America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network

Technical Report

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Foreword by Commission Chairman Lowell Weicker, Jr.

With the mapping of the human genome, we are on the verge of a new wave of advances in health. With this remarkable achievement, researchers will be able to shed new light on the links between genetic predisposition and such factors as behavior and exposures to pollutants in the environment in order to prevent many of the chronic diseases that today cause so much suffering.

But there is a catch. We must have the basic information about the health of Americans and our environment before we can make the fullest use of this exciting genetic knowledge. The way to get this basic data is to track it—systematically, comprehensively, on a coordinated basis at all levels from the local community to the nation as a whole. We have to track what and where the hazards are in the environment, whether people are at risk from exposures to these hazards, and the health of our communities. Our information about environmental factors must run as deep and be as comprehensive as our knowledge of the genome.

This report examines our current public health response capabilities to environmental threats, and recommends the establishment of a Nationwide Health Tracking Network. The Pew Environmental Health Commission was charged with developing a blueprint to rebuild the nation's public health defenses against environmental threats. We know there are pollutants entering our air and water each year with suspected or known adverse effects on the health of our communities. What we are limited in knowing is if there is a link between that pollution and the increases we are seeing in chronic diseases because we aren't tracking environmental health factors.

We need to gather the facts now. Americans have a right, and the need, to know.

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Technical Report Overview

The fundamental goal of the Pew Environmental Health Commission Environmental Health Tracking Project is to enhance the public health response to environmental health threats through a national strategy for tracking hazards, exposures, and health outcomes. This report describes the Commission's examination of the national capacity for tracking:

- > To examine the existing public health capacity for environmental health tracking;
- To identify the environmental health needs and priorities of the Nation's public health agencies;
- > To examine issues of leadership and coordination in environmental health tracking;
- ➤ To develop recommendations for designing and implementing an effective national strategy for environmental health tracking.

Chapter 1 presents a synthesis of the findings and the recommendations of the Commission to create a federally supported Nationwide Health Tracking Network with appropriate privacy protections that informs consumers, communities, public health practitioners, researchers, and policymakers on chronic diseases and related environmental hazards and population exposures.

The proposed Network would be comprised of five key components:

- 1. National baseline tracking network for diseases and exposures;
- 2. Nationwide early warning system for critical environmental health threats;
- 3. State pilot tracking programs to test diseases, exposures and approaches for national tracking;
- 4. Federal investigative response capability; and
- 5. Tracking links to communities and research.

The Commission includes a list of health outcomes for national tracking including birth defects, developmental disabilities, asthma and chronic respiratory disease, and neurological diseases including multiple sclerosis, Parkinson's and Alzheimer's disease. The Commission also calls for exposure tracking, including persistent organic pollutants, heavy metals, and pesticides.

Chapters 2 through 6 describes Commission's the step-wise investigation that included: a review of the historical role of tracking in public health and the evolution of current strategies; a examination of the national infrastructure including a survey of federal, state, and local public health agencies; a review of the scientific literature and available federal survey data to identify health endpoints for tracking; and the convening of an Environmental Health Tracking Summit bringing together federal, state, and local leaders in environmental health to develop recommendations for the Commission.

Chapter 2 presents an historical perspective on the role of tracking in public health. The three components of environmental health tracking, hazard tracking, exposure tracking, and health outcome tracking, are defined and examples of current national efforts are presented. The chapter also describes the evolving detachment of public health agencies from environmental regulatory activities and the erosion of their capacity to conduct effective tracking.

Chapter 3 profiles the Nation's environmental health infrastructure, presenting the results of a national outreach effort and survey. The results reveal that the infrastructure for environmental health tracking has been neglected, particularly at the state and local level. The environmental health leaders of the Nation's public health agencies describe a pervasive lack of adequate support, personnel, and tracking data resources to meet the increasing challenges of protecting public health.

Chapter 4 summarizes available information on the link between environmental exposures and disease. Potential adverse health effects that have been linked to or influenced by environmental exposures include: respiratory, neurological, skin, liver, heart, developmental, reproductive, kidney, immune conditions, birth defects, cancer, and endocrine disorders. An examination of available national data indicates that the reported prevalence of a number of these categories of diseases has been increasing including: endocrine and metabolic disorders (up 21.7%); neurological conditions (up 20%); respiratory diseases (up 20%) and reproductive disorders also increased during this time (up 7.3%). Current tracking of these diseases is very limited, and the impact of the environment on their cause or severity is unknown.

Chapter 5 presents the recommendations from the Commission's Environmental Health Summit co-sponsored by the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Public Health Foundation. The Summit attendees included broad representation of the environmental health leadership at the federal, state, and local levels. Participants strongly endorsed the Commission's efforts, and developed a tiered approach to national environmental health tracking that provided a basis for the Commission's five-tier recommendation. It includes: national tracking for high-priority outcomes and exposures; a sentinel network to identify acute and emerging hazards; a coordinated network of pilot regional, state and local tracking programs; and aggressive research efforts to guide and evaluate tracking.

Chapter 6 presents the conclusions of the project, underscoring the critical need to strengthen the Nation's capacity for environmental health tracking. There is currently no cohesive national strategy to identify environmental hazards, measure population exposures, and track health conditions that may be related to the environment. As a result, basic information on the incidence and trends in health conditions that may be related or influence by the environment is largely unavailable. Advances in technology provide unprecedented opportunities to understand disease, measure exposures, and provide access to information. The Commission calls upon our national leaders to seize these opportunities to revitalize the public health infrastructure and close America's environmental health gap.

Chapter 1. Executive Summary of Commission Recommendations

At the dawn of the 21st century, America is facing an environmental health gap. This is a gap in critical knowledge that hinders our national efforts to reduce or eliminate diseases that might be prevented by better managing environmental factors. This is especially true for chronic diseases and conditions, such as birth defects, asthma and childhood cancer, which strike hundreds of thousands of American families each and every year.

What is the environmental health gap? It is the lack of basic information that could document possible links between environmental hazards and chronic disease. It is the lack of critical information that our communities and public health professionals need to reduce and prevent these health problems. While overt poisoning from environmental toxins has long been recognized, the environmental links to a broad array of chronic diseases of uncertain cause is unknown.

The national cost of chronic disease is staggering: 4 of every 5 deaths annually, 100 million people suffering each year and \$325 billion in annual healthcare and lost productivity. While our healthcare system is one of the best in the world in treating disease, the environmental health gap is crippling our ability to reduce and prevent chronic disease and help Americans live longer, healthier lives.

The Pew Environmental Health Commission proposes a **Nationwide Health Tracking Network** to close this critical gap. With a comprehensive tracking network, we can advance our ability to:

- Identify populations at risk and respond to outbreaks, clusters and emerging threats;
- Establish the relationship between environmental hazards and disease;
- Guide intervention and prevention strategies, including lifestyle improvements;
- Identify, reduce and prevent harmful environmental risks;
- Improve the public health basis for policymaking;
- Enable the public's right to know about health and the environment; and
- Track progress towards achieving a healthier nation and environment.

The proposed Network would be comprised of five key components:

- 1) national baseline tracking network for diseases and exposures;
- 2) nationwide early warning system for critical environmental health threats;
- 3) state pilot tracking programs to test diseases, exposures and approaches for national tracking;
- 4) federal investigative response capability; and
- 5) tracking links to communities and research.

Investing in prevention through these five components is estimated to cost the federal government \$275 million annually – less than 0.1 percent of the current annual economic cost of treating and living with chronic disease – a very modest investment in a healthier America.

The Grim Picture – An Environmental Health and Prevention Gap

Americans today are sophisticated about their health. More of us are asking if there is something in the air, water or our diet that could be making us sick. Is it our behavior – or something in our genes? Unfortunately, we are left with too many unanswered questions.

Recently, a major research study found that most types of cancer are not inherited genetic defects, but are explained mainly by environmental factors. Environmental factors include environmental tobacco smoke, toxic chemicals, dietary habits and viral infections. Despite many years of effort, scientists still are searching for answers about the relationship among the factors in our behavior, genes and the environment that cause disease and disability.

Earlier this year, it was announced that researchers have mapped the human genome, a breakthrough that is expected to open new doors to understanding chronic disease. Scientists will use this emerging genetic knowledge to fight disease. But if we are going to prevent disease, researchers also need more complete information about environmental factors, their effect on people, and the resulting health outcomes. In this way, scientists will have the capability to link genetic and environmental information and could begin to answer our questions about the complex causes and prevention of chronic disease.

Few would dispute that we should keep track of the hazards of pollutants in the environment, human exposures, and the resulting health outcomes—and that this information should be easily accessible to public health professionals, policymakers and the public. Yet even today we remain surprisingly in the dark about our nation's environmental health.

We have as a nation invested heavily in identifying and tracking pollutants in the environment, particularly for regulatory and ecological purposes, but have only invested minimally in tracking exposures and the distribution of disease and its relationship to the environment. As a result of decades of neglect, we have a public health system that is working without even the most basic information about chronic disease and potential environmental factors. The Commission found that information on trends in health conditions potentially related to the environment is largely unavailable. Here are a few illustrations of what this environmental health gap means:

- Only four states report tracking autoimmune diseases such as Lupus, even though there is increasing evidence that rates of these diseases are rising and the environmental links remain unknown.
- Despite evidence that learning disability diagnoses have risen 50 percent in the past 10 years, only six states track these disorders and we have no answers about causes or possible prevention strategies. Most states do not track severe developmental disabilities like autism, cerebral palsy and mental retardation. A recent report of the National Academy of Sciences estimates that 25 percent of developmental disorders in children are caused by environmental factors.
- Endocrine and metabolic disorders such as diabetes, and neurological conditions such as migraines and multiple sclerosis, have increased approximately 20 percent between 1986

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¹ Published in the July 13, 2000, edition of the *New England Journal of Medicine*, the study examined the medical histories of 44,788 pairs of twins listed in the Swedish, Danish and Finnish twin registries in order to assess risks of cancer at 28 anatomical sites for the twins of persons with cancer. It concluded that genetic factors make a minor contribution to susceptibility to most types of neoplasms, and the environment has the principal role in causing sporadic cancer.

and 1995, based on surveys by the Centers for Disease Control and Prevention (CDC). Most states do not systematically track these diseases and conditions.

- For most of the United States, there is no systematic tracking of asthma despite the disease having reached epidemic proportions and being the No. 1 cause of school absenteeism. Between 1980 and 1994, the number of people with asthma in the United States jumped by 75 percent. Without prevention efforts that include a strong tracking component, the Commission has estimated that the number of asthma cases will double by 2020.
- Birth defects are the leading cause of infant mortality in the United States, with about 6,500 deaths annually. Since the mid-1980s, rates of low birth weight and pre-term births have been rising steadily despite increased prevention efforts. The causes of 80 percent of all birth defects and related conditions remain elusive even as evidence mounts that environmental factors play an important role. The Commission found that less than half the nation's population is covered by state birth defect registries, which inhibits our ability to find solutions.

The tracking programs that do exist at the state and local levels are a patchwork because there are no agreed-upon minimum standards or requirements for environmental health tracking. The Commission found different standards, created to meet different objectives or regulatory requirements, and little synchronization in the collection, analysis and dissemination of information. In addition, much of the data collected are never analyzed or interpreted in a way that could identify targets for further action. Most of this information is never released to the public.

There is limited ability to take action at the state level without additional resources and leadership from the federal government. For decades, state and local health agencies have suffered declining resources, with the result that many now face the 21st century with outdated information systems, limited laboratory access, inadequate staff training and an inability to develop viable tracking programs. The Commission's survey of state and local agencies found a critical lack of funding for these activities despite unprecedented public demands.

Environmental tracking for pollutants is crucial, because often the hazards can be removed or abated before they cause harm. But such monitoring is not sufficient by itself. Tracking actual human exposures to hazards in the environment is frequently the missing link between public health efforts to evaluate a risk nationally and the ability to respond to a health threat in a specific community. This should include improving national efforts to track population exposures to contaminants and providing the investigative tools for local health officials.

Finally, there is a national leadership void, resulting in little or no coordination of environmental health activities. As a result, public health prevention efforts are fragmented and too often ineffective at reducing chronic and disabling diseases and conditions.

The CDC and EPA have some basic building blocks of a tracking network in place, but much more needs to be done. Currently 50 infectious diseases are tracked on a national basis. We need a comparable modern network to track chronic diseases and discover the environmental contributions to them.

The Public's Expectations

The public understands that we are not doing enough to protect our communities. A recent national survey of registered voters found that the majority are concerned about risks to their health from pollutants in the environment, and believe that government is tracking these hazards and possible links to chronic health problems.² When they learn that in reality there is no disease tracking, they are concerned—seriously concerned. Most Americans surveyed say that taking a national approach to tracking environmental health should be a priority of government at all levels.

Without comprehensive environmental health tracking, policymakers and public health practitioners lack information that is critical to establishing sound environmental health priorities. In addition, the public is denied the right to know about environmental hazards, exposure levels and health outcomes in their communities—information they want and have every reason to expect.

At the same time Americans demand a right to know about these hazards, they also expect government to gather health information in a way that protects citizens' privacy. Americans understand the importance of population-based health tracking as well as the need to keep individual health records private. Fortunately, public health agencies have an outstanding track record for zealously guarding the public's confidentiality and privacy. To ensure this continued balance, the Pew Commission established a set of principles for Protecting Privacy and Confidentiality and Our Environmental Health Right-to-Know (listed in the back of this report). The Commission believes that adherence to these principles will enable public health agencies to continue their traditional commitment to the confidentiality of individually identifiable health records without significantly hampering their obligations to the public health.

The federal government tracks many things all the time. It knows how many women dye their hair every year (three out of five), but has only rough estimates of how many people have Parkinson's disease, asthma, or most other chronic diseases that cause four of every five deaths in the U.S. each year. We have the right to know more.

The Pew Environmental Health Commission's Recommendation – A Right to Know our Environmental Health

To fill the Environmental Health Gap, the first step is to establish a tracking capacity for chronic diseases and environmental exposures that also link to hazard data. To this end, the Commission offers the following comprehensive recommendation:

Create a federally supported Nationwide Health Tracking Network with the appropriate privacy protections that informs consumers, communities, public health practitioners, researchers, and policymakers on chronic diseases and related environmental hazards and population exposures. This will provide the capacity to better understand, respond to and prevent chronic disease in this country.

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² Health-Track is a project supported by The Pew Charitable Trusts through a grant to Georgetown University. The survey, by Princeton Survey Research Associates, was conducted in April 2000 of 1,565 registered U.S. voters and has a margin of error of ± 3 percent for results based on a full sample.

This tracking network would use a tiered approach, with a national baseline list of high-priority disease outcomes and exposures that allows flexibility at the state and local level for specific concerns. At a minimum, all information would include race, ethnicity, gender, age and occupation. The blueprint for the Nationwide Health Tracking Network has five components of information and action:

Tier 1: National Baseline Tracking of Diseases and Exposures

This will be a nationwide network of local, state and federal public health agencies that tracks the trends of priority chronic diseases and relevant environmental factors in all 50 states, including Washington, DC, Puerto Rico and US territories. The information will allow us to identify populations at high risk, to examine health concerns at the state level, to recognize related environmental factors, and to begin to establish prevention strategies.

The federal government will have the responsibility to establish minimum national standards for health and exposure data collection. The state and local public health agencies, with federal support and guidance, would be responsible for the collection, reporting, analysis and response.

As a starting point, the Commission identified certain diseases and exposures that should be collected by all 50 states, based on review of the scientific literature, environmental data, reported health trends and targets identified by public health agencies. These are:

Diseases and Conditions

Birth defects

Developmental disabilities such as cerebral palsy, autism and mental retardation

Asthma and chronic respiratory diseases such as chronic bronchitis and emphysema

Cancer, including childhood cancers

Neurological Diseases, including Parkinson's, Multiple Sclerosis and Alzheimer's

Exposures

Persistent organic pollutants such as PCBs and dioxin

Heavy metals such as mercury and lead

Pesticides such as organophosphates and carbamates

Air contaminants such as toluene and fine particles

Drinking water contaminants, including pathogens

To translate this information into action will require a revitalization of the public health infrastructure by providing adequately trained health professionals to collect and interpret the data at the local, state and national levels; to respond to concerns and to ensure a healthy environment. The information produced by the network will be widely disseminated and easily accessible--simultaneously protecting both the public's right to know and individuals' privacy.

Finally, all of these efforts will be coordinated and made available to our communities and public health researchers. To ensure the information is accessible and useful in evaluating the progress of disease prevention efforts, a National Environmental Report Card should be jointly developed by CDC and EPA by 2003. It would provide an annual overview of key environmental factors and health outcomes, allowing all interested parties to track progress and shape national goals. It

should be adaptable so that state and local agencies can build on it for their own Environmental Health Report Cards.

Tier 2: National Early Warning System

An early warning system would act as a sentinel to allow rapid identification of immediate health problems, including chemical catastrophes. It would build on the existing infectious disease monitoring network around the country by including environmental sentinel exposures and health outcomes. The existing partnership of hospitals, poison centers and public health agencies that make up the tracking network for outbreaks like food and waterborne illnesses and bioterrorism attacks also should identify and track early warning signs of outbreaks of health effects that may result from environmental factors. This would be the first stage in an environmental outbreak response capability. At minimum, the Commission recommends that this tracking system should include:

Acute sensory irritation such as eye and respiratory problems

Heavy metal poisoning

Pesticide poisoning

For example, if a terrorist or accidental event occurred involving misuse or release of toxic chemicals, an early warning system with environmental capacity could quickly recognize the episode, identify the chemical exposure and rapidly initiate effective treatment and response.

Tier 3: State Pilot Tracking Programs

The Network also would support a coordinated series of 20 state pilot programs in order to respond to regional concerns and to test for exposures and disease outcomes that could be tracked on a national level. These pilots would be "bellwethers" for better understanding potential health and environmental problems.

Selecting appropriate health and environmental indicators is essential to the success of a national network. This requires systematic development of tracking methods that are flexible, practical and adaptable to the unique public health needs of states.

States may be interested in developing pilot tracking capacity for certain disorders, diseases and exposures in order to strengthen the response to local health concerns. For example, there have been increasing concerns about environmental links to attention deficit disorder, lupus and endocrine disorders, such as diabetes.

Pilot programs covering specific health problems also would provide the Network with a broad reach for rapidly addressing many different health concerns, while at the same time testing methods and evaluating the need for broader tracking of certain health problems.

Tier 4: Public Health Investigative Response

Trained public health officials at the federal, state and local level need to be able to respond to health concerns that are identified through this network. The federal government must provide states and localities with the support and capacity to assure a coordinated response to investigate threats linked to the environment.

By developing the capacity to track trends at the national level and conduct investigative surveys anywhere in the nation, the Network would be prepared to respond to outbreaks, clusters and emerging threats. While this is a routine response for infectious outbreaks, we presently lack a similar ability to respond to chronic disease investigations.

There are many needs for a response capacity. For example, the recent National Academy of Sciences study on mercury and its neurodevelopmental effects on children exposed in utero underscored the need to study exposures and health outcomes of pregnant women across America. This capability also would permit quick response at the local level to citizens' concerns about potential problems, such as spontaneous abortions among women who live near hazardous waste sites.

Tier 5: Tracking Links to Communities and Research

The Network would depend on a strong community and scientific foundation to ensure its relevance, effectiveness and vitality.

The public has a right to know the status of our environmental health at the national, state and local level. It is paramount that the Network be grounded in community groups so that local concerns are adequately addressed in the design of the system, that tracking data is readily accessible and that this information is useful for local level activities. To insure this interaction, the Network should support community-based organizations to routinely evaluate the tracking systems with regard to individual and local needs and to ensure dissemination and interpretation of the Network data.

Action Steps Needed to Develop the Network

To establish this Nationwide Health Tracking Network, the Commission calls on the Administration, Congress, the Secretary of Health and Human Services, and the Administrator of the Environmental Protection Agency to support and implement the following action plan:

- ➤ The Administration and Congress should provide funding support within one year to develop and establish the Nationwide Health Tracking Network. This should include support and incentives for state and local agencies, healthcare providers, community based-agencies and insurers to become active partners in tracking population health and identifying, treating, and preventing health problems related to the environment. The Commission estimates that the annual cost for a Nationwide Health Tracking Network is \$275 million.
- ➤ The Administration and Congress should guarantee public access to the Nationwide Health Tracking Network to better understand community environmental exposure and health outcome information. As part of this right-to-know requirement, the EPA, CDC and the Surgeon General should jointly develop a National Environmental Health Report Card by 2003, which will give all Americans an annual overview of key hazards, exposures, and health outcomes in order to gauge progress and shape national goals. The approach should be adaptable to the needs of state and local agencies to facilitate similar report cards at the state and local levels.
- ➤ The Secretary of Health and Human Services, in collaboration with the EPA Administrator, should by 2001:

- Designate a national lead authority for environmental health tracking to oversee development of a nationwide network and coordinate all related health and exposure monitoring activities, including those of EPA, CDC and the Agency for Toxic Substances and Disease Registry (ATSDR); and
- Establish a Council on Environmental Health Tracking to work with the HHS, EPA and state tracking leadership to set up science-based criteria, minimum state standards and privacy and confidentiality guidelines for a tiered approach that supports both national priorities and state flexibility.
- ➤ Every governor should appoint an environmental health lead in the state health department.
- > CDC/ATSDR should help build state capacity to launch the Network, monitor the data, and respond to potential health concerns by:
 - Placing an Environmental Health Investigator in every state;
 - Expanding the CDC Epidemic Intelligence Service and Public Health Prevention Service to recruit and train public health officers in environmental epidemiology and tracking;
 - Working with the National Association of County and City Health Officials to develop similar leadership capacity at the local level with support and guidance from HHS; and
 - Providing technical resources to local and state public health agencies, including improvement of regional, state and local laboratory capacity to evaluate community exposures and complement state investigative abilities.

The Case of Libby, Montana

Last November, federal agencies began investigating what is believed to be the single most significant source of asbestos exposure in the United States. Residents of the small town of Libby, Montana, have watched for decades as neighbors, friends, and loved ones fell ill with respiratory problems. Many died. Townspeople thought it might have something to do with the vermiculite mine that was the town's largest employer from its opening in the 1920s until it was shut down in 1990. But until the federal health investigation this year, no one knew for certain. As far back as the mid-1950s, state health officials had reported on the toxic asbestos dust in the mine, but no one followed up on possible exposures or health impacts to the town's 2,700 residents.

It turned out that along with vermiculite, the mine also was releasing tons of tremolite, a natural but rare and highly toxic form of asbestos, into the region's environment. It takes 10 to 40 years for asbestos exposure to manifest in chronic, and often fatal, respiratory diseases, including asbestosis, rare cancers and emphysema. Therefore, early intervention as soon as potential or actual exposures were detected could have prevented these long-term harms.

So far, nearly 200 people reportedly have died from diseases connected to the asbestos-tainted vermiculite. Newspapers account that another 400 have been diagnosed with asbestos-related disease, including mesothelioma, a rare and fatal cancer of the lung lining associated with asbestos exposure. Every month, more Libby area residents are diagnosed with asbestos-related diseases. As many as 5,000 people are expected to undergo medical testing for asbestos-related diseases by Fall 2000.

"Active [tracking] of asbestos-related disease might have picked this up much sooner, and started preventive activities 10-20 years ago," said Dr. Henry Falk, administrator of the Agency for Toxic Substances and Disease Registry. In that case, more lives would have been saved and the severity and possible spread of the outbreak reduced.

Now, public health officials have to cope not only with ensuring that Libby residents are protected from this environmental hazard, but also investigating other sites and possible worker exposures around the country where this asbestos-laden vermiculite was shipped, processed and used in large quantities.

Clearly, this case illustrates the tragedy of not tracking the environmental health of our communities. Every year there are towns and cities across the United States where residents are asking themselves, their health officials and elected leaders, why they or their children are getting sick. Until we establish a national tracking network capable of bringing together in a coordinated fashion the information about environmental hazards in the community, the exposures of people, and data on health problems, we will risk having more cases like Libby, Montana.

The Case of Pesticides in Mississippi

In November 1996, one of the nation's worst and most costly public health disasters involving pesticide misuse was discovered in rural Jackson County, Mississippi. The event in Jackson came on the heels of similar events in Ohio and Michigan.

Initially, health officials became aware of a possible problem when church members reported a noxious odor and yellowed walls in their church after fumigation. Before long, numerous residents began complaining of various symptoms, mainly resembling influenza. Suddenly, officials were facing a possible pesticide threat potentially larger than any in Mississippi's history.

The initial investigation revealed that illegal pest control spraying in homes and businesses had taken place, potentially exposing thousands of residents in the area to methyl parathion (MP), an organophosphate insecticide intended for outdoor use that attacks the central nervous system, causing nausea, dizziness, headaches, vomiting and in severe cases, death. EPA officials began considering relocation of residents and decontamination of homes at what would be a staggering cost.

Fortunately, public health officials had a health-tracking tool that was able to pinpoint who was at immediate risk and allowed for a more targeted, rapid response. Using biomonitoring - the direct measurement of human exposure to a contaminant by measuring biological samples, such as hair, blood or urine - health officials could determine individuals' exposure levels to MP. In this case, biomonitoring allowed scientists to identify the residents who were most at risk and prioritize evacuation and cleanup in the most dangerous situations, not just every house suspected.

Armed with this information, EPA, ATSDR and state health officials were able to implement an effective health defense plan. In Mississippi and Alabama, over 1,700 residents had to be temporarily relocated and nearly 500 homes and businesses had to be decontaminated at a cost of almost \$41 million. While no one died or was seriously injured in the short term, many of the early victims were misdiagnosed with the influenza virus-a fact that only underscores the need for a nationwide health tracking network to monitor environmental threats.

A national early warning system for pesticide poisoning might have detected this problem sooner and led to a quicker halt of the illegal pesticide applications in other states. In turn, this would have prevented widespread exposures, and in some cases, evacuations, and higher human and financial costs. This case also points to the importance of another feature of a network-the laboratory resources and other infrastructure to conduct rapid and effective biomonitoring to protect the health of our communities.

The Commission's Health Tracking Analysis

In the 1970s and 1980s, the nation's environmental regulatory infrastructure was built, fueled by the passage of federal laws aimed at cleaning up the environment. Unfortunately, these same laws failed to support core public health functions of environmental health. More than a decade ago, the Institute of Medicine report, *The Future of Public Health*, sounded a warning, saying the nation had "lost sight of its public health goals" and allowed the public health system to "fall into disarray." With diminishing authority and resources, public health agencies at all levels of government grew detached from environmental decision-making, and the infrastructure failed to keep pace with growing concerns about health and environment.

The Commission's study of health tracking found that today, there still is no cohesive national strategy to identify environmental hazards, measure population exposures, and track health conditions that may be related to the environment. Just as important, there is a national leadership void, resulting in little or no coordination of environmental health tracking activities.

The few existing environmental health tracking efforts are a widely varied mix of programs across multiple federal, state and local agencies. These programs have evolved, often in isolation from each other, to respond to disparate regulatory mandates or program needs. Unfortunately, there are no identifiable linkages between hazard, exposure and outcome tracking, and there is limited coordination in the collection, analysis, or dissemination of information. The combination of lack of leadership, planning, coordination and resources have left important questions about the relationship between health and the environment unanswered. For example:

- Are environmental exposures related to clusters of childhood cancer and autism?
- What are the impacts of pesticide exposure on children's health?
- What proportion of birth defects is related to environmental factors?
- Are changes in the environment related to the dramatic increase in asthma?
- Are adult-onset diseases like Parkinson's and Alzheimer's related to cumulative environmental exposures?
- Are there increases in Systemic Lupus Erythmetosis (SLE) and multiple sclerosis (MS) in communities with hazardous waste sites?
- Are learning disabilities related to environmental factors?
- Is attention deficit disorder (ADD) related to exposures that occur in a child in the womb?
- Are endocrine disrupting pollutants in the environment related to the increasing incidence of breast and prostate cancers?
- How does particulate air pollution increase the risk of death in the elderly?
- What is the relation of diet and lifestyle to chronic disease?

With the exception of childhood blood lead screening, there have been few systematic efforts to track individual levels of exposure to any hazardous substance. CDC and EPA have developed the methodologies for biological and environmental monitoring of a wide range of substances. However, inadequate support and inconsistent funding have restricted their application and availability. These findings were underscored in a recent report of the U.S. General Accounting Office (GAO) that calls for a long-term coordinated strategy to measure exposures to pollutants. With the goal of improving the public health response to environmental threats, the Pew Environmental Health Commission conducted an examination of the national capacity for

tracking environmental hazards, exposures and health outcomes. The study had the following objectives:

- > To examine the existing public health capacity for environmental health tracking;
- To identify the environmental health priorities of the nation's public health agencies;
- To examine the coordination among agencies, healthcare providers and researchers on environmental health tracking efforts; and
- > To develop recommendations for implementing an effective national strategy for environmental health tracking.

The complete study is available at the Commission's website: http://pewenvirohealth.jhsph.edu.

A Look at National Capacity for Tracking

"Tracking" is synonymous with the CDC's concept of public health surveillance, which is defined as "the ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know (Thacker et al., 1988)." Effective environmental health tracking requires a coordinated approach that identifies hazards, evaluates exposures, and tracks the health of the population. Figure 1 provides a schematic representation of the steps in environmental health tracking.

Agent is a hazard

Agent is present in the environment

Route of exposure exists

Host is exposed to agent

Agent reaches target tissue

Agent produces adverse effect

Figure 1: Environmental Health Tracking

Adapted from Thacker, et al., AJPH 86: 633-638 (1996)

Adverse effect becomes clinically apparent

Note: 'Tracking' is substituted for 'surveillance', which appeared in the original publication in AJPH, for the purposes of this report.

Health Outcome Tracking

Hazard Tracking

What are the hazards to health in our environment? Environmental hazard tracking identifies potential hazards and examines their distribution and trends in the environment. It is an essential component in prevention strategies, particularly in the absence of definitive knowledge about the health impacts of environmental exposures. EPA and the state environmental agencies have primary responsibility for hazard tracking, which includes networks for data collection on water and air quality, environmental emissions, hazardous and radioactive waste generation, storage, and disposal, and the use of toxic substances and pesticides. These efforts are the foundation of our national environmental protection efforts.

The EPA Toxics Release Inventory (TRI) is an example of an effective and publicly accessible hazard tracking program. The TRI contains data on annual estimated releases of over 644 toxic chemicals to the air and water by major industries. Data are reported as annual total releases by chemical. TRI is an innovative way to provide communities with information about the nature and magnitude of pollution in their neighborhoods. While there are many pollution sources not covered and a two-year time lag in making the data public, TRI provides the best snapshot of local and national environmental releases of key toxins by major industries.

The Commission analyzed the 1997 TRI data to determine the ranking of 11 categories of associated possible toxicological effects (Table 1). Substances with potential respiratory effects were released in the largest amount in 1997. Neurotoxicants and skin toxicants were next highest in total pounds released. Actual population exposures to these toxicants are not currently tracked and their relationship to disease is unclear. This approach to hazard tracking provided the Commission with an important starting point for identifying needs for tracking exposure and health outcomes.

Table 1: Ranking of Toxicants based on 1997 Toxics Release Inventory (TRI)³

Types of health effects	Ranking based on total 1997 TRI release	Total Air & Water Releases (Pounds)
Respiratory	1	1,248,977,984
Neurologic	2	1,211,458,945
Skin or sense organ	3	1,109,718,312
Gastrointestinal or liver	4	1,086,264,404
Cardiovascular or blood	5	823,375,664
Developmental	6	811,686,192
Reproductive	7	498,142,705
Kidney	8	488,554,582
Immunological	9	234,713,891
Carcinogenesis	10	209,271,142
Endocrine	11	173,331,065

Reference: Environmental Defense Scorecard (www.scorecard.org)

³ This analysis includes both suspected and recognized toxicants. An agent is listed as a recognized toxicant if it has been studied by national or international authoritative and scientific regulatory agency hazard identification efforts. Suspected agents are included if they are shown to have target organ toxicity in either humans or two mammalian species by a relevant route of exposure.

While the nation has developed a hazard tracking network, little has been done to link these findings to efforts to track actual population exposure levels or track the health of communities where these releases occur.

Exposure Tracking

Are communities being exposed to harmful levels of pollutants? Understanding exposure levels is essential in understanding and preventing environmentally related disease. Ideally, exposure tracking includes the systematic measurement of harmful environmental agents to which individuals are exposed. Exposure tracking also helps evaluate the effectiveness of public health policies. It should be closely coordinated with ongoing hazard tracking.

The National Health and Nutrition Examination Survey (NHANES) illustrates a national approach to exposures. The survey examines a nationally representative sample of about 5,000 Americans each year. Environmental exposure measurements are only one part of NHANES, a broad-based national survey of nutrition and health.

One of its strengths is that it allows policymakers to evaluate public health intervention policies. For example, NHANES data showed a drop in average blood lead levels between 1976 and 1980, a period that corresponded with the removal of lead from gasoline. These data enabled policymakers and regulators to determine that the ban on leaded gasoline was effective. NHANES has also provided a national profile of exposure to environmental tobacco smoke, thus supporting initiatives to reduce exposures.

Unfortunately, NHANES is not designed to track exposures at the state and local level, and so does little to help public health professionals in responding to a community's local concerns about a possible cluster of health problems related to the environment.

There is potential for progress, however, given advances in sampling and detection for a broad array of human monitoring techniques. But the failure to develop and support a national capacity for exposure tracking and coordinate with ongoing environmental hazard tracking has left a large gap in our approach to environmental protection. The GAO underscored the need to close this gap in a report that called for a national approach to measuring Americans' exposures to pollutants in order to strengthen prevention efforts.

Health Outcome Tracking

Are environmental exposures and population exposures related to increased disease? Understanding trends in the incidence of diseases that may be related to environmental exposures is fundamental to protecting public health. The Commission reviewed a number of national health outcome databases to examine the availability of information on diseases that may be linked to the environment. Three are particularly worth noting:

- The National Hospital Discharge Survey (NHDS) conducted since 1965 is a continuous survey based on a sampling of patient medical records discharged from hospitals. The survey collects demographic information, admission and discharge dates, diagnoses and procedures performed.
- The National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) are national surveys

designed to provide information on the types and uses of outpatient health care services for office-based physicians, emergency rooms and hospital outpatient centers, respectively. This allows us to measure the number of doctor visits pertaining to specific health concerns that may be environmentally related, such as asthma.

The National Health Interview Survey (NHIS) is a multistage sample designed to represent the civilian, non-institutionalized population in the United States. The survey is conducted by the CDC's National Center for Health Statistics (NCHS). It has been conducted continuously since 1957. Due to budget reductions, the survey was redesigned in 1997 to track a much more limited set of health problems.

These databases are not designed to describe either state or local communities or environmentally related health outcomes, but they provide warning signals or "big picture" level information on the prevalence and trends of health outcomes in need of closer study. For instance, the NHIS data show the 10-year national trend in rising rates of asthma and clearly established it as an epidemic chronic disease. From 1986-1995, the surveys of about 5,000 people annually found that endocrine and metabolic disorders increased by 22 percent, while neurological and respiratory disease increased by 20 percent.

However, the role of the environment in these health outcomes remains unknown. Without an adequate tracking process, such links are difficult to clarify. This type of snapshot data does not provide the full panoramic view needed by health professionals to identify clusters, uncover risks or guide the prevention programs that make people healthier.

A Look at State and Local Capacity for Tracking

The Commission interviewed environmental health leaders from public health agencies in the 50 states and a sample of local health departments as part of its examination of state and local public health capacity for environmental health tracking. While some states and localities have well-developed programs, others have virtually no capacity for environmental health tracking. Overall, the survey found that the state and local infrastructure for environmental health tracking has been neglected; with the result that today many have outmoded equipment and information systems, and lack technical and laboratory support. As a result, fundamental information about community health status and environmental exposures is not available.

In a Commission survey of state health officials, it was found that while over three quarters of state health departments track blood lead levels, biomonitoring for other substances, including hazardous pesticides, is very limited. Only about 25 percent said their departments could measure human exposure to environmental contaminants by monitoring the air in a person's breathing zone, an important investigative capability in responding to a health threat. Most of the chronic diseases and health problems that the Commission identified as priorities are not being tracked.

Even for health problems that most states do track – cancer, infectious disease and birth defects – tracking efforts have significant problems. For instance, an earlier Pew Commission report found that while 33 states have birth defect registries, the majority was inadequate in terms of

generally recognized standards for an effective tracking program. Another Commission study found similar gaps in state efforts.

Finally, information that is tracked according to current standards is often not usable for intervention, policy, and scientific purposes. First, state data sets commonly lack enough samples from more refined geographic areas to make it possible to characterize health hazards, exposures and outcomes at the local level. In addition, the Commission's survey found that many departments lack the staffing, expertise, or technology to analyze and in some cases even to access existing data sets relevant to local environmental health. Rather, local health practitioners find themselves focusing on enforcement and reacting to complaints. Another concern is the absence of national standards to ensure consistent data collection.

State and local public health agencies are the foundation of the nation's health tracking capacity. The first requirement for an effective, integrated network is strong state and territorial public health organizations with linkages to strong local health agencies, as well as federal agencies, healthcare providers, state environmental agencies and communities. While the states and localities may have the will, this vision of a Nationwide Health Tracking Network will only come together with the support, guidance and leadership of the federal government.

The Time is Right

Advances in hazard identification, exposure assessment, health outcome data collection and information technology provide unprecedented opportunities for advancing tracking and improving our understanding of the environment and health.

Despite the challenges, there are unprecedented opportunities to strengthen the national infrastructure for environmental health information, expand public access to this important information and protect the privacy of individuals. New technologies in biomonitoring have the potential to transform the nation's capacity to track exposures to pollutants and understand their impacts on health. Advances in communication and information technology have expanded opportunities for public access and given us new tools to analyze, map and disseminate health data. New technology also can improve safeguards to protect the confidentiality of identifiable personal health information. We have better tools than ever before to meet the public health missions of protecting Americans' health and privacy.

New initiatives at CDC and EPA have the potential to address tracking needs, including information technology development and state and local capacity-building, along with exposure measurement, interagency coordination and public access to health information. Opportunities exist, but we need to do more to advance the science and support for inclusion of environmental health components.

The integration of public health information and tracking systems is listed as a top priority of the CDC. Spurred by concerns about bioterrorism, a Health Alert Network is being developed to improve tracking and information sharing on key infectious diseases and priority chemical and poison agents that may be used in terrorist attacks. In addition, there are several other data systems being developed by CDC and EPA that could be building blocks in a national tracking

network. However, national vision and leadership to bring this all together on behalf of environmental health issues will be required if any of these current initiatives are to become building blocks for a national environmental health tracking network.

Environmental health tracking will give us an unprecedented opportunity to ensure our environmental policies are successfully reducing exposures in our communities and safeguarding public health.

Reduction of risks from hazards in the environment and people's exposures and the improvement of public health are fundamental goals of environmental regulations. At present, tracking activities are focused primarily on hazard identification for regulatory permitting and enforcement. Improved capacity to measure peoples' exposures to hazards and track health outcomes will strengthen the scientific basis for these important policy decisions. In addition, environmental health tracking will give practitioners and policymakers better indicators of progress, and assure that benefits of healthier communities continue well into the future.

The public increasingly wants and demands more credible environmental health information so that they can make independent and fully informed decisions. The Internet explosion has further fueled this desire.

Recent public opinion research confirms that Americans want to have access to national, state and community level health data. In fact, they are incredulous when informed that health tracking information is not readily available. The Internet now allows the public quick and highly accessible information on most facets of their lives. There is a widespread belief that health tracking information should be and needs to be available to the public. With growing concerns about environment and health, this public demand should help support the Network.

Recently, a group of environmental health leaders held a summit co-sponsored by the Pew Environmental Health Commission, the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Public Health Foundation at which they strongly endorsed the Commission's efforts to strengthen environmental health tracking.

Summit participants endorsed a tiered approach to national environmental health tracking that is consistent with the Commission's five-tier recommendation. It includes: national tracking for high-priority outcomes and exposures; a sentinel network to identify acute and emerging hazards; a coordinated network of pilot regional, state and local tracking programs; and aggressive research efforts to guide and evaluate tracking.

Why We Need a Health Tracking Network Now

Earlier this year, a scientific breakthrough was announced that has incredible potential to help us understand the links between people, their environment and behaviors, genetic inheritance and health.

As researchers begin to apply this new genetic knowledge to the study of disease, we will have more information than ever before to use in revealing the connections between environmental exposures, people's behaviors and genetic predisposition to health problems. But only if we

have the basic information about what is going on in our communities—the hazards, the exposures and health problems that Americans are experiencing.

The "building blocks" of knowledge provided by the Nationwide Health Tracking Network will enable scientists to answer many of the troubling questions we are asking today about what is making us sick. The Network will provide the basis for communities, health officials, businesses and policymakers to take action for making this nation healthier. The result will be new prevention strategies aimed at reducing and preventing many of the chronic diseases and disabling conditions that afflict millions of Americans.

The Commission is calling upon our national leaders to take the steps outlined in this report, and with a minimal investment, revitalize our nation's public health defenses to meet the challenges of this new century. It is time to close America's environmental health gap.

The Pew Commission Principles for Protecting Privacy and Confidentiality And Our Environmental Health Right-to-Know

Without a dynamic information collection and analysis network, public health agencies would be ineffective in protecting health. The Commission recognizes the substantial benefits that accrue from personally identifiable health information and provides these principles to assist agencies in addressing privacy and confidentiality concerns associated with collection and use of this information in environmental health investigations.

The Commission is aware of the sensitivity of individually identifiable health information and is committed to protecting the privacy of such information and to preventing genetic and other sensitive health information from being used to discriminate against individuals. The Commission believes that the values of public health activities and privacy must be reasonably balanced.

The Commission also is aware of the need to increase public confidence in our nation's public health system by making nonidentifiable health information and trends widely available and providing access to the analyses of collected data. This also will serve to better inform communities about the value of public health data.

The Commission believes that adherence to the following principles will enable public health agencies to honor their traditional commitment to the confidentiality of individually identifiable health records without significantly hampering execution of their obligations to the public health:

- Recognize that it is largely possible to balance the protection of individually identifiable health information and the acquisition, storage and use of that information for environmental health purposes;
- Protect individuals' privacy by ensuring the confidentiality of identifiable health information;
- Disclose only as much information as is necessary for the purpose in cases where the public health requires disclosure of identifiable information;
- Require that entities to which identifiable information has been disclosed take the same measures to ensure confidentiality that are taken by the disclosing agency;
- Utilize the best available organizational and technological means to preserve confidentiality of information (includes such measures as limiting access, staff training, agreements and penalties as well as updating of security measures);
- Provide individuals the opportunity to review, copy and request correction of identifiable health information.

Chapter 2. Background on Environmental Health Tracking

Protecting and improving the health of the public is a fundamental goal of our national environmental policies. Similarly, a healthy environment is a cornerstone of our national public health goals detailed by the Department of Health and Human Services in *Healthy People 2010* (U.S.Department of Health and Human Services, 2000). Achieving these goals requires a strong public health foundation to identify hazards, track population exposures and health status, and implement effective environmental health strategies.

Unfortunately, America has failed to invest in the public health infrastructure for environmental health. Today, we remain unable to track the health of our communities; unable to identify and measure individual exposures to the thousands of possible contaminants in food, homes, water, and air; and unable to understand and prevent the broad range of diseases and disabilities that may be related to hazards in the environment. As a result, fundamental questions about the relationship between health and the environment remain unanswered. Table 2 lists examples of the types of questions faced by public health practitioners, which the Commission uncovered in its investigation. The first step in addressing these questions is the development of basic information on the incidence and distribution of these diseases and exposures – environmental health tracking.

Table 2: Examples of Questions Facing Communities and Public Health Officials in Environmental Health

- Are environmental exposures related to clusters of childhood cancer and autism?
- What are the impacts of pesticide exposure on children's health?
- What proportion of birth defects is related to environmental exposures?
- Are changes in the environment related to the dramatic increase in asthma?
- Are adult onset diseases such as Parkinson's and Alzheimer's related to cumulative environmental exposures?
- Are there increases in Systemic Lupus Erythmetosis (SLE) and Multiple Sclerosis (MS) in communities with hazardous waste sites?
- Are learning disabilities related to environmental exposures?
- Is Attention Deficit Disorder (ADD) related to *in utero* exposures to contaminants in the environment?
- Are there endocrine disrupting pollutants in the environment related to the increasing incidence of breast and prostate cancers?
- How does particulate air pollution increase the risk of death in the elderly?

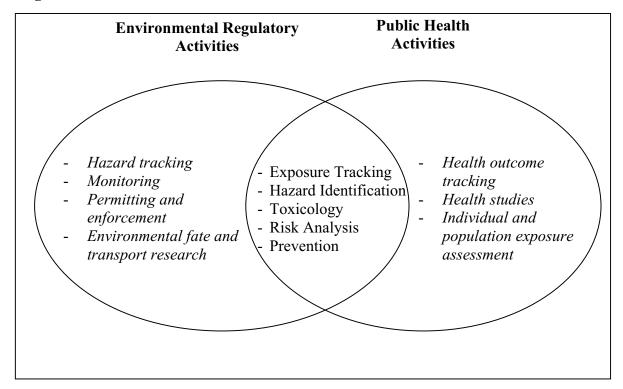
Throughout the 1970s and 1980s, the nation's environmental regulatory infrastructure emerged, fueled by the passage of national laws. At the same time, these laws failed to support the core environmental health activities of public health agencies (Figure 2). Over a decade ago, the Institute of Medicine report, *The Future of Public Health*, sounded a warning, finding that the nation had "lost sight of its public health goals" and allowed the public health system to "fall into

disarray" (Institute of Medicine, 1988b). With diminishing authority and resources, public health agencies at all levels of government grew detached from environmental decision-making, and the infrastructure failed to keep pace with growing concerns about health and environment.

Despite the dramatic improvements in environmental quality over the past three decades, comparable improvements in public health indicators that may be related to the environment have not been realized. Understanding the relationship between public health and the environment is essential to continued progress in environmental protection. Yet, the United States still lacks a cohesive strategy to coordinate the identification of environmental hazards, measurement of population exposures, and assessment of related health effects or diseases.

Figure 2 depicts the core environmental health activities of environmental regulatory agencies and public health agencies. Though there are clear differences, these activities are complementary and essential to protect the environment and public health. As the picture shows, there is substantial common ground among environmental and health activities, particularly regarding tracking environmental exposures, understanding population risks, and developing prevention strategies. Presently there is a critical lack of support for the traditional public health activities and the integration of activities, which in many instances are carried out by multiple agencies and organizations.

Figure 2: Core Environmental Health Activities



Defining "Environmental Health Tracking"

"Tracking" is synonymous with the CDC's concept of public health surveillance, which is defined as "the ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know (Thacker & Berkelman, 1988)." While it is recognized that surveillance is the historically based term of art, for consistency, this report uses the term "tracking". Effective environmental health tracking requires a coordinated approach that identifies hazards, evaluates exposures, and tracks the health of the population.

Tracking is the backbone of public health practice. The Institute of Medicine (IOM) report, *The Future of Public Health*, identified three core functions of public health: assessment, policy development and assurance. To perform the first core function, assessment, the IOM recommended that every public health agency systematically collect, assemble, analyze, and disseminate information on the health status of communities, including health statistics, community health needs, and epidemiologic and other studies of health concerns (IOM, 1988, p. 7).

Public health tracking systems are critical to carrying out these core functions. These systems serve as the conduit of information between public health practitioners, environmental regulators, and affected parties and provide the basis for subsequent public health action. Tracking has far reaching implications for building capacity for assessment, and is key to the core functions of policy development and assurance as well.

The Goals of Environmental Health Tracking

In addition to describing the types of tracking activities, it is important to recognize the goals and benefits of an environmental health tracking system. Dr. William Halperin, in several publications, framed the goals for occupational health (Halperin, 1993); (Halperin, 1995). Because of their relevance to environmental health, they are adapted and summarized below. An effective National Tracking Network should:

- ➤ Be structured in a manner that facilitates the identification of new and emerging problems. Early recognition enables public health practitioners, policy makers, and affected populations to respond appropriately and prevent future adverse events.
- ➤ Have the capacity to identify sentinel cases or epidemics. The use of sentinel events provides practitioners with an early opportunity to isolate and investigate situations where a prevention system has failed and devise appropriate remedies either locally or more broadly.
- > Provide the capacity to estimate the magnitude of public health problems, which is essential to developing a public health response.
- ➤ Provide the ability to track and report trends in population health status, environmental exposures, and hazardous substances and their sources.
- ➤ Identify specific populations that may be at increased risk of environmentally related diseases or are highly exposed to harmful environmental pollutants.

➤ Guide priority setting by providing a basis for public health professionals, policy-makers, planners, and communities to channel resources towards the most pressing problems and most effective prevention strategies.

Within the framework of environmental health, effective tracking requires an integration of information on hazards in the environment (i.e., environmental hazards), how these hazards come in contact with the population (i.e., environmental exposures) and whether these hazards cause adverse health effects in the population (i.e., health effects). Moreover, a successful tracking system requires coordination across many agencies and organizations involved in public health and environmental protection to facilitate the timeliness and relevance of data collection, analysis, and response. Figure 3 provides a schematic representation of the steps in environmental health tracking.

Agent is a hazard

Agent is present in the environment

Route of exposure exists

Host is exposed to agent

Agent reaches target tissue

Agent produces adverse effect

Adverse effect becomes clinically apparent

Hazard Tracking

Exposure Tracking

Health Outcome Tracking

Figure 3: Three Types of Public Health Tracking for Adverse Environmental Threats

Adapted from Thacker, et al., AJPH 86: 633-638 (1996)

Note: 'Tracking' is substituted for 'surveillance', which appeared in the original publication in AJPH, for the purposes of this report.

The Components of Environmental Health Tracking

Hazard Tracking

Environmental hazard tracking examines the distribution and trends of hazards in the environment. It represents an essential component of our prevention strategies in environmental health, particularly in the absence of definitive knowledge about the health impacts of environmental exposures. EPA and the state environmental agencies have primary responsibility for hazard tracking, which includes an extensive network of data collection on water and air quality, environmental emissions, hazardous and radioactive waste generation, storage, and disposal, and the use of toxic substances and pesticides. Funded by federal support through EPA-state agreements (state implementation plans, SIPS) these efforts are the foundation of our national environmental protection efforts. Table 3 describes a range of national data systems designed to track environmental hazards.

LIMITATIONS

There are two major categories that describe the limitations of current hazard tracking systems: limitations about the data and their structure and limitations about the uses of such data when used to make policy decisions. With regard to the former, hazard tracking data are narrow in terms of their chemical and source coverage, and they are often site-specific as well as substance-specific, thereby limiting the scope of hazard assessments and precluding policy alternatives and decision-making. For example, in the Toxics Release Inventory, facilities are only required to report if they: 1) are included within a refined set of Standard Industrial Classification (SIC) groups defined by EPA; 2) employ 10 or more full-time employees; and 3) import, process, or use toxic chemicals that exceed a certain threshold as defined by EPA. Thus, this inventory represents a small proportion of toxic emissions to the environment. For a system like the Comprehensive Environmental Response, Compensation, and Liability Information System (CERCLIS), data are collected on a site-by-site, substance-by-substance basis, limiting its utility in offering insight about the potential health risks that may result from exposure to hazardous substances at or near waste sites.

With respect to the latter limitation, hazard tracking systems fail to make the connection to potential population exposures and adverse health effects; they represent only one component of the public health tracking triad. Without strong linkages to exposure and health outcomes data, EPA and many state agencies are forced to rely upon hazard information, coupled only with assumption-laden exposure and risk models to make regulatory decisions.

Table 3: A Sample of Hazard Tracking Systems

Database Name	Source	Type of Reporting	Media Covered
Aeromatic Information Retrieval System (AIRS)	EPA	Quarterly	Air
The Toxics Release Inventory (TRI)	EPA	Annual	Water, Soil, Air,Waste
National Pollution Discharge Elimination System(NPDES)/ Permit Compliance System	EPA	Periodic, monthly, Quarterly	Water
The Storage and Retrieval System for Water and Biological Monitoring Data (STORET)	EPA	Periodic, Biennial	Water
Comprehensive Environmental Response Compensation and Liability Information System (CERCLIS)	EPA	One time at registration of site and as updates needed	Water, Air, Soil, Waste
Resource Conservation and Recovery Information System (RCRIS)	EPA	Periodic, at time of permit applications	Water, Soil, Waste
The RCRA Biennial Report System (BRS)	EPA	Biennial	Water, Soil, Air, Waste
The Accidental Release Information Program (ARIP)	EPA	Follow-up response to accidental release	Water
Trogram (zuen)		information provided by EPA Emergency Response	Soil
		Notification System.(see ERNS)	Air
The Emergency Response Notification System (ERNS)	EPA	Daily-weekly entries	Water
Notification System (EKNS)			Soil
			Air

Note: Adapted from US EPA Inventory of Exposure-Related Data Systems Sponsored by Federal Agencies (EPA/600/R-92/078). May 1992. Additional information collected from http://www.epa.gov/ceisweb/ceishome.

Exposure Tracking

Are communities being exposed to harmful levels of pollutants? Understanding the exposure levels is an essential step in understanding and preventing environmentally-related disease.

Ideally, exposure tracking includes a systematic approach to measuring the levels of harmful environmental agents to which individuals are exposed. Exposure tracking can also provide a means for measuring environmental health progress and evaluating the effectiveness of policies. The National Health and Nutrition Examination Survey (NHANES), is one example of a national approach to develop information on population exposures to environmental agents and to track spatial and temporal trends. The current survey design examines a nationally representative sample of about 5,000 persons each year. Environmental exposure measurements are only one part of NHANES, which is a broad-based national survey of nutrition and health (http://www.cdc.gov/nchs/nhanes.htm).

One of the strengths of NHANES as an exposure tracking system is that it enables policy makers to evaluate the effectiveness of public health intervention policy. For example, NHANES data showed a drop in average blood lead levels between 1976 and 1980, a period that corresponded with the removal of lead from gasoline. These data enabled policy-makers and regulators to evaluate the effectiveness of regulatory policies regarding the ban of leaded gasoline in the United States. NHANES has also provided a national profile of exposure to environmental tobacco smoke, which has supported national, state, and local initiatives to reduce exposures. The current NHANES effort will track a broader range of environmental exposures than ever before. These results will offer new insights into individual exposure levels to over 200 substances including metals, pesticides, dioxins, and a broad range of contaminants from consumer products, dietary exposures, and industrial emissions.

Unfortunately, NHANES has limited application for tracking exposures at the state and local level. In fact, exposure information is often a missing link in the efforts of health agencies to evaluate environmental health risks. At the state and local level, a survey by the Pew Environmental Health Commission found that public health practitioners are unable to address fundamental community concerns because of limited capacity to measure and evaluate actual levels of exposure.

The National Human Exposure Assessment Survey (NHEXAS) represents another national commitment to measure population exposures to environmental chemicals through the design of a multimedia, multi-pollutant, geographic-based approach that is suited for risk characterization and/or status and trends assessments of toxicants (Burke & Sexton, 1995). It is an exposure measurement program designed to provide information on the magnitude and extent of population exposures to environmental contaminants in the air, water, soil, and food; and, to inform the risk assessment and risk management processes established to protect population health (Sexton, 1991); (1992).

While NHEXAS represents a major step forward in our ability to measure individual exposures to environmental pollutants, the project has a number of limitations. The investigations have been primarily cross-sectional in design, and cannot track trends in population exposure. In addition, there are a restricted set of pollutants included, and limited geographic coverage. Perhaps the most important limitation of NHEXAS is that initial funding was inadequate to complete the analysis of findings and make the data available to researchers, policy makers and the public. Finally, NHEXAS is not linked to any ongoing health surveillance – the linkage between environmental exposures and health was not included in the design.

There is tremendous potential for progress in measuring population exposures to environmental pollutants, particularly given advances in sampling and detection. For example, the National Center for Environmental Health has developed unprecedented capabilities for biological monitoring of human exposures. However, the failure to develop and support the national capacity for exposure tracking, including laboratory capacity, has left a large gap in our approach to environmental protection. This has been underscored by a recent report by the U.S. General Accounting Office (GAO), which called for a long-term strategy to measure exposure in humans (United States General Accounting Office, 2000). The GAO underscored the need to close this gap in a report that called for a national approach to measuring Americans' exposures to pollutants in order to strengthen prevention efforts. The bottom line in exposure tracking is that we know very little about what the public is being exposed to, or the actual levels of exposure.

STRENGTHS AND LIMITATIONS

Exposure tracking is essential to answer fundamental concerns and questions about individual and population exposures to environmental agents (Sexton, Selevan, Wagener, & Lybarger, 1992). It is recognized as a vital tool for shaping national environmental policies and providing the baseline data to evaluate the effectiveness of regulatory efforts (Burke et al., 1995); (Sexton et al., 1992); (Graham et al., 1992); (Burke et al., 1992); (Goldman, Gomez, & Greenfield, 1992); (Matanoski et al., 1992). Unfortunately, the absence of exposure information complicates the efforts of health agencies to evaluate environmental health risks.

The national environmental laws have provided virtually no funding support for the development of exposure tracking. As a result there is a paucity of available data. This is ironic, since much of the current national debate concerning the uncertainties of regulatory risk assessment focuses upon the lack of information on actual individual exposure levels.

The lack of practical exposure tracking tools has profoundly impacted many environmental health programs. For example, many of the health assessments conducted at Superfund sites have been inconclusive due to the lack of information on levels of exposure in the surrounding communities. At the state and local level, public health practitioners are unable to address fundamental community concerns because of limited capacity to measure and evaluate actual levels of exposure.

Health Outcome Tracking

Are environmental exposures and population exposures related to increased disease? Understanding trends in the incidence of diseases that may be related to environmental exposures is fundamental to protecting public health. Public health tracking efforts must rely on a number of data sources to capture morbidity, mortality, and disability trends. The following databases reflect efforts at the national level to understand health trends and can serve as potential instruments to carry out environmental health tracking activities and guide states and localities in structuring smaller scale efforts. While the following discussion is not comprehensive, these data sets provide a snapshot of available information on the incidence and prevalence of chronic disease endpoints, mortality trends and costs of diseases, as well as health care utilization patterns, which are important in understanding the burden of disease and developing comprehensive prevention and intervention programs (Sainfort & Remington, 1995). Brief

descriptions of the health outcome data are provided in this section and are summarized in Table 4.

The Surveillance, Epidemiology, and End Results (SEER) program is one example of a population-based registry of cancer incidence and mortality in the United States. The SEER data are based on state cancer registry information for a select group of states. The cancer registries cover 14 percent of the US population and have collected data since 1975. In 1992, the CDC established the National Program for Cancer Registries (NPCR). This program provides funding and technical support for cancer tracking nationwide. As of 1999, the CDC supported 45 states, 3 territories and the District of Columbia for cancer registration (National Center for Chronic Disease Prevention and Health Promotion, 2000).

The National Hospital Discharge Survey (NHDS), which has been conducted since 1965, is a continuous survey based on a sampling of medical records for patients discharged from non-federal short-stay hospitals (e.g., hospitals with an average length of stay less than 30 days, general hospitals and children's general hospitals). The survey collects information on demographic characteristics, admission and discharge dates, discharge status, diagnoses, and procedures performed. In 1996, approximately 480 hospitals participated in the survey and over a quarter of a million hospital records were reviewed.

The National Health Interview Survey (NHIS) is a multistage sample designed to represent the civilian, non-institutionalized population in the United States. The survey is conducted by the National Center for Health Statistics (NCHS) and the Center for Disease Control and Prevention (CDC). It has been conducted continuously since 1957.

Vital and Health Statistics provide data on events including births, deaths, marriages, divorces, and fetal deaths. Vital statistics are provided through state-operated registration systems. States and the NCHS work together to share costs and ensure uniformity in data collection. Related to the National Vital Statistics System are the Linked Birth and Infant Death Data Set, the National Maternal and Infant Health Survey, the National Mortality Followback Survey, the National Survey of Family Growth, and the National Death Index (http://www.cdc.gov/nchswww/about/major/nvss/nvss.htm).

The National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) are national surveys designed to provide information on the provision and use of ambulatory medical care services for office-based physicians, emergency rooms and hospital outpatient centers, respectively. NAMCS was conducted annually from 1974-1981 and was reinstated on an annual basis in 1989. Annual data collection for NHAMCS began in 1992 (http://www.cdc.gov/nchswww/about/major/ahcd/ahcd1.htm).

These health surveys are important in offering information on patients' symptoms, physicians' diagnoses, and medications ordered or provided. On an aggregate basis, they offer trends in disease and practice patterns. Such data have been critical to the recognition of the nation's increasing prevalence of asthma, which has prompted national efforts to investigate trends, risk factors, and potential environmental links.

STRENGTHS AND LIMITATIONS

Our national infrastructure to monitor health trends is comprehensive and informative. However, as described briefly throughout this section, there are fundamental barriers to teasing out the

health of local communities from national data, which is crucial for understanding the role of environment at the local level. Presently, limited funding for local health agencies, insufficient technological capacity, and competing public health crises preclude the establishment and maintenance of sound tracking at the local level. Additionally, national surveys do not accurately describe health outcomes for 25 percent of the population that is either Hispanic or African American unless oversampling techniques are employed.

At a national and regional level, the SEER registry and the NHDS provide useful information. However, at the local level, understanding disease trends is complicated by difficulties in coordinating between state and local agencies, addressing privacy concerns, and managing incomplete and inaccurate data files. Additionally, there are numerous statistical challenges such as ascertainment of accurate population denominators.

The NHIS survey is a useful complement to other national data systems yet it is limited in providing useful information at more refined geographic scales. This is a major concern for local health officials attempting to characterize the health of communities within their jurisdictions. Vital and health statistic reporting systems offer a tremendous resource for understanding health status of the population throughout the United States and are available at different geographic scales down to county or more refined levels pending appropriate approvals by internal review boards.

Table 4: A Sample of Health Outcomes Tracking Systems

Database Name	Source	Type of Reporting	Type of data collected (related to environmental health)	Select Environmental Health Outcomes Covered
The Surveillance, Epidemiology, and End Results (SEER)	NCI	Periodic	Cancer Incidence and Mortality	> Cancer
The National Hospital Discharge Survey (NHDS)	NCHS	Annual	 Patient Characteristics Diagnosis and Multiple Diagnosis 	 Cancer Birth Defects Low Birth Weight Chronic Liver Disease Lung and Respiratory Diseases Asthma and COPD Spontaneous Abortions and Other Reproductive Disorders Neurodegenerative Diseases of Aging and Neurotoxic Disorders Kidney Disease Dermatitis and Dermatosis
National Ambulatory Medical Care Survey (NAMCS)	NCHS	Annual 1974- 1981,1985, Annual 1989- present	> Diagnosis and treatment	SAME AS ABOVE
The National Hospital Ambulatory Care Survey (NHAMCS)	NCHS	Annual	Diagnosis and treatment	SAME AS ABOVE
National Health Interview Survey (NHIS)	NCHS	Annual	Health Status and Disability	 Cancer Reproductive Disorders Developmental Disabilities Chronic Liver Disease Lung and Respiratory Diseases Asthma and COPD Kidney Disease Endocrine and Metabolic Disorders Neurologic Disease
Vital and Health Statistics-Vital Statistics Cooperative Program (VSCP)	NCHS	Annual	 Life Expectancy Causes of Death Infant Mortality Prenatal Care and Birthweight Birth Rates Pregnancy Outcomes Occupational Mortality 	SAME AS ABOVE

Note: Adapted from National Center for Health Statistics, US Department of Health and Human Services-Overview, DHHS Publication Number (PHS) 99-1200, August 1999.

Historical Perspectives on Public Health Surveillance (Tracking)

"Whoever wishes to investigate medicine properly should proceed thus: in the first place to consider the seasons of the year, and what effects each of them produces...then the winds, the hot and the cold...and the qualities of the waters, for as they differ from one another in taste and weight, so also do they differ much in their qualities. In the same manner, when one comes into the city to which he is a stranger, he ought to consider its situation, how it lies as to the winds and the rising of the sun; for its influence is not the same whether it lies to the north or the south, to the rising or to the setting sun. These things one ought to consider most attentively, and concerning the waters which the inhabitants use, whether they be marshy and soft, or hard, and running from elevated and rocky situations, and then if saltish and unfit for cooking; and the ground, whether it be naked and deficient in water, or wooded and well watered, and whether it lies in a hollow, confined situation, or is elevated and cold; and the mode in which the inhabitants live, and what are their pursuits, whether they are fond of drinking and eating to excess, and given to indolence, or are fond of exercise and labor, and not given to excess in eating and drinking." (Hippocrates, as cited in (Adams, 1939))

Understanding the health status of the population, including trends in mortality and illness, is essential to the effective practice of public health. The ideas behind "surveillance" are not new. While the term "surveillance" came into currency in the middle of the 1900s, for millenia, scientists and philosophers have recognized that the health of the environment is intricately linked to the health of the population.

In the 1600s, John Graunt used the Bills of Mortality to capture health trends in London (Thacker et al., 1988). He was the first person to compile data on births, deaths, and illnesses in London. Johann Peter Frank is credited with designing one of the most comprehensive systems of public health surveillance of his time during the late 1700s. Not only was he a pioneer in public health but he was also a pioneer in social medicine, committed to understanding how the social environment affected individual health (Sigerist, 1956).

William Farr, who is often referred to as the father of surveillance, recognized the benefits of having readily available mortality data for practicing physicians to examine trends at the neighborhood level and compare these trends to other localities. Dr. John Snow, a colleague of Farr, traced the origins of cholera to the public drinking water supply in the 1850s. Snow used mortality data acquired from Farr to investigate the spatial and temporal patterns of cholera cases in London. Through scientific reasoning and common sense, Dr. Snow was able to establish the causal link between environmental contamination of the public water supply and the consequent spread of infectious disease.

In the United States, the history of public health surveillance is mostly rooted in monitoring and reporting infectious disease incidence. The first reporting mandates date back to 1743 in Rhode Island when the Colony mandated the reporting of smallpox, yellow fever, and cholera (Thacker et al., 1988). Over a century passed before monitoring efforts became a national priority. In 1878, the responsibilities of the Marine Hospital Service, the forerunner to the Public Health Service, were expanded to include the collection of morbidity reports on infectious diseases such as cholera, smallpox, plague, and yellow fever. States and municipalities were assisted in collecting these data on a weekly basis and by the turn of the century, all states and localities required reporting of infectious diseases (Thacker et al., 1988).

The surveillance of infectious diseases became more sophisticated as the century wore on and public health victories such as the global eradication of smallpox demonstrated the utility in comprehensive monitoring and reporting activities and the importance of primary prevention techniques such as immunization. In fact, D.A. Henderson, in his leadership on worldwide eradication of smallpox, recognized surveillance as the "neurologic system of public health" (Halperin, 1995).

Through increases in wealth, improvements in diet, advances in medicine, and innovations in public works and environmental controls, (e.g., water, sewage, housing, other public health measures) this century has witnessed a shift in the leading causes of mortality and morbidity (Smith, 1983); (Antonovsky, 1967). Consequently, our health priorities have broadened beyond that of treating and managing infectious diseases to include chronic diseases such as heart disease, cancer, chronic obstructive pulmonary disease, cerebrovascular disease, liver disease, kidney disease, and diabetes. These conditions account for almost 70 percent of all deaths (CDC, 1992). Unfortunately, while the burden of these diseases has shifted, support for tracking-related efforts has lagged.

Tracking Today

Public health tracking has been instrumental in monitoring disease patterns and developing and implementing intervention strategies leading to the control of infectious agents. With the shift in the disease pendulum towards non-communicable disease endpoints, there is an increasing need for tracking systems to track acute, non-infectious disease endpoints, chronic diseases, and reproductive and developmental disorders. This is particularly true in environmental health, where there is a need to track hazards, exposures, and health outcomes in order to monitor changes in individual exposures and elucidate the associations between environmental exposures and health status (National Research Council, 1997); (Thacker, Stroup, Gibson Parrish, & Anderson, 1996); (Thacker et al., 1988).

Comprehensive tracking systems provide a means to coordinate efforts across federal, state and local levels, and to address the continuum of environmental health concerns about pollution sources, environmental exposures, and disease. At the present time, however, the public environmental health infrastructure is ill-equipped to perform this core function of public health effectively (Burke, Shalauta, Tran, & Stern, 1997).

Over the past three decades, we have made great strides in improving the quality of our environment. However, during this time, the capacity of public health agencies to track and respond to environmental health hazards has eroded. The Institute of Medicine observed this over a decade ago in its landmark report, "The Future of Public Health." The Committee concluded the following:

"The removal of environmental health authority from public health agencies has led to fragmented responsibility, lack of coordination, and inadequate attention to the public health dimensions of environmental issues (Institute of Medicine, 1988a)."

The history of environmental health in the US follows two tracks; one within the traditional public health bureaucracy that evolved over the past century; and the other that emerged with the establishment of the EPA in 1970 and the regulatory strategies that followed. As the regulatory-driven EPA track has gained momentum over the past three decades, the public health track has

lost its grounding in environmental health. Consequently, the establishment of the EPA and the parallel shift in public health responsibility for environmental health-related matters resulted in a chasm between the public health and environmental policy-makers. Frankly put, the nation's public health leaders and practitioners across all levels of government have little involvement in shaping the environmental agenda.

Driven by differing mandates and traditions, public health and environmental regulatory agencies also depend upon different tools to evaluate and respond to environmental health problems. Although they share common public health goals, the EPA and state environmental agencies depend primarily on a risk-based regulatory approach, while public health agencies draw upon a tracking-based population approach.

The risk-based regulatory approach is primarily structured to characterize the cancer risks attributed to single hazards via specific environmental media, and is largely based upon extrapolation from animal toxicology tests. It is driven from the federal level of government and reflects a complex set of environmental laws that divide along environmental media lines (e.g., air, water, soil, waste). For each of these programs, specific pollutants of concern have been isolated and a risk-based approach has prevailed as the basis for driving the permitting and enforcement systems (Burke, 1996). A risk-based approach refers to a process dependent upon the four steps of risk assessment, as introduced in the 1983 report entitled *Risk Assessment in the Federal Government: Managing the Process* (National Research Council, 1983) -- hazard identification, dose-response assessment, exposure assessment, and risk characterization.

In contrast to this approach, the "tracking-based population approach" goes beyond single hazards to consider population health impacts in a broader context. This approach integrates public health sciences such as epidemiology, and relies upon hazard, exposure, and health outcome tracking data to guide decisions. Both approaches are important and interdependent components of the continuum of understanding and responding to environmental health risks. Ideally, they should be used in concert as part of a cohesive national strategy.

The creation of the Agency for Toxic Substances and Disease Registry (ATSDR) by the 1980 Superfund law represented a potential turning point in the disparate paths of environmental protection and public health agencies. Three years after the passage of Superfund, ATSDR was established as an agency of the Public Health Service, funded through EPA, to implement the health-related sections of the law. With Superfund reauthorization in 1986, the Agency received specific mandates to conduct public health tracking activities to assess the health of communities exposed to hazardous substances and register and track individuals exposed to hazardous substances (Agency for Toxic Substances and Disease Registry, 1998).

While the ATSDR mandates for tracking are clear, implementation has been limited from the onset by insufficient resources, lack of necessary data on exposure and population health status and reliance upon EPA remediation-based risk assessments (United States General Accounting Office, 1991). Despite numerous limitations, ATSDR has played an important role in rebuilding state-level public health capacity, implementing a national exposure registry, and supporting numerous site-specific tracking projects that track populations exposed to hazardous substances (Johnson, 1999).

Recognizing the Environmental Health Gap

The quest for a stronger public health basis for environmental decision-making has challenged practitioners and policy makers for decades. For example, in 1979, the NCHS empanelled a group of environmental health scientists and epidemiologists to participate in a workshop on environmental health data. The panel addressed the challenges in detecting environmental impacts on human health using existing publicly available data as well as other sources. The panel underscored the need for better, more comprehensive data and the coordination of agencies and their activities related to environmental health data collection and analysis (National Center for Health Statistics, 1980); (National Center for Health Statistics, 1981).⁴

A decade later, in 1990, the EPA Science Advisory Board concluded that because its program offices have been responsible for implementing their media-specific laws, environmental problems have been considered in isolation of one another. This has left a legacy of unanswered questions that may pose the greatest uncertainty and ultimately the greatest risks. As a result of this gap between the highest priority programs and the knowledge about the greatest risks, EPA recognized the lack of correlation between the resources that are allocated to different environmental problems and the relative risks to environment and health posed by these problems (US Environmental Protection Agency, 1990).

Goldstein described the shift in public health responsibility for environment health matters by detailing the changes in representation of public health professionals within the US EPA's workforce. For example, in 1970, the EPA employed 650 US Public Health Service commissioned officers and almost 40 percent of staff were former employees of the then Department of Health, Education, and Welfare. Today, while the EPA has doubled its workforce, there are less than 250 commissioned officers and a negligible representation of staff trained in the public health sciences (Goldstein, 1995). Consequently, the Agency is greatly constrained in its ability to respond to broader public health needs.

In 1995, Burke and others described the role of the national environmental laws in shaping federal and state environmental protection programs. This led to the waning of public health influence in environmental decision-making and a diminishing role for state and local health agencies (Burke, Shalauta, & Tran, 1995).

Tracking Data and Coordination Needs

Several previous efforts have underscored the need for a coordinated tracking approach. For example, in 1992, the Environmental Protection Agency, the National Center for Health Statistics, and the Agency for Toxic Substances and Disease Registry sponsored a workshop on "Making Use of Environmental Exposure Data Bases." The results of the workshop were presented in a dedicated issue of the Archives of Environmental Health (Sexton et al., 1992). In

⁴ The Committee reviewed data available at the time and identified 64 data collection systems in 18 agencies. 39 of the systems gathered health-related information, 21 collected data on environment-related information, and four systems included data on both health and environment. The Committee championed the development and enhancement of data systems and national surveillance activities that linked health and environmental data, arguing that these integrated data collection systems offered the greatest research potential (National Center for Health Statistics, 1980).

that issue, Matanoski and others wrote that the primary purpose of extant exposure tracking databases is to satisfy regulatory requirements and track compliance with regulatory standards. The authors emphasized the need to broaden the scope of these systems so that they are meaningful for epidemiology-based public health evaluations.

In 1995, the CDC released its report entitled "Integrating Public Health Information and Surveillance Systems." The report laid the foundation for building an integrated public health information system. The major recommendations included the development and adoption of universal standards, the establishment of a communications infrastructure, and the promotion of data access, sharing, and burden reduction through legislative and policy action. Since then, the CDC has established the National Electronic Disease Surveillance System (NEDSS), which is designed to electronically integrate and link together surveillance activities from a wide range of programs and improve reporting of disease between CDC and states and localities. The NEDSS will integrate over 100 independent tracking and health information systems and will facilitate improved tracking and access to health information.

In 1996, the National Center for Environmental Health (NCEH) collaborated with the Council of State and Territorial Epidemiologists (CSTE) and the National Environmental Health Association (NEHA) to develop recommendations for developing an environmental public health tracking system. The goals of the workshop were to: 1) lay out the necessary infrastructure for state-based systems and to identify the necessary information to be surveyed; 2) identify the appropriate process and mechanisms for data collection and analysis; and 3) address the format and content of tracking data. This effort underscored the need for both public and private entities to rethink approaches to understanding the relationship between environmental exposures and health at the national, state and local levels.

At the state level, health officials also recognize the importance of sound tracking to facilitate their jobs in protecting the public's health from environmental threats. In 1997, the Council for State and Territorial Epidemiologists, the Association of Schools of Public Health, and the CDC conducted a survey of the 50 states, the District of Columbia, and Puerto Rico to determine whether states were making progress towards the Healthy People 2000 (HP2000) objectives. The survey found that across 51 jurisdictions there were 174 environmental public health tracking systems. These systems included monitoring childhood blood lead levels, poisoning from pesticides, mercury, arsenic, and cadmium, methemoglobinemia, carbon monoxide poisoning, asthma, heatstroke, and hypothermia. While the survey concluded that states were making progress, it also found that current resources were inadequate and increased awareness about the value of tracking systems in preventing and controlling diseases was necessary to achieve the national objectives of HP2000 (Zeitz, Anderson, & Hughes, 1998).

Recently, the Department of Health and Human Services released its Healthy People 2010 Objectives (U.S. Department of Health and Human Services, 1998). In detailing specific charges under the environmental health section, the objectives reflect the recognition that current national information on levels of exposures to hazardous substances and environmentally related health outcomes is insufficient and incomplete. Furthermore, information on measures of health status is often not available to demonstrate progress toward the elimination of hazards in the environment (U.S. Department of Health and Human Services, 1998).

Conclusions

The examples presented above all share several common themes for improving environmental health practice and research and for reinvigorating the public health basis for environmental decision-making: better public health data; improved coordination among public health and environmental agencies; and enhanced training of the environmental workforce in the public health sciences.

Chapter 3. An Examination of the National Infrastructure for Environmental Health Tracking

Federal, state and local public health agencies constitute the foundation of the national health tracking infrastructure. The first requirement for the development of an integrated environmental health tracking network is a strong public health infrastructure with linkages to state and local health agencies, the health care delivery sector, state environmental agencies, and affected communities. To examine federal, state and local public health tracking infrastructure and activities, the Commission interviewed environmental health leaders from key environmental health agencies, public health agencies in all of the states, and a select group of local health departments.

The aims of the interviews were the following:

- > To examine the existing public health infrastructure and capacity for environmental health tracking;
- > To describe agency needs for effective environmental health tracking, including financial, technical, and scientific support;
- > To examine interagency coordination in environmental health tracking at the federal, state, and local levels; and
- > To examine financial and technical support for tracking activities, and interagency support and collaboration, and

The findings from this survey provide a profile of current state and local capacities, needs and priorities to help shape the final recommendations by the Pew Commission to strengthen the national public health infrastructure.

Federal Environmental Health Tracking Interviews

Beginning in November 1999, the Pew Tracking Team reached out to key officials throughout the Federal government who have been involved in environmental health tracking activities. The team also interviewed national organizations representing state and local environmental health interests to gain insight about environmental health tracking activities across the different organizations and Federal agencies. Representatives from these organizations were interviewed about environmental health tracking priorities, personnel and training issues related to tracking, interaction/collaboration with state and local constituencies, and funding allocations for tracking.

The agencies contacted included: the National Institute of Environmental Health Sciences, the Centers for Disease Control and Prevention (CDC), the Public Health Practice Program Office (PHPPO), the National Center for Environmental Health (NCEH), the National Center for Health Statistics (NCHS), the National Institute for Occupational Safety and Health, and the Agency for Toxic Substances and Disease Registry (ATSDR), and the US Environmental Protection Agency (EPA). The organizations contacted include the National Association of County and City Health Officials (NACCHO), Public Health Foundation (PHF), Association of State and Territorial Health Officials (ASTHO), and the Council of State and Territorial Epidemiologists (CSTE).

Synthesis of Federal Interviews

Leadership

Leaders from the nation's federal agencies agreed that a cohesive national strategy is necessary to adequately understand environmental hazards, measure population exposures, and track health conditions related to the environment. Officials explained that current environmental health tracking efforts are a patchwork of programs across multiple federal, state and local agencies. These programs have evolved, often in isolation from each other, to respond to disparate regulatory mandates or programmatic needs. At present there is little or no coordination of environmental health tracking activities, nor is there an identifiable mechanism to establish linkages between hazard, exposure and outcome data.

Infrastructure

Additionally, the infrastructure for environmental health tracking has been neglected, particularly at the state and local level. For decades, state and local entities have faced declining resources. This has resulted in outdated, inadequate, and incompatible information systems, lack of adequately trained staff, and an inability to develop viable tracking strategies. As a result, fundamental information about community health status and environmental exposures is not available. This places severe limitations on the capabilities of health agencies to respond to concerns about environmental hazards. States and localities have critical needs for guidance on the establishment of systems, identification of appropriate exposure and health endpoints to track, and coordination with other states and ongoing federal efforts.

Exposure

A systematic approach is needed to measure, evaluate, and report individual exposure levels to hazardous environmental pollutants. With the exception of childhood blood lead screening, there have been no systematic efforts to track individual levels of exposure to hazardous pollutants. CDC and EPA have developed the methodologies for biological and environmental monitoring of a wide range of substances for use in the NHANES and NHEXAS studies. However, inadequate levels of funding have restricted their application and availability. As a result, little is known about the actual day-to-day exposures of Americans. These findings have been underscored by a recent report of the U.S. General Accounting Office, which calls for a long-term coordinated strategy to measure exposures.

Information Access

Basic information on the incidence and trends in health conditions related to the environment is largely unavailable. On the national level there are a broad range of initiatives that collect and report various health outcome data. While they represent important data resources, they have not been designed to examine the relationship between health and the environment. For example, for many areas of the country, there is no systematic tracking of the prevalence of asthma, or of many other acute and chronic conditions that may be related to environmental exposures.

Environmental tracking data should be easily accessible to public health professionals, policy makers, and the public. With a few notable exceptions such as the EPA Toxics Release Inventory, there has been little effort or support for making the current environmental health

tracking data accessible or useful to those who need to know. As a result, policy makers and public health practitioners lack information that is critical to establishing sound environmental health priorities. Most importantly, the public is denied their "right to know" about environmental risks and the health of their communities.

Future Directions

Improved environmental health tracking is necessary to evaluate the effectiveness of environmental regulations and assure that current policies are reducing exposures and safeguarding public health. Reduction of population exposures and risks and the improvement of public health are fundamental goals of our environmental regulations. Current tracking activities are primarily focused upon hazard tracking and are inadequate to determine if population exposures and adverse health impacts have actually been reduced. The resulting uncertainty has contributed to a lack of confidence in the scientific basis for policy decisions and raised fundamental questions about the public health benefits of environmental regulations.

Despite the many limitations, there are currently unprecedented opportunities to enhance environmental health tracking, improve access to information, establish new partnerships, and strengthen the national infrastructure for health information. New technologies in biomonitoring have the potential to transform the nation's capacity to track exposures and understand their impacts on health. Advances in communication and information technologies have enhanced public access to information and provided new tools for the analysis, mapping, and dissemination of tracking information.

Several new CDC initiatives have the potential to address tracking needs including information technology development, state and local capacity building, exposure measurement, interagency coordination, and public access to health information. The integration of public health information and tracking systems is a top priority of the CDC. Spurred by concerns about bioterrorism, the Health Alert Network is being developed to improve the national public health infrastructure for communication and tracking. The implementation of the National Electronic Disease Surveillance System (NEDSS), the National Exposure Report Card, and National Public Health Performance Standards represent important steps forward. However, improved support for the environmental health components of these initiatives is essential if they are to provide a foundation for a national environmental health tracking network.

The EPA also has initiated several projects that aim to improve public access to community-level environmental health information. One example is the Environmental Monitoring for Public Access and Community Tracking (EMPACT) project, which characterizes local environmental hazards and makes this information available to the public in a timely and understandable manner. Another important EPA initiative is the Cumulative Exposure Project, which aims to estimate population exposures to hazardous substances in our air, water and food and to gain a clearer picture of individual exposures and their cumulative effects across communities and special populations. These are only a few of the data systems being developed by CDC and EPA that could serve as building blocks in a national tracking network.

State Environmental Health Tracking Interviews

The Approach

An interview tool was developed to capture the state component of tracking. The composition of the interview tool reflected reviews of existing peer-reviewed literature on tracking research. In addition, published and unpublished reports by federal, state, and local governments and national organizations on relevant environmental health tracking-related activities, processes, policies, technical advances, emerging trends, and barriers were examined. The scope of the interview and the types of questions it contained also reflected extensive outreach over the past year with leaders in environmental, injury and occupational tracking, including representatives from the federal government, academic institutions, professional organizations, non-governmental organizations, and state agencies.

The interviews focused on the following areas: organization; data use; quality and access; financial and technical resources; barriers; and priorities. In collaboration with CDC, the CSTE, and representatives from the NACCHO, PHF, and ASTHO, contacts were identified for each state based on the CDC's list of Epidemiologic Intelligence Service, the ASTHO Environmental Policy Committee Members, and other recommendations. As a last resort, the Carroll's State Directory was consulted. In some cases, the first contacts referred commission staff to others in their departments.

The survey focused on environmental health activities conducted by state health agencies. Recognizing that some environmental health tracking functions are conducted by other agencies, the survey attempted to identify related activities outside the health departments. The interview period began in March 2000 and was completed in July 2000.

Synthesis of State Interviews

Forty-nine states participated in the Environmental Health Tracking interview. Describing environmental health tracking at the state level is a daunting task. There is tremendous diversity in the organization, functions, and resources of state environmental health programs. The states reflect a wide range of priorities, constituents, and political support for environmental health activities. Despite their diversity, virtually every state contacted expressed enthusiastic support for the effort and endorsed the need for improved environmental health capacity, and coordination and cooperation across federal, state, and local agencies to track environmental exposures and related health conditions.

Organization

There is a wide range of organizational capacity for tracking. While some states have well-developed programs, other states have virtually no capacity for environmental health tracking. Environmental health tracking activities typically span across state departments of health and environment. For example, the large majority of state respondents indicated that tracking of environmental hazards, such as ambient air monitoring, surface and groundwater quality, non-point discharge monitoring, and hazardous waste management were handled by the state environmental agencies.

Recognizing that environmental health services involve multiple agencies and divisions within agencies, state health officials were asked whether the health department had a designated lead in environmental health tracking. More than half the states identified a contact person responsible for overseeing tracking-related activities.

Beyond intra-state partnerships, states were asked about the agencies they called upon for tracking-related issues. Almost all states reported that they worked with the Agency for Toxic Substances and Disease Registry and the Centers for Disease Control and Prevention. Over three-quarters of the respondents also indicated that they worked with the National Center for Environmental Health and the Department of Housing and Urban Development. Almost three-quarters of the states also relied upon the Departments of Defense and the Agriculture for tracking-related issues.

Table 5 provides a detailed list of the federal, state, and local agencies that state health officials access for environmental health purposes. Agencies listed in the table were identified as having some role in environmental health issues. Other departments mentioned by the states as having a role in environmental health activities that were not included in the original list of agencies included the Department of Justice (federal), the U.S. Army Corps of Engineers, the United States Geological Survey, fish and wildlife departments (federal and state), state-level emergency management departments, departments of education (state and local), Natural Resources, Consumer Protection agencies, Planning agencies (state and local), state attorneys general, Offices of Corrections, Police Departments (local), and school nurses (local). Other centers that work actively with states and are key to tracking include the CDC National Center for Infectious Disease, the CDC National Center for HIV, STD, and TB Prevention, the CDC National Center for Chronic Disease Prevention and Health Program, and the CDC National Immunization Program. Because of the focus on environmental health, these centers and programs were not specifically listed but rather assumed under the umbrella of the CDC. Table 5 illustrates the complex of agencies involved in environmental health activities and underscores the need for leadership and coordination in developing a national approach to tracking.

Table 5: Agencies Involved in State-Level Environmental Health Tracking

Agency		No (%)	Reference Material Only (%)	Not Sure (%)
FEDERAL				
Consumer Product Safety Commission	41	46	4	9
Department of Agriculture	72	22	0	6
US Census Bureau	59	15	20	6
Department of Defense	74	20	0	6
Department of Energy	48	46	0	6
National Institutes of Health	61	28	2	9
National Institute of Environmental Health Sciences	50	37	2	11
Public Health Service	89	4	0	7
Agency for Toxic Substances and Disease Registry	96	0	0	4
Centers for Disease Control and Prevention	96	0	0	4
National Center for Environmental Health	87	9	0	4
National Center for Health Statistics	61	30	0	9
National Institute for Occupational Health	78	15	0	7
and Safety				
Food and Drug Administration	78	15	0	7
Department of Housing and Urban Development	84	3	0	13
Department of Interior	28	59	0	13
Department of Labor	54	39	0	7
Occupational Safety and Health Administration	61	33	0	6
Environmental Protection Agency	96	0	0	4
National Aeronautics and Space Administration	0	89	0	11
Federal Emergency Management Administration	33	46	0	21
STATE				
Department of Agriculture	83	9	0	8
Department of Environment	91	0	0	9
Department of Labor	61	28	2	9
Department of Social Services	48	44	0	8
LOCAL				
Department of Commerce	6	83	0	11
Department of Health	89	4	0	7
Department of Housing	22	65	0	13
Department of Public Utilities	18	67	0	15
Department of Social Services	39	35	20	6

Data Collection and Use

HAZARD TRACKING

State respondents indicated that while hazard tracking is essential to understanding the potential impacts of environment on health status, much of the currently available enforcement focused information on environmental hazards has limited utility for public health practitioners. Currently, the data are often not translatable to individual exposure levels or potential population health impacts.

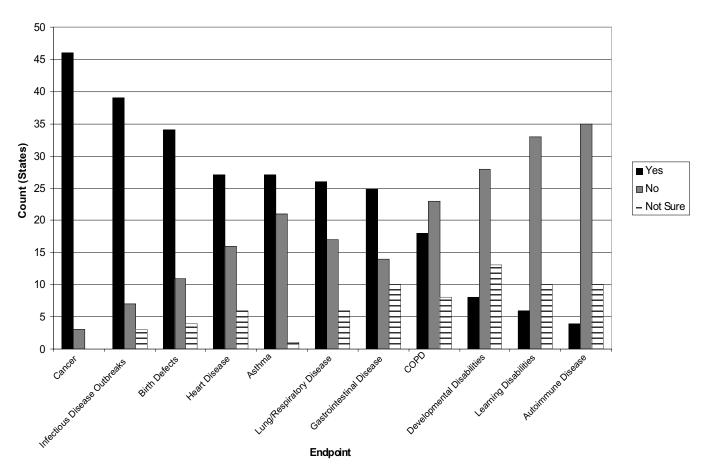
EXPOSURE TRACKING

Tracking of exposures at the state level is limited. Only a quarter of respondents indicated that personal air monitoring data were collected (15 percent within department). When asked about biomonitoring, three-quarters of health departments collected information on blood lead levels. Biomonitoring for other substances, including pesticides is very limited. States underscored the need for better and more timely population exposure data to improve state and local investigations and the ability of officials to respond to citizen concerns.

HEALTH OUTCOME TRACKING

States were asked whether they collect information on a range of health endpoints, which were identified in the literature as having a potential environmental etiology. Figure 4 presents a profile of state tracking of activities for key health outcomes. Cancer, infectious outbreaks, and birth defects are tracked by a majority of the states. However, there remain a large number of states with no active tracking of asthma and other respiratory diseases. Almost no states have the current capacity to track emerging environmental health concerns such as developmental disabilities, learning disorders, or autoimmune diseases.

Figure 4: State Tracking of Key Health Endpoints



 $^{^{\}star}$ As reported to Pew Researchers by State Environmental Health Personnel or State Epidemiologists

States were asked about which routine health and exposure data they used to facilitate their investigations and basic tracking responsibilities. In general, most states indicated they had access to vital statistics and cancer information on incidence and mortality. Additionally, states frequently referred to the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Surveillance System (YRBSS), and the National Health and Nutrition Examination Survey (NHANES) for information on health trends. Table 6 provides more detail on how the states responded. The responses suggest that a wide range of tracking data is used by states despite current limitations on endpoints, population coverage, and geographic scale.

Table 6: Health Data Resources Accessed for Tracking-Related Activities

Health Data Resources	Yes (%)	No (%)	Not Sure (%)
Vital Statistics	96	4	0
Cancer Incidence Data	96	4	0
Behavioral Risk Factor Surveillance System	74	22	4
Hospital Discharge Data	70	30	0
National Health and Nutrition Examination Survey	61	28	11
Youth Risk Behavior Surveillance System	61	28	11
Poison Control Center	60	33	7
Emergency Room Data	55	41	4
National Health Interview Survey	37	52	11
Insurance Claims	25	68	7
National Human Exposure Assessment Survey	22	48	30

Financial and Technical Resources

The US Environmental Protection Agency plays a major role in providing financial resources to state agencies for enforcement-related activities. Less than a quarter of state health departments call upon the EPA for technical assistance. The survey also indicated limited interaction between many state environmental and health agencies. About ten percent reported they received financial support from their state counterpart and about one third reported that they received technical assistance. One fifth of the states indicated they did not receive any financial or technical support from their state environmental counterpart.

When asked about partnerships with academic institutions, almost all states reported having outside linkages with academic institutions and more than a third of the states indicated they worked with non-governmental entities.

States were asked more broadly to describe the range of funding sources for tracking-related activities. The major sources of funding to support environmental health tracking activities include federal prevention block grants, state general funds, fee-based regulatory programs, and cooperative agreements with agencies such as the ATSDR.

From a technological perspective, states underscored the importance of Internet resources and improved technology to facilitate communication with the public. More than three quarters of the states indicated that health and environmental data were electronically available for internal use. A smaller percentage of states indicated that health data were available to the public in limited electronic formats and geographic scales.

State Environmental Health Tracking Priorities

When asked about their highest priorities for environmental health tracking, states identified a range of issues. Table 7 lists these issues by hazards/exposures, outcomes and general concerns. In general, the major issues that were identified included adverse exposures in the drinking water supplies and potential health effects, metals poisoning, and food protection. From an outcomes perspective, asthma and cancer were mentioned as high priority areas. Several states underscored the need for support to set up basic capacity for tracking and called for flexible approaches rather than prescriptive mandates for endpoint-specific tracking. The diversity of priorities identified by state officials suggests the need for tracking systems that are flexible enough to address local and regional environmental issues.

Table 7: State-Specific Top Priorities for Environmental Health Tracking

Environmental Priorities	Number of States Responding
Hazard / Ex	xposure
Drinking water	17
Arsenic in drinking water	1
Air pollution	10
Indoor air (e.g., carbon monoxide)	5
Food protection (subsistence food sources such as f including shellfish)	fish, 13
Hazardous waste (superfund, other waste sites,	12
underground storage tanks)	
Metals and metal compounds	28
Lead	24
Mercury	3
Lead Arsenate	1
Pesticide exposures	6
Radiation	4
Ionizing	3
Non-ionizing (e.g., Electromagnetic fields)	1
Sanitation	3
Bioterrorism	3
Emergency events	2
Asbestos	1
Rodent control	1
Chemical spills	1
Hog farms	1
Housing quality	1
Outcon	
Asthma	13
Cancer	6
Communicable disease	3
Clusters	3
Birth defects	2
Occupational disease	2
Disease mapping Rabies	2 1
Gener	
Basic capacity for tracking	2
Infrastructure	2
Technology (e.g., GIS)	2
Interagency coordination	1
Timeliness and completion of data collection	1

Barriers

FINANCIAL AND HUMAN RESOURCES

The greatest barriers to effective environmental health tracking include scarce financial and human resources. The absence of such resources precludes long-term strategies to build capacity and track environmental health issues over time. Limited resources prevent state health officials from adequately responding to public health issues in a timely and efficient manner. While funding opportunities such as ATSDR cooperative agreements are important, they come at a cost due to their restrictive format. States underscored the need for flexible funding strategies that enable them to establish programs based on their needs.

LACK OF POLITICAL WILL

Moreover, states expressed concerns about the lack of political will to support environmental health-related infrastructure, program development, and state regulations and policies. The connection between environment and health is often challenged, and without tracking information from environmental agencies, their job becomes increasingly difficult in justifying budgets for activities like environmental health tracking.

POOR COMMUNICATION

States also emphasized the importance of increased communication and data sharing between state agencies and across state borders on environmental health issues. They also championed the designation of environmental epidemiologists in every health department. Finally, states called for better guidance from federal agencies on the design, costs, and implementation of tracking systems, including identification of priority health conditions and environmental exposures to be tracked.

Local Tracking Interviews

The Approach

To create the local health department interview tool, minor modifications were made to the tool used for state health department interviews. Modifications were based on conversations with local health department officials and a review of materials that guide local health department activities, including the National Association of City and County Health Officials' Protocol for Assessing Community Excellence in Environmental Health (PACE-EH document).

The following groups of interviewees were selected to participate:

1) All twelve local representatives on the National Association of City and County Health Officials (NACCHO) Environmental Health and Prevention Advisory Committee were contacted. These individuals were selected because of their familiarity with tracking-related issues and their willingness to participate in this effort. While most of the participants are based in health departments, several were based in other departments such as environmental protection.

2) Ten local health departments were selected from among all city and county health departments in the country in the following manner. First, NACCHO provided a list of the 133 local health department leaders who had indicated "environmental health" as an area of interest. Next, states in which local health departments had already been contacted were eliminated from the list. Finally, every tenth local health department was selected from the remaining list. This method was used to provide diversity in geography and among urban/suburban/rural departments.

The major areas addressed included organization, data use and access, financial and technical resources, barriers, and priorities.

Synthesis of Local Interviews

Nineteen local health departments have been contacted to participate in the Pew Environmental Health Tracking Survey of Local Officials. A preliminary analysis based on these data is provided. Local health departments have highly diverse organization, functions, and resources, and the localities themselves have a wide range of priorities, constituents, and political support for environmental health activities. The interviewees represented departments in cities, counties, townships, city/county departments, and regions of states. The populations they served ranged from millions down to 7,000. The local health officials contacted were supportive of the goals of the Pew Environmental Health Commission, and were insightful about the current activities, opportunities, and barriers facing environmental health surveillance at the local level.

Organization

Local health departments exhibited a wide range of organizational capacity for tracking. While a few departments, particularly in the larger cities, described established surveillance mechanisms, most of the departments said they did not do tracking per se, but rather, used existing capacity to focus on enforcement and responding to complaints. Indeed, one important difference between state and local health departments is that at the local level, the health department is often the primary agency responsible for enforcing environmental regulations.

Participants were asked about the extent to which their environmental health activities were restricted to those legally required versus non-regulatory priorities and needs. Responses varied but a substantial portion of the interviewees indicated little to no flexibility beyond mandates. While indicating limited capacity to perform tracking-related activities, local health officials actively disseminate environmental health data, conduct environmental investigations, and initiate environmental interventions.

Because of limited capacity to carry out environmental health tracking activities, local health departments must work with others in order to learn about the hazards, exposures and outcomes within their jurisdictions. Almost all of the local health departments contacted said that they had designated lead individuals for environmental health surveillance and designated liaisons to coordinate environmental health activities across agencies. In many cases, these were the health department directors.

Local health departments were asked to name the top three agencies with which they had relationships at the federal, state and local levels. Most participants said their existing partnerships with federal agencies were weak, and were mediated through state departments. At

the local level, health departments typically worked closely with a wide range of local agencies, including fire and police departments for emergency response situations.

To further understand how local health departments leveraged their limited resources to conduct environmental health and tracking activities, they were asked to provide examples of their work with academic institutions, non-governmental organizations, and the media. Many described proactive and innovative collaborations, particularly with the media. Some local health department staff, however, could not list any substantive examples of working with these outside groups on tracking.

Data Collection and Use

There is little information available about environmental hazards, exposures or outcomes at the local level. Few local health departments conduct routine data collection, particularly on hazards or exposures. The lack of locally collected data is compounded by the fact that state and national level data sets commonly lack enough samples from refined geographic areas to make it possible to characterize local situations.

Many local health departments do not make use of them. For data that are available, most do not have dedicated epidemiologists with the expertise and time to analyze existing data, but rather, share epidemiological staff with other health department programs. Others lack the technology to analyze and in some cases even to access data provided from other sources.

Financial and Technical Resources

Local health departments commonly rely primarily on fees and permits derived from enforcement activities to support their environmental health activities. Beyond fees, other funding sources include local general funds, state environmental departments, and in some cases, state health departments. Some local programs interviewed had federal or private sector grants.

Since fees are the primary funding source for local environmental health activities, priorities tend to focus on enforcement-related activities. Thus, non-environmental regulatory activities, such as tracking, may be overlooked or rank lower in agency priorities.

In terms of technology, local health departments vary in their access to current computer software and/or hardware, and in their ability to use technology to its full extent. Many have difficulty accessing and interpreting data provided by others, due to the lack of standardization in state, county and other data systems. Since many local health departments do little of their own data collection, it is particularly important that they be able to access data from others.

Local Environmental Health Tracking Priorities

Preliminary analysis suggests that the most common priority based on money spent was food protection, followed by waste management, water quality (both groundwater and surface water), and ambient air quality. The most common priorities based on needs included the above, plus indoor air, bioterrorism and emergency response, and land use issues.

Barriers

Local health department officials stated that the greatest barriers to effective environmental health tracking were limited financial and human resources (both expertise and staffing levels). Some officials cited a lack of commitment, or even an opposition among local leaders and the

public to spend local money or provide a mandate for tracking. A number of participants felt their departments were already stretched beyond existing capacity, and were concerned about new recommendations or requirements for tracking without attendant funding. Other barriers included under-reporting of data and a need for standardized and improved technology.

Conclusions

Surveying the environmental health leadership from federal, state and local organizations provided Pew researchers an opportunity to understand current capacity and needs for environmental health tracking across all levels of government. The current infrastructure for environmental health tracking is fragile, and lacks adequate support, personnel and data resources to meet the increasing challenges of environmental health. Participants universally recognized the importance of strong capacity for tracking within their agencies. At the state and local level, limited support and capacity impede the use of health tracking information to inform decisions and protect public health.

The major needs identified by the environmental health leaders include:

- > Improved coordination;
- > Guidance and support for capacity building;
- > Improved information networks within and across affected agencies;
- ➤ Increased training in environmental epidemiology;
- > Designation of an environmental epidemiologist in every state;
- Increased guidance and technical support on identifying priority health conditions; and,
- > Improved capacity to assess population exposures.

Chapter 4. Selection of Health Endpoints for Tracking: An Examination of Available Information

Introduction

The tracking of population health is an essential component of effective public health practice. However, given the many gaps in our current understanding of the role of the environment in disease, the Commission was faced with a fundamental yet vexing question: "What health endpoints should be tracked?"

To address this question, a stepwise approach was undertaken to evaluate available national data to identify health endpoints that may be appropriate for inclusion in a National Environmental Health Tracking Network. The three-step approach included the following:

- An examination of national environmental release data to identify broad categories of health effects that may be related to those pollutants released in large quantities.
- An evaluation of current agency activities and the scientific literature to identify specific health effects that have been related to environmental exposures and may serve as environmental health indicators.
- An analysis of available national level health outcome data for selected endpoints to identify those with high or increasing prevalence or responsible for heavy utilization of health care.

The following sections describe the approach and findings.

An Examination of Environmental Releases: the Toxics Release Inventory

The first step in this analysis was to examine what is known about the potential health effects of pollutants that are released to the environment in large amounts. The EPA Toxic Release Inventory (TRI) is an example of an effective and publicly accessible hazard tracking program. The TRI contains data on annual releases of over 644 toxic chemicals to the air and water by the nation's major industries. Each year, every covered facility reports the total amount of each chemical released. These data are publicly available and posted on the Internet, providing communities with information about the nature and magnitude of pollution in their neighborhoods.

The Commission analyzed the 1997 TRI data, aggregated nationally to examine total releases and identify the types of health effects that may be related to pollutant-specific exposures. Based upon the volume of total releases and toxicological and epidemiological data compiled by EPA and Environmental Defense, 11 broad categories of possible health effects⁵ were identified and ranked.(US Environmental Protection Agency, 1999), (Environmental Defense Fund, 2000)

⁵ This analysis includes both suspected and recognized toxicants. An agent is listed as a recognized toxicant if it has been studied by national or international authoritative and scientific regulatory agency hazard identification efforts. Suspected agents are included if they are shown to have target organ toxicity in either humans or two mammalian species by a relevant route of exposure.

Table 8 lists the total pounds of each class of toxicants released to the air and water based upon the Environmental Defense's Scorecard database. Substances with potential respiratory effects were released in the largest amount in 1997. Neurotoxicants and skin toxicants were next highest in total pounds released. Other categories included developmental, reproductive and endocrine effects.

Table 8: Ranking of Toxicants based on 1997 Toxic Release Inventory (TRI)

Types of health effects	Ranking based on	Total Air & Water
	total 1997 TRI	Releases (Pounds)
	release	
	rerease	
Respiratory	1	1,248,977,984
Neurologic	2	1,211,458,945
Skin or sense organ	3	1,109,718,312
Gastrointestinal or liver	4	1,086,264,404
Cardiovascular or blood	5	823,375,664
Developmental	6	811,686,192
Reproductive	7	498,142,705
Kidney	8	488,554,582
Immunological	9	234,713,891
Cancer	10	209,271,142
Endocrine	11	173,331,065

Reference: Environmental Defense Scorecard (www.scorecard.org)

The Commission recognized that this analysis has a number of limitations. Most importantly, the volume released does not indicate the level of actual community exposure. These exposures are not tracked at the community level. In addition, the approach oversimplifies the complex nature of chemical toxicants. Multiple health effects can be associated with an individual toxicant, and complex interactions between toxicants can further impact human health. Also, the TRI is limited to major industrial facilities and does not include all potential sources of these pollutants. Finally, the 644 substances included captures only a fraction of total chemicals in common use potentially released to the environment. Nevertheless, this approach provided the Commission with a starting point for identifying the categories of health endpoints to be considered for tracking. Given the large amount of toxic pollutants released, there is a clear need to improve the tracking of population exposures and to be watchful for any evidence of adverse health impacts.

Identification of Health Endpoints

Step two consisted of a review of the literature, including published work by health and environmental agencies identifying diseases or health endpoints that have been or may be related to environmental exposures. These endpoints are sometimes referred to as environmental health indicators⁶. At the present time there is strong interest by EPA, CDC and others in developing a

⁶ Health indicators are the assessment tools of choice for a number of current national and international health and environment initiatives including the Health and Environment Analysis for Decision-Making Project (HEADLAMP)

list of environmental health indicators to provide measures of population health that can be related to environmental conditions, providing a public health yardstick for measuring environmental progress.

Table 9 presents a listing of broad categories of health effects and related specific health effects or diseases that have been identified as environmental indicators. The broad categories include those that were identified based upon the TRI environmental release and toxicity data: respiratory, neurological, skin, liver, heart, developmental, reproductive, kidney, and immune conditions, and cancer. This listing also includes an additional listing for birth defects, with multiple references to environmental links. In the previous analysis birth defects were included under the broader definition of developmental effects. The findings also include a number of specific diagnoses or health outcomes such as asthma, chronic obstructive pulmonary disease (COPD), anemias (sickle cell, aplastic), methemoglobinemia, congenital anomalies, low birth weight, spontaneous abortion, diabetes and various types of cancers.

Several of the health endpoints identified in Table 8 are conditions for which environmental exposures have been implicated (Silbergeld, 1994); (Kjellstrom & Corvalan, 1995); (Wills & Briggs, 1995). Others include pre-existing health conditions that may be exacerbated by exposure to environmental pollutants (Kelsall, Samet, Zeger, & Xu, 1997); (Rios, Poje, & Detels, 1993).

The list also reflects agency priorities, including ATSDR's seven broad categories of priority health conditions, and the HHS Healthy People Objectives community and environmental health indicators (Healthy People 2000 and 2010). Although this list of health endpoints is culled from numerous sources with diverse criteria, the categories and endpoints generally correspond with the target organ effects identified in the previous TRI analysis.

Table 9: Health Endpoints Identified as Environmental Indicators

Broad Category of Health Outcomes	Specific Health Outcomes	References ¹
Diseases of Respiratory/Lung	Asthma Chronic obstructive pulmonary disease (COPD)	2, 3, 6 2, 3, 4, 5, 7 1, 2, 3
Neurological Disorders		5, 6
Skin Disorders	Dermatitis, dermatosis	4
Chronic Liver Disease and Cirrhosis		1, 2
Diseases of the Heart		1, 2, 3
Diseases of the Blood or Blood Forming System	Sickle cell anemia Aplastic anemia Methemoglobinemia	2 4 7
Birth Defects	Congenital anomalies Low birth weight	1, 4, 6, 7 4, 5, 7
Developmental Disabilities		7
Reproductive Disorders	Spontaneous abortions	6 4
Kidney Diseases		2, 6, 7
Immune Disorders		6
Malignant Neoplasms	Leukemia Lung Kidney Bladder Liver Stomach Upper GI Prostate Skin	1, 4, 6, 7
Endocrine Disorders	Diabetes Mellitus	1, 2

Note 1: 1) (CDC, 1991); 2) (Rios et al., 1993); 3) (Kelsall et al., 1997); 4) (Kjellstrom et al., 1995); 5) (Silbergeld, 1994); 6) (Lybarger & Spengler, 1993); 7) (U.S.Department of Health and Human Services, 1998).

A Look at National Health Outcome Databases

The third step in the process of identifying appropriate endpoints for environmental health tracking was to examine the available information on those diseases that may be linked to the environment. In order to investigate trends and public health impacts of the identified list of environmental health endpoints, the Commission reviewed a number of national health outcome databases. There is virtually no comprehensive national tracking of these diseases (excepting cancer). However, three data sets based on national survey data provided useful insights into some of these endpoints. Data from the following surveys conducted by the CDC National Center for Health Statistics are presented in the following analysis:

- The National Health Interview Survey (NHIS)
- The National Hospital Discharge Survey (NHDS)
- The National Ambulatory Medical Care Survey (NAMCS) and the National Hospital Ambulatory Medical Care Survey (NHAMCS) (National Center for Health Statistics, 1996)

Initially the analysis was intended to be limited to environmental health outcomes that are clinically observable and classifiable by ICD-9 codes⁷, and that have been linked to identifiable exposures to environmental agents. Table 10 and Table 11 are examples of such health outcomes identifiable by ICD-9 codes and implicated environmental (or occupational) agents for the categories of respiratory and neurological toxic effects, respectively. Because of the limitations of the available survey and emerging interests in a broader range of health endpoints, the analysis includes a number of endpoints without known environmental causes. Inclusion of a disease in this analysis is not meant to imply environmental etiology. Given the present limitations of knowledge, even in most cases where an environmental exposure has been shown to contribute to the development of adverse effects, it is not possible to quantify the proportion of risk attributed to the environment.

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⁷ The ICD-9 is an acronym for the International Classification of Diseases, 9th Revision. It is a statistical classification system that arranges diseases and injuries into groups according to established criteria. These codes, which consist of 3-4,and 5-digit classifications, are revised every ten years by the World Health Organization. Annual updates are published by the Health Care Financing Administration (HCFA) (U.S.Public Health Service & Health Care Financing Administration, 1998)

Table 10: Lung and Respiratory Diseases with Indication of Environmental Etiology

Lung and Respiratory Diseases	ICD-9	Reference	Implicated Environmental Agents
Chronic Sinusitis	473	3	Atmospheric changes
Allergic Rhinitis	477		-
Pollen	477.0		
Allergen	477.8		
Chronic Bronchitis	491	1	Cr VI
Emphysema	492	1	Chlorine
Asthma	493		
Chronic airway obstruction, not elsewhere classified	495	2	Organic Allergens
Coal worker's pneumoconiosis	500	2	Coal dust
Asbestosis	501	2	Asbestos
Pneumoconiosis due to other silica or silicates	502	2	Silica
Pneumoconiosis due to other inorganic dusts	503		Inorganic dusts
Pneumonopathy due to inhalation of other dust	504		Other dusts
Pneumoconiosis, unspecified	505		
Respiratory conditions due to chemical fumes and vapors	506	2	Oxides of metals
Pneumonitis due to solids and liquids(Levy – irritant gases)	507	2	Irritant gases
Respiratory conditions due to other and unspecified external agents	508		-
Postinflammatory pulmonary fibrosis	515	1	Asbestos
Other diseases of the lung	518		
Interstitial emphysema	518.1	1	Aluminum abrasives
Acute Edema	518.4	1	Be, HF, O3, Phosgene

References: 1. (Klassen, 1996); 2. (Levy & Wegman, 1988); 3. (Anderson, Glanze, Anderson, & C.V.Mosby Company, 1990)

Table 11: Neurological Disorders with Indication of Environmental Etiology

Neurodegenerative & Neurotoxic		ICD-9	Reference	Implicated Environmental Agents
Disorders				
Senile and presenile organic psychotic conditions	290		1	Aluminum
Transient organic psychotic conditions, acute	293		1	Hexachlorophene
delerium	222			
Encephalitis, myelitis, and encephalomyelitis	323	222.7	1 2	C14
Toxic encephalitis		323.7	1, 2	Carbon tetrachloride, lead, mercury, thallium
Other cerebral degenerations	331			
Alzheimer's disease		331.0	1	Aluminum
Parkinson's Disease	332		1, 3	Carbon monoxide, cyanide, MPTP
Other extrapyramidal disease and abnormal	333			• •
movement disorders				
Other degenerative diseases of the basal ganglia		333.0	2	Iron pigments
Spinocerebellar disease	334			
Primary cerebellar degeneration	334	334.2	1	Azide, diphenylhydantoin, lithium, metronidazole
Othercerebellar ataxia		334.3	•	7121de, dipilenyinyddinoni, mindin, medomdd201e
Other diseases of spinal cord	336	555		
Other Myelopathy	220	336.8	4	Radiation
Disorders of the autonomic nervous system	337		1, 4	Arsenic, lead, methyl bromide, thallium,
			,	acrylamide, carbon disulfide, chloroquine, ethylene
				oxide, platinum, organophosphorus compounds, etc
Other demyelinating diseases of central nervous	341		1	Lysolecithin, telurium, perhexilene, cyanate, amiodarone, gold, carbon monoxide, cyanide.
Migraine	346		2	Alcohol, iodine rich foods
Other conditions of brain	348			,
Encephalopathy		348.3	1, 4	Mercury
Cerebral edema		348.5		Ethidium bromide, cuprizone, triethyltin, arsenic, lead thallium
Other & unspecified disorders of the nervous system	349			
Other specified disorders of the nervous	5.,			
system, includes toxic encephalopathy		349.8		
-,,,				
Mononeuritis of upper limb and mononeuritis	354			
multiplex				
Carpal tunnel syndrome		354.0		Occupational, repetitive motion
	357		4	
Inflammatory and toxic neuropathy				m ·
Inflammatory and toxic neuropathy Myoneural disorders	358			Toxic
Myoneural disorders Toxic myoneural disorders	358	358.2		Toxic
Myoneural disorders	358 359	358.2		Toxic

References: 1. (Klassen, 1996); 2. (Anderson et al., 1990); 3. NIEHS http://www.niehs.nih.gov/oc/factsheets/parkinson.htm; 4. Environmental Defense Fund. Scorecard: Health Effects. http://www.edf.org/scorecard, accessed 12/21/99.

Examination of the National Health Interview Survey

The National Health Interview Survey (NHIS) provides valuable national level information on the prevalence of and trends for some key health outcomes. For example, the Commission report *Attack Asthma* (Pew Commission, 2000) drew upon NHIS data to describe the dramatic rise is asthma over the past decade. However, NHIS is not designed to specifically address environmentally related health outcomes. Therefore the information on environmental health endpoints is limited, and some categories of endpoints may include endpoints that are not linked to the environment.

Published NHIS estimates for both chronic and acute conditions are available as far back as 1984. Categories of endpoints are grouped by ICD-9 codes⁸ in a process called the NHIS recode. Depending upon the disease category, these groupings may or may not be specific to environmental health endpoints. In addition, these categories may include a limited number of endpoints and may provide a misleading estimate of the prevalence of disease in the population. For example, the NHIS grouping for neurological diseases includes migraine headaches, but excludes diseases of growing interest such as Alzheimer's and Parkinson's diseases, thus resulting in an underestimation of prevalence of neurological diseases in the population. This is a major limitation of the NHIS data set when evaluating disease trends that may be influenced by environmental exposures. On the other hand, respiratory diseases are adequately captured by the NHIS recode. The disease prevalence and incidence rates give an adequate assessment of respiratory conditions with environmental etiology such as asthma and emphysema. More detailed examples of the limitations resulting from the NHIS recode system can be found in Appendix 1.

Figure 5 shows ten-year trend data for the self-reported prevalence of a number of broad categories of health conditions including:

- Respiratory Conditions
- Skin Diseases
- Neurological Disorders
- Reproductive and Fertility Conditions
- Endocrine and Metabolic Conditions.

An increasing trend in the reported prevalence for all of these categories between 1986 and 1995 in illustrated in figures 6-8. In Figure 6, endocrine and metabolic disorders show the greatest increase (21.7%) followed by neurological (20%) and respiratory diseases (20%). As previously noted, due to the NHIS recodes, these broad categories of health conditions are combinations of conditions, reflecting endpoints with and without known environmental etiologies.

National Center for Health Statistics [producer], 1996. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor], 1999.

⁸ U.S. Department of Health and Human Services, National Center for Health Statistics. National Health Interview Survey, 1996 [Computer File]. ICPSR version. Hyattsville, MD: U.S. Dept. of Health and Human Services,

Figure 7 provides a greater level of detail showing the 10-year trends for the specific health outcomes included in these each broad categories of health conditions. Specific diseases with increasing prevalence include:

Endocrine and metabolic diseases

- thyroid disorders 36.3%, diabetes 19.1%

Neurological diseases

- multiple sclerosis 21.2%, migraine headaches 26%

Respiratory conditions

– asthma 38.6%, chronic bronchitis 15.3%

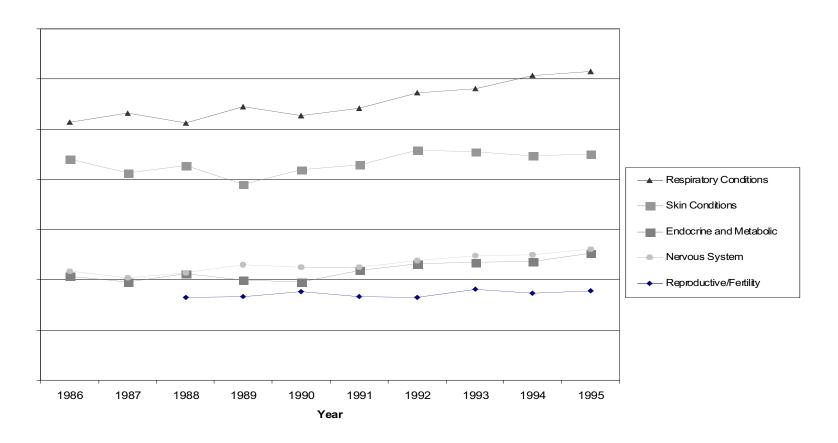
Reproductive conditions

- prostate diseases 48% (non-cancer including hyperplasia, inflammation)
- disorders of female reproductive organs 28.6% (i.e., ovarian cysts, disorders of the uterus and cervix)

Figure 8 presents baseline prevalence information for 1997 for a number of childhood health conditions. With increasing concerns about the possible relationship between environmental exposures and neuro-developmental disorders in children, NHIS provides important baseline data on outcomes such as attention deficit disorder (ADD) and autism. According to NHIS, ADD currently affects over 5% of all children. Such estimates are limited, reflecting a single survey and self-reporting.

The role of the environment in the prevalence of these health outcomes remains unknown. These data should not be interpreted as an implication of environmental causality. However, the increasing trends in a number of diseases with potential links to environmental exposures underscore the need for improved tracking to increase our understanding of risk factors, identify populations at high risk, and develop coordinated prevention efforts.

Figure 5: Self-Reported Prevalence for Selected Categories of Disease



active and fertility endpoints were available for years 1988-1995

nal Health Interview Survey, 1986-1995. Data for reproductive and fertility endpoints were available for years 1988-1995.

Figure 6: Health Trends for Key Health Categories

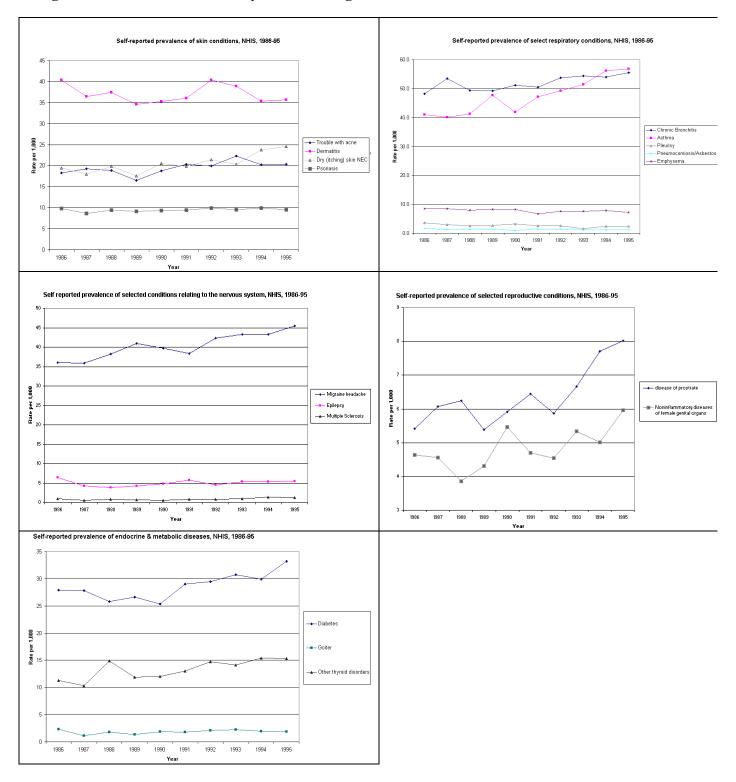
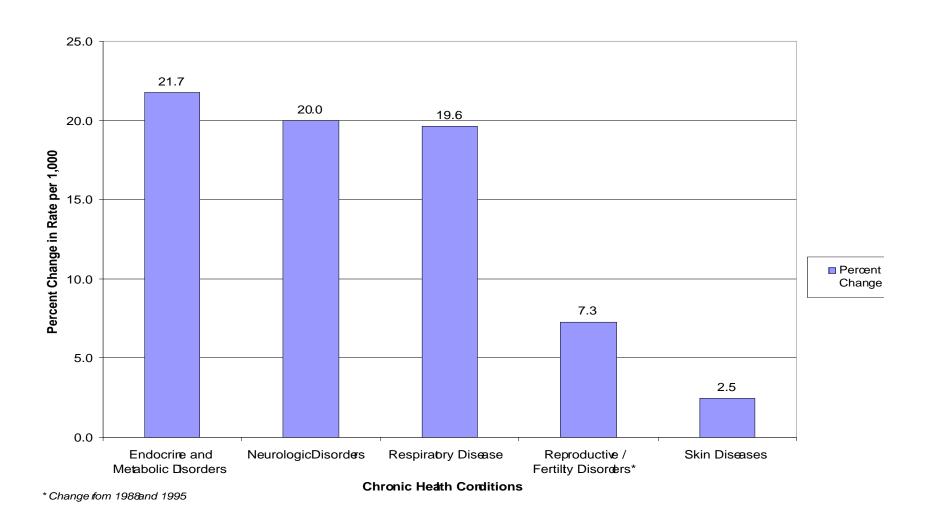


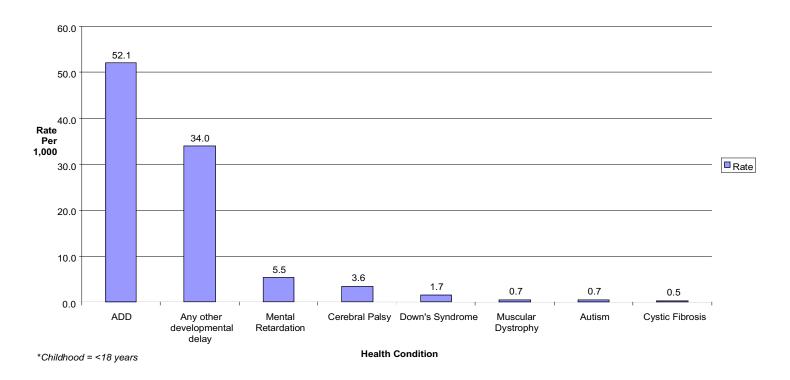
Figure 7: Percent Increase in Self-Reported Prevalence of Select Categories of Disease



Source: National Health Interview Survey, 1986-1995.

Changes in reproductive and fertility outcomes reflect years 1988-1995.

Figure 8: Self-Reported Prevalence of Childhood Chronic Health Conditions



Examination of Health Care Data

In addition to disease trends, the Commission reviewed health care information from the 1996 National Hospital Discharge Survey (NHDS), National Ambulatory Medical Care Survey (NAMCS) and National Hospital Ambulatory Medical Care Survey (NHAMCS) that related to the environmental health indicators identified in Table 9.

Table 12 provides a summary of the number of hospital discharges, emergency room visits, hospital outpatient care visits and doctor's office visits for six broad groupings of health outcomes, including:

- Lung and Respiratory Conditions
- Neurological Conditions
- Reproductive and Fertility Conditions
- Blood Disorders
- Liver Disease
- Cardiovascular Disorders

Specific disease endpoints within these broad classifications are included where information was available.

As expected, cardiovascular diseases required the most health care resources, including over 48 million doctor visits and 4.6 million hospitalizations. Although pollution exposures have been indicated for some types of cardiovascular diseases, many other environmental risk factors, including lifestyle and obesity, have been implicated as contributing causes. Lung and respiratory diseases (33.6 million doctor visits and over 3 million emergency room visits) and neurological conditions (8.7 million doctor visits) also required large amounts of health care services. Of all the lung and respiratory health conditions resulting in utilization of the health care system, asthma and chronic bronchitis accounted for largest proportion of hospital, emergency room, outpatient and doctor visits in 1996. Among the endocrine conditions, diabetes resulted in the most health care use (over 15 million physician visits). Of the neurologic conditions requiring health care, a relatively small fraction were due to neuro-degenerative diseases such as senility, cerebral degeneration, Alzheimer's disease and Parkinson's diseases. However, these diseases have a devastating impact on the quality of life and require care that may not be measured by these surveys.

Although limited to populations with access to health care, rates of health care utilization from these databases serve as a proxy for disease impact on society. These measures can inform the decision process of selecting health outcomes for tracking, and provide indications of the potential benefits of prevention.

Table 12: Total Number of Hospital Discharges, Emergency Room, Outpatient, and Doctor Visits in 1996 for Selected Health Outcomes.

	Total No. of Hospital discharge	Total No. of Emergency Room visits	Total No. of Outpatient visits	Total No. of Doctor's visits
Lung/Respiratory	1,307,000	3,072,000	1,911,000	33,586,000
Chronic bronchitis	404,000	276,000	49,000	1,069,000
Emphysema	31,000	17,000	21,000	315,000
Asthma	474,000	1,935,000	903,000	9,051,000
Neurological	502,000	1,149,000	939,000	8,654,000
Senility	70,000	6,000	5,000	165,000
Cerebral Degeneration	36,000	19,000	133,000	414,000
Alzheimer's	16,000	11,000	84,000	195,000
Parkinson's	20,000	18,000	36,000	638,000
Immuno/Endocrine				
Diabetes	503,000	330,000	2,684,000	15,896,000
Lupus	17,000	1,000	36,000	186,000
Reproductive/Infertility	74,000	63,000	296,000	896,000
Blood	272,000	251,000	289,000	3,171,000
Liver	129,000	71,000	83,000	394,000
Cardiovascular	4,628,000	3,109,000	4,125,000	48,251,000

Sources: NHDS, NAMCS and NHAMCS, 1996 Surveys

Conclusions from the Examination of Available Tracking Data

This examination was conducted to assist the Commission in developing recommendations for diseases and health outcomes to be included in the Nationwide Health Tracking Network. A step-wise approach was used to identify health effects based upon potential adverse effects of major pollutants and specific diseases or health outcomes linked to environmental exposures. These health outcomes were then examined through available national tracking surveys to identify those that are increasing in prevalence and result in significant use of health care. Based upon the findings the following conclusions are offered.

- Existing toxicological and epidemiological data indicate that a broad range of health effects may be related to exposure to toxic pollutants in the environment.
- While the impact of these pollutants on population health is unknown, available data indicates that a large amount of pollutants with known or suspected toxic effects is released into the environment with no tracking of population exposure levels.
- Potential adverse health effects that have been linked to or influenced by environmental exposures include: respiratory, neurological, skin, liver, heart, developmental, reproductive, kidney, immune conditions, birth defects, cancer, and endocrine disorders.
- The review of the literature reveals a number of specific diseases and adverse health outcomes that may be causally linked or influenced by environmental exposures. This list includes: asthma, COPD, anemias (sickle cell, aplastic), methemoglobinemia, congenital anomalies, low birth weight, spontaneous abortion, diabetes and various types of cancer.
- An examination of available national survey data indicates that the reported prevalence of these categories of diseases has been increasing. Between 1986 and 1995 the largest increases were reported in endocrine and metabolic disorders (up 21.7%) followed by neurological (up 20%) and respiratory diseases (up 20%). Reproductive disorders also increased during this time (up 7.3%).
- Available data on health care utilization for these outcomes indicates that cardiovascular disease requires the greatest use of health care, with respiratory (over 33 million doctor visits and 3 million emergency room visits) and neurological diseases (over 8 million doctor visits) also requiring large amounts of health care services.
- Based upon this analysis, respiratory diseases and neurological diseases are recommended as priorities for tracking. Specific endpoints recommended for tracking include asthma and chronic respiratory diseases, and chronic neuro-degenerative diseases such as multiple sclerosis. Based upon trends in reported prevalence, consideration should also be given to developmental disabilities, reproductive disorders, and endocrine/metabolic disorders. Strengthening of current efforts to track cancer and birth defects should also be included as components of a Nationwide Health Tracking Network.

Chapter 5. The Environmental Health Tracking Summit

Introduction

The support and involvement of the environmental health leadership is key to the success of building a strong environmental health tracking network. To develop this support and examine the needs of practitioners, the Commission hosted an Environmental Health Tracking Summit on June 8, 2000 at Baltimore's Inner Harbor. The Summit was co-sponsored by the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Public Health Foundation. The participants included broad representation of the environmental health leadership at the federal, state, and local levels.

Goals of the Summit

The goal of the summit was to develop policy recommendations for the establishment and implementation of an approach to environmental health tracking. Key considerations in the development of such recommendations included the following:

- To improve coordination across agencies and organizations with key roles in environmental health;
- ➤ To enhance existing capacity across agencies and organizations to track health status and population exposures through improved laboratory infrastructure, linkages across and within states and localities and the private health care sector, and information technology and access;
- To bridge research and practice, improving the translation of environmental health research into practice, and using tracking information to shape research priorities;
- > To develop flexible guidelines on key outcomes and exposures of concern that are candidates for tracking and that are feasible for states to implement and monitor over time; and
- > To provide funding mechanisms to facilitate implementation and ultimately assure public health action.

Participation

Among the federal participants were leaders from the CDC National Center for Environmental Health (NCEH), CDC National Center for Health Statistics (NCHS), CDC National Institute for Occupational Safety and Health (NIOSH), Agency for Toxic Substances and Disease Registry (ATSDR), NIH National Institute of Environmental Health Sciences (NIEHS), Environmental Protection Agency (EPA), and the Department of Defense (DOD). The Summit provided the Commission a "view from the trenches" from leading practitioners in environmental health.

Key Recommendations

Summit participants developed specific recommendations for improving the national environmental health infrastructure and capacity for tracking. These recommendations focused on developing leadership, improving the scientific basis for tracking, identifying key

environmental health indicators for tracking, and enhancing reporting, access to information, and response.

Developing Leadership

- ➤ Designate a national lead authority for environmental health tracking by the Secretary of Health and Human Services to oversee the development of the national network and coordinate all related activities. This leader shall also be responsible for implementing the Healthy People 2010 objectives for Environmental Health Infrastructure and Surveillance.
- Establish a Council on Environmental Health Tracking to advise and oversee the national tracking activities. The Council shall include leadership from HHS, EPA, and other federal agencies, representatives from state and local environmental health programs, the Council of State and Territorial Epidemiologists, the research and academic communities, health care providers and insurers, and both national and community level environmental and health organizations. The Council shall provide an annual report to Congress on the National Environmental Health Tracking Network.
- ➤ Require every Governor to appoint an environmental health lead in every state health department, and require CDC and the National Association of County and City Health Officials to develop similar leadership capacity at the local level.
- Expand the CDC Epidemic Intelligence Service and Public Health Prevention Service to recruit and train public health officers in environmental epidemiology and tracking, bolster the capacity of public health agencies, and establish a national network of expertise.

Strengthening Environmental Health Science

- ➤ Develop and fund a CDC/EPA/NIEHS collaborative federal research agenda for environmental health tracking that includes support for five National Academic Centers of Excellence to research appropriate endpoints for tracking, develop linkages between research and practice, train the public health workforce, and improve the translation of tracking results to prevention.
- ➤ Develop a coordinated national approach to exposure tracking that includes the National Exposure Report Card, National Health and Nutrition Examination Survey, and the EPA National Human Exposure Assessment Survey, and that improves state and local laboratory capacity to evaluate community exposures.
- Require the Council on Environmental Health Tracking to develop science-based criteria for recommending hazards, exposures, and health outcomes to be included in the National Environmental Tracking Network and to develop recommended minimum standards for environmental health tracking at the federal, state and local level.
- Expand the tracking initiatives of the National Center for Health Statistics (such as NHANES and NHIS) to increase data accessibility and utility to state and local environmental health practitioners, the public, and the research community.

Improving Capacity for Reporting and Response

- ➤ Develop a model Community Health Right-to-Know Act, which builds upon the foundation of the Toxic Release Inventory to support the environmental health tracking infrastructure and assure community access to environmental exposure and health outcome information.
- ➤ Require EPA and CDC to jointly develop a National Environmental Health Report Card, which provides an annual overview of key hazards, exposures, and health outcomes, to track progress and shape national goals. The approach should be adaptable to the needs of state and local agencies to facilitate the development of state and community-level Environmental Health Report Cards
- Develop a pilot network of state environmental health tracking projects to establish capacity and address a range of different state environmental health priorities. The pilots should be supported jointly by EPA and CDC through expansion of the current ATSDR cooperative agreement program, EPA state implementation plans (SIPS) and public health block grants.
- ➤ Through the CDC National Electronic Disease Surveillance Systems (NEDSS), provide the technical infrastructure support and national data standards for The Nationwide Environmental Health Tracking Network. This should include support and incentives for state and local agencies, health care providers, and insurers to become active partners in tracking population health and identifying, treating, and preventing diseases and disabilities related to the environment.

Selecting Endpoints for Tracking: Toward A Tiered Approach

Summit participants recognized the current limitations of knowledge concerning the role of environment in disease, as well as state and regional differences in environmental health tracking priorities. To address these limitations and the diversity of state and local needs they recommended a flexible tiered tracking network including the following components:

- National tracking for high priority outcomes and exposures;
- A sentinel network to identify acute and emerging hazards;
- A coordinated network of pilot regional, state, and local tracking programs; and,
- An aggressive research program to guide and evaluate tracking.

Conclusions

The Summit provided a foundation for the Commission's recommendations and shaped the tiered approach of the National Health Tracking Network. The participants also identified the following key conditions to assure successful implementation:

- Coordination of multiple agency efforts at the federal, state, and local level;
- > Development of the national environmental health information infrastructure;
- Establishment of minimum performance standards to guide agency-specific tracking efforts;

- ➤ Broad coverage to assure identification of populations at high risk of environmental exposures and adverse health effects;
- ➤ Regular reporting of findings and improved public access to information;
- > Strong linkages to prevention.

The Summit represented an opportunity for the environmental leadership to join together in crafting recommendations for improving environmental health tracking. The broad range of recommendations focused on the themes of leadership development, strengthening the scientific basis for tracking, and improving national capacity for tracking, reporting, and response. Finally, the discussions at the Summit reflected an urgent need to improve current national capacities, and in particular to bolster the fragile infrastructure at the state and local levels.

Chapter 6. Conclusions and Future Directions

The fundamental goal of the Pew Environmental Health Commission Environmental Health Tracking Project is to enhance the public health response to environmental health threats through a national strategy for tracking hazards, exposures, and health outcomes. An environmental health tracking network can provide greater assurances about the safety of our environment; guard against adverse health consequences; help to identify and prevent harmful exposures; measure the effectiveness of prevention and regulatory strategies; and ultimately improve our understanding of the role of the environment in public health.

This report describes the Commission's examination of the national capacity for tracking. The objectives of the project included the following:

- To examine the existing public health capacity for environmental health tracking;
- > To identify the environmental health needs and priorities of the Nation's public health agencies;
- > To examine issues of leadership and coordination in environmental health tracking;
- > To develop recommendations for designing and implementing an effective national strategy for environmental health tracking.

The approach for the investigation was step-wise and included: a review of the historical role of tracking in public health and the evolution of current strategies; a examination of the national infrastructure including a survey of federal, state, and local public health agencies; a review of the scientific literature and available federal survey data to identify health endpoints for tracking; and the convening of an Environmental Health Tracking Summit bringing together federal, state, and local leaders in environmental health to develop recommendations for the Commission. Based upon the findings of Tracking Project the Commission proposed a Nationwide Health Tracking Network that is described in Chapter 1.

Summary of Findings

- Environmental health tracking is an essential part of effective public health practice and our national environmental protection efforts. Yet, there is currently no cohesive national strategy to identify environmental hazards, measure population exposures, and track health conditions that may be related to the environment.
- The infrastructure for environmental health tracking has been neglected, particularly at the state and local level. Commission outreach to federal, state, and local environmental health leaders revealed a critical lack of resources necessary to address public concerns and answer fundamental questions about the impact of the environment on the health of communities.
- ➤ Basic information on the incidence and trends in health conditions that may be related to or influenced by the environment is largely unavailable. This information gap is most apparent at the state and local level. Every community should have access to basic information about

- environmental hazards, potential exposures, and community health status. Environmental tracking data should be easily accessible and understandable for the public.
- Current tracking efforts should be enhanced to include a broader range of diseases and health outcomes that may be related to or influenced by the environment. Based upon a review of the literature, available information on disease trends, and outreach to environmental health practitioners across the country, the Commission identified a list of health outcomes for national tracking including birth defects, developmental disabilities, asthma and chronic respiratory disease, and neurological diseases including multiple sclerosis, Parkinson's and Alzheimer's disease.
- Available environmental release information indicates the potential for population exposures to a wide range of pollutants linked to adverse health impacts, yet little is done to measure community exposures. A systematic national approach is needed to measure, evaluate, and report individual exposure levels to hazardous environmental pollutants. The Commission recommends that exposure tracking include persistent pollutants, heavy metals, and pesticides.
- ➤ Based upon the findings of this project, the Commission recommends a federally supported Nationwide Health Tracking Network with the appropriate privacy protections that informs consumers, communities, public health practitioners, researchers, and policymakers on chronic diseases and related environmental hazards and population exposures. This will provide the capacity to better understand, respond and prevent chronic disease in this country.

The proposed Network would be comprised of five key components:

- National baseline tracking network for diseases and exposures;
- Nationwide early warning system for critical environmental health threats;
- State pilot tracking programs to test diseases, exposures and approaches for national tracking;
- Federal investigative response capability; and
- Tracking links to communities and research.

Future Directions

The turn of the millennium brings an exiting and challenging time for environmental health. The environmental progress of the past century brought about unprecedented gains in communicable disease prevention and environmental quality. Now, we face the daunting challenge of continuing that progress by identifying and preventing hazards in an increasingly complex environment, and conquering the chronic diseases that have become the major causes of mortality and morbidity.

Advances in hazard identification, exposure assessment, health outcome data collection and information technology provide unprecedented opportunities for advancing tracking and improving our understanding of the environment and health. This advances, coupled with deep public concern, provide a window of opportunity to strengthen the national infrastructure for

environmental health information, expand public access to this important information and protect the privacy of individuals. New technologies in biomonitoring have the potential to transform the nation's capacity to track exposures to pollutants and understand their impacts on health. Advances in communication and information technology have expanded opportunities for public access and given us new tools to analyze, map and disseminate health data. New technology also can improve safeguards to protect the confidentiality of identifiable personal health information. We have better tools than ever before to meet the public health missions of protecting Americans' health while at the same time protecting privacy.

The Nation's growing concern about biological and chemical terrorism has underscored the need for a strong tracking infrastructure. In response, CDC has initiated a number of tracking and capacity building programs. The National Electronic Disease Surveillance System (NEDSS) will integrate over 100 independent tracking and health information systems and will facilitate improved tracking and access to health information. Complementing this effort, the Information Network for Public Health Officials (INPHO) and Health Alert Network provide essential support for state and local tracking capacity, providing support for information technology, disease tracking, and professional workforce development. In addition to these projects, the CDC Public Health Practice Office is developing model standards to assure that state health agencies have the capacity to carry out the core functions of public health including the first essential service of tracking health status and identifying health problems.

To address the need for improved exposure tracking the CDC National Center for Environmental Health is developing two programs. The Rapid Toxic Screen will rapidly measure up to 150 chemicals in blood and urine to identify exposed individuals and protect health during acute chemical emergencies. To better understand and track chronic population exposures, the National Exposure Report Card will measure and report the exposure of the U.S. population to 25 priority toxic substances, and expand to 100 substances in FY2001. Both of these programs offer opportunities to coordinate with ongoing environmental hazard and disease surveillance, and provide health professionals and the public with new tools for prevention.

The public increasingly wants and demands more credible environmental health information so that they can make independent and fully informed decisions. The Internet explosion has further fueled this desire. Recent public opinion research confirms that Americans want to have access to national, state and community level health data. In fact, they are incredulous when informed that health tracking information is not readily available. The Internet now allows the public quick and highly accessible information on most facets of their lives. There is a widespread belief that health tracking information should be and needs to be available to the public.

Why We Need a Health Tracking Network Now

Earlier this year, a scientific breakthrough was announced that has incredible potential to help us understand the links between people, their environment and behaviors, genetic inheritance and health. As researchers begin to apply this new genetic knowledge to the study of disease, we will have more information than ever before to use in revealing the connections between environmental exposures, people's behaviors and genetic predisposition to health problems. But only if we have the basic information about what is going on in our communities—the hazards, the exposures and health problems that Americans are experiencing.

The "building blocks" of knowledge provided by the Nationwide Health Tracking Network will enable scientists to answer many of the troubling questions we are asking today about what is making us sick. The Network will provide the basis for communities, health officials, businesses and policymakers to take action for making this nation healthier. The result will be new prevention strategies aimed at reducing and preventing many of the chronic diseases and disabling conditions that afflict millions of Americans.

The Commission is calling upon our national leaders to take the steps outlined in this report, and with a minimal investment, revitalize our nation's public health defenses to meet the challenges of this new century. It is time to close America's environmental health gap.

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Appendices

Appendix 1: Limitation of NHIS Grouping of Health Outcomes

<u>Lung and respiratory diseases:</u> Many of the NHIS recode conditions correlate singly and specifically to specific health outcomes that have been shown to have an environmental etiology, e.g. asthma, or groups of outcomes with known environmental etiology such as pneumoconiosis and asbestosis.

<u>Neurodegenerative and Neurotoxic disorders:</u> With the exception of migraine, numerous neurotoxic disorders are not included in the NHIS recodes, resulting in a great potential for underestimation of prevalence of environmentally related neurological health outcomes in the population.

<u>Disorders of the blood and blood-forming organs</u>: NHIS data only include outcomes that fall under the umbrella of "anemias." This includes ICD-9 codes 280-285, most of which have indications of environmental etiology. The exception is ICD-9 code 281, which deals with infectious agents as etiologic factors. A number of relevant conditions are excluded from collection, specifically ICD-9 codes 286-289.

<u>Cardiovascular disease</u>: The National Health Interview Survey provides a broad range of estimates for cardiovascular disease, however, few of the conditions within the NHIS recodes have shown indication of environmental etiology. Thus using NHIS recodes would result in gross overstatements of the number of cardiovascular conditions present in the population due to environmental causes.

<u>Reproductive disorders</u>: Incidence of female infertility can be obtained from the acute grouping, "other conditions in the female genital tract." Neither male nor female infertility was included in the NHIS recodes and thus prevalence rates could not be ascertained. The other NHIS recode that contains outcomes with possible environmental etiology is "delivery and other conditions of pregnancy and puerperium." However, this grouping contains complications from pregnancy and fetal abnormalities affecting the mother to those of legally and illegally-induced abortions, and conditions arising from perinatal infections. Aside from male infertility, a number of potentially environmentally-related conditions were not included in the NHIS recodes.

Appendix 2: Environmental Health Definitions for Tracking Project

Environmental Health- Pew Environmental Health Commission Working Definition (May, 1999)

"Environmental health comprises those aspects of human health, including quality of life, that are determined by interaction with physical, biological, and social factors in the environment. It also refers to the theory and practice of assessing, correcting, and preventing those factors in the environment that may adversely effect the health of present and future generations."

Public Health Tracking- CDC Working Definition

"The ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes functional capacity for data collection, analysis, and dissemination linked to public health programs (Thacker and Berkelman, 1988)."

Environmental Health Tracking - Working Definitions

Hazard Tracking

The "assessment of the occurrence of, distribution of, and the secular trends in levels of hazards (toxic chemical agents, physical agents, biomechanical stressors, biologic agents) responsible for disease and injury" (Wegman, D.H., 1992)¹⁰

Examples: EPA's Regulatory Monitoring programs -- Aeromatic Information Retrieval System (AIRS), Toxic Release Inventory (TRI) or Accidental Release Information Program (ARIP)

Exposure Tracking

The "monitoring of individual members of the population for the presence of an environmental agent or its clinically unapparent (e.g., sub-clinical or preclinical) effects (Thacker et al., 1996)."

Examples: National Center for Health Statistics; National Health and Nutrition Examination Survey I, II, III, IV (NHANES); National Center for Environmental Health bio-monitoring programs and blood-lead exposure programs; and National Human Exposure Assessment Survey (NHEXAS).

Outcome Tracking

The "on-going, systematic collection, analysis, and interpretation of outcome data that affect the population, followed and paralled by the timely dissemination of this information to public health officials and the affected public (Thacker and Berkelman, 1988)."

⁹ Thacker, S.B. 1994. Historical Development. In Principles and Practice of Public Health Surveillance. Edited by W. Baker E.L. Halperin. New York: Van Norstrand Reinhold.

¹⁰ Wegman, D.H. 1992. Hazard Surveillance. In *Public Health Surveillance*. Edited by W. Baker E.L. Halperin. New York: Van Nostrand Reinhold.

¹¹ Thacker, S.B. et al., "Surveillance in Environmental Public Health: Issues, Systems, and Sources," AJPH 86: 633-638(1996).

Examples: National Hospital Discharge Data; National Health Interview Survey; Sentinel Event Notification for Occupational Risks (SENSOR); NHANES

Indicators - Working Definition

"A measure of a hazardous exposure or health outcome which have been derived from routinely collected or otherwise available information for the purpose of planning or evaluating population-based interventions, or developing [environmental] health policies (Pastides, 1995)"

Appendix 3: Pew Environmental Health Tracking Project Working Group Members

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