Lesson 5
Public Health Surveillance

Public health surveillance is the mechanism that public health agencies use to monitor the health of their communities. Its purpose is to provide a factual basis from which agencies can appropriately set priorities, plan programs, and take actions to promote and protect the public's health.

Objectives

After studying this lesson and answering the questions in the exercises, a student will be able to do the following:

Define public health surveillance and its critical components
List the main uses of surveillance data
Describe sources for data that can be used for public health surveillance
Describe the flow of information for reportable diseases in the United States
List the attributes used to evaluate surveillance systems
List the major considerations in starting a surveillance system

Introduction to Public Health Surveillance

Public health surveillance is the ongoing systematic collection, analysis, interpretation, and dissemination of health data (21). Public health agencies use surveillance data to describe and monitor health events in their jurisdictions, set priorities, and to assist in the planning, implementation, and evaluation of public health interventions and programs.

Surveillance systems are often considered information loops or cycles involving health care providers, public health agencies, and the public, as illustrated in Figure 5.1. The cycle begins when cases of disease occur and are reported by health care providers to the public health agencies.

The cycle is not completed until information about these cases is relayed to those responsible for disease prevention and control and others ``who need to know.'' Because health care providers, health agencies, and the public all have some responsibility for disease prevention and control, they all should be included among those who receive feedback of surveillance information. Depending on the circumstances, others who need to know may include other government agencies, potentially exposed individuals, employers, vaccine manufacturers, private voluntary organizations, legislators on the health subcommittee, and innumerable others.

In the United States, the concept public health surveillance does not include administration of prevention and control programs, but does include an intended link with those programs (11). In other words, the goal of surveillance is not merely to collect data for analysis, but to guide public health policy and action. In fact, surveillance has been defined quite succinctly as ``information for action (15).'' Figure 5.2, for example, outlines some of the actions that are based, in part at least, on information from surveillance activities.

The concept of public health surveillance has evolved over time and is still confused

with other uses of the term surveillance. The current concept of surveillance as the monitoring of disease occurrence in populations was promoted by Dr. Alexander D. Langmuir as a function of the newly created Communicable Disease Center (now the Centers for Disease Control and Prevention, (CDC)) (10). Before that, surveillance had meant the close observation of persons who had been exposed to a communicable disease in order to detect early symptoms and to institute prompt isolation and control measures. To distinguish between these two surveillance activities, we now use public health surveillance to describe monitoring health events in populations, and use the term medical surveillance to describe monitoring potentially exposed individuals to detect early symptoms.

Surveillance systems today take many forms. The oldest and most well-established systems are those that monitor the occurrence of communicable diseases through required reporting by such health care providers as physicians, laboratories, and hospitals. Hospital infection control personnel serve a dual role conducting surveillance in the hospital and reporting cases of notifiable disease to public health authorities. More recently established surveillance systems monitor a broader variety of health conditions, including injuries, birth defects, chronic diseases, and health behaviors. Many of these newer systems rely on secondary data analysis--that is, analysis of data collected for other purposes. For example, some of these surveillance systems use vital records, health care utilization records such as hospital discharge data, and various national and local surveys that are conducted for other purposes.

Although this chapter focuses on surveillance as an activity of public health agencies, surveillance is conducted in many other settings. For example, surveillance for nosocomial (hospital-acquired) infections is an important activity within many hospitals. Surveillance activities are also usually initiated in emergency situations such as refugee camps and areas that have experienced a natural disaster such as a flood or hurricane.

Purposes and Uses of Surveillance

Ultimately, the purpose for conducting public health surveillance is to learn the ongoing pattern of disease occurrence and the potential for disease in a population so that we can be effective in investigating, controlling, and preventing disease in that population. Historically, public health agencies responded to reports of communicable diseases primarily by applying standard control measures such as quarantine. Now agencies can use surveillance data as the basis for planning more effective disease control and prevention activities.

However, we do not limit public health surveillance to diseases for which we have effective control measures. We can justify surveillance for two additional purposes: First, through surveillance we can learn more about the natural history, clinical spectrum, and epidemiology of a disease (who is at risk, when and where it occurs, the exposures or risk factors that are critical to its occurrence). This knowledge may lead to the development of prevention and control measures. Second, surveillance will provide us with a baseline of data which we can use to assess prevention and control measures when they are developed and implemented.

We routinely use surveillance data in a variety of ways which are discussed below. Primarily these are related to monitoring disease and providing linkage to prevention and

control programs (20).

Monitoring Health Events

We monitor health events for the following purposes:

-- To detect sudden changes in disease occurrence and distribution

-- To follow secular (long-term) trends and patterns of disease

-- To identify changes in agents and host factors

-- To detect changes in health care practices

Local health agencies--and to a lesser degree national ones--use surveillance data for detecting sudden increases in disease occurrence, such as epidemics. When appropriate, agencies may investigate and subsequently initiate control and prevention activities.

Health agencies at all levels need to be aware of the secular (long-term) trends and patterns of disease among the populations they serve, and to explain any change in those patterns. For example, surveillance of malaria in the United States revealed several changes in its incidence that were of interest to public health officials. As Figure 5.3 shows, changes in malaria occurrence could be correlated with the importation of cases from foreign wars, foreign immigration, and increased international travel by U.S. citizens.

To target strategies and anticipate needs, public health decision-makers must know the patterns of disease occurrence by risk group. For example, the surveillance of acquired immunodeficiency syndrome (AIDS) includes the identification of the probable route of exposure. From this information, we have been able to follow the expansion and shift in risk groups from predominantly homosexual men to injection drug users and their sex partners.

By monitoring patterns to date we may be able to forecast the future pattern of disease occurrence. Such forecasts are useful for planning resource needs.

We monitor changes in agents and host factors to assess the potential for future disease occurrence. For example, laboratory scientists monitor certain infectious agents for changes in their antigenic pattern or resistance to antibiotics. The influenza viruses are among these agents. By identifying antigenic drifts and shifts in these viruses, we can direct vaccine production and anticipate the effect of influenza on the community.

The Behavioral Risk Factor Surveillance System is an excellent example of the surveillance of host factors (16). This national system monitors changes in such factors as smoking, alcohol use, obesity, and seat-belt use.

Actions have been taken at both the national level and within health care facilities as a result of monitoring changes in health care practices. For example, when some hospitals identified a marked increase in cesarean deliveries they established decision-making protocols. Similarly, when surveillance of dentists in the early 1980's showed that routine use of masks and gloves was not rising as quickly as the incidence of AIDS, health authorities implemented intensive educational efforts for dentists.

Link to Public Health Action

Investigation and control

When many of the notifiable diseases are reported, local, state, and even national or international health agencies may take action. One action is to search for the source or sources which, when found, may prompt further actions--closure of a restaurant, counseling and treatment of an asymptomatic patient, withdrawal of a commercial product, or warnings to the public. In addition, health agencies may act to intensify surveillance of the disease and identification of other susceptible and potentially exposed persons who may be at risk of developing disease. When these persons are identified, they may be offered testing, counseling, treatment, vaccination, or prophylaxis as appropriate. For example, a TB registry is used to monitor and follow up cases. Within a workplace, surveillance may prompt similar actions within the facility, including identification of others at risk and elimination of workplace hazards.

Planning

As noted earlier, the goal of surveillance is to provide a factual basis for rational decision making. By monitoring changes in disease occurrence over time and place, agencies can anticipate when and where resources will be needed, and thus will be able to plan how to allocate them effectively.

Evaluating prevention and control measures

Surveillance data are used frequently to quantify the impact of program interventions. Figure 5.4 shows the incidence of measles in the United States over a period of 35 years. The precipitous drop in the mid-1960's reflects the impact of the National Measles Vaccination Program. The resurgence in the late 1980's led to a revision in recommendations from a 1-dose to a 2-dose vaccination policy. Agencies can use surveillance data in a similar way to monitor and modify educational and other risk-reduction programs.

Generating hypotheses and stimulating public health research

Because we collect and analyze surveillance data on an ongoing basis, our findings often generate questions and hypotheses that provide direction for further research. For example, in 1980 surveillance systems documented the nationwide occurrence of a new disease which came to be known as toxic shock syndrome (TSS) (19). From a review of the initial surveillance data, epidemiologists realized that many of the cases occurred in menstruating women. They conducted a series of increasingly focused case-control studies. In less than a year they found a strong association between TSS and a particular brand of tampon, which was promptly withdrawn from the market.

Other Uses of Surveillance

Testing hypotheses

Surveillance data can sometimes be used to test hypotheses regarding the impact of exposures on disease occurrence. For example, in 1973, two infants with dissimilar birth defects were born to parents who had used spray adhesives extensively while engaged in the hobby of ``foil art.'' As a result, the Consumer Product Safety Commission banned the sale of these spray adhesive compounds. The ban was lifted after birth defect

surveillance data for 1970-1973 showed a slight decrease in the total number of birth defects and in the number of birth defects in infants, despite a 5-fold increase in spray adhesive sales during the same period (5).

Archive of disease activity

While collection of data simply to provide an archive of disease activity is not one of the primary goals of surveillance, it is a byproduct of the process. These data are often reported in annual summaries issued by the responsible health agencies. Since surveillance data are usually acted on locally, they become more historical as they are reported to successively higher levels.

Even archival data, however, can be put to use. For example, epidemiologists used historical surveillance data to develop statistical models to predict the feasibility of proposed policies for eradicating measles and polio (22).

Sources of Data

Many sources of data are available that can be used for public health surveillance. The World Health Organization listed the following as key sources of surveillance data (23):

-- Mortality reports
-- Morbidity reports
-- Epidemic reports
-- Reports of laboratory utilization (including laboratory test results)
-- Reports of individual case investigations
-- Reports of epidemic investigations
-- Special surveys (e.g., hospital admissions, disease registers, and serologic surveys)
-- Information on animal reservoirs and vectors
-- Demographic data
-- Environmental data

In the United States, these and other sources of data have been used for public health surveillance purposes. Some are collected as part of a surveillance system. Others are collected for other reasons, but may be used for surveillance purposes. The most common sources of data are described on the following pages.

Mortality Data

Vital statistics

Vital statistics include data on birth, death, marriage, and divorce. Records may be available at the local and state level within a matter of days or weeks, but they are not always coded or computerized. CDC's National Center for Health Statistics (NCHS) collects a monthly national sample of death certificates and publishes a report based on these sample data 3 months later. NCHS also provides complete national mortality data within 2 to 3 years. On the other hand, 121 cities around the United States report to CDC the number of deaths by age from all causes combined and from pneumonia or influenza within about 3 weeks of occurrence. These data are published the following week in the

Morbidity and Mortality Weekly Report (MMWR). More information on the surveillance of influenza is provided on pages 308-309.

Medical examiner data

Coroners and medical examiners can provide information on sudden or unexpected deaths. Their reports are available at the state or county level, and include details about the cause and nature of death that are not given on the death certificate. These reports are particularly valuable for surveillance of intentional and unintentional injuries and of sudden deaths of unknown cause.

Morbidity Data

Notifiable disease reports

Each state government establishes what health events must be reported by health care providers in that state. Some states require as few as 35 conditions to be reported; others require as many as 130 conditions. Most states also require that an outbreak of any condition be reported. Table 5.1 on page 304 lists the conditions that are reportable in many states. As that table shows, reportable conditions are primarily acute (sudden) infectious diseases, although some chronic and noninfectious diseases are reportable in some states. Health agencies at the local, state, and national level routinely use the reported data for public health surveillance.

Laboratory data

Laboratory reports form the basis of surveillance for selected diseases, including many viral illnesses and those caused by enteric pathogens such as Salmonella and Shigella. These may or may not be part of the notifiable disease reporting system.

Hospital data

Almost all hospitals have computerized discharge records, primarily for financial purposes. These records may be used for surveillance purposes, however, and several states now compile hospital discharge data for public use. These records typically include demographic data, diagnoses, operative procedures, length of stay, and costs, but exclude names, addresses, and other information which could identify individuals.

Several sources provide hospital discharge data on a national level. For example, you can get annual data on a national random sample of hospital records from the National Hospital Discharge Survey conducted by NCHS. In addition, you can get complete and sampled data on Medicare inpatient and outpatient visits from the Health Care Financing Administration for Medicare recipients. Also, you can buy discharge data from two large private abstracting firms; these data have been abstracted from the hospitals where these companies have contracts.

Statewide and national surveillance systems collect data from samples of hospitals for a variety of specific health events. These include systems for surveillance of birth defects, nosocomial infections, injuries, and drug-related emergency room visits.

Outpatient health care data

Although France has developed an extensive computerized surveillance system for outpatient data from physicians' offices, there is no comprehensive, timely outpatient surveillance system in the United States. At the local or state level, you may be able to get outpatient data from some physicians and health maintenance organizations that have computerized their medical records. At the national level, you can get outpatient data from the National Ambulatory Medical Care Survey, which is conducted periodically by NCHS, and from the commercial National Drug and Therapeutic Index. Both are random samples from office-based physicians of diagnostic, specialty, therapeutic, and disposition data. Finally, outpatient data are available from a network of interested family practice physicians who report on a few selected health problems, including influenza-like illness.

Specific topics

Over 30 states now have some form of cancer registry. Eleven of these registries are part of the Surveillance, Epidemiology and End Results (SEER) system supported by the National Cancer Institute. Each SEER Center attempts to identify every patient diagnosed with cancer in a designated geographic area (usually a state or large metropolitan area). For each patient, the SEER Center collects relevant demographic data as well as details on the type, site, and treatment of the cancer.

Post-marketing surveillance of adverse drug reactions and other adverse health events to detect potential safety problems of marketed drugs is the responsibility of the Food and Drug Administration (FDA). Each year, over 10,000 reports of adverse events are submitted to the FDA by health care providers and pharmaceutical manufacturers.

In recent years, injury surveillance systems have increased. A number of systems in different jurisdictions now collect information on different types of injuries. At the national level, the National Highway Traffic Safety Administration collects information on fatal crashes occurring on public roadways.

Occupational illness is another area of current expansion. Surveillance for occupational lead poisoning, pneumoconioses, and other occupationally-related illnesses is conducted in a growing number of states. Several states and CDC are also working to reestablish surveillance for elevated blood lead levels in children.

Surveys of Health and General Populations

All surveillance systems described above collect data on the occurrence of some type of disease or other adverse health condition. Some systems, however, have been established to sample the health status of citizens in the community. For example, NCHS periodically conducts the National Health and Nutrition Examination Survey (NHANES). In this survey, NCHS examines a random sample of the U.S. population and records clinical examination and laboratory data, as well as demographic and medical history information. NCHS has conducted NHANES three times since 1960.

NCHS also conducts the Health Interview Survey, which collects information on illness, disability, health service utilization, and activity restriction from a continuous sampling of over 40,000 civilian households.

Finally, more than 40 state health departments participate in the Behavioral Risk Factor Surveillance System in collaboration with CDC. This surveillance system uses

telephone interviewers to collect information on smoking, alcohol use, seat-belt use, hypertension, weight, and other factors which affect health.

Surveillance Systems of Disease Indicators

Still other surveillance systems collect data on indicators of disease or of disease potential. These systems fall into four categories: animal populations, environmental data, drug/biologic utilization, and student and employee data. Of these categories, the animal and environmental systems act as early-warning systems of disease potential. The other two categories collect disease-indicator data that are more accessible than data on the particular diseases themselves. Each of these categories is described in more detail below.

Animal populations

Monitoring animal populations is an important part of the surveillance system for certain diseases. Animal surveillance may include detecting and measuring:

1. Animal morbidity and mortality caused by a disease that can affect humans (e.g., rabies)
2. The presence of a disease agent in wild and domestic sentinel animals (e.g., survey of rodents for plague, of chickens for St. Louis encephalitis)
3. Changes in the size and distribution of the animal reservoirs and vectors of a disease (e.g., monitoring deer and ticks which are hosts for the agent that causes Lyme disease)

Environmental data

Public health agencies conduct routine environmental surveillance at the community level to detect contamination of public water, milk, and food supplies. Agencies may also use environmental surveillance to focus on conditions in nature that support animal populations that may be reservoirs or vectors of disease. For example, agencies may monitor tire dumps and other potential breeding sites for mosquitoes. Other types of environmental surveillance have become important in recent years, such as environmental monitoring for radiation. In the workplace ``hazard surveillance,'' such as monitoring potentially harmful chemical, biological, and physical agents, guides strategies for preventing illness and injury.

Drug/biologic utilization

State health departments and CDC are the only sources for a number of biologics and drugs (e.g., botulism antitoxin, diphtheria antitoxin, and until 1983, the anti-pneumocystis drug, pentamidine). By monitoring requests for these controlled biologics, state health departments and CDC have an effective surveillance system for the diseases or exposures that these materials treat. Indeed, CDC noted an upsurge in pentamidine requests in 1981. This observation quickly led to the recognition of a nationwide epidemic of a disease soon to be named acquired immunodeficiency syndrome (AIDS).

Student and employee data

Public health agencies routinely use school absenteeism records to assess the pervasiveness of influenza-like illness in a community. Employee records, workers' compensation claims, and other occupational data are increasingly being used for surveillance of occupational illness and injuries.

Exercise 5.1

Assume you are working in a state in which none of the conditions below is on the state list of reportable diseases. For each condition, what sources of data might be available if you wished to conduct surveillance? What factors make one source of data more appropriate than another?

A. Listeriosis (case definition in Appendix C)

B. Spinal cord injury

C. Lung cancer in non-smokers

Answers on page 335.

Conducting Surveillance

Conducting surveillance requires the collection, analysis, interpretation, and dissemination of health data. Each of these activities is described below.

Collection of Surveillance Data

Diseases notifiable by law

Reporting from individual to local health department to state health department. Each state has a morbidity reporting system that is based on state laws or regulations adopted by the state board or department of health. In most states, state health authorities are empowered by the state legislature to establish and modify reporting requirements. In a few states, the legislature keeps that authority.

Typically, the regulations specify the following:

-- The diseases and conditions that must be reported

-- Who is responsible for reporting

-- What information is required on each case of disease reported (States can modify this requirement when circumstances require different or additional information.)

-- How, to whom, and how quickly the information is to be reported

-- Control measures to be taken for specified diseases

The list of notifiable diseases differs from state to state, reflecting variations in public health priorities. In general, a state includes a disease on its list if the disease (1) causes serious morbidity or death, (2) has the potential to affect additional people beyond the reported case, and (3) can be controlled or prevented with proper intervention. The number of diseases on the lists of the various states ranges from 35 to more than 100. Table 5.1 shows the notifiable diseases that are reportable in most states, and indicates those that are notifiable at the national level as well.

State health departments commonly specify two other circumstances that must be reported: any outbreak or unusually high incidence of any disease, and any occurrence of an unusual disease of public health importance. Some states also provide for immediately adding to its reportable disease list any disease that becomes important from

a public health standpoint. In most states, reporting known or suspected cases of a reportable disease is generally considered to be an obligation of

-- Physicians, dentists, nurses, and other health professionals
-- Medical examiners
-- Administrators of hospitals, clinics, nursing homes, schools, and nurseries

Some states also require or request reporting from:

-- Laboratory directors
-- Any individual who knows of or suspects the existence of a reportable disease

In most states, anyone responsible for reporting diseases is required to send a case report within a week of diagnosis, but certain special threats to the public, such as botulism, quarantinable diseases, and epidemics, must be reported immediately by telephone.

Individual reports are usually considered confidential and are not available for public inspection.

Usually, the case report is sent to the local health department, which has primary responsibility for taking appropriate action. The local health department then forwards a copy of the case report to the state health department. A few states, however, have the initial case reports sent directly to the state health department. In these states, there may be no local health department in the area where the case occurred, or the local health department--for whatever reason--cannot effectively respond to the reports, or the state health department has decided to take primary responsibility for responding to case reports. This cycle of information is illustrated in Figure 5.5.

This form of data collection, in which health care providers send reports to a health department based on a known set of rules and regulations, is called passive (provider-initiated) surveillance. Less commonly, health department staff may call or visit health care providers to solicit reports. This active (health-department-initiated) surveillance is usually limited to specific diseases over a limited period of time, such as after a community exposure or during an epidemic.

Most state health departments require the use of a standard form for case reports. Figure 5.6 shows the form used in Washington State. Some states, however, allow reporting by telephone in lieu of written reports, and some are experimenting with reporting by computer telecommunications.

At a minimum, most case report forms ask for the patient's name, age, sex, race, address, telephone number, the name of the patient's head-of-household, the date of onset of illness, the name and telephone number of the person reporting, and the date of the report. The place and date of hospitalization, if applicable, are also commonly requested. For many diseases, additional information is also collected about the diagnosis, manifestations, and epidemiologic features.

While it is the intention of the laws and regulations of each state that every case of a reportable disease be reported, the reality is otherwise. For rare, serious diseases of public health importance such as rabies, plague, or botulism, the percentage of cases actually reported may approach 100%. On the other hand, for some other diseases such as aseptic meningitis, reporting has been found to be as low as 5%. Figure 5.7 illustrates the typical fall-off from infection through disease reporting for shigellosis.

The laws and regulations often include penalties for failure to report a notifiable condition, such as a fine or suspension of a license to practice, but these penalties are rarely enforced. Incomplete reporting of some diseases can be attributed to lack of knowledge of what is reportable, lack of knowledge of how to report, and the perception that reporting is not important.

Reporting from state health department to CDC. The Council of State and Territorial Epidemiologists (CSTE) determines which diseases states should report to CDC, revising the list as necessary. In 1961, they listed the 6 quarantinable diseases (cholera, plague, louse-borne relapsing fever, smallpox, epidemic typhus fever, and yellow fever), 16 additional infectious diseases of humans, and 1 infectious disease in animals (rabies). Since then, CSTE has revised the list several times, adding newly recognized diseases (TSS, legionellosis, AIDS), adding categories of disease (e.g., hepatitis A, hepatitis B, hepatitis non-A, non-B, and hepatitis, unspecified), and dropping some diseases(e.g., streptococcal sore throat and scarlet fever, chickenpox). Table 5.1 on page 304 indicates the diseases that were nationally notifiable in 1990. The notifiable disease list in each state is longer than the nationally notifiable list, reflecting state surveillance of diseases and conditions of local importance.

The procedures for reporting are published in CDC's Manual of Procedures for National Morbidity Reporting and Public Health Surveillance Activities (4). In general, each week each state health department provides to CDC by computer telecommunication the case reports of all nationally notifiable diseases that were reported in the state during the preceding 7 days. These reports represent provisional data, since the diagnosis may not be confirmed and other data items may be incomplete. The actual disease report forms, which contain much more detailed information, follow by mail, though increasing use is being made of telecommunications. Usually, these reports are stripped of names and other personal identifiers by the state before being sent to CDC.

CDC compiles the case reports from the various states and--within a few days of their receipt--publishes a summary of the data in the MMWR. CDC also publishes more detailed surveillance reports on various diseases based on the case report forms and on other reports of cases, laboratory isolates, epidemics, and investigations.

Reporting by CDC to World Health Organization. By international agreement, CDC promptly reports to the World Health Organization any reported cases of the internationally quarantinable diseases--plague, cholera, and yellow fever. CDC also reports influenza virus isolates and summarizes annual morbidity for the diseases from reports received the previous year.

The practice of reporting morbidity data to successively higher levels of government not only keeps each level informed of the current incidence in its jurisdiction, but also makes possible the compilation of data for successively larger areas. These compilations provide opportunities for identifying common factors not discernible at lower levels--especially when the incidence of a disease is low in most local areas.

Other local-state-national surveillance systems

In addition to the reports received through the nationally notifiable diseases surveillance system, CDC receives regular reports of a few diseases through other

channels. For example, the surveillance systems for salmonellosis and shigellosis are based on reports of isolates sent by state laboratories to CDC.

Surveillance for influenza is particularly interesting. Since it is impractical for health care providers to report individual cases of influenza-like illness, health authorities at all levels had to find other sources of data.

At the state and local levels, health authorities use reports of outbreaks of influenza-like illness, laboratory identification of influenza virus from nasopharyngeal swabs, and reports from schools of excess absenteeism (e.g., greater than 10% of student body). In addition, some local systems monitor death certificates for pneumonia and influenza, arrange for selected physicians to report the number of patients they see with influenza-like illness each week, and ask selected businesses to report excess employee absenteeism. At least one county health department monitors the number of chest X rays a mobile radiology group does of nursing home patients; when chest X rays are more than 50% of the total X rays ordered, an influenza epidemic is usually in progress.

At the national level, CDC uses four different surveillance systems during the influenza season from October through May. All four systems receive and analyze reports weekly. The systems are described below and illustrated in Figure 5.8.

-- In the laboratory-based system, approximately 60 state, city, and university hospital laboratories report influenza virus isolates each week.

-- In the 121-City Mortality Reporting System, 121 cities and counties across the country report the total number of deaths for the week by age and the proportion of those deaths attributed to pneumonia or influenza.

-- In the sentinel physician system, a network of 150 family practice physicians report the number of patients seen during the week with influenza-like illness.

-- Finally, each state epidemiologist assesses the level of influenza activity in his/her state each week and reports one of the following, as appropriate: ``No Activity,'' ``Sporadic,'' ``Regional,'' or ``Widespread.''

By using a variety of data sources at all levels--local, state, and national--we are able to assess influenza activity reliably throughout the United States without asking all health care providers to report individual cases.

Sentinel surveillance

The widely recognized underreporting of cases creates a problem in interpretation, since health officials generally do not know which cases are reported and which are not. As an alternative to the passive, all-inclusive system established by regulation, health authorities sometimes set up a sentinel system. In a sentinel surveillance system, a pre-arranged sample of reporting sources agree to report all cases of one or more conditions. Usually the sample is not selected randomly, but is made up of sources (physicians, clinics, hospitals, etc.) that are likely to see cases of the condition(s). The network of physicians reporting influenza-like illness, described above, is an example of sentinel surveillance.

In many developing countries, where it is not feasible for health authorities to use national population-based surveillance for HIV infection, sentinel surveillance provides a practical alternative. Under this strategy, health officials define homogeneous population subgroups and the regions to be sampled. They then identify institutions that serve the

population subgroups of interest, and that can and will conduct serosurveys. These institutions then conduct serosurveys at least annually to provide statistically valid estimates of HIV prevalence.

Surveillance systems based on secondary data analysis

Health authorities are becoming more creative in using available data sets for surveillance. These are sets of data that were created for other purposes. For example, Medicare data, state and private national hospital discharge data, and workers' compensation data were originally compiled for accounting or financial management purposes. Other data sets are compiled primarily for marketing or patient management. Because these data sets contain health information, however, health authorities are analyzing them from a surveillance perspective. This strategy is the primary approach for chronic disease surveillance. With increasing frequency, this strategy is also being applied to infectious diseases that do not have established surveillance systems (e.g., diarrheal diseases in children in the U.S.) and even to some that do (e.g., AIDS, influenza).

Surveillance with available data sets differs from traditional surveillance in several ways: First, the level of surveillance must be at the community--not the individual--level, because most data sets lack personal identifiers. Second, because secondary data are not available on a timely basis but go through a long process of being collected, compiled, edited, and packaged before they are made available to health authorities, this approach is more appropriate for guiding long-term rather than short-term interventions. Third, because the data are often collected for administrative reasons, more cases may be included than in passive surveillance systems, but the quality of the data items most useful for surveillance, such as disease information, may be low.

Analysis of Surveillance Data

Knowledge of the specific patterns of disease occurrence within a health agency's jurisdiction is required to identify changes in disease occurrence and disease potential, which in turn spark public health action. This knowledge can be obtained only through a continuous, systematic process of consolidation and analysis of available surveillance data.

As with all descriptive epidemiologic data, we first analyze surveillance data in terms of time, place, and person. Traditionally, we use simple tabular and graphic techniques to analyze and display these data. Recently, we have begun to assess the usefulness of more sophisticated techniques such as cluster and time series analyses and computer mapping.

In analyzing surveillance data, we compare current data with some ``expected'' value, identify how these differ, and assess the importance of the difference. Most commonly, we base the expected value on figures for recent reporting periods or for the corresponding period of previous years. In addition, we may compare data from one area with data from neighboring areas (e.g., one county with its neighboring counties), or we may compare data from an area with those from the larger area to which it belongs (e.g., state data with national data).

Proper analysis of surveillance data includes determination of both numbers and rates. One critical step before calculating rates is identifying appropriate denominator data.

For a state or county, denominators may be available from the U.S. Bureau of the Census or from a state planning agency. For other settings such as a hospital, the denominator may be the total number of patients or the number of patients on a particular floor.

Time

We usually conduct basic analysis by time in several different ways to detect acute changes in disease incidence. Our first analysis involves comparing the number of case reports received for the current week with the number received in each of the preceding 4 weeks. We can organize these data into a table or a graph or both. Simply by looking at the table or graph we can detect an abrupt increase as well as a gradual buildup in the number of cases. This method works well when new cases are reported promptly.

For example, examine the data in Figure 5.9 for Clark County during Week 5. Compare the 8 cases of hepatitis A reported that week with the level of hepatitis A in Clark County for the preceding 4 weeks, and with the level of hepatitis A in other counties for Week 5. If you had been the person in Clark County responsible for this surveillance system, this very simple comparison would have alerted you as early as Week 5 to the subsequent outbreak of hepatitis A in your county, and you would have called this increase to the attention of those responsible for taking further investigation and control actions.

Another way we commonly analyze surveillance data is by comparing the number of cases during the current period (e.g., this month) with the number reported during the same period in each of the last 3 years. For example, examine the data in Figure 5.10 for Clark County. The eight cases in Clark County in 1991 are very high compared with 1990 (zero cases) and 1989 (three cases), but not compared with 1988 (six cases). Was there also an outbreak in 1988?

To analyze long-term (secular) trends in a disease, we usually graph the occurrence of the disease by year, as in Figure 5.3 on page 294 and Figure 5.4 on page 296. We may note on the graphs when any events occurred that we believe had an impact on the secular trend, such as the implementation or cessation of an intervention program. We also note any changes in a surveillance system that may influence the appearance of long-term trends, particularly changes in diagnostic criteria, reporting requirements, or changes in the level of emphasis on active case detection (e.g., case investigation and screening programs).

Although we base the analysis of many notifiable diseases on the number of case reports received, we commonly use two variations.

First, to take into account the size of the population from which the cases arose, we analyze disease rates. Because different geographic areas have different population sizes, and because the population of any area changes over time, it is important that we use rates rather than case counts when we compare different geographic areas and when we analyze secular trends.

Second, when delays occur between diagnosis and reporting, we analyze data by date of onset rather than by date of report. Under these conditions, this method is a better representation of disease incidence over time. Unfortunately, because of the delays, this method is most practical for analyzing secular trends rather than detecting outbreaks promptly.

Place

If we find an increase in disease incidence when we analyze our data by time, we then analyze the data by place to determine where the cases are occurring. On the other hand, even if our time analysis is unrevealing, we may identify a localized outbreak if we analyze the data by place. As a practical matter, we can analyze disease occurrence by time and place simultaneously, as in Figure 5.9. To analyze by place, we usually organize our data into a table, a map, or both. Although analysis by place is usually by reporting source or area, it can be helpful to analyze data by potential sites of exposure as well. Also, analysis of both number of cases and rates may be appropriate.

Person

Analyzing surveillance data by characteristics of the affected persons may also be helpful. Age and sex are usually provided on most case reports. Race is less consistently available for analysis. Other variables, such as school or workplace, hospitalization, and risk factors for specific diseases such as recent travel, may also be reported.

Age. Age is usually well documented, and is probably the most frequently analyzed ``person'' characteristic. The first step in analyzing data by age is to create appropriate age groups or categories. Creating categories for a continuous variable such as age was described in Lesson 4.

As described in Lesson 4, we usually rely on standard, well-accepted age groupings for different diseases. In general, these groupings reflect the characteristic age distribution of a disease, with narrower age categories for the ages of peak occurrence and wider categories for the ages where the disease is less common. If the age distribution changes over time, or differs in different parts of the world, the categories may be changed to reflect those differences.

We also want to use age categories that are compatible to those used by others. Standard age categories for several childhood illnesses are less than 1 year, 1 through 4, 5 through 9, 10 through 14, 15 through 19, and greater than or equal to 20 years. Conversely, for pneumonia and influenza mortality which usually affects the elderly, the standard categories have been less than 1 year, 1 through 24, 25 through 44, 45 through 64, and greater than or equal to 65 years. Since two-thirds of all deaths from pneumonia and influenza occur among those aged 65 years and older, however, the last category has recently been further divided into 65 through 74, 75 through 84, and greater than or equal to 85 years. The narrower categories within the most commonly affected age groups help to pinpoint where the problem is occurring.

The categories we use should be mutually exclusive and all inclusive. ``Mutually exclusive'' means the end of one category should not overlap the beginning of the next category, e.g., 1 through 4 and 5 through 9 rather than 1 through 5 and 5 through 9. ``All inclusive'' means that the categories should cover all possibilities, including the extremes of age (e.g., less than 1 year) and unknowns.

Finally, to be able to analyze our data as rates we must use categories for the surveillance (numerator) data that are consistent with available population/census (denominator) data. Census data are usually published as less than 5 years, 5 through 9, 10 through 14, and so on in 5-year age groups. We could not use these data if we categorized our surveillance data in the following 5-year age groups: 1 through 5, 6

through 10, 11 through 15, and so on.

Race and ethnic group. In the United States, the following definitions, categories, and coding rules from the Bureau of the Census are recommended for case records and surveillance forms (13):

1. Definitions

The basic racial and ethnic categories for federal statistics and program administrative reporting are defined as follows:

a. American Indian or Alaskan Native. A person who has origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliation or community recognition.

b. Asian or Pacific Islander. A person who has origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa.

c. Black. A person who has origins in any of the black racial groups of Africa.

d. Hispanic. A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.

e. White. A person who has origins in any of the original peoples of Europe, North Africa, or the Middle East.

2. Utilization

To provide flexibility, it is preferable to collect data on race and ethnicity separately. If separate race and ethnic categories are used, the minimum designations should be the following:

a. Race American Indian or Alaskan Native
Asian or Pacific Islander
Black
White
Other

b. Ethnicity Hispanic origin
Not of Hispanic origin

If data on race and ethnicity is collected separately, we must be able to identify the number of white and black persons who are Hispanic, and must report them in a common category ``Hispanic.''

To combine race and ethnic categories, our minimum designations must be the following:

American Indian or Alaskan Native
Asian or Pacific Islander
Black, not of Hispanic origin
White, not of Hispanic origin
Hispanic
Other

To categorize persons who have mixed racial and/or ethnic origins, we usually use the category that most closely reflects the individual's recognition in his or her community. Various data sources, however, do use different classification methods. For example, on birth certificates, race is based on the race of the mother.

Risk factors. For certain diseases, we routinely collect and analyze information on

specific risk factors. For example, for reported cases of hepatitis A, we would want to know whether any patients are foodhandlers who can expose (or may have exposed) unsuspecting patrons. For hepatitis B case reports, we would want to know whether more than one report lists the same dentist as a potential source. We base our analysis of specific risk factors on knowledge of the characteristics of the particular disease, but the desired information is not always asked or provided on standard report forms.

Interpretation

When a surveillance system shows that the expected pattern for a disease is different than what we expect for that disease in that population at that particular time and place, we may need to investigate further. A local health department usually determines the amount of excess necessary for action based on the priorities assigned to the various diseases, and the interests, capabilities, and resources of the department. Public, political, or media attention and pressure, however, can sometimes make it necessary to investigate minor variations in disease occurrence that the health department might otherwise not pursue.

Not all apparent increases in disease occurrence represent true increases. For example, an increase in population size, improved diagnostic procedures, enhanced reporting, duplicate reporting, reporting of cases in batches, and other changes in the system could all increase the number of case reports in one week. Nonetheless, we should consider an apparent increase real until proven otherwise.

Sometimes a health agency may launch an investigation if two or more cases of a disease are suspected to have a common source of infection. The suspicion might be aroused from finding an apparent commonality among the cases, such as patients' sex or age group, their place of residence or occupation, their surnames, or the time of onset of their illness. Physicians or other knowledgeable persons sometimes bring these cases to the attention of a health department by reporting that they have observed several current or recent cases which are apparently of the same disease and related epidemiologically.

Dissemination of Surveillance Data

Dissemination of surveillance data to those who need to know is a critical component of a surveillance system, but, unfortunately, the one most frequently overlooked. The audience should include those who do (or should) provide reports, e.g., health care providers and laboratory directors, and those who need to know for administrative, program planning, and decision-making purposes.

A surveillance report which targets both the medical and public health communities serves two primary purposes: to inform and to motivate. A surveillance report which includes summary information on the occurrence of disease by time, place, and person informs local physicians about the probability of their encountering various conditions in their patients. Clear graphical presentations tend to be more appealing and more easily understood than detailed tables. Other useful information might include reports of antibiotic resistance patterns, revised recommendations for vaccination and other prevention and control strategies, and summaries of investigations and other studies.

A surveillance report can also be a strong motivational factor. It demonstrates that the health department actually looks at the case reports that are submitted, and acts on

those reports. At least one state health department newsletter provides recognition and thanks to each individual and institution who submitted a case report that year by publishing every reporter's name in its December issue (14). Such efforts are important in maintaining a spirit of collaboration among the public health and medical communities, which, in turn, improves reporting to the surveillance system.

Most state and many local health departments publish a weekly or monthly newsletter which they distribute to the local medical and public health community. These newsletters usually provide tables of current surveillance data, such as the number of each disease reported during the last reporting period (perhaps by area), the number of cases in a previous period, and other relevant information. They also usually contain information of current interest about the prevention, diagnosis, and treatment of selected diseases, and summarize current or recently completed epidemiologic investigations.

At the national level, CDC provides similar information through its Morbidity and Mortality Weekly Report (MMWR), MMWR Annual Summary of Notifiable Diseases, MMWR Surveillance Summaries, and individual surveillance reports that are published either by CDC or in peer-reviewed public health and medical journals.

Link to Public Health Action

As the phrase ``information for action'' implies, a surveillance system should be functionally linked with public health programs. To ensure that the right information is collected and will be acted on, the organization that is responsible for program action should, whenever possible, be responsible for surveillance.

The link between problem identification and public health response is well established for many communicable diseases. A communicable disease outbreak usually leads to an investigation and appropriate public health action, whether it be the removal of a salmonella-contaminated food product, exclusion from school and measles vaccination of susceptible school children, or treatment of a hospital water supply that is contaminated with Legionella. Even the occurrence of a single case can spur public health investigation and intervention, particularly if the disease, such as meningococcal meningitis, rabies, plague, or cholera, is uncommon in an area, potentially fatal, and indicative that others are potentially at risk.

On a broader basis, surveillance data may be used to target or modify education, immunization, and other risk-reduction programs, including elimination of hazards in the environment or workplace.

Unfortunately, the link between chronic disease surveillance systems and public health programs is less well characterized. In part, this reflects the recency of most chronic disease surveillance efforts. This also reflects, however, the chronic nature of the diseases under surveillance and the time frame in which a response is appropriate. Rather than warranting an acute response, changes in chronic disease occurrence are more likely to result in initiation of new community intervention programs which may affect disease occurrence 10 or even 20 years in the future.

Exercise 5.2

To answer the following questions, you may need to contact your local or state health department.

A. Identify the reporting requirements and the list of reportable diseases in your state or district. Compare your list with that in Table 5.1, page 304.

B. How does your state or local health department disseminate surveillance information to those who need to know? In your opinion, is this adequate and if not, what should be added?

Answers on page 335.

Evaluation of a Surveillance System

Every surveillance system should be evaluated periodically to ensure that it is serving a useful public health function and is meeting its objectives. A thorough evaluation should identify ways to improve the system's operation and efficiency. In a thorough evaluation, the following facets of the system should be addressed (3):

-- The public health importance of the health event under surveillance
-- The objectives and operation of the system
-- The system's usefulness
-- Attributes or qualities of the surveillance system, including simplicity, flexibility, acceptability, sensitivity, predictive value positive, representativeness, and timeliness
-- Cost or resource requirements for system operation

Each of these five facets is described below.

Importance

The importance of a health event and the need to have that health event under surveillance can be assessed with the following measures:

-- The current impact of the health event
-- total number of cases: incidence, prevalence
-- severity of illness: case-fatality rate, death-to-case ratio
-- mortality: overall and age-specific mortality rates, years of potential life lost
-- morbidity: hospitalization, disability
-- health care costs
-- Its potential for spread
-- Its preventability

By considering the ``potential for spread,'' we recognize the need to maintain surveillance for diseases that currently may be rare or under control, but that could recur. By considering ``preventability,'' we reflect the intended link between surveillance and public health intervention.

A flow chart for a surveillance system is shown in Figure 5.11.

Objectives and Operations

The objectives of a surveillance system should be clear to those who maintain and who contribute to the system. It may be helpful to consider first what information is needed for effective prevention and control, then to determine which objectives are most appropriate. Objectives may include any of the uses of surveillance described earlier (see page 293). For example, one of the objectives of a surveillance system may be to be to determine the occurrence of a health event or to monitor a program's progress in eradicating a disease.

To characterize the operations of a surveillance system, we must answer the following questions:

-- What is the case definition of the health event? Is it practical in this setting?

-- What is the population under surveillance?

-- What is the time period of data collection (weekly, monthly, annually)?

-- What information is collected? Is it what programs need?

-- What are the reporting sources or data sources? Who is supposed to report? Who actually does report?

-- How are the data handled? How are they routed, transferred, stored? Are there unnecessary delays? How is confidentiality maintained?

-- How are the data analyzed? By whom? How often? How thoroughly?

-- How is the information disseminated? How often are reports distributed? To whom? Does it get to all those who need to know, including the medical and public health communities and policymakers?

Sometimes it is helpful to sketch a flow chart of a surveillance system to portray the flow of information visually.

Usefulness

Under usefulness, we address whether a surveillance system makes a difference. We may assess usefulness by answering the following:

-- What actions have been taken to date (public health, clinical, legislative, etc.) as a result of information from the surveillance system?

-- Who has used the information to make decisions and take actions?

-- What other future uses might the information have?

The usefulness of a system is influenced greatly by its operation, including its feedback mechanism to those who need to know, and by the system's attributes, described below.

Attributes

Several qualities or attributes described below affect the operation and usefulness of a surveillance system. To evaluate a surveillance system we must assess, either qualitatively or quantitatively, each of these.

Simplicity

Simplicity refers to the ease of operation of the system as a whole and each of its components (case definition, reporting procedures, etc.). In general, a surveillance system should be as simple as possible while still meeting its objectives. A simple system is more

likely to provide timely data with fewer resource needs than a complex system.

Flexibility

Flexibility refers to the ability of a surveillance system to accommodate changes in operating conditions or information needs with little additional cost in time, personnel, or funds. Usually, flexibility is necessary when changes occur in case definitions, or reporting forms and procedures. Flexibility also includes the system's ability to add new health events.

Acceptability

Acceptability reflects the willingness of individuals and organizations to participate in a surveillance system. We may gauge acceptability of reporting by the proportion who report cases (of those who should report) and by how complete their report forms are. For systems that use interviews with subjects, acceptability may also be measured by interview completion rates. In general, acceptability of reporting is influenced greatly by how much time the reporter must invest.

We may also consider acceptability in terms of the intended link with programs. Are the program managers and others responsible for action responsive to the information provided by the surveillance system?

Sensitivity

Sensitivity is the ability of a system to detect the cases or other health events it is intended to detect. We may measure sensitivity by conducting a representative survey and comparing the results with those from the surveillance system.

Sensitivity also refers to the system's ability to detect epidemics and other changes in disease occurrence. As noted earlier, many surveillance systems detect only a small proportion of the cases that actually occur. We must then judge whether a system that is not 100% sensitive in terms of individual cases is nonetheless sufficiently sensitive to identify community-wide problems.

Predictive Value Positive

Predictive value positive is the proportion of reported cases which truly are cases or the proportion of reported epidemics which were actual epidemics. That is, it is a measure of the predictive value of a reported case or epidemic.

We measure predictive value positive by investigating whether the reported cases and epidemics meet our definition for a true case or real epidemic. The more ``false-positive'' reports there are in a surveillance system, the lower the predictive value of the reports. These result in unnecessary investigations, wasteful allocation of resources, and--especially for false reports of epidemics--unwarranted public anxiety.

Representativeness

Representativeness is the extent to which a surveillance system accurately portrays the incidence of a health event in a population by person, place, and time. It includes the

quality or accuracy of the data provided and is influenced by the acceptability and sensitivity of the system. For us to generalize or draw conclusions about a community from surveillance data, the system must be representative.

In calculating rates from surveillance data, it is important not to assume without evaluation--as is too often done--that the system is representative. In evaluating the representativeness of a system, we seek to identify important subpopulations systematically excluded by the system.

Timeliness

Timeliness is the availability of data in time for appropriate action. Public health authorities may not be able to initiate prompt intervention or provide timely feedback if delays occur in any aspect of a surveillance system--whether in data collection, management, analysis, interpretation, or dissemination.

Resource Requirements (Costs)

The direct costs of a surveillance system include the personnel and financial resources expended to maintain all phases of the system, including collection, analysis, and dissemination. We usually assess these direct costs against the system's objectives and usefulness, and against the expected costs of possible modifications or alternatives to the system.

Conclusions

We evaluate a surveillance system so that we can draw conclusions about its present state and make recommendations about its future potential. In our conclusions, we should state whether the system addresses an important public health problem, whether it is meeting its objectives, and whether it is operating efficiently. If it is not doing these things, we should recommend modifications in the system, or address the question of whether the system should be continued at all.

In making recommendations for modifications, we must recognize that the various attributes and costs are interrelated and potentially conflicting. For example, efforts to improve sensitivity may reduce predictive value positive. For any surveillance system, some attributes are more important than others. We must consider each attribute and balance it against the others to ensure that the system's objectives will be met.

Limitations of the Notifiable Disease Reporting System

Although surveillance systems need not be perfect to be useful, such systems do suffer from limitations that sometimes compromise their usefulness. Underreporting, lack of representativeness, lack of timeliness, and inconsistency of case definitions are just four of the limitations of some present surveillance systems.

Underreporting

For most notifiable diseases, data collection is generally based on passive reporting by physicians and other health care providers. Studies have shown that, in most jurisdictions, only 5-60% of cases of the reportable diseases overall are ever reported (1,

12). The most obvious result of such underreporting is that effective action is delayed, and cases occur which might have been prevented by prompt reporting and prompt initiation of control measures.

Listed below are some of the many reasons provided by physicians and others to explain why many cases are never reported (9). It is important that public health agencies recognize these barriers to reporting, since many are within the agencies' power to address or correct. Some strategies to address the most common problems and to improve reporting are discussed in the next section.

Lack of knowledge of the reporting requirement

-- Unaware of responsibility to report
-- Assume that someone else (e.g., a laboratory) would report
-- Unaware of which diseases must be reported
-- Unaware of how or to whom to report

Negative attitude toward reporting

-- Time consuming
-- Too much hassle (e.g., unwieldy report form or procedure)
-- Lack of incentive
-- Lack of feedback
-- Distrust of government

Misconceptions that result from lack of knowledge or negative attitude

-- Compromises patient-physician relationship
-- Concern that report may result in a breach of confidentiality
-- Disagreement with need to report
-- judgment that the disease is not that serious
-- belief that no effective public health measures exist
-- perception that health department does not act on the reports

Lack of Representativeness of Reported Cases

Underreporting is not uniform or random. Two important biases act to distort surveillance data. First, health care providers are more likely to report a case that results in severe illness and hospitalization than a mild case--although a person with mild illness may be more likely to transmit infection to others. This bias results in an inflated estimate of disease severity in measures such as the death-to-case ratio. Second, health care providers are more likely to report cases when the disease is receiving a flurry of publicity than they are at other times. This bias results in an underestimate of the baseline incidence of disease.

Both biases were operating in 1981 during the national epidemic of tampon-associated TSS. Early reports indicated a death-to-case ratio much higher than the ratio determined by subsequent studies, and reported cases declined more than incident cases after the publicity waned.

Lack of Timeliness

Lack of timeliness can occur at each phase of a surveillance system. The reasons for the delays vary. Some delays are disease dependent. For example, physicians cannot diagnose some diseases until confirmatory laboratory and other tests have been completed. Some delays are caused by the reporting procedure: If the procedure is cumbersome or inefficient, delays in reporting will occur. Delays in analysis are common when the surveillance system is seen as a rote function rather than one that provides information for action. Finally, delays at any step may culminate in delays in dissemination, with the result that the medical and public health communities do not have the information they need to take prompt action.

Inconsistency of Case Definitions

Until recently, few states had provided practitioners with case definitions for reporting (18). Many states simply accepted the diagnosis of a physician, regardless of how the diagnosis was made. For example, what is reported as aseptic meningitis may vary from state to state and even from one physician to another within a state. Some surveillance systems encourage reporting of any suspected case, then go through the sometimes tedious task of verifying the diagnosis. To improve consistency and predictive value positive of case reporting, the Council of State and Territorial Epidemiologists (CSTE) has recently developed standard case definitions. These case definitions, listed in Appendix C, are currently being adopted by each state health department (2).

Ways to Improve a Surveillance System

The preceding limitations of reporting systems suggest several steps which could be taken in a local or state health department to improve reporting.

Improve Awareness of Practitioners

Most important, all persons who have a responsibility to report must be aware of this responsibility. The health department should actively publicize the list of reportable diseases and the mechanisms by which to report a case.

Simplify Reporting

Reporting should be as simple and painless as possible for the reporter. Many health departments accept telephone reports. One health department experimented with a toll-free telephone number. If forms are used, they should be widely available, easy to complete, and ask only relevant information.

Frequent Feedback

The role of feedback cannot be overemphasized. Feedback may be written, such as a monthly newsletter, or oral, such as a monthly update at Grand Rounds. Ideally, the feedback should be timely, informative, interesting, and relevant to practice. In addition to providing information, feedback about disease patterns and control activities based on surveillance data increases awareness and reinforces the importance of participating in a meaningful public health activity.

Widen the Net

Traditionally, the notifiable disease surveillance system has relied on reporting by physicians. Although reporting by commercial and hospital laboratories is not required in some states, at least one state noted that laboratories were its most important source of surveillance data. Other health care staff such as infection control personnel and school nurses may be appropriate but underutilized sources of surveillance reports.

Active Surveillance

Active surveillance shifts the burden for report generation from the health care provider to the health department. Active surveillance has been shown to increase the number and proportion of reported cases. Since health department staff contact health care providers on a regular basis, active surveillance also promotes closer personal ties between the providers and the health department staff. Active surveillance is relatively expensive, however, and its cost-effectiveness is not entirely clear. In practice, active surveillance is usually limited to disease elimination programs to short-term intensive investigation and control activities, or to seasonal problems, such as some arbovirus diseases.

Establishing a Surveillance System

Numerous situations arise that induce health authorities to consider establishing a new surveillance system. For example, they may consider establishing a surveillance system in emergency settings such as a refugee camp or when a serious new disease has been identified. Before establishing a new system, however, they should explicitly consider its justification, objectives, case definition, and operation.

Justification

Is a new system really needed? To answer this question, health authorities should determine whether the system would meet one or more of the following criteria:

-- The disease is important in this area, or at least potentially so. Surveillance for diseases which cause serious illness, death, or disability is easily justified.

-- Surveillance is necessary to guide, monitor, and evaluate prevention and/or control measures. This presumes that effective prevention and/or control measures are available, and that the public health agency will take the appropriate action.

-- Surveillance is necessary to establish baseline incidence because prevention and/or control measures are on the horizon. These measures will be evaluated on the basis of their impact on disease occurrence compared with pre-intervention disease occurrence. Therefore, having reliable pre-intervention incidence data is important.

-- Surveillance is justified because the disease is new, and data are needed to learn more about its patterns of occurrence, clinical spectrum, risk groups, and potential for intervention. Serious new diseases such as TSS, Legionnaires' disease, and eosinophilia-myalgia syndrome are often placed under surveillance to capture as many cases as possible as quickly as possible. These cases are studied promptly by public health officials and researchers to learn more about the disease itself, its pattern of occurrence and population at risk, and its causes.

-- Available data and alternative sources of data will not suffice. Existing data, even if not ideal, can sometimes be used in place of establishing a new surveillance system. Similarly, a one-time or periodic survey will sometimes provide whatever information is needed with less effort than would be required to establish an ongoing surveillance system.

Objectives

If health authorities can justify a new surveillance system, their next step is to describe its objectives. The objectives should clearly describe what information is needed, who needs it, and how the data are to be used.

A clear statement of the objectives provides a common understanding among participants in the surveillance system and provides a framework for its design. For example, the desire to collect very detailed information about each case may compete with the need to determine quickly the number of cases. If the system's primary objective is to obtain rapid case counts, then less information should be collected about each case to avoid delays and disincentives for reporting.

Case Definition

The condition or conditions to be included in the surveillance system must be clearly defined. A clear case definition will ensure that the same criteria will be used in different places by different people. Some case definitions require laboratory confirmation; others rely on a constellation of signs or symptoms for syndromes or conditions for which no laboratory test is readily available.

A case definition must be simple, understandable, and acceptable. It must be practical for the setting and usable by the persons on whom the system will rely for reporting. For example, if the case definition requires laboratory confirmation, the laboratory test must be readily available and competently performed.

Ideally, the case definition should be sufficiently sensitive to identify most persons with the condition under surveillance, but sufficiently specific to exclude persons who do not have the condition. These characteristics, along with the prevalence of the condition in the community, determine the likelihood that a case which fits the case definition is an actual case of the disease in question.A broad (sensitive, but not very specific) case definition may be adequate in an area with a high prevalence of disease, since most persons with illnessesthat fit the case definition will be true cases. For example, in many parts of Africa, the case definition for malaria is anyone with fever. In low prevalence areas, a narrower (more specific) case definition is necessary to avoid unnecessary expenditure of effort and resources. An additional consideration is whether only confirmed cases should be reported or whether suspect cases should be reported as well.

Health authorities may be able to use a case definition from the uniform case definitions of the CSTE that are given in Appendix C. These case definitions are for surveillance, and may differ from the criteria used for clinical diagnosis and treatment. Persons with unusual features of the disease may not fit the surveillance case definition, but they should be considered clinical cases and treated accordingly. This difference should be made clear to health care providers who report to a surveillance system.

Operations

Procedures for collecting, analyzing, interpreting, and distributing the information must all be established in advance. As with the case definitions, the procedures should be simple and workable. To the extent possible, new systems should piggyback on existing systems to avoid unnecessary duplication of effort and to maintain a single reporting mechanism for reporters.

In deciding data collection and management issues, health authorities must address numerous details. Will the system rely on active surveillance (better, more timely data, but greater agency effort) or passive surveillance? Who is expected to report? What forms or mechanisms will be used? Exactly what information will be collected on the forms? How will the forms be processed? Will personal identifiers be included, and if so, how will confidentiality be assured?

Plans for a surveillance system must include how the data will be analyzed, including designation of software (if the data are computerized), standard tables, graphs, and maps, and the frequency of analysis.

Finally, dissemination plans should include how the data will be communicated, how frequently, to whom, and how the data will or should be used.

Cooperation

Public health surveillance is a cooperative venture among those who provide reports (usually, health care professionals and laboratory staff), those who process the reports (usually, public health agency workers), and those who use the information for clinical uses (health care professionals again), for public health planning and action (usually, public health program managers and staff), and for other applications. Before implementing a surveillance system it is essential to assure that those responsible for reporting, processing, and using the information will support the system.

For example, given that most notifiable diseases are underreported, it is evident that passing a law or regulation requiring the reporting of a disease is not enough. To gain the support and cooperation of those who are expected to provide the data, the public health agency should inform health care professionals not only of their responsibility to report, but why it is important that they do so. In return, the agency should provide timely feedback to the medical community (through newsletters, bulletins, seminars, or other mechanisms) that will aid prevention, diagnosis, and treatment.

Similarly, since the primary purpose of most surveillance systems is to gather information for action, those who are responsible for the action must be cooperative. Have the program managers and staff been included in the decision making? Do they care if the surveillance system is implemented? Will it provide the information they want? Will they even use the data to make programmatic decisions?

Implementation

Planning and assurance of cooperation are long term efforts that require monitoring and continuing attention. After initial planning is complete and cooperation is assured, however, the surveillance system should be implemented quickly. Data collection should begin as soon as the procedures and systems are in place, while reporters are still motivated. The data should be analyzed and disseminated promptly to maintain support.

In so doing, the health agency follows the advice to ``share the data, share the responsibility, share the credit.'' (8)

Review Exercises

Exercise 5.3

State funding for a childhood injury prevention program has just become available. To gather baseline data on childhood injuries, the staff is discussing whether to conduct a survey or establish a surveillance system. Discuss the advantages and disadvantages of these two approaches.

Answer on page 335.

Exercise 5.4

Discuss the relative merits of a passive surveillance system and an active surveillance system.

Answer on page 336.

Exercise 5.5

A researcher is urging the state health department to add chlamydial infections to the state's list of reportable diseases. What are the arguments for and against? What alternative methods of surveillance for chlamydial infection might you propose?

Answer on page 337.

Exercise 5.6

During the previous 6 years, 1-3 cases per year of Kawasaki syndrome had been reported a state health department. During the past 3 months, 17 cases have been reported. All but two of these cases have been reported from one county. The local newspaper carried an article about one of the first reported cases, a young girl. Describe the possible causes of the increase in reported cases.

Answer on page 337.

Exercise 5.7

You have recently been hired by a state health department to run surveillance activities, among other tasks. All surveillance data are entered into a personal computer and transmitted to CDC each week. The state, however, has never generated its own set of tables for analysis. What three tables might you want to generate by computer each week?

Answer on page 338.

Exercise 5.8

Last week, the state public health laboratory diagnosed rabies in 4 raccoons that had been captured in a wooded residential neighborhood. This information will be duly reported in the tables of the monthly state health department newsletter. Is this sufficient? Who needs to know this information?

Answer on page 338.

Answers to Exercises

Answer--Exercise 5.1 (page 302)

A. Listeriosis: Wide spectrum of nonspecific clinical illness and, low case-fatality rate (except in newborns). Therefore, surveillance must be based on morbidity rather than mortality; diagnosis should be confirmed in the laboratory. Possible sources of surveillance data include laboratory reports, hospital discharge data (although many cases are not hospitalized), or adding listeriosis to the reportable disease list.

B. Spinal cord injury: Severe health event, substantial mortality, almost all cases brought to a hospital. Therefore, surveillance most logically based on hospital records and mortality data (death certificates, medical examiner data). Special efforts might be directed to regional trauma centers. The use of data from emergency medical services and rehabilitation centers might also be explored.

C. Lung cancer in nonsmokers: Like spinal cord injury, lung cancer is a severe health event with high morbidity and mortality. Unfortunately, hospital discharge records and vital records do not routinely provide smoking information. For this condition, cancer registries may provide the best opportunity for surveillance if smoking information is routinely collected. Alternatively, you could attempt to establish surveillance with interested internists, oncologists, and other health care providers likely to see lung cancer patients.

Factors which influence the choice of one source of data over another include severity of illness (hospitalization and mortality); need for laboratory confirmation of diagnosis; rarity of the condition; specialization of the health care provider; quality, reliability, or availability of the relevant data; timeliness of the data in terms of need for response; and others.

Answer--Exercise 5.2 (page 318)

Answers are dependent upon your local or state health department.

Answer--Exercise 5.3 (page 332)

SURVEY

Advantages

-- More control over the quality of the data

-- More in-depth data can be collected on each case than is usually possible with surveillance

-- Can identify spectrum of childhood injuries, including those which do not warrant medical care

-- More accurate assessment of true incidence and prevalence

Disadvantages

-- More costly to perform since survey requires development of de novo data collection system and hiring of interviewers who require training and supervision

-- Represents only single point in time (``snapshot''); may miss seasonal trends; misses rare diseases; misses rapidly fatal diseases

-- Tells little if anything about changes over time in incidence or prevalence of a behavior or outcome

-- Recall bias more likely to affect results since data collected retrospectively (surveillance is usually prospective)

SURVEILLANCE

Advantages

-- Cheaper (for the health department)

-- Can often use existing systems and health personnel for data collection.

-- Allows monitoring of trends over time

-- Ongoing data collection may allow collection of an adequate number of cases to study those at risk. With surveys, an event may be too infrequent to gather enough cases for study; with surveillance, the observation period can be extended until sufficient numbers of cases are collected.

Disadvantages

-- May not provide a representative picture of the incidence or prevalence unless care is taken in selecting reporting sites and assuring complete reporting

-- Data that can be collected are limited by the skill, time, and good will of the data collectors, who usually have other responsibilities.

-- Quality control may be a major problem in data collection.

-- The quality of data may vary between collection sites.

Answer--Exercise 5.4 (page 332)

Merits of a passive surveillance system (where health care providers and others are expected to send reports to the health department without prompting):

-- Easy (for the health department)

-- Inexpensive

-- Easier to institutionalize and continue

Merits of an active surveillance system (where health department staff contact persons likely to see cases to request reports):

-- More complete case ascertainment (more sensitive)

-- Higher quality data

-- More uniform data

-- More flexible

-- More opportunity for feedback, education

-- Builds relationships between health department staff and reporters that may have other benefits, such as improved reporting of other conditions and more support for public health

Answer--Exercise 5.5 (page 333)

Arguments in favor:

-- Surveillance will provide an estimate of the true prevalence of this important but often overlooked condition.

-- Infection is treatable, and transmission is preventable.

-- Untreated, chlamydial infection is a major cause of pelvic inflammatory disease and infertility.

Arguments against:

-- Clinicians are likely to ignore the addition of chlamydia to a list they feel is already

too long. They may feel they should only be required to report communicable diseases with high morbidity and/or mortality that will lead to immediate intervention by the health department.

-- Adding chlamydia to the list will not lead to better diagnosis and treatment, since many infections are asymptomatic.

-- As a result, surveillance will provide a rather poor estimate of the true prevalence.

Alternatives might include:

-- Enroll interested and appropriate health care providers (e.g., obstetrician/gynecologists) and clinics in a sentinel surveillance system.

-- Laboratory-based surveillance.

Answer--Exercise 5.6 (page 333)

1. Change in surveillance system / policy of reporting
2. Change in case definition
3. Improved diagnosis

-- new laboratory test

-- increased physician awareness of the syndrome, new physician in town, etc.

-- increase in publicity / public awareness may have prompted individuals or parents to seek medical attention for compatible illness

4. Increase in reporting, i.e., improved awareness of requirement to report
5. Batch reporting (unlikely in this scenario)
6. True increase in incidence

Answer--Exercise 5.7 (page 334)

No right answer, but one sequence might be as follows:

Table 1: Number of reported cases this week, disease by county

Table 2: Number of reported cases, disease by week (going back 6-8 weeks for comparison)

Table 3: Number of reported cases for past 4 weeks, disease by year (going back 5 years for comparison)

Table 1 addresses disease occurrence by place. Tables 2 and 3 address disease occurrence by time. Together, these tables should give an indication of whether an unusual cluster or pattern of disease is occurring. If such a pattern is detected, person characteristics may then be explored.

Answer--Exercise 5.8 (page 334)

Many state health department newsletters do not go to ``all who need to know.'' Even among those who receive the newsletter, some do not read it at all, and many others skim the articles and ignore the tables altogether. In addition, depending on the timing of the laboratory report and publication deadlines, the information may be delayed by up to several weeks.

This information is important for all who may be affected, and for all who may be able to take preventive measures, including:

-- Other public health agencies, e.g., neighboring local health departments, animal control staff, etc.
-- Health care providers
-- Veterinarians
-- The public (inform by issuing press release to the media)

Self-Assessment Quiz 5

Now that you have read Lesson 5 and have completed the exercises, you should be ready to take the self-assessment quiz. This quiz is designed to help you assess how well you have learned the content of this lesson. You may refer to the lesson text whenever you are unsure of the answer, but keep in mind that the final is a closed book examination. Circle ALL correct choices in each question.

1. As defined in this lesson, public health surveillance includes which activities? (Circle ALL that apply.)

A. Data collection
B. Data analysis
C. Data interpretation
D. Data dissemination
E. Intervention

2. How does public health surveillance differ from medical surveillance?

A. Those who conduct public health surveillance are generally not physicians.
B. Public health surveillance refers to monitoring of populations, while medical surveillance refers to monitoring of individuals.
C. Public health surveillance is generally based on laboratory-confirmed diagnoses rather than clinical diagnoses.
D. Public health surveillance comes from public clinics, while medical surveillance comes from private health care providers.

3. The primary difference between surveillance systems for communicable diseases and most surveillance systems for chronic diseases occurs as part of which activity?

A. Data collection
B. Data analysis
C. Data interpretation
D. Data dissemination
E. Link to programs

4. Among the common uses and applications of public health surveillance are: (Circle ALL that apply.)

A. detecting changes in an infectious agent
B. evaluating prevention and control measures
C. monitoring long-term trends
D. planning future resource needs for prevention
E. suggesting topics for further research

5. Vital statistics are important sources of data on: (Circle ALL that apply.)

A. morbidity
B. mortality

C. risk factor prevalence
D. injury and disability
E. outpatient health-care utilization

6. Important sources of morbidity data include: (Circle ALL that apply.)

A. notifiable disease reports
B. laboratory reports
C. hospital discharge data
D. vital records
E. environmental monitoring data

7. Surveillance activities focused on animal populations are not usually intended to:

A. detect changes in the size and distribution of reservoir populations
B. detect changes in the size and distribution of vector populations
C. detect disease agents which might be present
D. detect epizootics (outbreaks of disease in animals)
E. substitute for surveillance of morbidity in humans

8. Dr. Mary Smith is a physician practicing in the town of Smallville in South County. South County has a county health department. The diseases she must report to authorities are generally dictated by the:

A. county health department
B. state government
C. CDC
D. Council of State and Territorial Epidemiologists
E. medical licensing board

9. Morbidity reporting regulations usually specify: (Circle ALL that apply.)

A. the diseases and conditions that must be reported
B. who is obligated to report cases of notifiable diseases
C. how and to whom the case reports are to be sent
D. what information is to be provided

10. The number of nationally notifiable diseases is approximately:

A. 3
B. 6
C. 17
D. 30
E. 45
F. 73

11. According to most morbidity reporting regulations, who among the following persons is required to notify health authorities of the occurrence of a notifiable disease? (Circle ALL that apply.)

A. Physician
B. Infection control nurse
C. Nurse practitioner
D. Hospital director
E. Dentist

12. Dr. Mary Smith is a physician practicing in the town of Smallville in South

County. South County has a county health department. Dr. Smith sees a patient with diarrhea who has recently returned from a trip to South America. Dr. Smith suspects the patient has cholera. Dr. Smith should notify the:
A. county health department
B. state health department
C. CDC
D. Pan American Health Organization, on behalf of the World Health Organization
E. U.S. Department of State

13. Active surveillance is characterized by:
A. health care providers taking the initiative to contact the health department
B. the health department taking the initiative to contact health care providers
C. the health department taking the initiative to track down contacts of case-patients
D. the health department taking the initiative to identify undetected cases through serosurveys
E. the health department taking the initiative to monitor potentially exposed individuals to detect early signs of disease

14. Routine analysis of notifiable disease surveillance data at the state level might include: (Circle ALL that apply.)
A. the number of cases of a disease reported this week and during the previous few weeks
B. the number of cases of a disease reported this week and the number reported during the comparable week(s) of the previous few years
C. the number of cases by age, race, and sex
D. the number of cases by county
E. the number of cases by county divided by the county's population

15. One week, CDC received by electronic telecommunication several times more case reports of a disease in one county than had been reported in the preceding 2 weeks. No increase was reported in neighboring counties. Possible explanations for this increase include: (Circle ALL that apply.)
A. epidemic
B. duplicate reports
C. batch reporting
D. increase in the county's population
E. new physician in the county

16. The primary reason for preparing and distributing periodic surveillance reports is to:
A. document recent epidemiologic investigations
B. provide current information on disease occurrence to those who need it
C. provide reprints of MMWR articles, reports, and recommendations
D. acknowledge the contributions of those who submitted case reports

17. The minimum number of human cases necessary for a health department action such as an investigation or control activities is:
A. one
B. two times the expected number
C. variable, depending on the disease, but at least two cases
D. variable, depending on the disease, but could be one or zero

E. variable, depending on public concern and political pressure

18. The primary purpose for evaluating a surveillance system is to ensure that the system is:

A. addressing an important public health problem
B. cost-effective
C. operating as efficiently as possible
D. serving a useful public health function

19. In evaluating a surveillance system, which measures can be used to quantify the ``importance'' of a disease? (Circle ALL that apply.)

A. Death-to-case ratio
B. Number of patients hospitalized for the disease
C. Disease-specific years of potential life lost
D. Health care costs attributable to the disease
E. Infectiousness of the disease

20. The ability of a surveillance system to detect the cases it is intended to detect is referred to as:

A. predictive value positive
B. representativeness
C. sensitivity
D. specificity

21. Public health officials have recently taken action to overcome a common limitation of the notifiable disease reporting system. This limitation is:

A. underreporting
B. lack of representativeness of reported cases
C. lack of timeliness
D. inconsistency of case definitions

22. A health department sometimes adds a disease to the notifiable disease list even if no effective control measures are available. This action is justifiable if:

A. the health department is well staffed and can handle the addition without compromising its other activities
B. the disease is on the notifiable disease list of a neighboring state with a similar population
C. the disease is new, and surveillance reports may shed light on its epidemiology
D. the incidence of the disease has been steadily increasing

23. The primary difference between a surveillance system and a survey is:

A. a surveillance system is population-based
B. a surveillance system is ongoing
C. a surveillance system cannot assure confidentiality
D. a survey is generally cheaper

24. A state health department decides to improve their reporting system. The ONE best step to do this is:

A. require more disease-specific forms from local health departments
B. make sure all persons with a responsibility to report understands their role clearly
C. narrow the focus of the reporting system down to a manageable amount of health events depending on the staff and resources

D. shift the burden for report generation from the health department to the health care provider

25. Public health surveillance requires the cooperation of people that are responsible for which of the following? (Circle ALL that apply.)

A. Providing disease reports
B. Processing disease reports
C. Using the information from disease reports for clinical use
D. Applying the information from disease reports to public health planning and action

Answers are in Appendix JIf you answer at least 20 questions correctly, you understandLesson 5 well enough to go to Lesson 6.

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Table
5.1
Notifiable diseases and conditions, United States, 1990

Diseases and Conditions Reportable in Most States	Diseases and Conditions Reportable in Some States Only
*Acquired immunodeficiency syndrome	
*Amebiasis	
*Anthrax	
*Botulism (foodborne, wound, and unspecified)	
*Brucellosis	
Campylobacteriosis	
*Chancroid	
***Cholera	
*Diphtheria	
*Encephalitis	
Giardiasis	
*Gonorrhea / gonococcal disease	
*Granuloma inguinale	
*Hansen's disease (leprosy)	
*Hemophilis influenzae, invasive	
*Hepatitis A	
*Hepatitis B	
*Hepatitis non-A, non-B	
Human immunodeficiency virus (HIV) infection	

Influenza outbreak
Kawasaki syndrome
*Legionellosis
*Leptospirosis
*Lyme disease
*Lymphogranuloma venereum
*Malaria
*Measles (rubeola)
*Meningitis, aseptic
Meningitis, bacterial
*Meningococcal disease
*Mumps outbreaks
*Pertussis
***Plague
*Poliomyelitis, paralytic
*Psittacosis
*Rabies, human
Reye syndrome
*Rocky Mountain spotted fever
*Rubella
*Rubella, congenital
*Salmonellosis
*Shigellosis
*Syphilis, primary & secondary
Syphilis, congenital
*Tetanus
*Toxic shock syndrome
*Trichinosis
*Tuberculosis
*Typhoid fever
***Typhus
Yellow fever
Abortion
Adverse drug reaction
Animal bite
Asbestosis
Blastomycosis
*Botulism, infant
Chickenpox (varicella)
Congenital defect
Coccidioidomycosis
Dengue fever
Diarrhea caused by
  Escherichia coli
Guillain-Barre syndrome

Herpes simplex
Histoplasmosis
Impetigo outbreak
Lead poisoning
Listeriosis
Mycobacterial infection,
atypical
Nonspecific urethritis
Nosocomial outbreak
Occupational disease, any
Ophthalmia neonatorum
Pesticide poisoning
Pneumoconiosis
Q fever
Rabies, animal
Relapsing fever
*Rheumatic fever, acute
Scarlet fever
Silicosis
Smallpox
Staphylococcal disease
Streptococcal disease
Toxoplasmosis
Trachoma
Yersiniosis

Source: 7
*Nationally notifiable disease
**Disease covered by International Quarantine Agreement

Figure
5.1
Information loop involving health care providers,
public health agencies, and the public

Figure
5.2
The components of surveillance and resulting public health action

Figure
5.3
Malaria by year of report, United States, 1930-1990

Source: 6

Figure
5.4
Annual measles incidence rates,
United States, 1955-1990; with inset of 1980-1990

Source: 6

Figure
5.5
The information cycle

Figure
5.6
Washington State Health Department Form

Figure
5.7
Completeness of case identification, reporting,
and investigation of shigellosis

Source: 17

Figure
5.8
Four different surveillance systems for influenza

Clockwise from top left, laboratory-based system, 121-city mortality reporting system, sentinel physician system, and weekly summary of influenza activity by state epidemiologists.

Figure
5.9
Reported cases of hepatitis A
by county and week of report, 1989

Source: CDC, unpublished data, 1991

Figure
5.10
Reported cases of hepatitis A
by county for weeks 1-4, 1988-1991

Source: CDC, unpublished data, 1991

Figure
5.11
Surveillance system flow chart