

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

## **Companion 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 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 is 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.

## Executive Summary

At the dawn of the 21<sup>st</sup> 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 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.<sup>1</sup> 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 only 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 to believe rates of these diseases are rising and the environmental links remain unknown.
- Despite evidence that learning disabilities 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.

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<sup>1</sup> 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.

- Endocrine and metabolic disorders such as diabetes, and neurological conditions such as migraines and multiple sclerosis, have increased approximately 20 percent between 1986 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 that is collected is never analyzed or interpreted in a way that could identify targets for further action. Most of this data 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 faced 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.<sup>2</sup> 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 and prevent chronic disease in this country.*

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<sup>2</sup> 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  $\pm 3$  percent for results based on a full sample.

This tracking network would be a tiered approach, with a national baseline 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 involves 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 this for their own Environmental Health Report Cards.

### **Tier 2: National Early Warning System**

This early warning system would act as a sentinel to allow rapid identification of immediate health problems, including chemical catastrophes. This 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 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 more 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 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 that calls for a long-term coordinated strategy to measure health 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.

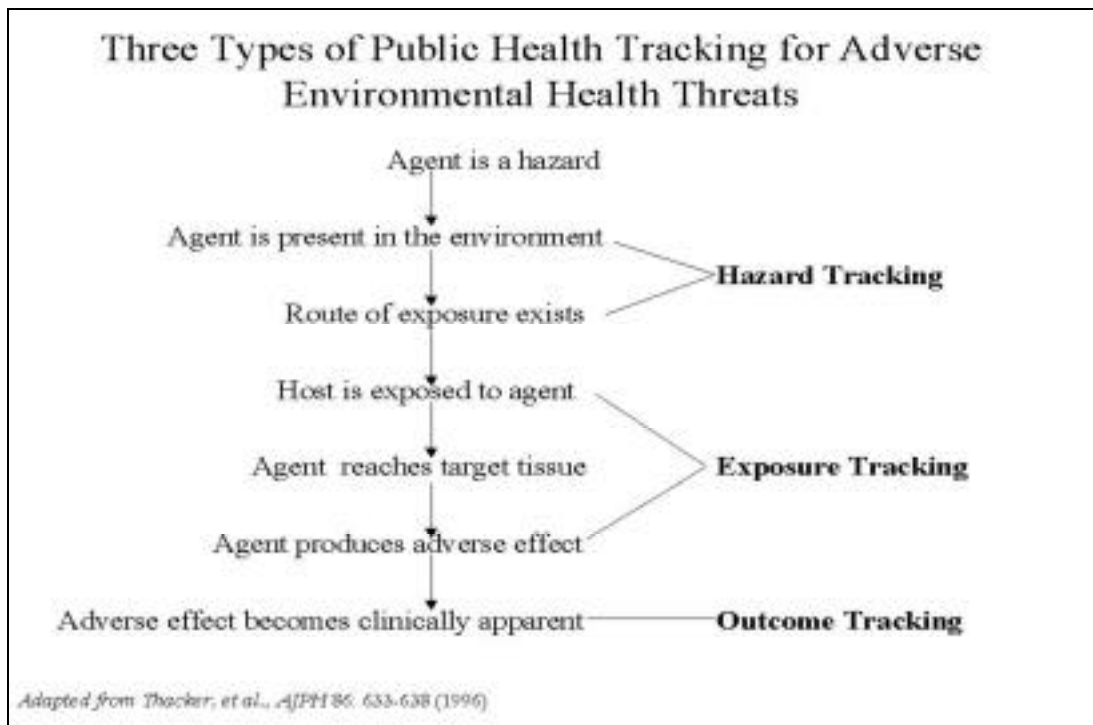
The complete study is available at the Commission’s website: <http://pewenvirohealth.jhsph.edu>.

### 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.

Figure 1: Environmental Health 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)<sup>3</sup>. 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)<sup>3</sup>**

<u>Types of health effects</u>	<u>Ranking based on total 1997 TRI release</u>	<u>Total Air &amp; Water Releases (Pounds)</u>
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

<sup>3</sup> 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.

<u>Types of health effects</u>	<u>Ranking based on total 1997 TRI release</u>	<u>Total Air &amp; Water Releases (Pounds)</u>
Endocrine	11	173,331,065

Reference: Environmental Defense Scorecard ([www.scorecard.org](http://www.scorecard.org))

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 and 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 can 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.