

Electronic Disease Reporting & Management

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ABSTRACT

The New Jersey Institute of Technology (NJIT) developed an Electronic Disease Reporting & Management System (EDRMS) that has the capability for the rapid collection, analysis, and dissemination of suspected outbreaks including Chemical and Bio-Terrorism events. Prior to EDRMS, agencies relied on dis-jointed phone and fax reporting and rudimentary methods for data collection, dissemination, follow-up, and remuneration. The objective of this system is to allow collaborative recognition across all the hospitals and public health offices in the state of New Jersey to detect as soon as possible an epidemic occurring of a known or unknown type.

KEY WORDS

Bio-terrorism, Chemical, Communicable Disease, Event Follow-up, Instant Alerting, Nuclear, Outbreak, Rapid Collection, Remuneration

INTRODUCTION

The collection and reporting of communicable disease information has long been a problem for public health officials. The Center for Disease Control and Prevention requires all states to report on over 100 communicable diseases. The states, in turn, have established various rules for physicians, hospitals, and medical laboratories to report such data, either directly to the state or via local health officials. In November 1997, the Center for Disease Control and Prevention issued a report entitled "Electronic Reporting of Laboratory Data for Public Health" [1]. Paramount in the CDC recommendations was the establishment of a facility in each state to accept HL 7 2.3 Observation Results Unsolicited (OPU) messages [2] to populate a database with positive communicable disease reports. In April 1998 the New Jersey Institute of Technology (NJIT) under contract to the New Jersey Department of Health and Senior Services (DHSS) began work on an "Electronic Laboratory Surveillance System" (ELS) to gather and report such data. During tests conducted under this contract in October, November and December 1998, only half of the communicable disease reports that were received via electronic transmission from one commercial laboratory were ever received on hard copy at the DHSS Infectious and Zoonotic Disease Department. This discovery reinforced the need for direct transmission of electronic reports from all laboratories to the New Jersey State Health Department.

Follow-on work at NJIT has led to the completion of the Electronic Disease Reporting & Management System (EDRMS) that has added capabilities for manual entry of suspected cases and rapid collection of suspected outbreak reports including Chemical and Bio-Terrorism events. Prior to September 11, 2001, although many state and federal agencies had prepared plans to deal with disasters, natural and man made, few had held comprehensive exercises to deal with large scale chemical or biological agents. Even those agencies that had detailed plans (in most cases) relied on phone and fax reporting and rudimentary methods for data collection, dissemination, follow-up, and remuneration. The NJIT developed EDRMS has been designed to fulfill these vital, rapid, automated functions.

HISTORY OF DEVELOPMENT

The New Jersey Electronic Laboratory Surveillance System (ELS) was envisioned to receive electronic submissions of positive disease reports in an HL 7 format from commercial and hospital laboratories. These reports were to be processed and loaded into the ELS database. The database was then to be accessible to state and local health officials using a secure web browser connected via the Internet. Follow-up was limited to gathering complete

patient demographics and determining the final disposition of the case. Clinical diagnosis was not included nor was Physician data. Therefore, ELS did not fulfill all of the requirements set out in [1] and [2].

With the concurrence of DHSS, the Electronic Laboratory Surveillance System was completely redesigned to be more user friendly and incorporate six improvements, including three new direct access functions, to enable authorized individuals to better follow-up communicable disease reports and renamed the Electronic Disease Reporting System (EDRS).

1. The Individual Case Listing was renamed “Open Reports.”
2. The Individual Report Listing was deleted from the main menu since all reports are accessible from the list of Open Reports.
3. Reporting Requirements and Reportable Diseases were moved in their entirety to the New Jersey Department of Health and Senior Services main web site.
4. The Data Entry Update Form was replaced by “New Report.”
5. A “Completed Reports” page was added for users to view reports deemed complete.
6. A “Search for Reports” page was added to enable all users to view selected reports for individual cases regardless of jurisdiction while remaining HIPAA compliant by not allowing access to patient demographic data - by unauthorized individuals.

ELECTRONIC DISEASE REPORTING & MANAGEMENT SYSTEM (EDRMS)

After the completion of the contract with the NJDHSS, NJIT continued to work on updates to EDRS to enable users to create a record manually and then follow-up on communicable disease outbreaks. NJIT renamed the enhancements to EDRS as the Electronic Disease Reporting & Management System (EDRMS).

All EDRMS screens display a left hand navigation pane to guide the user through EDRMS including the ability to update the individual user’s profile that is the basis for access and notification.

PATIENT RECORD

The foundation for EDRMS is the patient record. The record can be entered manually, created automatically by an electronic HL 7 message or the manual creation of an outbreak (see below). The left hand column (white on blue) enumerates the report section titles that are links to the section edit screens. Clicking on the “Case History” button displays a sequential listing of all entries and updates of the record, time and date stamped with the user’s ID. Clicking on the disease from any EDRMS screen displays the disease definition, which includes all of the clinical parameters associated with the classification of the disease. Clicking on the Outbreak Number will bring up the Outbreak screen (see below) to show related cases.

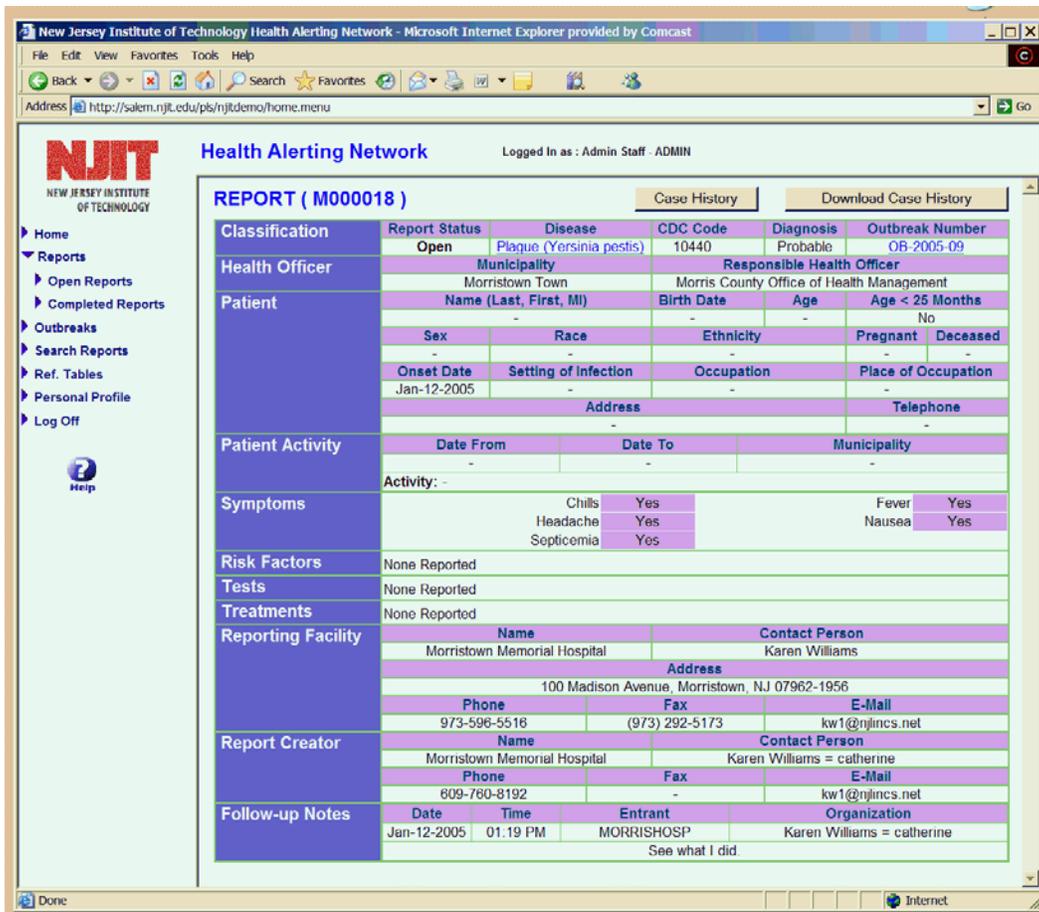


Figure 1: Patient Record Screen

REPORT LISTINGS

Individual patient records are accessed from the Open or Closed Reports screen or by utilizing the Search Reports function. Clicking on the Report Number will bring up the individual report. Clicking on the Health Officer opens the system's e-mail with the health officer's e-mail address as the "To" addressee.

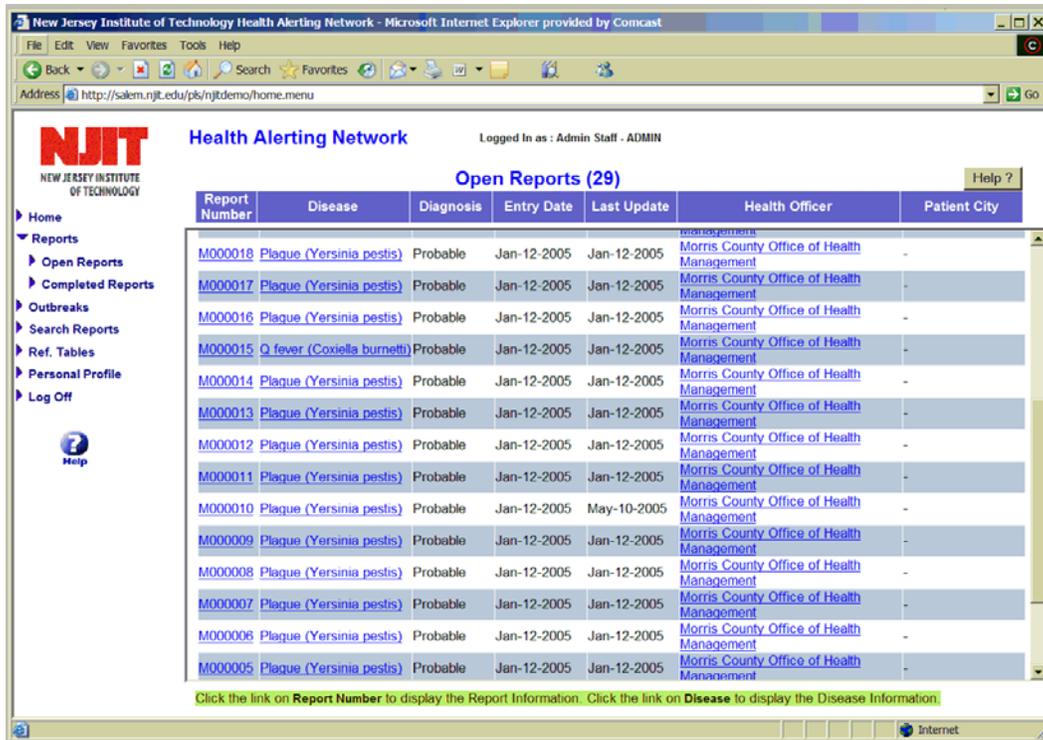


Figure 2: Open Reports Screen

OUTBREAKS

In the “new” EDRMS, an Outbreak Record, a vital part of the enhanced system, was added to display individual reports currently believed to be part of a perceived outbreak. The upper section of the new page displays the Initial Reporting Facility, the Current and Initial diagnosis (Onset Date, Disease, Diagnosis and Municipality). Links were added to EDIT the current values, ADD REPORTs to the outbreak and review the Symptoms associated with the outbreak.

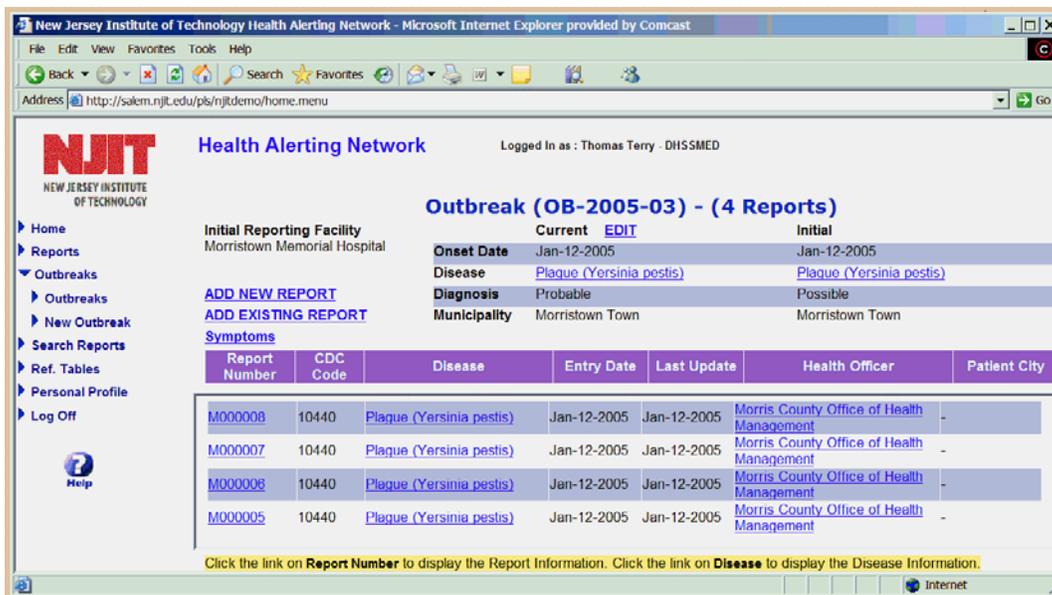


Figure 3: Outbreak Screen

- The EDIT link allows the user to edit all individual reports in the outbreak as a group.
- The ADD NEW REPORT button allows the user to create a new report which is to be included in the outbreak.
- The ADD EXISTING REPORT button allows the user to add an existing report to the outbreak.
- The Symptoms button allows the user to add any or all symptoms to every user a group. An individual's symptoms can be added to the patient's personal record.

The lower section of the page, individual records, is similar in format to that of the “Open” and “Completed” report listing of EDRMS. The Report Number in the outbreak screen serves as an anchor to view and update individual reports. Reports that are later deemed not to be part of the outbreak are easily removed from the outbreak by changing the diagnosis. Other existing reports can be made part of the outbreak and new reports added to the outbreak at any time as described above.

The “Symptoms” button on the Outbreak Record Listing allows the user to review the symptoms common to the outbreak and also symptoms of individuals considered part of the outbreak that may or may not be part of the common set of symptoms. This proved helpful in removing records later deemed not part of the outbreak.

CONCEPT OF OPERATIONS

A New Outbreak is created by first selecting the symptoms present. The authorized user, possibly a hospital emergency room person, selects, from 100 plus common symptoms, those symptoms present in the ill individuals.

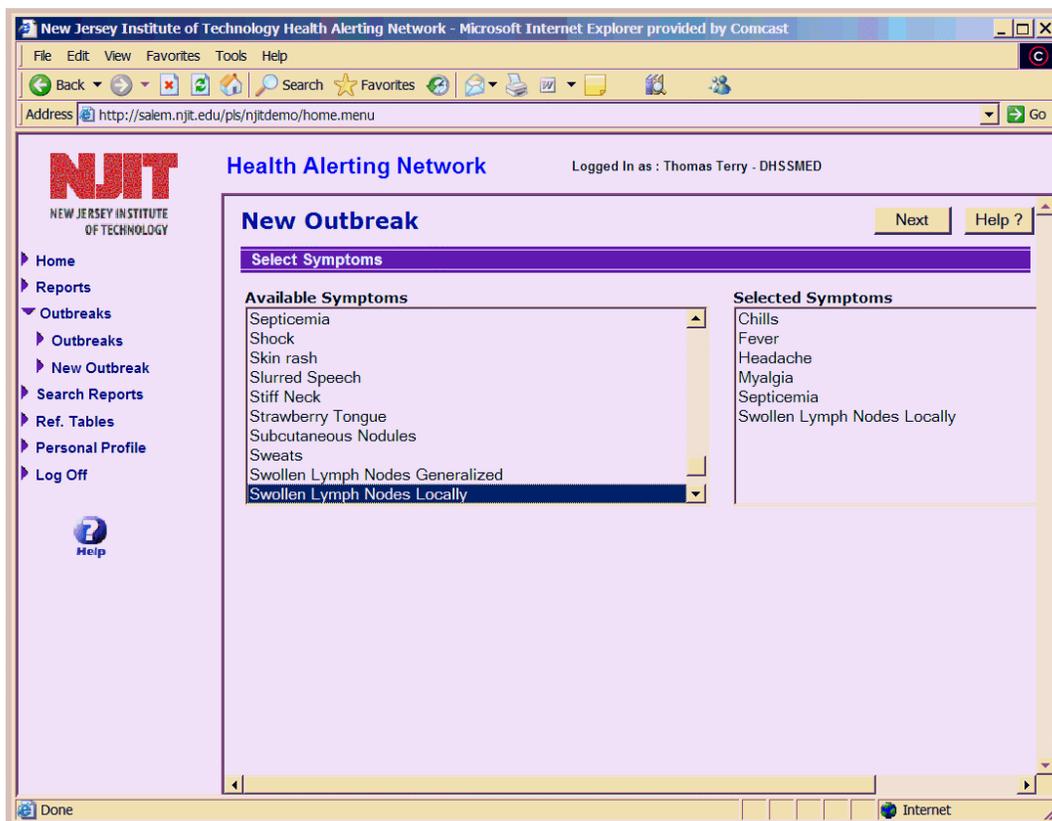


Figure 4: Symptom Selection

Once the symptoms are entered, the user selects the most probable disease from those with corresponding symptoms ranked by number of matches. The user can also make a general selection, such as “Respiratory, Non-specific.”

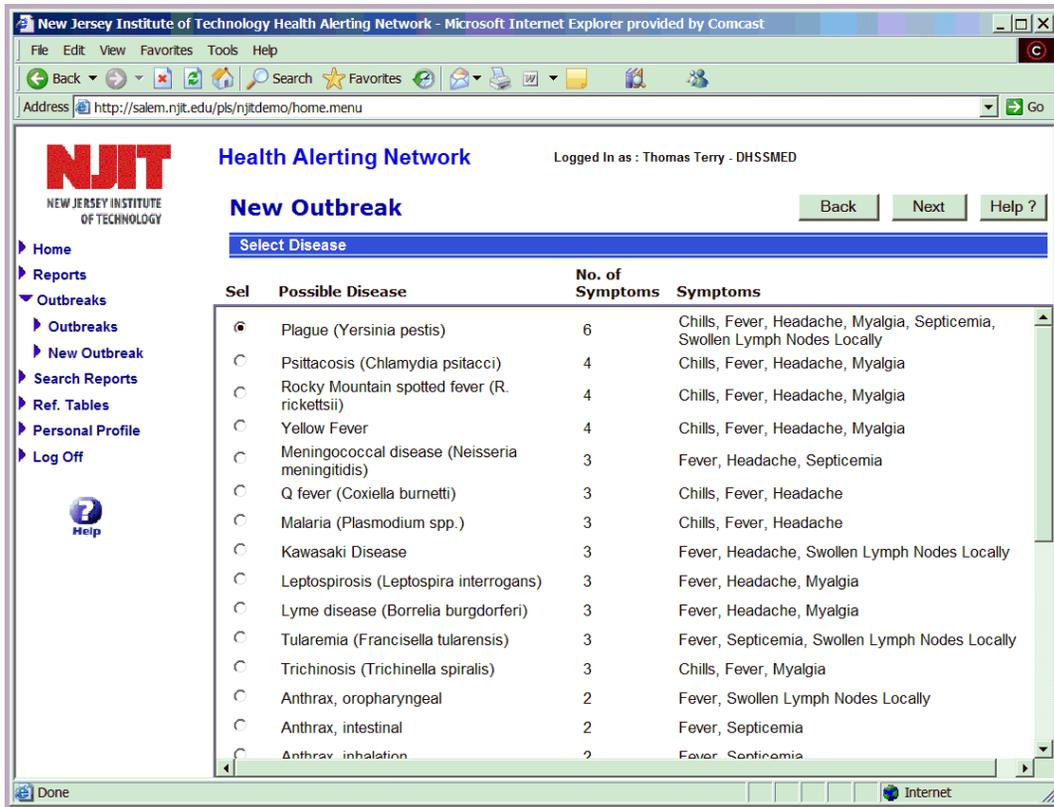


Figure 5: Disease Selection

Once the disease is selected, the user enters the Onset Date and the First Name and Last Name of the patients diagnosed with the possible disease or the Patient Chart Number. Five names can be entered on the screen. If there are more than five patients, an "Add Patients" button will display room for additional patients, five at a time. When all the patients have been entered, the "Add Reports" button assigns outbreak number and creates individual records for each patient, linked to the outbreak and the initial entry process is complete. All outbreaks are classified as "Possible" upon entry. Follow-up action is required to raise the classification to "Probable" or "Positive."

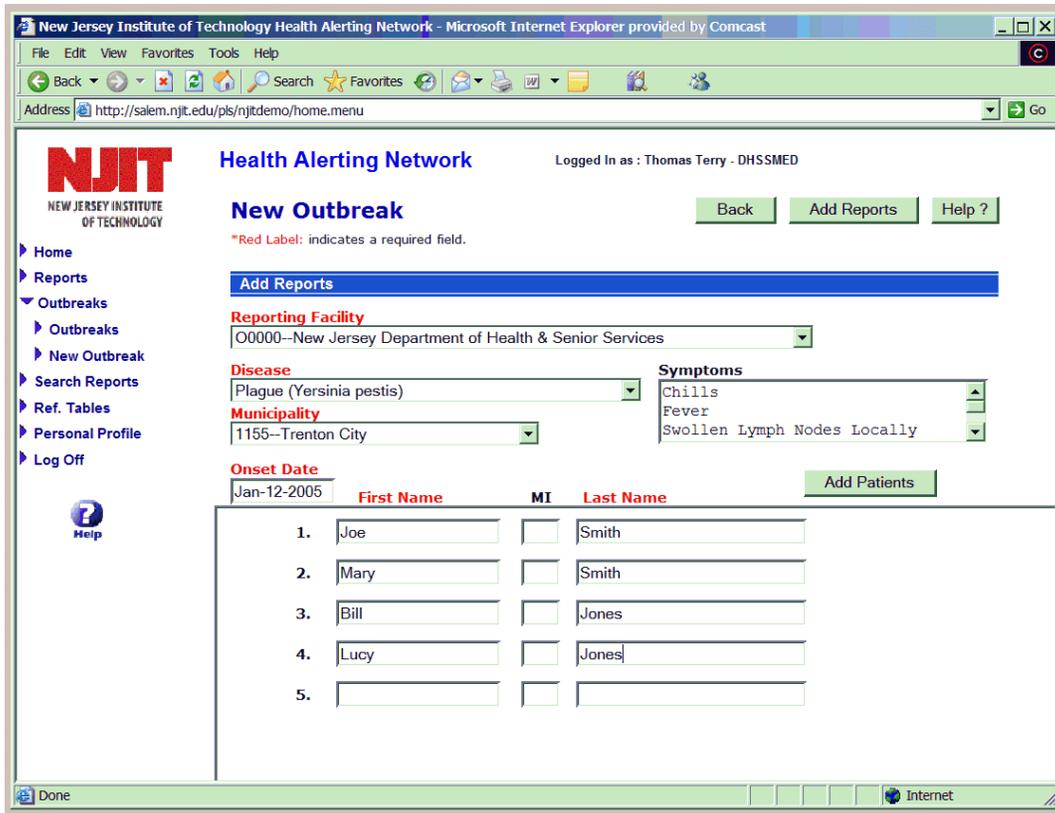


Figure 6: Patient Entry Screen

Follow-up is assigned to the local health officer of the reporting facility's jurisdiction until the addresses of affected individuals are entered into individual report records. Follow-up of each outbreak report is executed using the same methodology as that of individual reports.

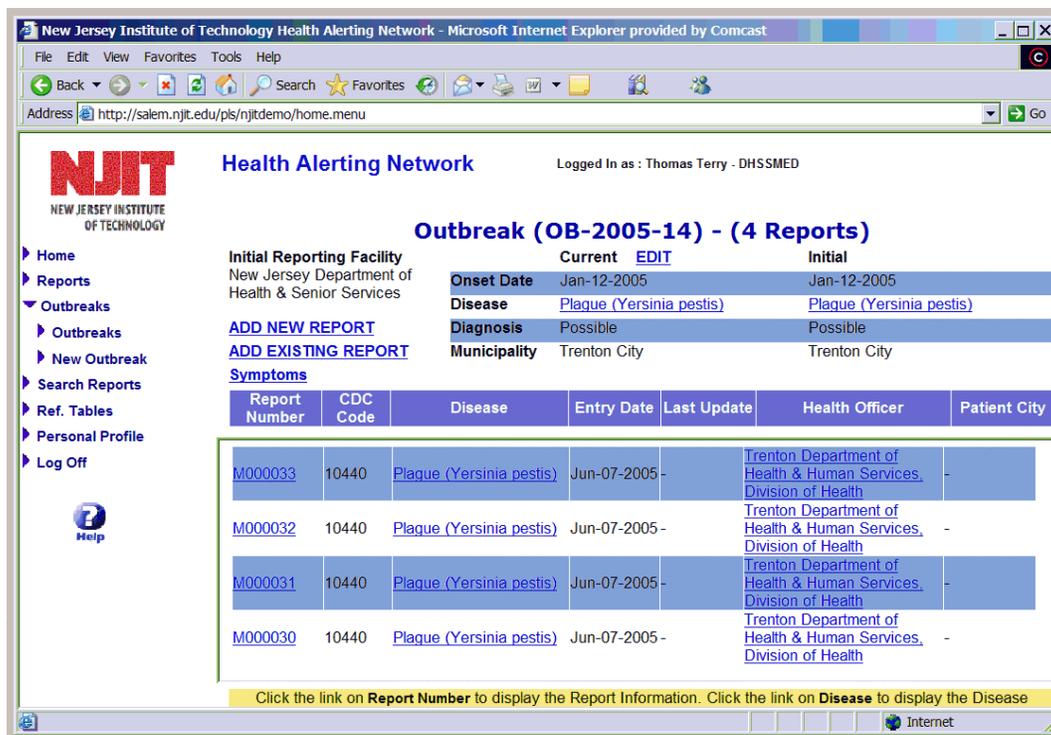


Figure 7: Completed Outbreak Screen

OUTBREAK NOTIFICATION

Immediately upon completion of the Outbreak creation process, state, county and local health officials are notified. Notification is accomplished by automated phone, fax, and e-mail. All messages contain the suspected disease (or agent), number of cases, reporting activity and outbreak number. The e-mail message contains a link to the outbreak record with an encoded script for immediate log-in and viewing of the outbreak screen. After review, state or county health officials can upgrade the classification to “Probable” or “Positive.” This action triggers notification of health officials in all counties and all local health officials in the effected county. If the disease is on the possible bio-terrorism list or is a suspected chemical or radiological event, the state and county Offices of Emergency Management (OEM) are also notified.

DEMONSTRATION EXERCISE

NJIT conducted a demonstration exercise on January 12, 2005. The exercise, similar to a “Table Top” exercise, was designed to show how EDRMS works in conjunction with an automated alerting system and a disaster management system. The major difference between the NJIT exercise and a “Table Top” exercise was that the NJIT exercise employed five PCs, each set up with a projector, so that the audience could observe what each participant in the “Table Top” exercise was doing in real time on a “live” system.

The exercise proceeded as follows:

- A participant, representing a hospital, entered a simple set of symptoms which in turn created a record of a “Possible” outbreak.
- Individual records for each suspected case were established automatically and placed in a group to indicate the suspected outbreak.
- At the completion of the entry of the “Possible” outbreak by the hospital, EDRMS sent a message with an addressee list to an automated voice, and fax message system (CALLMASTER for this exercise). E-mail messages were sent via the NJIT r-mail server.

- Individuals on the list who represented the local health officer and NJ State Epidemiologist received both the automated voice telephone and e-mail.
- The individual representing the state epidemiologist, using a microphone held to his cell phone, enabled the audience to hear the automated alerting message.
- Exercise participants and the audience viewed the e-mail on the PCs. The message included the URL of the suspected outbreak. By clicking on the URL, they logged into EDRMS to view the suspected outbreak record and examine individual cases.
- The outbreak was upgraded to “Probable” in EDRMS after further “tests” at the hospital and follow up by the local HO (or State HO).
- A second sequence of automated voice and e-mail messages were sent to all health officers statewide and to hospitals in the effected county.
- Once the outbreak was classified as “Probable,” and because the disease was on the possible bio-terrorism list, EDRMS posted an automated message to the NJ State and affected county’s Office of Emergency Management system (in this case E-Team). This message alerted these offices to the possible needs for quarantine, road closure and crowd control measures that OEM might have to undertake.
- An individual, representing an additional hospital, added a new individual patient record of a suspected case to the outbreak.
- Subsequently, the original reporting hospital removed one false positive case from the outbreak.

Overall, the exercise took less than an hour but demonstrated to the participants and observers that EDRMS could manage, “in real time” the medical consequences of an outbreak using commercially available systems (CALLMASTER & E-Team) for alerting and disaster management respectively.”

The audience then asked questions and parts of the demonstration were repeated over the course of a second hour. The NJ State Police was represented by the Captain in charge of NJ State OEM. He said in a follow up e-mail, and I quote:

“For what it's worth, I thought the EDRMS demo was very impressive and deserves a look.”

EDRMS is an excellent vehicle for bio-terrorism remuneration since it is easy to use, can utilize any state’s health alerting network, and can link directly to the state’s OEM. A new user can be trained in as little as 30 minutes to use all of the function of EDRMS.

EDRMS SPECIFICATIONS

- EDRMS uses an Oracle or MS SQL database with a web-enabled front end
- EDRMS is entirely table driven.
- The disease table includes individual disease incubation times and the number of cases over a specific period which constitutes a possible outbreak.
- Designated “super users” have full control of the maintenance of tables residing in the EDRMS database (e.g. disease case definitions including primary symptoms, risk factors, additional tests and treatments; LOINC codes; SNOMED codes; municipal codes, etc.).
- Designated “super users” also have the ability to expand the data collection beyond the CDC reportable diseases to include chemical & radiological agents and non-communicable diseases.
- Laboratory reports and/or symptoms are used as the foundation for EDRMS.
- Designated users have access the data via a secure Internet path with the digital certificates.
- An HL7 reader is used for decoding all automated electronic laboratory reports.
- An automated selection process is available to state health officials for electronic reports requiring follow up.
- The system incorporates an automatic routing mechanism, for all open cases, to the appropriate local health officers.
- The system supports direct hospital on-line reporting. (The system could be easily expanded to incorporate physician on-line reporting with appropriate security measures.)

- Designated users have the ability, as required, to enter into the database cases received via fax or phone.
- A geographical mapping mechanism is available which makes it easy to identify disease clusters or outbreaks.
- An automated notification procedure alerts the local health officers of cases falling under their jurisdiction.
- A process for matching of patients to create a uniform case report when information for the same patient is received from multiple sources (e.g., multiple lab or manual reports for the same patient).
- Longitudinal plotting as a mechanism for Syndromic Surveillance.

CONCLUSION: EDRMS as a Bio-Terrorism Reporting & Management Tool

In today's world, biological, chemical, and radiological threats are a fact of life. EDRMS has the capability to assist in the determination of the extent of the spread of the problem and minimize the consequences through rapid reporting and dissemination of critical information. Many individuals feel that Syndromic Surveillance is an effective Bio-Terrorism et al reporting mechanism. However, Syndromic Surveillance is based on reports of relatively large numbers of cases, spread over defined time intervals, and often reported hours or even days after the first onset. EDRMS on the other hand can not only provide the same broad view as Syndromic Surveillance, but can be used to identify a single case and then link other cases into a Bio-event such as was the case for the Anthrax scare of the fall of 2001.

ACKNOWLEDGMENTS

Marsha Roberts was the initial designer of the ELS and EDRMS databases including the HL 7 parser. She was assisted by Lily Wang who developed the EDRMS screens, Tariq Majeed who produced the entry and edit functions, and Arvind Cheruku who added the geo-plotting function. Midway through the EDRMS development process, Tariq assumed all responsibility for the entire EDRMS project including many enhancements. Several individuals from the New Jersey Department of Health and Senior Services and others from the Morris County New Jersey Office of Health Management provided vital input as to the construction and operation of EDRMS.

REFERENCES

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ABOUT THE AUTHOR

Thomas J. Terry, Jr. received his B.S. degree in Systems Engineering from the U.S. Naval Academy, Annapolis, MD in 1960 and M.S. degrees in Management Science and Computer Science from The Johns Hopkins University, Baltimore, MD in 1975 and 1977, respectively. He was a U.S. Navy Officer serving in destroyers and nuclear submarines (1960 to 1972), Manager, Operations Analysis at General Physics Corporation, Columbia, MD (1972 to 1977), Manager, Advanced Systems Analysis, Gould Corporation, Ocean Systems Division, Cleveland, OH (1977 to 1979), Senior Scientist (1979 to 1982), Director, MIS, (1982 to 1988), Emerson Electric, Electronics & Space Division, St. Louis, MO and CIO New Jersey Institute of Technology (1988 to 1999). He was Associate Vice President, Information Resource Development at NJIT from 1999 until his retirement in 2005. During that time he was involved in various

aspects of public health data collection and communication since 1993. Under his direction, NJIT operated and continues to operate the Health Alerting Network for the State of New Jersey. He continues to be active in the disease management arena with NJIT and several organizations, public and private, nationwide.