

Chapter 23: 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 designed as an archival system 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 after 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 after being vaccinated 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 to 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 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 Surveillance Activities for Vaccine-Preventable Diseases

In cooperation with jurisdictions' health departments, CDC coordinates national surveillance for diseases and conditions in the National Notifiable Diseases Surveillance System (NNDSS),³ which include, but are not limited to, measles, mumps, rubella, congenital rubella syndrome, diphtheria, tetanus, pertussis, poliovirus infection (nonparalytic), paralytic poliomyelitis, *Haemophilus influenzae* invasive disease, invasive pneumococcal disease (IPD), meningococcal disease, hepatitis A, hepatitis B, novel influenza A virus infections, influenza-associated pediatric mortality, and varicella. In NNDSS, CDC is notified



of cases of diseases and conditions under national surveillance by 52 jurisdiction health departments (i.e., the 50 states, New York City, and the District of Columbia), as designated by the Council of State and Territorial Epidemiologists (CSTE). In general, CDC encourages state health departments to submit provisional data through NNDSS before completing case investigations; however, cases are included for publication in CDC's *Morbidity and Mortality Weekly Report (MMWR)* as described in the case status print criteria approved by CSTE.⁴

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

Development of computer data systems during the 1980s allowed electronic reporting to supplant the previous system of reporting aggregate data to NNDSS by telephone. Beginning in 1989, state health departments were able to report data electronically to NNDSS via the National Electronic Telecommunications System for Surveillance (NETSS).⁵ In 2000, states began receiving federal funding to plan and implement integrated electronic systems for disease surveillance, which developed into the National Electronic Disease Surveillance System (NEDSS).⁶ Subsequently, rapid advances in technology and data and exchange standards have necessitated the evolution of electronic surveillance infrastructure, including sending/receiving mechanisms and reporting procedures.^{7,8} The primary focus has been on development of harmonized messages supported by interoperable standards (e.g., PHIN, LOINC, SNOMED) and shared services, rather than specific systems, to support Meaningful Use and electronic consumption of health data.^{9,10} Electronic reporting, case notification, data management, and data analysis can provide timely access to demographic, epidemiologic, and laboratory, and other public health data for each case in NNDSS. Enhancing the capability of surveillance systems to link electronic case notifications with existing electronic clinical and laboratory data is anticipated to improve data quality and reduce the burden of reporting.¹¹

III. Vaccine-Preventable Diseases and Conditions in NNDSS

State and local public health officials rely on healthcare 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.^{12,13} CDC and CSTE have established a policy under which state health departments send notifications of cases of selected diseases to CDC through NNDSS. Electronic reporting and data management were developed to provide timely access to demographic and epidemiologic information on each case in the NNDSS.

Diphtheria

Reports of diphtheria cases from state health departments to NNDSS are supplemented by additional cases identified through requests received by CDC for diphtheria antitoxin. Clinical data on the severity of illness, patient's vaccination status, outcome, and final diagnosis are obtained for all suspected diphtheria cases. A surveillance worksheet is available to provide guidance for case investigation (Appendix 3).

Haemophilus influenzae type b (Hib)

No supplemental surveillance system for Hib existed before development of the NETSS extended record for collecting supplemental information on Hib cases. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, and serotype of cases are collected (Appendix 4).

Influenza (novel influenza and pediatric influenza deaths)

Because influenza viruses undergo constant antigenic change, both virologic surveillance (in which influenza viruses are isolated and used for antigenic and genetic analysis as well as for antiviral resistance testing) and disease surveillance are necessary to 1) identify influenza new virus variants; 2) monitor the health impact in populations; and 3) provide data necessary for selection of influenza vaccine components each year. Influenza-associated deaths among children younger than 18 years of age and human infection with a novel influenza A virus are reported through the NNDSS. Other influenza virus infections are not nationally notifiable but may be reported in some states. Local health departments should contact the state health department for guidelines on reporting individual cases or outbreaks of influenza.

Invasive pneumococcal disease

No supplemental surveillance system for IPD existed before development of the NETSS extended record for collecting supplemental information on IPD cases. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, and serotype of cases are collected (Appendix 13).

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 included in published reports. In 2000, experts agreed that indigenous transmission of measles had been eliminated in the United States.¹⁴

In 1985, the National Immunization Program at CDC, developed the Rapid Surveillance Helper (RASH) system to electronically collect supplemental (e.g., epidemiologic, laboratory, clinical) data on measles cases. RASH has now been supplanted by electronic transmission of supplemental data to NNDSS via NETSS and other electronic submissions of data using messages supported by interoperable standards. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, importation status, and molecular epidemiology of cases are collected (Appendix 8).

Meningococcal disease

No supplemental surveillance system for meningococcal disease existed prior to the development of the NETSS extended record for collecting supplemental information on meningococcal disease cases. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, and serogroup of cases are collected (Appendix 9).

Mumps

No supplemental surveillance system for mumps existed prior to the development of the NETSS extended record for collecting supplemental information on mumps cases. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, importation status, and molecular epidemiology of cases are collected (Appendix 10).

Pertussis

In 1979, the Supplementary Pertussis Surveillance System (SPSS) was developed to allow health departments to collect detailed clinical, demographic, and laboratory information on each case of pertussis.

Supplemental data on pertussis cases, including expanded patient vaccination history information, are now reported electronically (Appendix 11). Information is collected on patient age, diphtheria-tetanus-pertussis vaccination history, and selected clinical characteristics, including duration of cough and occurrence of complications such as pneumonia, seizures, encephalopathy, hospitalization, and death. Results of confirmatory laboratory tests and information on antimicrobial therapy are also collected. Reports of encephalopathy and death are confirmed by telephone.

Poliomyelitis, paralytic and poliovirus infection, non-paralytic

Detailed demographic, clinical, and epidemiologic data are collected on all suspected paralytic poliomyelitis cases for which CDC receives a notification from the jurisdiction (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, paralytic poliomyelitis cases have been classified as sporadic, epidemic, imported, or occurring in immunologically abnormal persons, and as being related to wild virus or vaccine virus.¹⁵ Poliovirus infection (asymptomatic, non-paralytic) was added to the list of nationally notifiable diseases and conditions in 2007.¹⁶

Rubella and congenital rubella syndrome

No supplemental surveillance system for rubella existed prior to the development of the NETSS extended record. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, importation status, and molecular epidemiology of cases are collected in NNDSS (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 reported through the registry, as well as cases reported through NNDSS, are classified as indigenous (exposure within the United States) or imported (exposure outside the United States). Registry cases are tabulated by year of birth, while cases reported to NNDSS are tabulated by year of notification.

Tetanus

In 1965, the Supplemental Tetanus Surveillance System was developed to allow state health departments to collect supplemental clinical and epidemiologic information on reported cases of tetanus. Case notifications are sent electronically to CDC as part of NNDSS. Information is collected on the clinical history, presence, and nature of associated risk factors, patient vaccination status, wound care, and clinical management (Appendix 18).

Varicella

In 1998, the CSTA recommended that varicella-related deaths be placed under national surveillance,¹⁷ and varicella-related deaths became nationally notifiable on January 1, 1999. In 2002, CSTE recommended that varicella be included in NNDSS. All states were encouraged to conduct ongoing varicella surveillance to monitor vaccine impact on morbidity.¹⁸ As of 2010, 36 states were conducting case-based varicella surveillance. Persons reporting should contact the state health department for state-specific reporting requirements.

IV. Interpretation Issues

Reporting of vaccine-preventable diseases by physicians and other providers to passive surveillance systems is far from complete. There is little evidence that reporting by physicians has improved greatly in the years since 1922–1923, when periodic community surveys in Hagerstown, Maryland, identified 560 cases of measles among the 7,424 residents. Sixty-four percent of these patients were seen by physicians, but only 40% of these cases were reported to the health department; overall, only 26% of cases identified by the surveys were reported to local health authorities.¹⁹ A study in 1992 showed that only an estimated 11.6% of pertussis cases in the United States were reported.²⁰ Although 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.²¹ In a review of measles reporting completeness in the U.S., hospital-based reporting for measles was found to be in the range of 45%–58%.²² A literature review of articles on surveillance data for measles, pertussis, mumps, and rubella in industrialized countries further illustrated that reporting is incomplete.²³

The completeness of reporting to supplemental surveillance systems has been evaluated by using capture–recapture methods.^{24,25} 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.²⁶ 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 systems.^{21,27} 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.

Cases reported to a surveillance system may not be representative of all cases. A comparison of hospitalized pertussis patients reported to SPSS with hospital data collected by the Commission on Professional and Hospital Activities’ (CPHAs’) Professional Activities Survey revealed that the case-patients reported to CDC were more likely to have pneumonia, seizures, and encephalitis than were 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.²¹

To improve specificity and enhance comparability of cases of vaccine-preventable diseases for which CDC receives notification, case definitions for public health 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 surveillance of all vaccine-preventable diseases were first published in 1990,²⁸ revised in 1997,²⁹ and have been subsequently updated as needed.⁴ However, implementation of uniform case definitions for reporting to local/state health departments and notification to CDC has been incomplete.

V. Future Directions

To maximize the usefulness of vaccine-preventable diseases surveillance data at the local, state/territorial, and federal levels, supplemental surveillance systems need to be fully integrated with notifiable disease data systems for NNDSS, and the data must be fully utilized. Submission of case notifications and supplemental data to CDC for NNDSS should include electronic data using messages supported by harmonized data elements and interoperable standards. Electronic systems of distributed data entry, with reporting from healthcare providers, laboratories, and local health departments, are used in some jurisdictions, supporting the benefits of rapid analysis of pertinent public health data at the local or county health department level.

There has been increasing interest in alternative approaches to traditional morbidity surveillance systems.^{30,31} Hospital discharge data sets may be useful for some purposes, although their usefulness in providing timely data for disease control purposes is limited. Interoperable electronic health records throughout the U.S. healthcare delivery system (e.g., physicians' offices and clinics) may provide public health data that are more meaningful, timely, accurate, and complete.³²⁻³⁴ The development of such systems is perhaps most advanced in large health maintenance organizations, hospitals, and large group 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.³⁵⁻³⁸ 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 for which clinical diagnosis is unreliable (e.g., rubella). Laboratory-based reports in such situations may be the only available source of accurate information. Improved links between laboratories and communicable disease surveillance activities at all levels are needed. Enhanced interoperable electronic links with commercial laboratories, clinical group practices, hospitals, and other healthcare providers will support more complete and timely data than are now available.

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This document can be found at: www.cdc.gov/vaccines/pubs/surv-manual/chpt23-natl-surv-vpd.html

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