Hazardous Substances Emergency Events Surveillance (HSEES)

Protocol

March 2004

Division of Health Studies
Agency for Toxic Substances and Disease Registry
U.S. Department of Health and Human Services
Public Health Service
Atlanta, Georgia 30333
Table of Contents

Introduction
   General
   Background
Goal and Objectives
   Goal
   Objectives
Methods
   Introduction
   Notification of a Reportable Event
   Surveillance Definition
   Information Needed to Achieve Objectives
   Data Collection
   Training Manual
   Data Sources
   Data Management
      Data Entry
      Timeliness and Completeness of Events
      Quality Control and Assurance
Reliability
Data Analysis
Prevention Outreach
Dissemination of Results
Reference
Appendix A – Training Manual
Appendix B – Hardcopy Data Collection Form
Appendix C – Industry Categories
Appendix D – Instructions for Prevention Outreach Plan and Logic Models
Appendix E – Initial Assessment Form for Prevention Outreach Activities
Appendix F – Data Clearance/Data Request Form
I. Introduction

A. General

The purpose of the protocol is to provide an overview of the functioning of the Hazardous Substances Emergency Events Surveillance (HSEES) system and the responsibilities of participating states and the Agency for Toxic Substances and Disease Registry (ATSDR). More detailed technical information can be found in the HSEES Training Manual (Appendix A), the HSEES Quick Reference Guide, the HSEES User Guide, Release Notes, and on the HSEES secure website.

B. Background

In an attempt to describe the morbidity and mortality experienced by employees, first responders, and the general public that result from hazardous substances emergencies, a surveillance system has been developed that is currently implemented in 15 states: Alabama, Colorado, Iowa, Louisiana, Minnesota, Mississippi, Missouri, New Jersey, New York, North Carolina, Oregon, Texas, Utah, Washington, and Wisconsin.

The need for a state-based surveillance system for acute releases of hazardous substances was first suggested in a 1988 study on the sensitivity of three existing databases: the National Response Center (NRC), the Department of Transportation's (DOT) Hazardous Materials Information System (HMIS), and the Acute Hazardous Events Data Base (1). The study reported the shortcomings of any single national reporting source when trying to assess both the number and effects of hazardous substances emergencies. Of the 587 events reported to these three national databases during the study period, only eight (1%) appeared in all three systems.
The purpose of these databases was not to assess adverse health outcomes that result from hazardous substances emergencies, but rather to serve as a mechanism of enforcement or notifying other agencies (e.g., environmental, enforcement, commercial clean-up, insurance). The raw numbers collected by these databases do not describe the many variables that are associated with the morbidity and mortality resulting from these emergencies, nor do they stratify by populations (i.e., employees, responders, general population) affected. In addition, these databases are limited because of the number of events missed by failure of reporting as well as by the selective reporting of substances.

Barriers that have prevented establishing a surveillance system to assess the morbidity and mortality associated with hazardous substances emergencies include: 1) no legal mandate requiring these data to be reported, 2) no standard definition of an acute release of a hazardous substance, 3) no standard definition as to when an acute release of a hazardous substance begins and when one ends, 4) defining the geographic area of concern, and 5) identifying the exposed population.

Data that are collected by federal (e.g., USEPA, DOT), state (e.g., departments of natural resources) and local agencies focus on the release of hazardous substances into, and the effects of these releases, on the environment as end-points. These data are not adequate to fully investigate the many risk factors associated with the morbidity and mortality resulting from the release of those hazardous substances.

Therefore, a surveillance system which focused on the public health, and not the environmental impact, of hazardous substances emergencies was established in 1989 by ATSDR. Five state health departments participated in the 1990–1992 pilot phase of the HSEES system.
By 1995, 14 state health departments were participating in the surveillance system, and by 2001, the number of participating states increased to 16. Currently, there are 15 participating state health departments.

Consistent with ATSDR’s mission to “serve the public by using the best science, taking responsive public health actions, and providing trusted health information to prevent harmful exposures and disease related to toxic substances,” ATSDR continues to make funds available for state health departments to participate in surveillance activities associated with hazardous substances emergencies.

II. Goal and Objectives

A. Goal

The primary purpose of this program is to build capacity in state health departments to develop and maintain a state-based surveillance system for monitoring acute releases of hazardous substances and conducting appropriate prevention activities. The goal of this surveillance system is to provide data that can be used to reduce the morbidity and mortality resulting from hazardous substances emergencies. Reductions in morbidity and mortality should occur in first responders, employees, and the general public.

B. Objectives

The objectives of the surveillance system are as follows:

1. To describe the distribution of hazardous substances emergencies within the participating states, as well as nationally.
2. To describe the type and cause of morbidity and mortality experienced by employees, responders, and the general public as a result of selected hazardous substances emergencies.

3. Analyze and describe risk factors associated with the morbidity and mortality; and

4. Develop and propose strategies to reduce subsequent morbidity and mortality when comparable events occur in the future.

III. Methods

A. Introduction

The surveillance system is predicated on the ability of state agencies to document the total number of hazardous substances emergencies that occur within their state. Once the mandated state agency is notified, a means must exist to notify the state health department of the event (see "Notification of a Reportable Event"). Once the acute release of a hazardous substance is reported to the participating state health department, the components of the surveillance system consist of: 1) data collection, 2) data management, 3) data analysis, and 4) regular dissemination of reports to promote strategies to reduce morbidity and mortality.

B. Notification of a Reportable Event

State health departments should identify and develop memoranda of understanding with the state and local notification agencies in their states. In some states, this might entail one agency (e.g., state police or public safety). In other states, multiple agencies might be called in the event of a release or threatened release of hazardous substances. Since the primary focus of this project is to assess and potentially prevent acute adverse health effects, the state health
departments need to be contacted within 48 hours of the release in order to have timely data entry (see Data Management section, 2. Timeliness and completion of events).

C. **Surveillance Definition**

Effective January 1, 1993, participating state health departments began collecting data on hazardous substances emergencies meeting the following case definition:

1. An uncontrolled or illegal release or threatened release of one or more hazardous substances, and

2. The substances that are actually released or threatened to be released include ALL hazardous substances except petroleum (Note: The Petroleum Exclusion clause of the CERCLA legislation excludes any forms of petroleum that have not been refined to the point of becoming single-chemical products such as pure xylene.), and

3. The quantity of the hazardous substances which are released, or are threatened to be released, need (or would need) to be removed, cleaned up, or neutralized according to federal, state, or local law; or

4. There is only a threatened release of hazardous substances, but this threat leads to a public health action (e.g., an evacuation) that can potentially impact on the health of employees, responders, or the general public. This action makes the event eligible for inclusion into the surveillance system if the other three criteria are also met, even though the hazardous substances are not released.

A hazardous substance includes any substance which might reasonable be expected to cause adverse health outcomes; except that the term "hazardous substance" does not include
petroleum. However, releases of petroleum along with qualifying chemicals are HSEES events, and the petroleum is reported along with the qualifying chemicals.

D. **Information Needed to Achieve Objectives**

In order to accomplish the objectives, both environmental and health data need to be collected. Environmental data are needed to identify the substance or substances involved in the release. Health data are needed to identify the public health consequences, morbidity and mortality, and evacuations associated with the event. The state health department must establish agreements with mandated or other appropriate notification agencies within their state to collect reports of hazardous substances releases. Information collected through these sources is used to complete all aspects of the web-based data entry system. States are no longer required to fill-out a hardcopy of the data collection form (Appendix B), however, all supporting documentation needs to be retained for at least three years. The hardcopy data collection form is reviewed and approved by the Office of Management and Budget (OMB) every three years. Minor modifications to the form are made at the time of renewal. The current data collection form expires on 11/30/2004.

E. **Data Collection**

Data collected in the web-based data entry system include the following items:

- Event identification and notification information
- Time, date, and day of the week of the event
- Event description including type of industry involved in the event
- Event type (fixed-facility or transportation-related event)
- Geographical location and place within the facility where the event occurred
Complete investigation of an event may involve gathering information from several sources and entering the information from all sources into the HSEES web-based surveillance system. The web-based data entry system used by the states to collect the necessary data is designed to leave little room for misinterpretation. However, open fields have been provided for event-specific comments.

F. Training Manual

To further reduce the possibility of misinterpretation, a training manual for the web-based data entry system is provided to each participating state (Appendix A). The training manual is a quick reference to the types of responses which are acceptable and unacceptable in the HSEES system. The training manual provides explanations and instructions for each question in the data entry system. The training manual is provided to new states and to new personnel when joining the HSEES system. If the HSEES Coordinator is unable to answer a question after referring to the training manual, the coordinator should contact the ATSDR technical advisor.
G. **Data Sources**

Sources of information that the participating states can use to complete data entry include, but are not limited to, state police and fire departments, environmental agencies, various offices of emergency government, the manifest or inventory (depending on whether the incident is a transportation or a fixed-facility event), the incident commander's report, the National Transportation Safety Board (NTSB) report, the Red Cross (for evacuation center/shelter data), hospital admission and discharge records, information reported to the NRC, the media, emergency medical technicians' or ambulance reports, hospitals, poison control centers, and interviews with witnesses and victims.

H. **Data Management**

Overall data management procedures are consistent with existing ATSDR policies and procedures. Participating state health departments are responsible for collecting HSEES data and entering it into the web-based application. ATSDR maintains one dataset consisting of the data from all participating states. ATSDR assigns industry codes (Appendix C) and chemical categories based on information entered into the system by the participating states. Data collected through the HSEES system consist of information on acute releases and not individuals. Therefore, no personal identifying information is collected.

1. **Data Entry**

For consistency in data collection and ease of analysis, ATSDR created a web-based data entry system as of January 1, 2000. The web-based application provides an easy way to enter data for qualifying acute releases into a centralized computer database. The advantages of the web-based system include 1) only one version of the data entry screen which facilitates changes,
such as updating the substance pick list from which chemicals are chosen; 2) only one version of the dataset, so revisions/corrections only need to be made in one location; and 3) real-time data entry.

A training manual is also provided to each of the participating states. As the state health departments are notified of events that meet the case definition, they enter the data into the web-based data entry system. This assures that the "case counts" are accurate at any given time.

Each event has a unique, sequential identification (ID) number which is generated by the software each time a new event is entered into the system. New information about an event can be entered into the computer by re-opening a particular event ID.

2. Timeliness and Completion of Events

In order to be able to effectively promote and protect public health, all data available within 48 hours of the release needs to be entered into the system. ATSDR understands that there may be a few fields where the data are still unknown, e.g., what injury type every victim had, which can be entered later. Events should be entered as quickly as possible; even if the information available is incomplete. ATSDR also anticipates that each state will have no more than 40% of events not meeting the 48 hour data entry deadline. If more than 40% of events are not entered within 48 hours of the release, a concerted effort to continuously improve performance in the timeliness of entering information into the system is expected. States should document the reason for an event being entered greater than 48 hours after the event occurred.

Additionally, data entry for fixed-facility and transportation events should be complete within two months and four months of the date of occurrence, respectively. Again, ATSDR understands that there may be extenuating circumstances that prevent some events from being
completed within these timeframes, however most events are expected to be completed within these timeframes.

3. Quality Control and Assurance

The states will retain documentation about the events. The web-based data entry system has built-in logical checks and range checks, as well as checks for valid values. ATSDR will perform checks for inconsistent or missing data periodically. Data checks will be conducted on a periodic basis with a two month lag time for fixed-facility events and 4 month lag time for transportation events. ATSDR will provide the states with a list of data items that are flagged as either inconsistent or as a critical missing field. States should check these flagged data items and make corrections in the system within one month of receiving the request.

Frequent data checks will improve completeness of the data and improve accuracy in reporting by allowing states to get all the information about an event while it is still fresh. Each state will review 10% of events quarterly to make sure data entry is accurate.

I. Reliability

One way to evaluate ATSDR’s HSEES program is to measure the reliability of the system. Reliability is measured by the ability of the system to receive uniformly recorded data from the state health departments. To address the reliability of HSEES, ATSDR mails to participating state health departments each quarter a case study (provided by one of the participating states) that has the information necessary to complete data entry for an event. State health departments review the case study and complete a hardcopy data collection form which is returned to ATSDR. ATSDR compares responses on state submitted data collection forms to each other as well as to ATSDR preferred responses. Should ATSDR detect major
inconsistencies in the completed data collection forms, issues in question may be addressed in
subsequent correspondence or as an update to the training manual.

J. **Data Analysis**

Analyses conducted by ATSDR include those using the combined data from all
participating states as well as data specific to each participating state. These analyses include,
but are not limited to, frequency distributions and cross tabulations of specific variables.

ATSDR provides participating state health departments and other interested parties with a
report describing the results of data collection from all states for the specific annual period.
ATSDR generates annual reports approximately 6 to 9 months after the end of the calendar year.
Annual reports consist of a series of tables and graphs describing the results of data collection, in
addition to a written summary of the data. In addition, ATSDR generates cumulative reports for
specific blocks of time (i.e., 5 year data analysis).

The state health departments, by downloading their own state-specific datasets, prepare
an annual report describing the results of data collection in their state for the specific year. The
states may also perform descriptive and hypothesis testing analyses.
K. Prevention Outreach

In all participating states, the Project Coordinator should work with the Principal Investigator to develop strategies aimed at reducing morbidity and mortality associated with acute releases of hazardous substances. State health departments who have participated in HSEES for three years or more need to conduct at least four activities each calendar year. One prevention outreach activity should be performed each quarter. At least two activities need to be supported by data from their state (data-driven) and involve a mix of target groups and primary and secondary prevention, while the other two activities can foster general awareness about the surveillance system. Instructions for formatting prevention outreach activities and corresponding logic models are presented in Appendix D. Prevention outreach plans and logic models for the following calendar year are due by December 31 of the current calendar year.

For state health departments who have participated in HSEES for less than three years, the schedule for conducting prevention outreach activities is as follows:

- 1st year: conduct two activities to foster general awareness about the surveillance system
- 2nd year: conduct two awareness activities and one data-driven activity
- 3rd year and beyond: conduct two awareness activities and two data-driven activities

Tracking the audience numbers and evaluations of the data-driven activities is useful in demonstrating the system’s effectiveness. Within two weeks of completing a prevention outreach activity, Project Coordinators will need to submit an Initial Assessment Form (Appendix E) stating the actual audience number (i.e., the number of fact sheets distributed, the
number of attendees at the conference session) and any anecdotal information or feedback about
the activity. If ATSDR does not receive the Initial Assessment Form within two weeks, the
participating state health department will be notified. ATDSR will also implement a new
tracking system to more formally track evaluations of data-driven activities. The evaluations of
data-driven activities will be linked to the effectiveness measures proposed in the prevention
outreach plans (i.e., comparing the number of events and/or victims for a specified time period
prior to the presentation/distribution of material to a specified time period after the
presentation/distribution to see if the numbers decreased).

A summary of the initial assessments of the current calendar year’s prevention outreach
activities is due by December 31. The summary should also include evaluations of data-driven
activities that were completed in the current calendar year.

Participating state health departments who are required to conduct four outreach activities
will be scored on how many prevention outreach activities are completed each calendar year.
Completed data-driven activities will be scored as 35% each and completed awareness activities
will be scored as 15% each for a total of 100%. It is expected that participating state health
departments will score 100%. For those scoring less than 100%, concerted efforts should be
made to increase their score in subsequent years. For prevention outreach activities that can not
be completed in the current calendar year, participating state health departments need to decide
by December 15th if they wish to 1) request a one-month extension to complete the activity, 2)
move the activity to the following year’s prevention outreach plan, or 3) drop the activity.

If requested, ATSDR will assist the states in accessing other states’ data or all states data
to strengthen analyses for prevention outreach and identify similar types of events that are
occurring regionally or system-wide; however, participating states do not routinely have access to the raw data from any other state.

Examples of awareness activities include distributing annual reports and presenting a general overview of the system to LEPCs, first responders and other interested parties. Examples of data-driven activities include analyzing county- or zip code-specific data for presentation to LEPCs; developing and distributing fact sheets on the most frequently released chemicals; providing HSEES data and collaborating with other state agencies to reduce mercury spills or meth lab events; and conducting a more intense evaluation of a previous year’s activity.

Data clearance forms for prevention outreach activities need to be submitted by the Principal Investigators (Appendix F) along with the material to be reviewed for approval by the ATSDR technical project advisor. ATSDR will attempt to review these materials as quickly as possible, but each review of a draft may take up to two weeks, and more than one draft may be necessary. Therefore, states should allow a month for the overall review process.

L. Dissemination of Results

Annual reports from the full dataset (all participating states) are disseminated to interested federal, state, and local agencies and the general public approximately 6-9 months after the close of the calendar year. Annual reports from 1995 on are also available from the ATSDR website.

States are encouraged to disseminate their data to those who can use it for prevention activities as well as to use their data for publications/presentations to appropriate audiences. Any data that is presented outside of the health department requires prior ATSDR approval before release or presentation. This includes quarterly, annual, and cumulative reports that will be
released to the public or any agency, organization, or group outside of the health department (not just sent to ATSDR); fact sheets, graphs, tables, maps, and other compilations of data; posters, slides, and any written text of oral presentations; articles for publication in state or private newsletters, magazines, or journals; and analyses conducted by third parties, such as universities. If it is necessary to release raw data to an entity outside of the HSEES program, a data sharing agreement should be completed. Instructions on how to do this can be obtained from the ATSDR technical advisor.

Principal Investigators need to complete a data clearance form (Appendix F) and submit it with the material to be reviewed for approval by the ATSDR technical project advisor. ATSDR will attempt to review these materials as quickly as possible, but each review of a draft may take up to two weeks, and more than one draft may be necessary. Therefore, states should allow a month for the overall review process.
IV. Reference