

5.e. Recipient Activity e: Analysis of Legislation and Regulations

Examine existing state/local legislation and/or regulations to determine if additional authority is required to collect new data, integrate data, and share data (with appropriate security and confidentiality restrictions).

5.e.1. Results and Accomplishments

In 2001, the Legislature began a process to establish an Environmental Health Surveillance System (EHSS) that could provide information on potential links between environmental exposures and chronic disease in California. SB 702 (Escutia, Chapter 538, Statutes of 2001⁹) mandated that a joint committee composed of California Department of Health Services (CDHS), the California Environmental Protection Agency (Cal/EPA), and the University of California (UC) establish an Expert Working Group to develop recommendations to the Legislature, CDHS, and Cal/EPA on possible approaches and anticipated costs of developing an environmental health tracking network in California. Their recommendations were released by the California Policy Research Center in February 2004 in a document entitled, “Strategies for Establishing an Environmental Health Surveillance System in California: A Report of the SB 702 Working Group.” This report and related materials can be found at: <http://www.catracking.com/sub/sb702.htm>. A report brief is included in APPENDIX ff: SB702 Report Brief.

Our program also conducted an assessment of the technical, business, and organizational capabilities and challenges of 12 key state health surveillance and environmental monitoring systems (see APPENDIX E: Phase 2 Future Assessment Report). The assessment found that no formal framework exists to support collaboration among health surveillance and environmental monitoring systems.

In 2003, SB 189 (Escutia, Chapter 407, Statutes of 2003¹⁰) mandated CDHS, Cal/EPA, and University of California to develop and sign a memorandum of understanding (MOU) to assess the feasibility of:

1. Integrating existing environmental hazard, exposure, and health outcome data; and
2. Describing how these data correspond to recommendations in the final report (“Strategies for Establishing an Environmental Health Surveillance System in California: A Report of the SB 702 Working Group”). The complete SB702 report and related materials can be found at:

⁹ Health and Safety Code, section 104324 et seq.

¹⁰ Health and Safety Code section 104324.25

<http://www.catracking.com/sub/sb702.htm>. See the report brief in APPENDIX ff: SB702 Report Brief.

This legislation recognized that data on environmental hazards and human health do not necessarily reside within a single agency and that it is necessary to act upon data sharing opportunities that will advance scientific understanding of the relationships between environment and health. The MOU was finally signed by UC, CDHS, and Cal/EPA in November, 2005. Because it is in the public interest for agencies to take advantage of data sharing opportunities, this agreement went beyond the specific requirement of SB 189 “to assess the feasibility of integrating existing environmental hazard, exposure, and health outcome data.” In addition, the MOU provides for the signatory agencies to begin data sharing when feasible. The MOU is intended to establish a substantive partnership between CDHS, UC, and Cal/EPA by increasing interaction and enhancing collaboration between the organizations to best serve and maintain the public’s health.

CDHS, UC, and Cal/EPA will ensure that activities conducted under the MOU are coordinated, non-duplicative, and supportive of the goals of the enabling legislation. The MOU outlines obligations that will ensure individual privacy, confidentiality of health information, and security of confidential business information. CDHS, Cal/EPA, and UC will:

1. Work together in partnership to collect, develop, and interpret interagency environmental and public health data.
2. Establish working partnerships with other federal, state, and local entities, and with community groups that will further the goals of the MOU.
3. Identify, delineate, and implement measures needed to resolve barriers to sharing environmental and public health data between their networks.
4. Conduct quarterly meetings to address issues such as:
 - Information technology architecture and systems structure requirements.
 - Administrative and technical methods for ensuring confidentiality of protected data.
 - Data quality, completeness, timeliness, exchange standards, and geographic specificity.
 - Administrative and technical methods for maintaining the security of the networks involved in this process.

Cal/EPA and CDHS will exchange data for the purposes of researching and characterizing links between environmental hazards, human exposures and health effects. Data exchange and linkage between both agencies will be used for environmental health surveillance and research pursuits. This agreement covers both confidential and publicly available environmental and health data under the jurisdiction of Cal/EPA (e.g., pesticide illness reporting, hazardous waste, air quality monitoring and emissions inventories) and CDHS (e.g., vital statistics data, water quality reporting). Both Cal/EPA and CDHS will comply with state and federal laws and regulations, as well as following the most advanced technical and administrative practices, to assure the protection of individual privacy and medical record confidentiality. This will include developing approvals from the State Committee for the Protection of Human Subjects, and acquiring permissions for securely communicating across both agencies' networks.

Bills mentioned above are included in APPENDIX L: Tracking Legislation.

We continue to track legislative development at the state and national level and to respond to comment and inquiries from various audiences involved with state and national legislation including legislative staff, NGO organization and governmental organizations. Additionally, we continue to analyze legislation to evaluate the potential impacts to our program. Finally, we provide ongoing assistance to CDC and other grantees with policy-related questions and updates to existing publications.

Related Legislation

SENATE BILL 1168

Senate Bill 1168 would have established the Healthy Californians Biomonitoring Fund. The fund would be utilized by the California Department of Health Services to support a state-wide biological monitoring program. The purpose for the program would be to reduce or eliminate toxic chemical exposure and mitigate harm caused by such exposure. The bill would have also required the department to provide public access to information, and to report to the Legislature and the public. This bill was consistent with the recommendations of the SB 702 Expert Working Group and members of our Planning Consortium were advocates for this legislation.

The bill was passed by the legislature but vetoed by the Governor. The bill's supporters are considering future legislation that would increase the use of biological monitoring information to improve exposure information in California.

ASSEMBLY BILL 1940

Assembly Bill 1940 would have required each manufacturer of a high production volume chemical or a reportable chemical, as defined, to provide the Environmental Protection Agency with an analytical method for each such chemical imported into, or offered for sale in, this state by the manufacturer. The bill would require the agency to adopt regulations that specify each medium for which an analytical method for a chemical is required to be provided by a manufacturer, to provide the agency with test methods, including chemical biomarkers of exposure, the octanol water partition coefficient, and the bioconcentration factor for that chemical. This bill is consistent with hazard tracking recommendations proposed by the SB 702 Expert Working Group and members of our Planning Consortium were advocates for this legislation.

The bill was not passed by the legislature. A contributing factor was industry opposition. Implementation costs were described as high.

ASSEMBLY BILL 2248

AB 2248 requires the California Department of Health Services to conduct epidemiological assessments of Parkinson's disease and establish a similar system for the collection of information determining the incidence of Parkinson's disease. This bill is consistent with recommendations proposed by the SB 702 Expert Working Group and members of our Planning Consortium were advocates for this legislation.

This bill passed the legislature and was signed in September 2004. As resources were not given to the California Department of Health Services in the bill, the Parkinson's Disease Institute was essentially deputized to carry out the mandate of AB2248.

5.e.2. Challenges and Barriers

- To date, no new resources have been appropriated by the Legislature to accomplish the directives in SB189. Therefore, within limits of any resources obtained from federal or foundation grants for this purpose, the signers of the MOU will take advantage of opportunities to link national environmental health information sources, including the U.S. EPA National Environmental Information Exchange Network (NEIEN) and the CDC Public Health Information Network (PHIN), with those in California. NEIEN is a program comprised of U.S. EPA, state, territorial, and tribal partners who are working together to develop a nationwide environmental information exchange network to address the challenges of collecting, sharing, and using environmental information to protect and enhance human health and the natural environment. PHIN is an initiative that promotes the use of health data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels. The vision to bring these two systems together within California will advance the goals of SB 702 and SB 189 by integrating surveillance systems that can transfer appropriate environmental, public health, laboratory, and clinical data efficiently and securely over the Internet.
- One of the key recommendations of the SB702 report was that a State interagency office of Environmental Health Tracking be developed which would be staffed with representation from both the California Department of Health Services and the California Environmental Health Protection Agency. This recommendation was developed into a bill (SB 849 - Escutia) in the 2004-2005 legislative session. The bill was passed by the State Senate but was held up in the Assembly due to appropriation and political issues. The bill was converted to a two-year bill and will be available for another attempt at passage in the 2005-06 legislative session.

5.e.3. Lessons Learned

- With any legislative initiatives, it is critical for the our program to remain engaged with our local and state-wide stakeholders to understand the underlying issues that inspire the

legislation to begin with, and to identify opportunities to partner with stakeholders to ensure that effective environmental health legislation has the opportunity to be introduced and enacted in California.

- The 2004 session illustrates where challenges and opportunities exist for tracking related legislation for California. The passage of AB 2248 suggests there is still strong interest in health tracking issues especially in the area of disease surveillance that can support research, although this is happening in an era of deficit spending.

5.e.4. Recommendations

- For policy changes to take place that will further EPHT in California, support from higher management and chronic disease surveillance programs is essential. Several programs within the State view the EPHT program with suspicion and we have not gained a tremendous amount of support. This is due to the misunderstanding that EPHT will subsume their functions and resources or to program turf issues. Data system owners believe that releasing environmental or health surveillance data in an environmental health tracking system could lead to misinterpretation and poor analysis in ecologic-type environmental health research studies.
- EPHT programs need to place more emphasis on collaborations with partners who can influence policies friendly to the program through legislation. Part of the problem is that bills which are specific to EPHT (e.g. the establishment of an Interagency Office of Tracking, SB 849) do not rank as high priorities for stakeholder groups due to the lack of specificity. EPHT programs should work more closely with local CBOs and national NGOs to develop strategies and implementation plans to affect funding sources and tracking-friendly state and national legislation. Additionally, entities with authorities to take actions to address environmental health problems should be identified and their information needs and interests assessed. These needs and issues should be specifically addressed in the design and implementation of an EPHTN.
- EPHT programs and their partners should work with environmental agencies, legislators, and policy makers to establish mandates to better track chemical hazards, and to collect more complete and up-to-date information on currently mandated hazard tracking programs.
- EPHT programs should ascertain information needs ahead of time and produce policy relevant findings including but not limited to facts about who is exposed and who is vulnerable, both of which are relevant to fairness.
- Entities that have authorities to take actions to address environmental health problems should be identified, along with their information needs and interests. These should be specifically addressed in the design of EPHT programs.
- EPHT programs, in partnership with and utilizing input from community groups, disease registries, and state and local health departments, should develop and employ community-responsive protocols for investigation of disease clusters.