

NEDSS INITIATIVE ACTIVITIES

As stated earlier, CDC has developed a variety of different infectious disease surveillance systems, most focused on specific diseases (such as HIV/AIDS) or multiple diseases of a certain category (such as sexually transmitted diseases or notifiable diseases). These individual systems are generally well received by our State and local health department partners; however, the number of systems continues to grow, facilitated by disease-specific categorical funding for surveillance activities.

NEDSS will overcome the obstacles discussed above by building upon the success of our current surveillance integration efforts. In particular, this initiative will tie together many of the current separate systems used for public health surveillance into a comprehensive solution that facilitates the efficient collection, analysis, and use of data and the sharing of computer software across disease-specific program areas. These integrated systems will reduce costs, improve efficiency, and better protect the public from infectious disease outbreaks and bioterrorist incidents.

To carry this out, CDC will: (1) Develop and implement national data standards for surveillance and reporting; (2) Provide technical infrastructure support for State and local communities; and (3) Establish State-based demonstration projects that will create linkages between the public health and health care systems. These efforts will achieve cost savings by eliminating inefficiencies and duplication of effort, increase the speed and reliability of data collection, and, consequently, enhance CDC's ability to protect the public from infectious disease outbreaks and bioterrorist attacks.

Development and Implementation of National Data Standards for Surveillance and Reporting (\$8 million)



Standardized data definitions

Creating a common language for reporting necessary data is the first step in establishing a national electronic network. In fact, it is a critical step because if the sending and receiving sites do not share the same data element standards (i.e., form, format, etc.), extensive custom programming and manual intervention is required to route, interpret, and merge the data into the system. CDC is developing a set of definitions and rules for collecting, coding, and using data elements that are shared across systems participating in the integration project. The definitions will ensure that uniform data are reported from health departments and the medical community. The adoption of common data definitions will enhance the ability of different program areas to share data, as appropriate, across the different surveillance systems.

for the core - ph. - adopting stds from elsewhere (HCFA, etc.)

are some variables unique to outbreaks made for uniform

Common user interface

To further progress toward integrated systems, a systems prototype will be identified, adapted, and implemented at CDC to provide a common user interface and information

systems architecture. This will ease the burden of data entry, along with the need for training and support on multiple systems with multiple user interfaces and analysis tools. Consequently, a common interface will create significant cost savings because it will allow users to train on any one data system and automatically be able to use any other. Resources will be used to adapt prototypes for the range of immediate surveillance needs. A common information system technology and architecture will also allow different software tools to be shared across surveillance systems, such as the expert software for automatic outbreak detection discussed above.

Secure data transmission via the Internet

Currently multiple systems use different methods for reporting electronic data, and many of these methods are slow and unreliable. To address this problem, CDC has adopted standards for secure methods for transferring files across the Internet. The agency will use this technology to implement a single "pipeline" for reporting surveillance data. This pipeline will eliminate the multiple, different methods for reporting electronic data that are currently in use. It will also ensure that the collection of data and the dissemination of information will occur in a timely and accurate manner.

CDC will develop standardized data definitions, a common user interface, and a secure Internet pipeline with in-house personnel and through contracts. Once developed, CDC will provide States with technical assistance for the proper implementation and maintenance of these systems. In addition, funds will be allocated for evaluation and testing of the new data networks.

Technical Infrastructure Support for State and Local Communities (\$27 million)

Provide technical support for State-specific system activities

Seamless, efficient electronic communications among local, State, and federal government health officials will be essential for dealing with infectious disease outbreaks and bioterrorist attacks. CDC will develop grants with State and local health departments to: (a) connect all local public health jurisdictions to the Internet via continuous, high-speed connections; (b) develop on-line information resources for protecting communities against bioterrorism and other public health threats; and (c) ensure the development of local and State systems for rapid receipt and broadcast of urgent health alerts, surveillance data, and other health information among local, State, and federal officials and community health care providers, managed care organizations, emergency rooms, poison control centers, etc. CDC expects to fund 25 - 35 States in FY 2000.

Enhanced training for the public health workforce personnel in surveillance and information technology

CDC's - and the nation's - ability to respond to today's threats to health depends on a highly skilled workforce of public health professionals. CDC will strengthen the capacity of the public health system at the State and local levels to provide leadership to their

communities in addressing current and emerging critical health problems by working with State and local health departments to identify the essential core requirements in information technology that a health department must have to protect its population against infectious disease threats. To this end, CDC will develop training in informatics and epidemiology for the public health workforce using a variety of methods, including self-study, computer-based training, satellite teleconferences, audio conference, etc. CDC will provide grants to academia and State and local health departments to develop and implement training programs and evaluate their effectiveness.

Establishment of State-based Demonstration Projects: Linkage from Health Care System to Public Health (\$5 million)

Expand linkages with commercial labs

CDC has demonstration projects in seven States to implement electronic reporting from commercial laboratories. Nationally these commercial labs account for 40 percent of all clinical tests reported to public health. It is expected that by 2001 over 60 percent of all reportable clinical test results will come from these labs. In demonstration projects in Hawaii, where reports are sent electronically from the laboratories responsible for 60-70% of all reportable tests, the number of reports has increased 2.3 fold over the previous paper-based system. Additionally, completeness of coverage has increased from 38% to 80% of all estimated reportable findings. The demonstration system in Washington State also has shown improvements in reporting by use of nationally-recognized standards for sending laboratory data and coding of laboratory tests and results. The approach in Washington can be scaled up to include more labs and can be applicable in other States. NEDSS will allow us to expand these system improvements to other States. The proposed expansion of linkages with commercial laboratories will be compatible with national data standards established by HIPAA. We will also work to systematically link data from commercial laboratories with HIPAA standardized demographic data on hospitalized patients. CDC will fund up to 5 grants to States in FY 2000 for demonstration projects.

Expand electronic reporting from emergency departments

CDC is coordinating a national effort to develop uniform specifications for injury data entered in emergency department patient records. The initial product is Data Elements for Emergency Department Systems, Release 1.0 (DEEDS). This effort will improve the speed and reliability of reporting injuries because most emergency departments record initial medical information on paper forms. Through NEDSS, CDC will expand DEEDS by developing common definitions needed for electronically reporting infectious diseases. Once common definitions are established, health departments can begin to establish electronic links with emergency departments. This system will enhance the public health community's speed in recognizing and responding to outbreaks. CDC will fund up to 5 demonstration projects for States and emergency rooms to implement and evaluate DEEDS.

very small demo in HI
8 of the 7 states
Wage commercial labs (technical policy boards)
6 state/local turf issues
none/fed (go confidentially submit rather than local to state to fed)

CONCLUSION

CDC has a long and successful history using surveillance methods to identify and respond to threats to the public's health. Over the years, CDC has used surveillance to control endemic malaria in the United States and to protect the safety of the country's food supply. We cannot rest on these efforts, though, because the country now faces grave threats such as foodborne illness, emerging infectious diseases, and bioterrorism. CDC is engaged in a number of efforts designed to enhance its ability to respond to these threats. For example, pilot projects have shown that developing electronic linkages between health departments and emergency rooms can enhance the speed and reliability of reported health data.

CDC faces many challenges in its effort to build upon the success of its current surveillance efforts. To start, the myriad surveillance systems now in place have led to inefficiencies and duplication of effort. Health departments must now use precious resources to train their staff in multiple systems, money that could be spent on programs. These systems are also often a slow and unreliable method of tracking disease; many surveillance systems are still paper based and many local health departments lack Internet access. Finally, reliable linkages do not now exist between important sources of data (e.g., multi-State commercial labs, emergency departments) and the local health officers who need the data to monitor and protect the health of the community.

CDC's vision is to overcome these challenges by building a national integrated surveillance system. Benefits from this initiative will allow rapid reporting of disease trends to control outbreaks, as occurred during the New Mexico hantavirus outbreak and the Colorado *E. coli* O157:H7 outbreak. It will create public and private health care sector linkages to increase the volume and accuracy of the data available for disease monitoring. Finally, this new system will enhance the ability of health departments to share information on infectious disease outbreaks or bioterrorist incidents.

To carry out this vision, CDC will: (1) Develop and implement national data standards for surveillance and reporting; (2) Provide technical infrastructure support for State and local communities; and (3) Establish State-based demonstration projects that will create electronic linkages between the public health and health care systems. Through these efforts, CDC will achieve substantial cost savings by moving toward its vision of an integrated system that automatically gathers health data from multiple sources on a real-time basis, facilitating our ability to monitor the health of communities, perform on-going analyses of trends, and provide information for taking public health action and setting public health policy. Most important, these actions will allow CDC to maintain its long tradition of protecting the American public from new and emerging health threats.

Date: 12/18/99

cc: RT

TH

MB

HIS Cam

FAX**Health Division**Office of Management and Budget
Executive Office of the President
Washington, DC 20503To: Dan Mendelson & Chris Jennings
Fax:

From: Barry Cleveland

Number of Pages (excluding cover):

Subject: FY01 NEISS Ancillary Initiative

Here is some information as requested:

Voice Numbers:

Health Division (Front Office)	202/395-4922
Health & Human Services Branch	202/395-4925
Health Programs & Services Branch	202/395-4926
Health Financing Branch	202/395-4930

Fax Numbers:

Health Division (Front Office)	202/395-3910
Health Division (Room 7001)	202/395-7840
Health Division (Room 7002)	202/395-5648

A - FY01 Pass Back - 120M

B - FY00 HHS Summary
on Integrated Surveillance
Initiative (May help
with a description)

C - FY01 HHS Justification

For Infectious Diseases (may help
with a press release writing)
1) - Article on 1999 CDC Pulse Net Award

12/17.

Don - Jan / FJ01 Settlement with

HHS included + 5 million \$

CDC Food Safety. I don't know
if that goes with NEISS.

BC

A

Selected FY 2001 Passback Detail

(Dollars in Millions)

(Non-adds are in italics; indented lines are non-adds to the line above; all non-adds are BA unless otherwise noted)

	<u>FY 2000 Enacted</u>	<u>FY 2001 Passback</u>
IHS		
Program Level	2,807.634	2,936.538
<i>Total Collections</i>	<i>380.087</i>	<i>409.290</i>
Budget Authority	2,397.547	2,497.248
<i>Total Services</i>	<i>2,078.967</i>	<i>2,171.929</i>
<i>Hospitals and Clinics</i>	<i>1,007.140</i>	<i>1,071.539</i>
<i>Dental Health</i>	<i>80.283</i>	<i>86.355</i>
<i>Contract Health Services</i>	<i>407.290</i>	<i>423.582</i>
<i>Public Health Nursing</i>	<i>34.556</i>	<i>38.849</i>
<i>Contract Support Costs</i>	<i>228.781</i>	<i>228.781</i>
<i>Total Facilities</i>	<i>318.580</i>	<i>312.937</i>
<i>Health Facilities Construction</i>	<i>52.000</i>	<i>44.692</i>
<i>Funds to be allocated per Passback Notes</i>	<i>N/A</i>	<i>12.382</i>
 CDC		
Budget Authority /5	3,035.761	3,105.261
<i>Prevent. Health Services Block Grant</i>	<i>180.204</i>	<i>180.204</i>
<i>HIV/AIDS Prevention /3</i>	<i>729.751</i>	<i>738.251</i>
<i>Global HIV /3</i>	<i>35.000</i>	<i>43.500</i>
<i>Sexually Transmitted Diseases</i>	<i>136.597</i>	<i>141.597</i>
<i>Immunization /3</i>	<i>509.875</i>	<i>519.875</i>
<i>Chronic & Environmental Diseases /3</i>	<i>381.155</i>	<i>381.155</i>
<i>Tobacco</i>	<i>100.913</i>	<i>105.913</i>
<i>One-time Global Micronutrients Funding /3</i>	<i>5.000</i>	<i>0.000</i>
<i>Infectious Diseases</i>	<i>175.610</i>	<i>196.610</i>
<i>Bioterrorism NEDSS in the PHSSEF</i>	<i>20.000</i>	<i>20.000</i>
<i>NEDSS</i>	<i>24.300</i>	<i>44.300</i>
<i>Foodborne Diseases</i>	<i>29.476</i>	<i>34.476</i>
<i>Hepatitis C</i>	<i>13.700</i>	<i>18.700</i>
<i>One-time Global Malaria Funding</i>	<i>9.000</i>	<i>0.000</i>
<i>Prevention Centers</i>	<i>18.200</i>	<i>15.200</i>
<i>Injury Control</i>	<i>86.198</i>	<i>91.198</i>
<i>Violence Against Women</i>	<i>11.000</i>	<i>16.000</i>
<i>NIOSH</i>	<i>215.500</i>	<i>215.500</i>
<i>NCHS (PL)</i>	<i>105.000</i>	<i>110.000</i>
<i>NCHS BA</i>	<i>33.310</i>	<i>33.310</i>
<i>Buildings and Facilities</i>	<i>60.000</i>	<i>80.000</i>
<i>Race & Health Demos</i>	<i>30.000</i>	<i>35.000</i>
<i>Office of the Director</i>	<i>38.322</i>	<i>36.322</i>

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5 pulse
net

Not for Further Distribution

Infectious Disease Increases

→ OMB staff noted that an additional \$20 million is included for NEDSS, an additional \$5 million is for PulseNet to expand disease surveillance in the area of foodborne diseases, and \$5 million is for Hepatitis C activities. OMB staff noted that in FY 2000 and FY 2001, Health Alert Network funding is not considered part of NEDSS and the focus of NEDSS should remain on building a consistent national architecture for surveillance.

STDs

The entire \$5 million increase is for the syphilis elimination efforts requested by HHS.

Injury Control

OMB staff noted that within the existing Injury Control totals (excluding the increase for Violence Against Women), \$2 million is provided in FY 2000 and FY 2001 for CPSC's National Electronic Injury Surveillance System.

Office of the Director

OMB staff noted that \$2 million in unrequested Congressional earmarks is reduced in FY 2001 from the Office of the Director. Within the remaining base, OMB staff note that CDC should direct the additional \$6 million in FY 2000 Congressional earmarks and other base resources towards the acquisition and development of the requested new core Financial Management Systems Technology.

Performance Plan

CDC's performance plan is generally fairly strong. However, several of the performance goals (particularly in infectious diseases) still seem to be output rather than outcome goals. Also, the link between CDC's performance goals/measures and how they are used by CDC to inform budget decisions and program managers' daily activities, is still not very clear. Many of the performance measures seem to be based on what CDC can measure rather than those that will help guide CDC's budget and management activities.

An example of a particularly strong performance measure is STDs and syphilis elimination:

- ▶ Increase the percentage of U.S. counties that will have an incidence of primary and secondary syphilis in the general population of less than or equal to 4 per 100,000.

An example of a weaker performance measure is CDC's HIV prevention performance goal since it (and the subsequent performance measures) are based on what's measurable – AIDS cases – rather than a strategic goal that could be used to guide prevention activities, such as the estimated number of people with HIV. While we understand that HIV reporting is still under development, we would propose the following strategic goal for HIV prevention activities:

B

CENTERS FOR DISEASE CONTROL AND PREVENTION

Integrated Surveillance Initiative

QUESTION:

What is CDC's FY 2000 Surveillance Initiative and how much is requested?

ANSWER:

- The budget outlines a plan to expend an additional \$65 million in funds from various initiatives and line items to support a major improvement in the coordination of public health surveillance and communication.
- Surveillance activities in bioterrorism (\$40 million) emerging infectious diseases (\$15 million) and food safety (\$10 million) will be coordinated in support of National Electronic Disease Surveillance Network Initiative (NEDSNI).
- Currently, the surveillance systems for infectious diseases, food safety and bioterrorism are largely independent and few health care plans and providers furnish timely information to State and local epidemiologists.
- This initiative will integrate CDC's surveillance activities into a National system that will collect and analyze epidemiological information on the occurrence of communicable diseases.
- In addition, the network will establish a link between the public health and medical communities for obtaining surveillance information electronically.

KEY INFORMATION:

The goal of CDC's FY 2000 Surveillance Initiative is to protect the public from new public health threats, such as bioterrorist attacks and infectious disease outbreaks, by unifying the current separate systems into an efficient, electronic system. To accomplish this goal, CDC will carry out the following:

- ▶ collaborate with States through cooperative agreements to assess existing information systems; identify current gaps, and develop new approaches and uses of sources of information;
- ▶ strengthen and enhance the integration and data standardization activities necessary to construct a national infrastructure;

- ▶ enhance electronic communications to allow for rapid analysis and reporting of disease outbreaks;
- ▶ develop provider-based sentinel networks to assure rapid detection and reporting of suspicious disease events to public health officials.
- ▶ help local and State health departments to recruit and train staff who are skilled in monitoring the provider networks and in detecting, investigating, and diagnosing disease outbreaks;
- ▶ expand the scope of the CDC/FDA/USDA Active Foodborne Disease Surveillance Program (FoodNet) at Emerging Infections Program (EIP) sites, in order to define the true incidence of many diagnosed foodborne infections and to assess the sources of these infections and potential for control; and
- ▶ establish an Emergency Response Unit which can be deployed to provide rapid field assessments in the event of a suspected release of a biological agent.

ADDITIONAL INFORMATION:

- ▶ CDC's Surveillance Initiative will transform the current patchwork of information systems into an integrated whole, thus allowing the agency to better protect the public from new and emerging health threats.
- ▶ The \$40 million in funds for bioterrorism that will support coordinated disease surveillance activities include \$20 million from the Public Health and Social Services Emergency Fund and \$20 million from Infectious Diseases.
- ▶ In 1992, CDC surveillance lead to identification of the food chain outbreak involving hamburger contaminated with *E. coli* O157:H7.

C

(CDC Justification
to OMB - 9/99)

INFECTIOUS DISEASES

AUTHORIZING LEGISLATION - Section 301, 307, 310, 311, 317, 318, 322, 325, 327, 352, 361-369 and 1102 of the Public Health Service Act and Sections 212, 234, and 412(b)(5) of the Immigration and Nationality Act.

	FY 1999 <u>Enacted</u>	FY 2000 President's <u>Budget</u>	FY 2001 <u>Request</u>	Increase or Decrease
BA	137,302,000	181,926,000	287,628,000	105,702,000
FTE	970	1,020	1,058	38

2001 Authorization. Indefinite

PROBLEM AND STRATEGY

Infectious diseases remain the leading cause of death worldwide and increasingly threaten public health and contribute significantly to the escalating costs of health care. They are a continuing menace to all segments of society, regardless of age, gender, lifestyle, ethnic background and socioeconomic status. Predictions of the elimination of infectious diseases did not take into account changes in demographics and human behaviors and the extraordinary ability of microbes to adapt, evolve, and develop resistance to drugs. Between 1973 and 1999, more than 35 newly emerging infectious diseases were identified.

The costs of infectious diseases in lives lost and dollars spent are enormous, and the cost-effectiveness of disease prevention has been demonstrated repeatedly. In the United States alone, an influenza pandemic would cause an estimated 89,000 to 207,000 deaths; 314,000-734,000 hospitalizations; and the economic impact would range from \$71-\$167 billion. We are overdue for the next influenza pandemic and the nation remains unprepared. Hospital-acquired infections kill 88,000 people annually in the United States and cost more than \$4.5 billion each year. Chronic liver disease is the tenth leading cause of death among adults in the United States and approximately 40% of chronic liver disease is caused by hepatitis C virus (HCV). The medical and work loss costs of HCV-related acute and chronic liver disease are estimated to exceed \$700 million annually. Foodborne disease costs the U.S. economy several billion dollars annually. The estimated burden of illness from foodborne diseases is up to 9,000 deaths and 6.5-33 million illnesses annually.

CDC's strategies to combat infectious diseases build on investment in the public health system established over a century ago and the preparedness to address the emergence of dangerous new threats. In 1995, CDC, in partnership with federal, state, and local agencies, universities, private industry, foreign governments, the World Health Organization (WHO), and many non-governmental organizations, launched the first phase of a nationwide program to revitalize national capacity to protect the public from infectious disease threats. These efforts were reaffirmed in 1996, when the Presidential Decision Directive on emerging infectious diseases established a new national policy to address the growing health and national security threat represented by infectious diseases. The second phase of this effort, CDC's strategic plan, *Preventing Emerging Infectious Diseases: A Strategy for the 21st Century*, published in 1998, continues these partnerships to build domestic and global capacity for recognizing and responding to infectious diseases.

Addressing emerging infectious diseases was identified as a top administration priority again for FY2001. Through the National Science and Technology Council (NSTC), the President identified a set of R&D national priorities requiring coordinated investments across government agencies. These interagency priorities reflect our objectives of maintaining excellence, maximizing effectiveness, and minimizing costs. Emerging infectious diseases and food safety are NSTC priority areas for FY2001 included in this initiative.

A key component of the strategy to combat bioterrorism will involve the development of the National Electronic Disease Surveillance System (NEDSS). This system is being developed in response to a pressing need to modernize and re-engineer public health surveillance in the United States in order to monitor the emergence and re-emergence of a variety of infectious diseases and strengthen the information infrastructure at the local, state, and federal levels.

In FY 1999, CDC began the Health Alert Network, supported through \$28 million in emergency supplemental funds for bioterrorism, and provided cooperative agreements to approximately 30 states to develop electronic communications between the local, state, and federal levels. CDC also supported pilot projects in five sites to implement electronic laboratory reporting of certain clinical tests from commercial laboratories to public health departments. Commercial labs account for 40% of clinical tests reported to public health and pilot projects have shown that direct electronic reporting from labs increases the timeliness, completeness, and number of cases of diseases reported.

With funding for FY 2000, CDC will initiate a more comprehensive approach consisting of three interdependent components: (1) development and implementation of national data and information system standards for surveillance reporting; (2) technical infrastructure support for state and local communities; and (3) establishment of state-based demonstration projects linking the health care system to public health. These efforts will initially focus on surveillance of infectious diseases and infrastructure needs for bioterrorism and hence, are funded through the infectious disease and bioterrorism budget activities. CDC will continue to fund approximately 30 cooperative agreements to states to support secure and improved electronic communications between local, state, and federal public health jurisdictions. CDC will also continue to support demonstration projects linking commercial laboratories and other components of the health care system with public health. Finally, CDC will support systems development including standardized data definitions for collecting, coding and using shared data across systems; identifying, adapting, and implementing a prototype common user interface and system architecture; and implementing a single, secure "pipeline" for reporting surveillance data.

CURRENT ACTIVITIES

CDC's base funding for infectious diseases includes support for CDC's infectious diseases laboratories which are the Nation's public health and reference laboratories. These laboratories provide global leadership in public health laboratory science. In addition to support for laboratory research, CDC's infectious diseases base funding supports surveillance, epidemic investigations, epidemiologic research, training, and public education.

CDC's efforts to prevent and control infectious diseases focus on four goals: (1) surveillance and response to detect, investigate, and monitor emerging pathogens, the diseases they cause, and the factors influencing their emergence, and respond to problems as they are identified; (2) applied research to integrate laboratory science and epidemiology to optimize public health practice; (3) infrastructure and training to strengthen public health infrastructures to support surveillance and research and to implement prevention and control programs; and (4) prevention and control to ensure prompt implementation of prevention strategies and enhance communication of public health information about emerging diseases.

With current funding, CDC will continue incremental implementation of its strategic plan focusing on rebuilding the basic core public health infrastructure to address infectious disease threats, including funding for:

- Forty-three state/local health departments, approximately \$12.1 million, under the Epidemiology and Laboratory Capacity (ELC) program to enhance the State/local health department capacity to detect, investigate, prevent and control infectious diseases. Of the 33 sites funded for the ELC program through FY 1999, 29 have used their federal funds to acquire pulsed-field gel electrophoresis capability, 21 have enhanced surveillance for Influenza, 14 have established surveillance for antimicrobial resistance, and all sites have significantly enhanced their information exchange capability. ELC cooperative agreement funds have been used to hire 94 public health professionals across the United States, including 36 epidemiologists and 31 laboratory workers.
- Nine population-based Emerging Infections Programs (EIPs), estimated \$13 million, to investigate emerging diseases and to integrate information from varying locations and populations about emerging disease problems. Much of the activity in the EIP network involves collaborative projects: population-based surveillance for invasive bacterial pathogens; a series of activities on foodborne diseases (FoodNet); and a study to investigate the causes of unexplained deaths and serious illnesses.
- Forty public health laboratories for PulseNet, a national electronic network of public health laboratories that perform DNA "fingerprinting" on bacteria causing foodborne diseases. PulseNet plays a vital role in surveillance and investigation of foodborne illness outbreaks. PulseNet allows recognition of cases of foodborne illness that may be due to a common exposure, such as a food item, occurring simultaneously in separate geographic locations. This recognition can lead to quick public health actions to control nationwide outbreaks, such as product recalls, and ultimately lead to changes that will prevent future problems.
- Five sentinel networks, approximately \$1.6 million, linking health care providers to improve the ability to detect and monitor emerging diseases, including a network along the U. S. -Mexico border; a network of travel medicine clinics in the United States and 22 countries; a network of academic emergency departments; and a network of infectious disease specialists throughout the United States. These networks are uniquely capable of identifying and responding to newly emerging infections that require immediate attention.
- Nine states with hepatitis C virus (HCV) programs, approximately \$1.6 million, for counseling, testing, and referral. Most of the estimated 4 million Americans chronically infected with HCV do not have symptoms and do not know they are infected. Identification of infected and at-risk individuals is a major focus of CDC's comprehensive prevention strategy.
- Three hundred sentinel surveillance sites for influenza, approximately \$1.25 million, in 45 states and the District of Columbia. In the United States, influenza surveillance is coordinated by CDC, who plays a leadership role in developing data critical for selecting the influenza strains that will be included in influenza vaccines used in the United States and recommended worldwide. By facilitating the early detection of variants of influenza virus and recommending the inclusion of these new antigenic variants in vaccines, this surveillance system provides the foundation for worldwide vaccination activities.
- Up to 22 extramural research grant awards, approximately \$4.8 million, to investigate novel diagnostics and high priority emerging infectious disease problems, including antimicrobial resistance, blood safety, and health care associated infections. Applied research on emerging infections emphasizes identification of behavioral factors and their influence on the emergence of prevention of emerging infections, characterization of the public health consequences of emerging infections, and evaluation of the effectiveness of prevention strategies.
- Thirty-two state health departments, non-profit groups, and academic institutions, estimated \$4.9 million, to fund research on Lyme disease. The number of annually reported cases of Lyme disease in the United States has increased about 25-fold since national surveillance began in 1982, and an average of approximately 12,500 cases annually were reported to CDC from 1993-1997. Although Lyme disease rarely is fatal, if left untreated some patients may develop arthritis, neurologic abnormalities, inflammation of the brain, and cardiac problems.

- Five cooperative agreements, totaling \$1.8 million, to academic institutions to conduct research on the transmission of Hantavirus. The hantavirus causes a condition known as hantavirus pulmonary syndrome (HPS), which only recently has been recognized as a disease in North America. HPS is a serious disease that progresses rapidly and can lead to death.

Funding for infectious diseases the last five years:

<u>FY</u>	<u>Funding</u>	<u>FTE</u>
1996	62,153,000	825
1997	87,720,000	863
1998	112,856,000	904
1999	137,302,000	970
2000	181,926,000	1020

RATIONALE FOR BUDGET REQUEST

The FY 2001 budget request of \$287,628,000 represents an increase of \$105,702,000 and 38 FTEs above the FY 2000 President's Budget. This initiative comprises three components: (1) Preventing Emerging Infectious Diseases--which encompasses programs that address antimicrobial drug resistance, chronic diseases with infectious origins, and pandemic influenza; (2) National Food Safety--which will enhance CDC's capacity to identify new foodborne hazards and characterize the risk posed by those hazards; and (3) Hepatitis C--which focuses on the ongoing implementation of the *National Prevention and Control Plan for Hepatitis C Virus*. Emerging Infectious Diseases and Food Safety are prominently listed in the President's FY2001 Interagency Research and Development Priorities outlined in April 1999 by the National Science and Technology Council. This CDC initiative supports the Council's priorities.

Preventing Emerging Infectious Diseases---\$52 Million and 16 FTEs

This component focuses on building a strong and flexible public health infrastructure, recognizing that skilled epidemiologists, strong public health laboratories, and coordinated communications and disease reporting systems are essential for developing sustainable disease prevention strategies, and are the best defense against any emerging and re-emerging disease outbreak. It stresses the need for developing emergency preparedness at all levels of government for an organized, rapid, and effective response in the event of pandemics (worldwide epidemics) and large scale disease outbreaks. The result of this reinvigorated public health system will be effective programs that protect the public health against existing, imminent, and emerging threats such as antimicrobial drug resistance, chronic diseases with infectious origins, and pandemic influenza.

This component also addresses global health issues, recognizing that with the ease and frequency of modern travel, it is no longer possible to protect the health of U.S. citizens without addressing infectious disease problems occurring elsewhere in the world. As stated in the 1996 Presidential Decision Directive on Emerging Infectious Disease, the United States is committed to working with international partners to promote an inclusive, global network for surveillance and response to infectious diseases. This will involve improving global communications, expanding disease surveillance, and preparing protocols for detecting and responding to outbreaks of emerging infectious diseases, particularly in developing nations where emerging diseases may go undetected for long periods.

The additional funding will accomplish:

- Completion of core epidemiology and laboratory capacity-building domestically by providing financial and technical assistance to all state and eligible large local health departments (total of 63) for enhanced surveillance and response to emerging diseases and antimicrobial resistance;
- Expansion of the network (total of 10) of regional population-based Emerging Infections Programs (EIP);
- Establishment of surveillance and research programs (total of 45) for antimicrobial use, resistance, and related risk factors;
- Development of guidelines and implementation of strategies for the prevention and treatment of infectious agents resulting in chronic diseases;
- Implementation of the *Influenza Pandemic Preparedness Plan for the United States*; and
- Strengthening the global capacity (total of 6 surveillance networks) to monitor and respond to emerging infectious diseases.

National Food Safety---\$15 Million and 10 FTEs

The National Food Safety component of this initiative will enhance CDC's capacity to identify new foodborne hazards and characterize the risk posed by those hazards, increase the speed with which the presence of hazards in foods can be determined and controlled, and improve the accuracy and timeliness of public health data that justify food safety control programs and evaluate their effectiveness. In 1997, in response to the growing concern about food safety, the President announced the National Food Safety Initiative. Working with the Food and Drug Administration and the Department of Agriculture, CDC's activities represent the ongoing expansion of the Presidential Initiative.

The public health burden of foodborne disease in the United States is substantial. New foodborne pathogens are emerging, old foodborne pathogens are showing up in new foods, and antimicrobial resistance in foods is increasing. Globalization of the food supply and the larger-scale nature of production and distribution of food pose additional risks to health. New efforts are required to address these issues.

CDC has principal responsibilities for identifying and monitoring foodborne illness and for documenting the effectiveness of prevention and control efforts, including both voluntary and regulatory measures. Federal agencies, states, and numerous others are highly dependent on CDC to accomplish their food safety missions and monitor progress. Failure to strengthen surveillance, epidemiologic, laboratory, and other public health capacity through CDC undercuts the nation's ability to assess and control foodborne illness, and evaluate the effectiveness of prevention efforts.

Current public health and food safety systems need to be strengthened in order to respond with the precision, speed and coordination necessary to limit the toll foodborne illness takes annually on public health and the economy. Specifically, additional resources will permit accomplishment of the following:

- Improve assessment of foodborne illness and strengthen state and local capacity to manage the public health impact of foodborne illness. New resources will be directed to:
 - assess and strengthen the capacity to investigate (up to 30 investigations) foodborne disease problems, including in-state and multi-state outbreaks;
 - evaluate contributing factors, and implement control measures, including enhancing surveillance, initiating Internet data exchanges and electronic reporting (total of 40 states), and integrating systems;
 - update analyses and estimates of the public health and economic burden of foodborne disease (7 studies) and exposure to environmental contaminants in food (2 state pilot projects); and
 - enhance the foodborne diseases active surveillance network, FoodNet, to measure burden and identify sources of foodborne disease by adding pathogens and syndromes to the network (12 total).

- Develop new methods for fingerprinting bacterial, viral and parasitic foodborne pathogens is critical. For example, PulseNet, a DNA fingerprinting and early warning network, is currently used for identification of only a few harmful foodborne bacteria. New resources would be directed to:
 - development, standardization, and transfer of state-of-the-art gene-based diagnostic and subtyping tools for bacteria (40-45 public health labs), parasites and viruses;
 - training personnel (600 laboratorians) in new technologies;
 - integrating existing electronic reporting (4 pilot projects) and information-exchange systems, and creating on-line resources; and
 - DPDx, an Internet-based exchange of information between CDC and state labs (20 states) that transmit images of parasites for diagnosis.
- Provide training and education for State and local public health personnel and other professionals. New resources would be directed to:
 - distance-based training of public health and laboratory personnel, health care providers and other professionals (20,000); and
 - implementing education programs (15 states) in schools and for the public about foodborne illness and prevention strategies
- Strengthen international collaboration in response to increasing globalization of the food supply and the increasing introduction of foodborne pathogens in other countries. New resources would be directed to:
 - improving foodborne disease surveillance in other countries (25 countries) to identify foodborne pathogens that may affect the U.S. food supply; and
 - assisting FDA and USDA in promoting high priority food safety initiatives associated with imported foods.

Hepatitis C---\$33 Million and 12 FTEs

The hepatitis C virus (HCV) component of the initiative focuses on the ongoing implementation of the *National Prevention and Control Plan for Hepatitis C Virus*. Approximately 4 million Americans are infected with HCV. Most of these chronically infected persons are not aware of their infection and are not clinically ill, because symptoms of hepatitis C-related chronic liver disease may not develop for 10 to 20 years after infection. Chronic liver disease is the tenth leading cause of death among adults in the United States, and it is estimated that 40-60% of chronic liver disease is caused by HCV. HCV-related acute and chronic liver disease causes 8,000-12,000 deaths annually.

The additional funding will permit accomplishment of:

- Identification, testing, and counseling prior transfusion recipients (50 states) and other persons at-risk for HCV infection;
- Educating health care and public health professionals to improve the identification of persons at risk of HCV infection and ensure appropriate diagnosis, medical management, treatment, and counseling; and
- Conducting surveillance to monitor disease trends and evaluate the effectiveness of efforts to identify infected persons and provide appropriate medical follow-up.

Pay Increase Costs---+\$5,702,000

The FY 2001 request includes \$5,702,000 to fund costs associated with pay increases.

OUTPUTS

	<u>FY 1999 Enacted</u>	<u>FY 2000 President's Budget</u>	<u>FY 2001 Request</u>	<u>Increase or Decrease</u>
<u>Emerging Infectious Diseases</u>				
Provide support to state/local health departments for epidemiologic and laboratory capacity (ELC)	33	43	63	20
Establish emerging infections programs (EIP)	8	9	10	1
Implement and support domestic and global sentinel surveillance networks for emerging diseases	4	5	6	1
Public Health Leadership Institute	1	1	1	0
CDC Information Network for Public Health Officials (CDC INPHO)	1	1	1	0
<u>Antimicrobial Resistance</u>				
Provide support to state/local health departments and hospitals for surveillance, prevention, and control of antimicrobial resistance	0	10	35	25
Implement comprehensive community-based demonstration projects on antimicrobial resistance prevention and control	2	2	10	8
<u>Influenza</u>				
Expand the number of domestic influenza sentinel surveillance sites	300	300	1000	700
Expand the number of global sentinel surveillance sites for influenza	110	110	130	20
Provide support to state health departments for state-based influenza pandemic coordination and response plans	0	0	50	50
	86			

	<u>FY 1999 Enacted</u>	<u>FY 2000 President's Budget</u>	<u>FY 2001 Request</u>	<u>Increase or Decrease</u>
<u>Food Safety Initiative</u>				
Investigations of foodborne disease outbreaks	23	24	30	6
Implement electronic reporting of foodborne disease data from state health departments to CDC	0	7	40	33
Expand the number of countries sharing surveillance information with CDC on foodborne diseases	12	12	25	13
Increase the number of state health departments using DPDx	10	15	20	5
Increase the pathogens and syndromes under active surveillance in FoodNet sites	9	10	12	2
Establish state-based pilot projects to investigate environmental conditions linked to foodborne outbreaks	0	0	2	2
Conduct evaluation studies of the economic impact of foodborne illnesses	3	6	7	1
Expand the number of public health laboratories capable of accessing PulseNet for:				
a) <i>E. Coli</i> O157:H7	29	40	45	5
b) <i>Salmonella</i> Typhimurium	7	40	45	5
c) <i>Listeria monocytogenes</i>	7	20	43	23
d) <i>Shigella sonnei</i>	0	7	20	13
Implement training programs for school personnel on food safety	0	0	15	15
<u>Hepatitis C Virus</u>				
Provide support to state health departments for comprehensive HCV programs in surveillance and evaluation and for counseling, testing, referral, and education.	0	9	50	41

	<u>FY 1999 Enacted</u>	<u>FY 2000 President's Budget</u>	<u>FY 2001 Request</u>	<u>Increase or Decrease</u>
<u>Lyme Disease</u>				
Research and evaluation cooperative agreements	32	32	32	0
<u>Hantavirus</u>				
Cooperative agreements	5	5	5	0
<u>NEDSS/Emerging Infections Surveillance</u>				
# of states with incremental implementation of elements of Electronic Laboratory Reporting (ELR)	0	10	30	20

INFECTIOUS DISEASES FUNCTIONAL TABLE:

	<u>FY 1999 Enacted</u>	<u>FY 2000 President's Budget</u>	<u>FY 2001 Request</u>	<u>Increase or Decrease</u>
Emerging Infections	\$ 79,106,000	\$ 94,106,000	179,856,000	15,750,000
Hepatitis C Virus (non-add)	[8,700,000]	[13,700,000]	[46,700,000]	[33,000,000]
Hantavirus	7,022,029	7,022,029	7,129,454	107,425
Lyme Disease	7,381,916	7,381,916	7,494,847	112,931
Foodborne Diseases	19,476,000	29,476,000	45,156,409	15,680,409
Waterborne Diseases	281,000	281,000	285,299	4,299
NEDSS/Infectious Diseases	0	20,000,000	20,305,967	305,967
Other Infectious Diseases	24,369,055	23,659,055	27,400,024	3,740,969
Secretary's 1% transfer reduction	(44,000)	0	0	0
Federal Administrative Rescission	<u>(290,000)</u>	<u>0</u>	<u>0</u>	<u>0</u>
Total	137,302,000	181,926,000	287,628,000	105,702,000

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NATIONAL ELECTRONIC DISEASE SURVEILLANCE SYSTEM
CDC Budget Initiative—Fiscal Year 2000
July 1, 1999

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NATIONAL ELECTRONIC DISEASE SURVEILLANCE SYSTEM

CDC Budget Initiative—Fiscal Year 2000

INTRODUCTION

Overview

The Centers for Disease Control and Prevention (CDC) is the nation's prevention agency. Its mission is to promote health and quality of life by working with its partners to prevent and control disease, injury, and disability. To accomplish this mission, CDC:

- Engages in surveillance to identify health problems and determine their cause,
- Develops and applies interventions, and
- Implements programs and evaluates their effectiveness.

Surveillance of health conditions is the foundation of CDC's efforts. In particular, surveillance is the ongoing, systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of those data to those who need to know. The final link of the surveillance chain is the application of these data to disease and injury prevention and control. An effective surveillance system includes a functional capacity for data collection, analysis, and dissemination which is linked to public health programs and action.

Unfortunately, a critical missing link in the nation's public health infrastructure is a national electronic surveillance system that allows local, State, and Federal public health agencies to collect and analyze epidemiological information rapidly in order to detect disease outbreaks and manage programs effectively. This \$40 million National Electronic Disease Surveillance System (NEDSS) Initiative enhances existing surveillance activities by implementing two important changes in the way surveillance systems are supported: a) it consolidates funding to develop capacity at the State and local level across infectious disease and bioterrorism programs; and b) it initiates electronic data linkages between the local public health community and the States.

Scope of Activities

The CDC initiative for national electronic disease surveillance features activities in three distinct but related areas:

- Development and implementation of national data standards for surveillance and reporting,
- Strengthening the State and local information infrastructure to protect the public's health against infectious diseases and bioterrorist threats, and
- Linking new data sources (commercial laboratories and emergency departments) with public health officials by rapid electronic connections.

Purpose

This paper will: a) illustrate several recent successful contributions of public health surveillance to prevent and control threatening infectious diseases; b) describe how this initiative will build upon a platform of current surveillance activities; c) provide the rationale for this initiative by identifying the factors and issues that challenge our capacity to improve public health surveillance systems; and d) describe the activities that will be supported by this initiative and how the activities will meet these challenges.

CONTRIBUTIONS FROM PUBLIC HEALTH SURVEILLANCE

Rational public health policy, effective and efficient program planning, and essential public health practice are dependent upon the availability of timely, accurate, and relevant public health data and information. Public health surveillance, which serves as the bedrock for all of CDC's program activities, is a time-tested method for gathering data and translating it into information. Public health surveillance is used to assess the health status of the public; to detect epidemics; to assist in health planning; to identify research needs; and to evaluate prevention and control programs.

The following describes several important contributions from public health surveillance.

Disease Eradication

Since its beginnings, CDC has relied upon surveillance data to guide its programs. Unlike most federal agencies, CDC is located in Atlanta, Georgia because it was created in 1946 through reorganization of the Malaria Control in War Areas Program. This World War II program was responsible for monitoring and controlling a parasitic disease still common at that time in the United States. This disease threatened military readiness--the health of Army recruits training at military bases in the South for deployment overseas. Today, CDC continues to use disease surveillance information to control and eradicate infectious diseases. Most recent examples include programs to eradicate polio and eliminate measles.

Medical Product Safety

Effective public health surveillance provides value because it can be used to rapidly detect problems, trigger investigations, identify causes, and implement control measures. Surveillance has been responsible for ensuring the safety of widely used medical products. In 1994, for example, hepatitis C virus (the most common cause of liver failure and the need for liver transplantation in the U.S.) was being transmitted through immunoglobulin given to patients with depressed immunity. Immunoglobulin is derived from blood products. The CDC and FDA detected this outbreak and initiated an investigation. The hepatitis C virus was traced to multiple lots of immunoglobulin manufactured by a single manufacturer. Worldwide recall of the product was initiated. To prevent future transmission of hepatitis C through immunoglobulin, the FDA now requires specific procedures in the manufacturing process to kill the virus.

Pattern Recognition Through New Technology

Although the basic steps in conducting public health surveillance--collecting, analyzing, interpreting, and using data--have remained the same, new technologies have enhanced our capacity to recognize patterns and linkages that previously went unnoticed. DNA fingerprinting of bacteria is one such technology. In 1997, the Colorado Department of Health investigated several seriously ill persons with hemolytic uremic syndrome (a

potentially fatal disorder of the blood and kidneys). Each of the patients had been infected by a bacteria (*E. coli* O157:H7) whose DNA fingerprint was the same. This led to recognition that the source of the infection was the same brand of frozen hamburger meat. As a result, over twenty-five million pounds of ground beef were recalled, and countless thousands of people—a potential outbreak of national scope—were protected from exposure to a potentially deadly disease.

Discovery of New Diseases

Although health officials traditionally monitor a list of recognized infectious diseases through reports sent by physicians to their local health department, surveillance can be used to identify new or emerging infectious diseases as well. In 1993, an outbreak of severe respiratory illness striking previously healthy young people occurred in New Mexico, Arizona, and Colorado. The New Mexico State Health Department, through their surveillance efforts, recognized this unusual cluster of disease and sought assistance from CDC. Epidemiologists set up an emergency surveillance system to identify additional patients and obtain blood samples for testing. An intensive laboratory investigation led to the identification of a new virus that was responsible for this "hantavirus pulmonary syndrome." Health officials implemented appropriate prevention and control measures.

Safe and Healthy Food

In this era of free trade and the availability of rapid transportation, the diet of Americans has become more dependent upon international sources of food. The fruits and produce we consume during the winter months frequently originate on orchards and farms overseas. Our citizens can be assured of a safe food supply in part because of public health surveillance. In 1997, an outbreak of hepatitis A among schoolchildren in Michigan was rapidly traced to frozen strawberries distributed through a USDA-sponsored lunch program. Although a company in California had processed and packed them, the berries were grown in Mexico. Rapid detection of the outbreak prevented additional children from being exposed and becoming ill.

Private Sector Adoption of Surveillance

Recently, the merits of public health surveillance have been recognized and adopted by the private sector. In 1997, General Motors, trying to cut costs from its car warranty program, consulted with CDC in an effort to search for ideas from other sectors, both public and private. When CDC explained to GM how within one week we solved the outbreak of hepatitis A among Michigan schoolchildren, GM officials immediately recognized that designing and operating surveillance systems had obvious parallels for their warranty process. They needed similar detection systems for identifying "outbreaks" of faulty parts that could signal manufacturing problems with large cost implications. As a result of consulting with CDC, GM reorganized their warranty process to operate as a detection and investigation unit that reflected the principles of public health surveillance. With this approach, GM plans to save \$1.6 billion in costs by 2001.

CURRENT SURVEILLANCE ACTIVITIES

One of the primary missions of the CDC, together with its many State and local partners in public health, is controlling and preventing the spread of infectious diseases. This mission is supported by public health surveillance -- the ongoing, systematic collection, analysis and dissemination of data for monitoring the health of the public. Historically, infectious disease surveillance activities have been organized to address specific conditions or categories of disease. At the federal level, these activities have been based on programmatic and budgetary authorities provided by Congress, while at the State and local level surveillance priorities are often set by State legislatures. For nearly two decades, computer-based information systems have been designed, implemented, and provided by CDC to State and local health departments to support surveillance for specific diseases and adverse health conditions (e.g., HIV, TB and STDs). These systems have met the programmatic needs for disease surveillance, and have provided the link between the CDC and its partners that allows surveillance to be conducted at the national level.

NEDSS is the next generation of surveillance systems for CDC and State surveillance networks. It will incorporate several aspects of the current surveillance systems and implement lessons learned from pilot projects currently underway. These pilot projects, which represent the latest developments in public health surveillance, are focused in two main areas. These are: (1) Establishment of electronic linkages from health care systems to public health, and (2) Development of new technologies. Together with our partners in public health, CDC will build upon the efforts currently underway in these areas to create an integrated national surveillance system for infectious diseases.

Establishment of Electronic Linkages From Health Care Systems to Public Health

Linking commercial laboratories and public health

CDC currently supports a series of pilot and demonstration projects to develop electronic reporting of laboratory results. These projects permit direct electronic laboratory reporting of disease reports (e.g., certain types of infections) from the multi-State commercial laboratories. Laboratory data are particularly useful for surveillance purposes because they provide specific and accurate diagnoses of diseases. The large commercial laboratories, which are rapidly consolidating and carving out market share, commonly will process specimens from people who reside in many different States. Several major commercial laboratories have indicated a willingness to collaborate with CDC. Thus, these laboratories are an important source of data, and developing new systems for electronic reporting needs to be further tested, refined, and implemented.

Linking hospitals and health care systems to public health

CDC, with its partners, has developed a set of common standards for electronic data records for emergency rooms, which have been proposed for inclusion in HIPAA. Emergency departments play a critical role in providing acute medical care, particularly

to those who may not have health insurance. However, most emergency departments as well as most in-patient hospitals and private physicians record initial medical information on paper forms. Creating a common language for reporting injuries and other necessary data is the first step in establishing a national electronic network. These standards will ensure that uniform data are reported from emergency departments.

These efforts need to be expanded to include data needed for tracking infectious diseases in hospital emergency rooms, infection control units and health care plans. Developing a common language for reporting infectious disease, (e.g., antimicrobial resistance, anthrax-like illnesses, pneumonia cases) as is being done for injury surveillance, will be a critical component of the NEDSS. Once we have a common language, health departments and local health care systems can begin to develop electronic linkages to public health and the broader health care community. Demonstrations of these linkages are already underway in Oregon, Massachusetts and other States.

Development Of New Technologies

Expert software for outbreak detection

In 1990, CDC began operating the Public Health Laboratory Information System, a system for linking State public health laboratories and managing their data for surveillance purposes. The system was subsequently enhanced to provide automated mechanisms for reviewing data and highlighting when certain bacteria are being reported in numbers greater than expected. Such an automatic signaling system has frequently provided the first (and often only) indication that there may be an unusual contamination of a food product causing illness in people. For example, in the spring of 1999 an outbreak detection algorithm flagged an unusual increase in the weekly number of *Salmonella* serotype Typhimurium infections in Colorado. In response to this information, the State health department and CDC initiated an investigation which found that infection with the outbreak strain was linked to consumption of commercially distributed clover sprouts grown from a contaminated lot of clover seed. The recall of the implicated clover sprouts and seed lot was followed by an immediate and dramatic decline in the number of reported *S. Typhimurium* infections in Colorado.

New laboratory and computer methodologies: digitized DNA fingerprinting

CDC, in collaboration with the FDA, the USDA and State health departments, recently developed PulseNet, a DNA fingerprint database that links public health laboratories in 20 States on-line. This system permits a laboratory to compare a local bacterial fingerprint with a national library of isolates and other recent isolates. The capacity to access and share these fingerprints will permit rapid detection of a common source outbreak of a nationally distributed product. If these fingerprints were not available, it would be nearly impossible to know that an ill person in one locale may be linked to ill people in other States through consumption of a common, commercial product. Thus,

PulseNet was recently used to identify a large multi-State outbreak of *Shigella* bacteria infection from eating fresh parsley grown and processed with unchlorinated water on a single farm.

MOTIVATORS FOR CHANGE

The environment for infectious disease surveillance has changed in recent years and now presents new challenges. The methods and model for surveillance for States and local communities have been influenced by new legislative mandates. The need to monitor the emergence and re-emergence of a variety of infectious diseases has led to the development of new and expanded information systems that link together health departments and laboratories across State boundaries. The movement from traditional hospital-based medicine to managed care presents opportunities to collect infectious disease data from broader segments of the population.

Data sources and surveillance methods have shifted to accommodate these changes, resulting in increasingly complex methods and tools for data collection and reporting. The sheer number and diversity of the CDC-developed surveillance software systems, while still essential tools for many partners, now represent a burden to many of these partners. This increased burden is due in part to the non-conformance and lack of standardization across these systems. As a result, many States have developed or are in the process of developing their own integrated surveillance solutions. While this may benefit the States, the creation of even more systems adds to the complexity of conducting surveillance at the national level.

In this section we identify three motivators for change of the current practice of public health surveillance. These are: (1) Surveillance systems are not standardized and integrated, (2) Weak infrastructure support for surveillance activities, and (3) Surveillance systems are not linked to the medical community. NEDSS will allow us to overcome these challenges so that we may build upon the foundation of our current surveillance efforts.

Surveillance Systems are Not Standardized and Integrated

Categorical funding of public health programs

At latest count, CDC operates about 120 surveillance or health information systems. Many of these surveillance systems have been in place for a number of years and were originally designed to detect a single organism or condition. Categorical funding has encouraged public health officials to design surveillance systems that can only fulfill the information needs of the particular program that has been authorized and funded. Moreover, the categorical approach to developing surveillance systems can significantly distort the priority setting process. What gets funded gets measured. Such an approach may inadvertently limit our capacity to detect emerging or new diseases—if surveillance for a particular condition is not funded, the condition may not get measured.

Surveillance systems are paper-based

Most public health surveillance information is generated in the provision of medical care. It is for this reason that there have been public health sections in each of the medical

privacy bills submitted to Congress during the past two years. And most medical records are kept in paper form. Many of the State surveillance systems still rely upon a physician completing a form that sometimes consists of multiple pages and mailing it to the local or State health department or CDC. Because these systems are paper-based and require that information from the medical record be extracted by hand, the data from these systems are often incomplete or delayed in reaching the appropriate public health authorities.

Electronic surveillance systems are not standardized

The lack of standardization is a consequence, in part, of the categorical approach to funding. The lack of standardization can generate significant inefficiencies and costs because a large number of systems need to be supported. Electronic surveillance systems will typically differ in the following ways: a) how conditions (e.g., diseases) are defined; b) how data are coded and stored; c) the types of computer systems; d) the software used (customized versus commercially available); e) the methods of data transmission; f) what the computer program looks like (i.e., the user *interface*). Since State health officials are increasingly interested in analyzing and summarizing surveillance data across multiple program activities, many health department staff are required to know how to use many different CDC-developed software packages. Consequently, the costs of maintaining these systems and training personnel in their use are high.

Weak Infrastructure Support for Surveillance Activities

Weak local information infrastructure

The infrastructure for information technology is weak in many local and State health departments. Results of a recent survey indicate that one-half of the approximately 3,000 local health departments in the U.S. lack high-speed Internet access that would allow rapid reporting of disease information or the ability to quickly learn of emerging problems. Moreover, one-fifth do not have access to electronic mail. Many local health departments are not connected to computer networks within their State or with CDC. Access to such connections would permit rapid sharing of data on infectious disease outbreaks or bioterrorist incidents.

Undertrained workforce

The US public health workforce comprises approximately 500,000 professionals practicing in public health and health care settings. Most lack formal training in public health. For instance, 78 percent of local health directors have not received public health training, and most public health nurses do not have baccalaureate education. Public health professionals need diagnostic capability and clinical expertise to respond properly to infectious disease outbreaks or bioterrorist attacks.

Surveillance Systems are Not Linked to the Medical Community

Insufficient linkage between the local public health and the local medical communities

Electronic linkages currently do not exist between important sources of data (e.g., the results of laboratory tests) and the local health officials who need the data to monitor the health of the community. However, these data, already available in electronic form in hospitals, managed care organizations, etc., could be used to design, implement, and target effective health promotion programs. Electronic linkages between these data providers and local health departments would help assure that public health decision makers have the information that they need to take timely public health action.

Most surveillance systems operate passively, relying upon the provider to submit a report

Most surveillance systems operate in a "passive" fashion--i.e., the health care provider must take the initiative to submit a disease report or notification. Because physicians and other health-care providers are busy or unaware of the reporting requirement, they often do not take the time to report data to health departments. This underreporting of disease causes many outbreaks to go undetected initially, with spread of contagion to an expanding group of contacts, enlarging the size of the epidemic before the health department becomes aware and can act. The alternative to "passive" systems are "active" ones, in which the health department takes the initiative to seek out cases of disease (e.g., through review of laboratory or hospital records by a health department agent). These active systems can work quite well, but they are also very resource intensive and expensive.

In closing, CDC faces three primary challenges in its attempt to effectively gather health data. The fact that surveillance systems are not standardized and integrated has led to high costs, inconsistent and often slow and unreliable data collection, and has limited our ability to detect emerging diseases. Weak infrastructure support for surveillance limits the ability of local health departments to rapidly share critical health information. Finally, the fact that surveillance systems are not electronically linked to the medical community prevents the public health community from accessing large amounts of critical health data.