



Nationwide Health Tracking: Investigating Life-Saving Discoveries

“Disease tracking is the most basic and necessary tool for disease prevention and control. The fact that America, the most technologically advanced country in the world, does not have such a national system in place in the 21st century is a tragedy. This is the key to saving millions of lives.”

-- Shelley A. Hearne, DrPH, Executive Director of Trust for America's Health

Introduction

Chronic diseases, such as cancer, asthma, Parkinson's, Alzheimer's and diabetes are responsible for seven out of ten deaths in America. These diseases strike more than a third of the U.S. population, over 100 million men, women and children. The costs of caring for people with chronic diseases account for more than 75 percent of the nation's \$1 trillion health care budget. By 2020, chronic disease is expected to afflict 134 million Americans.

The Centers for Disease Control and Prevention (CDC) estimates that a majority of these deaths could be prevented. However, the country does not have the fundamental scientific system needed to identify and understand the factors that are causing or contributing to preventable deaths -- **a nationwide health tracking network (NHTN)**.

A nationwide health tracking network involves health scientists connecting rates of disease with a range of studies, including environmental (viral agents, pollution, etc.), occupational, and lifestyle or behavioral (diet, etc.). In addition, a NHTN yields information about the varying rates of disease by geography and ethnicity, providing answers about whether or not there are “clusters” of diseases occurring in particular communities or population groups. Once disease causes are known, public health experts, health care providers, and policymakers can develop informed strategies to reduce and eliminate disease and lower the cost of medical treatment.

The impact of environmental exposures and disease is well-documented. The National Academy of Sciences estimates that 25 percent of developmental diseases, such as cerebral palsy, autism, and mental retardation, are caused by environmental factors. In addition, some researchers are exploring concerns that diseases such as multiple sclerosis, Parkinson's disease, and Alzheimer's disease may be linked to environmental hazard exposures. The American Cancer Society estimates that one-third of cancer deaths could be prevented through lifestyle or environmental changes.

*Health tracking is essential for the nation to understand, respond to, and prevent disease. Even very limited health tracking efforts has helped yield **LIFE-SAVING DISCOVERIES**, including:*

- *Folic acid intake can reduce birth defects.*
- *Better understanding of the connection between lung cancer and smoking.*
- *Improved cervical screening guidelines.*

Nationwide Health Tracking Components

A 2000 Pew Environmental Health Commission report surveyed 50 states and several local jurisdictions to inform its findings and recommendations on what a nationwide health tracking network would look like. The report, “*America’s Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*,” stressed the importance of timely and comprehensive data and uniting disjointed jurisdictions and information systems.

The commission recommended five core components of a NHTN:

- Nationwide baseline tracking of priority diseases -- asthma and chronic respiratory diseases; birth defects; developmental diseases; cancers, especially childhood cancers; neurological diseases such as Alzheimer’s, MS and Parkinson’s -- and priority exposures such as PCBs, and dioxin; heavy metals such as mercury and lead; pesticides; and water and air contaminants.
- Monitoring of immediate health crises such as heavy metal and pesticide poisonings or chemical terrorism to serve as early warning systems that trigger action against hazards.
- Establishing pilot programs to allow 20 different regional and state initiatives to investigate local environmental health priorities, provide flexibility for local officials, allow community groups to gather more information and serve as a model for potential inclusion in the nationwide network.
- Developing a federal, state and local rapid response capability to investigate disease clusters, outbreaks and emerging threats.
- Support of community interests and scientific research to further health tracking efforts.

The responsibility for tracking chronic disease rests primarily with state health departments. However, most of these agencies have little capacity for chronic disease and exposure tracking, according to the Pew report. The goal of a federally supported NHTN would be the creation of a system to coordinate local, state, and federal health agencies’ collection of information in all fifty states, including:

NHTN would require the ongoing collection, integration and interpretation of data about environmental hazards, exposure to environmental hazards, and human health effects

potentially related to environmental exposures. Information-collection would focus on respiratory diseases like asthma, developmental disorders such as autism, neurological diseases like Alzheimer's, birth defects, juvenile diabetes, and cancers, especially childhood cancers.

Biomonitoring

An essential component of health tracking is called “biomonitoring” or exposure monitoring. Today most states’ public health laboratories do not have this needed laboratory capacity and are forced to rely on CDC, resulting in enormous delays for communities hoping to identify and prevent diseases linked to toxic chemicals. These tools can perform “double duty” and be used to rapidly respond during a chemical weapon event and to detect chronic environmental exposures.

Biomonitoring – the testing of blood, urine, or other human tissues for chemicals – has become the worldwide standard for assessing human exposures to toxic substances. This laboratory capacity, which measures chemicals in a very small amount – often a teaspoon or less – provides health officials and communities with data needed to make urgent decisions to protect public health.

Existing Health Surveillance Systems in the U.S.

Currently, the U.S. Department of Health and Human Services (HHS) operates more than 200 separate data systems in seven broad programmatic areas. These systems are not coordinated and do not track most of the major causes of death in the U.S., including most chronic diseases.

The existing surveillance systems range from state cancer registries to ArboNET, which tracks West Nile viruses and other mosquito-borne illness. For foodborne illness alone, there are 20 different surveillance systems that record information. Although the various food surveillance systems have contributed to improved safety, the usefulness of the systems is marred by both outdated data and by gaps in the data collected.

Fragmentation has developed largely due to disparate legal authorities and sources of funding. The legal authority for tracking rests at the state and local level. No uniform standards for data elements, collection procedures, storage, and transmission have been developed, and the funding for these systems is largely categorical to address particular specialized problems.

The lack of uniformity and diversity of systems has made it difficult to work collaboratively, to stay up to date and manage the range of systems, and to work with the private sector to develop more effective surveillance networks. States and localities, therefore, vary greatly in their access to updated or urgent information, which even leaves some to rely on antiquated methods of paper-based reports, telephone connections, and the U.S. mail as their

primary means of obtaining and reporting information. For more specific information, see “Appendix: Existing Data and Surveillance Systems.”

Status of a Nationwide Health Tracking Network

The U.S. Congress funded pilot programs for health tracking for the first time in Fiscal Year 2002. It appropriated \$17.5 million to the Centers for Disease Control and Prevention (CDC), which was intended to supplement current resources for these critical public health tasks and build on established programs in the state.

“This new program provides a strategic opportunity to address some of the most challenging public health problems. By linking environmental and health data on a national level, we will be better equipped to identify problems and effective solutions, thereby reducing the burden of environment-related diseases on the American people.” -Dr. Julie Gerberding, Director, CDC.

The health tracking grants were awarded to state and local health departments specifically to

- 1) Build environmental public health capacity;
- 2) Increase collaboration between environmental and health agencies;
- 3) Identify and evaluate existing data systems;
- 4) Build partnerships with non-governmental organizations and communities; and,
- 5) Develop model systems that link environmental and human health data that can be applied to other states or localities.

Also, grantees were expected to evaluate the usefulness of environmental public health indicators. Health indicators are used to measure the health of a specific community, county, city, state, or even the nation as a whole. Among other uses, indicators can be used to build core surveillance or tracking capacity in state and local public health agencies.

2002 Health Tracking Grants

To account for the wide variety of capacity among states, CDC offered two types of health tracking grants, Part A -- Planning and Capacity Building and Part B -- Enhancement and Demonstration Projects. Part A offered grantees the opportunity to receive funding of \$400,000-\$600,000 per year for three consecutive years to develop plans and components of a standards-based, coordinated health tracking network. Part B offered grantees the opportunity to receive funding of \$600,000-\$800,000 per year for three consecutive years to develop or enhance exposure health effects surveillance systems and to conduct projects to assess the utility of linking and reporting health effect data with exposure or hazard data. All grantees would be tasked with working on the overall development of a standards-based health tracking system.

Schools of Public Health also were invited to apply for a grant to become a Center of Excellence in Environmental Public Health Tracking. The Centers would provide expertise and support to the CDC and to the state/city grantees in developing and using the data

collected from the pilot programs and investigating potential links between health effects and the environment.

In the first year alone, 33 entities applied for the health tracking grants. A total of 23 were accepted, receiving funding from CDC in September 2002. The first health tracking grantees were California, Connecticut, District of Columbia, Illinois, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Mexico, New York, Oregon, Pennsylvania, Utah, Washington, Wisconsin, the City of Houston, the City of New York, the University of California at Berkeley, Johns Hopkins University, and Tulane University.

Once the initial funds were awarded, CDC's National Center for Environmental Health created a new Environmental Public Health Tracking (EPHT) Branch to oversee and offer technical assistance for the nationwide network.

FY 2003 and FY 2004 Funding and Grants

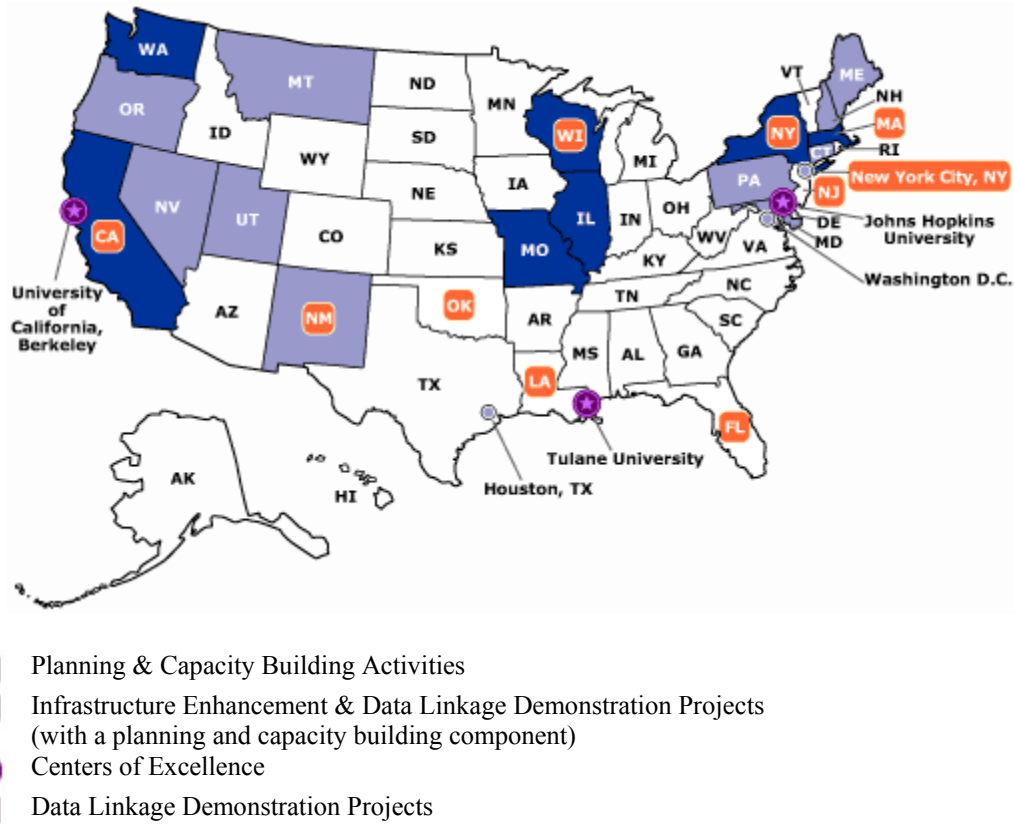
In FY 2003, the health tracking program at CDC received nearly a 30 percent increase from the previous year's funding, to \$27.8 million through Congressional appropriations.

Ten new grants were funded with the \$10.5 million increase, ranging from \$294,000-\$475,000. Four new states: Florida, Louisiana, New Jersey, and Oklahoma received the grants. The remaining six grants went to states that received funding previously from the 2002 grants: California, Massachusetts, New Mexico, New York, New York City, and Wisconsin; these grants were awarded to conduct different activities and research related to furthering a nationwide health tracking network.

The Pew Environmental Health Commission stated that full funding of the nationwide health tracking network would require \$275 million. This level of support would allow CDC to take the lessons learned from the demonstration projects and put a true nationwide system into action. In the interim, the pilot projects are a good foundation for developing a functioning nationwide health tracking network.

In FY 2004, the health tracking program was level-funded by Congress. Pilot programs continue to operate with funding from the original three-year grant.

The chart below illustrates all of the CDC's environmental public health tracking grantees to date (information from CDC's National Center for Environmental Health, Environmental Public Health Tracking Page.)



Grantee Activity to Date

For recipients of the initial three-year 2002 Environmental Public Health Tracking grant cycle, the process of building a nationwide public health tracking network is well-underway. The first year of funding was spent on planning and evaluation activities. The states received guidance and assistance from the CDC on implementation of the pilot projects through national meetings, conference calls, and site visits. The state and local grantees have been paired with a Center of Excellence, generally within the same region of the nation. The Centers of Excellence help its state and local partners work together on issues of mutual interest. For example, Johns Hopkins University is helping the Northeastern state grantees assess air pollution and its impact on related chronic diseases. Most states have met their measurable objectives for the first grant year, but a large number were impaired in the early months by state budget difficulties or statewide hiring freezes.

Typical Year One activity included:

- Developing a planning consortium or advisory council;
- Taking inventory of other health surveillance systems in the state;
- Recruiting and hiring additional staff; studying applicable state laws and regulations as they apply to the health tracking program; and
- Building relationships with state agencies or departments and other interested stakeholders.

Trust for America's Health Recommendations for Reaching the Goal of a Nationwide Health Tracking Network

Federal recommendations

- Congress should provide full funding for the environmental public health tracking program. The mandate, resources and support should be provided to establish a centralized disease tracking center within CDC for nationwide health tracking. This would include tracking animal-diseases, chronic diseases, such as cancer, asthma, events related to bioterrorism, and environmental risks.
- Improved cooperation and integration between functions and offices that have a role in the tracking initiative (specifically within CDC, but also selected offices of the U.S. Department of Health and Human Services (HHS) and the U.S. Environmental Protection Agency (EPA)).

State recommendations

- States should devote greater resources and attention toward improving coordination among health and environmental agencies at the state and local levels, including increased collaboration and information sharing with chronic disease surveillance programs in the state.
- State health agencies should better integrate members of the community representing health concerns into the development of health tracking programs.

Appendix: Existing Data and Surveillance Systems

CDC has implemented various initiatives to attempt to improve information and data systems and health tracking. These initiatives, however, often fall short due to limited funding, lack of prioritization, the difficulty of implementation across the various states and localities, and the difficulty in implementing a range of technologies and systems.

- In 1992, CDC and state health departments developed the Information Network for Public Health Officials (INPHO) to make information more accessible and to allow for rapid, secure exchange of data. Under INPHO, CDC provided grant funds to build networks linking state and local health agencies.
- CDC has also developed the Epidemic Information Exchange (Epi-X) to enable secure, Web-based communications among federal, state, and local epidemiologists, laboratories, and other public health officials. This system allows them to instantly notify others about urgent public health events.
- The Health Alert Network (HAN) is a system for electronic communication between health departments and CDC using the Internet. Although parts of the system are still in development, CDC used HAN at noon on September 11, 2001, to advise health officials to begin heightened disease surveillance. HAN also permits distance-learning activities and gives health departments at all levels the capacity to broadcast and receive health alerts. According to TFAH's December 2003 report, *Ready or Not? Protecting the Public's Health in the Age of Bioterrorism*, approximately 89 percent of the U.S. population is linked to the HAN via a continuous, high-speed Internet connection and has established the capacity to support emergency communications.
- The National Electronic Disease Surveillance System (NEDSS) was developed to integrate a variety of surveillance activities and the reporting systems for diseases such as hepatitis, tuberculosis, vaccine-preventable diseases, and eventually HIV/AIDS. The system is also intended to facilitate more accurate and timely disease reporting to CDC and state and local health departments.
- Plans for a Public Health Information Network (PHIN) are also in development. PHIN will enable consistent collection and exchange of response, health, and disease tracking data among public health partners. This network encompasses four key components: (1) detection and monitoring; (2) analysis and interpretation; (3) information dissemination and knowledge management; and (4) public health response.

Appendix: State Highlights

SPOTLIGHT ON MAINE – PLANNING AND CAPACITY BUILDING GRANT

Maine has the highest prevalence of asthma among adults in any state in the country.

- The Maine tracking grant proposed a data linkage project that would look at ambient air ozone data and hospital emergency department data on asthma visits. The Technical Working Group produced a vision document of this project. By linking these two existing databases, the state can determine where a “Bad Air Alert” worked and where it did not, so the state can be more aggressive in their prevention activities.
- EPHTN is being coordinated with the development of Maine’s new Integrated Public Health Information System (IPHIS) (based on CDC’s NEDSS and HAN systems). The IPHIS is funded through Maine’s federal bioterrorism grants.
- Partnering with the American Lung Association of Maine (ALAM), on the continuing development of ALAM’s statewide health data repository and web-based reporting system (contains a variety of databases including birth and death records, behavioral risk factor surveillance, and data on outdoor and indoor air hazards) to assess its potential use as a prototype for an Environmental Public Health Tracking component.

SPOTLIGHT ON NEW YORK - ENHANCEMENT AND DEMONSTRATION PROJECT

New York proposed a project to assess the relation between air pollution and pregnancy outcomes, asthma development, and childhood mortality. By linking available systems, NY is taking the lead at looking at the impact of air pollution on several different health outcomes and beginning to understand how these different health outcomes interact with exposures and each other.

- New York identified the health outcome data systems most critical to the Environmental Public Health Tracking program by creating a multidisciplinary group with expertise in environmental epidemiology, chronic diseases, and information technology.
- The State is working in close coordination with the New York City grantee, on technical aspects and is sharing staff expertise. For example, the State staff participated in the City’s focus group and the City grantee’s Principal Investigator serves on the State’s Planning Consortium. In addition, the State has involved the New York biomonitoring grant recipients, as well.
- The Planning Consortium includes members for the New York Cancer Surveillance Improvement Initiative and the March of Dimes and will be tasked with advising on environmental public health indicators and methodology for the demonstration project.

SPOTLIGHT ON CALIFORNIA – ENHANCEMENT AND DEMONSTRATION PROJECT

California has long been at the forefront of public health activities, including passage of a health tracking law.

- California is planning to conduct a pilot project that will track asthma prevalence and adverse pregnancy outcomes and link these data to existing environmental hazard data on traffic exhaust exposure. The state has one of the strongest birth defects registries in the country and by linking the information that is already available in their registry with existing environmental hazard data, California is again leading the way to a comprehensive and coordinated approach to public health.
- As part of the pilot project, the data analysis for birth outcomes has been completed and mapping of the data has shown significant geographic disparities. Further findings are expected when the analysis of asthma and traffic data is complete. This could lead to new information about the impact of air pollution on fetal health.
- An Environmental Public Health Tracking website (www.catracking.com), fact sheets, program packets, and newsletter were developed to communicate information about tracking efforts to the public.
- Community groups have been actively engaged in California’s tracking efforts. Examples include providing funds to a local community group to conduct a pilot project; a community-driven and designed study on diesel trucks in West Oakland; participating in community environmental health projects; and involving community groups in the Planning Consortium.