

California Environmental Health Tracking Program



Future Assessment Survey and Report

Phase II Report

• • • • • • • •
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California
Department of
Health Services



Synergy Consulting, Inc.

A Subsidiary of AMS

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1. EXECUTIVE SUMMARY

Scientific research has identified an increasing incidence of environmentally-related chronic diseases. This research, however, is limited due to the lack of a comprehensive system to identify and track human exposures to environmental hazards and their corresponding impacts on health.

Recently chaptered legislation (Senate Bills 702 and 189) authorizes the California Department of Health Services (DHS), the California Environmental Protection Agency (Cal/EPA) and the University of California to establish an Environmental Health Tracking Network (EHTN) to collect and track data to better support research. The EHTN will track environmental hazards and diseases to identify locations that require action-- to reduce levels of exposure, monitor the success of interventions, and provide information for the development of related public policies.

The California Environmental Health Tracking Program (CEHTP) was created to develop the EHTN. The CEHTP is currently in the planning phase to develop technical aspects of the EHTN. In July 2003, the CEHTP initiated the Future Assessment Survey and Report to assess the current and future capabilities for health surveillance and environmental monitoring systems to provide data to the EHTN on an ongoing basis.

The first phase of the Future Assessment was completed in October 2003. This first phase assessed 20 systems and selected 12 systems to include in a Phase II detailed assessment to determine their readiness to become EHTN data sharing partners. Phase II included further technical assessment of the systems, and discussion between the CEHTP and systems owners to develop a collaborative relationship for sharing data. The results of the Phase II technical assessment supplement the information gathered in the first phase. The second phase is complete with the delivery and acceptance of this report.

Owners of the following systems were contacted to participate in Phase II of the Future Assessment.

Health Systems	Environmental Systems
California Birth Defects Monitoring Program Registry (CBDMP)	Aerometric Data Analysis and Management System (ADAM)
California Health Interview Survey (CHIS)	California Emissions Inventory Development and Reporting System (CEIDARS)
EUREKA (California Cancer Registry)	Highway Performance Monitoring System (HPMS)
Medical Care Statistics Section Database (MCSS)	Pesticide Use Report Database (PUR)
Patient Discharge Database (PDD)	Toxics Release Inventory (TRI)
Automated Vital Statistics System (AVSS)	Water Quality Monitoring Database (WQMD)

While the California Birth Defects Monitoring Program completed the Phase II technical survey, consent to participate in Phase II discussions was not obtained within the timeframe of the project. System owners from the remaining 11 systems participated in Phase II discussions and in reviewing technical capabilities of their respective systems.

The systems included in Phase II were assessed to determine the feasibility of contributing to the CEHTP's development of the EHTN. The Phase II assessment included discussions with system owners, reviewing systems documentation, and consolidating individual system strengths and weaknesses with those identified in Phase I. Based on this assessment, the following enablers were identified to promote a collaborative working relationship between the CEHTP and system owners:

- Common recognition of the increasing demand for linkage of environmental and health data
- System owner willingness to participate, and collaborate with the CEHTP
- Selected system's enhancements will consider CEHTP requirements
- Selected systems data are high quality
- Limited use/integration of external data in selected systems

The Future Assessment also identified challenges to the development and implementation of the EHTN. The challenges consist of external threats, outside the direct control of the CEHTP, and internal weaknesses that may be controlled through administrative or operational activities of the CEHTP. The following challenges exist for the CEHTP to address:

- External
 - Current funding mechanisms and budget constraints create a difficult environment in which to develop and maintain information systems
 - Requirements to protect privacy and confidentiality of data continue to increase
 - Organizations cannot keep pace with technological advances
- Internal
 - No formal framework exists to support collaboration among health surveillance and environmental monitoring systems
 - Organizations lack adequate information technology resources
 - Unclear and inconsistent standards for data confidentiality, privacy, and security

The following objectives were identified to position the CEHTP to take advantage of the strengths that exist, address the challenges that face the development of the EHTN, and create an environment for success:

1. Develop the Memorandum of Understanding (MOU) between the DHS, Cal/EPA and University of California, as prescribed in SB 189
2. Complete the needs assessment for local agencies and other stakeholders
3. Work with the DHS Internal Review Board (IRB) to identify their requirements and provide the necessary documentation for approval to obtain, and use the restricted health information
4. Develop a technical architecture that will support the short- and long-term goals of the CEHTP
5. Identify additional pilot projects with system owners
6. Create the business infrastructure authorized by SB 702 to support the CEHTP

7. Educate stakeholders on the benefits of the CEHTP and the security required to protect data and maintain confidentiality

2. INTRODUCTION

The environment plays an important role in the health of populations. Researchers have linked environmental hazards with specific health events. This research has identified an increasing incidence of environmentally related chronic diseases such as asthma, specific cancers, neurological disorders, and auto-immune diseases. However, research efforts have been limited to target populations and on a pilot basis. Currently, there is no comprehensive system to identify levels of human exposure to environmental hazards and the corresponding impacts on the health of these individuals. The development of such a system, or network of systems, would support the collection, analysis and interpretation of data to link environmental hazard and health surveillance data.

“Environmentally-related chronic diseases are taking a fiscal and human toll on Californians. For only nine of these diseases ... total costs for Californians are an estimated \$10 billion per year ... An effective surveillance system that reduces only 1% of cost of the environmentally-related chronic diseases would save the State \$100 million annually.”

Source: Draft Report of the SB 702 Expert Working Group on Environmental Health Surveillance.

Environmental Health Tracking

Recognizing the value of linking environmental hazards to human health prompted Congress to provide the Centers for Disease Control and Prevention (CDC) with funding to begin the development of State and local environmental tracking systems. Environmental health tracking is the systematic and ongoing collection, collation and analysis of data related to environmentally linked diseases, environmental hazards, and environmental exposures. Tracking this data within a comprehensive system is intended to provide the timely dissemination of information to those who need to know so that action can be taken.

An Environmental Health Tracking Network would track environmental hazards and diseases to monitor “hotspots” where exposure to environmental hazards is excessive and requires action to reduce levels. This tracking would allow trends to be monitored over an extended period of time to measure the success of these interventions and the overall effectiveness of public policies related to environmental protection and public health.

In October 2001, the Governor signed Senate Bill (SB) 702 into law. This law declares the State’s intent to build an Environmental Health Tracking Network (EHTN) for chronic diseases and environmental exposures. The California Environmental Health Tracking Program (CEHTP) was created to support the development of the EHTN and build a collaborative effort between the California Department of Health Services (DHS), the California Environmental Protection Agency (Cal/EPA), and the University of California (UC).

In addition, SB 189 was signed into law in September 2003. This legislation enacts the California Health Tracking Act of 2003 and requires the DHS, Cal/EPA and UC to sign a Memorandum of Understanding (MOU) to assess the feasibility of integrating existing environmental hazard, exposure and health surveillance systems data. This Act also authorizes the CEHTP to collect relevant information from State agencies to support the EHTN.

In June 2003, the DHS Environmental Health Investigations Branch (EHIB), on behalf of the CEHTP engaged Synergy Consulting, Inc to develop a Future Assessment Survey and Report. The purpose of the assessment is to describe the current, and future capability of health surveillance and environmental monitoring systems to provide data to the EHTN. The assessment is separated into two phases. The first phase identified 20 systems that are candidates to participate with the CEHTP to create the EHTN, and narrowed the list of systems to 12. The second phase further assessed the 12 systems to determine specific technical capabilities, and initiate discussions between the CEHTP and systems owners to plan collaborative data sharing arrangements.

This report documents the results of Phase II discussions with the 12 systems owners. The results of Phase II were combined with Phase I information to identify EHTN development challenges, as well as enabling capabilities of selected systems to support its development. Additional strengths and limitations of systems were identified in Phase II and are presented in *Table 2. System Strengths and Limitations*, along with those presented in the Phase I Briefing Report.

3. PHASE II PROJECT APPROACH

The approach to Phase II of the Future Assessment Survey and Report included four major tasks as outlined below in *Exhibit 1. Summary Tasks, Work Products and Deliverables*. Phase II activities focused on collecting more detailed information on systems selected during Phase I activities, to include documenting initial challenges related to data sharing. Phase II activities included the assessment of the technical, business and organizational requirements, and identification of enablers and challenges of the selected systems through facilitated data sharing discussions between system owners and the CEHTP staff. While not specifically mentioned in the Phase II tasks, project management activities continued during this phase.

Phase II objectives, highlighted in discussions with system owners include:

1. Develop a mutual understanding of the CEHTP and how the selected monitoring or surveillance system could support CEHTP activities;
2. Initiate discussions between the CEHTP and system owners to identify opportunities for data sharing;
3. Collect additional technical information on each selected system.

System owners, for the 12 systems identified in Phase I, were contacted to discuss their participation in Phase II of the Future Assessment. Eleven of 12 system owners agreed to participate in Phase II activities. During this initial contact, system owners identified other interested individuals to participate in the discussions with CEHTP leadership. A brief survey was distributed, prior to these meetings, to supplement technical information collected in the more comprehensive Phase I survey. Surveys were either completed prior to the meetings with CEHTP, at the meeting, or in follow-up conversations.

Task 2 included a review of technical documentation, for each of the systems participating in Phase II, to identify data elements relevant to the proposed CEHTP analyses. The documentation included data dictionaries, data file descriptions, or other systems documentation containing information on the data collected and stored in each system. System data elements, extracted from this documentation, were summarized in an Excel spreadsheet related to events (what occurred and when), location (where the event occurred), how the event was measured, and population identifiers or attributes. The Excel spreadsheet and supporting documentation were transmitted as “working papers” to the CEHTP.

Task 3 included the coordination and facilitation of meetings between representatives of the CEHTP and system owners. In some instances, this was the first direct contact between the two organizations. These facilitated discussions were the core activity of Phase II. The discussions focused on building new relationships or strengthening existing relationships by identifying mutually beneficial data sharing opportunities.

The discussions focused on the following items:

- Geographic Information System (GIS) capabilities and opportunities for enhancement and collaboration
- Approaches to overcome data sharing challenges related to:
 - Standards (Data, and technical capabilities to exchange data)
 - Data confidentiality

- Data ownership vs. data stewardship
- Change process for system enhancements to support the CEHTP/EHTN
- Funding support
- Other system specific questions, issues or concerns
- Existing use of data for environmental and health tracking, other than the CEHTP
- Process for ongoing communication related to the CEHTP

In Task 4, the information collected from the Phase II meetings, technical surveys, and Phase I documentation was analyzed to identify fundamental enablers and challenges to each individual system’s ability to support the CEHTP in the development of the EHTN. The results are presented in Section 4 of this report.

Exhibit 1. Summary Tasks, Work Products, and Deliverables

PHASE II			
Major Task	Description of Work	Work Products	Formal Deliverables
Task 1 – Prepare Phase II Information Systems Inventory	<ul style="list-style-type: none"> ▪ Contact 12 information system owners (identified in Phase I) for inclusion in Phase II assessment 	<ul style="list-style-type: none"> ▪ List of individuals to participate in Phase II survey and discussion ▪ Survey to collect additional technical information 	
Task 2 – Conduct detailed Assessment	<ul style="list-style-type: none"> ▪ Review and analyze surveillance systems and supporting processes and organizations ▪ Review data dictionaries and data models 	<ul style="list-style-type: none"> ▪ Summary of existing infrastructure, systems, data resources, processes, and funding ▪ Documentation of data elements critical to the EHTN 	
Task 3 – Facilitate CEHTP / Information System Owners Meetings	<ul style="list-style-type: none"> ▪ Identify relevant stakeholders ▪ Schedule and facilitate 12 high-level meetings 	<ul style="list-style-type: none"> ▪ Summary of methods for improving interoperability and data quality and potential steps to initiate formal data sharing relationships 	
Task 4 – Create Future Assessment Report	<ul style="list-style-type: none"> ▪ Compile and analyze results from Phase II survey and discussion ▪ Draft Future Assessment ▪ CEHTP IT Manager reviews draft deliverable 	<ul style="list-style-type: none"> ▪ Future Assessment results 	Future Assessment Report

4. RESULTS OF PHASE II ASSESSMENT ACTIVITIES

Phase I of the Future Assessment identified 12 systems to participate in Phase II activities, as detailed in *Table 1. Phase II EHTN Candidate Systems*. These systems were selected for additional assessment to determine the feasibility of the system's participation in the CEHTP.

Table 1. Phase II EHTN Candidate Systems

Health Systems	Environmental Systems
California Birth Defects Monitoring Program Registry (CBDMP)	Aerometric Data Analysis and Management System (ADAM)
California Health Interview Survey (CHIS)	California Emissions Inventory Development and Reporting System (CEIDARS)
EUREKA (California Cancer Registry)	Highway Performance Monitoring System (HPMS)
Medical Care Statistics Section Database (MCSS)	Pesticide Use Report Database (PUR)
Patient Discharge Database (PDD)	Toxics Release Inventory (TRI)
Automated Vital Statistics System (AVSS)	Water Quality Monitoring Database (WQMD)

While the California Birth Defects Monitoring Program completed the Phase II technical survey, consent to participate in Phase II discussions was not obtained within the timeframe of the project. System owners, for the remaining 11 systems, participated in the Phase II discussions and responded to the technical survey. *Appendix A. List of System Owner Contacts for Phase II* includes a list of system owners contacted to participate in Phase II.

The individual Phase II meetings were used to inform system owners of the objectives and goals of the CEHTP planning process, supporting legislation that authorizes the CEHTP to perform an inventory of data systems, and how their system information may contribute to the success of the CEHTP. The dialogue also focused on how to exchange information in the near- and long-term.

The CEHTP communicated to system owners the importance of collaboration in system enhancement efforts as well as in searching for cooperative funding opportunities. Both the technical and administrative functions of the CEHTP will be influenced by future development efforts to improve the capacity of a partner system to exchange data and make their existing data more suitable for linkage within the EHTN. There was also a brainstorming of issues that pertain to the inter- and intra-departmental IT governance, and issues that need to be addressed to ensure a smooth collaborative data sharing relationship.

Some systems (e.g., California Emissions Inventory Development and Reporting System (CEIDARS), Medical Care Statistics Section Database) already provide data to the EHIB, and the discussion focused on expanding this relationship to increase the efficiency of sharing data with the CEHTP. In other system discussions, the CEHTP was provided an opportunity to further explore collaborative relationships with additional programs and their supporting systems. The Phase II meetings ended with a consensus to continue discussions and develop a plan to incorporate various organizations and systems into the CEHTP.

The meetings and Phase II technical survey provided information on the current technical capacity of environmental monitoring and health surveillance systems. They also provided a forum to identify and discuss technical, administrative, regulatory, and financial issues that may influence the direction of the CEHTP development. This information will provide a baseline for the next steps of the CEHTP to gather requirements. The information, presented in the following sections, summarizes areas that enable the collaborative aspects of CEHTP candidate systems, and challenges to address in order to ensure the successful development of the EHTN. Specific technical information collected during this phase is considered confidential (i.e., security architecture) and will be provided to the CEHTP under separate cover.

4.1 Summary of Enablers for the CEHTP

The Future Assessment Phase I and II activities identified several positive factors that enable the effective development of an EHTN. These enablers also create an environment that promotes the development of collaborative working relationships between health surveillance and environmental monitoring programs, and the CEHTP.

The enablers include:

- **COMMON RECOGNITION OF THE INCREASING DEMAND FOR LINKAGE OF ENVIRONMENTAL AND HEALTH DATA**

The CDC EHTN project funding, and the State's recent legislative actions demonstrate the growing demand on environmental monitoring and health surveillance systems to:

 - Enhance disease surveillance activities
 - Improve the timeliness of collection and access to information that impacts public health
 - Improve the detection and linkage of environmental hazards and exposures to disease patterns
- **SYSTEM OWNER WILLINGNESS TO PARTICIPATE, AND COLLABORATE WITH THE CEHTP**
 - Participants in Phase II welcomed the opportunity to learn about the CEHTP and to discuss data sharing opportunities
 - Several organizations suggested opportunities to initiate (or continue participation in) pilots to demonstrate a data sharing arrangement with the CEHTP. Examples include:
 - Water Quality Monitoring Database participants offered their support to initiate a pilot to determine water distribution patterns within local water systems
 - Expansion of a CDC funded pilot with Cal/EPA ARB to validate hypotheses related to the linkage of air emissions with reproductive outcomes and neuro-behavioral disorders
 - Opportunities were discussed to exchange data using existing capabilities (email, CD) until direct connectivity is further evaluated and established
 - Health surveillance system owners support a collaborative effort to obtain approval from the Internal Review Board (IRB) and the Committee for the Protection of Human Subjects to exchange confidential data

- System owners are willing to share expertise or assist in providing access to systems experts
- There was agreement to have further discussion related to the progress of CEHTP, and identification of activities to contribute to the CEHTP
- **SELECTED SYSTEM'S ENHANCEMENTS WILL CONSIDER CEHTP REQUIREMENTS**
 - System owners described planned enhancements to their systems and acknowledged the need to accommodate CEHTP requirements, where possible
 - Opportunities for alternative funding sources were discussed to support specific system enhancements that may benefit the CEHTP, such as the incorporation of real-time GIS capabilities
- **SELECTED SYSTEMS DATA ARE HIGH QUALITY**
 - The systems participating in Phase II maintain extensive quality assurance activities to ensure the accuracy and completeness of data (i.e., the Cal/EPA Pesticide Use Report is nationally recognized as a comprehensive source of high quality data)
 - Systems provide information to other, high profile programs throughout the State
- **LIMITED USE/INTEGRATION OF EXTERNAL DATA IN SELECTED SYSTEMS**
 - Systems maintain data collected internally which reduces dependence on third party data sources
 - Data that is internally collected, validated and maintained promotes State control over the use, quality, and dependability of data

4.2 Fundamental Challenges Facing the CEHTP

During the Future Assessment activities, several challenges to the implementation of the EHTN were identified. These challenges must be addressed to successfully implement the EHTN and to attain the short- and long-term goals of the CEHTP.

The challenges are categorized as either “external” or “internal,” to the CEHTP. The external challenges are those “threats” to the CEHTP that are outside the direct control of the CEHTP, or key stakeholders (i.e., DHS and Cal/EPA). External challenges require the development of remediation plans to minimize their impact on the CEHTP. Internal challenges relate to weaknesses that may impact the CEHTP that are within the control of the CEHTP and key stakeholders. Internal challenges can be addressed through operational and administrative efforts.

4.2.1 External Challenges

- **CURRENT FUNDING MECHANISMS AND BUDGET CONSTRAINTS CREATE A DIFFICULT ENVIRONMENT IN WHICH TO DEVELOP AND MAINTAIN INFORMATION SYSTEMS**
 - Designated funding from multiple external sources makes it difficult to control the use of the funds to integrate and coordinate efforts across health surveillance and environmental monitoring programs
 - For many public health and environmental programs, the constrained fiscal situation makes it difficult to initiate and complete technology projects that may provide valuable information to the program, and subsequently to the CEHTP

- Often, the cost of ongoing operations and administration of information systems are not factored into the overall project cost and the program's ongoing annual budget
- **REQUIREMENTS TO PROTECT PRIVACY AND CONFIDENTIALITY OF DATA CONTINUE TO INCREASE**
 - The public, legislature, and advocacy groups are increasingly aware of privacy and confidentiality concerns, and although demanding more controls, need additional information and education on the need to protect personal privacy while allowing public health research and surveillance to continue
 - The Health Insurance Portability and Accountability Act (HIPAA) impacts current and future public health information systems and processes. There are differing interpretations regarding the applicability of HIPAA confidentiality rules to the use and exchange of data for public health purposes
 - The CEHTP must implement, maintain, communicate, and adhere to public health privacy and confidentiality standards to ensure the protection of personally identifiable information
 - Many public health stakeholders believe that the age of certain technologies and corresponding security measures, coupled with the growing amount of data stored and accessed electronically, increases the potential for unauthorized access to public health data
- **ORGANIZATIONS CANNOT KEEP PACE WITH TECHNOLOGICAL ADVANCES**
 - The cost of keeping up with technical changes and advancements can be high, especially if information systems are not able to share common standards-based technology, processing and data components
 - Many of the local entities that submit data to public health and environmental monitoring programs have developed, or are developing sophisticated information systems at a faster pace than State programs. For example, specific information, such as geographic coordinates may be available, and State systems are not capable of receiving the information (e.g., the PUR cannot currently accept geographic data that are available in some County systems).

4.2.2 Internal Challenges

- **NO FORMAL FRAMEWORK EXISTS TO SUPPORT COLLABORATION AMONG HEALTH SURVEILLANCE AND ENVIRONMENTAL MONITORING SYSTEMS**
 - There is currently no structure to facilitate formal collaboration efforts among the various public health and environmental programs to share and link systems data
 - Information technology governance, project approval and initiation processes, and resources are unique to DHS and Cal/EPA. Several of the organizations participating in Phase II define IT governance at the program level
 - Phase II discussions initiated data sharing efforts and collaboration between specific organizations; this effort must continue

- **ORGANIZATIONS LACK ADEQUATE INFORMATION TECHNOLOGY RESOURCES**
 - For some organizations, the limited availability of centralized, knowledgeable technical resources requires key program staff to split their responsibilities between operational activities and maintenance of systems
 - Public health and environmental monitoring systems may not be able to leverage technical capabilities and assets (including systems, licenses, skills, tools, and knowledge) across program boundaries
 - There is no standard IT systems development process to encourage collaboration on projects and the sharing of ideas, technologies, or solutions across programs, departments or agencies
- **UNCLEAR AND INCONSISTENT STANDARDS FOR DATA CONFIDENTIALITY, PRIVACY, AND SECURITY**
 - Public health programs are concerned about their liability related to sharing private information
 - There are concerns about the potential misuse of data
 - There is limited understanding of the department-wide (DHS or Cal/EPA) security protocols and standards

4.3 Specific System Strengths and Limitations Related to Participation with the CEHTP

The following table presents strengths and limitations specific to each of the eleven systems participating in Phase II of the Future Assessment. This table combines the strengths and limitations identified in Phase I with those observed during the Phase II activities. The strengths and limitations are presented in the following categories:

- Geographic Specificity – The geographic specificity of the data and the ability to link health and environmental events at a specific location
- Data Confidentiality – The ability to securely exchange required, confidential data
- Collaboration – The specific parties involved and the willingness of those parties to participate in the CEHTP
- Data Exchange – The current and future ability to exchange data through automated systems
- Data Availability – The timely receipt and validation of the data to allow linkage between health and environmental events at a specific point in time
- Data Completeness – The completeness of data within each record and the receipt of the universe of available records
- Data Specificity and Quality – Data collected includes the level of detail necessary to support linkage hypotheses
- System Enhancements to Support the CEHTP – The consideration of the goals of the CEHTP when planning and implementing enhancements
- Other considerations that may influence the ability to contribute to the CEHTP

Table 2. System Strengths and Limitations

ENVIRONMENTAL MONITORING SYSTEMS

System	Strengths	Limitations
ADAM	<ul style="list-style-type: none"> • Data Confidentiality – Includes no confidential data • Data Exchange – Information is currently available on CD or can be accessed through a privileged ODBC connection • Data Availability <ul style="list-style-type: none"> – Provides access to unofficial data within 2 – 4 months of collection – Maintains historical data to the 1960s • Data Completeness – Collects and maintains data from monitoring stations throughout the State on a regular basis • Data Specificity and Quality – Captures specific monitoring location information • System Enhancements to Support the CEHTP – Discussions to merge air quality data with emissions data in the Community Health Air Pollution Information System (CHAPIS) pilot 	<ul style="list-style-type: none"> • Geographic Specificity – Spatial resolution of monitoring data is dependent on the physical spacing of monitoring stations • Data Availability – Release of official data in July for entire previous year – 18 month lag • Data Completeness – Updates to data may occur 2 – 3 years after it is certified • Data Specificity and Quality – Interpretation of data requires understanding of measurements
CEIDARS	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – The CHAPIS pilot will model emission data and other source data (e.g., mobile, pesticides) into continuous surface at approximately 1 km resolution – Maintains specific source location within meters – Latitude and longitude coordinates are 	<ul style="list-style-type: none"> • Data Availability <ul style="list-style-type: none"> – Timeliness of data submittal varies by regional air districts – Release of unofficial data up to 9 months after year end – 21 month lag – and release official data after quality review • Data Exchange – No standards-based interface exists for exchanging tabular emissions data

System	Strengths	Limitations
	<p>calculated for source locations</p> <ul style="list-style-type: none"> • Data Confidentiality – Confidential data limited to competitive information • Data Exchange – Tabular extracts of emissions data may be requested • Collaboration – Established working relationship with EHIB and the CEHTP through pilot projects • Data Specificity and Quality <ul style="list-style-type: none"> – Recognized as the best source of air pollutant data in the State – Data available on a variety of criteria and toxic pollutants • System Enhancement to Support the CEHTP – SB 189 or follow-on legislation may provide an opportunity to collect additional information, or increase the frequency of air districts updates 	<ul style="list-style-type: none"> • Data Completeness – Regional air districts may not report all data on emissions measurements • Data Completeness – Data may be updated by air districts in subsequent years • Data Specificity and Quality – Annual emission measurements are estimates • Data Specificity and Quality – Emissions measurements may be estimates based on facility operating averages
<p>HPMS and FUNC</p>	<ul style="list-style-type: none"> • Geographic Specificity – Conflation project is underway (contracted to GDT), with 14 counties complete, and the 44 remaining counties are scheduled to be completed in Spring 2004 • Collaboration – Willing to discuss a pilot to demonstrate capabilities (and document requirements) to facilitate more comprehensive traffic data reporting on non-highway arterials • Data Exchange – Raw data files are available to calculate the Annual Average Daily Traffic (AADT) estimate • Data Completeness – Maintains data for most traveled roads in California; AADT is available for 	<ul style="list-style-type: none"> • Geographic Specificity – Captures geographic identifier by ‘segment’ which vary in length and may be too long for microscale exposure assumptions • Collaboration – HPMS is a federally mandated, and funded project. Further discussion should include the Federal Highway Administration (FHWA) and Federal EPA. • Data Exchange – No standards-based interface exists for exchanging FUNC GIS coverage • Data Availability <ul style="list-style-type: none"> – The conflation data is proprietary to GDT

System	Strengths	Limitations
	<p>each section</p> <ul style="list-style-type: none"> • Data Specificity and Quality <ul style="list-style-type: none"> – Provides comprehensive source of information related to traffic patterns – Individual point count data is available through the Traffic Volumes Section – K-factor describes peak volumes and is available for individual highway segments • System Enhancements to Support the CEHTP – Plans to include vehicle class breakdown (i.e., trucks) for non-highway arterials 	<ul style="list-style-type: none"> – Release official data 10 months after year end (the first availability of information) – 22 month lag • Data Completeness – Dependent upon information collected from 460 cities and 58 counties throughout the State. Cities and counties are not required to report; reporting is done on a voluntary basis • Data Specificity and Quality <ul style="list-style-type: none"> – Derives AADT using complex algorithms – The HPMS data is categorized by cities, counties, and MPOs – Traffic data is not processed into seasonal volumes
Pesticide Use Report (PUR)	<ul style="list-style-type: none"> • Geographic Specificity – Counties are in the process of digitizing fields • Data Confidentiality – Confidential data limited to competitive information • Collaboration – Agreed to participate in a pilot to exchange data with the CEHTP • Data Exchange <ul style="list-style-type: none"> – Willing to explore alternatives to transmit existing data electronically through an automated technology solution – Approval processes for data exchange are internal to the DPR • Data Availability <ul style="list-style-type: none"> – “Unofficial data” is available for CEHTP use 	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – There is a need to improve spatial resolution within the state reporting system – Some counties are developing or have developed capabilities to capture specific geographic information at the field level, but the PUR cannot accept or store this data – Captures pesticide application by geographic section (1 mile) • Data Availability – Release official data in October for previous FY which results in a 16 month lag for some data • Data Exchange – No standards-based interface exists for exchanging tabular PUR data

System	Strengths	Limitations
	<ul style="list-style-type: none"> – Maintains data transmitted electronically from counties (unofficial data) 1 – 2 months after the pesticide application • Data Specificity and Quality <ul style="list-style-type: none"> – The PUR is recognized as one of the best sources for pesticide use information in the country – Provides a comprehensive source of information related to agricultural use of pesticides • System Enhancement to Support the CEHTP – Willing to explore alternative funding mechanisms with the Cal/EPA and the CEHTP for enhancements and standards-based data exchange 	<ul style="list-style-type: none"> • Data Completeness <ul style="list-style-type: none"> – Timeliness of data is dependent on growers to submit data to the County Agricultural departments, and entered into the PUR – Current backlog of 7 months for entry of event received from counties • Data Specificity and Quality <ul style="list-style-type: none"> – Structural pesticide use is summarized by company for all uses throughout the county – Excludes industrial and institutional pesticide use
TRI	<ul style="list-style-type: none"> • Geographic Specificity – Maintains latitude and longitude coordinates for chemical release points • Data Confidentiality – Confidential data limited to competitive information for a small number of facilities and threshold determination of chemical amounts • Data Exchange – Working with the Central Data Exchange (CDX) to allow states access to their data through secure data nodes • Data Specificity and Quality <ul style="list-style-type: none"> – Includes data for facilities with 10 or more FTEs who manufacture, or use, over 10,000 pounds of chemicals – Provides comprehensive source of chemical 	<ul style="list-style-type: none"> • Data Availability – Facilities submit unofficial CY reports by July of the following year – 18 month lag • Data Availability – Release of official data up to 18 months after year-end reporting period – 30 month lag • Data Completeness <ul style="list-style-type: none"> – Difficult to determine if facilities are complying with reporting requirements – Allows retroactive updates to data back to 1987, including withdrawal of reported information – A subset of the information may be duplicated in other Cal/EPA systems

System	Strengths	Limitations
	<p>release (air, water, and ground) information from large population of facilities</p> <ul style="list-style-type: none"> • System Enhancements to Support the CEHTP – portal development to share data is two years away; designed to improve access and decrease the reporting burden 	<ul style="list-style-type: none"> • Data Specificity and Quality <ul style="list-style-type: none"> – Data is aggregated on an annual basis and does not distinguish between seasonal and peak periods – Facilities directed to report using their best available data
Water Quality Monitoring	<ul style="list-style-type: none"> • Geographic Specificity – Maintains coordinates of sampling locations, Source Water Assessment Program (SWAP) locates well sources within 5 meters • Collaboration – Willing to support and collaborate on a pilot project with specific water systems to characterize consumer service areas relative to upstream sampling locations • Data Exchange <ul style="list-style-type: none"> – Current information is available for the CEHTP to use on request – Willing to pursue a goal to exchange data using XML and federal standards • Data Availability <ul style="list-style-type: none"> – Maintains data submitted within one month of test (unofficial data) – Maintains official data available within two months of test • Data Specificity and Quality – Provides comprehensive source of chemical testing for drinking water 	<ul style="list-style-type: none"> • Geographic Specificity – The ability to systematically link consumer connections with specific upstream sampling stations, does not currently exist • Data Confidentiality – Restricted access to source location • Data Exchange – No standards-based interface exists for exchanging tabular WQMD data • Data Completeness – Detection limits on non-detect samples are only required for reporting on analytes with actionable concentration levels. • Data Specificity and Quality – Water systems are self-monitored, with contracted laboratories performing the analysis and providing test results • Data Specificity and Quality <ul style="list-style-type: none"> – Does not maintain water delivery systems or multiple source flow contribution data – Point of treatment relative to raw water sampling stations within system not captured – Target species for treatment not captured – Date of treatment off/online not captured

HEALTH SURVEILLANCE SYSTEMS

System	Strengths	Limitations
CHIS	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – Geographic information is collected by the survey contractor (Westat), and geo-coded in the CHIS database – There are plans to collect address information in the current survey • Collaboration – Environmental health expertise is welcomed, and encouraged in the development of the survey • Data Exchange – CHIS data is provided to the DHS • Data Availability <ul style="list-style-type: none"> – Release of survey information (unofficial data) on a daily basis – Full release of survey information, including identifiers is available to CHIS researchers • Data Specificity and Quality <ul style="list-style-type: none"> – CHIS survey includes every County and is large enough to collect information on a broad range of issues and public health concerns – Maintains survey data from a large sample population throughout the state, and specific demographic groups – Maintains information on rare diseases collected from a large survey population • System Enhancements to Support the CEHTP <ul style="list-style-type: none"> – Exploring the possibility to collect residential 	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – Specific geographic information is not available in the 2001 survey and will not be available until the 2003 results are compiled – Maintains zip code as the geographic identifier for survey participant • Data Availability <ul style="list-style-type: none"> – Release of summary official data by end of the survey year – Full release of survey information, including identifiers is limited to CHIS researchers • Data Completeness – Future collection of data may be limited by the decline in telephone responses • Data Specificity and Quality <ul style="list-style-type: none"> – Data is self reported with no clinical documentation – No validation of self-reported data accuracy – Maintains data collected every two years and over a several month period • System Enhancements to Support the CEHTP – Changes to the survey to add questions is a complex process, with more requests for additions than can be accommodated

System	Strengths	Limitations
	<p>and occupational history</p> <ul style="list-style-type: none"> – Survey may be modified to include specific health-related topics • Other – CHIS staff have used the data to complete research on the linkage of uncontrolled asthma and ozone levels 	
EUREKA	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – Data is geo-coded on a quarterly basis – Maintains patient address and is collected with geographic coding of that address • Data Confidentiality – There is an existing process to review data requests for research purposes • Collaboration – National Cancer Institute (NCI) has funded geographic-based activities to assess screening capabilities, and rural/urban registrants to identify special needs for these populations • Data Availability – Maintains data submitted from hospitals within 6 months of admission • Data Completeness – Provides comprehensive source of single and multiple cancer diagnoses data 	<ul style="list-style-type: none"> • Data Availability – Release of official data up to 18 months after report • Data Completeness – Data is primarily collected from hospitals and requires a cumbersome process to identify and collect information from physician offices and laboratories • Data Specificity and Quality – Interpretation of the data is complex, and may create problems if released to the public without adequate explanation
Medical Care Statistics Section (MCSS)	<ul style="list-style-type: none"> • Geographic Specificity – Maintains patient address information • Data Confidentiality – MCSS has provided information, with IRB approval, to the EHIB for use in existing studies • Collaboration – MCSS will assist to establish a long-term Medi-cal data sharing relationship with 	<ul style="list-style-type: none"> • Data Availability – Maintenance of Medi-cal data, and access is through ITSD • Data Specificity and Quality <ul style="list-style-type: none"> – Managed Care data is incomplete – Maintains data limited to Medi-Cal population

System	Strengths	Limitations
	<p>the DHS Information Technology Services Division (ITSD)</p> <ul style="list-style-type: none"> • Data Availability – Maintains data collected on a monthly basis from source systems and officially available within one month of receipt • Data Specificity and Quality <ul style="list-style-type: none"> – Medi-cal data is recognized as one of the best sources of Medicaid data in the Country, along with their willingness to share the information – Provides a comprehensive source of medical information for the Medi-Cal population 	
<p>Patient Discharge Database (PDD)</p>	<ul style="list-style-type: none"> • Data Confidentiality – Patient SSN is collected and available within the database • Collaboration – Willing to explore alternatives to provide CEHTP access to the PDD • Data Exchange – Data is currently provided to DHS • Data Availability – Release of official data within 4 months after the reporting period – 10 month lag • Data Specificity and Quality – Provides a comprehensive source of hospital discharge information for all inpatient admissions • System Enhancements to Support the CEHTP <ul style="list-style-type: none"> – Collection of address information is planned with the implementation if the ANSI 835 reporting records from hospitals – Plans to collect Emergency Department and 	<ul style="list-style-type: none"> • Geographic Specificity <ul style="list-style-type: none"> – Specific geographic information is limited and there are no plans to update existing system to collect and store this information – Regulations would need to be changed to add address data elements – Does not capture patient address information (may be available when records are abstracted from the ANSI 837 format and submitted to OSHPD) – Maintains zip code as the geographic identifier information • Data Completeness – There is no requirement for hospital to report if the SSN is missing

System	Strengths	Limitations
	<p>Ambulatory Surgery Center data by end of 2004</p>	
<p>Automated Vital Statistics System (AVSS)</p>	<ul style="list-style-type: none"> • Data Confidentiality – Patient information is available with appropriate human subjects approvals • Data Exchange – Ability to export data from a central database • Data Availability – Data is generally received from County Registrar offices within one month, for birth records • Data Specificity and Quality <ul style="list-style-type: none"> – Statistical Master File is produced from AVSS, combined with other files to create a comprehensive source of birth and death records – Maintains birth certificate information from hospitals, birthing centers and other sources – Maintains data from hospitals or counties, collected on a daily basis 	<ul style="list-style-type: none"> • Geographic Specificity – Maintains address information but may not be reliable, zip code is the most reliable geographic identifier • Data Exchange – Currently, there is no capability for the system to generate and transmit data on a regular basis • Data Availability – Release of official data 12 – 18 months after events are recorded and updated in the Statistical Master File • Data Specificity and Quality <ul style="list-style-type: none"> – Amended records are not updated in AVSS – Data prior to 1990 is less robust and reliable

5. CONCLUSION AND NEXT STEPS

The focus of Phase II of the Future Assessment was to establish a business relationship between the CEHTP and “owners” of selected health surveillance and environmental monitoring systems. There was overwhelming support of the efforts of the CEHTP, and a willingness to promote the collaboration between systems. The CEHTP has pilot programs underway with the Air Resources Board of the Cal/EPA, the Childhood Lead Poison Prevention Branch, and may be used as a model for working with other systems to share resources and data.

In an age of budget constraints, and uncertainty, the selected systems are open to further discussions of how resources (human, financial, technology) can be shared to meet future requirements. With the need to modernize systems, this presents the State with an opportunity to upgrade systems and improve the way it does future collection, management, and analysis of data to determine the linkages between environmental hazards and diseases.

The CEHTP is currently in a position (with the assumption there are no significant changes in the funding of the program) to continue development of the EHTN and address the challenges identified during this assessment. Specific objectives for the CEHTP over the next 9 months should include the following:

Objective 1: Develop the MOU between the DHS, Cal/EPA and UC, as prescribed in SB 189

Objective 2: Complete the needs assessment for local agencies and other stakeholders

Objective 3: Work with the DHS IRB to identify their requirements and provide the necessary documentation for approval to obtain, and use restricted health information

Objective 4: Develop a technical architecture that will support the short and long-term goals of the CEHTP

Objective 5: Identify additional pilot projects with system owners

Objective 6: Create the business infrastructure authorized by SB 702 to support the CEHTP

Objective 7: Educate stakeholders on the benefits of the CEHTP and the security required to protect data and maintain confidentiality

Appendix A. List of System Owner Contacts for Phase II

Environmental Monitoring Systems	Contact Person/Title/Organization
Aerometric Data Analysis and Management System /	Ron Rothacker, Manager, Air Quality Data Section
California Emissions Inventory Development and Reporting System	Dr. Michael T. Benjamin, Manager, Emissions Inventory Systems Section, Air Resources Board
Highway Performance Monitoring System	Brian Domsic, Chief, Highway Performance Monitoring Branch, Caltrans
Pesticide Use Report Database	Ada Ann Scott, Data Processing Manager I, County Permit and Use Reporting Program, DPR Linda Lichtenberger, Associate Information System Analyst, County Permit & Use Reporting Program
Toxics Release Inventory	Josh Woodyard, Project Officer, Toxics Release Inventory Program, US EPA
Water Quality Monitoring Database	Paul Collins, Data Processing Manager II, Drinking Water Program, DHS

Health Surveillance Systems	Contact Person/Title/Organization
California Birth Defects Monitoring Program	Dr. John Harris, Program Chief
California Health Interview Survey	Rick Brown, Director, UCLA Center for Health Policy Research
EUREKA (California Cancer Registry)	Steve Fuchslin, Systems Support Manager, Cancer Surveillance Section, DHS Carlos Sola-Llonch, Lead Architect, Cancer Surveillance Section, DHS
Medical Care Statistics Section System	Jim Klein, Research Specialist, Medical Care Statistics Section, DHS
Patient Discharge Database	Candace Diamond, Manager Patient Discharge Section, OSHPD Mike Kassis, Chief Information Officer, OSHPD
Automated Vital Statistics System	Mike Quinn, Chief, Office of Information and Research, DHS