Chapter 20: National Surveillance of Vaccine-preventable Diseases

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I. Background

The national reporting system for infectious diseases in the United States was initially an archival system designed to document trends in disease occurrence rather than to provide epidemiologically important information needed for prevention and control of diseases.[1,2] As national immunization programs developed, so did the need for surveillance of vaccine-preventable diseases. The first major support for immunization at the federal level came following the licensure of inactivated poliomyelitis vaccine (IPV) in 1955. During the 2 weeks following the announcement of the results from the successful field trial of this polio vaccine, approximately 4 million doses of vaccine were administered, mostly to elementary schoolchildren. On April 25, 1955, an infant with paralytic poliomyelitis was admitted to a Chicago hospital 9 days following vaccination with IPV. The next day, five additional cases of paralytic poliomyelitis were reported from California among children who had received vaccine produced by the same manufacturer of the vaccine administered in the child in Chicago. In each case, paralysis first developed in the limb in which vaccine had been given. On April 27, 1955, the Surgeon General asked the manufacturer to recall all remaining lots of vaccine. The following day, the Poliomyelitis Surveillance Unit was established at the Communicable Disease Center (now the Centers for Disease Control and Prevention [CDC]).

State health officers were asked to designate a polio reporting officer responsible for reporting cases of poliomyelitis among vaccinated persons; later, cases among their family members and other contacts were included. Case reports were transmitted by telephone or telegraph to the Poliomyelitis Surveillance Unit where the data were collated, analyzed, and disseminated via poliomyelitis surveillance reports; the first report was mailed out on May 1, 1955—only 3 days after the surveillance activity was initiated. The report was prepared and distributed daily for 5 weeks, weekly for the remainder of the summer and fall, and once every 3–4 weeks during the winter.

During the first days of the surveillance program, as more cases were reported, the data demonstrated with increasing certainty that the problem was confined to vaccine produced by a single manufacturer. Production procedures were reviewed and other manufacturers were encouraged to continue vaccine production. Without the surveillance program and the rapid clarification of the scope of the problem that was provided by the analysis of national surveillance data, the manufacture of poliomyelitis vaccine might have been halted in the United States.

This episode highlights several important aspects of modern public health surveillance. Data were collected, analyzed, and disseminated rapidly to allow policy makers to base their decisions on the best information available. Morbidity data were not collected for publication in archival tables but rather to characterize an important public health problem and to facilitate effective public health action.

II. National Immunization Program surveillance activities

In cooperation with state health departments and CDC's Epidemiology Program Office (EPO), the National Immunization Program (NIP) at CDC performs national surveillance for measles, mumps, rubella, congenital rubella syndrome, diphtheria, tetanus, pertussis, poliomyelitis, and varicella. Responsibility for the surveillance of other vaccine-preventable diseases (hepatitis A and B and influenza) is managed by National Center for Infectious Diseases (NCID), CDC, and NIP and NCID share responsibilities for national surveillance of *Haemophilus influenzae* type b invasive disease (Hib) and pneumococcal disease. Cases reported to state health departments are reported to the National Notifiable Diseases Surveillance System (NNDSS), overseen by EPO. In general, CDC encourages health departments to report provisional data to the NNDSS before completing case investigations, but there are exceptions. Since 1983, only confirmed cases of measles have been reported to the NNDSS. For other vaccine-preventable diseases, cases that are classified as suspected, probable, or under investigation may be reported provisionally. (The data reported in the *Morbidity and Mortality Weekly Report* [*MMWR*], however, include only confirmed cases of paralytic poliomyelitis; suspected cases are enumerated in a footnote.)

All state health departments now have their surveillance data computerized, and development of these systems during the 1980s allowed electronic reporting to supplant the previous system of reporting aggregate data to the NNDSS by telephone. Since 1989, state health departments have reported data electronically to the NNDSS via the National Electronic Telecommunications System for Surveillance (NETSS).[3] With the introduction of computerized data management, additional demographic information on age, sex, race, and ethnicity for each case patient has been collected and reported to the NNDSS, along with county of residence and date of onset of illness.

The data collected by the NNDSS are supplemented by other surveillance systems operated by NIP. Supplemental surveillance systems provide data on vaccination status, laboratory confirmation, complications, and epidemiologic linkage to other cases; these data provide important information for disease control activities and policy making. Most of the supplemental systems originally were developed as paper-based systems, but now the capacity for electronic reporting of supplemental data on many vaccine-preventable diseases via NETSS exists at the state health department level. Computerizing these data at the state level has made surveillance data more useful for state health departments. Electronic

reporting also facilitates more rapid analysis and dissemination of results at the national level.

CDC publishes NNDSS data weekly in *MMWR* and yearly in the "Annual Summary of Notifiable Diseases." NNDSS data and data reported to supplemental surveillance systems are analyzed by NIP staff and disseminated through regular surveillance reports, articles in *MMWR, MMWR Surveillance Summaries*, and other published articles.

III. Vaccine-preventable diseases reported to NNDSS

State and local public health officials rely on health-care providers, laboratories, and other public health personnel to report the occurrence of notifiable diseases to state and local health departments. In the United States, requirements for reporting diseases are mandated by state laws or regulations, and the list of reportable diseases in each state differs. CDC and the Council of State and Territorial Epidemiologists (CSTE) have established a policy that requires state health departments to report cases of selected diseases to CDC's National Notifiable Disease Surveillance System (NNDSS).

Diphtheria

Reports of diphtheria cases from state health departments to NNDSS are supplemented by additional cases identified through requests received by NIP for diphtheria and antitoxin. Clinical data on the severity of illness, vaccination status, outcome, and final diagnosis are obtained for all suspected diphtheria cases identified through diphtheria antitoxin requests. No formal supplemental surveillance system for diphtheria exists, however, a surveillance worksheet is available to provide guidance for case investigation (**Appendix 3**).

Measles

Since 1978, substantial effort has been invested in measles surveillance at the state and local levels. In 1979, a standard clinical case definition for measles was adopted, and cases were further classified as suspected, probable, or confirmed. Since 1983, only confirmed cases have been reported.

The National Immunization Program (NIP), CDC developed the Rapid Surveillance Helper (RASH) system to electronically collect supplemental data on measles cases. The software was first introduced in 1985 and subsequently underwent several modifications. RASH has now been supplanted by electronic reporting of supplemental data via NETSS. Data on vaccination status, complications, setting of transmission, and serologic confirmation of cases are collected (**Appendix 7**). Cases identified with particular outbreaks can also be linked.

Mumps

No supplemental surveillance system for mumps existed before development of the NETSS extended record for collecting additional information on mumps cases. Data on vaccination status, complications, setting of transmission, and serologic confirmation of cases are collected (**Appendix 8**).

Pertussis

Since 1979, health departments have reported detailed clinical, demographic, and laboratory information on each case of pertussis through the Supplementary Pertussis Surveillance System (SPSS) (**Appendix 9**). Information is collected on age, diphtheria-tetanus-pertussis vaccination history, and selected clinical characteristics including duration of cough and the occurrence of complications such as pneumonia, seizures, encephalopathy, hospitalization, and death. Results of laboratory tests, including cultures and direct fluorescent antibody tests for *Bordetella pertussis*, and information on antimicrobial therapy are also collected (**Appendix 9**). Reports of encephalopathy and death are confirmed by telephone.

Supplemental data on pertussis cases, including expanded vaccination history information, are reported electronically via NETSS.

Poliomyelitis

Detailed demographic, clinical, and epidemiological data are collected on all suspected cases of paralytic poliomyelitis reported to CDC (**Appendix 14**). Experts who are not affiliated with CDC review suspected cases and determine whether they meet the case definition for paralytic poliomyelitis. Since the adoption of a new case classification system in the 1980s, cases have been classified as sporadic, epidemic, imported, or occurring in immunologically abnormal persons, and as being related to wild virus or vaccine virus.[4]

Rubella and congenital rubella syndrome (CRS)

No supplemental surveillance system for rubella existed before the development of the NETSS extended record, although some states previously included vaccination status and pregnancy status in the data they reported to the NNDSS. Data on vaccination status, complications, setting of transmission, and serologic confirmation of cases are now collected (**Appendix 16**).

The National Congenital Rubella Syndrome Registry (NCRSR) collects additional clinical and laboratory information on cases of suspected congenital rubella syndrome in the United States (**Appendix 17**). The registry, established in 1969, includes data only on cases classified as confirmed or compatible. Cases are also classified as indigenous (exposure within the United States) and imported (exposure outside the United States) and are tabulated by year of birth. In contrast, cases reported to the NNDSS are tabulated by year of report.

Tetanus

Since 1965, state health departments have reported supplemental clinical and epidemiological information on reported cases of tetanus to the Supplemental Tetanus Surveillance System. Information is collected on the clinical history, presence, and nature of associated risk factors, vaccination status, wound care, and clinical management. Data may be collected using worksheets and are reported on the tetanus surveillance case report form (**Appendix 18**) or electronically via NETSS.

IV. Interpretation issues

Reporting of vaccine-preventable diseases by physicians and other providers to passive surveillance systems is far from complete. Periodic community surveys in Hagerstown, Maryland, in 1922–1923 identified 560 cases of measles among the 7,424 residents. Sixty-four percent of these patients were seen by physicians, and only 40% of these cases were reported to the health department; overall, only 26% of cases were reported to local health authorities.[5] There is little evidence that reporting by physicians has improved dramatically in the years since the Hagerstown study. Only an estimated 11.6% of pertussis cases in the United States are reported.[6] Although the reporting of sporadic cases of measles is thought to be more complete than that estimated for pertussis, in 1991 an investigation of reporting during an urban outbreak suggested that only 45% of measles patients treated in hospitals were reported.[7]

The completeness of reporting to supplemental surveillance systems has been evaluated by using capture-recapture methods.[8,9] After comparing congenital rubella syndrome cases reported to the NCRSR with those identified by the Birth Defects Monitoring Program during 1970–1985, Cochi and colleagues determined that only 22% of these cases were reported to the NCRSR.[10] By comparing the number of deaths reported to CDC surveillance systems with the number reported on death certificates to CDC's National Center for Health Statistics, Sutter and colleagues estimated that only 40% of tetanus-related deaths during 1979–1984 and 33% of pertussis-related deaths during 1985–1988 were reported to CDC supplemental surveillance system.[6,11] Likewise, during 1985–1988, an estimated 32% of pertussis-related hospitalizations were reported to SPSS, and during 1985–1991, only 41% of measles-related hospitalizations were reported to RASH.

Those cases reported to a surveillance system may not be representative of all cases. A comparison of hospitalized pertussis case patients reported to SPSS with hospital data collected by the Commission on Professional and Hospital Activities' (CPHA) Professional Activities Survey revealed that the case patients reported to CDC were more likely to have pneumonia, seizures, and encephalitis than those identified in the CPHA sample. The average hospitalization was longer for those case-patients reported to SPSS than for those in the CPHA sample, suggesting that more severe cases were more likely to be reported to CDC.[5]

To improve specificity and enhance comparability of state-reported cases of vaccine-preventable diseases, case definitions for surveillance have been developed. A standard case definition of paralytic poliomyelitis was introduced in 1958, and a clinical case definition of measles was adopted in 1979. Standard case definitions for the surveillance of all vaccine-preventable diseases were first published in 1990[12] and are updated as needed. However, implementation of uniform case definitions for reporting by state health departments has been incomplete.

V. Future directions

To maximize the usefulness of vaccine-preventable diseases surveillance data at the state level, the existing supplemental surveillance systems need to be fully integrated with state notifiable disease data systems and fully utilized. Development of systems of distributed data entry, with electronic reporting from local health departments, is underway in some states and will allow the benefits of rapid analysis of pertinent public health data to be realized at the local or county health department level.

In addition, CDC in collaboration with the states, is developing the National Electronic Disease Surveillance System (NEDSS). CDC is developing the NEDSS Base System, a platform for states to use for entering, updating, and searching for demographic and notifiable disease data. NEDSS will allow rapid reporting of disease trends to control outbreaks and early detection. It will increase the volume, accuracy, completeness, and timeliness of vaccine-preventable disease data.[14]

There has been increasing interest in alternative approaches to traditional morbidity surveillance systems. Hospital discharge data sets may be useful for some purposes, although they are of limited usefulness in providing timely data for disease control purposes. Ultimately, computerized medical records in physicians' offices and clinics may provide data that are timely, accurate, and complete. The development of such systems is perhaps most advanced in large health maintenance organizations and other large group practices, but rarely available in smaller practices. Aside from the other technological barriers, maintaining patient confidentiality remains a primary concern, and data quality must be assured.

The use of both current and new data sources needs to be improved. Laboratory based reporting is a valuable adjunct to traditional provider reports. It is essential for the surveillance of some conditions for which the case definition is based on results of laboratory testing (e.g., Hib) and for certain conditions where clinical diagnosis is unreliable (e.g., rubella); laboratory based reports may be the only source of accurate information. Improved links between laboratories and communicable disease surveillance activities within state and local health departments are needed. The Public Health Laboratory Information System (PHLIS), the electronic reporting system developed by the Association of Public Health Laboratories (APHL) and NCID, CDC, may provide an important electronic link within state health

departments.[13] In the future, electronic links with commercial laboratories, and ultimately large group practices and clinics, may provide more complete and timely data than are now available.

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