

Guide to Building an Environmental Public Health Tracking Network

National Center for Environmental Health
Division of Environmental Hazards and Health Effects



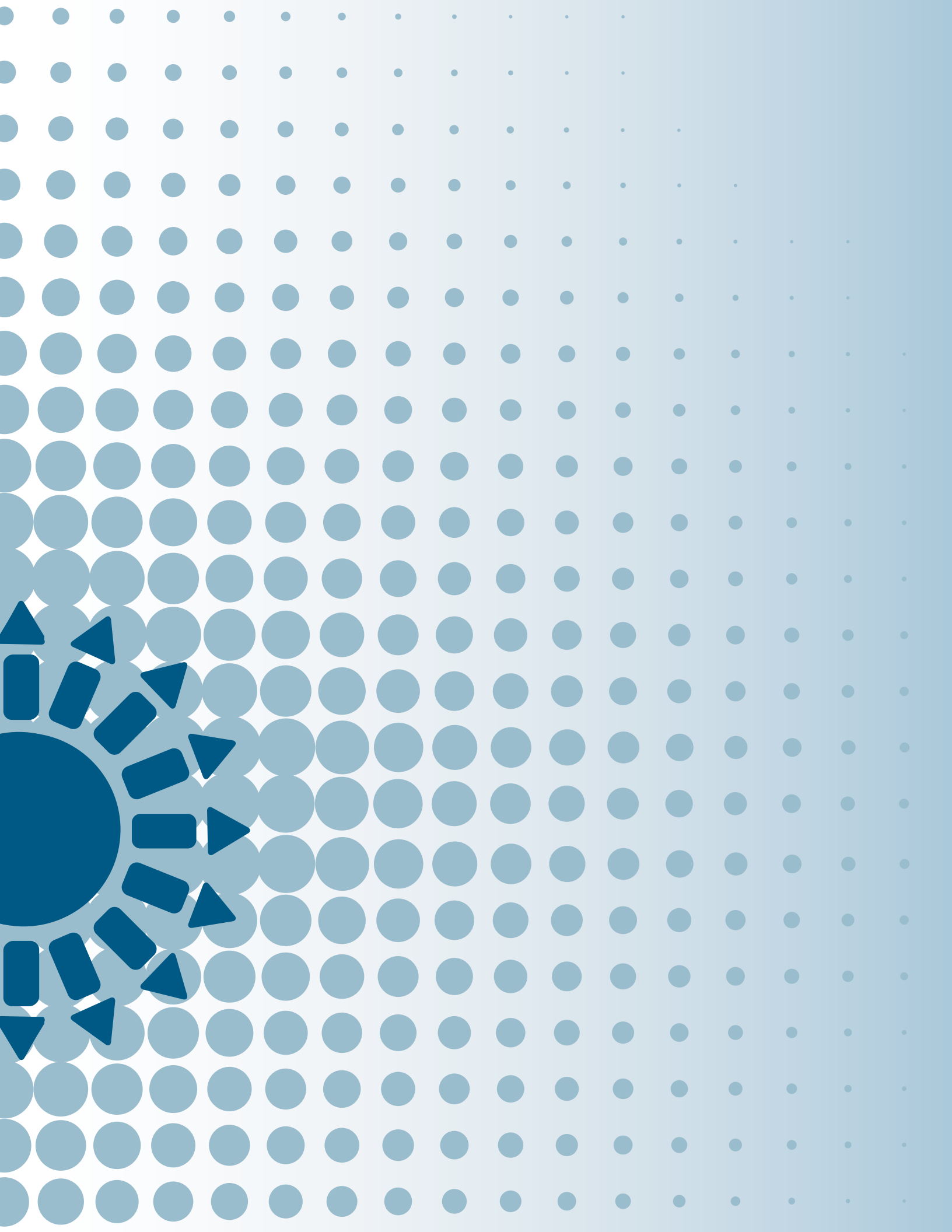




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Background and Introduction

Welcome to the National Environmental Public Health Tracking Program (Tracking Program) “How To Guide.”

This document will help new and experienced health professionals develop and launch a Tracking Program. It contains specific approaches, methods, and resources that you can use to:

- Learn the history of, and CDC’s approach to, building a sustainable nationwide Tracking Network with national, state, and local components
- Evaluate your state, city, or other entity’s capacity to launch a tracking network
- Develop tracking program communications and outreach materials and strategies
- Establish a tracking workforce and infrastructure
- Learn more about existing Tracking Programs and their challenges

The guide will be available to you electronically. In the electronic version, all blue text will link users to more detailed reference materials. To view these references, just place your mouse over the blue text, right click, and select “Open Hyperlink” from the menu. The Guide also highlights a full list of Web addresses for all resource materials (Appendix A).

The Guide’s Purpose

The Tracking Program “How to Guide” is an evolving resource. It provides the materials, tools, methods, recommendations, and products needed to develop and to put in place local or state environmental public health tracking programs. In fact, Tracking Program staff from several states provided valuable information to this Guide. As the CDC Tracking Program develops new materials and information, we’ll update this Guide to better assist state and local tracking programs. For additional information, please visit the National Environmental Public Health Tracking Program Web site at <http://www.cdc.gov/nceh/tracking>.



Section I

Environmental Public Health Tracking Overview

Today, we have overwhelming evidence that our environment can affect our health. But we have only limited information on how to address concerns about exposure to chemicals and other agents in the environment. The same is true about health outcomes such as asthma, cancer, birth defects, and other chronic conditions. In 2000, the Pew Environmental Health Commission urged establishment of a “Nationwide Environmental Health Tracking Network.” The network would focus on reducing and preventing health problems and would increase our understanding of the relationship between the environment and health. CDC responded to this need by creating the National Environmental Public Health Tracking (Tracking) Program, with the Nationwide Tracking Network as its cornerstone.

CDC’s Tracking Program is a multidisciplinary collaboration. The program collects, integrates, analyzes, interprets, and distributes data from environmental hazard monitoring, human exposure surveillance, and health effects surveillance. The Tracking Program’s principal effort is the development of the National Environmental Public Health Tracking Network (Tracking Network), a Web-based data and information system. State and local pilot projects served as “proofs of concept” and laid the groundwork for the Tracking Network. CDC first launched the national Tracking Network in 2009, along with tracking networks in 16 states and New York City.

Federal, state, and local agencies that use information and tools developed through the Tracking Program are now better prepared to develop and start public health actions quickly. Such quick development and startup will more effectively prevent or control diseases possibly linked to hazards in the environment. Moreover, healthcare providers and agencies can use the data to target preventive services. The public can use the data to better understand any community-related health trends and events.

Environmental public health tracking is similar to public health surveillance. But a key distinction is tracking's emphasis on data integration across health, human exposure, and hazard information systems.¹ Yet in the final analysis, tracking—like traditional public health surveillance—provides information that drives public health decision-making and actions (refer to the conceptual diagram in Figure 1). Specifically, tracking data can:

- Estimate the magnitude of a problem;
- Detecting unusual trends and occurrences of diseases and environmental exposures across space and/or time;
- Identifying vulnerable populations who may be at risk;
- Generating hypotheses about the relationship between health and environment and stimulating further research;
- Directing and evaluating prevention and control strategies; and
- Facilitating policy development

Thacker et al. (1966)² first proposed the conceptual environmental health-tracking model. Hertz-Picciotto et al. (1966)³ expanded it. The model outlines a direct, causal pathway that starts with a hazardous agent found in the environment. The model depicts a population first exposed to that agent. Then the population receives a dose from it. The model ends with a clinically apparent, adverse health effect. To follow this model, a robust Tracking Network must include as key data collection points: *Hazard, Exposure, and Health Effects*

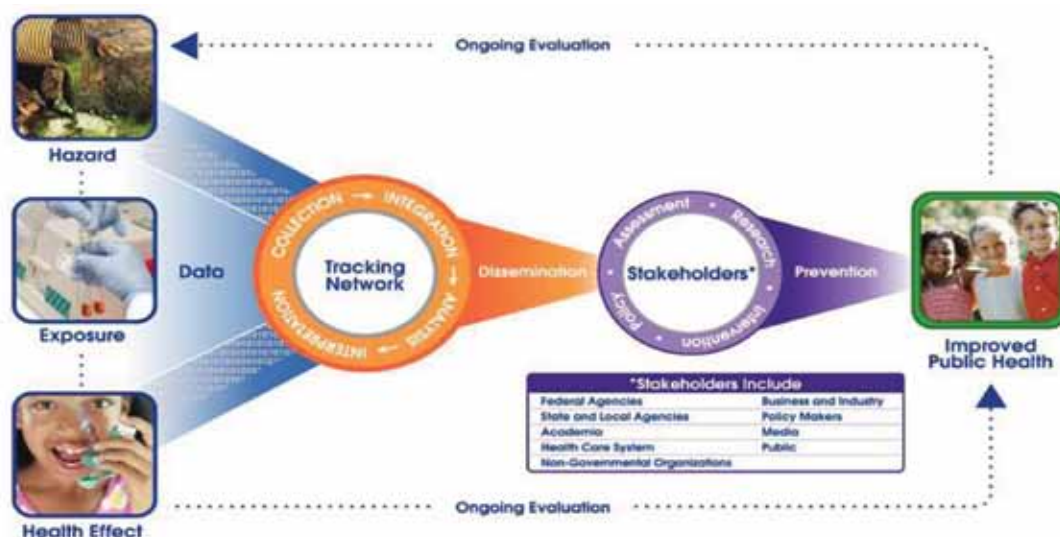
Any one of these data types provides important information for public health practice. But collecting, analyzing, and circulating data from a combination or from all of the data types together is what really characterizes environmental public health tracking. Tracking Network development necessarily depends on the availability, quality, timeliness, compatibility, and utility of available hazard, exposure, and health-effects data.

1 McGeehin MA, Qualters JR, and Niskar AS. 2004. National environmental public health tracking program: Bridging the information gap. *Environ Health Perspect* 112(14):1409–413.

2 Thacker SB, Stroup DF, Parrish G, Anderson HA 1996. Surveillance in environmental public health: issues, systems, and sources. *Am J Public Health* 86:633–38.

3 Hertz-Picciotto I. 1996. Comment: toward a coordinated system for the surveillance of environmental health hazards. *Am J Public Health* 86:638–41.

Environmental Public Health Tracking



Here are a few important terms to keep in mind as you go through this Guide:

A. Tracking-related Terminology

Tracking: Environmental public health surveillance

Tracking Program: CDC's tracking program

Tracking Network: CDC's tracking network

Nationwide Tracking Network: CDC and state/local tracking networks combined

Let's move on to the Tracking Program's vision, mission, and goals:

B. Program Vision, Mission, and Goals

1. Vision: Healthy, Informed Communities

This is the Tracking Program's primary task: translate environmental and public health data into meaningful information and increased knowledge. Then apply that knowledge to improve community health.

2. Mission: a Nationwide Network of Integrated Health and Environmental Data that Improves Community Health

Environmental Public Health Tracking's mission is, simply, to realize its vision. Tracking should empower environmental and public health practitioners, healthcare providers, community members, policymakers, and others. They can then make information-driven decisions that help protect community health. At the local, state, and national levels, the Network includes a core set of:

- Health, exposure, and hazards data
- Information summaries
- Tools for analysis, visualization, and reporting

Goals

GOAL 1	Expand and Sustain a National Environmental Public Health Tracking Network When federal, state, and local agencies use information from the Tracking Network they will be better prepared to develop and evaluate effective public health actions. These actions will prevent or control health effects linked to hazards in the environment.
GOAL 2	Advance Environmental Public Health Science Collection of tracking data is only one of many steps. Science and research will produce critical information about: Pathways from hazard source to population exposure (e.g., measured through bio-monitoring) to disease Patterns of disease and environmental agents over time and space Relations and risks among health, environment, and other risk factors Methods and tools appropriate for tracking and analysis
GOAL 3	Distribute Information to Guide Policy, Practice, and Other Actions to Improve the Nation's Health The public, environmental and public health practitioners, healthcare providers, policy makers, and others will gain a better understanding of what is occurring in communities and what actions they might take to protect or improve health.
GOAL 4	Improve Environmental Public Health Tracking Workforce and Infrastructure Improving infrastructure and developing the workforce will ensure essential services for current and emerging environmental public health issues. But program sustainability depends on a trained workforce and adequate equipment, data, and tools for putting the data to use.
GOAL 5	Promote Cooperation Among Health and Environmental Programs Agencies, organizations, and entities with a stake in Tracking will accelerate the impact of the Program. Strengthening these partnerships will enable increased interaction and collaboration.

C. Funding Opportunities

1. State and Local

CDC uses competitive grants in the form of cooperative agreements to support selected state and local health departments. In fiscal year (FY) 2002, Congress for the first time provided funds for CDC to begin development of the tracking network. This included development of environmental health capacity at state and local health departments. Initial efforts focused on capacity building and pilot projects evaluating environmental public health indicators and linkage of health and environmental data. In FY 2006, after announcement of a new funding opportunity, CDC granted funds to sixteen states and one city for entry into the Tracking Network's first phase. These grantees included

- California
- Connecticut
- Florida
- Maine
- Maryland
- Massachusetts
- Missouri
- New Hampshire
- New Jersey
- New Mexico
- New York City
- New York State
- Oregon
- Pennsylvania
- Utah
- Washington
- Wisconsin

The program supported grantee cooperation with CDC and other appropriate partners to build statewide networks, adopt already developed standards and specifications for network startup, and participate in the development of future network standards and specifications, communications, and outreach. In fiscal years 2009 and 2010, CDC received additional funding from Congress to expand the Tracking Program.

CDC added the following seven states;

- Colorado
- Iowa
- Kansas
- Louisiana
- Minnesota
- South Carolina
- Vermont

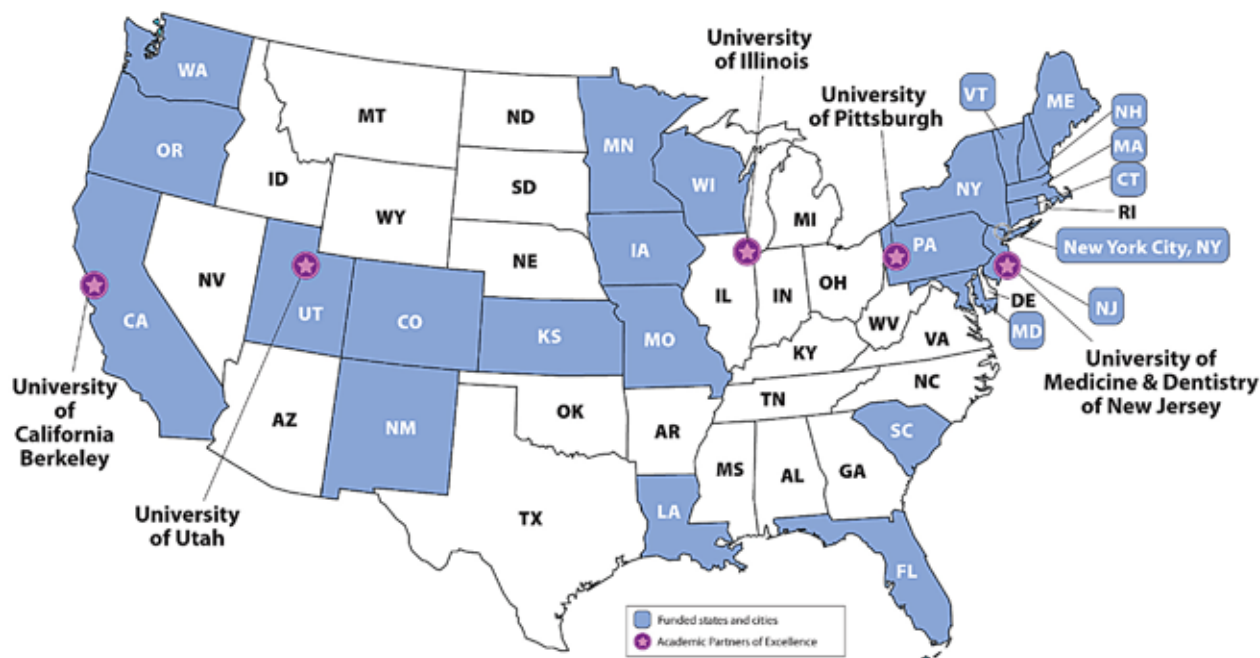


Figure 2. Tracking Program Grantees

2. Academic Partners

Since 2002, CDC has funded specific projects at schools of public health that support Tracking Program development. These projects also improve our understanding of the relationship between particular health effects and environmental exposures or hazards. Academic partner activities have focused on:

- Development and application of surveillance methods and tools
- Exposure assessment
- Linkage of health and environmental data
- Statistical analyses
- The conduct of environmental epidemiologic research

In 2010, CDC contracted with the following academic partners in order to conduct research projects on the following specific topics:

Topic 1: Development of environmental epidemiologic and statistical methods for use on the Tracking Network

University of California, Berkeley - A Multi-level Geographic Model for Environmental Public Health Tracking

Topic 2: Development of environmental epidemiologic and statistical methods for use on the Tracking Network

University of Pittsburgh - Ecological and Case Control Study of Ambient Air levels and Childhood Blood Lead Levels

Topic 3: Development of environmental epidemiologic and statistical methods for use on the Tracking Network

University of California, Berkeley - PM2.5-Cardiovascular Disease Associations; Use of Modeled Hierarchical Bayesian vs. Ambient Monitoring Exposure Data; Use of Census-based Geographic and Lifestyle Variables; Exploration of Biomarkers of Exposure and Effect

University of Pittsburgh - Linkage Study of Air Quality PM2.5 and Cardiovascular Effects Data from the Tracking Network

University of Medicine and Dentistry of New Jersey - Linkage Study of Air Quality PM2.5 and Cardiovascular Effects Data from the Tracking Network

Topic 4: Development of environmental epidemiologic and statistical methods for use on the Tracking Network

University of Utah - Advancing the Science of Linkage Studies between Drinking Water Contaminants and Adverse Birth Outcomes

University of Illinois at Chicago - A Linkage Study of Health Outcome Data in Children and Agrichemical Water Contamination Data in the Midwest

3. Other Partnerships:

Since the program's inception, CDC's National Tracking Program has worked closely with governmental and nongovernmental partners at the local, state, and federal levels. Tracking partners have helped drive the Program's direction. Tracking Program's success depends on partnerships within and across health and environmental agencies, with nongovernmental organizations, and with academic institutions. The following list is an example of some Tracking Program partners:

- American Public Health Association (APHA)
- Association of State and Territorial Health Organizations (ASTHO)
- Council of State and Territorial Epidemiologist (CSTE)
- National Aeronautics and Space Administration (NASA)
- National Association for Public Health Statistics and Information Systems (NAPHSIS)
- National Association of City County and Health Organizations (NACCHO)
- National Association of Health Data Organizations (NAHDO)
- National Birth Defects Prevention Network (NBDPN)
- National Cancer Institute (NCI)
- National Conference of State Legislators (NCSL)
- National Environmental Health Association (NEHA)
- National Oceanic and Atmospheric Administration (NOAA)
- North American Association of Central Cancer Registries (NAACCR)
- Trust for America's Health (TfAH)
- U.S. Environmental Protection Agency (USEPA)
- U.S. Geological Survey (USGS)

D. Future Direction

As CDC increases the National Tracking Network's available data types and adds new features, the network will continue to grow. And as more funding becomes available, CDC hopes to expand the Tracking Network across all 50 states. This expansion will allow more people from around the country to access vital public health and environmental information about their communities. Currently, these data types are available on the National Tracking Network:

- Age of housing
- Birth defects
- Cancer
- Carbon monoxide
- Child blood lead levels and testing
- Drinking water
- Hospitalizations for asthma
- Hospitalizations for myocardial infarction
- Ozone and particulate matter monitoring and modeled data
- Population characteristics
- Reproductive health outcomes from vital statistics

Additional data on asthma prevalence, built environment, and climate change will soon become available. The National Tracking Network will continue to expand and will over time include other types of data as determined by the Tracking Program.



Section II

Guidelines for Planning and Building a Tracking Program

This section contains instructions on how to begin data transfer to the national tracking data repository of nationally consistent data and measures (NCDMs) and their associated metadata.⁴ It details some of the planning and capacity building elements necessary for effective tracking program startup. It outlines strategies for identifying and contacting organizations or partners or universities such as those in the health and environmental agencies, including community stakeholders. Lastly, this section describes content workgroups and stresses the importance of these workgroups to the success of network implementation.

A. Assess and Build Program Capacity

The first step in assessing and improving program capacity is to understand state and local needs, priorities, and program requirements. Look for documents on CDC Standards at: <http://www.cdc.gov/nceh/tracking/pdfs/GranteePortalRequirements.pdf>. Six major areas to consider are:

1. Current surveillance systems
2. Data and information needs and priorities
3. Workforce capacity
4. Partnership development
5. Ability to access and re-release data on state tracking networks and to CDC
6. Information technology infrastructure to support a state/local tracking network

Essentially, the three aspects of capacity building are to:

1. Evaluate needs and priorities
2. Develop the workforce
3. Develop partnerships

We discuss these aspects in more detail below.

1. Evaluate Needs and Priorities

This means you will first need to sort out state and local needs related to tracking health effects, exposures, and hazards. That is, what types of health or environmental conditions do you want most to track? You'll need to incorporate these data into a tracking network for your jurisdiction. But be sure to examine thoroughly any current state/local legislation or regulations to determine whether you'll require additional authority to collect, integrate, and share data—with appropriate security and confidentiality restrictions, of course.

⁴ The Technical Network Information Plan contains more information on this topic.



As part of the building process for a state or local tracking network, you should evaluate and identify current system capacity and data sources. Then secure any agreements necessary for acquiring those data. At a minimum, you should inventory current surveillance systems such as those for hazard and exposure monitoring and for noninfectious health effects. This will help you identify potential data sources for the tracking network. It will also help you identify issues related to data sharing and any needed surveillance system/data upgrades. Appendix A contains more guidance on these topics.

2. Workforce Development

To set up a tracking network, you'll need to thoroughly assess your health/environmental staff to determine its expertise and training levels. You'll need to know the extent to which your staff needs basic training in tracking principles. You'll need to help with the training of state and local health department workforces and their partners. All of these activities will take time, but they will establish a common understanding of the program. At a minimum, everyone needs to complete CDC training course [Environmental Public Health Tracking 101](http://www.nehacert.org). It's hosted on the E – Learning site at <http://www.nehacert.org>. Other NEHA online educational training in the Environmental Health Tracking & Informatics Series includes:

- [EHT0903: Assessing Environmental Health in Your Community](http://nehacert.org/moodle/course/view.php?id=168)
- [EHT0905: Assessing the Risks to Public Health from Contamination in Potable Wells Using the Geographic Information System \(GIS\)](http://nehacert.org/moodle/course/view.php?id=170)
- [GEH0604: Lessons Learned from the Implementation of a GIS Program at the Bernalillo County Office of Environmental Health](http://nehacert.org/moodle/course/view.php?id=28)

3. Partnership Development

Developing partnerships with local, state, tribal, and federal governments; healthcare providers; nongovernmental organizations; and private for-profit and nonprofit groups is essential to the success of the program and to the development and implementation of a tracking network.

CDC recommends that programs establish Technical Advisory Groups (TAG). A typical TAG would include epidemiologists, informatics/information technology specialists, environmental professionals, communication specialists, laboratorians, and public health program officials. A TAG would assist in fashioning a state or local network that's compatible with the National Tracking Network standards and architecture. A TAG would plan action steps, set interim goals and deadlines, address problems, and ensure task completion. A TAG could also increase stakeholder cooperation and involvement.

B. Build a Network

The National Tracking Network consists of local, state, and national components. Although each agency might have specific guidelines and requirements for information systems, CDC has adopted specific standards that all funded states/locals are required to follow. These include standards for data transfer, data format, security, metadata, and general portal functionality. The Technical Network Implementation Plan (TNIP) contains detailed information on program components and processes related to the structure of the National Tracking Network, its state and local components, data submission, and standards development. These requirements provide consistency across the National Tracking Network and are outlined in this section. We have based the requirements on functional areas and have included some general requirements that apply across the Tracking Network

1. *Portals and Gateways*

The National Tracking Network comprises a national portal maintained by the Tracking Program and a series of individual portals maintained by Tracking Program-funded grantees. There are two types of portals: public and secure. Public portals are fully accessible on the Internet. They provide the primary means by which most users view National Tracking Network general information and non-sensitive data. Secure portals' more detailed data require user preauthorization.

Gateways are how the National Tracking Network participants exchange data with the Tracking Program. They transport NCDMs and other data the Tracking Network publishes or uses. A gateway is not a single technology. It's a collection of transport mechanisms that guide the secure exchange of data. Grantees use prescribed technology standards to develop gateways for data exchange with the national gateway. The gateways are for machine-to-machine transactions—a server at one site pulls or pushes data from a server at another site.

2. *Portal Requirements*

To develop a state or local public portal, the first step is to understand CDC requirements and recommendations, and states' Informatics requirements. These will determine what you can and cannot do in portal design and development. The next step is to understand thoroughly your user or "customer" requirements. The developed portal must address user needs. This process is known as requirements-gathering. Scientific and information technology experts must become involved in the requirements-gathering process. Success relates directly to these two disciplines staying in active communication.

The Tracking Program has identified several steps that have been consistent across state/local programs in building and launching their tracking networks. The timeline of each step can vary between programs based on existing capacity within the health department. The steps are broken up into two phases: a) Capacity Building/Development and b) Startup:

a. Capacity Building/Development Phase:

- Hire appropriate IT staff
- Establish IT requirements
- Get started with IT system planning
- Develop the portal
- Set up a good documentation procedure

b. Startup Phase:

- Develop and submit NCDMs
- Establish and test the portal
- Launch secure and public portals
- Evaluate, revise, and improve the Web site
- Maintain the system
- Monitor Web site usage
- Develop system documentation



3. Useful References and Background Materials for Network Planning

Developing a sustainable standards-based tracking network is an ongoing process. But when the network is up and running it enables direct electronic data reporting and linkage within and across health effects, exposure, and hazard data. It also interoperates with other environmental public health systems.

Over the past several years, CDC has developed new documents that incorporate current IT processes to explain in detail the theory and practice of the Tracking Network development. Partners might find these documents beneficial when developing their own public and secure portals.

- **Rational Unified Process (RUP)**

http://www.ibm.com/developerworks/rational/library/content/03July/1000/1251/1251_bestpractices_TP026B.pdf

The Rational Unified Process (RUP) is the framework for all development projects. RUP is a comprehensive, flexible, software engineering methodology created by the Rational Software Corporation. RUP directs users through the software development lifecycle and guides them through requirements identification and startup of their portal and supporting architecture. It also divides a project's lifecycle into four distinct phases: 1) Inception, 2) Elaboration, 3) Construction, and 4) Transition.

- **EPHT Vision Document** (<http://www.cdc.gov/nceh/tracking/pdfs/netvision.pdf>)

The Environmental Public Health Tracking Network document is an artifact of the inception phase mentioned above. It was the first formal document describing the features necessary to support environmental public health tracking nationwide. The goals and objectives detailed in the Vision Document will help partners during the inception phase of developing state or local public and secure portals.

- **GEO-Primer Tracking (Version 1.0)** (<http://www.cdc.gov/nceh/tracking/pdfs/geoprimer.pdf>)

Geographic data are critical to environmental public health tracking for identifying hazards, monitoring distribution, and analyzing trends. The Geo-Primer provides an introduction of concepts surrounding the usage of geographic data to public health professionals involved in Environmental Public Health Tracking Network startup and offers an overview of key terminology and the use of these types of data.

- **National Network Implementation Plan (NNIP)** (<http://www.cdc.gov/nceh/tracking/pdfs/nnip.pdf>)

The NNIP is a guide for using the National Network. It documents all the activities that went into building the Tracking Network.

The NNIP shows how to achieve immediate and long-term success. It also directs and guides the many stakeholders who contribute to the Tracking Network's program phase-in and ongoing development.

Specifically, the NNIP:

- Describes the Tracking Network's background, context, needs, and goals.
- Outlines the Tracking Network's principal functions and components.
- Discusses the steps needed to install the components.
- Identifies the entities responsible for the installation steps.

- **The Technical Network Implementation Plan (TNIP) (version 1.0)**

(http://www.cdc.gov/nceh/tracking/pdfs/TNIP_V1.pdf)

The TNIP guides the Tracking Network's technical development and deployment. It complements, refines, and extends the NNIP by further specifying the technical scope, development approach, and phase-in of the Tracking Network's functions and components.

State and local Tracking programs should develop a technical document that parallels the TNIP. Technical and scientific staff in the grantee's program should use the TNIP as a road map to guide their Tracking Network's development. The TNIP is updated periodically as we gain experience and as the Network components are installed and refined. The revised Technical Network Implementation Plan (version 2.0) is due for release in 2011.

- **Tracking Grantee Portal Standards and Recommendation (version 1.0)**
(www.cdc.gov/nceh/tracking/pdfs/GranteePortalRequirements.pdf)

This document outlines requirements developed in collaboration with states, local health departments, and national stakeholders currently contributing to the National Network. As the Tracking Network grows to include new partners, these practices and guidelines will provide a valuable tool for them. The CDC Recommendations for Nationally Consistent Data and Measures with the Environmental Public Health Tracking Network Document (version 2.0) summarize the Part I data recommendations from CDC's perspective. The original recommendations are modified to standardize the measures across content areas. The document also contains the standard template we asked each data content workgroup to use in reporting their recommendations.

C. Create a Startup Plan

1. *Technical Network Implementation Plan (TNIP):*

You'll have to create a TNIP. In that plan you'll have to show your state or locality has the capacity necessary for phasing in and maintaining a standardized Tracking Network. Your plan should address:

- Adoption/establishment of Tracking and other appropriate standards within your agency for Tracking Network startup.
- Program requirements, including but not limited to staffing needs, equipment, and software.
- Evaluation of jurisdiction or agency standards and policies governing information technology. Examples include front-end format/style guides and policies, your information technology environment, and your state or locality's security requirements.
- Requirements for your state or locality's network and an evaluation of technical options for network architecture and infrastructure.
- How you'll make NCDMs available on local networks and on the national network, and how you'll develop capacity to track data and other measures for state-specific priorities.
- Schedule for key network start-up milestones.

2. *Usability Testing*

Usability testing is important, especially during the development and ongoing evolution of local/state/national tracking networks. Usability evaluation methods measure the probable effectiveness of a computer system or tool by looking at how learnable, efficient, memorable, safe, and satisfying that system is for a given set of users.

During the development of the National Tracking Network Web site, the Tracking Program conducted extensive usability testing. The Program gained valuable information that became important in developing the National Public Portal. Testing results allowed CDC to better understand why and how the public user would access the Tracking Network and helped define the vocabulary needed to explain complex concepts to the user.

During CDC's usability testing, we identified several characteristics about public users. For example:

- Users liked to get into the data. They would enter the Network in one of three ways:
 - a. Look for how the environment might affect a particular health condition.
 - b. Inquire how a particular environmental condition might affect their health.
 - c. Ask about health and environmental issues in their area.
- Users expected to see tables of data in response to a query. They wanted charts and maps to help them understand the tables.
- Although user-testing might have identified words with specific meanings for public health professionals, general users found that some of those words were not meaningful. Not all

states and local programs can conduct the same level of usability testing conducted for the National Network. Lower cost, effective methods are available to assess tracking network usability. For example, the State of Washington conducted low-cost usability testing of its tracking portal that yielded quality results. One way Washington minimized expenses was to recruit tracking program staff to assist with observation and note-taking during the testing sessions. There is specialty software and equipment available, but can be expensive. The Washington Tracking Program learned from the usability tests what users did not understand and what they wanted to see on the portal. Washington used this feedback to improve the portal's architecture, navigation, labeling, and content.

D. Data Content

Among the Tracking Network's primary features is its ability to provide access to a variety of widely dispersed environmental and public health data and to support the two-way exchange of data between partners. Users have various levels of access, depending on a user's role and purpose.

1. Data Sharing Agreements and MOUs

Partners play an essential role in contributing data to a tracking network. Two critical partners are TAG members and Data Stewards. A TAG member can provide state/local tracking networks with phase-in advice that will make the network interoperable and compatible with the National Network standards and architecture.

In some cases, the state/local tracking program must develop a data sharing agreement with its partners. Such an agreement might be necessary to make specific data available on public portals and to submit data to the National Network. Data sharing agreements determine how the data are shared and presented. The agreement should specify the data steward's role and responsibilities as well as the role and responsibilities of the state/local tracking programs. For example, a data sharing agreement might specify whether the state/local tracking program has access to individual-level data and specify the types of analyses researchers can do with those data.

2. Sample Data Sharing Agreements

- CDC, National Center for Health Statistics (<http://www.cdc.gov/rdc/Data/B4/AccessAgreement.pdf>)
- National Association of Health Data Organizations (NAHDO) http://www.nahdo.org/data_resources/data_dissemination
- National Cancer Institute, Surveillance Epidemiology and End Results (SEER) http://seer.cancer.gov/cgi-bin/seer_track/view_void_pua.pl
- Utah Environmental Public Health Tracking Program <http://health.utah.gov/enviroepi/activities/EPHTP/NewEPHT/Research%20-%20Data%20Agreement.pdf>
- Acquisition/ModelDataUseAgreements/tabid/128/Default.aspx)

The following link provides a toolkit designed by NAHDO to assist states (both tracking and nontracking) to approach hospital data stewards for acquiring and using their hospital discharge data for the tracking networks.

It identifies some common barriers to accessing and sharing data that tracking partners have experienced or anticipate in their public health endeavors. Solutions to addressing these challenges are also included in this document: <http://www.nahdo.org/sites/nahdo.centralpointdev.com/files/Resources/Publications/nex%20steps%20in%20x%20border.pdf>

3. Memorandum of Understanding

A Memorandum of Understanding (MOU) differs from a data sharing agreement. An MOU establishes a formal partnership between two organizations or entities. For example, CDC's National Center for Environmental Health/Agency for Toxic Substances and Disease Registry has an MOU with NASA's Office of Earth Science. That MOU provides the agencies will work together to examine public health applications

of satellite observations. Another MOU is between HHS, acting through CDC, and U.S. EPA. Each organization agrees to develop and improve the cooperative relationship to support both CDC's Tracking Network and U.S. EPA's National Environmental Information Exchange Network (NEIEN).

These MOUs are available online at the following URLs:

- EPA 2007 - http://www.cdc.gov/nceh/tracking/partners/epa_mou_2007.htm
- NASA 2004 - http://www.cdc.gov/nceh/tracking/partners/nasa_mou.htm
- NASA 2009 - http://www.cdc.gov/nceh/tracking/partners/nasa_mou_2009.htm
- USEPA 2002 - http://www.cdc.gov/nceh/tracking/partners/epa_mou.htm

4. Data Standards

CDC requires that state/local networks create and maintain a core dataset. The networks are required to make this dataset available to CDC for inclusion on the National Tracking Network. State/local networks also need to add new core data and measures yearly, based on recommendations of the Content Workgroup. CDC solicits recommendations from its Tracking Content Workgroup on nationally consistent indicators, measures, and data for inclusion on the Nationwide Tracking Network. CDC reviews these recommendations and makes the final decision as to adoption of standards for the Nationwide Network. CDC also evaluates how well these standards work. CDC will refine or add to them as needed.

The Content Workgroup recommended data and content for the National Network. Recommendations included a document describing the indicators and measures, how-to-guides providing methods for extracting necessary data and generating the measures, and a data dictionary describing the data to be shared with CDC. Recommendations were reviewed for scientific rigor, utility for Tracking, and feasibility of each grantee generating the measures and where specified providing data to CDC for use on the National Portal. CDC has used these recommendations to create standards, referred to as Nationally Consistent Data and Measures, for tracking data and XML schema for submitting data to CDC.

5. Data on the Tracking Network

The Network includes three types of data: Health, Exposure, and Hazards:

- Health data on the Tracking Network focuses on noninfectious health conditions such as carbon monoxide or lead poisonings, asthma and other respiratory disease, cancers, and birth defects.
- Exposure (or biomonitoring) data include observations of an environmental agent or its metabolite in people. Examples include lead or cotinine in blood and arsenic in urine.
- Hazard data can include chemical agents such as arsenic, physical agents such as dust particles, and biologic toxins such as harmful algal blooms. These hazardous agents can appear in air, water, soil, food, or other environmental media. We obtain hazard data by direct measurement or by mathematical-model estimates.

6. Nationally Consistent Data and Measures (NCDM)

The National Tracking Network includes a core set of nationally consistent data and measures (NCDM) concerning health, exposures, and environmental hazards. NCDMs are the result of collaboration with partners and data stewards at the national, state, and local levels. CDC adopted them as Tracking standards. NCDMs are indicators and measures as well as the underlying data required to generate them. As noted previously, health data on the Tracking Network are available for noninfectious health conditions, such as asthma, cancers, and birth defects. Exposure or biomonitoring data can establish the presence of an environmental agent or its metabolite in persons. The Tracking Network currently has data on blood lead levels in children. Hazard data measure chemical agents, physical agents, or biologic toxins in air, water, soil, food, or other environmental media. The Tracking Network offers data on some chemical agents in air and water. To determine data needs for the Tracking Network, a group of experts, including data stewards, evaluated data to determine whether they were suitable for environmental public health tracking. Critical elements from these data contributed to the development of recommendations for nationally consistent Tracking Network data.

Appendix B contains additional information regarding the NCDMs.

7. Grantee-Specific Data

Data on the state and local networks fall into two general areas:

- Nationally consistent data and measures required by all grantees.
- Environmental and health data that are priorities to each grantee.

State data typically provide source material for these data and measures. CDC or other federal data partners might make some data available to the states at the national level. Multiple states that track the same noncore data and measures should collaborate with CDC to develop data standards and share lessons learned. Some examples of the types of noncore data grantees track include climate change in California and pests and pesticide use in New York City.

8. Descriptive Metadata

Descriptive Tracking Network metadata provide a standard way of describing data on the Network. Metadata also assist in search and discovery operations. All data in the Tracking Network have associated metadata. The CDC Tracking Program has adopted a tracking metadata standard profile based on the Federal Geographic Data Committee (FGDC) metadata standard. The Metadata subgroup also developed guidance and tools to help tracking grantees create and maintain metadata using the Tracking Network metadata profile. The Metadata subgroup developed a metadata creation tool (MCT) modeled on the Tracking metadata profile. This Web-based tool allows data stewards to create and submit metadata to the Tracking Network. Grantees can create metadata using the MCT or using their own metadata creation tools.

Grantees have these options to access/install the MCT:

- Install a local instance of the MCT at their sites.
- Request CDC employee clearance (background checks) for remote MCT access within CDC Intranet.

For more information on installing the MCT and creating metadata, read the Metadata Transport Guide found on the National Tracking Network Secure Portal.

E. Communications and Outreach

Developing a Communication Plan is an important part of any tracking program. Communications personnel can promote interest and awareness among key audiences regarding the national, States and NYC Tracking Programs. As part of this process, programs should develop a comprehensive communications plan. Such a plan would include strategies for delivering national, state, and local messages to key local audiences and stakeholders. Strategies would include at a minimum a phased communications plan and a risk communications plan.

1. Phased Communication Plan

You can use a phased approach for assembling a communications plan and putting it to work. This approach proved successful in the early stages of building the Nationwide Network at the national and local levels. That plan included three phases:

- Phase 1: The time from network development to network launch. This included development of: 1) specific messages for each audience, 2) strategies for communicating messages, 3) a timeline, and 4) evaluation methods.
- Phase 2: Begins with tracking network launch. The goal for this phase is to maintain communication with internal partners and begin outreach to current and potential external audiences. This phase may include media outreach, if appropriate.
- Phase 3: Involves maintenance of existing partnerships and new partner outreach.

2. Risk Communication Plan

For Tracking Program purposes, risk communication refers to when you identify a hazard, an exposure, a health problem, or a combination thereof. While communicating risk has no “one true way,” experts in the field generally accept these risk communication practice recommendations:

- Include risk communication in the risk management process. You communicate far more to people by what you do than by what you say.
- Recognize the gaps between scientific facts about a risk and the public perception of that risk. These gaps can threaten public health, thus becoming risks that need managing.
- Trust is fundamentally important for effective risk communication. Every action you take will affect your audience’s trust in you. It’s far easier to lose trust than to gain it.
- Establish ways to empower real community input—but if you don’t give the input real attention after you’ve received it, you lose trust.
- Recognize that to include risk communication in the risk management process is to change fundamentally the process itself. Many organizations push back against risk communication methods that involve sharing control, admitting mistakes, and being open and honest about negative information.
- Design each specific risk communication item as carefully as possible, given the time and budgetary constraints under which you’re working.

F. CDC Tracking Workgroups

The Tracking Program currently has four workgroups that focus on Content, Standards and Network Development, Program Marketing and Outreach, and Geospatial. Each of these groups has subgroups or teams that focus on specific subareas. CDC expects that all grantees have a representative on each of the workgroups.

1. Content Workgroup (CWG)

The overall mission of the CWG is to support the development and maintenance of content on the Tracking Network, especially as this relates to NCDs and methods. CDC initially formed the Content Work Group (CWG) in fall 2006 to explore possible indicators for inclusion on the National Environmental Public Health Tracking Network. CDC organized teams of state and local grantees, data stewards, and other data experts to identify available data and to develop detailed recommendations for creating measures and indicators to display on the Nationwide Tracking Network. Currently, the CWG provides an organizational framework to:

- Identify and explore potential content for the Nationwide Tracking Network.
- Consider and gain agreement on content for recommendation to the Nationwide Tracking Network.
- Support development of recommendations for standards and guidelines to help with Nationwide Tracking Network data collection, organization, presentation; measures; and indicators.
- Ensure data flows to maintain and improve the Nationwide Tracking Network’s current content.
- Review and modify current recommendations as necessary.
- Promote and support partnerships among grantees, the CDC Tracking Branch, and data stewards.



2. Program Marketing and Outreach Workgroup (PMO)

CDC recommends that all grantees should designate staff to actively participate in the Program Marketing and Outreach (PMO) Workgroup. PMO workgroup members help shape communication activities at the National level.

The PMO workgroup helps CDC and the grantees develop plans and activities for program outreach and marketing. The group also develops appropriate education and outreach materials that emphasize and support the goals, objectives, and timely promotion of the national environmental public health tracking effort.

Some examples of PMO activities include:

- Developing materials that communicate tracking messages for key audiences and users that assist grantees in their state/local communication and outreach activities.
- Creating “core messages”—simple, consistent ideas about tracking that ensure CDC and its partners stay on the same page.
- Sharing best practices such as risk communication and outreach guidelines and training with grantees that need communication assistance.
- Supporting other workgroup’s communication/data and context needs.

3. Standards and Network Development Workgroup (SND)

This workgroup ensures that CDC and its other partners collaborate on recommendations for Nationwide Tracking Network development as it relates to Network functions, requirements, and data and information technology specifications. The workgroup’s activities are listed:

- Develop data definitions.
- Examine the availability and applicability of current data standards and data exchange messages. Industry standards include but are not limited to the Health Level Seven (HL7) Reference Information Model and its vocabularies.
- Collaborate with national standards setting organizations to define new data specifications based on those standards.
- Define a logical data model and data exchange messages for the Nationwide Environmental Public Health Tracking Network.

4. Geospatial Workgroup

The overall mission of the Geospatial Workgroup is to serve as a forum to discuss draft recommendations for geospatial applications on Tracking Network portals. Geospatial also acts as a “community of practice” for portal communication using geospatial tools.

This workgroup also provides an organizational framework to:

- Identify multi-faceted geospatial issues for Tracking Network content areas.
- Identify and describe best practices and recommendations for displaying data geospatially. Those data should communicate content in the best ways and do it for a variety of audiences.
- Improve the ability for Tracking Network stakeholders to query, display, and use geospatial representations of Tracking content.
- Recommend training, approaches, and tools to further the ability of Tracking Network developers such as CDC and its grantees to reference data geographically and use geospatial tools.
- Provide opportunities to discuss and suggest potential geospatial approaches as the CWG teams develop NCDM recommendations.
- Provide suggestions to the PMO workgroup on geospatial options to improve usability of the national portal. Usability includes user interface presentation options, navigation, and manipulation of online maps.

Section III

Funded State and Local Tracking Programs

This section contains information regarding the CDC National Environmental Public Health Tracking Program's funded partners. This section includes descriptions of the state and local projects and contact information.

A. State/NYC Profiles

CDC funds 23 states and 1 local health department to build local tracking networks. Read grantees' profiles at: <http://ephtracking.cdc.gov/showCommunicationFeatures.action#profiles>.

California	Colorado	Connecticut
Florida	Iowa	Kansas
Louisiana	Maine	Maryland
Massachusetts	Minnesota	Missouri
New Hampshire	New Jersey	New York State
New York City	New Mexico	Oregon
Pennsylvania	South Carolina	Utah
Vermont	Washington	Wisconsin

B. Documenting Tracking's Effect: Success Stories

Tracking provides the data, information, tools, and workforce expertise needed to understand how the environment affects health. Tracking will help identify who might be vulnerable. Documenting success stories substantiates and confirms tracking's long-term benefits. Success stories can also engage potential participants, partners, and funders.

The content and format for success stories can vary. The type of story usually depends on the audience and purpose. All funded states provide information to CDC on public health actions resulting from Tracking as a demonstration of performance. This ensures that each program fulfills tracking's basic mission: *drive actions that improve community health*. Examples of these success stories are:

1. Maine



In Maine, carbon monoxide poisoning is an ongoing public health concern. After a 1998 ice storm that left half of Maine's population without power for days or weeks, a major outbreak of CO₂ poisonings occurred. Today, the Maine Tracking Program can track data on the number of carbon monoxide poisonings each year and the percent of Maine homes with a carbon monoxide alarm. These data have influenced state policy. Carbon monoxide poisoning is now a reportable condition in Maine, and a recent law requires carbon monoxide alarms in rental property, new homes, and existing homes.

on a transfer of ownership. To further help people prevent carbon monoxide poisoning, the Maine Tracking Program has also developed radio and television public service announcements for use during major weather events in the state.

2. Utah



The Utah Department of Health received a call from a citizen concerned about cases of cancer in the neighborhood. In the past, a similar call would have prompted a study that might have taken up to a year to complete, with most of that year spent waiting for data. In less than a day, the Utah Tracking Program let this resident know that the likelihood of cancer in that neighborhood was no greater than in the state as a whole. The Utah Tracking staff used an analytic tool developed with tracking funds to conduct two independent investigations—related in space and time—of the cancer rates centered on the caller’s neighborhood.

C. Case Studies

In fact, CDC and its tracking partners have developed several case studies. They use them as a way to share state-specific approaches and practices. They also illustrate ways to build capacity and infrastructure and to get tracking networks underway.

The case studies are also an educational tool. They show how to create and manage an environmental public health tracking program. Additionally, case studies can stimulate funded-unfunded program discussions on the various approaches to problems faced during tracking program planning and startup. Case studies can offer alternative solutions and probable outcomes. Appendix B contains state-specific case study examples from New Jersey, Maryland, and Florida.

D. Mentorships

In collaboration with the Association of State and Territorial Health Officials (ASTHO), the Tracking Network established fellowships as a means by which unfunded states can build tracking capacity. The fellowship solicits proposals from unfunded states and hosts visits between selected fellows and funded tracking states. Unfunded states learn about their mentor’s Tracking Program. They also get assistance with developing a project in their state that demonstrates the advantages of environmental public health tracking.

In 2009, ASTHO and the Tracking Network arranged three fellowships—in 2010, five fellowships. Mentors and mentees agreed that the fellowships provided a useful learning opportunity and were a worthwhile use of their time and resources. Find additional information about the mentorship process at:

<http://www.astho.org/t/article.aspx?artid=6272>

E. Information Sharing about Concepts and Methods

Appendix C contains lessons learned by CDC, Utah, New York State, and Massachusetts. These lessons provide insight to guide public health professionals, current grantees, unfunded locals, and others interested in learning about designing and getting started with specific strategies, policies, and measures to increase awareness about the Nationwide Tracking Network. These lessons identify possible strategies and solutions to challenges and obstacles encountered during planning, capacity building, and startup phases.

Section IV

Tools/Resources /Web links /Appendices

This section offers links to various tools and resources to enhance the information found in this guide.

Glossary: definitions of tracking-related terms
<http://www.cdc.gov/nceh/tracking/lib/glossary.htm>

Publications: a collection of documents on a variety of tracking-related topics
<http://www.cdc.gov/nceh/tracking/publications.htm>

Tracking-Related Programs: CDC programs related to tracking
<http://www.cdc.gov/nceh/tracking/related.htm>

Webinars: archived tracking-related Webinars from 2004–2008
<http://www.cdc.gov/nceh/tracking/webinars/home.htm>

Special Projects: early tracking program pilot projects
<http://www.cdc.gov/nceh/tracking/special.htm>

Monographs: mini-monographs in Environmental Health Perspectives Online
<http://www.cdc.gov/nceh/tracking/monographs.htm>

Communication Resources: the following items are on the National Tracking Network:
<http://ephtracking.cdc.gov/showCommunicationFeatures.action>

- **Matte article:** this formatted, ready-to-print article “Tracking Health in Your Community” is free to use in any publication.
- **Video:** this video is hosted on CDC’s YouTube channel. You can access it by searching YouTube for “Environmental Public Health Tracking” or on the Communication Features page of the National Tracking Network.
- http://www.youtube.com/watch?v=J42CLZH1NlE&feature=player_embedded a compressed version is also available only if desired—you can show it on a computer and it doesn’t require Internet access.
www.cdc.gov/ephtracking
- **Keeping Track, Promoting Health:** this short book explains the need for the National Network, the impetus behind the creation of the Network, and some early pilot-project success stories.
- **National Network fact sheet:** this fact sheet describes information available on the Network, shows how to use that information, and provides a snapshot of funded state and city projects.
- **Data sources sheet:** easy to read chart and maps with data from national, state, and local partners.
- **Podcasts:** Tracking-related podcasts on a variety of topics.
- **Tracking Widget:** This is also available for direct download at:
<http://www.cdc.gov/widgets/>

These resources are available upon request:

- Key Messages and Talking Points: intend for the National Environmental Public Health Tracking Network's multiple audiences. These messages represent the general tone and content we like to use to drive our communication objectives: encourage support, use, and participation in the Network.
- Local press release template: this is a public relations announcement issued to the news media and other targeted publications to let the public know about environmental public health tracking program developments. You can customize this template for your use.

CDC's Tracking Program Communications Team can assist you with developing a strategy for identifying and communicating with key internal and external partners, providing materials for the national tracking program, consulting on materials you develop, and other technical communications and marketing assistance. National Tracking Program materials and other resources appear below. You can obtain templates and examples for each phase of your communication plan.

Additional templates, guidelines, and examples for a communication plan and a risk communication plan are available from your CDC Communications liaison or on request.



Appendix A.

Web Links and Resources

A. Assessing and Enhancing Program Capacity

- **CDC's Tracking Program**
<http://www.cdc.gov/nceh/tracking/>
- **CDC's Tracking Network Support**
trackingsupport@cdc.gov
- **NEHA e-Learning Courses**
<http://nehacert.org/moodle/login/index.php>
- **Environmental Public Health Tracking 101**
<http://nehacert.org/moodle/>
- **EHT0903 - Assessing Environmental Health in Your Community**
<http://nehacert.org/moodle/course/view.php?id=168>
- **EHT0905 - Assessing the Risks to Public Health from Contamination in Potable Wells Using the Geographic Information System (GIS)**
<http://nehacert.org/moodle/course/view.php?id=170>
- **Lessons Learned from the Implementation of a GIS Program at the Bernalillo County Office of Environmental Health**
<http://nehacert.org/moodle/course/view.php?id=28>
- **GEH0605 - How GPS Works**
<http://nehacert.org/moodle/course/view.php?id=27>

B. Building a Network

- **Tracking Grantee Portal Standards and Recommendations**
<http://ephtracking.cdc.gov/docs/GranteePortalRequirements.pdf>
- **Environmental Public Health Tracking Network Vision**
<http://www.cdc.gov/nceh/tracking/pdfs/netvision.pdf>
- **Rational Unified Process**
http://www.ibm.com/developerworks/rational/library/content/03July/1000/1251/1251_bestpractices_TP026B.pdf
- **National Network Implementation Plan**
<http://www.cdc.gov/nceh/tracking/pdfs/nnip.pdf>
- **National Environmental Public Health Tracking Network User Guide**
http://ephtracking.cdc.gov/docs/Tracking_User_Guide_Jan_10.pdf
- **National Environmental Public Health Tracking Network Technical Implementation Plan**
http://www.cdc.gov/nceh/tracking/pdfs/TNIP_V1.pdf

C. Data Content

- **Model Data Use Agreements – National Association of Health Data Organizations (NAHDO)**
http://journals.lww.com/jphmp/Abstract/2008/11000/Lessons_Learned_in_Using_Hospital_Discharge_Data.5.aspx
- **Recommendations for Nationally Consistent Data and Measures within the National Environmental Public Health Tracking Network - CDC**
http://ephtracking.cdc.gov/docs/CDC_NCDM_Pt1_1.3.pdf
- **National Environmental Public Health Tracking Network Data Re-Release Plan**
<http://ephtracking.cdc.gov/docs/Tracking%20Re-Release%20Plan%20v2.5.pdf>
- **CDC's Memorandum of Understanding with EPA, 2007**
http://www.cdc.gov/nceh/tracking/partners/epa_mou_2007.htm
- **CDC's Memorandum of Understanding with EPA, 2002**
http://www.cdc.gov/nceh/tracking/partners/epa_mou.htm
- **CDC's Memorandum of Understanding with NASA, 2009**
http://www.cdc.gov/nceh/tracking/partners/nasa_mou.htm

D. Communications and Outreach

- **National Environmental Public Health Tracking Network Communication Features**
<http://ephtracking.cdc.gov/showCommunicationFeatures.action>
- **National Environmental Public Health Tracking Network Widget**
<http://www.cdc.gov/widgets/#envpublichealth>
- **National Environmental Public Health Tracking Program Communications Library**
<http://www.cdc.gov/nceh/tracking/lib/glossary.htm>
- **National Environmental Public Health Tracking Program Publications**
<http://www.cdc.gov/nceh/tracking/publications.htm>
- **National Environmental Public Health Tracking Program – Related Programs**
<http://www.cdc.gov/nceh/tracking/related.htm>
- **National Environmental Public Health Tracking Program – Webinars**
<http://www.cdc.gov/nceh/tracking/webinars/home.htm>
- **National Environmental Public Health Tracking Program – Special Projects**
<http://www.cdc.gov/nceh/tracking/special.htm>
- **National Environmental Public Health Tracking Program Mini-Monograph in Environmental Health Perspectives On-line**
<http://www.cdc.gov/nceh/tracking/monographs.htm>
- **Tracking Issue of the Journal of Public Health Management and Practice**
<http://journals.lww.com/jphmp/toc/2008/11000>



E. Tracking Partners

- **State and Local Tracking Programs**
<http://ephtracking.cdc.gov/showStateTracking.action>
- **American Public Health Association (APHA)**
<http://www.apha.org/programs/environment/>
- **Association of State and Territorial Health Officials (ASTHO) – Tracking Environmental Health Hazards**
<http://www.astho.org/Programs/Environmental-Health/Tracking-Environmental-Health-Hazards/>
- **Council of State and Territorial Epidemiologists (CSTE)**
<http://www.cste.org>
- **Environmental Protection Agency (EPA) - Delivering Public Health Relevant Air Quality Estimates to Improve Local Information for Public Health Tracking Programs (PHASE)**
<http://www.epa.gov/geoss/ami/phase.html>
- **North American Association of Central Cancer Registry (NAACCR)**
<http://www.naacr.org/>
- **National Association of County and City Health Officials (NACCHO) – Environmental Public Health Tracking**
<http://www.naccho.org/topics/environmental/EPHT/>
- **National Association of Health Data Organizations (NAHDO)**
<http://www.nahdo.org/>
- **National Association for Public Health Statistics and Information Systems (NAPHSIS)**
<http://www.naphsis.org/>
- **National Aeronautics and Space Agency (NASA)**
http://weather.msfc.nasa.gov/applied_science/helix.html
- **National Birth Defects Prevention Network (NBDPN)**
<http://www.nbdpn.org/>
- **National Cancer Institute, National Institutes of Health (NCI)**
<http://www.cancer.gov/>
- **National Council of State Legislatures (NCSL)**
<http://www.ncsl.org/>
- **National Environmental Health Association (NEHA)**
<http://www.neha.org>
- **National Oceanic and Atmospheric Administration (NOAA)**
<http://www.noaa.gov/index.html>
- **Trust for America's Health (TfAH)**
<http://healthyamericans.org/>
- **U.S. Geological Survey (USGS)**
<http://www.usgs.gov/>



Appendix B.

State Case Studies

A. New Jersey Department of Health and Senior Services

1. *Organization Background/Profile*

The New Jersey Department of Health and Senior Services (NJDHSS) has over 1,800 employees. The NJDHSS is headquartered in the Health and Agriculture building in the state's capital complex in Trenton, New Jersey.

The NJ Tracking Program is in the Consumer, Environmental and Occupational Health Service (CEOHS), Division of Epidemiology, Environmental and Occupational Health (DEEOH). Organizationally, DEEOH is in the Public Health Services Branch, which contains many public health surveillance and service functions, including CEOHS, Family Health Services, Cancer Epidemiology Service, and Communicable Disease Service. It is helpful that the branch contains many of NJ Tracking Program's key NJDHSS data steward partners: the New Jersey State Cancer Registry; the New Jersey Childhood Lead Poisoning Prevention Surveillance System; the Special Child Health and Intervention Services (SCHS) Registry, also known as the New Jersey Birth Defects Registry; and the Adult Blood Lead Epidemiology and Surveillance Project (ABLES). Other important NJ EPHT partners are located in the NJDHSS Office of Management and Administration: the New Jersey Center for Health Statistics (CHS) and the NJDHSS Office of Information Technology Services. The NJ EPHT project is a joint effort of the NJDHSS and the New Jersey Department of Environmental Protection (NJDEP). Key data stewards within NJDEP include Bureau of Air Quality, Bureau of Safe Drinking Water, and Office of Climate and Energy.



2. *Jurisdictional Health and Environmental Aspects*

New Jersey is a densely populated, diverse state with a legacy of environmental pollution from its history as an industrial center and transportation corridor. Residents have a heightened awareness of environmental and public health issues and a well-developed governmental infrastructure for environmental and public health protection.

a. New Jersey's Population

New Jersey is the most densely populated state in the United States, having the fifth smallest land area and the ninth largest population (an estimated 8.7 million people in 2008). New Jersey has a diverse population that, in the aggregate, closely mirrors that of the United States as a whole: 62% of the population is non-Hispanic white, 13% is non-Hispanic black, and 9% is Asian, Pacific Islander, American Native, or of two or more races. Approximately 16% of the population is Hispanic. The percentage of foreign-born persons is higher in New Jersey than in the United States as a whole, and New Jersey's population has a higher average income and education level than does the nation. New Jersey's population has been increasing, with a nearly 9% growth in population between 1990 and 2000. According to U.S. Census Bureau, 94% of New Jersey's population lives in an urban setting, while 6% of the population is considered rural.

New Jersey is a center of industry, academic and industrial research, transportation, and tourism. Major industries include trade, manufacturing, real estate, finance and insurance, health care and social services, professional and technical services, and government. The largest manufacturing sectors are chemicals, food products, fabricated metal products, and computer and electronic products. The transportation network includes major toll roads, freeways, and railways on which huge quantities of goods move. New Jersey has one major airport and multiple smaller ones, major oil and natural gas pipelines, and major shipping ports in the New York and Newark Bays and the Delaware River.

b. Environmental Hazards

Air Quality: All 21 of New Jersey's counties are considered in nonattainment of the National Ambient Air Quality Standard for the 8-hour ozone standard, and 13 counties are considered in nonattainment of the fine particulate matter (PM_{2.5}) standard. From 1988 through 2003, the number of days in which the ozone 8-hour standard was exceeded ranged from 19 to 68 days per year. In 2004, 211 days were rated "moderate" and 19 days were "unhealthy for sensitive subgroups" or "unhealthy" according to the Air Quality Index (AQI), with ozone and particulate matter responsible for the unhealthy AQIs. According to the 1996 USEPA National-scale Air Toxics Assessment (NATA), 19 chemicals were estimated to exceed health benchmarks statewide or in at least one county. For many of the NATA chemicals, vehicles are considered the major source of the toxics in New Jersey air.

Drinking Water Quality: One of 622 public water supply systems serves approximately 90% of New Jersey's population. The remainder receive water from private wells. About two-thirds of the population served by public water supply systems receives water from surface sources (rivers, reservoirs); disinfection of surface water results in the formation of byproduct chemicals such as trihalomethanes and haloacetic acids. Public and private water supplies using groundwater sources are susceptible to contamination from solvents and other chemicals. During the 1980s, as much as 15% of the population served by public water supplies in New Jersey was exposed to halogenated solvents such as trichloroethylene. Other drinking water quality issues include radium, arsenic, lead, mercury, and nitrate.

c. Hazardous Sites

New Jersey has the largest number of National Priorities List (NPL) sites in the nation. As of 2009, there are 141 NPL sites and more than 400 non-NPL sites in the CERCLIS Database. In addition, the NJDEP is currently managing the investigation and remediation of more than 16,500 other sites on its Known Contaminated Sites list, many of which may also pose threats to the environment and public health.

Many of New Jersey's NPL and other contaminated sites are located in or near densely populated areas. Frequent exposure pathways related to NPL or other sites include ingestion of contaminants in community and private drinking water supplies, inhalation of air pollutants emitted from sites, and ingestion of or skin contact with chemicals in dusts and soils. Common substances with documented human exposure from waste sites include halogenated organic solvents, fuel-related chemicals, other synthetic organic chemicals, and heavy metals.

d. Environmental Public Health Issues

New Jersey has established public health objectives for the year 2010 to guide programs improving the health and quality of life of its citizens. The objectives include specific targets for improvements and indicators to measure progress toward these targets. A significant focus of the objectives is to reduce or eliminate racial and ethnic health disparities. Major health categories with objectives include environmental health, healthy mothers and children, heart disease and stroke, cancer and asthma. Environmental health objectives include targets for ambient air quality, including ozone and particulate matter, and for drinking water quality. Objectives for healthy mothers and children include targets for low birth weight and for childhood lead exposure. Objectives for asthma, cancer, and heart disease set targets for mortality and hospitalization rates.

3. Current IT Business Situation

New Jersey's Information Technology (IT) is a hybrid model, deploying people and resources both at a statewide level and within individual agencies. The state Office of Information Technology (OIT) provides Internet access, interagency communications, GIS services and a shared three-tier Web application infrastructure in addition to various coordination and governance functions. NJDHSS's internal IT unit helps collaboration between agency staff and state OIT, develops and manages applications and Web content, operates an intra-agency network, and administers the servers that run many of NJDHSS's applications, both internal and public-facing.

NJDHSS develops and runs Java/WebLogic and .NET applications and Oracle and SQL Server databases. NJDHSS uses Wintel platforms—VMware virtualization and a defense-in-depth security model. Communication with local health departments and secure external file transfer use a separate Internet connection outside of New Jersey's Garden State Network. Major internally developed Web applications include infectious disease tracking, immunization management and vaccine tracking, and a GIS-enabled real time situational awareness system for public health emergency preparedness and response.

4. Selected Solution of Choice (software and services)

In December 2008, New Jersey launched its public portal, <http://www.nj.gov/health/epht/>, and an accompanying indicator display and data query system known as NJ SHAD, <http://www.nj.gov/health/shad/>. The NJ Tracking Program partnered with the Department's Center for Health Statistics (CHS) and Office of Information Technology Services (OITS) to develop and phase in the portal. The NJ SHAD (State Health Assessment Data) system, by design, is utilized for both tracking and nontracking content and data.

NJ SHAD is New Jersey's adapted version of the Utah Department of Health's Indicator-Based Information System for Public Health (IBIS-PH), <http://www.ibisph.org/trac/>. With help from Utah and others in the IBIS-PH Community of Practice, New Jersey's team adopted, adapted, and continues to enhance the software, most of which is community-supported "open source." The current configuration uses the state's shared Web infrastructure (Sun Web server and Java app server, on Solaris) for the first and second tiers, the third-tier SAS-based query back-end runs on a NJDHSS-administered Wintel server. By July 29, 2009, NJ SHAD published 36 tracking health indicators and 76 additional nontracking indicators.

Queryable data sets are available for mortality and birth data for the years 2000 to 2005. Future queryable datasets will include infant deaths, fetal deaths, hospitalizations, behavioral risk factor data, emergency department encounters, fatal and nonfatal injuries, and communicable diseases.

5. Results and Benefits

The NJDHSS decision to adopt and adapt the Utah IBIS-PH software for the tracking program and its partners has worked well. The NJ SHAD system combines the convenience of one-stop-shopping for users, tested and proven software, organizational sustainability through wide utility, and a low relative cost through the use of existing open source software, existing staff, and an active community of practice. The IBIS community of practice benefits NJDHSS through ongoing development and sharing of open-source software, highly specialized technical expertise, and by leveraging technical skills across states and organizational units.

6. Challenges of Implementation

Scientific, technical, and ethical challenges remain in starting state and national tracking networks. Among these are whether environmental hazard data collection systems result in sufficiently fine geographic and temporal resolution to meet the purposes of public health tracking, and whether the data are meaningful in terms of human exposure assessment. Another important challenge is that communities want environmental hazard and public health surveillance data for small geographic areas and short time periods. Such data may be statistically unstable, and its release may conflict with requirements to protect privacy and confidentiality. Yet another technical and organizational challenge is environmental and health data systems that have been developed at different times, for different purposes, and under multiple distinct authorities.

From an IT and operational standpoint, challenges included understanding the many moving parts of the IBIS-PH system well enough to implement and customize it for New Jersey's needs, especially with limited documentation and a deployment platform unlike Utah's. Negotiating hosting arrangements and updates with the statewide IT group, and procuring the SAS server license and qualified developer support, also posed challenges.

7. Lessons Learned from the Demonstration Projects

Through demonstration projects, New Jersey has learned important lessons applicable to the development of national and state tracking programs. The most important lesson is that meaningful collaboration with environmental and health data stewards is an essential component of tracking. Data stewards of existing environmental data collection systems and public health surveillance systems understand their content areas and the strengths and limitations of their data, and face specific obligations and mandates outside of tracking. State and national tracking programs must provide value-added services to data stewards for data sharing to be a success. These services might include statistical and epidemiologic analysis, data visualization, geocoding, or assistance with community inquiries. The tracking program must also respect and comply with data confidentiality requirements of each data steward. Establishing solid collaborative relationships with data stewards requires tracking program staff to involve data stewards early in the planning process. This takes advantage of their knowledge and insight, ensures that tracking products are of mutual benefit, and further assures those products are useful to policymakers and the public.

Among the important technical lessons from the NJ Tracking Program demonstration projects is that careful attention must be paid to the geographic pattern of geocoding completeness. If geocoding (for example, in rural areas) is correlated with an exposure of interest, then spurious results may occur due to differential misclassification or selection bias. Another lesson is the importance of developing environmental metrics that are meaningful surrogates of human exposure. Particular data sets (air pollution and drinking water) appear to be the most useful; sufficient geographic and temporal data density may be available, and all measures are close to points of human contact with contaminated media. Note, however, that mapping interpolation or smoothing techniques may create an illusion of data density. Always keep in mind the quality of underlying data.

Outline of New Jersey Tracking Partnerships

NJ Tracking Partners	Partnership Type: 1. Written agreement 2. Regular meeting schedule 3. Collaborative projects 4. Exchange of funding 5. Data exchange 6. Personnel sharing	Date Partnership established	Specific Partnership Outcomes
NJDEP	1, 2, 3, 4, 5, & 6	Since 2003	Conducted joint pilot projects, jointly developed content for NJ Tracking Program and national tracking portals. Web pages and indicators published and more currently in development
NJDHSS Center for Health Statistics (CHS)	2, 3, 4, 5 & 6	Since 2006	Headed adoption, adaptation, and deployment of Utah IBIS in NJ. Additionally, CHS is the data steward for birth outcomes/vital records, hospitalization, behavioral risk factor, and injury data. Created numerous birth outcomes indicators & non-tracking indicators. Deployed query option within NJSHAD for births and death data.
NJDHSS Office of Technology Services (OITS)	2, 3, 4, 6	Since 2006	Jointly worked out technical details of adoption and deployment of Utah IBIS with CHS for NJDHSS. Managed activities with NJ OIT, advised/managed IT issues
NJDHSS Data Stewards			
NJ State Cancer Registry/ Cancer Epi Services	2, 3, 5, 6	Since 2003	Conducted joint pilot projects. Web pages and indicators currently in development.
Family Health Services (asthma, birth defects, childhood lead)	2, 3, 5, 6	Since 2003	Conducted joint pilot projects. Web pages and indicators in development for birth defects and completed for asthma hospitalization, and childhood lead.
Occupational Health Services (adult lead)	5	Since 2008	Web pages and indicators completed.

B. Maryland Department of Health and Mental Hygiene Case Study

1. Organization Background/Profile

The Maryland Environmental Public Health Tracking program is located in the Maryland Department of Health and Mental Hygiene (MDDHMH). It was developed in cooperation with the Maryland Department of the Environment (MDE). MDDHMH has more than 9,000 employees responsible for public health services, health care finance (Medicaid), behavioral health and chronic care facilities, health care quality and licensure, and other public health functions. MDDHMH, headquartered in Baltimore, coordinates the activities of 24 local health departments across the state. MDE, with more than 900 employees, delegates many of its authorities to and works closely with the 24 local health departments, especially the environmental health sections of the health departments.



Administratively, the MD Tracking Program is in the newly formed Infectious Disease and Environmental Health Administration (IDEHA), Office of Environmental Health and Food Protection, in the Center for Environmental Health Coordination (CEHC). IDEHA is in the Deputy Secretariat for Public Health Services, which also includes the Family Health Administration, Laboratories Administration, Chief Medical Examiner, Anatomy Board, and the Office of Public Health Preparedness. Together, these organizations perform all of the core public health functions associated with disease prevention and surveillance for chronic and acute diseases, health promotion activities, and outbreak response.

The MD Tracking Program has established formal and informal partnerships with a number of programs in MD DHMH: the Cancer Control and Prevention program; the Cancer Registry; the Birth Defects Reporting and Information System; the Maryland Health Services Cost Review Commission and Maryland Health Care Commission. At MDE, the Tracking Program works closely with the Water Administration and the Air and Radiation Management Administration.

2. Jurisdictional Health and Environmental Aspects

Maryland is a geographically diverse state with unique geographical features dominated by the Chesapeake Bay, the nation's largest tidal estuary. The state has a history of agriculture that thrives even today, particularly on the Eastern Shore, still home to extensive poultry and farming operations. At the same time, agriculture, population pressures, and development threaten the natural ecosystems of the Chesapeake Bay and its tributaries. The state has been engaged along with Virginia, Delaware, Pennsylvania, and the District of Columbia in efforts to reclaim those areas of the Chesapeake that have not thus far yielded significant improvements.

a. Maryland's Population and Geography

Maryland has a population of 5.6 million, with an age and sex distribution similar to the United States. The racial composition of the population is 63.4% white, 29.4% black, 0.4% American Indian and Alaska Native, 5.1% Asian, and 0.1% Native Hawaiian and Other Pacific Islander. It has a Hispanic or Latino population of 6.7%. The median household income is \$67,989, with the highest per capita income in the country. Its most distinct geographic feature is America's largest estuary, the Chesapeake Bay. The state has 9,844 square miles of land mass, 623 square miles of water, and 623 square miles of inland water.

b. Environmental Hazards

- **Air Quality:** The Baltimore-Washington corridor, which includes most of the state's population, has suffered impaired air quality as a result of both industry and transportation. Although many of the historically polluting industrial sources have declined over time, the corridor still has impaired air quality because of the dense population and associated transportation. While carbon monoxide and hazardous organic pollutants in the air have undergone substantial reductions, a need remains to reduce ground-level ozone and fine particulate matter.

- **Drinking Water Quality:** Most of Maryland's population is served by public water supplies, but private wells still serve a portion of people within the state. Data on public drinking water shows that Maryland's public water is generally safe and high quality.
- **Hazardous Sites:** Maryland does have several sites on the National Priority List, and several very large industrial sites that require extensive remediation.
- **Environmental Public Health Issues:** Maryland's environmental public health problems are similar to its neighbors. The problems include historical pollution sources, including large industry and military operations. Ongoing environmental health challenges include lead in homes, toxic substances in consumer products, hazardous air pollutants, indoor environmental hazards, and agricultural chemical use.

3. *Existing IT Business Situation*

MD DHMH has an extremely decentralized IT organization in which each agency unit develops and supports its own applications. The only centralized services are for network applications such as email; otherwise, the agency's units have little in the way of direction or support. As a result, considerable flexibility and considerable inconsistency accompany the ways different agency units develop IT applications. The agency relies primarily on SQL server applications, but does have some Oracle installations. Before the MD Tracking Program, the agency had essentially very little GIS capability. By contrast, the Maryland Department of the Environment has been using GIS for several years.

During the first three years of the MD Tracking Program, the absence of any prior history of GIS applications and centralized IT support made it both necessary and possible to develop an extensive IT infrastructure within the tracking program. An early decision was to use Oracle and ESRI products. This commitment helped to determine subsequent decisions about the structure of the Maryland Tracking Network.

a. **Selected Solution of Choice (software and services)**

The MD Tracking Network's public portal, <http://dhmh.md.gov/eh/tracking>, and accompanying indicator display and data query system known as the Maryland Tracking Network (MTN) launched in February 2009. The tracking program partnered with the University of Maryland, College Park School of Public Health (UMCP). After several false starts, MD DHMH selected UMCP to design a customized application that would make the best use of the installed Oracle and ESRI hardware and software.

Maryland made several decisions early on regarding both the public and secure portal, which helped to drive other design decisions. One decision was to get the user to data as early as possible, without having to go through a lot of text. Another decision was to customize a solution, rather than adapting a commercial off-the-shelf product. Yet another decision was to avoid commercial "business intelligence" software, because of the need to continuously adapt the programming. A final decision was that the system design should allow sufficient flexibility to create user-defined geographic units of analysis.

The result was that Maryland adopted the following design for its network: an Oracle data base back end with a .NET custom query page and a mapping function based on ArcGIS Server 9.2.

b **Results and Benefits**

The MDDHMH decision to create a custom solution for the state's tracking program has had some pluses and some minuses. On the plus side, the public portal and secure portal reflect largely the EPHT staff's original design. In addition, they have been able to adapt the network to new requirements without having to "undo" a lot of previous system design. On the minus side, they have had to create systems that already existed in some form, and this has required additional programming on the part of the developers. The decision not to use commercial business intelligence systems means that they had more financial resources to customize their application. But business intelligence systems offer some attractive advantages for presentation and repetitive applications.

c. Phase-in Challenges

Maryland's Tracking Program has had the same challenges as other networks. The Maryland Tracking Network's phase-in saw challenges in developing new technology, creating data sharing partnerships with other programs, and in explaining the value of tracking to potential stakeholders.

A substantial challenge was the creation of data sharing agreements. Part of that challenge was the lack of a system to demonstrate the concepts, requiring protracted discussions with potential data partners without a physical demonstration. Another part of the challenge was explaining the potential benefits of tracking to the partners, particularly because data were provided not only to another state agency (which they routinely do), but also to the CDC Tracking Program and a nebulous entity known as the National Tracking Network. This continues to be a challenge for surveillance programs with statutory requirements to keep their data confidential or whose statutory mandate extends only to in-state entities.

Another challenge in this regard was the desire of stakeholders for community-level and local data, which had to be balanced against state laws and policies on privacy. Maryland has a history of strong confidentiality protection. This affected both the structure and wording of data sharing agreements and the structure of the network itself. The MD tracking program was very eager to make data available at multiple levels of resolution, but it was continuously challenged to balance that desire against the legal requirements for privacy protection, especially in looking at local environmental health problems.

From an IT perspective, the challenges were plentiful. Early in development Maryland learned of another MD DHMH program to make health data available online using SAS Business Intelligence. Had the programs collaborated earlier, it might have been possible to merge the two initiatives and achieve significant synergy. But neither program was able to bridge the divide. As a result, the department probably lost a valuable opportunity to create a more integrated application for health and environmental data.

4. Benefits

Even with these challenges, the MD tracking program was able to create a comprehensive network that meets the state's needs and is fully consistent with the requirements of the National Tracking Network. The strengths of the Maryland Tracking Network are:

- Rapid access to data queries in a simple interface
- An array of GIS resources that will enable users to analyze and visualize data in a variety of scales and settings, especially users of the secure portal
- Strong interactions with data partners in environmental public health across agencies and the state

At the end of the project period, the sustainability of the MD Tracking Program will depend on how well the project meets Maryland's needs for comprehensive environmental public health information, as well as the nation's needs for an integrated national environmental public health Tracking Network.



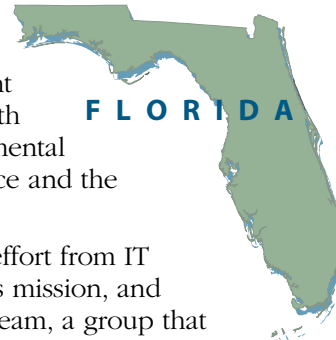
Outline of Maryland Tracking Partnerships

MD Tracking Partners	Partnership Type:	Date Partnership established	Specific Partnership Outcomes
	1. Written agreement 2. Regular meeting schedule 3. Collaborative projects 4. Exchange of funding 5. Data exchange 6. Personnel sharing		
MD Department of the Environment	1, 2, 3, 4, 5	Since 2003	Jointly developed content for MD Tracking Program and national tracking portals. MDE co-leads tracking project.
MD DHMH Laboratories Administration	2, 3, 4, 5	Since 2003	Formal partnership on tracking project. Laboratories funded for equipment, personnel related to biological monitoring methods development.
MD Cancer Registry	1, 3, 4, 5, 6	Since 2003	Developed cancer cluster protocol, brochure and worked on several investigations. Data sharing agreement negotiated.
MD Lead Registry	1, 3, 4, 5	Since 2006	New data sharing agreement in place. Also helping to fund, host transition to new data system, HHL PSS (Healthy Homes/Lead Poisoning Surveillance System)
MD Vital Statistics Administration	1, 5	Since 2003	Formal DSA for vital statistics data. VSA advises on data usage, suppression rules, and technical aspects of vital statistics data interpretation.
MD Health Care Commission/Hospital Services Cost Review Commission	2, 3, 5, 6	Since 2008	Formal DSA for use of hospitalization, emergency department data. Serve as hospitalization data repository for other DHMH programs.
MD Birth Defects Program	1, 3, 4, 5	Since 2006	Funded upgrades to Birth Defects Reporting and Information System. Did outreach using tracking display for birth defects reporting by hospitals.
University of Maryland School of Public Health	1, 2, 3, 4	Since 2007	Developer of tracking interface (public and secure portals) and assistance with GIS technology

C. Florida Department of Health Case Study

1. Organization Background/Profile

The Florida Department of Health has employees who are located at headquarters offices in Tallahassee and in all 67 county health departments. Unlike many other jurisdictions across the country, county health department employees are also state employees. The Florida Environmental Public Health Tracking Program is housed in the central office of the Division of Environmental Health, and employs five full-time staff. At the HQ office complex, their office and the Division of Information Technology (IT) are housed in adjacent buildings.



But Environmental Health has not been able to obtain significant time and effort from IT in most of its technology projects. IT is understaffed relative to the size of its mission, and need more. One area in which IT has been helpful is the Data Integration Team, a group that has helped the tracking program exchange data with other agencies. IT has also assisted with the PHIN Messaging System (PHIN MS) used by the tracking program. However, IT has not been of much help in other areas, such as database management, Web application development, metadata creation, and Enterprise GIS (as previously mentioned).

Yet even in this climate, the tracking program has had a great deal of success in partnering with another DOH Division (the Office of Health Statistics and Community Health Assessment). The partnership with key personnel in this office has led to technology that lives by IT rules but does not rely on IT staff to implement those rules. The Florida Tracking Program feels that this has provided tangible results that could not have been obtained in a reasonable amount of time by partnering with the IT alone.

2. Jurisdictional Health and Environmental Aspects

Florida has more than 18 million residents (with twice as many annual tourists), and a subtropical environment that offers year-round opportunities for exposure to a surprising range of environmental hazards. Agriculture, mining, aerospace, power plants, and other industries may be exposing workers and surrounding populations to chemicals potentially hazardous to human health. In addition, Florida has a great many uninsured residents and a large population of retirees, both of which strain the health care system with chronic disease outcomes.

Florida has a large number of state agencies. There are so many, in fact, that responsibilities often fragment even within a single area (e.g., three separate agencies handle food service inspections, depending on the type of facility). This complex government structure has resulted in many data silos that can be difficult to break down. But Florida does have a strong tradition of making government data publicly accessible whenever possible (so called “Government in the Sunshine”). Environmental data are considered public access and are routinely released on the Web. Even GIS data that have taken many years to collect are usually shared at greatly reduced or at no cost. Government agencies abide by a rule of sharing data freely within the constraints of HIPAA and other state statutes. In recent years, these data sharing efforts have resulted in interagency agreements that allow for electronic, secure access (often SFTP). For example, the Florida Tracking Program has been able to transfer securely data from the Agency for Health Care Administration (ACHA), which manages hospitalization and ER data in Florida. Strong firewalls (both policy and physical barriers) remain, however, between state agencies. This sometimes hinders efforts to automate data exchange. This is why the tracking program is so important to Florida. It represents one of the best and most successful efforts to unite health and environmental data in a way that is sustainable, fully documented, and standardized.

3. Current IT Business Situation

The Florida DOH Division of IT is understaffed relative to the size of its mission. IT's priorities are driven by mandatory disease reporting and the management of a large number of servers in what is called the Shared Resource Center. As a result, the Division of EH typically only receives IT attention "as time allows." But EH is still expected to follow all of IT's policies and procedures, such as:

- Governance – a tiered system of review committees that must approve all IT related projects (broadly defined as anything that uses IT resources). Until recently, many projects had to go all the way up to the Tier 3 level, which includes review by the State Surgeon General and the agency's deputy secretaries.
- Change Management – a committee that meets once a week to review all changes to production systems (database and Web applications).
- Project Management – a well-intended effort to monitor IT projects using certified project managers. Yet not enough of the PMPs are available, which means that they can't get to know their projects very well.

The overall effect of these IT policies has been to stifle innovation and creativity in the development of IT solutions, with only the largest and best-funded projects having the resources to navigate successfully the processes listed above.

4. Selected Solution of Choice (software and services)

Given the hurdles mentioned previously, the tracking program chose to partner with another DOH Division that has a proven track record of delivering Web-based systems. This Division (Health Statistics and Community Health Assessment – known as HPE) created the successful Web portal at www.floridacharts.com in the early 2000s. The HPE Division Director has a history of working around IT challenges while still following IT's policies and procedures. Because of longstanding, trusted relationships with IT, the HPE system administrators can manage their own database and Web servers for www.floridcharts.com. HPE's simple management strategy allows them to roll out Web application updates in a fraction of the time that it takes IT. Furthermore, HPE has a proven track record of using Web-based mapping with ESRI products. It is the first division to have an ArcIMS solution on the Internet for public access, and it has been very successful with ArcGIS Server.

For all of these reasons, the Florida Tracking Program chose to partner with HPE instead of trying to fund a position within the IT. In fact, because of their separation of duties (no single person is allowed to be on their Database Team and Server Team, for example), it was determined that a single position could not make enough of a difference within IT. In return, the HPE system administrator, who is also a database administrator, helps to manage Florida's Web portal. He also takes care of Florida's security needs, such as role-based authentication, through a combination of Windows-based and database security procedures. This has been critically important for Florida's state tracking network secure portal, as it needed a mechanism to share restricted access data with valid research partners. As a result this partnership, the tracking Web portal at www.floridatracking.com is now operational.

5. Results and Benefits

With the help of another DOH Division, the Florida Tracking Program created and deployed a Web portal on the Internet (using .Net technology) in fewer than six months. With the help of our partner HPE, they also secured dedicated URLs for the Florida Web portal (<http://www.floridatracking.com> and <https://www.fltracking.com/FLEPHT/login.aspx>). The dedicated URLs were important to brand and market the Web portal as a new and significant Web site for the Florida public and environmental health researchers. Now that Florida has phased in its state tracking Web portal, the state is looking forward to deploying data updates (additional years of health/environmental data), and loading some additional indicators: cancer and vital statistics data available in 2010, and climate change and built environment indicators. The primary benefits of the HPE partnership have been speed and flexibility. Because Florida had money and bureaucratic authority to create one new position for Web portal creation, the program needed to partner with a division that had already received the needed IT approvals for their Web portal. By offering funding for a Web application programmer, the state was able to benefit both EH and HPE to deploy and update the respective Web portals.

Outline of Florida Tracking Partnerships

FL Tracking Partners	Partnership Type:	Date Partnership established	Specific Partnership Outcomes
	1. Written agreement 2. Regular meeting schedule 3. Collaborative projects 4. Exchange of funding 5. Data exchange 6. Personnel sharing		
FL DEP	3, 5	Since 2004	FLDEP air person (Tammy Eagan) serves on tracking Air Team. She also advises on messaging and data issues for the state portal. They also receive PWS Water data from them, but the contact for that does not serve on Water team (they have DOH person do that)
FL Office of Health Statistics and Community Health Assessment (HPE)	1, 2, 3, 4, 5 & 6	Since 2004	Main partner for technology and IT issues (as explained in text). Also a provider of Vital Stats data.
FL Division of IT (IT)	3, 5	Since 2006	Mainly a partner on server maintenance and the setup of PHIN MS.
FDOH Data Stewards			
FL Cancer Data System (Univ. of Miami under contract to FDOH)	1, 3, 4, 5	Since 2004	FCDS works under contract with the tracking program and provides cancer indicator development and messaging guidance.
FL CLPPP Program (housed in Division of EH) and Healthy Homes Program	2, 3, 5	Since 2004	Provider of Lead data. They also serve on the tracking Lead Team.
FL Birth Defects Registry	1, 2, 3, 4, 5	Since 2004	Maintenance of FBDR provided by University of South Florida. They work under contract to the tracking program to provide indicator data and messaging guidance.
FL Agency for Health Care Administration (AHCA)	1, 5	Since 2004	Sister state agency that is a provider of hospitalization data.

Appendix C.

Information Sharing About Concepts and Methods

A. Utah

Stay focused:

- To stay focused on your vision is important. Planning for the abstract is difficult. For example, costs are difficult to estimate.
- Accept that some things are out of your control.
- Organizational uncertainties make planning and execution difficult.
- You have no way to test an application in development using outside stakeholders.



Be flexible:

- Adoption and promotion of standards are critical to success, but so is flexibility.
- Everyone will be required to step outside the comfort zone of his or her discipline and routine.
- Reuse of existing tools and services is good, but recognize that some customization may be necessary.
- “Network” with partners. Staying connected with partners is essential. Collaborative development takes a long time but yields solid stakeholder buy-in.

Know your users:

- Understand the needs and requirements of different users, particularly between public and secure portals users.
- “User requirements must have higher priority than solutions that are technologically exciting.”⁵

Spread the word! Engage in marketing:

- Carefully inventory all resources you can leverage to start the network. Identify decision makers for those resources and start coordinating early with them on how to leverage those resources for the Tracking Network. Utah identified two important resources to leverage for tracking: the NEDSS project and the IBIS-PH project. The NEDSS project provided a hardware and software architectural framework, which it used to start the EPHTN. IBIS-PH provides a readymade, well-known, and growing public Web-based portal they could leverage. By bringing the NEDSS community and the IBIS-PH community into the tracking planning and working groups, they were able to move this project along.

5 Lombardo JA and Buckeridge DL. Disease surveillance: A public health informatics approach, 2007) [John Wiley & Sons, Inc. New Jersey, 2007]

Leverage the state tracking network for other state interests:

- When appropriate opportunities come up volunteer tracking as a mechanism to support other public health needs or interests. Epidemiologists in Utah wanted to start an occupational health and safety surveillance system. The tracking staff quickly volunteered the Tracking Network as architecture on which to design and build the OSH surveillance system. The tracking network already had quite a bit of the data the OSH system would need and had operational and technical experience that has been useful for building the OSH system. The tracking network benefited in having an additional group promoting the Tracking Network at executive levels of involved state agencies. In addition, they leveraged the tracking network to enhance the departments HSEES and HHA projects. The tracking network is now a frequently sought resource for other projects. In the last few months, people worked on influenza surveillance as well as obesity, and with other groups in UDOH interested in starting or enhancing their surveillance efforts.

Work the network as soon as possible:

- Don't wait for it to be perfectly functional. As soon as functionality becomes available, start using it. Utah's cancer data was the first dataset to appear in a secure query module on IBIS-PH and in the RIF. As soon as these were working correctly, they made the module and application available to their regional and local health department epidemiologists. When the University of Utah Informatics wanted a test bed for a GRID project, the Tracking Network was made available to them, even though they were still finishing up the phase-in of important components related to access of the data. The Utah network has also worked with Utah State University, UDEQ, and other agencies to assist them in taking advantage of tracking resources before the network was completed. This resulted in executive level demonstration of the network functionality and early value returned.

Use a quick phased approach.

- Get something working even if it's not the final product. This will help stimulate ideas and recommendations. It also gets an early value return and helps plan for upgrades. Since Utah submitted its start-up plan to CDC, the technology has grown.

Give credit.

- Partners need credit to stay involved. Utah acknowledges their partners in every presentation and analysis. Their efforts are highlighted at conferences and in reports.

Build a tracking team of can-do people.

- Utah has a can do attitude; they approach each opportunity with enthusiasm and work within in the framework of the rules, policies, procedures, etc.

B. New York State

Obtain Buy-In from All interested Partners; (IT Dept. onboard/Data Stewards). New York State used a team approach for the development of its Environmental Public Health Tracking Network data development, messaging and user interface that involved data stewards, program area experts, Web developers and data programmers. The team developed/used the following tools that streamline the development process and created efficiency and buy-in from all interested parties:



- Environmental health messaging templates. Each content area followed a messaging template, which ultimately became the template for all static HTML messaging files.
- Standardized data packages. These packages contained all data and data displays using a standardized format for all content areas. These were extremely useful for not only streamlining the upload of data,



but for illustrating expectations for charts, maps and tables. Standardized naming conventions also were used for version control as files were transferred between data stewards to data programmers.

- Previews of the portal during development. Team members would come together to preview major developments and provide review and input at intervals during the development process. This helped keep everyone on the same page about specifications and look and feel and addressed major issues prior to deadlines.
- Good workflow processes. Team developed and used member's databases as change request logs and list serves to consolidate communications in one place and specifications in one place.

C. Massachusetts

Obtain buy-in from all interested parties:

- Even though the Bureau of Environmental Health is data steward to several databases (e.g. lead, pediatric asthma); they needed to obtain tracking data from two other bureaus and another state agency. Obtaining signed data use agreements involved lengthy discussion over case level and data information that would be made publically available, particularly in electronic format. The lesson learned from this experience is to include these external agencies early in the planning process and to meet with data stewards regularly. Regular "tracking data stewards meeting" helped resolve misunderstandings, problems, and conflicts as they arose. Regular meetings helped to insure timely renewal of all Data Use Agreements (DUA).



Remember to tap all potential participants:

- Massachusetts has successfully partnered with local boards of health and the Massachusetts School Nurses Organization and educational officials. Including these partners at the tracking planning table is imperative.

Continuous monitoring:

- The portal is operational 24/7 and requires dedicated staff to monitor, provide oversight, alerts and maintenance should the system fail. For Web and telephone inquiries tracking staff monitor a toll-free phone line and a dedicated email box during normal business hours.

Other: Massachusetts adds the following additional lessons learned:

- As you begin to develop a tracking system, think "big picture" and know that building a tracking portal will require room for continuous growth and expansion. Questions to consider include:
 - What are your needs?
 - What are your state's IT rules and regulations and what restrictions exist?
 - Are there issues such as "fire walls" to consider?

Answers to these questions will help determine whether you will build a tracking portal "internally" or "externally" from your state portal. Will you need to hire a contractor? Consider all costs involved when deciding on the internal vs. external host model. Always be thinking ahead to ways the system can expand (as eventually you will add more data and new datasets). Other considerations include ADA compatibility, mapping features, and user printability (black & white vs. color options).



Appendix D.

Guidance for Assessing Data Systems for Tracking and Accessing Current NCDMs

A description of surveillance systems and data should include, but should not be limited to:

- 1.** Purpose – what is the purpose of the system and the intended use of the data?
- 2.** Data collection/case identification methods – What data should I track and how should it be analyzed?
- 3.** Data elements and format – what data elements are available and what format are they in?
- 4.** Completeness – how well does the system capture events/cases, how complete are the data elements for each event/case?
- 5.** Time– what years are covered by the system?
- 6.** Timeliness – when are new data available and how often are they updated?
- 7.** Spatial coverage – what areas are covered?
- 8.** Spatial resolution – at what geographic resolution are data collected?
- 9.** Geocoding – are data geocoded?
- 10.** Data limitations - are there ways the data should not be used?
- 11.** Access constraints – are there any restrictions on accessing the data?
- 12.** Use constraints – are there any restrictions on using the data?
- 13.** Policies governing collection and use of data – are there any legal restrictions on using the data?
- 14.** Native data environment – what technologies, platforms, tools, software or operating system are used to collect, manage, and store data?
- 15.** All data in the Tracking Network have associated metadata – how is metadata used?

- 16.** To protect individual privacy and patient's identity, the datasets submitted to the National Tracking Program are de-identified and aggregated spatially and temporally at the county level. In summary, data are:
- a. Used with other health outcomes data, exposure and biomonitoring data, and environmental hazards and environmental monitoring data, by association through spatial proximity, temporal proximity, or membership in a population subgroup.
 - b. Processed to generate derived data (e.g., geocoded, geo-referenced, code standardized, smoothed, age-adjusted).
 - c. Aggregated into standardized stratification schema (e.g., counts of events by event code, by location, by period, by demographic strata) or summarized (e.g., average for location by period, by demographic strata).
 - d. Rereleased to the public, in aggregate form with confidentiality measures in place, through a Public Portal as nationally consistent public use data and measures.
 - e. Rereleased, in aggregate form but without suppression, to registered users through the Secure Portal, with approval from the original data steward.

To improve and expand the Tracking Network's utility, you might want to add additional data, indicators, and content areas, and you might want to update current NCDMs.



