

# California Environmental Health Tracking Program



## Future Assessment Survey and Report

### *Phase I Briefing Report*

• • • • • • • •  
October 23, 2003



California  
Department of  
Health Services



Synergy Consulting, Inc.

A Subsidiary of AMS

## TABLE OF CONTENTS

<b>1. EXECUTIVE SUMMARY .....</b>	<b>2</b>
<b>2. INTRODUCTION.....</b>	<b>4</b>
<b>3. PHASE I PROJECT APPROACH .....</b>	<b>7</b>
<b>4. RESULTS OF SURVEY AND PHASE I ASSESSMENT .....</b>	<b>9</b>
4.1 STRENGTHS AND LIMITATIONS OF SYSTEMS .....	9
4.1.1 <i>Common System Characteristics</i> .....	10
4.1.2 <i>Specific Systems Differences</i> .....	10
4.2 CRITERIA FOR PHASE II SYSTEMS SELECTION .....	20
4.2.1 <i>Criterion #1: Data Critical to CEHTP Analyses</i> .....	20
4.2.2 <i>Criterion #2: Geographic Specificity</i> .....	21
4.2.3 <i>Criterion #3: Availability of Official Data</i> .....	23
4.2.4 <i>Criterion #4: Availability of Unofficial Data</i> .....	24
4.2.5 <i>Overall System Ratings</i> .....	25
<b>5. RECOMMENDATIONS.....</b>	<b>26</b>
<b>6. NEXT STEPS.....</b>	<b>27</b>

### APPENDICES

- A. LIST OF INTERVIEWEES
- B. SYSTEM SUMMARIES

This report was supported by a subcontract from Impact Assessment, Inc. with funds provided by Cooperative Agreement Number U50/CCU922449-10 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of Impact Assessment, Inc. or the CDC.

## 1. EXECUTIVE SUMMARY

In October 2001, with the Governor's signature of Senate Bill 702, California became the first State to initiate planning with the intent to establish an Environmental Health Tracking Network (EHTN) for chronic diseases and environmental exposures. In October 2002, Congress provided the Centers for Disease Control and Prevention (CDC) with funding to begin development of a nationwide EHTN. The funding also included State and local development of environmental health tracking capabilities. According to the CDC, the EHTN should be a system, or network of systems, accessible to the public, that provides information about chronic diseases and emerging health conditions and identifies the relationship to environmental exposures.

In response to this funding, the State formed the California Environmental Health Tracking Program (CEHTP), a collaborative initiative of the Department of Health Services (DHS), Division of Environmental and Occupational Disease Control; the California Environmental Protection Agency (Cal/EPA), Office of Environmental Health Hazard Assessment; and, the University of California. The goal of the CEHTP is to "include the development of a comprehensive plan to create a standards-based, coordinated, and integrated EHTN at the state level that allows for linkage and reporting of health effects and environmental hazards data."

A Future Assessment Survey and Report project initiates the technical aspects of this planning process. The purpose of the assessment is to describe the future capability of health and environmental departments to incorporate their existing surveillance and monitoring data infrastructure into the EHTN. The first phase of this project is complete with the delivery and acceptance of this Briefing Report. Phase I included the assessment of 20 potential environmental monitoring and health surveillance systems. Phase II will examine a subset of systems from Phase I and include a more detailed assessment of the selected systems, as well as initiate discussions between CEHTP and systems owners in planning data sharing relationships. This briefing report documents the results of Phase I, including the approach, systems description, explanation of selection criteria and scoring for Phase II, recommendations, and next steps.

Phase II recommended systems include:

<b>Health Systems</b>	<b>Environmental Systems</b>
<ul style="list-style-type: none"> <li>• California Birth Defects Monitoring Program Registry</li> <li>• California Health Interview Survey (CHIS)</li> <li>• EUREKA (California Cancer Registry)</li> <li>• Medical Care Statistics Section Database</li> <li>• Patient Discharge Database</li> <li>• Automated Vital Statistics System</li> </ul>	<ul style="list-style-type: none"> <li>• Aerometric Data Analysis and Management Systems (ADAM)</li> <li>• California Emissions Inventory Development and Reporting System (CEIDARS)</li> <li>• Highway Performance Monitoring System (HPMS)</li> <li>• Pesticide Use Report Database</li> <li>• Toxics Release Inventory</li> <li>• Water Quality Monitoring Database</li> </ul>

These systems are recommended due to their breadth of data critical to analyses, the spatial specificity by which they can be geographically linked to corresponding

environmental or health events, and the timing for the availability of both official and unofficial data.

Systems included in the assessment and not selected for Phase II include:

**Health Systems**

- Behavioral Risk Factor Survey
- California Women's Health Survey
- Elevated Lead Visual Information System
- Response and Surveillance System for Childhood Lead Exposure
- SENSOR Asthma
- SENSOR Pesticide Illness

**Environmental Systems**

- National Emissions Inventory
- Superfund National Priorities List Assessment Program

## 2. INTRODUCTION

The environment plays an important role in the health of populations. Researchers have linked exposures to certain environmental hazards with specific diseases. However, additional research is needed to determine associations between other environmental exposures and the effects on human health. Currently, no comprehensive systems exist at the State or federal level to track many of the human exposures to environmental hazards and the impact on the health of individuals, and overall public health. Such a system, or network of systems, would support the ongoing collection, integration, analysis, and interpretation of data about environmental hazards, exposure and the linkage with human disease.

**"Few would dispute that we should keep track of the hazards of pollutants in the environment, human exposures, and the resulting health outcomes--and that this information should be easily accessible to public health professionals, 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.

### ***The Need for an Environmental Health Tracking Network***

In January 2001, the Pew Environmental Health Commission issued the report "America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network." The report concluded that the existing environmental health system is neither adequate nor well organized to support ongoing scientific analysis of the relationships among hazards, exposures, and health effects. The report presented a compelling case for a comprehensive environmental health tracking network.

In October 2002, Congress provided the Centers for Disease Control and Prevention (CDC) with funding to begin development of a nationwide Environmental Health Tracking Network (EHTN). Funding was also included to allow State and local development of environmental health tracking capabilities. Using information from an EHTN, federal, State, and local agencies will be better prepared to identify the impact of environmental hazards on human health. With this information, public health officials can develop and evaluate effective public health actions to prevent or control chronic and acute diseases that are linked to hazards in the environment.

According to the CDC, the EHTN 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

### ***California's Environmental Health Tracking Network Efforts***

California has taken significant steps to establish a statewide EHTN. In October 2001, the Governor signed into law Senate Bill 702, which declares the State's intent to establish an EHTN for chronic diseases and environmental exposures. California became the first state to begin planning a statewide environmental health tracking

network for chronic diseases and environmental hazards and exposures. California recently received a three-year grant from the CDC to support the development of an EHTN. Subsequently, the California Environmental Health Tracking Program (CEHTP) was formed. The CEHTP is a collaborative initiative of the Department of Health Services (DHS), Division of Environmental and Occupational Disease Control; the California Environmental Protection Agency (Cal/EPA), Office of Environmental Health Hazard Assessment; and the University of California.

The intent and need for the Environmental Health Tracking Program and a data-sharing network was further reinforced with the passage of SB 189 (Escutia). SB 189 enacts the California Health Tracking Act of 2003 and authorizes the CEHTP to assess the feasibility of current systems to integrate existing environmental hazard, exposure and health outcome data relevant to SB702 recommended analyses.

The goal of the CEHTP is to “include the development of a comprehensive plan to create a standards-based, coordinated, and integrated EHTN at the state level that allows for linkage and reporting of health effects and environmental hazards data.” To facilitate the development of a statewide EHTN, a Planning Consortium was convened to address issues of planning, implementation, and evaluation of the CEHTP.

One of the four teams created by the consortium to address specific strategies supporting the CEHTP’s goal is the Technical Team. The Technical Team draws upon the expertise of health and environmental program staff, technical support, and key stakeholders to advise on information technology, data management, and technical issues pertaining to the planning of the CEHTP. One responsibility of the Technical Team is to complete a future assessment of environmental monitoring and health surveillance systems to characterize technological infrastructure, internal and external decision-making bureaucracy affecting IT projects, and resources necessary for surveillance applications. The assessment would include specific systems and describe their purpose; scope; capabilities; and human, technological, and financial resources.

The Future Assessment Report, and selection and prioritization of data tracking partners, provides the foundation for the definition of the EHTN hardware and software requirements, data dissemination tools, and direct data accessibility. The report will also provide high-level technical descriptions of existing capabilities to create the architectural framework for linking environmental, hazard, exposure and outcome data. The architectural framework will subsequently be used to draft a network development and deployment plan.

In June of 2003, the DHS Environmental Health Investigations Branch, on behalf of the CEHTP, engaged Synergy Consulting, Inc. to develop a Future Assessment Survey and Report in support of the Technical Team activities. The purpose of the assessment is to describe the future capability of health and environmental departments to incorporate their existing surveillance and monitoring infrastructure into 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 narrow down to an estimated 10 systems. The second phase will further assess the selected subset of systems to determine specific technical capabilities, and initiate discussions between CEHTP and systems owners in planning collaborative data sharing arrangements.

Selected systems will support initial EHTN goals to establish a network that shares data between systems that track data relevant to adverse health outcomes that have known or hypothesized links to environmental phenomena. Initial EHTN goals include:

- 1) Identify systems that maintain current, quality and accessible data that can be integrated in the tracking network in a timely manner.
- 2) Determine which of these systems track known hazards, exposure and health outcomes data and can best provide timely and useful information.
- 3) Develop technical plans for an electronic standards-based tracking network.

This briefing report documents the results of Phase I. It includes a description of the process used to collect information on the 20 systems, prioritize the systems, and select the systems recommended to include in Phase II. A set of selection criteria was developed to assist in prioritizing and selecting candidate systems, using information collected through discussions, surveys, and reviewing of systems documentation. While the goal of Phase I was to select 10 systems, the recommendation includes 12 systems to include in Phase II.

### 3. PHASE I PROJECT APPROACH

The approach to Phase I of the Future Assessment Survey and Report included five major tasks, as outlined below in *Exhibit 1. Summary Tasks, Work Products and Deliverables*. This approach provided the framework for the project team to identify and analyze current environmental and health information systems that are potential candidates to participate in the CEHTP’s development of the EHTN. As shown below, the major tasks included project management activities and a collaborative effort, with the CEHTP Technical Team, to assess data systems technical, administrative, and financial capacity for future CEHTP data sharing.

The objective of Phase I was to complete a high level assessment of 20 environmental monitoring and health surveillance information systems, and identify a subset of systems to include in Phase II. The results of the assessment were used to prioritize the systems, using specific selection criteria and a corresponding scoring matrix. The criteria for selecting the 20 systems that are included in the Future Assessment Survey and Report was based on CEHTP staff knowledge and experience in the systems’ technological ability to contribute quality and priority data resources to the EHTN.

Task 2 included the development of an Information Systems Inventory assessment survey. The survey was distributed to “system owners” and included questions related to the type of data maintained, methods of data collection, the age of available historical data, the currency of official data (i.e., data has been validated and quality control checks have been completed), geographic specificity of location information relevant to linkage, and the technological capabilities supporting the system. The survey was used as a guide during interviews to collect the appropriate information.

Task 3 initiated the survey, with follow-on interviews of candidate system owners. Once the interviews and documentation review for each system were complete, the assessment of each system was summarized. Prior to finalizing this assessment documentation, the interviewees were given the opportunity to confirm the information and provide updates. Their input is included in *Appendix B. System Summaries*.

Interview notes and system documentation were used to identify the strengths and limitations of each system. This information was also used to finalize systems selection criteria. The 20 systems were assessed using these criteria to prioritize the systems for inclusion in Phase II activities.

**Exhibit 1. Summary Tasks, Work Products, and Deliverables**

PHASE I			
Major Task	Description of Work	Work Products	Formal Deliverables
Task 1 – Initiate and Manage Project	<ul style="list-style-type: none"> <li>▪ Project kick-off meeting and planning</li> <li>▪ Project planning and management</li> </ul>	<ul style="list-style-type: none"> <li>▪ Project work plan</li> <li>▪ Refined scope, goals, and objectives</li> <li>▪ Communications plan</li> </ul>	<ul style="list-style-type: none"> <li>▪ Project Control Document</li> </ul>
Task 2 – Prepare Phase I Information Systems Inventory	<ul style="list-style-type: none"> <li>▪ Confirm list of potential information systems</li> <li>▪ Select 20 information systems for high-level assessment</li> <li>▪ Develop selection criteria for inclusion in Phase II</li> </ul>	<ul style="list-style-type: none"> <li>▪ List of 20 information systems for Phase I assessment</li> <li>▪ Phase II inclusion criteria</li> </ul>	

<b>PHASE I</b>			
<b>Major Task</b>	<b>Description of Work</b>	<b>Work Products</b>	<b>Formal Deliverables</b>
Task 3 – Conduct High-Level Assessment	<ul style="list-style-type: none"> <li>▪ Survey and solicit information for specific information systems</li> <li>▪ Obtain documentation on specific information systems</li> <li>▪ Review IT activities and support for each of the systems</li> <li>▪ Conduct high-level analysis of specific information systems</li> </ul>	<ul style="list-style-type: none"> <li>▪ Summary of relevant information regarding the data collection process, quality assurance activities, timeliness of data, the specificity of data elements and technical support of the systems</li> <li>▪ Summary of existing information systems, resources, cross-system linkage potential</li> </ul>	
Task 4 – Attend CEHTP Technical Team Meetings	<ul style="list-style-type: none"> <li>▪ Develop presentation of preliminary findings</li> <li>▪ Attend meeting</li> </ul>	<ul style="list-style-type: none"> <li>▪ CEHTP Technical Team Presentation</li> <li>▪ Incorporate feedback from the team on preliminary results</li> </ul>	
Task 5 – Create Briefing Report	<ul style="list-style-type: none"> <li>▪ Compile and analyze assessment results</li> <li>▪ Draft Briefing Report</li> <li>▪ CEHTP IT Manager reviews draft deliverable</li> </ul>	<ul style="list-style-type: none"> <li>▪ High-level assessment results</li> </ul>	Briefing Report

## 4. RESULTS OF SURVEY AND PHASE I ASSESSMENT

The CEHTP leadership team provided the list of systems to include in the Phase I assessment. The following systems were included in the assessment:

### Environmental Monitoring Systems

- Aerometric Data Analysis and Management Systems (ADAM)
- California Emissions Inventory Development and Reporting System (CEIDARS)
- Highway Performance Monitoring System (HPMS)
- National Emissions Inventory Database (NEI)
- Pesticide Use Report Database (PUR)
- Superfund National Priorities List Assessment Program (SNAP)
- Toxics Release Inventory (TRI)
- Water Quality Monitoring Database

### Health Surveillance Systems

- Behavioral Risk Factor Survey (BRFS)
- California Birth Defects Monitoring Program Registry (CBDMP Registry)
- California Health Interview Survey (CHIS)
- California Women's Health Survey (CWHS)
- Elevated Lead Visual Information System (ELVIS)
- EUREKA (California Cancer Registry)
- Medical Care Statistics Section System
- Patient Discharge Database
- Response & Surveillance System for Childhood Lead Exposure (RASSCLE)
- SENSOR Asthma Database
- SENSOR Pesticide Illness Database
- Automated Vital Statistics System (AVSS)

*Appendix A. List of Interviewees* includes the participants interviewed for the systems assessment and *Appendix B. System Summaries* includes a summary of each system included in the assessment.

### 4.1 Strengths and Limitations of Systems

The 20 systems that were assessed are all candidates to participate in the EHTN. The information they maintain has representative data for a variety of health concerns and environmental hazards that could be useful to the CEHTP analyses of the association between diseases and environmental hazards. Phase I of the CEHTP Future Assessment and Survey provides an in-depth review of these systems to identify the best candidates to include in further evaluation (Phase II), and to determine their involvement in the initial development of the EHTN.

To evaluate system candidates against these goals, the systems were reviewed to identify their strengths associated with the overall goals of the CEHTP, and areas that may limit a system's ability to provide access to data critical to the EHTN. These limitations are not deficiencies in the effectiveness of the system to support their intended purpose, but are identified in relevance to the initial goals for the CEHTP. System strengths and limitations are summarized in *Table 1. Strengths and Limitations of Systems*.

System strengths and limitations were analyzed to identify common system characteristics as well as to identify specific system differences. These commonalities and differences are presented in the following sections.

#### **4.1.1 Common System Characteristics**

Prior to the official release of data for program purposes, research, or other public uses, all assessed systems complete a thorough review process to assure data quality. While the data may be available in the system (e.g., to perform edits, validity checks, verification of accuracy) prior to the official release, most systems restrict access to this data to internal users. Depending on the system, the quality control process and official data release may take days or months. The systems maintain historical official data and indicate, for the most part, that the data are continuously available (without gaps) in the historical files.

During the assessment, all system owners indicated their willingness to participate in the development of the EHTN, although each owner highlighted system constraints and, in some cases, confidentiality concerns. The environmental monitoring systems contain limited confidential information (e.g., facility information related to competitive output). The health surveillance systems include a significant amount of confidential personal and medical information, and the release of this information is subject to State and federal restrictions. Within the State, the primary process to monitor the release and use of confidential health information requires an organization to submit an information request for review and approval/denial by the Committee for the Protection of Human Subjects. An assessment of the process requirements for this committee as well as opportunities for streamlining this process will be integral activities of the Phase II review.

The systems included in the Phase I assessment are primarily maintained by staff within the programs they support. Typically, smaller systems are maintained on a part-time basis by operational program staff. Larger systems generally are maintained by full-time program staff, by dedicated information technology (IT) staff, or a combination of both. DHS and Cal/EPA departmental IT organizations provide some support, to include the use of the organization's IT infrastructure for information distribution.

#### **4.1.2 Specific Systems Differences**

The focus of specific systems strengths and limitations included the following broad categories:

- Collection of data elements that support the CEHTP/EHTN
- Identification of specific geographic components related to monitoring or surveillance of an event
- Timeliness of information receipt and quality control processes

These categories were also used to develop specific criteria to determine the prioritization of systems for inclusion in Phase II. The individual system strengths and limitations, including these categories are highlighted in *Table 1. Strengths and Limitations of Systems* beginning on the next page.

**Table 1. Strengths and Limitation of Systems**

**ENVIRONMENTAL MONITORING SYSTEMS**

System	Organization	Strengths	Limitations
ADAM	Cal/EPA Air Resources Board	<ul style="list-style-type: none"> <li>• Maintains data from monitoring stations throughout the State</li> <li>• Captures specific monitoring location information</li> <li>• Provides access to unofficial data within 2 – 4 months of collection</li> <li>• Maintains historical data to the 1960s</li> <li>• Includes no confidential data</li> <li>• Plans to merge air quality data with emissions data</li> </ul>	<ul style="list-style-type: none"> <li>• Interpretation of data requires understanding of measurements and complex algorithms</li> <li>• Release of official data in July for entire previous year – 18 month lag</li> <li>• Updates to data may occur 2 – 3 years after it is certified</li> </ul>
CEIDARS	Cal/EPA Air Resources Board	<ul style="list-style-type: none"> <li>• Maintains specific source location within meters</li> <li>• Latitude and longitude coordinates are calculated for source locations</li> <li>• Data available on a variety of criteria and toxic pollutants</li> <li>• Confidential data limited to competitive information</li> </ul>	<ul style="list-style-type: none"> <li>• Annual measurements</li> <li>• Emissions measurements may be estimates based on facility operating averages</li> <li>• Release of unofficial data up to 9 months after year end – 21 month lag – and release official data after quality review</li> </ul>
HPMS and FUNC	Caltrans	<ul style="list-style-type: none"> <li>• Provides comprehensive source of information related to traffic patterns</li> <li>• Maintains data for most roads in California</li> </ul>	<ul style="list-style-type: none"> <li>• Derives data using complex algorithms</li> <li>• Captures geographic identifier by ‘segment’ which vary in length</li> </ul>

System	Organization	Strengths	Limitations
		<ul style="list-style-type: none"> <li>Plans to identify specific geographic location of collection source</li> </ul>	<ul style="list-style-type: none"> <li>Release official data 10 months after year end (the first availability of information) – 22 month lag</li> </ul>
NEI	US EPA	<ul style="list-style-type: none"> <li>Maintains latitude and longitude coordinates for emission release points</li> <li>Captures information from industry groups on specific emitters (e.g., mining) that may not be available in State systems</li> <li>Confidential data limited to competitive information</li> </ul>	<ul style="list-style-type: none"> <li>Updates to State systems are not transmitted to NEI; therefore, State systems data are up-to-date and more reliable</li> <li>Release of official data 1 year after year-end reporting data submitted – 24 month lag</li> </ul>
Pesticide Use Report	Cal/EPA Department of Pesticide Regulation	<ul style="list-style-type: none"> <li>Provides a comprehensive source of information related to agricultural use of pesticides</li> <li>Maintains data transmitted electronically from counties (unofficial data) 1 – 2 months after the pesticide application</li> <li>In process of digitizing fields to capture the specific location for pesticide application using geographic coding</li> <li>Confidential data limited to competitive information</li> </ul>	<ul style="list-style-type: none"> <li>Excludes industrial and institutional pesticide use</li> <li>Captures pesticide application by geographic section (1 mile)</li> <li>Current backlog of 7 months for event data entry</li> <li>Release official data in October for previous FY – 16 month lag</li> </ul>
SNAP	US EPA	<ul style="list-style-type: none"> <li>Maintains data on soil contamination</li> <li>Captures specific geographic location of source site</li> <li>Provides access to site information</li> </ul>	<ul style="list-style-type: none"> <li>There are a limited number of superfund sites in the State</li> <li>Excludes contaminated sites for which clean-up efforts are complete,</li> </ul>

System	Organization	Strengths	Limitations
		<p>(unofficial data) for sites identified by the State and proposed in the Federal Register.</p> <ul style="list-style-type: none"> <li>Provides access to site information (official data) upon completion of the Federal Register public review and comment period</li> </ul>	<p>if the site is not identified by the State, or for sites with a lower hazard rating</p> <ul style="list-style-type: none"> <li>Public review period for the proposed site may take several years</li> </ul>
TRI	US EPA	<ul style="list-style-type: none"> <li>Provides comprehensive source of chemical release (air, water, and ground) information from large population of facilities</li> <li>Maintains latitude and longitude coordinates for chemical release points</li> <li>Confidential data limited to competitive information for a small number of facilities</li> </ul>	<ul style="list-style-type: none"> <li>Facilities submit unofficial CY reports by July of the following year – 18 month lag</li> <li>Release of official data up to 18 months after year-end reporting period – 30 month lag</li> <li>Allows retroactive updates to data back to 1987</li> <li>A subset of the information may be duplicated in other Cal/EPA systems</li> </ul>
Water Quality Monitoring	DHS Drinking Water	<ul style="list-style-type: none"> <li>Provides comprehensive source of chemical testing for drinking water</li> <li>Maintains sampling location, geographically identified. Source Water Assessment Program (SWAP) locates well sources within 5 meters</li> <li>Maintains data submitted within one month of test (unofficial data)</li> <li>Maintains official data available within two months of test</li> </ul>	<ul style="list-style-type: none"> <li>Restricted access to source location, considered confidential data</li> <li>Does not maintain water delivery systems or multiple source flow contribution data; there is no systematic method or centralized data system to assist in linking sampling stations with service areas.</li> <li>Point of treatment relative to raw water sampling stations within</li> </ul>

System	Organization	Strengths	Limitations
			system not captured <ul style="list-style-type: none"> <li>• Target species for treatment not captured</li> <li>• Date of treatment off/online not captured</li> </ul>

**HEALTH SURVEILLANCE SYSTEMS**

System	Organization	Strengths	Limitations
BRFS	DHS Consortium	<ul style="list-style-type: none"> <li>• Maintains specific data associated with health-related behaviors</li> <li>• Maintains survey data collected on a daily basis</li> </ul>	<ul style="list-style-type: none"> <li>• Limits survey to small sample of population</li> <li>• No validation of self-reported data accuracy</li> <li>• Maintains zip code as the geographic identifier for survey participant</li> <li>• Release of annual official data after first quarter of the following year – 15 month lag</li> </ul>
CBDMD	California Birth Defects Monitoring Program Registry	<ul style="list-style-type: none"> <li>• Maintains data collected from reviews of hospital and laboratory records</li> <li>• Maintains address information collected from the mother’s medical record</li> <li>• Release of unofficial data at time of</li> </ul>	<ul style="list-style-type: none"> <li>• Maintains data collected from high population areas for only ½ the state (San Diego County, Orange County, Los Angeles County, San Francisco Bay Area, Central Valley)</li> <li>• Release official data on an annual basis in June of the following year –</li> </ul>

System	Organization	Strengths	Limitations
CHIS	California Health Interview Survey (CHIS)	<p>collection (every 6 months)</p> <ul style="list-style-type: none"> <li>• Maintains survey data from a large sample population throughout the state, and specific demographic groups</li> <li>• Release of survey information (unofficial data) on a daily basis</li> <li>• Maintains information on rare diseases collected from a large survey population</li> <li>• Plans to collect address information</li> <li>• Survey may be modified to include specific health-related topics</li> </ul>	<p>18 month lag</p> <ul style="list-style-type: none"> <li>• No validation of self-reported data accuracy</li> <li>• Maintains zip code as the geographic identifier for survey participant</li> <li>• Maintains data collected every two years and over a several month period</li> <li>• Release of summary official data by end of the survey year</li> </ul>
CWHS	DHS Consortium	<ul style="list-style-type: none"> <li>• Provides specific data associated with women’s health</li> <li>• Maintains survey data collected on a daily basis</li> </ul>	<ul style="list-style-type: none"> <li>• Limits survey to small sample of population</li> <li>• No validation of self-reported data accuracy</li> <li>• Population data is aggregated by zip code</li> <li>• Release of annual official data after first quarter of the following year</li> </ul>
ELVIS	DHS Occupational Health Branch	<ul style="list-style-type: none"> <li>• In 2003, began collection of results for all blood levels, not just those exceeding a threshold</li> <li>• Maintains patient address information</li> <li>• Maintains data submitted within one month of test (daily for excessive</li> </ul>	<ul style="list-style-type: none"> <li>• Maintains data limited to occupational reports of lead</li> <li>• Maintains data for blood lead levels exceeding a standard</li> <li>• Records received from laboratories may have limited information, as a result of not receiving the</li> </ul>

System	Organization	Strengths	Limitations
		<p>levels), and official data available within the following month – 2 month lag</p>	<p>information from the referring physician</p>
EUREKA	California Cancer Registry	<ul style="list-style-type: none"> <li>• Provides comprehensive source of single and multiple cancer diagnoses data</li> <li>• Maintains patient address and is collected with geographic coding of that address</li> <li>• Maintains data submitted from hospitals within 6 months of admission</li> </ul>	<ul style="list-style-type: none"> <li>• Release of official data up to 18 months after report</li> </ul>
Medical Care Statistics Section	Medi-Cal	<ul style="list-style-type: none"> <li>• Provides a comprehensive source of medical information for the Medi-Cal population</li> <li>• Maintains patient address information</li> <li>• Maintains data collected on a monthly basis from source systems and officially available within one month of receipt</li> </ul>	<ul style="list-style-type: none"> <li>• Does not include Managed Care data which excludes children required to join a Managed Care plan</li> <li>• Maintains data limited to Medi-Cal population</li> </ul>
Patient Discharge	Office of Statewide Health Planning and Development (OSHPD)	<ul style="list-style-type: none"> <li>• Provides a comprehensive source of hospital discharge information for all inpatient admissions</li> <li>• Hospitals report on a 6 month basis; release of unofficial data within 3 months after the reporting period – 9 month lag</li> <li>• Release of official data within 4</li> </ul>	<ul style="list-style-type: none"> <li>• Does not capture patient address information (may be available when records are abstracted from the ANSI 837 format and submitted to OSHPD)</li> <li>• Maintains zip code as the geographic identifier information</li> </ul>

System	Organization	Strengths	Limitations
		<p>months after the reporting period – 10 month lag</p> <ul style="list-style-type: none"> <li>Plans to collect Emergency Department and Ambulatory Surgery Center data by end of 2004</li> </ul>	
RASSCLE	DHS Childhood Lead Poisoning Prevention Branch	<ul style="list-style-type: none"> <li>Provides comprehensive source of lead poisoning in children</li> <li>In 2003, began collection of results for all blood levels, not just those exceeding a threshold</li> <li>Maintains patient address information</li> <li>Plans to include geographic coding with implementation of RASSCLE II</li> <li>Maintains data submitted within one month of test (daily for levels that exceed threshold), and official data available within the following month – 2 month lag</li> </ul>	<ul style="list-style-type: none"> <li>Maintains data for blood lead levels exceeding a standard</li> <li>Records received from laboratories may have limited information, as a result of not receiving the information from the referring physician</li> <li>Updates to County systems may not be updated in State-level system</li> </ul>
SENSOR Asthma	DHS Occupational Health Branch	<ul style="list-style-type: none"> <li>Maintains medical information from providers as well as self-reported information</li> <li>Maintains patient address information</li> <li>Developing a single database to combine existing databases</li> <li>Release of unofficial data 6 – 8 months after doctors visit</li> </ul>	<ul style="list-style-type: none"> <li>Maintains data limited to occupational reports of asthma</li> <li>Data are incomplete; not all Doctors First Reports or cases are received</li> <li>Data resides in two separate databases</li> </ul>

System	Organization	Strengths	Limitations
SENSOR Pesticide Illness	DHS Occupational Health Branch	<ul style="list-style-type: none"> <li>• Release of official data 6 – 12 months after doctors visit</li> <li>• Maintains medical information from providers as well as self-reported information</li> <li>• Maintains patient address information</li> <li>• Release of unofficial data 6 – 8 months after doctors visit</li> </ul>	<ul style="list-style-type: none"> <li>• Maintains data limited to occupational reports of pesticide illness</li> <li>• Reports of an incident with multiple workers may not include information on specific individuals</li> <li>• Data are incomplete; not all Doctors First Reports or cases are received</li> <li>• Recent official release of 2001 data indicates 20 month lag</li> </ul>
Automated Vital Statistics System (AVSS)	DHS Center for Health Statistics	<ul style="list-style-type: none"> <li>• Statistical master file is produced from AVSS, combined with other files to create a comprehensive source of birth and death records</li> <li>• Maintains birth certificate information from hospitals, birthing centers and other sources</li> <li>• Maintains data from hospitals or counties, collected on a daily basis</li> </ul>	<ul style="list-style-type: none"> <li>• Amended records are not updated in AVSS</li> <li>• Data prior to 1990 is less robust and reliable</li> <li>• Maintains address information but may not be reliable, zip code is the most reliable geographic identifier</li> <li>• Release of official data 12 – 18 months after events are recorded and updated in the statistical master file</li> </ul>

## 4.2 Criteria for Phase II Systems Selection

Phase I interview information, system documentation, and analysis of systems strengths and limitations serve as the basis for prioritizing and selecting a limited number of systems for further assessment in Phase II. To guide this prioritization, four selection criteria were identified to compare and rate/score the data contained in the systems, and the timeliness of access to the data. The four selection criteria were ranked in order of importance and impact on effective implementation of the EHTN. Each of these criteria was assigned a numeric factor, depending on its importance. The sum of the factors totals 100.

Once the selection criteria were ranked, each of the 20 systems was then assessed to determine their standing within each criterion. The result of this assessment provided a range of system functionality for each criterion. Using this information, a rating scale was developed for each criterion. The highest level of functionality within the criterion scale or range was set as the standard, and assigned the highest point factor. Next, each system was assigned the applicable rating from the criterion scale based on the functionality of the specific system. The rating for each system was multiplied against the criterion's numeric factor. The product of this calculation is a system score for each criterion.

The criteria, and the associated factors include:

- Criterion #1: Data Critical to CEHTP Analysis                      Factor = 40
- Criterion #2: Geographic Specificity                                      Factor = 30
- Criterion #3: Availability of Official Data                              Factor = 15
- Criterion #4: Availability of Unofficial Data                              Factor = 15

Finally, the individual criterion scores for each system are totaled to provide an objective measure to compare and prioritize these systems. Detail on each criterion and the corresponding system scores are presented below.

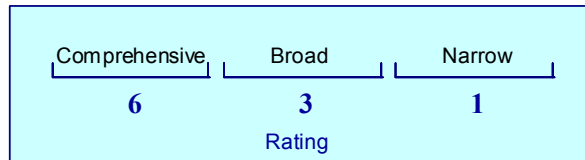
### 4.2.1 Criterion #1: Data Critical to CEHTP Analyses

This criterion presents a measure of each system's capability to provide data (e.g., the number and type of data elements collected, the number of records collected annually) supporting the CEHTP activities. This criterion ranks first in importance and a factor of 40 is multiplied against the rating to determine each system score. The higher system scores indicate that the system includes data critical to proposed analytical efforts, and maintains a relevant population or record size.

Systems were rated based on interviews, research findings (from system documentation and web sites), and input from CEHTP project team members, currently involved in the preparation of a final report detailing SB702 critical data needs. Data elements were reviewed for compatibility with CEHTP analytical requirements to associate diseases with environmental hazards where there is knowledge regarding population risk for exposures and a measurable level of morbidity or mortality resulting from the environmental exposures. The systems were also reviewed to determine the population included in the data collection process. A large population includes a statewide sample of all event data (e.g., auto emissions, lead poisoning) vs. a small population, which may include specific sample locations, or a subset of events (e.g., data from specific counties, surveys related to specific events).

*Exhibit 2. Data Critical to CEHTP Analyses and Scoring* presents a simple categorization of data collection efforts, which includes three categories: Comprehensive (for a large population, captures a sizeable number of critical data elements for priority health or environmental event); Broad (for an average population, captures multiple critical data elements for priority health or environmental event); and Narrow (for a limited population, captures specific critical data elements for priority health or environmental event).

**Exhibit 2. Data Critical to CEHTP Analyses and Scoring**



*Table 2. System Rating for Data Critical to CEHTP Analyses* presents the results of the system ratings. Twelve systems that receive the highest rating of 6, or Comprehensive, are highlighted in blue.

**Table 2. System Rating for Data Critical to CEHTP Analyses**

System Rating - Selection Criteria Score		
	Data Critical to Analysis	
	(Criteria Rating 40/Maximum 240)	
	Rating	Score
<b>System Name - Environmental</b>		
<b>Aerometric Data Analysis and Management System</b>	6	240
<b>California Emissions Inventory Development &amp; Reporting System</b>	6	240
<b>Highway Performance Monitoring System</b>	6	240
National Emissions Inventory Database	3	120
<b>Pesticide Use Report Database</b>	6	240
Superfund National Priorities List Assessment Program	1	40
<b>Toxics Release Inventory</b>	6	240
<b>Water Quality Monitoring Database</b>	6	240
<b>System Name - Health</b>		
Behavioral Risk Factor Survey	1	40
California Birth Defects Monitoring Program Registry	3	120
<b>California Health Interview Survey</b>	6	240
California Women's Health Survey	1	40
Elevated Lead Visual Information System	3	120
<b>EUREKA (California Cancer Registry)</b>	6	240
<b>Medical Care Statistics Section Database</b>	6	240
<b>Patient Discharge Database</b>	6	240
<b>Response &amp; Surveillance System for Childhood Lead Exposure</b>	6	240
SENSOR Asthma Database	1	40
SENSOR Pesticide Illness Database	1	40
<b>Automated Vital Statistics System</b>	6	240

**4.2.2 Criterion #2: Geographic Specificity**

This criterion measures how precisely a system locates an event or a population (e.g., facility, person, street segment) relative to linking with other datasets. This criterion ranks second in importance and a factor of 30 is multiplied against the rating to

determine each system score. Geographic specificity is key to potentially linking health events to environmental hazard locations. Higher system scores indicate that the event or population location data are more specific, as shown in *Exhibit 3. Geographic Specificity and Scoring*. Geographic specificity ranges from within 5 to 50 meters (includes street address) scoring 5, to 1-3 kilometers or highway segments scoring 3, and census tract, zip code, and county specificity scoring 2.

**Exhibit 3. Geographic Specificity and Scoring**

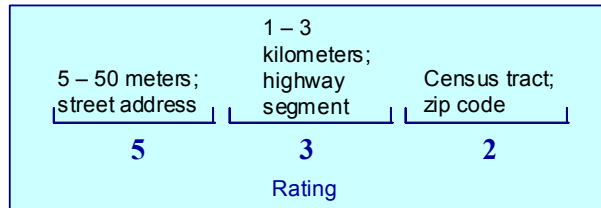


Table 3. System Rating for Geographic Specificity presents the results of the system geographic specificity ratings. Fourteen systems, highlighted in blue, receive a rating of 5, indicating they capture a minimum of a street address or identify locations within a precision of 50 meters.

**Table 3. System Rating for Geographic Specificity**

System Rating - Selection Criteria Score		Geographic Specificity (Criteria Rating 30/Maximum 150)	
	Rating	Score	
<b>System Name - Environmental</b>			
<b>Aerometric Data Analysis and Management System</b>	5	150	
<b>California Emissions Inventory Development &amp; Reporting System</b>	5	150	
Highway Performance Monitoring System	3	90	
<b>National Emissions Inventory Database</b>	5	150	
Pesticide Use Report Database	3	90	
<b>Superfund National Priorities List Assessment Program</b>	5	150	
<b>Toxics Release Inventory</b>	5	150	
Water Quality Monitoring Database	2	60	
<b>System Name - Health</b>			
Behavioral Risk Factor Survey	2	60	
<b>California Birth Defects Monitoring Program Registry</b>	5	150	
California Health Interview Survey	2	60	
California Women's Health Survey	2	60	
<b>Elevated Lead Visual Information System</b>	5	150	
<b>EUREKA (California Cancer Registry)</b>	5	150	
<b>Medical Care Statistics Section Database</b>	5	150	
Patient Discharge Database	2	60	
<b>Response &amp; Surveillance System for Childhood Lead Exposure</b>	5	150	
<b>SENSOR Asthma Database</b>	5	150	
<b>SENSOR Pesticide Illness Database</b>	5	150	
<b>Automated Vital Statistics System</b>	5	150	

### 4.2.3 Criterion #3: Availability of Official Data

This criterion describes the amount of lag time before collected data are reviewed and released as official data. This criterion ranks third in importance and a factor of 15 is multiplied against each system rating. Higher system scores indicate data are available more immediately, as shown in *Exhibit 4. Availability of Official Data and Scoring*. Official data are available from within 1 month to 24 months. In the spirit of surveillance, the EHTN will encourage and assist environmental and health data systems to move towards real-time data release. However, recognizing that none of the assessed data systems are currently reporting real-time events, a lower weighting, than otherwise may be appropriate, is placed on official data release to better satisfy the initial goals of the EHTN. As systems upgrade their reporting and quality control protocols, the importance of official data release will increase as a criterion in the overall EHTN vision.

#### **Exhibit 4. Availability of Official Data and Scoring**

0 – 6 months	7 – 12 months	13 – 18 months	19 – 24 months
4	3	2	1
Rating			

*Table 4. System Rating for Availability of Official Data* presents the results of the system official data set ratings. Five systems, highlighted in blue, receive a rating of 4 indicating they release data as official within six months from the date of data capture.

**Table 4. System Rating for Availability of Official Data**

System Rating - Selection Criteria Score		Official Data (Criteria Rating 15/Maximum 60)	
		Rating	Score
<b>System Name - Environmental</b>			
Aerometric Data Analysis and Management System		2	30
California Emissions Inventory Development & Reporting System		1	15
Highway Performance Monitoring System		1	15
National Emissions Inventory Database		1	15
Pesticide Use Report Database		2	30
<b>Superfund National Priorities List Assessment Program</b>		4	60
Toxics Release Inventory		1	15
<b>Water Quality Monitoring Database</b>		4	60
<b>System Name - Health</b>			
Behavioral Risk Factor Survey		2	30
California Birth Defects Monitoring Program Registry		2	30
California Health Interview Survey		3	45
California Women's Health Survey		2	30
<b>Elevated Lead Visual Information System</b>		4	60
EUREKA (California Cancer Registry)		2	30
<b>Medical Care Statistics Section Database</b>		4	60
Patient Discharge Database		3	45
<b>Response &amp; Surveillance System for Childhood Lead Exposure</b>		4	60
SENSOR Asthma Database		3	45
SENSOR Pesticide Illness Database		1	15
Automated Vital Statistics System		2	30

**4.2.4 Criterion #4: Availability of Unofficial Data**

This criterion describes the amount of lag time between the initial collection of the data and entry of the data into the system, and the ability to access the data (i.e., unofficial data – quality control reviews are not complete, data not released as official for use). Although this criterion ranks fourth in importance, it carries the same rank as the Availability of Official Data criterion. Unofficial data can be used by the CEHTP to develop hypotheses of environmental and disease linkages, that may later be confirmed with detailed official data. A factor of 15 is multiplied against each system rating. Higher system scores indicate data are available more immediately, as shown in *Exhibit 5. Availability of Unofficial Data and Scoring* below.

**Exhibit 5. Availability of Unofficial Data and Scoring**

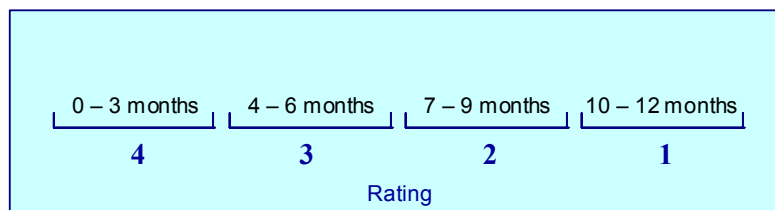


Table 5. System Rating for Availability of Unofficial Data presents ten systems, highlighted in blue, that receive a rating of 4 indicating they release unofficial data within three months from the date of data capture.

**Table 5. System Rating for Availability of Unofficial Data**

System Rating - Selection Criteria Score		
System Name - Environmental	Unofficial Data (Criteria Rating 15/Maximum 60)	
	Rating	Score
<b>Aerometric Data Analysis and Management System</b>	4	60
California Emissions Inventory Development & Reporting System	1	15
Highway Performance Monitoring System	1	15
National Emissions Inventory Database	1	15
Pesticide Use Report Database	2	30
<b>Superfund National Priorities List Assessment Program</b>	4	60
Toxics Release Inventory	1	15
<b>Water Quality Monitoring Database</b>	4	60
<b>System Name - Health</b>		
<b>Behavioral Risk Factor Survey</b>	4	60
California Birth Defects Monitoring Program Registry	3	45
<b>California Health Interview Survey</b>	4	60
<b>California Women's Health Survey</b>	4	60
<b>Elevated Lead Visual Information System</b>	4	60
Eureka (California Cancer Registry)	3	45
<b>Medical Care Statistics Section Database</b>	4	60
Patient Discharge Database	2	30
<b>Response &amp; Surveillance System for Childhood Lead Exposure</b>	4	60
SENSOR Asthma Database	2	30
SENSOR Pesticide Illness Database	2	30
<b>Automated Vital Statistics System</b>	4	60

#### 4.2.5 Overall System Ratings

Table 6. System Ratings Total Score combines the criteria scores for each system to calculate a total score. The maximum score for any system is 510. Thirteen systems have a total score in excess of 350 and are highlighted in blue.

**Table 6. System Ratings Total Score**

<b>System Rating - Selection Criteria Score</b>	
<b>System Name - Environmental</b>	<b>Total Score</b>
<b>Aerometric Data Analysis and Management System</b>	480
<b>California Emissions Inventory Development &amp; Reporting System</b>	420
<b>Highway Performance Monitoring System</b>	360
National Emissions Inventory Database	300
<b>Pesticide Use Report Database</b>	390
Superfund National Priorities List Assessment Program	310
<b>Toxics Release Inventory</b>	420
<b>Water Quality Monitoring Database</b>	420
<b>System Name - Health</b>	
Behavioral Risk Factor Survey	190
California Birth Defects Monitoring Program Registry	345
<b>California Health Interview Survey</b>	405
California Women's Health Survey	190
<b>Elevated Lead Visual Information System</b>	390
<b>EUREKA (California Cancer Registry)</b>	465
<b>Medical Care Statistics Section Database</b>	510
<b>Patient Discharge Database</b>	375
<b>Response &amp; Surveillance System for Childhood Lead Exposure</b>	510
SENSOR Asthma Database	265
SENSOR Pesticide Illness Database	235
<b>Automated Vital Statistics System</b>	480

## 5. RECOMMENDATIONS

Based on the criteria rating process discussed above, we recommend twelve systems presented in the table below for inclusion in the CEHTP Future Assessment Survey and Report – Phase II.

**Table 7. Systems Recommended for CEHTP Future Assessment Survey Phase II**

<b>Health Systems</b>	<b>Environmental Systems</b>
California Birth Defects Monitoring Program Registry	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	Pesticide Use Report Database
Patient Discharge Database	Toxics Release Inventory
Automated Vital Statistics System	Water Quality Monitoring Database

Although the California Birth Defects Monitoring Program Registry score was 345, this database is the only system capturing this critical health information and is therefore a system recommended for inclusion in Phase II.

Two other systems, the Response and Surveillance System for Childhood Lead Exposure (RASSCLE) with a score of 510 and the Elevated Lead Visual Information System (ELVIS) with of score of 390, are recommended for inclusion during the initial implementation of the EHTN, but not in the Phase II assessment. The CEHTP team is familiar with both the RASSCLE and ELVIS technical architecture and functionality, is co-located with RASSCLE and ELVIS staff, and currently has a collaborative relationship with RASSCLE and ELVIS system owners.

To obtain detailed descriptions of the recommended 12 health surveillance and environmental monitoring information systems see *Appendix B. System Summaries*.

## 6. NEXT STEPS

Once the recommended systems are approved, Phase II activities will be initiated. The activities for Phase II will support the following objectives:

**Objective 1:** Obtain detailed descriptions of 12 specified health surveillance and environmental monitoring information systems. In the absence of established data exchange infrastructure, identify possible areas of technological and funding opportunity to create or enhance this infrastructure through collaboration.

**Objective 2:** Identify internal and external IT governance protocols, procedures, and oversight organizations, which have a stake in data sharing agreements and technology.

**Objective 3:** Facilitate meetings between key decision-making and system management personnel to initiate formal data sharing relationships and confirm the need for surveillance and monitoring information in an environmental health tracking framework.

**Objective 4:** Summarize Phase II activities and findings within a Future Assessment Report.

To accomplish these objectives, Synergy and CEHTP project team members will jointly facilitate meetings with selected system owners. These meetings will communicate the need for surveillance and monitoring information to support the CEHTP/EHTN; identify methods for improving interoperability and data quality; and initiate formal data sharing relationships.

In addition, during these meetings the project team will collect detailed information about each system's ability to exchange data with the CEHTP/EHTN, the organizational process to approve their participation, external and internal IT governance procedures that influence data sharing relationships, and next steps in planning the exchange of data. The information gathered through this review will serve to augment and confirm the information gathered through the Phase I system owner meetings. The meetings with health surveillance systems will also include a discussion of the release of confidential information and the process to receive and streamline approval.

The project team will draft a CEHTP Future Assessment Report, which will compile second phase assessment information and strategies for proceeding to the next project phase of the CEHTP.