# 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 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 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 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 Surveillance Activities for Vaccine-Preventable Diseases

In cooperation with state health departments, CDC coordinates national surveillance for diseases and conditions included in the National Notifiable Diseases Surveillance System (NNDSS),[3] including, but not limited to, measles, mumps, rubella, congenital rubella syndrome, diphtheria, tetanus, pertussis, poliovirus infection (nonparalytic), paralytic poliomyelitis, *Haemophilus influenzae* invasive disease, invasive pneumococcal disease, meningococcal disease, hepatitis A, hepatitis B, varicella, novel influenza A virus infections, influenza-associated pediatric mortality, and varicella deaths. Cases of diseases and conditions under national surveillance, as designated by the Council of State and Territorial Epidemiologists (CSTE), are reported to CDC from state

health departments through NNDSS; these data are reported in the *Morbidity and Mortality Weekly Report (MMWR).* In general, CDC encourages state health departments to report provisional data through NNDSS before completing case investigations; however, cases are included for publication in the *MMWR* as described in the case confirmation status print criteria approved by CSTE.[4]

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; this has developed into the National Electronic Disease Surveillance System (NEDSS).[6] Electronic reporting and data management were developed to provide timely access to additional demographic and epidemiologic information on each case-patient reported to NNDSS.

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

## III. Vaccine-preventable diseases reported to 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.[7] CDC and CSTE have established a policy under which state health departments report cases of selected diseases to CDC through the NNDSS. In the past, supplemental surveillance systems were developed for some diseases to gather additional epidemiologically important information. However, with the development of electronic data systems, some of these supplemental systems may no longer be needed.

### *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).

### *Measles*

Since 1978, substantial effort has been invested in measles surveillance at 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.[8]

In 1985, the National Immunization Program (NIP), CDC, developed the Rapid Surveillance Helper (RASH) system to electronically collect supplemental data on measles cases. RASH has now been supplanted by electronic reporting of supplemental data via NETSS and NEDSS. Data on patient vaccination status, complications, setting of transmission, laboratory confirmation, importation status, and molecular epidemiology of cases are collected (Appendix 8).

### *Mumps*

No supplemental surveillance system for mumps existed before development of the NETSS extended record for collecting epidemiologic 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 report 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 via NETSS or NEDSS (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*

Detailed demographic, clinical, and epidemiologic 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, 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.[9] Poliovirus infection (asymptomatic) was added to the list of nationally notifiable diseases and conditions in 2007.[10]

### *Rubella and congenital rubella syndrome*

No supplemental surveillance system for rubella existed before 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 report.

### *Tetanus*

In 1965, the Supplemental Tetanus Surveillance System was developed to allow state health departments to report supplemental clinical and epidemiologic information on reported cases of tetanus. Data are now reported electronically to NNDSS via NETSS or NEDSS. Information is collected on the clinical history, presence, and nature of associated risk factors, patient vaccination status, wound care, and clinical management (Appendix 18).

## 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 were reported to local health authorities.[11] A 1992 study showed that only an estimated 11.6% of pertussis cases in the United States were reported.[12] 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.[13] A recent literature review of articles on surveillance data for measles, pertussis, mumps, and rubella in industrialized countries further illustrates that reporting is incomplete.[14]

The completeness of reporting to supplemental surveillance systems has been evaluated by using capture–recapture methods.[15, 16] 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.[17] 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.[12, 18] 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 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 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.[12]

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 surveillance of all vaccine-preventable diseases were first published in 1990,[19] revised in 1997,[20] and have been subsequently 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 the data must be fully utilized. Development of systems of distributed data entry, with electronic reporting from laboratories and local health departments, is under way 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, has developed the National Electronic Disease Surveillance System (NEDSS).[6] Electronic reporting and data management were developed to provide timely access to additional demographic and epidemiologic information on each case-patient reported to NNDSS. CDC has developed the NEDSS Base System, a platform used by some states to enter, update, and search for demographic and notifiable disease data; other states have developed NEDSS-compatible electronic data systems to collect and transmit surveillance data.

There has been increasing interest in alternative approaches to traditional morbidity surveillance systems.[21, 22] Hospital discharge data sets may be useful for some purposes, although their usefulness in providing timely data for disease control purposes is limited. Ultimately, computerized medical records in physicians' offices and clinics may provide data that are timely, accurate, and complete.[23, 24] The development of such systems is perhaps most advanced in large health maintenance organizations, hospitals, and 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.[25, 26] 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 source of accurate information. Improved links between laboratories and communicable disease surveillance activities within state and local health departments are needed. In the future, electronic links with commercial laboratories, and ultimately large group practices, hospitals, and clinics, may provide more complete and timely data than are now available.

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