

EXECUTIVE SUMMARY

TRACKING NETWORK WORKGROUPS SPRING 2002 REPORT

Accessing, analyzing, and acting on health and health-related data are fundamental to the practice of public health. Yet, the public health system as it relates to environmental public health often does not have access to health data. In January 2001, The Pew Environmental Health Commission addressed the environmental public health capacity of the United States in its report, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*. The report described a lack of basic information with which to document possible links between environmental toxins and chronic and other diseases. The Pew report presented a compelling way to address this gap: integrate tracking systems for chronic and other diseases, environmental exposures, and environmental hazards; link and analyze data from these systems; and implement disease prevention strategies and applied research.

In August 2001, following up on the Pew report, CDC and ATSDR developed a document entitled *CDC and ATSDR's Proposed Plan for an Environmental Public Health Tracking Network*. The plan described methods to 1) develop and implement an integrated tracking system, 2) strengthen the environmental public health workforce at the state and local levels, and 3) improve collaboration among agencies and organizations that have environmental public health and environmental protection responsibilities.

To develop practical recommendations for implementing an environmental health tracking network as envisioned in *CDC and ATSDR's Proposed Plan for an Environmental Public Health Tracking Network*, NCEH, the lead CDC organization for the tracking program, identified senior scientists, managers, and policy specialists from 27 agencies and organizations to serve on workgroups to address tracking issues. Workgroups provided input without regard to current and future budget projections of CDC and ATSDR and partners, while recognizing that the pace by which recommendations can be addressed is influenced by dollar and staff resources.

NCEH sponsored four workgroup meetings: an orientation meeting for workgroup members in October 2001 and three 2-day workgroup meetings in December 2001 and January and March 2002. The workgroups addressed the following areas:

- **Workgroup 1: Organization and management** to define roles and promote collaboration between state and local public health and environmental agencies and among CDC and ATSDR, the Environmental Protection Agency (EPA), and other partners; and to identify state and local capacity needed to implement the tracking network
- **Workgroup 2: Data technology and tracking methodology** to identify relevant national data standards; to establish system specifications; and to describe potential prototypes or models for automating, linking, and analyzing hazard, exposure, and health outcome data

- **Workgroup 3: Tracking system inventory and needs assessment** to identify and describe existing tracking systems at the national, state, and local levels; to determine priorities for integrating existing tracking systems; and to identify and prioritize the development of new systems
- **Workgroup 4: Translation, policy, and public health action** to define state, local, and federal actions that can ensure rapid and effective responses to data and other information generated by the environmental public health tracking network (e.g., implementing disease prevention strategies and initiating prevention research)

The tracking workgroup process identified numerous practical and valuable recommendations. The process brought diverse disciplines to the table and resulted in the development of new and redefined professional relationships among professionals representing many tracking-related disciplines. The creativity harnessed by this process will accelerate progress toward full and effective implementation of the tracking program as envisioned by the Pew Environmental Health Commission, CDC and ATSDR, and their partners.

Implementing an environmental public health tracking program is a high priority for CDC and ATSDR and their partners because it provides a strategic opportunity to address some of the most challenging public health problems facing local, state, and national public health and environmental leaders. Its successful implementation will provide information about the possible relations between environmental exposures and chronic and other diseases that can lead to interventions to reduce the burden of these illnesses. CDC and ATSDR and their partners have a unique and historic opportunity to implement a program that will monitor and safeguard the health of all people living in the United States.

REPORT OF THE TRACKING NETWORK WORKGROUPS

BACKGROUND

The environment unquestionably plays an important role in human development and health. Although some links between environmental exposures and diseases--such as asbestos and lung cancer--are well documented, others--such as environmental exposures and childhood cancers--remain unproven. Domestic environmental public health concerns need to be addressed first; however, ultimately global issues need to be addressed because many environmental public health threats do not respect national boundaries.

We need to be able to respond to *all* the environmental public health objectives presented in *Healthy People 2010*. The critical importance of achieving these objectives is reflected in the “Environmental Health” component of this document where it states, “Poor environmental quality is estimated to be directly responsible for approximately 25 percent of all preventable ill health in the world...” Source: *Report of the CDC/ATSDR Working Group on a Shared Vision for Environmental Public Health at CDC/ATSDR*, December 2000.

Accessing, analyzing, and acting on health and health-related data are fundamental to the practice of public health. Yet, the public health system as it relates to environmental public health often does not have access to health data. In January 2001, The Pew Environmental Health Commission addressed the environmental public health capacity of the U.S. in its report, *America’s Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*. The report described a lack of basic information with which to document possible links between environmental toxins and chronic and other diseases. The Pew report also indicated that the nation’s preparedness against terrorism underscored the need for a strong tracking infrastructure to detect and respond to environmental threats and disease outbreaks caused by terrorist attacks. The Pew report presented a compelling way to address this gap: integrate tracking systems for chronic and other diseases, environmental exposures, and environmental hazards; link and analyze data from these systems; and implement disease prevention strategies.

“Few would dispute that we should keep track of the hazards of pollutants in the environment, human exposures, and the resulting health outcomes--and that this information should be easily accessible to public health professionals, policy makers, and the public. Yet even today we remain surprisingly in the dark about our nation’s environmental health.” Source: Pew Environmental Health Commission, *America’s Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*.

FROM THE PEW REPORT INTO ACTION

The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) work jointly on important environmental public health problems. In August 2001, following up on the Pew report, CDC and ATSDR developed a document entitled *CDC and ATSDR's Proposed Plan for an Environmental Public Health Tracking Network*. The plan described methods to 1) develop and implement an integrated tracking system, 2) strengthen the environmental public health workforce at the state and local levels, and 3) improve collaboration among agencies and organizations that have environmental public health and environmental protection responsibilities.

THE CDC and ATSDR TRACKING VISION

The CDC and ATSDR tracking vision is that human health will be improved by tracking and linking health data to environmental hazards and exposures and ensuring that communities have the capacity act on this information. Implicit in this vision are the following elements:

- A nationwide environmental public health tracking network (EPHTN) that will lead to local public health actions
- State and local public health and environmental protection agencies that have the human and financial resources necessary to develop comprehensive and sustainable environmental health programs grounded in good science
- Federal environmental public health and environmental protection systems linked to each other and to states, communities, and citizens

When fully implemented, the tracking network is expected to enable public health and environmental protection agencies to rapidly detect emerging environmental public health threats, including disease clusters; to develop, implement, and evaluate the efficacy of control strategies; and to ensure an informed and participating public.

THE WORKGROUP PROCESS

To develop practical recommendations for implementing an EPHTN as envisioned in *CDC and ATSDR's Proposed Plan for an Environmental Public Health Tracking Network*, NCEH, the lead CDC organization for the tracking program, identified 75 senior scientists, managers, and policy specialists from 27 agencies and organizations to serve on workgroups to address tracking issues (Attachment A). Where appropriate, the workgroups were asked to suggest recommendations for CDC Requests for Proposals (RFP) for tracking projects and to develop recommendations for

the tracking network as a whole. Workgroups provided input without regard to current and future budget projections of CDC and ATSDR and partners while recognizing that the pace by which recommendations can be addressed is influenced by dollar and staff resources.

NCEH sponsored four workgroup meetings: an orientation meeting for workgroup members in October 2001 and three, 2-day workgroup meetings in December 2001 and January and March 2002.

The workgroups addressed the following areas:

- **Workgroup 1: Organization and management** (led by Mr. Michael J. Sage, Associate Director, Office of Policy, Planning, and Evaluation, NCEH) to define roles and promote collaboration between state and local public health and environmental protection agencies and among CDC and ATSDR, the Environmental Protection Agency (EPA), and other partners; and to identify state and local capacity needed to implement the tracking network
- **Workgroup 2: Data technology and tracking methodology** (led by Ms. Donna Knutson, Executive Director, Council of State and Territorial Epidemiologists) to identify relevant national data standards; to establish system specifications; and to describe potential prototypes or models for automating, linking, and analyzing hazard, exposure, and health outcome data
- **Workgroup 3: Tracking system inventory and needs assessment** (led by Ms. Leslie Tucker, Director of Environmental Health, American College of Preventive Medicine) to identify and describe existing tracking systems at the national, state, and local levels; to determine priorities for integrating existing tracking systems; and to identify and prioritize the development of new systems
- **Workgroup 4: Translation, policy, and public health action** (led by Ms. Georgi Jones, Director, Office of Policy and External Affairs, ATSDR) to define state, local, and federal actions that can ensure rapid and effective responses to data and other information generated by the environmental public health tracking network (e.g., implementing disease prevention strategies and initiating prevention research)

WORKGROUP RECOMMENDATIONS

Workgroup 1: Organization and Management

This workgroup focused on the need for an expanded and redefined relationship between CDC and ATSDR and EPA as it relates to tracking. Although these agencies have collaborated on many issues over the years, the workgroup recognized that collaboration needs to be strengthened

to ensure the success of the tracking program. EPA maintains many environmental hazard data bases at the national level and in state environmental protection agencies, and these need to be integrated with exposure and health outcome databases maintained by state public health agencies, CDC and ATSDR, and others. Additionally, interventions derived from analyses of linked data will in many cases need to be developed and implemented by both public health and environmental protection agencies.

Short-term recommendations

- 1) Representatives from CDC, ATSDR, EPA, and other partner organizations should meet with state public health and environmental protection officials to identify barriers to collaboration and determine ways to remove these barriers and enhance collaboration.
- 2) Lead tracking agencies in the states need to facilitate collaboration among all relevant parties because responsibility for critical health and environmental data often rests in disparate government agencies (e.g., state fish and wildlife, agriculture, and Medicaid agencies).
- 3) Relevant local public health and environmental agencies and organizations must be partners in tracking because a substantial amount of health and environmental data are collected at the local level, and disease prevention strategies are often implemented at the local level.

Long-term recommendations

CDC and ATSDR's Proposed Plan for an Environmental Public Health Tracking Network should be reviewed to determine whether it needs to be updated to reflect workgroup recommendations.

Request for Proposal (RFP) recommendations

- 1) Both public health and environmental protection agencies should be eligible to receive funding for tracking. Either entity can serve as the lead tracking agency and must tangibly demonstrate interagency collaboration through written agreements. (NOTE: After the development of this recommendation, Congress appropriated \$17.5 million to CDC in fiscal year FY 2002 “for development and implementation of a nationwide environmental health tracking network and capacity development at State and local health departments.” Thus, state environmental protection agencies and other entities within states were not eligible to apply for FY 2002 tracking funds. However, applicants should ensure and document that appropriate collaboration has been or will be established and maintained with state environmental protection agencies.)

2) RFPs should be tiered so that eligibility encompasses public health agencies with existing capacity such that they can begin some tracking activities immediately as well as agencies that propose to develop the infrastructure to implement tracking activities.

3) Essential public health and corresponding environmental functions should be integrated into RFP requirements.

4) Tracking program grantees should be given reasonable flexibility in the hazards, exposures, and health effects their networks will address.

5) Local agencies and organizations should be given sufficient fiscal and programmatic support to cover tracking program requirements and responsibilities. State-level grantees should be allowed to form consortia with such local agencies and organizations as necessary to further the aims of tracking activities, including the transfer of financial and other resources to such agencies.

Workgroup 2: Data Technology and Tracking Methodology

Workgroup 2 addressed issues related to information technology and its application to data acquisition, data management, and data analyses. This workgroup's charge was to recommend ways to apply new technologies to the development of a nationwide environmental health tracking network. Because of the complexity of this workgroup's charge and the resulting length of its report, only its principle recommendations are displayed below. Reference Attachment B for the complete Workgroup 2 report.

Recommendations

1) The EPHTN should be developed in cooperation with CDC's National Electronic Disease Surveillance System (NEDSS), EPA's National Environmental Information Exchange Network, and other national data architectures.

2) The EPHTN should consist of a system of distributed data sources, all of which can receive or send data. Data providers should, to the extent possible, maintain their data at their location, in the data's original form, in the data provider's preferred database, and in the preferred format.

3) The EPHTN should adopt metadata standards that allow users to find and use data available in the network.

4) EPHTN architects should work with federal partners and private standard-setting organizations to share, create, or modify data processing, performance, and technology standards.

5) EPHTN architects should adopt a formal technology-neutral methodology for modeling, analysis, and design of the tracking network. This will provide both an architectural framework and technical guideline for the surveillance facts of the diseases, conditions, environmental hazards, and environmental exposures relevant to the tracking network. Formal models should be developed to encompass the business model, workflow models, partner models, process models, use case models, options analysis models, data-flow models, and data models.

6) The EPHTN should identify, integrate, and make available tools for data analysis, interpretation, and presentation. To the extent possible, data dissemination should use automation tools, such that “the data find the user” rather than forcing users to repeatedly search for information when new updates become available.

7) EPHTN architects should explore developing relationships with private providers (e.g., physicians, administrators of health care plans, pharmacy staff, emergency department staff, poison control center staff, laboratory personnel) to gain access to nontraditional surveillance and tracking data sources.

8) EPHTN architects should ensure data sharing agreements exist between relevant agencies at the state and federal levels. These interagency agreements, or memoranda of understanding, allow agencies that collect data under specific legal authority to release those data to the agencies who need them for program and policy development planning. Such agencies include state and local agencies, EPA, poison control centers, the National Institutes of Health (NIH), the U.S. Geologic Survey (USGS), the Department of Energy (DOE), the Department of Housing and Urban Development (HUD), and the National Aeronautics and Space Administration (NASA).

9) EPHTN architects should develop a comprehensive information security plan and include technical specifications describing the plan in the construction of the network.

Workgroup 3: Tracking System Inventory and Needs Assessment

This workgroup’s recommendations focus on capturing and strategically leveraging current and future opportunities. The recommendations aim to put in place the foundations necessary to develop and support environmental public health tracking. They emphasize coordinating and consulting between public health and environmental protection practitioners, linking existing tools, and sharpening a select few of the tools to better capture environmental health endpoints. At the same time, the recommendations envision the need for a successful tracking system to serve as a platform for creating the next major additions to the public health tool box, specifically through leveraging Health Insurance Portability and Accountability Act (HIPAA) standardization requirements for administrative and clinical encounter data, and renewing an appreciation for the role of public health laboratories in protecting public health and safety.

Because of the complexity of this workgroup's charge and the resulting length of its report, only its principle recommendations are displayed below. Reference Attachment C for the complete Workgroup 3 report.

Recommendations

- 1) As an initial step, the EPHTN should support states to create or build on links across health and related data sources for priority chronic disease and environmental health endpoints. Such links may be as simple as the copresentation of indicators for diseases and conditions of interest in a common medium (e.g., narrative report or geographic display), or as elaborate as fully integrated software systems, depending upon the state's current level of sophistication.
- 2) A demonstrated relationship between state departments of health and state environmental protection agencies (or their appropriate analogues) that will facilitate data linkage, interpretation, and development should be a prerequisite for health tracking support. Opportunities for connectivity and leverage include shared geographic information system (GIS) platforms, interdepartmental liaisons, ATSDR cooperative agreements, and state public health and environmental laboratories.
- 3A) CDC, ATSDR, and EPA should establish a regular forum for intensive, hands on (applied) exchange between state and federal public health and environmental data developers, statisticians, and other users.
- 3B) CDC and ATSDR should facilitate evaluation of GIS for application to the EPHTN.
- 4) CDC and ATSDR should enhance core chronic and environmental health surveillance systems to better capture information about environmental exposures and conduct state pilots as part of the EPHTN.
- 5) Concurrently, CDC and ATSDR should improve the ability of existing systems to capture priority health endpoints.
- 6) CDC and ATSDR should actively and routinely survey the federal government's planned and ongoing studies for appropriate opportunities to integrate environmental health questions.
- 7) Tracking programs should focus on the increasing importance of ambulatory settings as sources of data because conditions of public health importance are increasingly being managed in these settings.
- 8) The EPHTN should support pilot projects to explore the trade-offs among different approaches to capturing epidemiologic data from the health services domain. For example, state public health

officials should be encouraged to develop relationships with health plans or other sources of encounter data for the populations within their jurisdictions.

9) CDC and ATSDR should provide technical assistance to states in developing data-sharing agreements based on lessons learned by other public and private data sharing partnerships in the health services domain (e.g., state Medicaid agencies and their contracted managed-care plans and CDC's own collaboration with the American Association of Health Plans and the HMO Group). CDC and ATSDR also should ensure regular feedback from state experiences to HHS data standards groups (including the HHS Health Data Council, the National Center for Vital and Health Statistics, the Center for Medicare and Medicaid Strategies, the Public Health Data Standards Consortium, and HL-7). Finally, on the basis of states' experiences, CDC and ATSDR should advocate within these groups for relevant variables, metrics, and coding practices.

10) CDC and ATSDR should pilot a modified "State National Health and Nutrition Examination Survey" with a smaller questionnaire and much larger sample with target oversampling.

RFP recommendations

The RFP should give highest priority to applications proposing to strengthen surveillance for one or more of the high-priority health conditions (e.g., asthma, birth defects, cancer, neurologic illnesses). Alternatively, applicants could offer the candidate condition(s) with a justification as to why it is a priority. The applicants may consider linking existing health data systems or proposing new, innovative approaches to capture the desired information. The value of proposals also should be examined regarding the impact and applications for other states. Starting with the surveillance of a selected health condition as the key element, proposals may be submitted under one of the following tiers:

Tier	Health Surveillance: Level of Linkage
Tier 1 Basic	Developing and testing surveillance methodology for a given health condition(s). Focused only on linking health data systems. Health Surveillance Data ∅ Health Surveillance Data
T i e r 2 : Enhanced	Developing and testing or using an existing surveillance methodology for a given health condition(s) and exploring linkage to existing human exposure (i.e., biomonitoring) or environmental data bases Surveillance Data b Environmental Data Biomonitoring Data
Tier 3 Advanced	Developing and testing surveillance methodology for a given health condition(s) and exploring linkage to existing human exposure (i.e., biomonitoring) and environmental data bases Environmental Data ∅ Biomonitoring Data ∅ Surveillance Data

The tier under which a state chooses to submit a proposal is assumed to be a function of the existing capacity and capability of that state. Thus, a state with rudimentary health tracking for the priority health conditions might opt to submit a proposal that would start at Tier 1 to begin to build basic capacity and capability. Similarly, a state with fairly advanced surveillance and environmental monitoring systems would be expected to submit a Tier 2 or 3 proposal. Proposals would be competed only within tiers. The ultimate goal is for all states to have the capacity and capability to link environmental, biomonitoring, and health surveillance data bases.

Consideration also should be given to proposals that chose to strengthen primarily biomonitoring systems. The following are of special interest: metals, pesticides, volatile organic solvents, persistent bioaccumulative toxicants, and EDCs. The applicants should address the development of analytical techniques and design and pilot a sampling strategy that would reflect the exposure status for the population of the state and/or a target subpopulation (e.g., children). Again the value of a proposal could also be examined as to how broad the impact and applications would be for other states. A tiered approach is envisioned:

Tier	Biomonitoring: Level of Linkage
Tier 1: Basic	Develop and test biomonitoring approach for population and subpopulation for selected class (es) of pollutants.
T i e r 2 : Enhanced	Develop and test biomonitoring approach for population/subpopulation for a selected class(es) of pollutants. and explore linkage to existing health surveillance or environmental data bases Biomonitoring Data b Surveillance Environmental Data Data
Tier 3: Advanced	Develop and test biomonitoring approach for population and subpopulation for selected class(es) of pollutants. and explore links to existing surveillance and environmental data bases Environmental Data ∅ Biomonitoring Data ∅ Surveillance Data

Workgroup 4: Translation, policy, and public health action

This workgroup focused on developing recommendations that will help ensure that information developed by tracking programs will lead to effective public health actions. These actions include detecting new health events and unusual disease occurrences associated with environmental exposures, developing and implementing health policies and disease prevention strategies, monitoring and assessing the effects of these policies and prevention strategies, increasing citizen understanding of environmental health issues in their communities, and guiding research initiatives.

Short-term recommendations

- 1) Conduct focus groups of key target audiences to determine what they want and need from an EPHTN and share that information with the successful applicants for the pilot projects.
- 2) Establish a system for ongoing communication between CDC and ATSDR staff and all of the pilot program staffs. That communication should share lessons learned and early evaluations of success.
- 3) Hold an annual meeting for the pilot projects, the current workgroups, and other interested parties.
- 4) Provide a briefing of the Trust for America’s Health staff once the final workgroup recommendations are consolidated. The briefing can be open to other interest groups and Congressional staff.

Long-term recommendations

- 1) Work with EPA to establish an indoor air monitoring program to identify key environmental tracking indicators that might be linked to critical diseases such as asthma.
- 2) Foster state and local health departments to fully implement their core capacities.
- 3) Ensure their surveillance research agenda addresses research needs that are identified in the pilot projects.
- 4) Continue to encourage a community-based research model.
- 5) Share research findings and agendas with other federal agencies, especially EPA and the National Institute of Environmental Health Sciences.
- 6) Establish a website to provide continuously updated information on the progress of the pilot projects and the overall status of the EPHTN.

RFP recommendations

- 1) Grant and cooperative agreement applicants should identify target audiences in their submissions. They should further specify how they would reach out to these groups for both planning and implementation purposes. Audiences should include:
 - The health community: federal, state, and local public health professionals; private health-care providers; the health insurance industry; and pharmaceutical companies
 - Affected communities: people affected by environmental factors and health outcomes, as well as advocacy groups for environmental and health causes
 - The media: TV, radio, journals, magazines, and newspapers involved in developing and delivering messages about environmental health issues
 - Politicians: Congress, the Administration, state governors and legislators, city and county political structures, and others responsible for funding and legislation affecting environmental public health tracking
- 2) Research to determine audience wants and needs should be undertaken at all levels (including the pilot projects).
- 3) Partnerships should be encouraged not only with local public health and environmental departments but also with key stakeholders such as schools, community advocates, local health-care providers, and local water boards. Applicants should identify specific steps for outreach to such organizations.

4) Grantees should allow full, public access to all data on the network with the appropriate medical confidentiality caveats.

5) Grantees are encouraged to use a wide variety of modes to present their data. Graphics should be used whenever appropriate (GIS mapping is an especially effective presentation and analytical tool). Tabular presentations, written text (especially “story telling”), and other methods should be also used as appropriate to the intended audience. The instruments for data presentation should also vary. Use of the Internet should include straight presentations, interactive standard queries, and independent analyses. Use of print materials and CD ROM formats should be considered as appropriate.

6) Tracking pilot projects should develop a public health action feedback loop. Surveillance should not be conducted for surveillance purposes alone. Rather, the tracking systems should be developed with the goal of positively affecting the public’s health. Applicants should discuss in their proposals how they will design their programs to affect public health actions and a commitment to report on at least an annual basis their success in meeting one or more of the following public health actions:

- Research: how disease “clusters” and possible links to environmental exposures were identified and research hypotheses generated from data analysis (e.g., children’s cancer clusters possibly related to contaminated water supplies)
- Policy changes: how new health or environmental policies were generated (e.g., requiring nonarsenic-treated wood used for playgrounds)
- Education: how public education efforts were undertaken to prevent future exposures to harmful environmental contamination (e.g., school campaigns to warn students about the dangers of playing with mercury)
- Strategic interventions and prevention: how actions were taken by public health officials to interdict exposure or mitigate the affects of exposure (e.g., providing alternative sources of water if existing water supplies are found to be contaminated)
- Linkage changes: how new partnerships were developed between organizations not traditionally associated with public health (e.g., forming new alliances between environmental and health agencies, with insurance companies, or with faith-based organizations)
- Health provider training: how feedback loops were established with local physicians informing them about disease clusters in their communities and training them to **diagnose** and treat those diseases

- Legislation and Regulation: how new or additional legislation or regulations were proposed to prevent continued exposure (e.g., banning smoking in public buildings)

7) Pilots should be chosen on the basis of greatest potential of success; however, some funding also should be directed for planning and capacity building.

8) The RFP should describe the EPA's National Environmental Information Exchange Network grant program and how these two programs can complement each other.

SUMMARY

“It is clear that the U.S. needs to establish a national environmental health monitoring system which strengthens the surveillance of key health conditions in conjunction with monitoring the presence of pollutants in our bodies and the environments with which we come into contact. The recent, tragic events in the U.S. further reinforce the critical need to have access to reliable data on environmental exposure and disease outcomes. In times of crisis, the information is needed quickly and in a usable format.” Source: Roundtable on Environmental Health Sciences, Institute of Medicine, The National Academies of Science, April 10-11, 2002, *Background and Goals for the Workshop, Environmental Health Indicators: Bridging the Chasm of Public Health and the Environment*.

We live in an era of major threats to our health but also in an era with unprecedented opportunities to conquer these threats. These opportunities include converging federal tracking-related initiatives that have significant political and citizen support and when coupled with advances in information technology and scientific breakthroughs, can revolutionize the practice of environmental public health in terms detecting and preventing disease, clarifying the role of our environment in disease causation, and empowering citizens and communities with information about the diseases and hazards in their communities. These opportunities include

- Bioterrorism funding to the states that will enhance overall public health capacity and competency
- Major CDC and ATSDR tracking-related initiatives under way (in partnership with state and local public health agencies and the private sector) that will accelerate progress and that represent comprehensive approaches to disease surveillance. These primarily include the National Electronic Disease Surveillance System (NEDSS), an electronic information system architecture for use in the states that establishes data standards and is designed to automatically gather health data from a variety of sources on a real-time basis; and the eHealth Initiative, a public-private partnership addressing ways to rapidly capture and transmit such information as emergency department visits, diagnoses, and laboratory transactions using NEDSS.

- EPA's National Environmental Information Exchange Network, a new nationwide initiative with the states to build locally and nationally accessible, cohesive, and coherent environmental information systems. The goals of this program are to improve the quality of environmental data, provide agencies and the public ready access to these data, and increase the ability of state agencies and EPA to employ this information to protect public health and the environment.
- The NCEH and ATSDR Shared Vision that builds on the complementary strengths of both agencies
- Expanded support for biomonitoring, the exposure component of the tracking equation, both at NCEH and in the states
- Unprecedented opportunities to study gene-environment interactions and their relation to disease causation
- The \$17.5 million FY 2002 appropriation to CDC to implement pilot tracking programs in the states

The tracking workgroup process identified numerous practical and valuable recommendations. The process brought diverse disciplines to the table and resulted in the development of new and redefined professional relationships among professionals representing many tracking-related disciplines. The creativity harnessed by this process will accelerate progress toward full and effective implementation of the tracking program as envisioned by The Pew Environmental Health Commission, CDC and ATSDR, and their partners.

Implementing an environmental public health tracking program is a high priority for CDC and ATSDR and their partners because it provides a strategic opportunity to address some of the most challenging public health problems facing local, state, and national public health and environmental leaders. Its successful implementation will provide information about the possible relations between environmental exposures and chronic and other diseases that can lead to interventions to reduce the burden of these illnesses. CDC and ATSDR and their partners have a unique and historic opportunity to implement a program that will monitor and safeguard the health of all people living in the United States.

MEMBER AGENCIES AND ORGANIZATIONS OF THE TRACKING WORKGROUPS

Agency for Toxic Substances and Disease Registry
Alaska Department of Environmental Conservation
American Association of Poison Control Centers
American Water Works Association
American College of Preventive Medicine
Association of State and Territorial Health Officials
California Department of Health Services
Centers for Disease Control and Prevention

- Epidemiology Program Office
- National Center for Birth Defects and Developmental Disabilities
- National Center for Chronic Disease Prevention and Health Promotion
- National Center for Environmental Health
- National Center for Health Statistics
- Office of the Director, Integrated Health Information Systems

Children’s Environmental Health Institute
Council of State and Territorial Epidemiologists
Delaware Department of Natural Resources
Dunlop Environmental Consulting
Environmental Council of the States
Indiana Department of Environmental Management
Ingham County (Michigan) Health Department
Johns Hopkins University
Lockheed Martin Technology Services
National Association of County and City Health Officials
New York State Department of Health
Physicians for Social Responsibility
The Trust for America’s Health
University of New Mexico
U.S. Environmental Protection Agency
U.S. Department of Housing and Urban Development
U.S. Department of the Interior, U.S. Geologic Survey
U.S. Public Interest Research Group
Washington State Department of Health

Final Report
Workgroup #2 - Data Technology and Tracking Methodology

CDC and ATSDR invited people from inside and outside the government to assist them in developing an Environmental Public Health Tracking Network (EPHTN). The EPHTN, designed to enhance sharing of information and knowledge to allow people to make the best possible health decisions, has received widespread support from local, state and federal public health agencies. CDC, ATSDR, and their tracking partners should address three components critical to understanding the link between the environment and health outcomes:

- Hazards tracking
- Exposure tracking
- Health outcome tracking

The Data Technology and Tracking Methodology Workgroup focused on recommendations that included not just technologies, but also relationships, laws, standards, systems, and applications. The Workgroup also provided recommendations about tools, such as geographic information systems, health statistics, and many forms of communication.

The workgroup believed that the EPHTN should build on the National Electronic Disease Surveillance Systems (NEDSS), perhaps constructed as a program application module and thus fully integrated with other NEDSS program application modules. The workgroup assumed that the EPHTN should be able to

- Conduct and support Web browser-based data entry and data management
- Accept, route, and process HL7 messages containing laboratory and clinical content
- Implement an integrated data repository
- Develop active data translation and exchange (integration broker) functionality
- Develop transportable business logic capability
- Develop data reporting and visualization capability
- Implement a shareable directory of public health personnel
- Implement a security system and appropriate security policies

The workgroup understood the EPHTN probably will have different developmental and use functions at the state and local levels than at the federal level.

Following are the recommendations of the workgroup.

RECOMMENDATION 1

The EPHTN should be developed in cooperation with NEDSS, the Environmental Protection Agency's (EPA's) National Environmental Health Exchange Network (The Exchange Network), and other national data architectures building upon existing partnerships between CDC, ATSDR, and other government, public, and private entities.

Rationale

- To help ensure consistency, compatibility and integration of conceptual and logical models, architects of the EPHTN should actively participate in the NEDSS development project to learn about NEDSS and provide environmental health perspectives to the ongoing NEDSS requirements-gathering processes.
- EPHTN architects should adopt existing NEDSS data and messaging standards where applicable. At the same time, they should participate in the NEDSS standards-development processes to help rectify deficiencies related to environmental health tracking.
- The EPHTN will benefit from learning and adopting best practices developed by the NEDSS architects. Furthermore, EPHTN architects could mitigate many of the risks by considering NEDSS' lessons learned, especially those resulting from work with such a broad base of stakeholders.

Next Steps

- Identify existing data and systems for feasibility of integration into the EPHTN development process
- Evaluate the NEDSS Base System and architectural elements for applicability to EPHTN requirements, and identify additional necessary elements (e.g.; geospatial components)

How does this relate to the RFP?

Proposals received should detail how the funding links NEDSS (CDC), the National Environmental Information Exchange Network (EPA), and other national architectures.

What are the short-term recommendations to CDC and ATSDR?

- Look at NEDSS (CDC) and the Exchange Network (EPA) architectures mentioned and determine whether they are useful tools
- Accelerate the integration of the blood lead screening and environmental health

surveillance into a NEDSS compatible format

- Develop a technical advisory workgroup of experts to further explore EXML schemas, and identify the commonalities between NEDSS (CDC) and the Exchange Network (EPA)
- Collaborate to develop a user-friendly version of the technical workbook on NEDSS

What are the long-term recommendations to CDC and ATSDR?

Develop a module that will assist in the integration of NEDSS-compatible systems (CDC) with the Exchange Network (EPA)

RECOMMENDATION 2

The EPHTN should consist of a network of distributed data sources, all of which could receive or send data. Data providers should, to the extent possible, maintain their data at their location, in the data's original form, in the data providers' preferred database, and in their preferred formats.

Rationale

- Reinforces the concept that data-sharing is the responsibility of federal, state, and local agencies
- Allows information to be collected locally and accessed, queried, and retrieved globally
- Preserves the data-providers' ownership of data. Allows data providers to control access to data that meets their local privacy requirements
- Probably minimizes the federal agencies' enforcement of state privacy requirements and thus protects data in case of a Freedom of Information Act request
- Allows data to be stored in native format, thus maintaining the original purpose of the data collection
- Minimizes the likelihood that a data provider will need to commit to reengineering existing systems to work within EPHTN
- Provides the ability for translating the native data model of the data provider to other data models
- Enables other data models to be either EPHTN standard data models or dynamically user-defined data models

- Allows tapping into large number of existing databases in shorter time
- Makes data location transparent to users

Next Steps

- Identify and contact for input and ideas the individual providers, industry groups, and other government agencies that support this approach
- Resolve the many issues that remain. These include whether one or multiple standard data model should be defined or whether the system should allow for an infinite number of "virtual" data models to be dynamically created; exploration of the pros and cons of the data model options; and research of open architecture standards and best practices.

How does this relate to the RFP?

- Proposed projects should prototype the concept of distributed data sources that moves away from data repositories and toward distributive services
- Funding should include pilots to test the integration of NEDSS, EPS's Exchange Network, and other national architectures

What are the short-term recommendations to CDC and ATSDR?

- The technical advisory workgroup suggested under recommendation #1 should explore the issues of integration of systems
- Integration completed by the technical advisory workgroup should be a funded project.

What are the long-term recommendations to CDC and ATSDR?

- Choose architecture for implementation and a distributed model from the recommendations of the pilots and the technical advisory workgroup.
- Measure for baseline information to ascertain where the state is as it relates to integration with the EPHTN; provide technical assistance to states to achieve integration by providing blueprints for measuring how far states need to go to fully integrate and measure success
- Create system for continued opportunities for discussion

RECOMMENDATION 3

The EPHTN should adopt metadata standards that allow users to find and use data available in the EPHTN.

Rationale

- Provides users the ability to search the Web for EPHTN-related reports and databases
- References both spatial and nonspatial components of the data. For example, nonspatial data may include textual and coded records on the clinical measurements of a disease, such as stage of cancer, or documentation of an exposure, such as mercury toxicity. Spatial data would reference geographic location of data such as the spatial distribution of an exposure or disease.
- Complies with existing Federal Geographic Data Committee (FGDC) metadata standards and ISO 11179 standards. An example of an ISO Metadata standard can be found on the FGDC website:
<http://www.fgdc.gov/clearinghouse/participation/annapolis/metastat/tsld003.htm>

Regardless of the metadata profile used (most profiles are searchable across existing data libraries), data documentation is a first step. Without it there is no data sharing and limited accessibility to data resources. Outside of the CDC firewall, and at its highest level of abstraction, one could envision the following EPHTN metadata core elements for documentation and sharing:

1. Title
 2. Author/contact/responsible party
 3. Abstract
 4. Date of publication of availability
 5. Date of last modification
 6. Medium (e.g., CD-ROM, URL)
 7. Geographic coverage (e.g., state, county, census tract, ZIP code, geocode)
 8. Key words (e.g., searchable)
 9. Access constraints
 10. Use constraints
 11. Data dictionaries (data fields and vocabulary)
- Enables EPHTN to link historical databases. To accomplish this task, databases need to define the appropriate metadata standards to assign to legacy databases. This will ensure maintenance of data compatibility, documentation of inconsistencies, and management of data files that have been created through different means over time.

Next Steps

- Establish an inventory of metadata standards (i.e., health outcomes, hazards, spatial, and

exposures) capability. At a minimum, models include existing FGDC metadata standards and applicable ISO 11179 standards. The inventory should include a description of the appropriate standard and a rationale for its application to a specific data source.

- Create an appropriate metadata standard-creating mechanisms for selected databases encompassed in the EPHTN. This standard also would include elements unique to the EPHTN (e.g., considered as extensions to existing metadata file elements). The EPHTN task force conceivably would lay the groundwork for a national metadata standard for environmental tracking and health, which easily could be searched through the FGDC Clearinghouse.

The public as well as the scientific community expect CDC and ATSDR information technology to provide easy and rapid access to information and data. A EPHTN metadata repository will fulfill this expectation.

How does this relate to the RFP?

Products of state grants should include metadata that relate to databases created with the funds

What are the short-term recommendations to CDC and ATSDR?

- Work with EPA to develop an agreement regarding metadata standards that would be useful to the EPHTN.
- Using the technical advisory workgroup suggested under recommendation #1, explore the issues of metadata standards

What are the long-term recommendations to CDC and ATSDR?

Implement this recommendation

RECOMMENDATION 4

EPHTN architects should work with federal partners and private standard-setting organizations to share, create, or modify data processing, performance, and technology standards.

Rationale

- Design of the EPHTN should be based on standards currently in place, but it should also be flexible enough to anticipate future changes and advances in technology and evolutions in standards, including hardware, software, transactions, and data and communications standards.

- The EPHTN should be technology-neutral. It should emphasize the functionality needed for environmental health tracking. The system for communications and data exchange should facilitate interchange of data at all stages of readiness and response, as well as for ongoing purposes such as surveillance and tracking of chronic diseases.
- The EPHTN should permit data sharing between public health and nonpublic health partners (e.g., hospitals, laboratories, health plans, urgent-care facilities, clinics, and providers).
- However, a security infrastructure must be in place to protect the integrity of the data and to recognize several different levels of access, from technical and maintenance and security protocols to clinical care coordination to public access inquiries. For example, the EPHTN should aim to provide public information through having standard FAQs and “off the shelf” answers (e.g., where are disease clusters?) as well as through allowing search engines for more tailored data inquiries from researchers and federal agency staff.

Although the EPHTN’s users may be the research community and other stakeholders, the EPHTN should be designed to provide accessible and useful information for policy makers and the public, while observing privacy and security standards.

Next Steps

- Design the EPHTN to incorporate three general domains of indicators: Hazards, Exposures, and Health Effects. Within the Health domain, data sources include laboratories, hospitals, health plans, private providers, and poison control centers, and other sources. Some standards may be unique to one domain; others may apply across sources (e.g., HIPAA privacy standards). Further investigation is needed.
- To ensure preparedness, identify and resolve contradictory and overlapping standards. This task is simply too large for any one group to plan or execute alone. Several models exist for standards development. For example, the public sector may require that private-sector standards be observed, as is the case with banking information and health plan data (also known as “deemed status”).

Development of the EPHTN is a complex, crosscutting effort that will require a collaborative, team-oriented approach within and across federal agencies.

How does this relate to the RFP?

Projects for pilots should identify which standards have been used for a specific project.

What are the short-term recommendations to CDC and ATSDR?

Inventory and compile a list of applicable standards

What are the long-term recommendations to CDC and ATSDR?

Implement, adopt, and use standards

RECOMMENDATION 5

EPHTN architects should adopt a formal technology-neutral methodology for modeling, analysis, and design of the EPHTN. This will provide both an architectural framework and technical guideline for the surveillance facts of the diseases, conditions, environmental hazards, and environmental exposures relevant to the EPHTN. Formal models should be developed to encompass the business model, workflow models, partner models, process models, use case models, options analysis models, data-flow models, and data models.

Rationale

- Ensures that clear lines of organizational barriers, communication, programmatic processing, scientific decisions, and technical implementations can be defined
- Documents decisions, defines stakeholders, and guides discussion to formalize these key facets of the network and enable implementers to take advantage of new technologies as the technology become available
- Provides improved communication and dialogue with existing models such as the NEDSS Public Health Conceptual Data Model (PHCD) and the Health Level 7 (HL7) Reference Information Model as well as models developed by other organizations

Next Steps

- Perform a tool kit needs-assessment and evaluation for the Unified Modeling Language (UML) methodology and notation to create and support the various models required for the EPHTN
- Create and define a formal process to develop formal models for the EPHTN
- Link models from the EPHTN to the enterprise architecture framework for the organizations involved in the EPHTN

How does this relate to the RFP?

The grantees should be required to include a project representative to participate in the modeling process

What are the short-term recommendations to CDC and ATSDR?

- Prioritize the model type, and find the methodology
- Establish capacity for technical assistance on modeling for the states to use in state projects funded under the RFP
- Develop, use, and evaluate case models

What are the long-term recommendations to CDC and ATSDR?

Choose a methodology from knowledge gained from this process

RECOMMENDATION 6

The EPHTN should identify, integrate, and make available tools for data analysis, interpretation, and presentation. To the extent possible, data dissemination should use automation tools, such that “the data finds the user” rather than forcing users to repeatedly search for information when new updates are available.

Rationale

EPHTN users, such as researchers, public health professionals, policy developers, members of Congress, public officials from other agencies, and the media, will have widely varying needs and levels of expertise. EPHTN should be available for all types of users and inquiries ranging from locating disease clusters to specific health effects of exposures. Therefore, the EPHTN should make it as simple as possible for those users to request and receive standardized information over the network, while offering advanced functionality for more sophisticated consumers. Essential elements include

- Answers FAQs, not necessarily data when appropriate
- Provides search and retrieval functions and customizable query systems
- Links issues through ecologic analysis, thus clarifying strengths and limitations for users
- Provides data visualization and exploratory data analysis
- Provides export capability to "industry" standard formats such as spreadsheet, database, text file (all nonproprietary)
- Provides a clearly defined and available open architecture so users can create tools

- Enables online data dissemination accompanied by release of printed standard reports, as appropriate, and electronic versions which should be available in a non-proprietary format (e.g., *.PDF) online
- Provides tight integration with NEDSS to allow EPHTN users access to SAS under the NEDSS license

Next Steps

- Define key user groups and their information needs
- Develop a conceptual framework for the EPHTN, which will encompass the user interface requirements for accessing and analyzing data, as well as presentation and report writing
- Assist with the interpretation and visualization of data for novice users or general audiences to help them make informed decisions
- On the basis of user interface and information requirements, identify specific functional components including linkages to pre-existing databases for retrieval
- Maintain applicable industry standards and flexibility to anticipate technologic changes

How does this relate to the RFP?

- Funded projects should include use of tools for data analysis, interpretation, and presentation.
- Grantee development of a public use data set (PUDS) or other accessible and understandable data dissemination, as appropriate, should be encouraged.

What are the short-term recommendations to CDC and ATSDR?

Work with the NEDSS Analysis, Visualization, and Reporting (AVR) team. The NEDSS AVR staff should collaborate with EPHTN staff to accelerate development of tools for data analysis, interpretation, and presentation

What are the long-term recommendations to CDC and ATSDR?

Make available for data analysis, interpretation, and presentation a suite of options and choices of tools that employ open architecture, and function as “turn-key” systems.

RECOMMENDATION 7

Architects of the EPHTN should explore developing relationships with private providers (i.e., physicians, health care plans, pharmacies, emergency departments, poison control centers, and laboratories) to gain access to nontraditional surveillance and tracking sources.

Rationale

- EPHTN will be designed to incorporate three general domains of indicators: hazards, exposures, and health effects. Each of these domains has several data and information sources reporting to different federal, state, and local agencies, ranging from mandatory reporting to voluntary reporting to no reporting.
- Potential data sources for the EPHTN are fragmented. For example, data on environmental hazards are tracked by ATSDR's Hazardous Substances Emergency Events Surveillance (HSEES) system. Several groups at EPA maintain a variety of databases, such as TRI and others, and generally monitoring is specific to releases of one chemical agent (e.g., chlorine) but without links to exposure.
- Exposures (e.g., to chemical agents) are tracked by the Departments of Defense and Veterans Affairs, but the source of exposure is not always clear. (Note: Military data may not be available for public use, but military installations should be included in local public health preparedness planning and exposure monitoring efforts). For example, biomonitoring data generally are available only through NHANES, which only has data from 5000 people nationally; until NCEH state biomonitoring planning grants progress to implementation, this will remain the case.

Next Steps

In addition to NEDSS, two large initiatives are under way that will directly affect the development of the EPHTN in terms of the availability of laboratory, medical, and public health data. Notably, CDC is participating in the eHealth Initiative, a consortium of vendors, health plans, and other industry leaders that are working on connectivity of clinical data systems.

CDC also has developed guidance for state applications for bioterrorism funding provided by Congress. In January 2002, Congress made about \$1 billion available to strengthen state and local preparedness for bioterrorism and "other public health emergencies" by upgrading disease reporting systems, increasing hospital and laboratory capacity, and improving communications systems.

- In collaboration with other workgroups and other initiatives at CDC and ATSDR, develop a framework for availability of EPHTN data by sources: already available, in development, not in development
- Identify the activities in CDC's eHealth Initiative that could develop infrastructure on which the EPHTN could build
- Evaluate the impact of CDC's technical guidance that accompanies bioterrorism preparedness funding for states, and identify the data sources and information systems that states are likely to develop and deploy
- Develop a strategy to monitor whether states are developing similar systems and models for connectivity of systems, particularly across jurisdictions and types of providers (e.g., data-sharing among hospitals in a metropolitan area)
- Develop priorities and a timeline for EPHTN development based on availability of data
- Identify exposure information and tracking capacity from poison control centers to integrate them with public health and medical data systems

It should be noted that each of these domains is governed by a variety of standards and is in varying stages of computerized record keeping, so some sources would be available sooner for building a prototype of the EPHTN than other sources.

How does this relate to the RFP?

- The RFP should strongly encourage collaboration with private partners
- The RFP should strongly encourage collaboration with other government agencies that are not among the usual public health partners.

What are the short-term recommendations to CDC and ATSDR?

Inventory private data sources

What are the long-term recommendations to CDC and ATSDR?

- Develop relationships with private partners that are formal data sharing partnerships
- Integrate data from these sources into the EPHTN

RECOMMENDATION 8:

EPHTN architects should ensure data-sharing agreements exist between relevant agencies at the state and federal levels. These interagency agreements, or memoranda of understanding (MOU), allow the agencies that collect data under specific legal authority to release those data to the agencies that need them for policy development and program planning (e.g., state, local, EPA, NIH, poison control centers, USGS, NOAA, NASA, DOE).

Rationale

- Protect integrity of its data transactions, guide data transaction security provisions, and schedule data submissions
- Outline the expectations for adherence to common data standards and technical infrastructures, and the means to define issues for which no established data standards—such as metadata and associated information—exist

The basic structure (in the form of an MOU template from which specifics can be developed) should be provided to EPHTN participants. EPHTN should provide technical assistance to its participants both during the development phase of MOUs, and during the implementation and operation phases, when MOU modifications may be desired. EPHTN should also provide direct assistance, through grant support, to offset agency staff time necessary for MOU development.

During the MOU development phase, separating (or at least clearly distinguishing) the MOU portions that address data, data access, and transfer mechanisms from those that address data use may be useful. Issues of data use are far more complex and political than those concerning secured access, yet the two can easily become confusing, and progress on each stymied. Furthermore, to the extent possible, MOUs should reference (and encourage) the use of common standards and exchange infrastructure. The EPHTN will not be able to achieve its broader goals unless this standard infrastructure is used, and if it is used, the MOUs can simply reference it, rather than having to duplicate it each time.

Elements of an MOU

The initial section of an interagency agreement (i.e., MOU) should state the purpose of the document and the public benefit from this relationship between the participating agencies. (For example, an MOU for surveillance does not stand alone but rather operates in the context of a broader interagency agreement.)

The second section of an MOU should describe the overall roles and responsibilities of the participating agencies and the relationship between them. It covers the statutory authority of each agency, arrangements for cost-sharing, mechanisms for resolution of differences (such as with data interpretation), and procedures for amendment of the MOU.

The final section of the MOU should specify details of activities. This includes the list of data systems, procedures for data transfer, frequency of data transfer, procedures for data quality control (such as compliance or enforcement for those reporting data), limitations on the use of data, mechanisms for preservation of confidentiality of data with personal identifiers (such as during record linking), conditions for data release, responsibility for interpretation and dissemination of results, procedures for identification and resolution of data gaps, specification of responsibility for follow-up investigations, and a statement of the need for flexibility to adapt to changing data needs. Typical MOUs for electronic data exchange additionally include arrangements for network administration, data standards, and data exchange templates.

How does this relate to the RFP?

CDC, ATSDR, and their partners should investigate and make available typical MOUs for data sharing and retrieval.

What are the short-term recommendations to CDC and ATSDR?

- Funded projects should develop MOUs, as appropriate
- Establish a MOU allowing CDC, ATSDR, and states access to EPA environmental data and allowing EPA and states access to CDC and ATSDR health data
- Work with staff from the EPA Exchange Network to develop standard templates for MOUs. Make these “boilerplate” MOU templates available to state health agencies, along with technical assistance to aid in necessary modifications to meet local needs

What are the long-term recommendations to CDC and ATSDR?

- In collaboration with Exchange Network staff, provide ongoing technical assistance to states in maintaining MOUs
- Develop MOUs with the full range of agencies that hold data appropriate for EPHTN

RECOMMENDATION 9

EPHTN architects should develop a comprehensive information security plan and include technical specifications describing the plan in the construction of the EPHTN.

Rationale

Several federal different statutes and regulations govern data security standards, and state privacy laws also apply. Individual agency protocols also influence security of data access and

transmission. CDC's recent technical guidance to states on bioterrorism funding applications also can be expected to play a major role in state data security protocols.

To ensure that federal privacy protections (e.g., HIPAA) are adequately addressed, EPHTN should

- Identify different types of users who may need access to EPHTN data
- Evaluate the data to be shared
- Develop a method for secure electronic information exchange (e.g., encryption, digital certificates, virtual private network, public/private key infrastructure, biometrics, secure tokens) for information so regulated (i.e., patient claim data under Medicaid or other insurance agency)
- Nonsecure, nonregulated information also could be transmitted using these methods or by more traditional means (unencrypted e-mail, FTP, U.S. mail, or overnight delivery service), depending on the volume of information to be exchanged and the capacity of the secure network to do so.

Access to data will be managed locally using lightweight directory access protocol (LDAP), by state and local health departments (or agents) in accordance with applicable state-specific laws and regulations (i.e., state partners will determine which data elements [table rows, columns, and cells] will be available for sharing).

However, the EPHTN architects need to allow for aggregated, de-identified data to become available for research and policy purposes, as well as for educating the public and policy makers about health effects associated with environmental exposures.

Although the EPHTN's primary users may be the research community, the EPHTN also should be designed to provide accessible and useful information for policy makers and the public, while observing privacy and security standards.

Next Steps

- Review CDC's "Public Health Information Technology Functions and Specifications" (for Emergency Preparedness and Bioterrorism) dated February 8, 2002
- Ensure that public health partners are involved in developing and implementing standards-based data specifications
- Identify the levels of access and types of user groups who will need access to EPHTN data

- Identify other federal agency models for providing “tiered access” to different user groups (e.g., anonymous access through the Web; registration using e-mail; registration using title, address, contact information; verification procedures)
- Develop a comprehensive, long-term strategy for “tiered access” to protect data security while making data available as appropriate for public use.

Final Report
Workgroup #3 - Tracking System Inventory and Needs Assessment

The charge to this workgroup was to identify and describe existing tracking systems at the national, state, and local levels; determine priorities for integrating existing tracking systems; and identify and prioritize the development of new systems.

The Environmental Public Health Tracking Network (EPHTN) should be a system, or network of systems, that

- Provides baseline and trend information about chronic diseases and conditions of current and emerging interest and concern at the national, state, and local levels
- Reintegrates public health and environmental practice and helps elucidate relations between environmental exposures and human diseases and conditions
- Is accessible and useful to local communities and to public health and environmental protection officials

Inventory and Description of Existing Health Tracking and Surveillance Systems

To focus its work, the workgroup prioritized health endpoints for the EPHTN. These health endpoints reflect the priorities articulated by the Pew Environmental Health Commission together with the recommendations of the experienced public health professionals who participated in the workgroup. They share common attributes: with the exception of "acute chemical poisoning," each is a chronic disease or condition of complex, multifactorial etiology that is little understood but in which environmental factors have been strongly implicated. The priority health endpoints are

- Birth defects
- Developmental disabilities (including cerebral palsy, autism, and mental retardation)
- Asthma and other chronic respiratory diseases
- Cancer, especially childhood cancers
- Neurologic diseases (including Alzheimer's disease, Parkinson's disease, and multiple sclerosis)
- Adverse reproductive outcomes
- Endocrine effects (including early menarche, hypospadias, and low sperm count)
- Autoimmune disease, especially lupus
- Acute chemical poisoning

Drawing on the expertise of its members and an extensive search of state, federal, and

health-related websites, the workgroup developed an inventory of chronic and environmental health tracking systems and a set of criteria for assessing these against the goals of an EPHTN.

The workgroup took a broadly inclusive approach¹ to the identification and description of disease tracking and surveillance systems. In addition to the many CDC and ATSDR sponsored federal and state health surveys and registries, the workgroup also included in its inventory specific National Institutes of Health (NIH) and Health Resources and Services Administration (HRSA) projects. Although epidemiologic work is only one component of these projects, the workgroup thought they nevertheless could represent good strategic leverage points for the EPHTN. Finally, a sampling of state disease tracking programs, large health-care administrative data sets and a number of unique commercial health data collection and linkage efforts were included. These are briefly described below.

To help assess the utility of each system in the inventory to the epidemiologic work of the EPHTN, the workgroup characterized the systems according to the following variables:

- Scope (e.g., national, statewide, multistate, city, multisite, demonstration project)
- Standard definitions (e.g., ICD-9/10, data-dictionary, serologic finding)
- Level at which data are statistically meaningful (e.g., individual, block, ZIP code, city, state)
- Type of measurement (e.g., incidence, prevalence, lifetime occurrence)
- Population (e.g., sample, cases, population, enrollees)
- Study design (e.g., longitudinal or cross-sectional)
- Method of data collection (e.g., questionnaire, telephone, interview, vital records, administrative records)

Other variables include whether the data source is linked to demographic information; whether it includes children; whether it includes or can be linked to exposure information; and, for local and demonstration programs, whether it can be replicated.

Overview

Public Health Data Sources

The primary tools for disease tracking include legal and administrative record systems such as vital statistics and hospital discharge data; disease registries such as cancer, birth defects, immunization, and hazardous exposure registries; population surveys such as the Behavioral Risk Factor Surveillance System (BRFSS), the National Health Interview Survey (NHIS), the National

¹ Although extensive, the workgroup's search was by no means exhaustive. The workgroup doubtless missed many important examples of state-level disease tracking initiatives, and we were able to include only a few examples of local projects. Because a fundamental premise of the EPHTN is that existing tracking systems do not adequately capture information about most of the priority health endpoints (diseases or conditions), we were most interested in casting a wide net to learn what other sources of this information might exist. The resulting inventory provided the opportunity to think more creatively and expansively about sources of epidemiologic data that bear on the EPHTN.

Health and Nutrition Examination Survey, and the State and Local Area Integrated Telephone Survey (SLAITS); and provider surveys such as the National Ambulatory Medical Care Survey (NAMCS), the National Hospital Medical Care Survey (NHMCS), the National Nursing Home Survey (NNHS), and the Medical Expenditure Panel Survey (MEPS). CDC and the states use many of these instruments, and most of these instruments have state modules that enable state health departments to include questions of specific local interest. Some are standardized at the national level, others are not. Some states use all of these instruments to develop a picture of priority conditions that is as comprehensive as possible (e.g., Connecticut's Asthma Report), while others use one or two, and may or may not integrate analyses.

The strengths and weaknesses of this public health "toolbox" for tracking and monitoring chronic and environmental health conditions have been summarized by The Pew Environmental Health Commission and others. As potential building blocks for the EPHTN, many of these systems are challenged by poor geographic specificity, lack of state-to-state comparability, inconsistent case definitions, few links to exposure measurement, and/or a focus on specific diseases rather than syndromes of potentially common etiology. To these assessments, the workgroup would add that tracking many EPHTN priority diseases and conditions will require a much greater emphasis on ambulatory care data than the current public health toolbox affords. Only a small fraction of conditions such as asthma and chronic respiratory illness or endocrine-related conditions will turn up in hospitals in any given year, and this fraction diminishes as the health system changes and evolves new means and settings to manage chronic health conditions and health conditions that are not life threatening. Traditional telephone surveys and self-reported questionnaires are imprecise alternatives for capturing information about these conditions consistently and meaningfully.

Other Health Data Sources

In addition to the major public health surveillance tools in regular use, the tracking system inventory includes the substantial health data systems under the Medicare and Medicaid programs. Given the nature of these programs, their data sets represent potentially rich sources of information about populations of special interest to public and environmental health (low income women and children, people with disabilities, and the elderly). The inventory also includes Public Health Service (PHS) programs such as Community Health Centers, Federally Qualified Health Centers, and Maternal and Child Health programs that also provide services to populations that may be of special interest or concern and that collect and maintain extensive diagnostic, service, and demographic information in uniform databases.

Also contained in the inventory are several NIH-supported activities (Centers of Excellence and longitudinal studies) focused on EPHTN priority diseases or conditions. Though designed to serve research needs rather than public health applications, these programs were included because they represent important opportunities to capture environmentally related risk factors and/or because they can provide springboards for collaborative epidemiologic research. One potentially applicable model for bridging the gap between NIH-sponsored academic research centers and

state health departments is the Prevention Research Centers program.

The inventory also identifies important surveys and longitudinal studies conducted by other federal departments. For example, the Department of Education collects extensive data under the Individuals with Disabilities Education Act that could support tracking of learning and developmental disabilities. These are priority conditions for the EPHTN.

In addition to federally sponsored health data and tracking systems, the inventory includes several exemplary surveys, registries, and databases developed by individual states that could contribute important information to disease tracking efforts (e.g., the Wisconsin Family Health Study). Some of these state-based initiatives were originally developed for surveillance purposes; others were established to capture health expenditure information or to support local or statewide planning and budgeting activities. Nevertheless, many contain useful health status, demographic, diagnostic, and utilization information.

Finally, the inventory contains information about a sampling of private sector health plans, data warehouses, and electronic data interchange (EDI) contractors, as well as physician practice research networks funded by a variety of interests that offer novel opportunities for broad population-based disease tracking.

Inventory and Description of Existing Environmental Tracking and Monitoring Systems

Following the work of The Pew Environmental Health Commission, the workgroup identified priority environmental hazards for inclusion in the EPHTN. These are

- Persistent organic pollutants, including polychlorinated biphenyl (PCB) and dioxin
- Heavy metals, including mercury and lead
- Pesticides, including organophosphates and carbamates
- Air contaminants, including toluene and fine particles
- Drinking water contaminants, including pathogens

The workgroup also developed descriptive criteria to assess the utility of existing environmental monitoring systems to EPHTN applications. These criteria are

- Type of exposure estimator (e.g., emissions, production, contamination, residue, personal monitor)
- Media (e.g., indoor or outdoor air; surface, drinking, or ground water; soil; food; human tissue; bulk chemicals)
- Geographic unit (e.g., national, regional, state, region of state, county, city, ZIP code, census, facility)
- Sample frequency (yearly, quarterly, monthly, weekly, daily, irregular, mixed)
- Sample locator (e.g., latitude and longitude; Universal Translocator System; metropolitan statistical area, city or municipality, county or parish, ZIP code, street address, Hydraulic

- Unit Codes, River Reach Number, other)
- Substances covered (e.g., acids, bases, PCBs, VOCs, metals, pesticides, criteria pollutants, aeroallergens, particulates, pathogens)

Data and information about priority environmental hazards are collected by a variety of state and federal agencies. However, few environmental monitoring systems were established with public health practice in mind, and as a result, they are not widely used by public health practitioners to characterize exposures that could potentially effect human health. Workgroup members were sensitive to complaints about the general quality of environmental data that currently are collected. A review of the major data sets in the inventory (Attachment) demonstrates four general issues:

1. What is measured: Data collection systems vary, but in most cases they exist to support EPA's ability to assess compliance with environmental regulations or the success of regulatory programs to reduce pollution. Thus, the monitors that capture environmental contaminants are generally placed at the source of known or suspected emissions and discharges (e.g., air monitors are placed in areas of high pollution, and water monitors are placed at the end of the discharge pipes), rather than distributed across areas where people are likely to come into contact with the contaminants. As a result, health investigators often must apply a still evolving complex of modeling techniques to assess "upwind" or "downstream" exposures, further complicating efforts to assess actual exposure effects.
2. How often it is measured: Some systems, such as the Air Quality Information System, take sample measurements every day and, for some pollutants, every hour; others, such as the Safe Drinking Water Information System, are required to report data only every quarter; and still others record information annually, or on an ad hoc basis in response to concerns about a particular area or event, such as an unintentional release of hazardous material. The fewer the number of measurements for any particular exposure, the more likely it is that the effect of that exposure, if one exists, will be underestimated.
3. How the measurements are defined: Because most measurements are taken to support environmental regulations, the threshold values captured can change with each new rulemaking.
4. How the information is reported to and aggregated at the national level.

Fortunately, many states may collect far more environmental monitoring information than they report to EPA, although, as the workgroup members noted, the quality of that information also can vary considerably from state to state. Generally, the quality and completeness of state environmental data are driven by the needs of state public health and environmental protection officials to address popular, legislative, and gubernatorial concerns. That fact may be useful for identifying states where pilot tracking projects are likely to be enthusiastically supported.

The workgroup noted that while the mixed quality of environmental hazard and exposure information has limited health research and epidemiologic studies for many years, many researchers have nevertheless found ways to work with existing data (e.g., the 6-cities study and New Jersey drinking water study)². In addition, EPA is committed to incorporating public health indicators into its program planning and evaluation efforts, which will help propel the development of better monitoring and exposure data. Finally, although there have been many calls and recommendations from the environmental health community for "better environmental exposure data," such calls have not often been accompanied by specific requests in the right venues for adjustments or enhancements to environmental monitoring systems. The EPHTN will create a strong venue for sharing practices and recommending refinements.

LEVEL I RECOMMENDATIONS: LINK EXISTING SYSTEMS

Recommendation #1: As an initial step, the EPHTN should support states to create or build on links across health and related data sources for priority chronic disease and environmental health endpoints. Such links may be as simple as the copresentation of indicators for diseases and conditions of interest in a common medium (e.g., narrative report or geographic display), or as elaborate as fully integrated software systems, depending upon the state's current level of sophistication. Health data links should address the following objectives:

A. Characterize the disease or condition, and triangulate data sources

In theory, national and state-specific data sets can be used in combination in studies of the prevalence of a disease or condition; the morbidity, disability, and mortality associated with it; its distribution (e.g., geographic and ethnic variation); its associated cost burden; and its evolution (i.e., natural history) in a population. However, in practice, multiple data sources are infrequently linked because relevant indicators (e.g., for asthma, doctor visits and missed school days) may be collected by different federal and state departments, may not be captured in common space and time (e.g., bi-annual statewide telephone sample surveys versus annual hospital service area discharge statistics), may not be available in a timely manner, and may use different definitions (e.g., physicians' diagnoses versus self reported asthma cases). For these very reasons, however, linkage efforts are so often valuable. As part of the effort, researchers learn how well or how poorly comparable data elements from multiple systems confirm one another and what those findings suggest about the strengths and weaknesses of individual systems for public health tracking.

² Bove F, Environmental Health Perspectives; Cator KP, Drinking water and cancer. *Cancer Causes and Control* 1997;8:292-308; Massachusetts Department of Public Health, Woburn Childhood Leukemia Follow-Up Study, Bureau of Environmental Health Assessment, Massachusetts Department of Public Health, 1997; New Jersey Department of Health and Senior Services, Case-control Study of Childhood Cancers in Dover Township (Ocean County), New Jersey, Division of Epidemiology, Environmental and Occupational Health, 2001; Cohn P, Klotz J, Bove F, Berkowitz M, Fagliano J, Drinking water contamination and the incidence of leukemia and non Hodgkin's lymphoma, *Environ Health Perspect* 1994;102:556-61; Croen LA, Todoroff K, Shaw GM, Maternal exposure to nitrate from drinking water and diet and risk for neural tube defects, *Am J Epidemiol* 2001;153:325-31; Munger R, Isacson P, Hu S, Burns T, Hanson J, Lynch CF, et al, Intrauterine growth retardation in Iowa communities with herbicide-contaminated drinking water supplies, *Environ Health Perspect* 1997;105:308-14.

Best practice examples of data linking (that do not depend upon integrated data systems *per se*) include Connecticut and Nebraska reports on childhood asthma. Each of these states has compiled asthma statistics from a variety of public health, administrative, and school-based tracking systems (e.g., hospital discharges, emergency department (ED) visits, BRFSS, missed schooldays, pharmacy records) to present a comprehensive picture of asthma prevalence and disease burden within its borders. Through such triangulated data (the copresentation of statistics from different systems), the states' public health officials have compensated, in some measure, for the imperfections of the individual data sources and assembled a baseline series of indicators to track asthma.³

How does this relate to the Requests for Proposals (RFP)?

Applicants should describe how they propose to create multidimensional baseline indicator reports for three chronic environmental health conditions. At least two of the three conditions should come from the priority list. Baseline indicators should include prevalence, morbidity, disability, mortality, ethnic variation, cost burden, and geographic and temporal trends.

In planning and compiling the reports, state health officials are encouraged to leverage resources beyond the traditional purview of health departments, including, as appropriate, schools, laboratories, Centers of Excellence, the aging network, Medicaid and Medicare data marts, health plans, and pharmacy sales. States should report to CDC and ATSDR on the concordance of these sources with other public health data sets (where they exist) for case definitions, key variables, and other characteristics relevant to their use as epidemiologic tools. The degree of actual data and software integration (versus copresentation in narrative or other reports) should be based on a realistic assessment of states' current data systems, with the goal of gradually enhancing sophistication and data integration capability.

Rationale Baseline data are needed for all EPHTN indicators. In addition, much learning, practice, and problem solving happens during the development of a data based report. State public health personnel will gain first-hand, applied knowledge of the availability of relevant data and data systems across programs and agencies. CDC and ATSDR will gain valuable insight into the potential contributions of nontraditional sources of public health information, as well as the obstacles to their integration with current CDC-sponsored systems.⁴

B. View and assess the "health" of local communities with respect to chronic disease

³ Even so, the vast majority of asthma cases present and are diagnosed in primary care physicians' offices, rather than in hospitals, so existing public health data systems that rely heavily on a combination of respondent self reports and hospital admissions, discharge, and ED data will fail to accurately capture true disease prevalence and thus produce poor estimates of associated burden. The workgroup underscored that state and local public health agencies must have much better information about the prevalence of diseases and conditions that present only or mostly in the non hospital ambulatory setting.

⁴ These insights should be communicated in a timely and thorough manner to the Public Health Data Standards Consortium (PHDSC), the National Committee for Vital and Health Statistics (NCVHS), and the HHS Health Data Council, which oversees development of national health data standards.

indicators

One goal of an environmental public health tracking system is to generate information about the co-occurrence of diseases or conditions (e.g., adverse reproductive outcomes, chronic respiratory diseases or neurologic disorders) that may share some etiologic agent(s), affected group(s), or other attribute(s) of interest and to compare this information across populations. However, as noted above, data on priority diseases and conditions, if they are collected at all, are collected and reported by different systems, registries, or surveys (e.g., cancer registries, birth defects surveillance systems, National Health Interview Surveys), making characterization of the health of a community with respect to any combination of these indicators exceedingly difficult.

Geographic information systems (GIS) provide one means of presenting such information in common space and time (i.e., geography is the common denominating variable), thus enabling a more complete picture of community health status with the potential to unfold patterns of public health significance on key indicators.

How does this relate to the RFP?

Applicants should describe an approach to co-presenting data on at least three EPHTN priority health endpoints at the substate (ideally community) level. At a minimum, these data should include incidence or prevalence and basic demographic information for each health endpoint. The applicant should describe how underlying data would be made available to researchers, the public, or others. CDC and ATSDR should provide technical assistance to system administrators on privacy and small area analysis issues.

Where appropriate, proposals should include a description of existing state GIS capacity, its platform, current uses, degree of public access, and whether and how it can incorporate priority environmental health indicators.

Rationale This is a core objective.

C. Assess specific populations

The workgroup also noted several state-based data linkage projects designed to better exploit the research and prevention potential of combined databases for specific populations. Many of these efforts were kindled under the Maternal and Child Health program and the Robert Wood Johnson Foundation Information for State Health Policymakers (InfoSHiP) grant programs, and thus focus on linking data sets that particularly describe the vital statistics, health status, risk factors, nutrition, and service utilization of pregnant women and children. Most projects also incorporate birth defects and tumor registries, and several include newborn metabolic and endocrine screening data. Because children and pregnant women are populations of interest for so many environmental exposures and conditions, these state based linkage projects could serve as platforms for more ambitious environmental public health data collection (including biomonitoring) and integration efforts.

How does this relate to the RFP?

Applicants should describe how they would integrate existing population-specific data linkage projects into their public environmental health tracking network. Applicants also should be encouraged to consider how routinely collected newborn blood spots and maternal cord blood samples could be used for environmental exposure measurement (biomonitoring).

Rationale Infants, children, and pregnant women are of great interest and concern to environmental health scientists, representing "sentinel" populations for many environmental exposures. The Maternal and Child Health/InfoSHiP projects capture important contextual variables (e.g., maternal health, nutrition status, limited blood analysis) to enable a rich assessment of potential contributors and confounders to specific health outcomes. In addition, because newborns and children under age 6 years are excluded from the NHANES biomonitoring protocol, environmental exposure data for this population have been lacking, but blood spots that could be used for this purpose are routinely collected as part of the MCH newborn screening program. Finally, many of the existing state data linkage projects are funded, not through CDC or ATSDR, but through other federal agencies, providing a leveraging opportunity for limited health tracking funds.

D. Leverage NIH support, resources, and collaboration:

NIH conducts a wide range of epidemiologic investigations pertinent to the EPHTN, and opportunities exist for coordination and collaboration with CDC and state public health officials. Examples of NIH projects that are relevant to the EPHTN include the National Institute of Environmental Health Sciences' (NIEHS) Environmental Genome Project, which currently is conducting population-based epidemiologic studies of Parkinson's disease, susceptibility to pesticides, and prostate cancer. Similarly, the National Cancer Institute (NCI) conducts large population-based studies on gene-environment interactions to explore the interplay between inherited susceptibility to cancer and environmental risk factors. Finally, NIH sponsors Centers of Excellence on several EPHTN priority health conditions, including Morris K. Udall Parkinson's Centers, Children's Environmental Health Centers, and Centers of Excellence for Autism and Developmental Disabilities. Where there is local concern about conditions within Centers' portfolios, public health officials should be able to leverage the extraordinary resources of these Centers to help support their own epidemiologic work. State health department collaboration with the Centers also could help ensure that new findings related to diseases and conditions of interest can be quickly assessed for their relevance to public health monitoring and assessment functions for both hazards and health effects. A model for such academic and public health coordination might be the Prevention Research Centers.

How does this relate to the RFP?

Applicants should be encouraged to link with NIH-supported population-based epidemiologic research on priority EPHTN health indicators.

Rationale Expand the resources available to environmental public health and the expeditious dissemination of new knowledge to the field.

Recommendation #2 A demonstrated relationship between state departments of health and state environmental protection agencies (or their appropriate analogues) that will facilitate data linkage, interpretation, and development should be a prerequisite for health tracking support. Opportunities for connectivity and leverage include shared GIS platforms, interdepartmental liaisons, ATSDR cooperative agreements, and state public health and environmental laboratories.

Fundamental to the EPHTN is the expectation that public health practitioners can characterize environmental hazards within their jurisdictions that could potentially affect human health. They should be able to identify the different types of hazards or pollutants; media and systems that can be affected (e.g., food; land; indoor and outdoor air; and lakes, rivers, pools, coastal areas; and public and private drinking water supplies); the likely sources of contaminants; the appropriate indicator organisms, trace elements, and chemicals; the manner in which humans are exposed to the contaminants; and the implications of exposures to peoples' health over time. In addition, health practitioners should know where chemicals are used and stored after manufacture and how the public is exposed. Finally, health officials should have the means to interpret environmental hazard and exposure data, including models necessary to convert raw data to relevant health information.

As noted above, however, although a wealth of environmental data exists, most of it has been developed for specific environmental regulatory purposes, making accurate interpretation and application of the data difficult for those outside the regulatory framework. An accessible resource with knowledge of the relevant questions, the ability to identify processes and linkages, and the ability to place the data in an appropriate context would make the data more meaningful to health officials. There are several models

1. The HHS Assistant Secretary for Planning and Evaluation (ASPE) maintains a database of state health data integration efforts (current as of 1998), and among the projects described are several that link health and environmental information. As expected, these examples turn up most frequently in states where departments of public health and environmental protection remain closely tied. One example is Colorado, which has instituted a GIS to serve both public health and environmental protection programs and has developed a cooperative Center for Health and Environment Statistics. A second example is Indiana, which also has developed a GIS that includes demographic, infrastructure, and environmental data to develop programs and track health outcomes at the community level, supplemented with a public and private Health Data Center that pulls information from public health, Medicaid, hospitals, workers' compensation, and other sources. Indiana's GIS was developed through the joint efforts of GIS users in many state agencies who had been using GIS to study trends within their agencies. Ongoing development of the system fits within a broader overall strategy to integrate data and empower local areas

to understand their local health and environmental issues. A new example is New York State's Cancer Surveillance Improvement Initiative, which includes a cancer registry that allows for the analysis of cancer incidence and its relation to environmental and other factors.

2. Using a different model, Alaska designates liaison personnel to manage information sharing between its public health and environment protection departments. The interdepartmental liaisons translate data, programs, and practices, and discern the right place in the other organization to pose questions or request assistance.
3. ATSDR's state cooperative agreements could naturally bridge public health and environmental protection functions. At the national level, ATSDR works closely with both CDC and EPA in responding to hazard releases. At the state level, ATSDR supports multidisciplinary teams of health professionals who characterize past and present chemical releases and assess health threats posed to communities living around approximately 500 National Priority List (NPL) hazardous waste sites. This broad expertise in toxicology, environmental assessment, exposure investigation, and community education is a tremendous resource for state environmental public health programs.
4. Finally, an important opportunity exists to expand and coordinate state laboratory capacity for environmental sampling and media monitoring with state and regional public health laboratories through ATSDR, CDC Bioterrorism Cooperative Agreements, and the Federal Emergency Management Agency.

How does this relate to the RFP?

Applicants should provide documentation of an agreement between the directors of the relevant public health and environmental protection agencies to collaborate on the development and interpretation of environmental data necessary to support the EPHTN. Applicants should explain how they intend to assess the capacity of existing environmental hazard data to provide information about patterns of exposure. They should select two health endpoints from the priority list, or one health endpoint from the priority list and one hazard of local concern (which need not be related to the health endpoint) with which to demonstrate links across health and environmental information sources. States should be encouraged to propose efforts to further develop these links using tools that serve common health and environmental monitoring purposes, including GIS, biomonitoring, ATSDR cooperative agreements, and environmental health laboratories. Applicants should describe a process by which "lessons learned" and recommendations to enhance and or refine health and environmental data to better serve the goals of the EPHTN will be communicated to the leadership of the relevant agencies and to CDC and ATSDR.

Rationale The use of data to reintegrate health and environmental practice is a core objective of the EPHTN. However, many public health professionals are not sufficiently familiar with

environmental databases to use them comfortably. Many state environmental protection officials, too, have expressed frustration that media monitoring requirements, driven by the regulatory enforcement system, do not generate the data to answer the public health questions that the public is asking of them. This recommendation will require a detailed assessment of the public health utility of state-level environmental data, and create a feedback loop to state officials and system architects to help them refine their instruments to better meet public health needs.

Recommendation #3A: CDC, ATSDR, and EPA should establish a regular forum for intensive, hands-on (applied) exchange between state and federal public health and environmental data developers, statisticians, and other users.

CDC, ATSDR, and EPA should provide national or regional training workshops for state public health and environmental protection officials to bring their own data sets together to approach and solve actual problems. The purpose of these workshops is to create a shared knowledge and facility across the two agencies' systems.

How does this relate to the RFP?

Applicants should agree to contribute to and actively participate in the workshops.

Rationale Peer-to-peer exchange on problem solving techniques and best practices will help data systems and practices evolve toward greater state-to-state consistency. This is a key goal of the EPHTN. Another important outcome of the workshops will be a feedback loop to state and federal data system architects about strengths and weaknesses of the systems for environmental health applications and the meaningful tracking of relevant indicators.

Recommendation #3B: CDC and ATSDR should facilitate evaluation of GIS for application to the EPHTN

More and more states are using GIS to begin to assess public health questions. However, GIS systems vary considerably from one another in the sophistication of their underlying statistical software, their ability to manage large amounts of multilevel information, their methods for small area analysis, and other characteristics important to epidemiologic and environmental health applications.

Similarly, states that actively use GIS have very different practices for managing, sharing, and presenting data. For example, New Mexico maintains a data repository that was codeveloped by the New Mexico Department of Health, the New Mexico Health Policy Commission, the New Mexico Tumor Registry, and the University of New Mexico. Clinicians and communities throughout the state can use the data repository to assess community health status. The software platform is ArcIMS, a commercial Internet-based platform requiring no preexisting knowledge of GIS to use the data. Washington developed Epi-QMS, which allows users to carry out exploratory geographic and statistical analysis and is available to users at three levels: 1) the

general public, 2) public health and medical practitioners, and 3) epidemiologists. Its database uses accumulated records, processed off line and uploaded, rather than record-level information. A key feature of the system is the availability of small-number adjustments that include nearest neighbor and empirical Bayesian smoothed rates. EpiQMS does not require purchase of mapping software but uses scalable vector graphics (SVG), a new Internet graphics standard that speeds up map production. Other states have evolved their own customized GIS platforms, applications, and access requirements..

Finally, EPA and ATSDR have built extensive mapping platforms that include U.S. Geologic Survey hydrology data, National Oceanic and Atmospheric Administration atmospheric data, and other information that supports environmental modeling. Building environmental public health datasets on top of one of these systems might be advantageous (provided they represent state-of-the-art and state-of-the-science technology and statistical packages).

CDC and ATSDR should convene a meeting of GIS data developers, users, and stakeholders to assess all of these options and decide "best-platforms" and "best practices" for GIS public environmental health applications. CDC, ATSDR, and EPA may need to sponsor development of a customized system that includes all relevant functions and can be regularly upgraded and made available to state and local public health departments for one license fee. Because state-to-state consistency is a chief objective of the EPHTN, one goal should be to encourage proliferation of compatible systems.

How does this relate to the RFP?

Not applicable; this recommendation is directed to the federal agencies.

Recommendation #4 CDC and ATSDR should enhance core chronic and environmental health surveillance systems to better capture information about environmental exposures and conduct state pilots as part of the EPHTN.

Birth Defects Surveillance: In FY 2002, CDC had cooperative agreements with 35 states to report on the incidence of major birth defects, particularly neural tube defects. Agreements in seven states supported Centers for Birth Defects Research and Prevention, which collect cases and controls for the National Birth Defects Prevention Study. The remaining 28 states received support for surveillance and use of data for public health purposes. Congress has provided funds explicitly to expand and enhance the registries. Tracking funds should support linkages of birth defects data with 1) related conditions of interest, 2) diagnostic centers, and 3) data derived from hazard and exposure systems, which potentially could result in new information about possible causes, risk factors, and opportunities for prevention. CDC and ATSDR should work with the centers and state birth defects surveillance projects to develop the key elements, formats, and variables to enable these linkages.

National Program of Cancer Registries: In FY 2002, CDC provided grants to 45 states, three

territories, and Washington, D.C., to improve cancer registries or develop new ones. However, many states still cannot effectively respond to reports of possible clusters of cancer cases. States need the ability to capture all the cancers in their states, determine whether a cancer cluster represents an excess cancer risk, and link information about environmental contamination with cancer registry data. Workgroup members noted that more effectively capturing data from physicians' offices is important because more and more detection, pathology, and treatment services appear to be occurring there. The workgroup noted that NCI's Surveillance, Epidemiology, and End Results program (SEER) is attempting to link registry data with medical records.

Behavioral Risk Factor Surveillance System: The BRFSS is a state-based telephone survey active in all 50 states, and a primary source of information about national and state trends in health risk behaviors. Adding an environmental health module to obtain information about environmentally related conditions and exposures could enhance the survey. However, because it is an interview survey and respondents are unlikely to have a detailed knowledge of local environmental factors or conditions to which they are exposed, the survey must be linked to environmental hazard or exposure data sources. Moreover, if the BRFSS is to become a platform for environmental health tracking, it must dramatically increase within state sample size, require standardized questions related to environmental health endpoints in ways that ensure state-to-state consistency and minimize bias (e.g., "Has a doctor diagnosed _____?" "Are you currently being treated for _____"), and better address the issue of households without telephones.

Hazardous Substances Emergency Events Surveillance System: Maintained by ATSDR, this system describes the public health consequences, including morbidity and mortality and associated risk factors, of acute releases of hazardous substances. Sixteen states currently implement this system. CDC and ATSDR might leverage bioterrorism funds to expand this program to the remaining states for dual use.

Recommendation #5 : Concurrently improve the ability of existing systems to capture priority health endpoints

The workgroup noted that many existing health data collection instruments do not precisely characterize priority environmental health endpoints, presenting challenges to accurate data collection, research, and interpretation, but also limiting opportunities to improve and expand surveillance capacity. Opportunities to improve the ability of existing systems to characterize and track health endpoints of interest reside in case definitions, coding and classifications systems, survey questions, sampling frames, and laboratory reporting practices.

CDC and ATSDR should accelerate work on standardizing case definitions for environmental public health tracking in concert with other federal and state agencies that use and report health statistics. Where possible, CDC and ATSDR should move to adopt case definitions that have achieved broad acceptance, with the understanding that retrospective adjustments may be needed.

Case Definitions: Developmental Disabilities

One of the chief obstacles to tracking childhood disabilities has been the lack of a standard case definitions. Capitalizing on recent conceptual and methodologic developments in the demographic, social, and biomedical study of disability, the National Institute of Child Health and Human Development is supporting the development of concise measures of childhood disability, with a focus on mental health and learning disabilities. The project relies on the 1994 and 1995 disability supplements to the NHIS, the 1997 NHIS, and the 1992 and 1993 Survey of Income and Program Participation (SIPP). The measures under development are specifically intended for use in population surveys and survey-based surveillance systems to monitor the prevalence of childhood disability.

Case Definitions: Mental Disorders and Cognitive Impairments

ASPE is reviewing survey elements for mental health and cognitive impairments that have been used in population-based national surveys. The project aims to review existing measures of mental disorders and cognitive or mental impairments, distinguishing diagnosis from impairment and symptoms in children, adolescents, working-age adults, and the elderly, and to document the validity and reliability of the measures to calculate prevalence. Additionally, coding and classification systems are not optimal for assessing many environmentally related health endpoints:

International Classification of Diseases

Most monitoring programs use the World Health Organization International Classification of Disease (ICD) codes, which is not particularly detailed. Biologically related conditions that nevertheless differ by etiology and pathogenesis might share the same ICD code; relatively few syndromes have a specific code; and many anomalies and conditions that are regarded generally as "minor" (although, as in the case of teratogen-induced conditions, they may be of diagnostic importance) cannot be easily coded. The birth defects system addressed this issue by appending modifiers to existing ICD-9 codes. The workgroup was uncertain to what degree similar issues inhere in other ambulatory coding schemes, HL-7 electronic data transaction standards, and the LOINC nomenclature that may confound efforts to track specific health endpoints.

CDC and ATSDR should assess coding schemes and transaction standards for their ability to capture with precision health effects that scientific evidence suggests may be linked to environmental factors and, where necessary, develop and advocate for necessary refinements.

National Health Interview Survey

The NHIS is one of the most important and often-used instruments in the public health toolbox. Because it serves as the sampling frame for many other federal surveys, it provides one of the few

platforms for data linkages. However, a recent regrouping and recoding of health outcomes within the NHIS creates new and significant limitations on its ability to capture diseases and conditions considered priority for the EPHTN⁵:

Lung and respiratory diseases: Many of the NHIS recode conditions correlate singly and specifically to specific health outcomes that have an environmental etiology (e.g., asthma) or groups of outcomes with known environmental etiologies (e.g., pneumoconiosis and asbestosis).

Neurodegenerative and neurotoxic disorders: With the exception of "migraine," numerous neurotoxic disorders are not included in the NHIS recodes, resulting in a great potential for underestimation of prevalence of environmentally related neurologic health outcomes.

Reproductive disorders: Neither male nor female infertility was included in the NHIS recodes, and thus prevalence rates can not be ascertained. One recode that does contain outcomes with possible environmental etiology is "delivery and other conditions of pregnancy and puerperium." However, this grouping contains complications ranging from pregnancy and fetal abnormalities affecting the mother to those of legally and illegally induced abortions and conditions arising from perinatal infections.

Surveillance Among Older Adults

The sample frames of household surveys (e.g., NHIS and BRFSS) consist of noninstitutionalized persons. Approximately 5 % of people aged 65 and over, and 20 percent of those aged 85 and over, are nursing home residents and therefore are not included in the sampling frame of household surveys. As a result, estimates of chronic diseases that are drawn from household surveys, including respiratory illness and neurodegenerative disorders such as Parkinson's disease, will underestimate the occurrence of these conditions. The NHIS and the Longitudinal Study on Aging used mixed modes of data collection and reliance on proxy reporters to improve sample coverage. However, more and better information about this population will require sampling frames composed substantially of older people⁶.

The Medicare Beneficiary surveys and claims files, the Nursing Home and Home Health provider surveys, and data maintained by organizations that focus on the aging population (including state agencies on aging) are valuable linkages and offer opportunity to coordinate information gathering across public health agencies. These surveys should be reviewed for their ability to capture health endpoints of interest and, if necessary, modified.

Laboratory Reporting Practices

⁵ Analysis originally conducted by the Pew Environmental Health Commission.

⁶ Blackman D, Kamimoto LA, Smith SM Overview: surveillance for selected public health indicators affecting older adults-United States. MMWR, December 17, 1999

Improved laboratory reporting practices facilitated by a developing common electronic reporting format and standardized data elements could offer numerous opportunities to contribute substantial information to the EPHTN.

For example, in New York, and probably in many other states, some cancer care is moving out of the hospital and into private physicians' offices. When diagnostic tests are conducted or ordered by an office-based provider from a free-standing laboratory, and the results are returned to that provider, the tumor registrar in the hospital is not alerted to the cases, and thus they are missed by the common channel of reporting. New York is moving to bring all cancer related laboratory tests from all laboratories under the state's reporting system to supplement the information provided by tumor registrars.

In addition, substantial opportunity exists to capture exposure and disease data lost through underreporting and threshold reporting. Many incidents of disease potentially related to environmental exposures remain largely unreported, and data necessary for good analysis are lost. For example, if readings of all blood lead levels (and other toxins) were made available, instead of only those surpassing thresholds, more realistic exposure patterns could be discerned.

With improved laboratory capacity and data standards, not only could the EPHTN achieve more complete reporting of health conditions, it could in many cases move toward more real time reporting. Thus, such systems can serve the needs of both chronic disease reporting and an early warning system.

Recommendation #6 CDC and ATSDR should actively and routinely survey the federal government's planned and ongoing studies for appropriate opportunities to integrate environmental health questions

LEVEL II RECOMMENDATIONS: AIMING TOWARD THE FUTURE:

The workgroup noted that HHS has a departmentwide effort, led by ASPE and the HHS Data Council and advised by NCVHS, to integrate data and data systems to better support program planning and accountability. This effort includes an initiative to integrate existing HHS survey instruments. At the same time, the major administrative simplification requirements under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) are effective this year, meaning that health-care transaction data, in both the public and commercial sectors, must conform to specified standards. Finally, despite early resistance by some in the medical community, electronic medical record systems are gradually coming on line. These developments, taken together, represent great potential for public health; they will allow the combining and sharing of data on a scale never before possible and will provide a font of clinical detail as yet unobtainable without painstaking and expensive manual medical record review.

All of these activities will take time to coalesce, even as they continue to evolve; however, the workgroup believed strongly that it is not too soon for public health practitioners to begin doing

some early hands-on assessment. In particular, the workgroup believed that the current early standardization requirements for administrative and clinical encounter data, both public and private, offer an opportunity for federal and state public health officials not only to gain valuable experience with health plan data systems—systems that will, because of their breadth and standardization, eventually become extraordinarily powerful epidemiologic resources—but to influence the ongoing evolution of data standards to more precisely meet public health needs. Taken together, Medicare, Medicaid, and health plan and insurer data will be able to provide detailed information for about 85%-90% of a state's population at any point in time. That observation alone suggest that this evolution could overcome many of the shortcomings of existing tracking systems. Moreover, data derived from these sources can be grouped and analyzed in small geographic units. They can yield information about patient demographics; complaints, diagnoses, comorbidities and risk-factors; inpatient, outpatient, and professional service utilization; and laboratory and pharmacy use. Finally, they can capture incidence and prevalence of ambulatory conditions and those for which incidence is too low to be well characterized even by statewide sample surveys.

Recommendation #7: Tracking programs should focus on the increasing importance of ambulatory settings as sources of data because conditions of public health importance are increasingly being managed in these settings.

The ability to track many priority chronic and environmental health endpoints requires a much greater emphasis on ambulatory care data than is afforded by current public health tools. Only a small fraction of conditions, such as asthma and chronic respiratory illness or endocrine-related conditions, will turn up in hospitals in any given year, and that fraction diminishes as the health system changes and evolves new means and settings to manage nonlife-threatening or chronic conditions. According to some estimates, over 80% of patient visits for asthma occur in the physician's office, as do 60% of all visits related to multiple sclerosis.

Telephone surveys and self-reported questionnaires are imprecise tools for consistently and meaningfully capturing information about these and other conditions. Fortunately, many other sources of ambulatory care data exist, and with the proper input from public health professionals, the movement toward data standardization should facilitate their integration into the EPHTN. These sources include Medicare and Medicaid claims files, provider surveys such as NAMCS and NHMCS, provider-based data warehouses such as those initiated by the National Medical Group Association, Ambulatory Practice Research Networks, EDI of provider claims to state health departments or warehouses, health plan data-sharing agreements, and large commercial data vendors.

Recommendation #8: The EPHTN should support pilot projects to explore the trade-offs among different approaches to capturing epidemiologic data from the health services domain. For example, state public health officials should be encouraged to develop relationships with health plans or other sources of encounter data for the populations within their jurisdictions.

CDC has already recognized the opportunities in private sector provider and health plan data. It maintains a working relationship with a cluster of the nation's largest, most research-oriented health plans for both epidemiologic and intervention studies on a wide range of health status, clinical, and performance issues.

The workgroup reviewed information about several state efforts to tap health plan and provider information for public health purposes. In Minnesota, for example, a statutory mandate requires data sharing between the state's health plans and the Minnesota Department of Health (MDOH), and as a result of relationships built in the course of implementing the mandate, the state's health plans are now also active participants in community health planning meetings and routine partners in primary and secondary prevention campaigns. One expressly articulated purpose of the data-sharing mandate is "information to assess the prevalence of chronic diseases and other emerging health issues." MDOH has collected fee-for-service and managed-care claims data from Blue Cross and three of the largest HMOs in the state; public program claims data from HHS; and fee-for-service Medicare data from the regional CMS Data Mart. One major challenge noted by the MDOH is the reconciliation of different Third Party Administrator (TPA) practices. Taking a slightly different tack, Wisconsin requires information to be submitted to the state health department directly by providers, thereby avoiding the TPA issue but also the opportunity to enlist plans as partners in prevention. In Rhode Island, relationships and data sharing are evolving slowly under a Health Plan Performance Evaluation mandate and a widely embraced Medicaid managed care/SCHIP quality assurance program. There are many other examples.

For tracking purposes, the advantages of working with such data include:

- The ability to track the prevalence, costs, and natural history of conditions that no public health surveillance systems currently captures, including morbidities of current and emergent interest in environmental health (e.g., asthma, neurologic impairments, autoimmune diseases, endocrine effects, and certain adverse reproductive outcomes)
- Broad population coverage (Medicare + Medicaid + insurers = 85%-90% of the population)
- Refined levels of geographic information
- The ability to access diagnostic data from multiple sources, including physician offices and clinics, and ability to match patient records
- The ability to track comorbidities and other indicators
- The ability to make entities that largely determine health services organization and delivery a partner in prevention
- The ability to do specific, local studies on conditions of interest concern, for example by

customizing data elements and analysis

- The cost of collecting the data is not borne by the state health department

Additional sources of private sector data include third-party administrators and large data warehouses that support pharmaceutical research and development. For example, the eHealth Initiative (eHI) represents the largest vendors of provider software in the United States, along with a handful of smaller companies. eHI already has approached CDC with a proposal to use this software to support bioterrorism surveillance activities. Similarly, Quintiles/Synergy is the world's largest data warehouse, capturing claims data from some 4,400 hospitals and 660,000 providers nationwide. It, too, has seen market potential in bioterrorism surveillance and public health applications. Representatives of both systems have testified publicly that their products could be integrated with the National Electronic Disease Surveillance System (NEDSS) architecture. The advantages of these systems are a large denominator and therefore presumed stability in the underlying population and near real time information. However, a national warehouse is less likely to be easily tailored to specific state concerns, to develop relationships with state health department officials, or to have a stake in what its findings suggest are opportunities for prevention and intervention. CDC and ATSDR should explore these trade-offs through state pilot programs under the auspices of the EPHTN.

How does this relate to the RFP?

Applicants should describe how they intend to initiate or expand relationships with the health services sector (e.g., health plans, providers, and data vendors) to access epidemiologic data for populations within their jurisdictions. At a minimum, they should anticipate the ability to collect and assess incidence and prevalence, location, demographic, and other variables related to health conditions of interest, their cost, and secular trends. Applicants should describe how they will develop, in consultation with state environmental protection officials, criteria for queries of such entities and entity reportable conditions, selecting at least two health conditions from the priority list. They should also describe how they will validate preliminary results of such queries against established public health data sources (e.g., registries, surveys, school reports) and agree to provide CDC and ATSDR with detailed reports on the strengths and limitations of such data sources.

Rationale The EHTN can help build the next-generation public health tool box by accessing the sources that build on HIPPA and e-Health Initiative momentum. Public health activities need to be positioned to help define and then meet the crest of this wave. Programs in the states should be encouraged to become engaged with and to use these tools early in their development. State programs should also establish a feedback loop to the architects of these tools.

Recommendation #9: CDC and ATSDR should provide technical assistance to states in developing data-sharing agreements based on lessons learned by other public and private data sharing partnerships in the health services domain (e.g., state Medicaid agencies and their

contracted managed-care plans and CDC's own collaboration with the American Association of Health Plans and the HMO group). CDC and ATSDR also should ensure regular feedback from state experiences to HHS data standards groups (including the HHS Health Data Council, the National Center for Vital and Health Statistics, the Center for Medicare and Medicaid Strategies, the Public Health Data Standards Consortium, and HL-7). Finally, on the basis of states' experiences, CDC and ATSDR should advocate within these data standards groups for relevant variables, metrics, and coding practices.

How does this relate to the RFP?

See recommendation 8. Recommendation 9 is directed to the federal agencies.

LEVEL III RECOMMENDATIONS: DEVELOP STATE SURVEY AND EXPOSURE MEASUREMENT CAPACITY

Recommendation #10: CDC and ATSDR should pilot a modified "State National Health and Nutrition Examination Survey" with a smaller questionnaire and much larger sample with target oversampling.

Adding geographic information into disease-specific data can help identify where prevention efforts need to be intensified. However, better quality of exposure information is needed to get below ecologic assessments of health and environment interactions. In fact, exposure measurement and assessment is the missing link in efforts to evaluate environmental health risks; without it, public health practitioners are hard-pressed to answer fundamental community concerns.

With the exception of childhood blood lead screening, few systematic efforts have tracked individual levels of exposure to any hazardous substance. Although CDC and EPA have developed the methodologies for biologic monitoring of a wide range of substances, their application and availability have been limited. A recent report of the U.S. General Accounting Office called for a long-term coordinated strategy to measure exposures to pollutants. It specifically called for coordination between the biomonitoring component of CDC's NHANES and EPA's National Human Exposure Assessment Survey.

For these reasons, the workgroup recommended that CDC and ATSDR also consider tracking proposals that would strengthen primarily biomonitoring systems for EPHTN priority hazards.

How Does this Relate to the RFP?

Level III (biomonitoring) applications should address the development of analytic techniques and design and pilot a sampling strategy that would reflect the exposure status for the population of the state or a target subpopulation (e.g., children). The value of the proposal should be assessed based on the breath of impact and potential application to other states. Highest priority should be

given to states that propose to link biomonitoring data with health data systems and/or environmental data bases.

CDC, ATSDR, and EPA should provide technical assistance to states in selecting hazards and health effects, appropriate metrics, survey design, biomonitoring protocols, and interpretation of results. In addition, CDC and ATSDR should assist states in planning for dual use of public health laboratory enhancements supported through bioterrorism funds for population-based screening.

Partnership for Integrated State Information Systems: This is a cooperative program between HRSA's MCH program and its Data Utilization and Enhancement (DUE) grantees (Arkansas, Florida, Hawaii, Kansas, Maine, Nevada, Rhode Island, Tennessee, and Utah). The purpose of this program, which lasts through FY 2002, is to improve coordination of maternal and child health-related data sets for planning, evaluation, and determining health status and health outcomes at state, substate, and national levels. Summaries of these state programs follow.

Arkansas: Links births and infant death certificates, inpatient hospital discharges, PRAMS, and the state birth defects registry in the Department of Health. Plans to bring in WIC and newborn screening programs, and Medicaid. Douglas Murray, dmurray@mail.doh.state.ar.us; 501-661-2633.

Florida: Links the Delivery Cohort Multi-year Linking Project (birth, infant death, prenatal and infant screening, prenatal and infant service) with GIS. Meade_Grigg@doh.state.fl.us; 850-245-4010 or 4465.

Hawaii: Its Perinatal Data System establishes interactive data flow between the Department of Health and the four birthing facilities in the state and links newborn metabolic screening and early intervention files to vital record files, and with Medicaid/QUEST, WIC, and hospital discharge files. (Based on New York system). Lorretta Fuddy; ljfuddy@fhsd.health.state.hi.us; 808-586-4122.

Kansas: Its enhanced Medicaid claims and birth record matching enables annual assessment of birth outcomes. lsaddi@kdhe.state.ks.us; 785-296-8627.

Maine: See Its system includes hospital inpatient, outpatient, ambulatory, and diagnostic data, and will incorporate Medicaid, vital statistics, and other MCH data sets. Alan.m.prysunka@astate.me.us; 207-624-8855.

Nevada: Its Information Network for Public Health Officials adopted Utah's Maternal Child Health Interactive Internet software to present birth, prenatal care, teen pregnancy, and fertility data; this network will add mortality, hospital discharge data, WIC, Medicaid, EMS, and trauma and cancer registries, with GIS functionality. Emil DeJan, edejan@govmail.state.nv.us; 775-684-4155

Rhode Island: This program builds on KIDSNET (child health profiles) to include metabolic, endocrine, and hemoglobinopathy screening data. It links with the birth defects surveillance system under development, and the Rhode Island Hearing Assessment Program and audiologists. See also New England Regional Newborn Screening Program. Amy Zimmerman; amyz@doh.state.ri.us; 401-222-5942

Tennessee: Children's Information Tennessee (CIT) is an integrated data system that connects health-related data bases in the Departments of Children's Services, Education, Health, Human Services, and TennCare. This system will be enhanced with specific condition, intervention, treatment, and outcome data. This program proposes to conduct an epidemiologic study of children with asthma. Richard Urbano; rurbano@mail.state.tn.us; 615-741-5001.

Utah: This program's model software, Maternal and Child Health Information Internetquery Module (MatCHIIM), will be augmented by WIC, PRAM, Newborn Screening, and other data sets. The program will transfer technology with Missouri's MICA system, the other model system independently developed. Lois Haggard; lhaggard@doh.state.ut.us; 801-538-9455.