Epidemiologists (CSTE) in collaboration with CDC.[12] (See table 1 for the 2004 national list of notifiable diseases maintained by CSTE.) This national list is reviewed annually and revised periodically.[13] State lists of notifiable diseases generally include cholera, plague, and yellow fever—consistent with WHO's International Health Regulations. On the other hand, according to state and federal health officials, states modify their list of notifiable diseases to reflect the public health needs of their region. States may include diseases on their state list that impact their state but do not appear on the national list. For example, one border state includes the gastrointestinal disease amebiasis—a disease most often found in the United States among immigrants from developing countries—in its state list of notifiable diseases. However, amebiasis is not included on the

[12]CSTE is a professional organization of public health epidemiologists from every U.S. state and territory, as well as Canada and Great Britain.

[13]For example, a disease might be added to the list as a new pathogen emerges, or a disease might be deleted as its incidence declines.

current national list of notifiable diseases. Conversely, states may exclude diseases that are on the national list but have little relevance for their state. For example, although Rocky Mountain spotted fever is listed on the national list of notifiable diseases, it was excluded from one state's list we reviewed because relatively few cases of this disease are reported in that area. Appendix II provides a description of diseases on the national notifiable disease list and other selected emerging infectious diseases.

Table 1: U.S. List of Nationally Notifiable Infectious Diseases, 2004

Acquired immunodeficiency syndrome (AIDS)	Lyme disease
Anthrax	Malaria
Botulism	Measles
• Botulism, foodborne	Meningococcal disease
• Botulism, infant	Mumps
• Botulism, other (wound & unspecified)	Pertussis
Brucellosis	Plague
Chancroid	Poliomyelitis, paralytic
Chlamydia trachomatis, genital infections	Psittacosis
Cholera	Q Fever
Coccidioidomycosis	Rabies
Cryptosporidiosis	• Rabies, animal
Cyclosporiasis	• Rabies, human
Diphtheria	Rocky Mountain spotted fever
Ehrlichiosis	Rubella
• Ehrlichiosis, human granulocytic	Rubella, congenital syndrome
• Ehrlichiosis, human monocytic	Salmonellosis
• Ehrlichiosis, human, other, or unspecified agent	Severe acute respiratory syndrome-associated
Encephalitis/meningitis, Arboviral	coronavirus (SARS-CoV) disease
• Encephalitis/meningitis, California	Shigellosis
serogroup viral	Smallpox
• Encephalitis/meningitis, eastern equine	Streptococcal disease, invasive, Group A
• Encephalitis/meningitis, Powassan	Streptococcal toxic-shock syndrome
• Encephalitis/meningitis, St. Louis	*Streptococcus pneumoniae*, drug resistant,
• Encephalitis/meningitis, western equine	invasive disease
• Encephalitis/meningitis, West Nile	*Streptococcus pneumoniae*, invasive in children
Enterohemorrhagic *Escherichia coli*	<5 years
• Enterohemorrhagic *Escherichia coli*, O157:H7	Syphilis
• Enterohemorrhagic *Escherichia coli*, shiga	• Syphilis, primary
toxin positive, serogroup non-O157	• Syphilis, secondary
• Enterohemorrhagic *Escherichia coli*, shiga	• Syphilis, latent
toxin + (not serogrouped)	• Syphilis, early latent
Giardiasis	• Syphilis, late latent
Gonorrhea	• Syphilis, latent unknown duration
Haemophilus influenzae, invasive disease	• Neurosyphilis
Hansen disease (leprosy)	• Syphilis, late, non-neurological

Hantavirus pulmonary syndrome	Syphilis, congenital
Hemolytic uremic syndrome, post-diarrheal	• Syphilitic Stillbirth
Hepatitis, viral, acute	Tetanus
• Hepatitis A, acute	Toxic-shock syndrome
• Hepatitis B, acute	Trichinosis
• Hepatitis B virus, perinatal infection	Tuberculosis
• Hepatitis C, acute	Tularemia
Hepatitis, viral, chronic	Typhoid fever
• Chronic Hepatitis B	Vancomycin—intermediate S*taphylococcus*
• Hepatitis C virus infection (past or present)	*aureus* (VISA)
HIV infection	Vancomycin—resistant *Staphylococcus aureus*
• HIV infection, adult (>=13 years)	(VRSA)
• HIV infection, pediatric (<13 years)	Varicella (morbidity)
Legionellosis	Varicella (deaths only)
Listeriosis	Yellow fever

Source: Council of State and Territorial Epidemiologists and Centers for Disease Control and Prevention.

States also vary in their requirements for who should report notifiable diseases, and the deadlines for reporting these diseases after they have been diagnosed vary by disease. Officials from the 11 states we interviewed told us that, in addition to health care providers, they require clinical laboratories to report notifiable diseases. On the other hand, some—but not all—of the11 states have expanded the responsibility for reporting suspected notifiable diseases. Depending on the state, those required to report suspected notifiable diseases can include veterinarians, day care centers, hotels, and food service establishments. Penalties for not reporting a notifiable disease vary by state. For example, failing to report a notifiable disease in one state is a misdemeanor, and upon conviction, violators may be fined from $50 to $1,000 and/or may be imprisoned for up to 90 days. In another state, the penalty ranges from $25 to $300. Depending on the contagiousness or virulence of the disease, some diseases have to be reported more quickly than others. For example, in one state, botulism must be reported immediately after a case or suspected case is identified, while chronic hepatitis B must be reported within one month of its identification.[14] Similarly, in another state, Q fever

[14]Botulism is a bacterial disease that is spread through the ingestion of contaminated food. It is a muscle-paralyzing disease that can cause a person to stop breathing and may result in death. In contrast, chronic hepatitis B is a viral disease affecting the liver that is transmitted through contact with blood or body fluids.

must be reported within one working day, while gonorrhea must be reported within one week.[15]

Health care providers rely on a variety of public and private laboratories to help them diagnose cases of notifiable diseases. In some cases only laboratory results can definitively identify pathogens. Every state has at least one state public health laboratory to support its infectious diseases surveillance activities and other public health programs. State laboratories conduct testing for routine surveillance or as part of clinical or epidemiologic studies. For rare or unusual pathogens, these laboratories provide diagnostic tests that are not always available in commercial laboratories. For more common pathogens, these laboratories provide testing using new technologies that still need controlled evaluation. State public health laboratories also provide specialized testing for low-incidence, high-risk diseases, such as tuberculosis and botulism. Results from state public health laboratories are used by epidemiologists to document trends and identify events that may indicate an emerging problem.

Upon diagnosing a case involving a notifiable disease, local health providers and others who report notifiable diseases are required to send the reports to state health departments[16] through a variety of state and local disease reporting systems, which range from paper-based reporting to secure, Internet-based systems. Our interviews of public health officials in 11 states found that about half of these states have systems that allow public health care providers to submit reports of notifiable diseases to their state health department over the Internet. For example, state officials in one state we interviewed said their public health department has supported a state-wide Internet-based electronic communicable disease reporting and outbreak alert system since 1995. Officials in another state

[15]Q fever is a zoonotic disease that became a notifiable disease in 1999. Infection of humans usually occurs through inhalation of the disease-causing bacteria. Q fever is difficult to diagnose and this highly infectious agent is resistant to heat and drying. This agent could be developed for use in biological warfare and is considered a potential terrorist threat. In contrast, gonorrhea is a sexually transmitted disease with symptoms that can usually be treated with a single dose of antibiotics.

[16]In some cases, depending on state law, providers and others report first to local health departments, which report the disease information to the state health department. Local health departments may also conduct their own follow-up investigations into reports of notifiable diseases.

told us that since 2002, the state has had a secure statewide Web-based hospital, laboratory, and physician disease-reporting system.

State health officials conduct their own analysis of disease data to verify cases, monitor the incidence of diseases, and identify possible outbreaks. States voluntarily report their notifiable disease data to CDC, using multiple and sometimes duplicative systems. For example, state officials currently report information on gonorrhea to CDC through two CDC systems: the Sexually Transmitted Disease Management Information System (STD*MIS) and the National Electronic Telecommunications System for Surveillance (NETSS). STD*MIS is a national electronic surveillance system that tracks sexually transmitted diseases, including gonorrhea throughout the United States. NETSS is a computerized public health information system used for tracking notifiable diseases. Although states are not legally required to report information on notifiable diseases to CDC, CDC officials explained the agency makes such reporting from the states a prerequisite for receiving certain types of CDC funding. Appendix III provides additional information on NETSS and other types of systems used for disease surveillance.

Federal Agencies and Departments Conduct and Support Disease Surveillance in a Variety of Ways

In partnership with states, the federal government also has a key role in disease surveillance. Federal agencies and departments collect and analyze national disease surveillance data and maintain disease surveillance systems. Federal agencies and departments become involved in investigating the causes of infectious diseases and maintain their own laboratory facilities. Federal agencies and departments also share disease surveillance information. In addition, federal agencies and departments provide funding and technical expertise to support disease surveillance efforts at the state, local, and international levels.

Federal Agencies and Departments Collect and Analyze Surveillance Data Gathered by States

One way federal agencies and departments support disease surveillance is by collecting and analyzing surveillance data gathered by the states. CDC, for example, analyzes the reports it receives from state health departments on cases of notifiable diseases in humans. CDC uses the reports from the states to monitor national health trends, formulate and implement prevention strategies, and evaluate state and federal disease prevention efforts. The agency publishes current data on notifiable diseases in its

Morbidity and Mortality Weekly Report.[17] Like CDC, USDA also collects surveillance data from the states. Specifically, USDA collects information from participating state veterinarians on the presence of specific confirmed clinical diseases in specific livestock, poultry, and aquaculture species in the United States. State animal health officials obtain this information from multiple sources—including veterinary laboratories, public health laboratories, and veterinarians—and report this information to the National Animal Health Reporting System (NAHRS).[18] Similarly, FDA, often in cooperation with CDC, receives and interprets state data. For example, FDA officials told us they analyze state information from CDC on outbreaks of infectious diseases that originate from foods that FDA regulates. FDA then uses this information to trace the regulated food back to its origin and investigate possible sources of contamination. In addition, FDA and CDC interpret data on emerging infectious diseases to establish safeguards to minimize the risk of infectious disease transmission from regulated biological products, such as blood and vaccines.

Federal agencies and departments also collect and analyze information from international sources. For example, CDC and DOD obtain information on potential outbreaks from WHO. According to CDC, in many cases the initial alert of potential outbreaks is reported to WHO through the Global Public Health Intelligence Network (GPHIN), a system developed by Canadian health officials and used by WHO since 1997.[19] GPHIN is an Internet-based application that searches more than 950 news feeds and discussion groups around the world in the media and on the Internet. WHO then verifies the reported outbreak and, if necessary, notifies the global health community. About 40 percent of the

[17]The *Morbidity and Mortality Weekly Report* may include weekly and annual tables on nationally notifiable diseases, periodic surveillance summaries on a wide variety of conditions, and articles on acute infectious disease outbreaks.

[18]NAHRS is a collaborative program with USDA, the U.S. Animal Health Association, the American Association of Veterinary Laboratory Diagnosticians, and participating states. State participation is voluntary and at the end of calendar year 2003, 40 states were active participants in the system, and 5 states were developing plans to begin reporting.

[19]GPHIN is a part of WHO's Global Outbreak Alert and Response Network (GOARN). GOARN is the primary mechanism by which WHO mobilizes technical resources for the investigation of, and response to, disease outbreaks of international importance.

approximately 200 outbreaks investigated and reported to WHO each year come from the GPHIN.[20]

In addition to these formal mechanisms for collecting and analyzing data, federal public health officials stressed the importance of obtaining information through their contacts at state and local health departments, other federal agencies and departments, foreign ministries of health, or other international organizations. For example, according to state public health officials, CDC learned of last year's monkeypox outbreak in one state through a phone call from the state public health department officials. After this initial contact, the state health department officials, in collaboration with officials from CDC, arranged a conference call that included federal officials from CDC and USDA, state and local health department officials, health care providers, and hospital epidemiologists to further share information on the outbreak.

Federal Agencies and Departments Operate and Fund Disease Surveillance Systems

Some federal agencies and departments conduct disease surveillance using disease surveillance systems they operate or fund. These systems gather data from various locations throughout the country to monitor the incidence of infectious diseases. These systems supplement the data on notifiable diseases collected by states and monitor surveillance information states do not collect. In general, these surveillance systems are distinguished from one another by the types of infectious diseases or syndromes they monitor and the sources from which they collect data. Some surveillance systems, known as sentinel surveillance systems, rely on groups of selected health care providers who have agreed to routinely supply information from clinical settings on targeted diseases. Other systems, known as syndromic surveillance systems, monitor the frequency and distribution of health-related symptoms—otherwise known as syndromes—among people within a specific geographic area.[21] Syndromic surveillance systems are designed to detect anomalous increases[22] in certain syndromes, such as skin rashes, that may indicate the beginning of

[20]U.S. General Accounting Office, *Emerging Infectious Diseases: Asian SARS Outbreak Challenged International and National Responses*, GAO-04-564 (Washington, D.C.: Apr. 28, 2004).

[21]Some syndromic surveillance systems monitor data from hospital and emergency room admissions or data from over-the-counter drug sales. Other data sources may include poison control centers, health plan medical records, first aid stations, emergency medical service data, insurer claims, and discharge diagnosis information.

[22]Some increases in symptoms are not anomalous, such as those associated with influenza during influenza season.

an infectious disease outbreak.[23] Because these systems monitor symptoms and other signs of disease outbreaks instead of waiting for clinically confirmed reports or diagnoses of a disease, some experts believe that syndromic surveillance systems help public health officials increase the speed with which they may identify outbreaks.

There are a number of disease surveillance systems operating in the United States that are operated or funded by federal agencies and departments. Some of these include the following:

- *IDSA-EIN—A Sentinel Disease Surveillance System*

  The Infectious Diseases Society of America Emerging Infections Network (IDSA-EIN) consists of about 900 physicians who specialize in infectious diseases.[24] The network conducts surveillance by contacting the physicians every six to eight weeks to request information about any unusual clinical cases they have encountered.[25] IDSA-EIN members, CDC, and state and territorial epidemiologists all receive summaries of the information obtained by the IDSA-EIN.

- *EIP Site Surveillance—Participants Conduct Population-Based Surveillance*

  Participants in CDC's Emerging Infections Programs (EIPs) conduct population-based[26] surveillance of specific diseases in certain locations throughout the United States. As of May 2004, there were 11 EIP sites nationwide that involved partnerships among CDC, state and local public health departments, and academic centers. The 11 EIP sites are California, Colorado, Connecticut, Georgia, Maryland, Minnesota, New Mexico, New York, Oregon, Tennessee, and Texas. The type of surveillance conducted

[23]Anomalous increases in certain syndromes may also indicate an environmental exposure representing a public health threat that may not be infectious.

[24]The IDSA-EIN is supported by a cooperative agreement from the CDC and is overseen by an executive committee with membership from CDC, IDSA, and the Pediatric Infectious Diseases Society.

[25]Members may also submit reports at their own initiative.

[26]The population base for EIP activities is roughly 36 million people, representing an approximation of the U.S. population with respect to demographic characteristics such as age, gender, residence, and race and health indicators, such as population density and percentage of persons at or below the poverty level.

by EIP sites depends on local priorities and expertise. For example, the Connecticut EIP conducts active surveillance for emerging tick-borne diseases in the state.

- *FoodNet—A National Surveillance System for Monitoring Foodborne Diseases*

  One of the principal systems used for surveillance of foodborne diseases is the Foodborne Disease Active Surveillance Network (FoodNet). FoodNet—a collaborative effort among CDC, USDA, FDA, and nine EIP sites[27]—is a system that collects information about the occurrence and causes of certain types of foodborne outbreaks. FoodNet is used to detect cases or outbreaks of foodborne disease, identify their source, recognize trends, and respond to outbreaks. Public health departments that participate in FoodNet receive funds from CDC, USDA, and FDA to systematically contact laboratories in their geographical areas and solicit incidence data. According to CDC, as a result of this active solicitation, FoodNet provides more accurate estimates of the occurrence of foodborne diseases than are otherwise available.

- *ESSENCE—A DOD Syndromic Surveillance System*

  Similar to CDC, DOD maintains its own surveillance system. DOD's ESSENCE is a syndromic surveillance system designed to increase the rapid detection of disease outbreaks. DOD's system collects data on patient symptoms from military treatment facilities and selected civilian populations. ESSENCE then classifies these symptoms into syndrome groups based on presented signs, symptoms, and diagnoses. These syndrome groups include respiratory, fever/malaise/sepsis, gastrointestinal, neurologic, dermatologic, and coma or sudden death. The frequency of these syndromes can be monitored by DOD and participating state public health officials on a daily basis, and unusual increases can be detected through data analysis.

Federal Agencies and Departments Maintain Laboratories and Support Networks of Laboratories

Federal agencies and departments also support networks of laboratories that test specimens and develop diagnostic tests for identifying infectious diseases and biological or chemical agents. In some cases, these laboratories provide highly specialized tests—such as tests for anthrax—that are not always available in state public health or commercial

[27]CDC officials told us that FoodNet would soon be in use in all 11 of its EIP sites.

laboratories, and they assist states with testing during outbreaks. These laboratories help diagnose life-threatening or unusual infectious diseases for which satisfactory tests are not widely or commercially available, and they confirm public or private laboratory test results.[28]

For example, to strengthen the nation's capacity to rapidly detect biological and chemical agents that could be used as a terrorist weapon, CDC, in partnership with the Federal Bureau of Investigation and the Association of Public Health Laboratories, created the Laboratory Response Network (LRN). According to CDC, the LRN, which was created in 1999, leverages the resources of 126 laboratories to maintain an integrated national and international network of laboratories that are fully equipped to respond quickly to acts of chemical or biological terrorism, emerging infectious diseases, and other public health threats and emergencies. The network includes the following types of laboratories—federal, state and local public health, military, and international laboratories, as well as laboratories that specialize in food, environmental, and veterinary testing. LRN laboratories have been used in several public health emergencies. For example, in 2001, a Florida LRN laboratory discovered the presence of *Bacillus anthracis*, the pathogen that causes anthrax, in a clinical specimen it tested.

CDC has also developed and operates PulseNet. PulseNet is a national network of public health laboratories that perform DNA "fingerprinting" on bacteria that may be foodborne.[29] The network identifies and labels each "fingerprint" pattern and permits rapid comparison of these patterns through an electronic database at CDC. This network is intended to provide an early warning system for outbreaks of foodborne disease.

FDA's system, the Electronic Laboratory Exchange Network (eLEXNET), is a Web-based system for real-time sharing of food safety laboratory data

[28]Laboratories are categorized as either Biosafety Level 1, 2, 3, or 4, with Biosafety Level 4 laboratories providing the highest degree of protection to personnel, the environment, and the community. Biosafety levels represent combinations of laboratory practices and techniques, safety equipment, and laboratory facilities. Each combination is specifically appropriate for the operations performed, the documented or suspected routes of transmission of the infectious agents, and the laboratory function or activity. Both CDC and DOD have one Biosafety Level 4 Laboratory.

[29]The "fingerprinting" is called pulsed field gel electrophoresis, which can distinguish strains of an organism, such as *Escherichia coli*, *Salmonella*, *Shigella*, or *Listeria* at the DNA level.

among federal, state, and local agencies. It is a secure system that allows public health officials at multiple government agencies engaged in food safety activities to compare and coordinate laboratory analysis findings. According to FDA officials, it enables public health officials to assess risks and analyze trends, and it provides the necessary infrastructure for an early warning system that identifies potentially hazardous foods. As of July 2004, FDA officials said there were 113 laboratories representing 50 states that are part of the eLEXNET system.

DOD also maintains laboratories that perform and develop diagnostic tests for infectious diseases. For example, the U.S. Army Medical Research Institute of Infectious Diseases (USAMRIID)[30] has the capability to diagnose infectious diseases that require relatively more advanced testing techniques. During the SARS outbreak, CDC requested assistance from USAMRIID to conduct laboratory testing related to the SARS investigation. USAMRIID is also a member of the LRN. In addition, DOD maintains a network of five overseas medical research laboratories that support worldwide efforts to detect and respond to infectious diseases.[31] These five overseas laboratories primarily focus on surveillance for drug-resistant pathogens, unexplained fevers, and influenza. In addition, two of these overseas laboratories are WHO Collaborating Centers.[32]

Like DOD and CDC, the USDA has laboratories that test for infectious diseases. USDA's National Veterinary Services Laboratories is the only federal program in the United States dedicated to testing for domestic and foreign animal diseases. In doing so, it supports surveillance for zoonotic diseases. The National Veterinary Services Laboratories have the ability to test for more than 100 diseases in animals, and some of these—such as rabies, anthrax, and BSE (also known as mad cow disease)—can be transmitted to humans. In addition, the National Animal Health Laboratory Network is a pilot program of diagnostic laboratories that provide animal

[30]USAMRIID is DOD's lead laboratory for conducting research to develop vaccines, drugs, and diagnostics for laboratory analysis related to countering the medical effects of agents used in biological warfare.

[31]These five laboratories are located in Peru, Indonesia, Egypt, Thailand, and Kenya.

[32]A WHO Collaborating Center is a national institution designated by WHO to form part of an international collaborative network that contributes to implementing WHO's program priorities and to strengthening institutional capacity in countries and regions. Collaborating Center activities include collection and dissemination of information, education and training, and participation in collaborative research developed under WHO's leadership. According to CDC, it has more that 20 Collaborating Centers.

disease surveillance testing and develop standardized and rapid diagnostic techniques.[33] According to a USDA official, this network has improved zoonotic disease detection due to the use of better technology, improved coordination among the network laboratories, and improved disease reporting.

Federal Agencies and Departments Share Disease Surveillance Information

As part of their role in national disease surveillance efforts, officials from federal agencies and departments share the surveillance information they collect and analyze with local, state, and international partners. One mechanism federal agencies and departments use to share information is their respective Internet sites. For example, in its annual "Summary of Notifiable Diseases," CDC posts on its Internet site the data it collects from state health departments. The agency also posts information on foodborne diseases on its FoodNet Internet page. During the SARS outbreak, CDC, USDA, FDA, DOD, and DHS posted information about the disease on their respective Web sites. Web site postings included information on clinical evaluation and diagnosis, travel advisories, and assessments of the impact of the outbreak on food consumption in various regions.

CDC also operates an early warning and response system, the Health Alert Network (HAN), that is designed to ensure that state and local health departments as well as other federal agencies and departments have timely access to emerging health information. Through HAN, CDC issues health alerts and other public health bulletins to an estimated 1 million public health officials, including physicians, nurses, laboratory staff, and others. During the SARS outbreak, for instance, CDC used HAN to disseminate what the agency knew about the emerging infectious disease. Also, state officials we interviewed reported receiving updates through HAN on the avian influenza outbreak in Asia. According to CDC, as of March 2003, 89 percent of local health departments have high-speed continuous Internet access and the ability to receive broadcast health alerts.

[33]The National Animal Health Laboratory Network was established as a collaboration among USDA, the National Veterinary Services Laboratories, the American Association of Veterinary Laboratory Diagnosticians, and state laboratory directors.

CDC also shares information on infectious diseases through a restricted communication system, the Epidemic Information Exchange (Epi-X).[34] Developed by CDC, this system is a secure, Web-based communication system operating in all 50 states. CDC uses this system primarily to share information relevant to disease outbreaks with state and local public health officials and with other federal officials. CDC uses Epi-X to issue emergency alerts, but unlike HAN, Epi-X also serves as a forum for routine professional discussions and non-emergency inquiries.[35] Authorized Epi-X users can post questions and reports, query CDC, and receive feedback on ongoing infectious disease control efforts. According to CDC, as of 2004, over 1,200 public health officials at the federal, state, and local levels had used the system to communicate with colleagues and experts, track information for outbreak investigations and response efforts, conduct online discussions, and request assistance. In addition, according to CDC, it has agreements with Canada and Mexico that allow international public health officials to become authorized Epi-X users. These international users include officials from both the Canadian and Mexican Ministries of Health and health officials in Mexican states that border the United States. In addition, CDC staff assigned to WHO and health care providers working internationally for the U.S. Department of State are authorized Epi-X users.

Federal Agencies and Departments Provide Training, Technical Assistance, and Funding

Federal agencies and departments also provide training, technical assistance, and funding to state and international public health officials. For example, to enhance the U.S. public health infrastructure for disease surveillance and response to infectious diseases, CDC operates several programs, including the Epidemiology and Laboratory Capacity (ELC) program, the Epidemic Intelligence Service (EIS) program, and EIP. The ELC program provides training, technical assistance, and funding to 58 state and local health departments. The program assists state and local health departments in maintaining surveillance for infectious diseases,

[34]Participation in Epi-X is limited to public health officials designated by individual health agencies, such as state health departments. These officials—experts engaged in identifying, investigating, and responding to health threats—must obtain pre-approval from the appropriate health agency. Access to Epi-X is limited to these designated officials to ensure the security necessary for the exchange of preliminary information.

[35]Both HAN and Epi-X are systems that operate as part of CDC's Public Health Information Network (PHIN), which coordinates information technology systems and related organizations that support various public health functions. PHIN is intended to enable real-time data flow, computer assisted analysis, professional collaboration, and rapid dissemination of information.

providing technical support through laboratory services, and investigating outbreaks. Additionally, the EIS is a 2-year postgraduate program intended to increase the number of federally trained epidemiologists working in public health. While the majority of EIS officers train at CDC headquarters, others are trained at state and large local health departments. Graduates of the program are employed in federal government, state health departments and other health care settings. Further, the EIP—which is a collaboration among CDC, state health departments, and other public health partners—is a network of sites that acts as a national resource for the surveillance, prevention, and control of emerging infectious diseases. These sites conduct population-based surveillance for selected diseases or syndromes and research that go beyond the routine functions of local health departments to address issues in infectious diseases and public health. CDC provided nearly $20 million in funding to EIPs in fiscal year 2003 in order to support their surveillance and research activities.

In selected foreign locations, CDC operates international training programs, such as the Field Epidemiology Training Program (FETP). For more than 20 years, CDC has collaborated with foreign ministries of health around the world to help establish and conduct field epidemiology training programs in those countries. CDC officials said that through FETP, CDC trains approximately 50 to 60 physicians and social scientists each year from these countries. This training in applied public health integrates disease surveillance, applied research, prevention, and control activities. Graduates of the FETP program serve in their native country and provide links between CDC and their respective ministries of health. CDC officials said that trainees from its international programs have frequently provided important information on disease outbreaks. Another international program sponsored by CDC is the International Emerging Infections Program (IEIP). IEIP sites are modeled on the EIP sites in the United States that integrate disease surveillance, applied research, training, and prevention and control activities. According to CDC, the IEIP in Thailand that was established in 2001 played a key role in the global response to the SARS and avian influenza outbreaks. DOD has also taken steps to increase the international disease surveillance expertise by providing various types of laboratory and epidemiology training through its overseas laboratories.

Some federal agencies and departments also provide direct technical assistance to foreign countries both directly and through WHO. For example, CDC officials told us they provide support in the form of technical assistance and training that supports the development of major international networks that are critical to enhancing global surveillance, such as the WHO Global Influenza Surveillance Network. Additionally,

throughout the SARS outbreak, CDC was the foremost participant in WHO's multilateral efforts to identify and respond to SARS in Asia, with CDC officials constituting about two-thirds of the 115 public health experts deployed to the region. CDC also contributed its expertise and resources by conducting epidemiological studies, laboratory testing, and clinical research on the disease. Specifically, CDC assigned epidemiologists, laboratory scientists, hospital infection control specialists, and environmental engineers to provide technical assistance in Asia. CDC also assigned senior epidemiologists to work locally with a WHO team to investigate the outbreak in China.[36] DOD has also provided technical assistance during investigations of potential outbreaks. For example, DOD established a field laboratory during the Rift Valley fever epidemic in Yemen in 2000 to assist with surveillance during the outbreak.

Public Health Officials Have Implemented Initiatives Intended to Enhance Disease Surveillance, but Challenges Remain

Public health officials at the state and federal level have undertaken several initiatives that are intended to enhance disease surveillance capabilities. Public health officials have implemented and expanded syndromic surveillance systems in order to detect outbreaks more quickly, but there are concerns that these systems are costly to run and still largely untested. Public health officials have also implemented initiatives designed to improve public health communications and disease reporting. However, some of these initiatives have not been fully implemented. Federal public health officials have also undertaken initiatives intended to improve the coordination of zoonotic surveillance efforts. Finally, federal officials have also expanded training programs for epidemiologists and other public health experts.

[36]For more information on CDC's role in fighting SARS in Asia, see U.S. General Accounting Office, *Emerging Infectious Diseases: Asian SARS Outbreak Challenged International and National Responses*, GAO-04-564 (Washington, D.C.: Apr. 28, 2004).

Public Health Officials Have Implemented and Expanded Syndromic Surveillance Systems, but There Are Some Concerns about the Value of This Type of Surveillance

In an effort to enhance the ability to detect infectious disease outbreaks, particularly in their early stages, states have implemented numerous syndromic surveillance systems.[37] Officials from each of the state public health departments we interviewed reported that at least one syndromic surveillance system was used in their state. These systems collect information on syndromes from a variety of sources. For example, the Real-time Outbreak and Disease Surveillance (RODS) system, used in four of the states in our study, automatically gathers patient data from hospital emergency room visits. This system identifies patients' chief medical complaints, classifies the complaints according to syndrome, and aggregates that data in order to look for anomalous increases in certain syndromes that may reveal an infectious disease outbreak.

Another syndromic surveillance system used by some state public health officials that we interviewed, the National Retail Data Monitor (NRDM), collects data from retail sources instead of hospitals. As of February 2004, NRDM collected sales data from about 19,000 stores, including pharmacies, in order to monitor sales patterns in such items as over-the counter influenza medications for signs of a developing infectious disease outbreak. The system looks for unusual sales patterns—such as a spike in the number of over-the-counter medications purchased in a particular city or county—that might indicate the onset of an infectious disease outbreak. The system monitors the data automatically on a daily basis and generates summaries of sales patterns using timelines and maps.

At the federal level, CDC has recently introduced a new syndromic surveillance system called BioSense. BioSense aggregates data from numerous electronic sources to enhance early detection of possible disease outbreaks, bioterrorist threats, or other urgent public health threats. The data are collected and analyzed by CDC and also made available to state and local public health departments. In the first quarter of 2004, BioSense became available for use, gathering data from DOD and the Department of Veterans Affairs medical treatment facilities in the United States and more than 10,000 over-the-counter retail drug stores nationwide. According to CDC, the agency plans to add other data sources, such as data from laboratories, poison control centers, health plan medical records, nursing call centers, emergency medical service

[37]Many syndromic surveillance systems currently in use in the United States were developed in response to the September 11, 2001 attacks on the World Trade Center and Pentagon and to the anthrax outbreaks that occurred shortly afterwards.

dispatches, health care provider billing claims, and pharmacy prescriptions.

Since the end of 2001, DOD has made enhancements designed to improve its syndromic surveillance system, ESSENCE. Specifically, DOD expanded ESSENCE to include data from all military treatment facilities worldwide and data from various civilian sources, such as civilian intensive care units, over-the-counter pharmacies, school attendance records and laboratory test results. In addition, DOD officials told us they are in the process of improving ESSENCE's mapping capabilities and developing more advanced statistical algorithms for identifying anomalous increases in syndromes. DOD officials also told us that they are exploring additional data sources for ESSENCE, such as large health maintenance organizations, and working on improving the speed at which the system's data can be accessed.

Although syndromic surveillance systems are used by federal agencies and departments and in all 11 of the states whose officials we interviewed, concerns about this approach to surveillance have been raised. Relative to traditional methods of surveillance, syndromic surveillance systems are costly to maintain and still largely untested. According to a recent IOM report, the resource requirements for automatic reporting of syndromic data from hospitals, clinics, and emergency departments are currently high, but these costs may lessen over time with standardization of software.[38] Syndromic surveillance systems require relatively more resources to operate than other types of surveillance systems, in part, because their sensitivity makes them more likely to issue false alarms, which in turn have the potential to overtax public health systems. Furthermore, some state officials as well as public health experts noted that it has not been demonstrated in a rigorous way that these systems can detect emerging infectious diseases or bioterrorist events more rapidly than they would otherwise be detected through traditional surveillance. According to public health experts, evaluation tools, performance measures and evidence-based standards for syndromic surveillance are needed. CDC recently published a "Framework for Evaluating Public

[38]See Institute of Medicine, *Microbial Threats to Health: Emergence, Detection and Response* (Washington, D.C.: 2003), 172.

Health Surveillance Systems for Early Detection of Outbreaks."[39] This framework creates a standardized evaluation methodology intended to help public health officials improve decision-making regarding the implementation of syndromic and other surveillance systems for outbreak detection.

Public Health Officials Are Implementing Initiatives Designed to Enhance Public Health Communications and Disease Reporting, but Some Initiatives Are Incomplete

CDC is taking steps to enhance its two public health communications systems, HAN and Epi-X, which are used in disease surveillance and response efforts. For example, CDC is working to increase the number of HAN participants who receive assistance with their communication capacities. According to CDC, the agency will continue to increase the number of local jurisdictions that have high-speed Internet capability from 90 percent to 100 percent. Similarly, CDC has expanded Epi-X by giving officials at other federal agencies and departments, such as DOD, the ability to use the system. In addition, CDC is also adding users to Epi-X from local health departments, giving access to CDC staff in other countries, and making the system available to FETPs located in 21 countries. Finally, CDC is facilitating Epi-X's interface with other data sources by allowing users to access GPHIN, the system that searches Web-based media for information on infectious disease outbreaks worldwide.

In addition to the efforts to enhance communication systems, public health officials are taking steps to enhance the reporting of notifiable disease data and other surveillance information. Some of the state public health officials we interviewed told us that they have implemented efforts to increase health care providers' reporting of notifiable diseases to their state health department. For example, an official from one state we interviewed said that the state health department now uses liaisons that regularly visit health care providers to establish regular communication between the providers and local public health authorities. The liaisons remind the providers of their responsibility for reporting cases of notifiable diseases to the state. Similarly, the Commissioner of Health from another state sent letters to health care providers in the state, reminding the providers of their important role in recognizing an infectious disease outbreak or bioterrorist event. The letter contained information on

[39]Department of Health and Human Services, Centers for Disease Control and Prevention, "Framework for Evaluating Public Health Surveillance Systems for Early Detection of Outbreaks," *Morbidity and Mortality Weekly Report*, vol. 53 (2004). According to CDC, this builds on the earlier *Updated Guidelines for Evaluating Public Health Surveillance Systems* published in 2001.

changes to the state's notifiable disease list, a listing of references and Internet sites for clinical information on specific pathogens, and information on the Internet-based communication system the state department of health used to disseminate and gather sensitive information regarding disease surveillance.

Despite some states' efforts to increase disease reporting by health care providers, some public health experts believe that underreporting by providers is still a problem. According to the IOM, many health care providers do not fully understand their role in infectious disease surveillance, including the importance of prompt reporting of clinical information to relevant public health authorities. According to the study, few medical or other health science schools' curricula emphasize the importance of and the requirements for reporting diseases of public health significance; residency programs seldom address the need for health care provider participation in public health surveillance; and little, if any, continuing medical education exists on the topic, nor is it widely integrated into board certification exams. Furthermore, despite the existence of state notifiable disease lists and related laws, some providers may be unaware of basic reporting requirements. One study noted that health care providers failed to report disease information because they often lacked information about what, when, and how to report such information.[40]

Other efforts by public health officials to enhance notifiable disease reporting target the information technology used in such reporting. For example, public health officials in several states told us that they are enhancing their electronic systems to permit providers in their states to report notifiable diseases to the states' health department. For example, public health officials in one state told us that they are enhancing their reporting system to permit 20,000 to 30,000 physicians to report 61 notifiable diseases using an integrated, secure, Web-based system. Similarly, some states have also implemented electronic reporting systems that obtain information on notifiable diseases directly from clinical laboratories. When the laboratories conduct tests for health care providers on cases that may involve notifiable diseases, in some states the results of those tests—if positive—are automatically reported to the state health

[40]Nkuchia M'ikanatha et al., "Use of the Web by State and Territorial Health Departments to Promote Reporting of Infectious Disease," *Journal of the American Medical Association*, vol. 291, no. 9, 1069-1070, (2004).

department. Several state public health officials we interviewed told us that they receive electronic laboratory reports from clinical laboratories in their state. Other state officials told us that they were developing or piloting this capability. According to state public health officials and IOM, automated laboratory reporting of notifiable infectious diseases has been shown to improve the timeliness of reporting on these diseases.

At the federal level, CDC is deploying a technological initiative known as NEDSS. According to CDC, this initiative is designed to make the electronic reporting from both clinical laboratories and practitioners to state and local health departments and from state and local health departments to CDC more timely, accurate, and complete. CDC officials said that NEDSS will facilitate reporting by supporting a unified and standardized way of transmitting information to CDC, and result in the integration of 60 to 100 different systems used by state health departments to report disease data to CDC. As part of the NEDSS initiative, CDC is developing an architecture that consists of a set of standards that can be used for creating interoperable[41] systems. These standards comprise (1) data standards,[42] (2) parameters for an Internet-based communications infrastructure and (3) policy-level agreements on data access and sharing as well as on protections for confidentiality. CDC has also developed ready-to-use software—the NEDSS-Base system (NBS)—that operates within these standards. State and local health departments that are updating their reporting systems have the option of either using the NBS software or developing their own systems based on the common NEDSS architecture.

According to CDC, when fully implemented, the use of NEDSS-architecture-compliant-software or NBS software by local and state public health departments and CDC will allow public health partners to exchange data, merge data from different laboratories, and obtain information on cross-jurisdictional outbreaks. Whereas states currently use multiple and sometimes duplicative systems to report different notifiable diseases to CDC, NEDSS will replace many of these systems with a single system. For example, the National Electronic Telecommunications System for

[41]Interoperability is the ability of two or more systems or components to exchange information and to use the information that has been exchanged.

[42]Data standards will govern the way surveillance data are assembled and transmitted. These standards include common definitions and codes for medical terms as well as accepted sequences for transmitting complex segments of data.

Surveillance (NETSS), STD*MIS (sexually transmitted diseases), TIMMS (tuberculosis), STELLAR (lead poisoning in children) and EHARS (HIV) will be consolidated through NEDSS.

Despite the advantages that may be gained from creating interoperable systems, the NEDSS initiative has not been implemented in many states. The NEDSS initiative first began in fiscal year 2000,[43] and by May 2004, only 4 states that use the NBS software are able to transfer data to CDC. According to CDC, 10 states are actively deploying NEDSS-architecture-compliant-software or NBS software and 16 states are in the preliminary process of developing their technical and security infrastructure to accommodate NEDSS standards. Some state officials told us that even though they have developed electronic systems that comply with the NEDSS standards, they have not been able to transfer data to CDC using their systems because the systems are still not compatible. CDC officials said that the national industry standards on design, development, and data transport have continued to evolve and they are working with the states to receive data from those who opted to use the NEDDS architecture to develop their own compliant software.[44]

Federal Public Health Officials Have Enhanced Federal Coordination on Zoonotic Disease Surveillance and Expanded Training Programs, but Surveillance Efforts Still Face Challenges

CDC, USDA, and FDA have made recent efforts to enhance their coordination of zoonotic disease surveillance. For example, CDC and UDSA are working with two national laboratory associations to enhance coordination of zoonotic disease surveillance by adding veterinary diagnostic laboratories to the LRN. As of May 2004, 10 veterinary laboratories have been added to the LRN, and CDC officials told us that they have plans to add more veterinary laboratories in the future. In addition, CDC officials told us it has appointed a staff person whose responsibility, in part, is to assist in finding ways to enhance zoonotic disease coordination efforts among federal agencies and departments and with other organizations. This person is helping CDC reconstruct a working group of officials from CDC, USDA, and FDA to coordinate on

[43]While the NEDSS initiative first began in fiscal year 2000, the 1995 report *Integrating Public Health Information and Surveillance Systems* by The Steering Committee on Public Health Information and Surveillance Systems was the basis for the NEDSS initiative.

[44]According to CDC, a recent effort by a standards development group has lead to an agreement on a standard message for transmission of data from states to CDC.

zoonotic disease surveillance.[45] According to CDC officials, the goal of this working group is to explore ways to link existing surveillance systems to better coordinate and integrate surveillance for wildlife, domestic animal, and human diseases. CDC officials also said that the feasibility of a pilot project to demonstrate this proposed integrated zoonotic disease surveillance system is being explored. Finally, USDA officials told us that they hired 23 wildlife biologists in the fall of 2003 to coordinate disease surveillance, monitoring, and management activities among USDA, CDC, states and other agencies. While each of these initiatives is intended to enhance the surveillance of zoonotic diseases, each is still in the planning stage or the very early stages of implementation.

Another way CDC has worked to enhance disease surveillance is through its support for epidemiological training programs. In general, these programs are aimed at developing an experienced workforce for state and local public health departments and disease surveillance systems.[46] For example, in recent years, CDC has expanded its EIS program. CDC has increased the number of participants in this program from 148 in 2001 to 167 in 2003. During this time period, CDC has also increased the number of EIS participants assigned to state and local health departments from 25-35 per year to about 50 per year. CDC has also enhanced the type of training the participants receive. All participants now receive training in terrorism preparedness and emergency response.

CDC has also expanded its training programs intended to increase the expertise involved in international disease surveillance efforts. For example, CDC is helping to implement a comprehensive system of surveillance and containment of global infectious diseases through the expansion of its IEIP and the creation of the Field Epidemiology and Laboratory Training Program (FELTP). CDC is enhancing a comprehensive global surveillance and response network for infectious diseases by adding two new IEIP sites in China and Kenya and by expanding activities in the existing site in Thailand. CDC officials said that the program in Kenya began in June 2004 and they may be able to begin

[45]This working group was created in response to a congressional mandate that the Secretary of Health and Human Services, through FDA and CDC, and USDA, coordinate the surveillance of zoonotic diseases. Public Health Security and Bioterrorism Preparedness and Response Act of 2002, Pub. L. No. 107-188, §313, 116 Stat. 594, 674 (2002).

[46]A recent IOM report notes that in 2001, it was estimated that U.S. public health departments needed at least 600 new epidemiologists merely to meet the requirements for bioterrorism preparedness.

recruitment for the program in China by the end of 2004. CDC is expanding its FETP program by creating a laboratory training component, known as the FELTP. According to CDC officials, FELTPs are designed to increase laboratory capacity in overseas locations. Currently, there is one FELTP located in Kenya whose students recently began their training program.

The efforts to build disease surveillance capacities abroad, which were discussed above, may also help domestic disease surveillance efforts. According to a recent IOM report, surveillance of and response to emerging infectious diseases in other parts of the world can directly benefit the United States as well as the country in which the disease is detected.[47] According to the IOM, some disease outbreaks that have been detected internationally allowed the United States to develop diagnostic tests, prepare for influenza outbreaks, or recognize zoonotic threats like avian influenza. Similarly, the IOM points out that coordination between U.S. and European sentinel surveillance systems have allowed several countries, including the United States, to remove products from the market that were contaminated with pathogens.

On the other hand, efforts to enhance international disease surveillance still face challenges. Foremost among these are limitations in the amount of surveillance information that many countries can collect and therefore share with international partners. Many developing countries lack health care infrastructures and the ability to administer simple diagnostic tests for diseases such as tuberculosis. We have previously reported that few developing countries have public heath laboratories.[48] Also, many developing countries lack the ability to compile basic health indices, such as death rates, causes of death, or general disease burden. Furthermore, even countries with public health infrastructures may lack developed surveillance systems for reporting crucial disease information to authorities. For example, officials in China noted that during the first SARS outbreak, a large number of cases in Beijing were not reported because there was no system to collect this information from hospitals in the city.

[47]Institute of Medicine, *Microbial Threats to Health: Emergence, Detection and Response* (Washington, D.C.: 2003).

[48]U.S. General Accounting Office, *Global Health: Challenges in Improving Infectious Disease Surveillance Systems*, GAO-01-722 (Washington, D.C.: Aug. 31, 2001).

Concluding Observations

The threat posed by infectious diseases has continued to grow as new diseases have emerged and as known diseases have reappeared with increased frequency. In addition, there are concerns about the threat posed by the deployment of infectious disease pathogens as instruments of terror or weapons of war. The U.S. surveillance system is built largely on cooperation among many different individuals and entities at the local level. State and federal initiatives to enhance their ongoing disease surveillance efforts are important to ensure that disease surveillance in the United States can meet the threat posed by infectious diseases. Some of these initiatives, such as improvements to information technology, offer the possibility of increasing the accuracy and timeliness of disease surveillance. As state and federal public health officials develop these initiatives, their ongoing evaluation efforts may help decision-makers address technical issues and allocate resources to the most effective disease surveillance systems.

Agency Comments and Our Evaluation

HHS, USDA, and DOD reviewed a draft of this report. HHS provided written comments.

In its written comments, HHS stated that the draft captures many important issues in surveillance. However, HHS stated that the draft includes a discussion of programs that do not directly pertain to surveillance for emerging infectious diseases. In this report, we defined surveillance activities to include detecting and reporting cases of disease, analyzing and confirming this information to identify possible outbreaks or longer-term trends, and applying the information to inform public health decision-making; and the programs and surveillance systems discussed in this report fit within that definition.

HHS's written comments also stated that the report should characterize the essential purpose of the NEDSS initiative as an initiative designed to transform surveillance at the local and/or state health department level. It said that the current gap NEDSS seeks to address is primarily between the clinical sector and local and state public health departments. We have added information to indicate that NEDSS is designed to enhance the electronic reporting of information from both clinical laboratories and practitioners to state and local health departments and from state and local health departments to CDC.

HHS's written comments also pointed out that FDA does not collect surveillance reports on foodborne outbreaks as a part of a national surveillance system, but that CDC shares its findings with FDA. We have clarified the report to say that FDA analyzes state information it receives from CDC. HHS's written comments also suggested that information be added to the draft report. Specifically, it said that the draft report should have described the PulseNet network and should have included information on CDC's technical advice and training that supports major international networks, such as the WHO Global Influenza Surveillance Network. Although this report only provides examples of selected surveillance systems and we could not describe all systems, we have added some information on these networks.

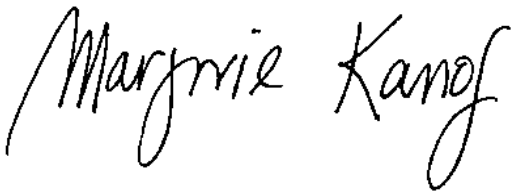
Finally, HHS said that we should clarify that CDC is the lead agency for human disease surveillance and that it fulfills this responsibility in close collaboration with states, other federal agencies, WHO, and other partners. As we noted in the draft report, CDC is charged with protecting the nation's public health by directing efforts to prevent and control diseases and CDC has primary responsibility for conducting national disease surveillance.

HHS's comments are reprinted in appendix IV. In providing oral comments on a draft of this report, DOD said it concurred and did not have any substantive comments. USDA said it had no comments on the draft report. HHS and USDA provided technical comments that we incorporated where appropriate.

As agreed with your office, we plan no further distribution of this report until 30 days from its date of issue, unless you publicly announce its contents. At that time, we will send copies of this report to the Secretaries of Health and Human Services, Agriculture, and Defense; appropriate congressional committees; and other interested parties. We will also make copies available to others upon request. In addition, the report will be available at no charge on GAO's Web site at http://www.gao.gov.

If you or your staff have any questions about this report, please contact me at (202) 512-7119. Other contacts and staff acknowledgments are listed in appendix V.

Sincerely yours,



Marjorie Kanof
Managing Director—Health Care Issues

Appendix I: Scope and Methodology

To describe how state and federal public health officials conduct disease surveillance, we reviewed state documents—such as state policy manuals, reports, cooperative agreements with the Centers for Disease Control and Prevention (CDC), and various other documents—from 11 states. These states—California, Colorado, Indiana, Louisiana, Minnesota, New York, Pennsylvania, Tennessee, Texas, Washington, and Wisconsin—were selected based on their participation in CDC's Emerging Infections Program, each state's most recent infectious disease outbreak, and their geographic location. Of these 11 states, California, Colorado, Minnesota, New York, Tennessee, and Texas participate in CDC's Emerging Infections Program. We also conducted structured interviews of state public health officials from these states. In addition to our structured questions, we asked public health officials from Colorado, Louisiana, and New York questions about their most recent West Nile outbreak. We asked public health officials from Indiana and Wisconsin questions about their monkeypox outbreak, and public health officials from Pennsylvania and Tennessee about their hepatitis A outbreak. We asked public health officials from the remaining states—California, Minnesota, Texas, and Washington—to describe their respective experiences with their most recent infectious disease outbreak, which included outbreaks of wound botulism and severe acute respiratory syndrome (SARS). We also reviewed documents and interviewed officials from the Departments of Agriculture, Defense, and Homeland Security; CDC, and the Food and Drug Administration. In addition, we interviewed representatives from professional associations representing state and local public health officials. These associations included the Association of Public Health Laboratories, the Association of State and Territorial Health Officials, Council of State and Territorial Epidemiologists, and the National Association of County and City Health Officials. We reviewed related publications by these professional organizations, including studies and position papers written by these associations.

To identify initiatives intended to enhance disease surveillance, we reviewed information on states' initiatives designed to enhance infectious disease surveillance, including the use of syndromic surveillance systems, information technology systems, and journal articles assessing the value of syndromic surveillance systems. We also interviewed public health officials from the 11 states and representatives from professional associations about their assessments of enhancements and continuing concern in infectious disease surveillance efforts. To identify federal initiatives to enhance disease surveillance, we reviewed related federal documents, including federal policy directives, agency and departmental strategies, and annual reports. In addition, we interviewed federal health

officials involved in disease surveillance, asking them about efforts to enhance existing surveillance programs and activities. We also reviewed reports and recommendations published by the Institute of Medicine related to emerging infectious diseases. We focused our review of initiatives intended to enhance surveillance on those currently underway or implemented since 2001. We conducted our work from October 2003 through July 2004 in accordance with generally accepted government auditing standards.

Appendix II: Information on Nationally Notifiable Infectious Diseases and Selected Worldwide Emerging Infectious Diseases

This appendix provides descriptions of the diseases contained on the U.S. List of Nationally Notifiable Infectious Diseases for 2004 as well as other selected worldwide emerging infectious diseases.

Description of U.S. List of Nationally Notifiable Infectious Diseases, 2004

Acquired immunodeficiency syndrome (AIDS) is caused by the human immunodeficiency virus (HIV), which progressively destroys the body's immune system. AIDS patients may contract opportunistic infections that usually do not make healthy people sick. Symptoms of opportunistic infections common in people with AIDS include coughing and shortness of breath, seizures, difficult or painful swallowing, fever, vision loss, nausea, weight loss and extreme fatigue, severe headaches, and coma. The term AIDS applies to the most advanced stages of HIV infection.

Anthrax is an acute infectious disease caused by a bacterium commonly found in the soil. Although anthrax can infect humans, it occurs most commonly in plant-eating animals. Human anthrax infections have usually resulted from occupational exposure to infected animals or contaminated animal products. Anthrax infection can take one of three forms: cutaneous, usually through a cut or an abrasion; gastrointestinal, usually by ingesting undercooked contaminated meat; or inhalation, by breathing airborne anthrax spores into the lungs. The symptoms are different for each form and usually occur within 7 days of exposure. Anthrax can be treated with antibiotics and a vaccine is available.

Botulism is a muscle-paralyzing disease caused by a bacterial toxin. Symptoms of botulism include double vision, blurred vision, drooping eyelids, slurred speech, difficulty swallowing, dry mouth, and muscle weakness that always descends through the body. Paralysis of breathing muscles can cause a person to stop breathing and die, unless mechanical assistance is provided. An antitoxin exists that is effective in reducing the severity of symptoms if administered early in the course of the disease.

Brucellosis, a disease of animals, is transmitted to humans through contact with infected animals or contaminated milk. Infection produces a wide range of symptoms, including fever, generalized aches and pains, and fatigue, which may last from a few weeks to several months. Brucellosis can be treated with antibiotics.

Chancroid is a highly contagious sexually transmitted disease (STD) caused by a bacterial infection. Transmission results through either skin-to-skin contact with open sore(s) or when contact is made with the pus-like fluid from the ulcer. Chancroid causes ulcers, usually of the genitals

and if left untreated, may facilitate the transmission of HIV. Chancroid can successfully be treated with antibiotics.

Chlamydial infection is a STD resulting from a bacterial infection. One of the most widespread bacterial STDs in the United States, genital chlamydial infection can occur during oral, vaginal, or anal sexual contact with an infected partner. Because chlamydial infection does not make most people sick, infected persons may not know they have it and symptoms that do develop may be mild. Chlamydial infection is treated with antibiotics. However, if left untreated, it can lead to serious illnesses.

Cholera is a bacterial illness that is contracted by ingesting contaminated water or food. Infection results in acute watery diarrhea, leading to extreme dehydration and death if left unaddressed. Known vaccines and antibiotics have only limited impact on the disease—treatment focuses on rehydration. In the United States, cholera has been virtually eliminated by modern sewage and water treatment systems. However, travelers have brought contaminated seafood back to the United States resulting in foodborne outbreaks.

Coccidioidomycosis is a disease caused by a fungus that grows as a mold in the soil. It is transmitted through inhalation after a disturbance of contaminated soil by humans or natural disasters, such as earthquakes and usually presents as a flu-like illness with symptoms such as fever, cough, headaches, and rash. Although most infections are undetectable, it can cause serious and life-threatening infections, especially among the immunosuppressed. The disease causing fungus is endemic in soil in semiarid areas, including the Southwestern United States. Various drugs are now available to treat this disease.

Cryptosporidiosis is caused by a microscopic parasite and can be spread through contaminated water, uncooked contaminated foods, including fruits and vegetables, and any surface that has been in contact with the parasite. Symptoms include diarrhea, stomach cramps or upset stomach, and a slight fever. People with weak immune systems may have more serious reactions. There is currently no consistently effective treatment for this disease.

Cyclosporiasis is a foodborne illness caused by a microscopic parasite that infects the small intestine. Humans contract the illness by ingesting contaminated water or food. Cyclosporiasis usually results in watery diarrhea. Other symptoms can include loss of appetite, substantial weight

loss, bloating, stomach cramps, nausea, muscle aches, and fatigue. This disease is often treated with a combination of two antibiotics.

Diphtheria is a respiratory disease occurring worldwide that is spread through coughing and sneezing. Symptoms range from mild to severe and can be complicated by damage to the heart muscle or peripheral nerves. Treatment for diphtheria consists of immediate administration of diphtheria antitoxin and antibiotics.

Ehrlichiosis is the general name used to describe several bacterial diseases that affect humans and animals. In the United States, the disease is transmitted through the bite of an infected tick. Early clinical presentations of ehrlichiosis may resemble nonspecific signs and symptoms of various other infectious and non-infectious diseases, such as fever, headache, and muscle ache. In some cases, patients develop a very mild form of the disease and may not seek medical attention or present any symptoms. In other cases, Ehrlichiosis may be treated with an antibiotic. The disease occurs primarily in the southeastern and south central regions of the United States.

Encephalitis, Arboviral is an inflammation of the brain that may be caused by arthropod-borne viruses, also called arboviruses. Six types of arboviral encephalitides are present in the United States—eastern equine encephalitis, western equine encephalitis, St. Louis encephalitis, La Crosse encephalitis, and West Nile encephalitis, all of which are transmitted by mosquitoes, and Powassan encephalitis, which is transmitted by ticks. The majority of human infections are asymptomatic or may result in a nonspecific flu-like syndrome. However, in a small proportion of cases, infections may lead to death or permanent neurologic damage. No effective antiviral drugs have been discovered and there are no commercially available human vaccines for these diseases.

Enterohemorrhagic *Escherichia coli (E. coli)* is a bacterium that includes multiple serotypes, such as E. coli O157:H7, that can cause gastroenteritis in humans. E. coli is normally found in the intestines and serves a useful function in the body. However, a minority of E. coli strains are capable of causing human illness. Transmission occurs by ingesting contaminated food or water. Infections vary in severity and may be characterized by diarrhea (often bloody) and abdominal cramps. The illness is usually self-limited and lasts for an average of 8 days.

Giardiasis is a diarrheal illness caused by a one-celled, microscopic parasite in the intestines of humans and animals. It has become recognized

as one of the most common causes of waterborne disease in humans in the United States. Humans may contract the disease by accidentally swallowing the parasite, such as through swallowing contaminated water or eating uncooked, contaminated food. Symptoms of giardiasis include diarrhea, loose or watery stool, stomach cramps, and upset stomach. Several drugs are available to treat this disease.

Gonorrhea is a bacterial STD that infects the genital tract, the mouth, and the rectum. Gonorrhea is transmitted during sexual intercourse and affects both women and men. Symptoms in women include bleeding associated with vaginal intercourse and painful or burning sensations when urinating. Symptoms in men include pus from the penis and pain and burning sensations during urination. Gonorrhea is usually treated with antibiotics.

Haemophilus influenzae is a bacterium found in the nose and throat that is transmitted through direct contact with respiratory droplets from a carrier or patient. It causes a variety of illnesses including meningitis (inflammation of the coverings of the spinal column and brain), bacteremia (infection of the blood), pneumonia (infection of the lungs), and septic arthritis (infection of the joints). Serious infections are treated with specific antibiotics.

Hansen's disease (leprosy) is a chronic bacterial infection for which the exact mode of transmission is not fully understood. However, most investigators think that the bacterium is usually spread from human-to-human through respiratory droplets. Primarily affecting the skin, nerves, and mucous membranes, leprosy causes deformities of the face and extremities after many years but those receiving antibiotic treatment are considered free of active infection.

Hantavirus pulmonary syndrome is caused by several strains of a virus that is transmitted by exposure to infected rodents. Symptoms include fever, fatigue, muscle aches, coughing, and shortness of breath; the onset of respiratory distress often leads to death. There is no specific treatment for the disease, other than appropriate management of respiratory problems. The virus was first identified in the Southwestern United States in 1993.

Hemolytic uremic syndrome is one of the most common causes of sudden, short-term kidney failure in children. Most cases occur after an infection of the digestive system by a specific E. coli bacterium. It develops when the bacteria lodged in the digestive system make toxins that enter the bloodstream and start to destroy red blood cells. Symptoms

may not become apparent until a week after the digestive problems and include, paleness, tiredness, and irritability, as well as small, unexplained bruises or bleeding from the nose or mouth. Treatments usually consist of maintaining normal salt and water levels in the body, but may include blood transfusions.

Hepatitis A is an acute viral infection of the liver. Human-to-human transmission of hepatitis A often occurs by placing something contaminated in the mouth. Symptoms include jaundice, fatigue, abdominal pain, loss of appetite, nausea, diarrhea, and fever. A vaccine is available for protection against hepatitis A and once a person has had the disease, it cannot be contracted again.

Hepatitis B is a viral infection of the liver that is transmitted by contact with the body fluids of an infected person. The virus may cause an acute illness, as well as a life-long infection that carries a high risk of serious illness or eventual death from liver cancer or cirrhosis. Symptoms include jaundice, fatigue, abdominal pain, loss of appetite, nausea, vomiting, and joint pain. An effective vaccine that has been available for this disease since 1982 is the best protection against hepatitis B. Treatment is also available for chronic hepatitis B.

Hepatitis C is a viral infection of the liver that may be either acute or chronic and is transmitted by contact with the body fluids of an infected person. Symptoms of this disease include jaundice, fatigue, dark urine, abdominal pain, loss of appetite, and nausea. There is currently no vaccine available for hepatitis C; however two drugs are available for treatment.

Human immunodeficiency virus (HIV) causes AIDS and is transmitted through contact with the body fluids of an infected person or from mother to baby. Infected adults may be asymptomatic for 10 years or more. Because the immune system is weakened there is eventually greater susceptibility to opportunistic diseases such as pneumonia and tuberculosis. Drugs are available that can prevent transmission from pregnant mothers to their unborn children and can help slow the onset of AIDS.

Legionellosis is a bacterial infection that has two distinct forms—Legionnaires' disease, the more severe form of infection, which includes pneumonia, and Pontiac fever, a milder illness. Legionellosis outbreaks have often occurred after persons have breathed mists that come from a contaminated water source. Symptoms for Legionnaires' disease usually include fever, chills, and a cough. Chest X-rays often show pneumonia;

however additional tests are needed to confirm diagnosis. Those with Pontiac fever experience fever and muscle aches and do not have pneumonia. Legionnaires' disease is treated with antibiotics, while those with Pontiac fever generally recover without treatment.

Listeriosis is a bacterial foodborne illness. The disease affects primarily pregnant women, newborns, and adults with weakened immune systems and is spread through the consumption of contaminated food. Symptoms of listeriosis include fever, muscle aches, and, at times, gastrointestinal symptoms, such as nausea or diarrhea. Listeriosis is treated with antibiotics.

Lyme disease is a bacterial illness transmitted by ticks. The area around the tick bite sometimes develops a "bull's eye" rash, typically accompanied by fever, headache, and musculoskeletal aches and pains. There is an effective vaccine for adults at high risk. If untreated by antibiotics, arthritis, neurologic abnormalities, and—rarely—cardiac problems may follow. The disease is rarely, if ever, fatal and is endemic in North America and Europe. The pathogen for Lyme disease was first detected in the United States in 1982.

Malaria is a parasitic disease transmitted by infected mosquitoes. Symptoms include fever, shivering, joint pain, headache, repeated vomiting, severe anemia, convulsions, coma, and, in severe cases, death. Malaria is becoming increasingly resistant to known antimalarial treatments and is now reemerging in countries where it was once under control.

Measles is a highly contagious viral disease, transmitted through human-to-human contact, such as by coughing or sneezing. It often strikes children and causes fever, conjunctivitis, congestion, and cough, followed by a rash. Secondary infections often cause further complications. A measles vaccine is available.

Meningococcal disease, caused by a particular type of bacteria, is transmitted by human-to-human contact and is characterized by sudden onset of fever, headache, neck stiffness, and altered consciousness. There is a vaccine for this disease, but it loses its effectiveness over time and must be repeated.

Mumps is a viral disease of the lymph nodes, transmitted though human-to-human contact, such as by coughing or sneezing. Symptoms include fever, headache, muscle ache, and swelling of the lymph nodes close to the jaw. A vaccine is available to prevent mumps.

Pertussis (whooping cough) is a highly contagious bacterial disease transmitted though human-to-human contact, such as by coughing or sneezing. Symptoms include runny nose and sneezing, a mild fever, and a cough that gradually becomes more severe, turning into coughing spasms that end in vomiting and exhaustion. Pertussis is treatable with antibiotics, and a pertussis vaccine is available.

Plague, a severe bacterial infection, is usually transmitted to humans by infected rodent fleas (bubonic plague) and uncommonly by human-to-human respiratory exposure (pneumonic plague). Symptoms of bubonic plague include swollen, painful lymph glands, fever, chills, headache, and exhaustion. People with pneumonic plague develop cough, bloody sputum, and breathing difficulty. Plague is treatable with antibiotics if diagnosed early.

Poliomyelitis, paralytic (polio) is a virus transmitted through human-to-human contact. In most cases, there are no symptoms or only mild, flu-like symptoms. However, it may lead to debility of the lower extremities. Although there is no cure, an effective vaccine is available.

Psittacosis (parrot fever) is a bacterial infection that is spread from birds to humans. Humans become infected by inhaling aerosolized dried bird droppings and by handling infected birds. Symptoms of psittacosis include fever, headache, rash, chills, and sometimes pneumonia. The disease is treatable with antibiotics.

Q Fever is a bacterial disease that is spread from livestock or domesticated pets to humans. Infection of humans usually occurs by inhalation of barnyard dust contaminated with animal fluids. Symptoms for Q fever are not specific to this disease, making it difficult to make an accurate diagnosis without appropriate laboratory testing. However, most acute cases begin with a sudden onset of symptoms such as high fevers, severe headache, confusion, sore throat, nausea, vomiting, abdominal pain, and chest pain. Q fever is treated with antibiotics.

Rabies is a viral disease transmitted through contact with saliva of infected animals. Symptoms progress from respiratory, gastrointestinal, or central nervous system affliction to hyperactivity to complete paralysis,

coma, and death. Once symptoms start to appear, the disease is not treatable. Multiple-dose courses of vaccine and immunoglobulin can be used to prevent onset of the disease if administered immediately after contact with a suspected carrier.

Rocky Mountain spotted fever is a bacterial disease spread to humans by ticks. It can be difficult to diagnose in the early stages. Initial signs and symptoms of the disease include sudden onset of fever, headache, and muscle pain, followed by the development of a rash. Without prompt and appropriate treatment of antibiotics, it can be fatal.

Rubella is a viral disease that is transmitted through human-to-human contact, such as by coughing and sneezing. Symptoms of this disease include a rash, conjunctivitis, low fever, and nausea. Natural rubella infection normally confers lifelong immunity. A number of vaccines for rubella are also available.

Congenital rubella syndrome is a form of rubella that is characterized by multiple defects, particularly to the brain, heart, eyes, and ears. This syndrome is an important cause of hearing and visual impairment and mental retardation in areas where the mild form of rubella has not been controlled or eliminated. The primary purpose of the rubella vaccine is to prevent the occurrence of this disease.

Salmonellosis (salmonella infection) is a bacterial infection transmitted to humans by eating contaminated foods. Most persons infected with salmonella develop diarrhea, fever, and abdominal cramps. Infections often do not require treatment unless the patient becomes severely dehydrated or the infection spreads from the intestines. In this latter instance, antibiotics are used to treat salmonellosis.

Severe acute respiratory syndrome (SARS) is an emerging, viral respiratory illness that seems to be transmitted primarily through close human-to-human contact, such as through coughing and sneezing. In general, SARS begins with a high fever. Other symptoms may include headache, an overall feeling of discomfort, and body aches. Some people also have mild respiratory symptoms at the onset and may develop a dry cough and most patients develop pneumonia. Currently, there is no definitive test to identify SARS during the early phase of the illness, which complicates diagnosis. Furthermore, there is no specific treatment for SARS. SARS was first reported in Asia in February 2003.

Shigellosis is a highly contagious, diarrheal disease caused by four strains of bacteria and is transmitted by human-to-human contact and contaminated food and water. One of these strains, an unusually virulent pathogen, causes large-scale, regional outbreaks of dysentery (bloody diarrhea). In addition to diarrhea, patients experience fever, abdominal cramps, and rectal pain. The disease is treatable by rehydration and antibiotics.

Smallpox is an acute, contagious, and sometimes fatal viral disease transmitted through human-to-human contact. Symptoms usually begin with high fever, head and body aches, and sometimes vomiting. A rash follows that spreads and progresses to raised bumps and pus-filled blisters that eventually fall off, leaving pitted scars. There is no treatment for smallpox. However, it can be prevented through use of the smallpox vaccine.

Streptococcal disease (invasive Group A) is a bacterial disease transmitted through direct contact with an infected person's mucus or through contact with wounds or sores on the skin. Invasive group A streptococcus (GAS) infections occur when bacteria get into parts of the body where they are not usually found, such as the blood, muscle, or lung. GAS infections can be treated with many different antibiotics.

Streptococcal toxic shock syndrome (STSS) is one of the most severe, but least common forms of invasive GAS diseases. STSS, which is not spread from human-to-human, causes blood pressure to rapidly drop and organs to fail. Symptoms include fever, dizziness, confusion and a flat red rash over large areas of the body. Early treatment of GAS infections with antibiotics may reduce the risk of death from invasive GAS disease.

Streptococcus pneumoniae is a bacterium that includes more than 90 strains and is transmitted through human-to-human contact. It is the cause of multiple diseases, including pneumonia, bacteremia, meningitis, and sinusitis. Some strains of this bacterium are becoming resistant to one or more antibiotics. CDC and several states are currently conducting additional surveillance for the resistant forms of this bacterium.

Syphilis is a bacterial STD with signs and symptoms that are indistinguishable from those of other diseases. Syphilis is passed from person-to-person through direct contact with a syphilis sore and progresses through three stages. The primary stage is usually marked by the appearance of a single sore. The second stage is involves a skin rash and mucous membrane lesions. Finally, the late stage begins when

secondary symptoms disappear. Many people infected with syphilis do not have any symptoms for years yet remain at risk for late complications if they are not treated. Syphilis is easy to treat in its early stages, usually with antibiotics.

Tetanus (lockjaw) is caused by a bacterium found in the intestines of many animals and in the soil. It is transmitted to humans through open wounds. Symptoms include generalized rigidity and convulsive spasms of the skeletal muscles. Tetanus can be treated with an antitoxin, and there is an effective vaccine.

Toxic shock syndrome is a bacterial disease that develops when the disease-causing bacterium colonizes skin and mucous membranes in humans. This disease has been associated with the use of tampons and intravaginal contraceptive devices in women and occurs as a complication of skin abscesses or surgery. Characterized by sudden onset of fever, chills, vomiting, diarrhea, muscle aches, and rash, toxic shock syndrome can rapidly progress to severe and intractable hypotension and multisystem dysfunction. Treatment usually includes the use of antibiotics and supportive treatment to prevent dehydration and organ failure.

Trichinosis (trichinellosis) is food-borne illness caused by eating raw or undercooked pork and wild game products infected with a species of worm larvae. It cannot be spread from human-to-human, but only through consumption of contaminated food. Symptoms include nausea, diarrhea, vomiting, fatigue, fever, and abdominal discomfort, followed by additional symptoms, such as headaches, fevers, chills, aching joints, and muscle pains. Several drugs are available to treat trichinosis.

Tuberculosis is a bacterial disease that is usually transmitted by contact with an infected person. People with healthy immune systems can become infected but not ill. Symptoms of tuberculosis can include a bad cough, coughing up blood, pain in the chest, fatigue, weight loss, fever, and chills. Several drugs can be used to treat tuberculosis, but the disease is becoming increasingly drug resistant.

Tularemia is caused by a bacterium often found in animals. Humans can contract tularemia in different ways, including being bitten by an infected tick or other insect, handling infected animal carcasses, by ingesting contaminated food or water, or by inhaling the bacterium. Symptoms of this disease can include sudden fever, chills, headaches, muscle aches, joint pain, dry cough, and progressive weakness. Tularemia is often treated with antibiotics.

Typhoid fever is a bacterial illness transmitted through contaminated food and water. Symptoms include high fever, stomach pains, and in some cases a rash. It is treatable by antibiotics and there is also a vaccine available, although it is not always effective.

Vancomycin-Intermediate/Resistant *Staphylococcus aureus* are specific bacteria resistant to the antimicrobial agent vancomycin. Persons that develop these infections have certain characteristics such as having several underlying health conditions (such as diabetes and kidney disease), recent hospitalizations, and recent exposure to vancomycin and other antimicrobial agents. Despite their resistance to vancomycin, these infections can be treated with several drugs.

Varicella (chickenpox) is highly infectious, viral disease that spreads from human-to-human contact, such as through coughing or sneezing. It results in a blister-like rash that appears first on the trunk and face, but can spread over the entire body. Other symptoms include itching, tiredness, and fever. Multiple drug treatments and a vaccine for varicella are available.

Yellow fever is a mosquito-borne viral disease that occurs in tropical and subtropical areas. The yellow fever virus is transmitted to humans through a specific mosquito. Symptoms include fever, muscle pain, headache, loss of appetite, and nausea. There is no treatment for yellow fever beyond supportive therapies. A vaccine for yellow fever is available.

Selected Worldwide Emerging Infectious Diseases

Variant Creutzfeldt-Jakob disease (vCJD) is a rare, degenerative, fatal brain disorder in humans. It is believed that vCJD is contracted through the consumption of cattle products contaminated with the agent of bovine spongiform encephalopathy (BSE) or “mad cow disease”—a slowly progressive, degenerative, fatal disease affecting the central nervous system of adult cattle. There is no known treatment of vCJD.

Dengue fever is a mosquito-borne infection that results in a severe, flu-like illness with specific symptoms that vary based on the age of the victim. Dengue hemorrhagic fever is a potentially lethal complication that may include convulsions. There is no vaccine for dengue fever, nor is there any treatment beyond supportive therapy.

Ebola hemorrhagic fever, a viral disease, is transmitted by direct contact with the body fluids of infected individuals, causing acute fever, diarrhea that can be bloody, vomiting, internal and external bleeding, and

other symptoms. There is no known cure, although some measures, including rehydration, can improve the odds of survival. Ebola kills more than half of those it infects. Identified for the first time in 1976, the Ebola virus is still considered rare, but there have been a number of outbreaks in central Africa.

Echinococcosis (Alveolar Hydatid disease) is caused by a parasitic tapeworm found mostly in the Northern Hemisphere. The disease is transmitted to humans when they swallow the tapeworm eggs, either on contaminated food, or after contact with an animal carrier. Symptoms are slow to appear, usually involving the liver—and may mimic liver cancer or cirrhosis—and can include abdominal pain, weakness, and weight loss. Surgery is the most common form of treatment, although follow-up medication is often needed.

Hendra virus infection occurs in both humans and many species of animals. In humans, it causes a respiratory disease that is often fatal. It was discovered in 1994, and has not been found outside of Australia.

Human monkeypox is a rare viral disease caused by a virus related to smallpox. It is transmitted to humans through contact with infected animals as well as through human-to-human contact. In humans, symptoms of monkeypox are similar to smallpox, but usually they are milder. Monkeypox symptoms include fever, muscle ache, swelling of the lymph nodes, and a fluid-filled rash. The first case of monkeypox in the United States occurred in June 2003. There is no specific treatment for monkeypox but the smallpox vaccine may offer protection against the disease.

Influenza A, H5N1 (avian influenza) is a type of influenza that infects birds and may be transmitted to humans. Symptoms of avian influenza in humans range from typical influenza-like symptoms to eye infections, pneumonia, acute respiratory distress, and other severe and life-threatening complications.

Lassa fever is a viral disease, transmitted through contact with infected rats. Symptoms include deafness, fever, nausea, vomiting, diarrhea, and, in more severe cases, seizures and hemorrhage. This disease is difficult to distinguish from several other diseases. No vaccine is currently available, although ribavirin has been used as a preventive measure as well as to treat the disease.

Marburg hemorrhagic fever is a rare and severe viral disease that affects both humans and animals. The mode of transmission from animals to humans is unknown. However, humans who become ill may spread the virus to other people. The onset of the disease is sudden and includes fever, chills, and headache. Symptoms progress to include a rash, nausea, vomiting, and chest pain as well as jaundice, inflammation of the pancreas, shock, massive hemorrhaging, and multi-organ dysfunction. Because many of the signs and symptoms of Marburg fever are similar to other infectious diseases, it may be difficult to diagnose. A specific treatment for this disease is unknown.

Nipah virus is an emerging disease causing encephalitis. It is believed to be transmitted through contact with infected pigs. Symptoms include headache, fever, muscle spasms, coma, and brain damage. There is no treatment beyond alleviation of symptoms.

O'nyong-nyong fever is a viral illness spread by mosquitoes. It causes symptoms such as joint pain, rash, high fever, and eye pain. Fatalities are rare.

Rift Valley fever is a viral disease that primarily affects animals—including domesticated livestock—but can be transmitted to people by mosquitoes or contact with the body fluids of infected animals. Rift Valley fever usually causes a flu-like illness lasting 4 to 7 days, but can develop into a more severe hemorrhagic fever that can result in death. There is no established course of treatment for infected patients. The disease has occurred in many parts of Africa and, in September 2000, was for the first time reported outside of Africa, in Saudi Arabia and Yemen.

Venezuelan equine encephalitis is a mosquito-borne viral disease that can be transmitted to humans from equine hosts. Symptoms in humans include flu-like symptoms of fever and headache. Severe illness and death can occur in the young and the elderly and those with weakened immune systems. The only treatment available is supportive therapy.

West Nile virus is a mosquito-borne viral disease that is transmitted to humans through infected mosquitoes. Many people infected with the virus do not become ill or show symptoms. Symptoms that do appear may be limited to headache, sore throat, backache, or fatigue. There is no vaccine for the West Nile virus, and no specific treatment besides supportive therapies. The disease occurs in Africa, Eastern Europe, West Asia, and the Middle East. This disease appeared for the first time in the United States in 1999.

Appendix III: Selected List of Systems and Networks Engaged in Disease Surveillance

Below we describe selected electronic systems and networks to support disease surveillance that are discussed in this report. This list encompasses electronic communications and surveillance systems as well as networks of laboratories and public health officials engaged in disease surveillance.

BioSense

BioSense is a syndromic surveillance system operated by CDC. BioSense aggregates syndromic data from a variety of electronic sources to improve early detection of possible disease outbreaks, bioterrorism threats, or other urgent public health threats. The data are collected and analyzed by CDC and also made available to state and local public health agencies. Data sources include patient encounters from the Department of Defense's medical treatment facilities in the United States, the Department of Veterans Affairs' medical facilities, national clinical laboratory test orders, and more than 10,000 over-the-counter retailers nationwide.

Electronic Laboratory Exchange Network (eLEXNET)

eLEXNET is a Web-based system for real-time sharing of food safety laboratory data among federal, state, and local agencies. It is a secure system that allows public health officials at multiple government agencies engaged in food safety activities to compare and coordinate laboratory analysis findings. According to FDA officials, it enables public health officials to assess risks, and analyze trends, and it provides the necessary infrastructure for an early warning system that identifies potentially hazardous foods. As of July 2004, FDA officials said there were 113 laboratories representing 50 states that are part of the eLEXNET system.

Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE)

ESSENCE is a syndromic surveillance system operated by DOD. ESSENCE is used in the early detection of infectious disease outbreaks and it provides epidemiological tools for improved investigation. The system collects data from hospitals and clinics on a daily basis. Epidemiologists can track, in near real-time, the syndromes being reported in a region through a daily feed of reported data. ESSENCE uses the daily data downloads, along with traditional epidemiological analyses using historical data for baseline comparisons and analytic methods such as a geographic information system. A geographic information system, among other things, can be used to identify spatial clustering of abnormal health events as the data are collected. This can assist public health officials in identifying affected areas. DOD is in the process of improving ESSENCE's mapping capabilities and developing more advanced statistical algorithms for identifying anomalous increases in syndromes.

Epidemic Information Exchange (Epi-X)

Epi-X is a secure, Web-based communication system operating in all 50 states. CDC uses this system primarily to share information relevant to disease outbreaks with state and local public health officials and with other federal officials. Epi-X also serves as a forum for routine professional discussions and non-emergency inquiries. Authorized Epi-X users can post questions and reports, query CDC, and receive feedback on ongoing infectious disease control efforts. According to CDC, as of 2004, over 1,200 public health officials at the federal, state, and local levels had used the system to communicate with colleagues and experts, track information for outbreak investigations and response efforts, conduct online discussions, and request assistance.

Foodborne Disease Active Surveillance Network (FoodNet)

FoodNet is a surveillance system that is a collaborative effort among CDC, USDA, and FDA. FoodNet operates in nine states that participate in CDC's Emerging Infections Program. FoodNet provides a network for responding to new and emerging foodborne diseases of national importance, monitoring foodborne diseases, and identifying the sources of specific foodborne diseases. FoodNet is used to detect cases or outbreaks of foodborne disease, identify their source, recognize trends, and respond to outbreaks. State public health departments that participate in FoodNet receive funds from CDC to systematically contact laboratories in their geographical areas to solicit incidence data. As a result of this active solicitation, FoodNet is intended to provide more accurate estimates of the occurrence of foodborne diseases than are otherwise available.

Global Outbreak Alert and Response Network (GOARN)

GOARN electronically links WHO member countries, disease experts, agencies, and laboratories in order to keep them informed of disease outbreaks, either rumored or confirmed. GOARN is the primary mechanism by which WHO mobilizes technical resources for the investigation of, and response to, disease outbreaks of international importance. GOARN issues real-time outbreak alerts and gathers global disease information from a number of sources, including media reports, ministries of health, laboratories, academic institutes, and WHO offices in various countries.

Global Public Health Intelligence Network (GPHIN)

GPHIN is an electronic system developed by Canadian health officials and used by WHO. GPHIN is an Internet-based application that searches in French and English more than 950 news feeds and discussion groups around the world in the media and on the Internet for information on possible outbreaks of infectious diseases. CDC officials said that

translation capabilities will be expanded in 2004 from French and English to also include Arabic, Chinese, Russian, and Spanish.

Health Alert Network (HAN)

CDC operates an early warning and response system, the Health Alert Network (HAN), that is designed to ensure that state and local health departments as well as other federal agencies and departments have timely access to emerging health information. Through HAN, CDC issues health alerts and other public health bulletins to an estimated 1 million public health officials, including physicians, nurses, laboratory staff, and others.

Infectious Diseases Society of America Emerging Infections Network (IDSA-EIN)

IDSA-EIN is a network of over 900 infectious disease practitioners. The network surveys its members regularly on topical issues in clinical infectious diseases. It also enhances communications and health education among its members, collaborates in research projects, and provides assistance during outbreak investigations. Its membership represents a source of infectious disease expertise for CDC and state health departments to draw on during outbreaks or when unusual illnesses occur.

Laboratory Response Network (LRN)

LRN is an integrated network of public health and clinical laboratories run by CDC to test specimens and develop diagnostic tests for identifying infectious diseases and biological or chemical agents. The network includes the following types of laboratories—federal, state and local public health, military, and international laboratories, as well as laboratories that specialize in food, environmental, and veterinary testing. Some LRN laboratories provide highly specialized tests not always available in state public health or commercial laboratories.

National Animal Health Reporting System (NAHRS)

NAHRS is collaborative program with USDA, the U.S. Animal Health Association, the American Association of Veterinary Laboratory Diagnosticians, and participating states. NAHRS collects data from state veterinarians in participating states on the presence of confirmed clinical diseases of major international significance in livestock, poultry and aquaculture species in the United States. Individual state reports are submitted monthly to the central collection point at the USDA where they are verified, summarized and compiled into a report.

National Electronic Disease Surveillance System (NEDSS)

CDC's NEDSS is an initiative that is designed to make the electronic reporting of disease surveillance data to CDC by state and local health departments more timely, accurate, and complete. Specifically, NEDSS is intended to replace or enhance the interoperability of CDC's numerous existing surveillance systems. Interoperability is the ability of two or more systems or components to exchange information and to use the information that has been exchanged. As part of the NEDSS initiative, CDC is developing an architecture that consists of a set of standards that can be used for creating interoperability among systems. These standards comprise (1) data standards, (2) parameters for an Internet-based communications infrastructure, and (3) policy-level agreements on data access and sharing as well as on protections for confidentiality. CDC has also developed ready-to-use software—the NEDSS-Base system (NBS)—that operates within these standards.

National Electronic Telecommunications System for Surveillance (NETSS)

NETSS is a computerized public health surveillance system that provides CDC with weekly data regarding cases of nationally notifiable diseases. Core surveillance data—date, county, age, sex, and race/ethnicity—and some disease-specific epidemiologic information for nationally notifiable diseases and for some nonnotifiable diseases are transmitted electronically by the state public health departments to CDC through NETSS each week. Data from NETSS is published in CDC's Morbidity and Mortality Weekly Report. NETSS will be phased out as NEDSS is deployed and implemented.

National Retail Data Monitor (NRDM)

NRDM is a syndromic surveillance system developed by the University of Pittsburgh in collaboration with CDC and others, and it is used by state public health officials. NRDM collects data from retail sources. NRDM collects sales data from 19,000 stores, including pharmacies, to monitor sales patterns in such items as over-the counter medications for signs of a developing infectious disease outbreak. The system looks for unusual sales patterns—such as -a spike in the number of over-the-counter medications purchased in a particular city or county—that might indicate the onset of an infectious disease outbreak. The system monitors the data automatically on a daily basis and generates summaries of sales patterns using timelines and maps.

National Veterinary Services Laboratories (NVSL)

NVSL are veterinary laboratories run by USDA. These laboratories are the only U.S. federal veterinary reference laboratories to provide diagnostics for domestic and foreign animal diseases. NVSL also provides diagnostic support for disease control and eradication programs, testing imported and exported animals, training, and laboratory certification for selected diseases.

PulseNet

PulseNet is a national network of public health laboratories that perform DNA "fingerprinting" on bacteria that may be foodborne. The network idenifies and labels each "fingerprint" pattern and permits rapid comparison of these patterns through an electronic database at CDC. This network is intended to provide an early warning system for outbreaks of foodborne disease.

Real-time Outbreak and Disease Surveillance (RODS)

RODS is a syndromic surveillance system developed by the University of Pittsburgh and used by state public health officials. RODS automatically gathers data from hospital clinical encounters in order to identify patients' chief medical complaints, classify them according to syndrome, and aggregate that data in order to look for anomalous increases in certain syndromes that may reveal an infectious disease outbreak.

Sexually Transmitted Disease Management Information System (STD*MIS)

STD*MIS is an electronic system used by state and local health departments to report sexually transmitted diseases to CDC.

Systematic Tracking of Elevated Lead Levels & Remediation (STELLAR)

STELLAR is an electronic system used by state and local health departments to report lead poisoning cases to CDC.

Appendix IV: Comments from the Department of Health and Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of Inspector General

Washington, D.C. 20201

JUL 22 2004

Ms. Marjorie Kanof
Managing Director, Health Care
United States Government Accountability Office
Washington, D.C. 20548

Dear Ms. Kanof:

Enclosed are the Department's comments on your draft report entitled, "Emerging Infectious Diseases: Review of State and Federal Disease Surveillance Efforts" (GAO-04-877). The comments represent the tentative position of the Department and are subject to reevaluation when the final version of this report is received.

The Department provided several technical comments directly to your staff.

The Department appreciates the opportunity to comment on this draft report before its publication.

Sincerely,

Dara Corrigan
Acting Principal Deputy Inspector General

Enclosure

The Office of Inspector General (OIG) is transmitting the Department's response to this draft report in our capacity as the Department's designated focal point and coordinator for Government Accountability Office reports. OIG has not conducted an independent assessment of these comments and therefore expresses no opinion on them.

Comments of the Department of Health and Human Services on the U.S. Government Accountability Office's Draft Report, *"Emerging Infectious Diseases: Review of State and Federal Disease Surveillance Efforts"* (GAO-04-877)

General Comments

The draft report covers a broad mix of surveillance, communications, and training programs, including existing or new programs and some that are still in planning stages, and programs that do not directly pertain to surveillance for emerging infectious diseases. While overall the draft report satisfactorily captures many important issues in surveillance, several key systems and issues deserve clarification. First, at the Federal level, the Centers for Disease Control and Prevention (CDC) is the lead agency for human disease surveillance. It fulfills this responsibility in close collaboration with States, other Federal agencies, the World Health Organization (WHO), and other partners. In addition, some specific systems and topics should be addressed including:

- The PulseNet network for subtyping bacterial pathogens, developed at and hosted by CDC, which links State public health laboratories, CDC, United States Department of Agriculture (USDA) and Food and Drug Administration (FDA) laboratories for molecular fingerprinting of bacterial food borne pathogens. (See http://www.cdc.gov/pulsenet/.)

- The support CDC provides in the form of technical advice and training to the development of major international networks that are critical to enhancing global surveillance, such as the WHO Global Influenza Surveillance Network (http://www.who.int/csr/disease/influenza/influenzanetwork/en/) and Global Salm Surv (http://www.who.int/salmsurv/en/).

The draft report currently presents the essential purpose of the National Electronic Disease Surveillance System (NEDSS) initiative as a mechanism to transmit surveillance data from States to CDC (which the National Electronic Telecommunications System for Surveillance (NETSS) already does). However, the essential purpose of the NEDSS initiative would be better represented as an initiative designed to transform surveillance at the local and/or State health department level. Obviously, CDC will also benefit by getting the data at the national level, but the current gap NEDSS seeks to address is primarily between the clinical sector and local/State public health. NEDSS does this by providing:

- an automatic electronic tool for sending disease information from the clinical diagnostic laboratory to the local and/or State health department, thus improving timeliness, accuracy, and completeness of disease reporting

- a web page instead of a paper form for submitting disease reports to the local and/or State health department

The draft report mentions multiple times that FDA collects surveillance reports on food-borne outbreaks. However, we are not aware that FDA collects these as part of a formal

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national surveillance system. Rather, CDC shares its findings with FDA. CDC operates the national reporting systems for outbreaks of food-borne and waterborne diseases. (See http://www.cdc.gov/foodborneoutbreaks/report_pub.htm for more information about the electronic food-borne outbreak-reporting system (EFORS) at CDC).

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Appendix V: GAO Contacts and Staff Acknowledgments

GAO Contacts

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Acknowledgments

In addition to the persons named above, Louise M. Duhamel, Krister Friday, Gay Hee Lee, and Merrile Sing made key contributions to this report.

Related GAO Products

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