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Principles and Practice of Public Health Surveillance

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Public health surveillance is the systematic, ongoing assessment of the health of a community including the timely collection, analysis, interpretation, dissemination and subsequent use of data. The book presents an organized approach to planning, developing, implementing, and evaluating public health surveillance systems. Chapters include: planning; data sources; system management and data quality control; analyzing surveillance data; special statistical issues; communication; evaluation; ethical issues; legal issues; use of computers; state and local issues; and surveillance in developing countries. The book is intended to serve as a desk reference for public health practitioners and as a text for students in public health.

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PREFACE

Since public health surveillance undergirds public health practice, it is unfortunate that no single resource has been available to provide a guide to the underlying principles and practice of surveillance. In recent years, a small number of courses on surveillance at schools of public health have been developed in recognition of the importance of surveillance, but no definitive textbook has appeared. *Principles and Practice of Public Health Surveillance* is intended to serve as a desk reference for those actively engaged in public health practice and as a text for students of public health.

The book is organized around the science of surveillance, i.e., the basic approaches to planning, organizing, analyzing, interpreting, and communicating surveillance information in the context of contemporary society and public health practice. Surveillance provides the information base for public health decision making. It must continually respond to the need for new information, such as about chronic diseases, occupational and environmental health, injuries, risk factors, and emerging health problems. It must also accommodate to changing priorities. Issues, such as long latency, migration, low frequencies, and the need for local data, must be addressed. New analytic methods and rapidly evolving technologies present new opportunities and create new demands. This book addresses many of these issues. Although many examples of surveillance systems are included, this is not intended to be a manual for establishing surveillance for any particular condition. We believe that this approach will provide the reader with ideas and concepts that can be adapted to her or his particular needs.

This book grew out of a recognition by the Surveillance Coordination Group at the Centers for Disease Control of the need to capture the art as well as the science of surveillance. Most of the authors are current or former staff in the Epidemiology Program Office at the Centers for Disease Control. These friends and colleagues have drawn on their own experience in surveillance in states, a diversity of federal programs, and in international health, as well as having provided an interweaving of the experience of others. We felt that the risks of being parochial were outweighed by the desirability of producing a consistent and systematic coverage of the subject. Although most

examples are drawn from the United States, they illustrate basic principles and approaches that can be applied in a wide variety of settings around the world.

We would like to acknowledge Douglas Klaucke, who pulled together many of the initial thoughts on organizing the book, and Stephen Thacker, the Director of the Epidemiology Program Office (EPO), and Donna Stroup, Director of the Division of Surveillance and Analysis, for their continued support and encouragement. We also acknowledge with gratitude the creative guidance and constructive criticism provided by EPO's Assistant Director for Science, Edwin Kilbourne. Finally, and most importantly of all, we gratefully recognize the expertise, the dedication, and the commitment of all the authors in assuring that this book became a reality.

SMT Atlanta, Georgia

REC August 1992

Chapter I

Introduction

Stephen B. Thacker

"If you don't know where you're going, any road will get you there."

Lewis Carroll

Public health surveillance is the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice (*1*). A surveillance system includes the functional capacity for data collection and analysis, as well as the timely dissemination of these data to persons who can undertake effective prevention and control activities. While the core of any surveillance system is the collection, analysis, and dissemination of data, the process can be only understood in the context of specific health outcomes.

BACKGROUND

The idea of observing, recording, and collecting facts, analyzing them and considering reasonable courses of action stems from Hippocrates (*2*). The first real public health action that can be related to surveillance probably occurred during the period of Bubonic plague, when public health authorities boarded ships in the port near the Republic of Venice to prevent persons ill with plague-like illness from disembarking (*3*). Before a large-scale organized system of surveillance could be developed, however, certain prerequisites needed to be fulfilled. First, there had to be some semblance of an organized health-care system in a stable government; in the Western world, this was not achieved until the time of the Roman Empire. Second, a classification system for disease and illness had to be established and accepted,

which only began to be functional in the 17th century with the work of Sydenham. Finally, adequate measurement methods were not developed until that time.

Current concepts of public health surveillance evolve from public health activities developed to control and prevent disease in the community. In the late Middle Ages, governments in Western Europe assumed responsibilities for both health protection and health care of the population of their towns and cities (*4*). A rudimentary system of monitoring illness led to regulations against polluting streets and public water, construction for burial and food handling, and the provision of some types of care (*5*). In 1766, Johann Peter Frank advocated a more comprehensive form of public health surveillance with the system of police medicine in Germany. It covered school health, injury prevention, maternal and child health, and public water and sewage (*4*). In addition, he delineated governmental measures to protect the public's health.

The roots of analysis of surveillance data can also be traced to the 17th century. In the 1680s, von Leibnitz called for the establishment of a health council and the application of a numerical analysis in mortality statistics to health planning (*2*). About the same time in London, John Graunt published a book, *Natural and Political Observations Made Upon the Bills of Mortality*, in which he attempted to define the basic laws of natality and mortality. In his work, Graunt developed some fundamental principles of public health surveillance, including disease-specific death counts, death rates, and the concept of disease patterns. In the next century, Achenwall introduced the term "statistics," and over the next several decades vital statistics became more widespread in Europe. Nearly a century later, in 1845, Thurnam published the first extensive report of mental health statistics in London.

Two prominent names in the development of the concepts of public health surveillance activities are Lemuel Shattuck and William Farr. Shattuck's 1850 report of the Massachusetts Sanitary Commission was a landmark publication that related death, infant and maternal mortality, and communicable diseases to living conditions. Shattuck recommended a decennial census, standardization of nomenclature of causes of disease and death, and a collection of health data by age, gender, occupation, socioeconomic level, and locality. He applied these concepts to program activities in immunization, school health, smoking, and alcohol abuse, and introduced these concepts into the teaching of preventive medicine.

William Farr (1807-1883) is recognized as one of the founders of modern concepts of surveillance (*6*). As superintendent of the statistical department of the Registrar General's office of England and Wales from 1839 to 1879, Farr concentrated his efforts on collecting vital statistics, on assembling and evaluating those data, and on reporting both to responsible health authorities and to the general public.

In the United States, public health surveillance has focused historically on infectious disease. Basic elements of surveillance were found in Rhode Island in 1741, when the colony passed an act requiring tavern keepers to report contagious disease among their patrons. Two years later, the colony passed a broader law requiring the reporting of smallpox, yellow fever, and cholera (*7*).

National disease monitoring activities did not begin in the United States until 1850 when mortality statistics based on death registration and the decennial census were first published by the Federal Government for the entire United States (*8*). Systematic reporting of disease in the United States began in 1874 when the Massachusetts State Board of Health instituted a voluntary plan for weekly reporting by physicians reporting on prevalent diseases, using a standard postcard-reporting format (*9,10*). In 1878, Congress authorized the forerunner of the Public Health Service (PHS) to collect morbidity data for use in quarantine measures against such pestilential diseases as cholera, smallpox, plague, and yellow fever (*11*).

In Europe, compulsory reporting of infectious diseases began in Italy in 1881 and Great Britain in 1890. In 1893, Michigan became the first U.S. jurisdiction to require the reporting of specific infectious diseases. Also in 1893, a law was enacted to provide for the collection of information each week from state and municipal authorities throughout the United States (*12*). By 1901, all state and municipal laws required notification (i.e., reporting) to local authorities of selected communicable diseases such as smallpox, tuberculosis, and cholera. In 1914, PHS personnel were appointed as collaborating epidemiologists to serve in state health departments to telegraph weekly disease reports to the PHS.

In the United States, it was not until 1925, however, following markedly increased reporting associated with the severe poliomyelitis epidemic in 1916 and the influenza pandemic in 1918-1919, that all states had begun participating in national morbidity

reporting (*13*). A national health survey of U.S. citizens was first conducted in 1935. After a 1948 PHS study led to the revision of morbidity reporting procedures, the National Office of Vital Statistics assumed the responsibility for morbidity reporting. In 1949, weekly statistics that had appeared for several years in *Public Health Reports* began being published by the National Office of Vital Statistics. In 1952, mortality data were added to the publication that was the forerunner of the *Morbidity and Mortality Weekly Report (MMWR)*. As of 1961, the responsibility for this publication and its content was transferred to the Communicable Disease Center (now, Centers for Disease Control [CDC]).

In the United States, the authority to require notification of cases of disease resides in the respective state legislatures. In some states, authority is enumerated in statutory provisions; in other states, authority to require reporting has been given to state boards of health; still other states require reports both under statutes and health department regulations. Variation among states also exists among conditions and diseases to be reported, time frames for reporting, agencies to receive reports, persons required to report, and conditions under which reports are required (*14*).

The Conference (now Council) of State and Territorial Epidemiologists (CSTE) was authorized in 1951 by its parent body, the Association of State and Territorial Health Officials to determine what diseases should be reported by states to the Public Health Service and to develop reporting procedures. CSTE meets annually, and in collaboration with CDC, recommends to its constituent members appropriate changes in morbidity reporting and surveillance, including what diseases should be reported to CDC and published in the *MMWR*.

DEVELOPMENT OF THE CONCEPT OF SURVEILLANCE

Until 1950, the term "surveillance" was restricted in public health practice to monitoring contacts of persons with serious communicable diseases such as smallpox, to detect early symptoms so that prompt isolation could be instituted (*15*). The critical demonstration in the United States of the importance of a broader, population-based view of surveillance was made following the Francis Field Trial of poliomyelitis vaccine in 1955 (*16,17*). Within 2 weeks of the announcement of the results of the

field trial and initiation of a nationwide vaccination program, six cases of paralytic poliomyelitis were reported through the notifiable-disease reporting system to state and local health departments; this surveillance lead to an epidemiologic investigation, which revealed that these children had received vaccine produced by a single manufacturer. Intensive surveillance and appropriate epidemiologic investigations by federal, state, and local health departments found 141 vaccine-associated cases of paralytic disease, 80 of which represented family contacts of vaccinees. Daily surveillance reports were distributed by CDC to all persons involved in these investigations. This national common-source epidemic was ultimately related to a particular brand of vaccine that had been contaminated with live poliovirus. The Surgeon General requested that the manufacturer recall all outstanding lots of vaccine and directed that a national poliomyelitis program be established at CDC. Had the surveillance program not been in existence, many and perhaps all vaccine manufacturers would have ceased production.

In 1963, Langmuir limited use of the term "surveillance" to the collection, analysis, and dissemination of data (*18*). This construct did not encompass direct responsibility for control activities. In 1965, the Director General of the World Health Organization (WHO) established the epidemiological surveillance unit in the Division of Communicable Diseases of WHO (*19*). The Division Director, Karel Raska, defined surveillance much more broadly than Langmuir, including "the epidemiological study of disease as a dynamic process." In the case of malaria, he saw epidemiologic surveillance as encompassing control and prevention activities. Indeed, the WHO definition of malaria surveillance included not only case detection, but also obtaining blood films, drug treatment, epidemiologic investigation, and follow-up (*20*).

In 1968, the 21st World Health Assembly focused on national and global surveillance of communicable diseases, applying the term to the diseases themselves rather than to the monitoring of individuals with communicable disease (*21*). Following an invitation from the Director General of WHO and with consultation from Raska, Langmuir developed a working paper and in the year prior to the Assembly obtained comments from throughout the world on the concepts and practices advocated in the paper. At the Assembly, with delegates from over 100 countries, the working paper was endorsed, and discussions on the national and global surveillance of communicable disease identified

three main features of surveillance that Langmuir had described in 1963: a) the systematic collection of pertinent data, b) the orderly consolidation and evaluation of these data, and c) the prompt dissemination of results to those who need to know--particularly those in position to take action.

The 1968 World Health Assembly discussions reflected the broadened concepts of "epidemiologic surveillance" and addressed the application of the concept to public health problems other than communicable disease (*20*). In addition, epidemiologic surveillance was said to imply "...the responsibility of following up to see that effective action has been taken."

Since that time, a wide variety of health events, such as childhood lead poisoning, leukemia, congenital malformations, abortions, injuries, and behavioral risk factors have been placed under surveillance. In 1976, recognition of the breadth of surveillance activities throughout the world was made evident by the fact that a special issue of the *International Journal of Epidemiology* was devoted to surveillance (*22*).

SURVEILLANCE IN PUBLIC HEALTH PRACTICE

The primary function of the application of the term "epidemiologic" to surveillance, which first appeared in the 1960s associated with the new WHO unit of that name, was to distinguish this activity from other forms of surveillance (e.g., military intelligence) and to reflect its broader applications. The use of the term "epidemiologic," however, engenders both confusion and controversy. In 1971, Langmuir noted that some epidemiologists tended to equate surveillance with epidemiology in its broadest sense, including epidemiologic investigations and research (*15*). He found this "both epidemiologically and administratively unwise," favoring a description of surveillance as "epidemiological intelligence."

What are the boundaries of surveillance practice? Is "epidemiologic" an appropriate modifier of surveillance in the context of public health practice? To address these questions, we must first examine the structure of public health practice. One can divide public health practice into surveillance; epidemiologic, behavioral, and laboratory research; service (including program evaluation); and training.

Surveillance data should be used to identify research and service needs, which, in turn, help to define training needs. Unless data are provided to those who set policy and implement programs, their use is limited to archives and academic pursuits, and the material is therefore appropriately considered to be health information rather than surveillance data. However, surveillance does not encompass epidemiologic research or service, which are related but independent public health activities that may or may not be based on surveillance. Thus, the boundary of surveillance practice excludes actual research and implementation of delivery programs.

Because of this separation, "epidemiologic" cannot accurately be used to modify surveillance (*1*). The term "public health surveillance" describes the scope (surveillance) and indicates the context in which it occurs (public health). It also obviates the need to accompany any use of the term "epidemiologic surveillance" with a list of all the examples this term does **not** cover. Surveillance is correctly--and necessarily--a component of public health practice, and should continue to be recognized as such.

PURPOSES AND USES OF PUBLIC HEALTH SURVEILLANCE DATA

Purposes

Public health surveillance data are used to assess public health status, define public health priorities, evaluate programs, and conduct research. Surveillance data tell the health officer where the problems are, whom they affect, and where programmatic and prevention activities should be directed. Such data can also be used to help define public health priorities in a quantitative manner and also in evaluations of the effectiveness of programmatic activities. Results of analysis of public health surveillance data also enable researchers to identify areas of interest for further investigation (*23*).

The analysis of surveillance data is, in principle, quite simple. Data are examined by measures of time, place, and person. The routine collection of information about reported cases of congenital syphilis in the United States, for example, reflects not only numbers of cases (Figure I.1), geographic distribution, and populations affected, but also indicates the effects of crack cocaine use and changing sexual practices over the past 10 years. The examination of routinely collected data show where rates of

salmonellosis by county in New Hampshire and in three contiguous states. Mapping these data illustrates the pattern of the spread of disease across state boundaries (Figure I.2). The examination of death certificates for data on homicide identifies high-risk groups and shows that the problem has reached epidemic proportions among young adult men (Figure I.3).

USES

The uses of surveillance are shown in Table I.1. Portrayal of the natural history of disease can be illustrated by the surveillance of malaria rates in the United States since 1930 (Figure I.4). In the 1940s, malaria was still an endemic health problem in the southeastern United States to the degree that persons with febrile illness were often treated for malaria until further tests were available. After the Malaria Control in the War Areas Program led to the virtual elimination of endemic malaria from the United States, rates of malaria decreased until the early 1950s, when military personnel involved in the conflict in Korea returned to the United States with malaria. The general downward trend in reported cases of malaria continued into the 1960s until, once again, numbers of cases of malaria rose, this time among veterans returning from the war in Vietnam. Since that time, we have continued to see increases in numbers of reported cases of malaria involving immigrant populations, as well as among U.S. citizens traveling abroad.

Surveillance data can be used also to detect epidemics. For example, during the swine influenza immunization program in 1976, a surveillance system was established to detect adverse sequelae related to the program (*24*). Working with state and local health departments, CDC was able to detect an epidemic of Guillain-Barré syndrome, which rapidly led to the termination of a program in which 40,000,000 U.S. citizens had been vaccinated. However, most epidemics are not detected by such analysis of routinely collected data but are identified through the astuteness and alertness of clinicians and public health officials of the community. From a pragmatic point of view, the key point is that when someone does note an unusual occurrence in the health picture of a community, the existence of organized surveillance efforts in the health department provides the infrastructure for conveying information to facilitate a timely and appropriate response.

The distribution and spread of disease can be documented from surveillance data, as seen in the county-specific data on salmonellosis (Figure I.2). U.S. cancer mortality statistics have also been mapped at the county level to identify a variety of geographic patterns that suggest hypotheses on etiology and risk (*25*). Recognition of such clusters can lead to further epidemiologic or laboratory research, sometimes using individuals identified in surveillance as subjects in epidemiologic studies. The association between the periconceptual use of multivitamins by women and the development of neural tube defects by their children was documented using children identified in a surveillance system for congenital malformations (*26*).

Surveillance data can also be used to test hypotheses. For example, in 1978 the U.S. Public Health Service announced a measles elimination program that included an active effort to vaccinate school-age children. Because of this program and the state laws that excluded from school students who had not been vaccinated, CDC anticipated a change in the age pattern of persons reported to have measles. Before the initiation of the program, the highest reported rates of measles were for children 10-14 years of age. As predicted, almost immediately after the school exclusion policy was implemented, there was not only a general decrease in the number of cases but also a shift in peak occurrence from school-age to preschool-age children (Figure I.5). By 1979, there were even lower levels of measles incidence and altered age-specific patterns.

Surveillance data can be applied in evaluating control and prevention measures. With routinely collected data, one can examine--without special studies--the effect of a health policy. For example, the introduction of inactivated poliovirus vaccine in the United States in the 1950s was followed by a dramatic decrease in the number of reported number of cases of paralytic poliomyelitis, and the subsequent introduction in the 1960s of oral poliovirus vaccine was followed by an even greater decline (Figure I.6).

Efforts to monitor changes in infectious agents have been facilitated by the use of surveillance data. In the late 1970s, antibiotic-resistant gonorrhea was introduced into the United States from Asia. Laboratory- and clinical-practice-based surveillance for cases of gonorrhea enabled public health officials to monitor the rapid diffusion of various strains of this bacterium nationally and facilitated

prevention activities, including notifying clinicians of proper treatment procedures (Figure I.7). Similarly, the National Nosocomial Infections Surveillance System, a voluntary, hospital-based surveillance system of hospital-acquired infections, has been used to monitor changes in antibiotic-resistance patterns of infectious agents associated with hospitalized patients.

As noted earlier, the first use of surveillance was to monitor persons with a view of imposing quarantine as necessary. Although this use of surveillance is rare in modern-day United States, in 1975--with the introduction of a suspected case of Lassa fever--over 500 potential contacts of the patient were monitored daily for 2 weeks to assure that secondary spread of this serious infectious agent did not occur (*27*).

Surveillance data can also be used to good effect for detecting changes in health practice. The increasing use of various technologies in health care has come to be an issue of growing concern over the past decade; surveillance data can provide useful information in this area (*28*). For example, in the United States since 1965, the rate of cesarean delivery has increased from approximately <5% to nearly 25% of all deliveries (Figure I.8). Data such as these are useful both in planning research to learn the causes of these changes and in monitoring the impact of such changes in practice and procedure on outcomes and costs associated with health care.

Finally, surveillance data are useful for planning. With knowledge about changes in the population structure or in the nature of conditions that might affect a population, officials can, with more confidence, plan for optimizing available resources. For example, data on refugees entering the United States from Southeast Asia in the early 1980s were broadly applicable; they told where people settled, described the age and gender structure of the population, and identified health problems that might be expected in that population. With this information, health officials were able to plan more effectively the appropriate health services and preventive activities for this new population.

THE FUTURE OF PUBLIC HEALTH SURVEILLANCE

As we approach the year 2000, several activities are expected to contribute to the evolution of public health surveillance. First, use of the computer--particularly the

microcomputer--has revolutionized the practice of public health surveillance. In the United States, the National Electronic Telecommunications System for Surveillance (NETSS) links all state health departments by computer for the routine collection, analysis, and dissemination of data on notifiable health conditions (*29*). Over the next several years, the growth will be within states, with state health departments being linked to county departments, and possibly even to health-care providers' offices for routine surveillance. The Minitel system currently in use in France has already demonstrated the essential utility of office-based surveillance of various conditions of public health importance (*30*).

The second area of renewed activity associated with surveillance is that of epidemiologic and statistical analysis. A by-product of the use of computers is the ability to make more effective use of sophisticated tools to detect changes in patterns of occurrence of health problems. In the 1980s, applications and methods of time series analysis and other techniques have enabled us to provide more meaningful interpretation of data collected in surveillance efforts (*31*). More sophisticated techniques will doubtless continue to be applied in the area of public health as they are developed.

Until recently, surveillance data were traditionally disseminated as written documents published periodically by government agencies. While paper reports will continue to be produced, and public health officials will continue to refine the use of print media, they are also beginning to use electronic media for the dissemination of surveillance data. More effective use of the electronic media, and all the other tools of communications, should facilitate the use of surveillance data for public health practice. At the same time, ready access to detailed information on individuals will continue to provide ethical and legal concerns that may constrain access to data of potential public health importance.

The 1990s will see surveillance concepts applied to new areas of public health practice such as chronic disease, environmental and occupational health, and injury control. The evolution and development of methods for these programmatic areas will continue to be a major challenge in public health.

A more fundamental principle that will underlie the ongoing development of surveillance is the increasing ability of people to look at public health surveillance as a scientific endeavor (*32*). A growing appreciation of the need for rigor in surveillance practice will no doubt improve the quality of surveillance programs and will therefore facilitate the analysis and use of surveillance data. An important result of this more vigorous approach to surveillance practice will be the increased frequency and quality of the evaluation of the practice of surveillance (*33*).

Finally, and probably most important, is the observation that surveillance needs to be used more consistently and thoughtfully by policymakers. Epidemiologists not only need to improve the quality of their analysis, interpretation, and display of data for public health use, they also need to listen to persons empowered to set policy in order to understand what stimulates the policymakers' interest and action. This assessment allows surveillance information to be crafted so that it is presented in its most useful form to the appropriate audience and in the necessary time frame. In turn, as we maximize the utility of data for decision making and better understand what is essential to that process, we will raise the area of public health surveillance to a new and higher level of importance.

The critical challenge in public health surveillance today, however, continues to be the assurance of its usefulness. In this effort, we must have rigorous evaluation of public health surveillance systems. Even more basic is the need to regard surveillance as a scientific endeavor. To do this properly, one must fully understand the principles of surveillance and its role in guiding epidemiologic research and influencing other aspects of the overall mission of public health. Epidemiologic methods based on public health surveillance must be developed; computer technology for efficient data collection, analysis, and graphic display must be applied; ethical and legal concerns must be addressed effectively; the use of surveillance systems must be reassessed on a routine basis; and surveillance principles must be applied to emerging areas of public health practice.

REFERENCES

1. Thacker SB, Berkelman RL. Public health surveillance in the United States. *Epidemiol Rev* 1988;10:164-90.

2. Eylenbosch WJ, Noah ND. Historical aspects. In: Surveillance in Health and disease. Oxford, England: Oxford University Press, 1988:3-8.

3. Moro ML, McCormick A. Surveillance for communicable disease. In: Eylenbosch WJ, Noah ND (eds.). Surveillance in health and disease. Oxford, England: Oxford University Press, 1988:166-82.

4. Hartgerink MJ. Health surveillance and planning for health care in the Netherlands. *Int J Epidemiol* 1976;5:87-91.

5. Anonymous (Editorial). Surveillance. *Int J Epidemiol* 1976;5:3-6.

6. Langmuir AD. William Farr: founder of modern concepts of surveillance. *Int J Epidemiol* 1976;5:13-8.

7. Hinman AR. Surveillance of communicable diseases. Presented at the 100th annual meeting of the American Public Health Association, Atlantic City, New Jersey, November 15, 1972.

8. Vital statistics of the United States, 1958. Washington, DC: National Office of Vital Statistics, 1959.

9. Trask JW. Vital statistics: a discussion of what they are and their uses in public health administration. *Public Health Rep* 1915;Suppl 12.

10. Bowditch HI, Webster DL, Hoadley JC *et al*. Letter from the Massachusetts State Board of Health to physicians. *Public Health Rep* 1915;Suppl 12:31.

11. Centers for Disease Control. Manual of procedures for national morbidity reporting and public health surveillance activities. Atlanta, Georgia: Public Health Service, 1985.

12. Chapin CV. State health organization. *JAMA* 1916;66:699-703.

13. National Office of Vital Statistics. Reported incidence selected notifiable disease: United States, each division and state, 1920-50. Vital Statistics Special Reports (National Summaries). 1953;37:1180-1.

14. Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. The reportable diseases. I. Mandatory reporting of infectious diseases by clinicians. *JAMA* 1989;262:3018-26.

15. Langmuir AD. Evolution of the concept of surveillance in the United States. *Proc R Soc Med* 1971;64:681-9.

16. Langmuir AD, Nathanson N, Hall WJ. Surveillance of poliomyelitis in the United States in 1955. *Am J Public Health* 1956;46:75-88.

17. Nathanson N, Langmuir AD. The Cutter incident: poliomyelitis following formaldehyde-inactivated poliovirus vaccination in the United States during the Spring of 1955. I. Background. *Am J Hyg* 1963;78:29-81.

18. Langmuir AD. The surveillance of communicable diseases of national importance. *N Engl J Med* 1963;268:182-92.

19. Raska K. National and international surveillance of communicable diseases. *WHO Chron* 1966;20:315-21.

20. Report for drafting committee. Terminology of malaria and of malaria eradication. Geneva, Switzerland: World Health Organization, 1963.

21. National and global surveillance of communicable disease. Report of the technical discussions at the Twenty-First World Health Assembly. A21/Technical Discussions/5. Geneva, Switzerland: World Health Organization, May 1968.

22. *Int J Epidemiol*. 1976;5:3-91.

23. Thacker SB. Les principes et la practique de la surveillance en santé publique: l'utilisation des donnees en sante publique. *Santé Publique* 1992;4:43-9.

24. Retailliau HF, Curtis AC, Starr G *et al*. Illness after influenza vaccination reported through a nationwide surveillance system, 1976-1977. *Am J Epidemiol* 1980;111:270-8.

25. Mason TJ, Fraumeni JF, Hoover R, Blot WJ. An atlas of mortality from selected diseases. Washington, D.C.: U.S. Department of Health and Human Services. NIH Publication No. 81-2397, May 1981.

26. Mulinare J, Cordero JF, Erickson D, Berry RJ. Periconceptional use of multivitamins and the occurrence of neural tube defects. *JAMA* 1988;260:3141-5.

27. Zweighaft RM, Fraser DW, Hattwick MAW *et al*. Lassa fever: response to an imported case. *N Engl J Med* 1977;297:803-7.

28. Thacker SB, Berkelman RL. Surveillance of medical technologies. *J Pub Health Pol* 1986;7:363-77.

29. Centers for Disease Control. National electronic communications systems for surveillance--United States, 1990-1991. *MMWR* 1991;40:502-3.

30. Valleron AJ, Bouvet E, Garnerin *et al*. A computer network for the surveillance of communicable diseases: the French experiment. *Am J Public Health* 1986;76:1289-92.

31. Stroup DF, Wharton M, Kafadar K, Dean AG. An evaluation of a method for detecting aberrations in public health surveillance data. *Am J Epidemiol* (In press).

32. Thacker SB, Berkelman RL, Stroup DF. The science of public health surveillance. *J Public Health Pol* 1989;10:187-203.

33. Centers for Disease Control. Guidelines for evaluating surveillance systems. *MMWR* 1988;37(Suppl No. S-5):1-20.

Chapter II

Planning a Surveillance System

Steven Teutsch

"Natural laws govern the occurrence of a disease, that these laws can be discovered by epidemiologic inquiry and that, when discovered, the causes of epidemics admit to a great extent of remedy."

William Farr

As described earlier, public health surveillance is the systematic and ongoing assessment of the health of a community, including the timely collection, analysis, interpretation, dissemination, and subsequent use of data. Surveillance provides information for action, information with a purpose. Surveillance systems evolve in response to ever-changing needs of society in general and of the public health community in particular. In order to understand and meet those needs, an organized approach to planning, developing, implementing, and maintaining surveillance systems is imperative. In the sections below, approaches to the planning and evaluation processes to be presented in more detail elsewhere in this book are discussed. The steps in planning a system are shown in Table II.1.

OBJECTIVES OF A SURVEILLANCE SYSTEM

Planning a surveillance system begins with a clear understanding of the purpose of surveillance, i.e., the answer to the question: "What do you want to know?" In the context of public health, surveillance may be established to meet a variety of objectives, including assessment of public health status, establishment of public health priorities, evaluation of programs, and conduct of research. Surveillance data can be used in all of the following ways:

- to estimate the magnitude of a health problem in the population at risk
- to understand the natural history of a disease or injury
- to detect outbreaks or epidemics
- to document the distribution and spread of a health event
- to test hypotheses about etiology
- to evaluate control strategies
- to monitor changes in infectious agents
- to monitor isolation activities
- to detect changes in health practice
- to identify research needs and facilitate epidemiologic and laboratory research
- to facilitate planning

Surveillance is inherently outcome oriented and focused on various outcomes associated with health-related events or their immediate antecedents. These include the frequency of an illness or injury, usually measured in terms of numbers of cases, incidence, or prevalence; the severity of the condition, measured as a case-fatality ratio, hospitalization rate, mortality rate, or disability; and the impact of the condition, measured in terms of cost. Where risk factors or specific procedures are incontrovertibly linked to health outcomes, it is often useful to measure the latter because health outcomes often more frequent (and hence more precisely ascertainable for small populations) and may be more closely linked to public health interventions. For example, mammography with suitable follow-up is the major prevention strategy for reducing mortality associated with breast cancer. Assessment of the level of

utilization of mammography by women can be regularly monitored and should be a more timely indicator of the impact of public health prevention programs than measurement of mortality from breast cancer. Surveillance data should also provide basic information on the utilization of mammography services by age and race/ethnicity of recipient, allowing better targeting of prevention efforts on the population sectors with the lowest utilization. In addition, over-utilization by some parts of the population (e.g., women <35 years of age who do not have other risk factors) might stimulate efforts to reduce unnecessary procedures.

High-priority health events should clearly be under surveillance. However, determining which should be considered high-priority events can be a daunting task. Both quantitative and qualitative approaches can be used in a selection process. Some quantitative factors are shown on Table II.2. In addition, criteria based on a consensus process to identify high-priority problems may identify emerging issues or problems that might otherwise not be considered. The consensus process leading to the Year 2000 Health Promotion and Disease Prevention Objectives in the United States is an example of a mechanism for identifying high-priority conditions, types of behavior, and interventions that require ongoing monitoring (*1*).

Because public health surveillance in the United States is driven by the public health need to be cognizant of diseases and injuries in the community and to respond appropriately, surveillance is inherently an applied science. Therefore, as surveillance has evolved, it is generally undertaken only when there is reasonable expectation that control measures will be taken as appropriate. For many conditions the link between surveillance and action is obvious (e.g., meningococcal meningitis prophylaxis for contacts of patients diagnosed as having meningitis). For emerging conditions, such as eosinophilia-myalgia syndrome, there is a compelling public health need to identify cases (delineate the magnitude of the problem), identify the mode of spread, and take appropriate action.

Surveillance data are usually augmented by additional studies to determine more precisely the causes, natural history, predisposing factors, and modes of transmission associated with the health problem. Yet, undertaking surveillance exclusively for research purposes is rarely warranted. Research needs are often better served by other, more precise (and often more costly) methods of case identification (e.g.,

registries), which facilitate more detailed data collection and tracking of cases. For example, registries of type I diabetes may have value for surveillance, but are justified primarily because they fill research needs. The ongoing public health application of these data is more limited. Scarce public health resources and the efforts of health-care providers to report cases need to be focused on problems for which the public health importance and the need for public health action can be readily recognized.

A primary role of surveillance is the assessment of the overall health status of a community. One approach to this issue is the development and identification of a set of indicators that measure major components of health status. Such a set has been developed in the United States to be used at a national, state, and local level (*2*). Another approach is to examine the most frequent, severe, costly, and preventable conditions in the community by examining most frequent causes of death, hospitalization, injury, disability, infection, work-site-associated illness and injury, and major risk factors for all the preceding items. This information can be obtained in most communities in terms of age, race/ethnicity, gender, and temporal trends. Regular assessments of the information can form the basis for educating the community about its major health problems and for identifying specific conditions that merit more intensive surveillance and intervention.

The specific objective and purpose of the surveillance system should be specified and general agreement obtained.

METHODS

Once the purpose of and need for a surveillance system has been identified, methods for obtaining, analyzing, disseminating, and using the information should be determined and implemented (see Chapters V, VI, and VII).

Because surveillance systems are ongoing and require the cooperation of many individuals, careful consideration must be given to the attributes discussed in Chapter VIII in the discussion on evaluation. The system adopted must be feasible and acceptable to those who will contribute to its success; it must be sensitive enough to provide the information required to do the job at hand, while having a high

predictive-value positive to minimize the expenditure of resources on following up false-positive cases. A surveillance system should be flexible enough to meet the continually evolving needs of the community and to accommodate changes in patterns of disease and injury. It must provide information that is timely enough to be acted upon. All of these considerations must be carefully balanced in order to design a system that can successfully meet identified needs without becoming excessively costly or burdensome.

Case Definitions

Practical epidemiology is heavily dependent on clear case definitions that include criteria for person, place, and time and that are potentially categorized by the degree of certainty regarding diagnosis as "suspected" or "confirmed" cases (3).

While high sensitivity and specificity are both desirable, generally one comes at the expense of the other. A balance must be struck between the desire for high sensitivity and level of effort required to track down false-positive cases. In addition, case definitions evolve over time. During periods of outbreaks, cases epidemiologically linked to the outbreak cases may be accepted as cases, whereas in non-epidemic periods, serologic or other more specific information may be required. Similarly, when active surveillance is used, such as in measles control programs, numbers of cases identified tend to rise.

As our understanding of a disease and its associated laboratory testing improves, alterations in case definitions often lead to changes in sensitivity and specificity. As new systems complement old ones (e.g., as a morbidity system supplements a mortality system for injury surveillance), the reported frequency and patterns of conditions change. These changes must be taken into account in analysis and interpretation of secular trends in the frequency of reporting. It is all too easy to define cases of various conditions with such different criteria that it is difficult to compare the essential descriptors of person, place, or time. For example, in surveillance of diabetes, one could determine the frequency of diabetes from surveys (self reports of diabetes), surveys using glucose determination (laboratory-confirmed), or from reviews of ambulatory or hospital records (physician-diagnoses). Each method provides a different perspective on the problem. Self reports are subject

to vagaries of recall and variation in interpretation (patient may be under treatment, may have "a touch of diabetes" or prediabetes, or may have a history of gestational diabetes). Glucose determinations allow detection of previously undiagnosed diabetes. Medical records identify only patients currently receiving medical care.

Case definitions should be specified including criteria for person, place, time, clinical or laboratory diagnosis, and epidemiologic features.

Data Collection

Information on diseases, injuries, and risk factors can be obtained in many ways. Each mechanism has characteristics that must be balanced against the purpose of the system (see Chapter III). Timeliness is of the essence for frequently fatal conditions such as plague, rabies, or meningococcal meningitis. Notifiable-disease systems are most appropriate for such potentially catastrophic conditions with high and urgent preventability constraints. Conversely, detailed information on influenza strains or *Salmonella* serotypes must come from laboratory-based systems. Long-term mortality patterns are available through vital records systems.

Often, existing data sets can provide surveillance data. Such sets include vital records, administrative systems, and risk-factor or health-interview surveys. Among administrative systems, hospital-discharge data, medical-management-information and billing systems, police records for violence, and school records for disabilities or injuries among children can all provide needed data. In addition, with some modification, an existing system might provide needed data more economically or efficiently than a newly initiated system.

Existing registries or surveys may collect information on defined populations. To the extent that the condition of interest is uniformly distributed, the population under study is reasonably representative, and the information collected is available on a timely basis, such systems can be valuable data sources. Although many registries are established for research purposes, they often provide valuable data for surveillance purposes. In particular, cancer registries have been widely used (*4*).

Sentinel providers can also constitute a network for collecting data on common conditions, such as influenza; more specialized providers can provide data on less common conditions, e.g., ophthalmologists who provide information on treatment of patients for diabetic retinopathy.

Standardization

Data-collection instruments should use generally recognized and, where suitable, computerized formats for each data element to facilitate analysis and comparison with data collected in other systems, e.g., census and other surveillance data. Careful consideration should be given to using identifiers. Although additional assurances of confidentiality and privacy considerations will be required, the ability to link data to other systems, such as through the National Death Index, may enhance the value of the system.

Active and passive systems

Primary surveillance-data-collection systems have traditionally been classified as passive or active. For example, most routine notifiable-disease surveillance relies on passive reporting. On the basis of a published list of conditions, health-care providers report notifiable diseases on a case-by-case basis to the local health department. This passive system has the advantage of being simple and not burdensome to the health department, but it is limited by variability and incompleteness in reporting. Although the completeness of reporting may be augmented by efforts to publicize the importance of reporting and by continued feedback to communications media representatives, passive reporting systems may still not be representative and they may fail to identify outbreaks. To obviate these problems, more active systems are often used for conditions of particular importance. These systems involve regular outreach to potential reporters to stimulate the reporting of specific diseases or injuries. Active systems can validate the representativeness of passive reports, assure more complete reporting of conditions, or be used in conjunction with specific epidemiologic investigations. Since resources are often limited, active systems are often used for brief periods for discrete purposes such as during the measles elimination efforts.

Limited surveillance systems

Some surveillance efforts may not require ongoing systems. Surveillance to deal with specific problems may be needed to address problems for which all cases must be identified in order to assess the level of risk. Such programs can be conducted to resolve specific problems and then be terminated (5). Similarly, for logistic and economic reasons, it may not be feasible to mount a surveillance system across large geographic areas, and representative populations may need to be selected. Sentinel providers can also provide information on common conditions or conditions of particular interest to them.

Field testing

The careful development and field testing of surveillance systems and procedures is important to facilitate the implementation of feasible systems and to avoid making changes as systems are implemented on a broad scale. The frustration engendered by a new and poorly executed system may undermine efforts to improve or use existing systems for the same or other conditions. As new surveillance systems or new instruments and procedures are developed, field tests of their feasibility and acceptability are appropriate. These field-test projects can demonstrate how readily the information can be obtained and can detect difficulties in data-collection procedures or in the content of specific questions. Analyses of this test information may also identify problems with the information collected. Model surveillance systems may facilitate the examination and comparison of a variety of approaches that would not be feasible on too large a scale and may identify methods suitable for other conditions or other settings.

The data to be collected by a surveillance system, the data sources and collection methods, and the procedures for handling the information should be developed and tested.

Data Analysis

A determination of the appropriate analytic approach to data should be an integral part of the planning of any surveillance system. The data needed to address the salient questions must be assessed to assure that the data source or collection process is adequate. Analyses may prove to be as simple as an ongoing review of all cases of rare but potentially devastating illnesses, such as plague. For most

conditions, however, an assessment of the crude number of cases and rates is followed by a description of the population in which the condition occurs (person), where the condition occurs (place), and the period over which the condition occurs (time). These basic analyses require decisions as to the kind of information that needs to be collected. The level of detail required varies substantially from condition to condition. For instance, one may need more detailed information regarding the population that is not receiving prenatal care than on the one that is exposed to meningococcal disease, because the nature of the intervention for the former is likely to be more complex and require an understanding of socioeconomic factors. Similarly, how one will collect data on geographic areas may depend on whether the data will be examined at the county, state, or census-tract level.

Most contemporary surveillance systems are maintained electronically. The types of analyses to be performed and the size of the data bases should suggest the type of hardware and software needed (see Chapter XI). As personal computers become more powerful, the capacity of data-storage devices continues to grow, and data-sharing systems such as local- and wide-area networks become more widely available, more surveillance systems can be operated on personal computers. Software to meet most basic analytic needs for surveillance, including mapping and graphing, is now widely available. The analytic approach often suggests a basic set of analyses that are performed on a regular basis. These analyses can be designed early in the development of the system and incorporated into an automated system, which can then be run by support personnel.

The adequacy of the data system and processing mechanisms should be assured.

Interpretation and Dissemination

Data must be analyzed and presented in a compelling manner so that decision makers at all levels can readily see and understand the implications of the information. Knowledge of the characteristics of the audiences for the information and how they might use it may dictate any of a variety of communications systems. Routine, public access to the data--consistent with privacy constraints--should be planned for and provided. This access can be facilitated with various electronic media, ranging from

systems with structured-analysis features suitable for general users to files of raw data for persons who can do special or more detailed analyses themselves.

The primary users of surveillance information, however, are public health professionals and health-care providers. Information directed primarily to those individuals should include the analyses and interpretation of surveillance results, along with recommendations that stem from the surveillance data. Graphs and maps should be used liberally to facilitate rapid review and comprehension of the data. Communications media represent a valuable secondary audience that can be used to amplify the messages from surveillance information. The media play an important role in presenting and reinforcing health messages. Innovative methods for presenting information capitalizing on current audiovisual technology should be explored (see Chapter VII).

Evaluation

Planning, like surveillance itself, is an iterative process requiring the regular reassessment of objectives and methods (see Chapter VIII). The fundamental question to be answered in evaluation is whether the purposes of the surveillance system have been met. Did the system generate needed answers to problems? Was the information timely? Was it useful for planners, researchers, health-care providers, and public health professionals? How was the information used? Was it indeed worth the effort? Would those who participated in the system wish to (be willing to) continue to do it? What could be done to enhance the attributes of the system (timeliness, simplicity, flexibility, acceptability, sensitivity, predictive-value positive, and representativeness)?

Answers to these questions will direct subsequent efforts to revise the system. Changes might be minor (e.g., the addition of data elements to existing forms), or major (e.g., the need to obtain information from entirely different data sources). For example, a system to determine utilization of mammography might be based on administrative billing systems. Yet, problems with reports of multiple mammography examinations for the same individual might require the addition of unique patient identifiers or the addition of questions on mammography use from self reports on health-interview surveys. If access emerges as a critical factor in mammography

utilization, then ongoing monitoring of the quantity and location of mammography facilities or monitoring for appropriate insurance coverage for mammography might be indicated.

Periodic rigorous evaluation assures that surveillance systems remain vibrant. Systems that assess problems whose only interest is historical should be discontinued or simplified to reduce the reporting burden. Contemporary systems should take advantage of the emergence of new technology for information collection, analysis, and dissemination. They should capitalize on new information systems. For example, sentinel surveillance systems have become more flexible to allow the inclusion of an array of topics. Electronic medical records and standardized clinical data bases all provide opportunities to obtain data that have been burdensome or difficult to secure (*6*). These information sources may also provide data in a more timely fashion and may allow individuals to be tracked, an option that would be virtually impossible without such electronic systems.

INVOLVEMENT OF INTERESTED PARTIES IN SURVEILLANCE

Virtually all surveillance systems involve networks of organizations and individuals. Surveillance of notifiable disease relies on health-care providers including clinicians, hospitals, and laboratories to report to local health departments, who have the initial responsibility for responding to reports and amassing data. In many states, epidemiologists in the state health departments are responsible for surveillance and control of notifiable diseases in their states. In larger states, other organizational units--such as those dealing with sexually transmitted disease, immunization, or tuberculosis control--often have primary responsibility for surveillance and control of specific diseases or injuries. The state epidemiologist is responsible for the ongoing quality control, collection, analysis, interpretation, dissemination, and use of notifiable-disease data within that state. Data are subsequently forwarded each week to the national level where they are again analyzed, interpreted, and disseminated.

Programs for injuries and chronic and environmental diseases also may have complex organizational structures and may involve a wide array of external professional and voluntary interest groups whose needs must be addressed. Some basic surveillance

information can be gleaned from such ongoing information systems as vital records, hospitalization programs, and registries. Although some of these conditions are part of state notifiable-disease lists, many require surveillance systems to be established in unique places (e.g., rehabilitation units and emergency medical services for spinal-cord injuries or radiology centers for mammography). The support and interest of these groups of constituents are valuable in establishing the systems; these groups can provide key input regarding purposes of systems and users of systems, as well as assistance in developing the systems themselves.

The complex relationships among these organizational units and their constituents requires open communication to establish priorities and methods consistent with the needs and resources of each group. The conflicting desire for more detailed information must be balanced against the associated burden and cost, as well as against the utility of collecting extensive amounts of data. For example, electronic systems that may facilitate higher quality, more complete, and more timely data also involve the commitment of equipment, training, and changes in day-to-day activities that may permeate all levels of the system. One must understand the needs of each recipient group for the information and assess and assure their commitment to the system. It is also critical to be attentive to how components of the system can best be integrated into the overall system in terms of day-to-day operations.

The Council of State and Territorial Epidemiologists, an affiliate of the Association of State and Territorial Health Officials, has the authority in the United States to recommend which health conditions should be notifiable. After this list has been agreed upon, it is then up to each state to determine whether and how the conditions should be made reportable. Although most states report all those conditions considered to be nationally notifiable, a wide range of conditions are reportable in only a few states (*3*). States may exercise their authority through regulations, boards of health, or legislative procedures. The diversity of these methods is described more fully in Chapter XII. Each of these mechanisms entails the involvement of groups with an array of medical, administrative, public health, and policy interests.

The success of surveillance depends heavily on the quality of the information entered into the system and on the value of the information to its intended users. A clear

understanding of how policy makers, voluntary and professional groups, researchers, and others might use surveillance data is valuable in garnering the support of these audiences for the surveillance system.

REFERENCES

1. Healthy People 2000. National health promotion and disease prevention objectives. DHHS Pub. No. (PHS) 91-50212. Washington, D.C.: U.S. Department of Health and Human Services, Public Health Service, 1991.

2. Centers for Disease Control. Consensus set of health status indicators for the general assessment of community health status--United States. *MMWR* 1991;40:449-51.

3. Chorba TL, Berkelman RL, Saffod SK, Gibbs NP, Hull HF. Mandatory reporting of infectious diseases by clinicians. *JAMA* 1989;262:3018-26.

4. American Cancer Society. Cancer facts and figures--1991. Atlanta, Georgia: American Cancer Society, 1991.

5. Teutsch SM, Herman WH, Dwyer DM, Lane JM. Mortality among diabetic patients using continuous subcutaneous insulin infusion pumps. *N Engl J Med* 1984;310:361-8.

6. Ellwood PM. Outcomes management. A technology of patient experience. *N Engl J Med* 1988;318:1549-56.

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Chapter III

Sources of Routinely Collected Data for Surveillance

Nancy E. Stroup

Matthew M. Zack

Melinda Wharton

"The real voyage of discovery consists not in seeing new landscapes but in having new eyes."

Marcel Proust

INTRODUCTION

This chapter reviews sources of routinely collected data that can be used for public health surveillance. In many instances, these sources will provide sufficient information so that active case-finding for the health event of interest many not be necessary. In other instances, analysis of routinely collected data, in conjunction

with active case-finding, will provide the basis for a comprehensive assessment of the public health impact of a particular health event.

For infectious diseases, surveillance activities have traditionally relied on "notifiable" disease reporting systems based on legally mandated reporting of cases to health officials. Depending on characteristics of the reporting system and of the specific health event, these systems can provide timely information that is particularly useful for monitoring short-term trends and for detecting outbreaks or epidemics of disease. While prevention and control of infectious diseases remains a mainstay of public health practice, there is increasing emphasis on monitoring the public health impact of non-infectious or chronic diseases and injuries, as well as risk factors for these conditions, including behavioral risk factors, demographic characteristics, and potential exposure to toxic agents. With the expansion in the number and type of health events under surveillance, the use of existing data sources, such as vital statistics and more recently hospital discharge data, has expanded; and new data sources, such as behavioral risk factor surveys, have been developed.

This chapter describes characteristics of six types of health information systems in which data are collected routinely and are generally available for analysis. The six are notifiable disease and related reporting systems, vital statistics, sentinel surveillance, registries, health surveys, and administrative data collection systems. As more sources of health information become available, effective surveillance for a specific health event, whether infectious or non-infectious, will rely on analysis and synthesis of information from a variety of sources, each of which has different strengths and limitations. In many instances, these sources will provide sufficient information so that active case-finding or other surveillance-related activities may not be necessary. In other instances, analysis of routinely collected data, in conjunction with other activities, will provide the basis for a comprehensive assessment of the public health impact of a particular health event. For cervical cancer, for instance, surveillance activities could include the following: comprehensive assessment of cancer incidence data and cancer mortality data; reports of cervical cytology and genital infections by laboratories; reports of pap smear histories, smoking patterns, genital infections and safe sex practices from health surveys; review of hospital-discharge data to monitor surgical treatment for advanced disease; and information from a variety of sources on attitudes, payment strategies,

and other barriers or inducements that could influence the prevention, early detection, and treatment of cervical cancer. The selection and appropriate use of data from these sources would depend primarily on the nature and scope of activities to be monitored as part of a cervical cancer control program.

Depending on the health event of interest, special short-term or demonstration projects can also provide information that is very useful for surveillance or other prevention-related activities. This chapter, however, focuses on sources of data in which information on a wide range of health events is collected on a routine, ongoing basis and is generally available for analysis.

The examples provided in this chapter are meant to be illustrative rather than exhaustive. Many examples are research- rather than surveillance-related, but they do highlight potential uses of these data sources for surveillance and related activities. The background information provided on the methods used to collect different types of data serves, however, as a starting point for a more detailed assessment of the strengths and limitations of these data systems for surveillance of a particular health event. The sources of data mentioned in this chapter are listed separately in Appendix A.

Information on the availability of routinely collected health and population data are available from a variety of sources. Federal agencies that provide data in the United States include the following organizations:

- the Centers for Disease Control (CDC), including the National Center for Health Statistics (NCHS);
- the National Institute of Health (NIH), including the National Cancer Institute (NCI), the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Drug Abuse (NIDA),
- the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute for Mental Health (NIMH);
- the Food and Drug Administration (FDA);
- the Agency for Health Care Planning and Research (AHCPR);
- the Indian Health Service (IHS);
- the Health Care Financing Administration (HCFA);

- the National Highway Traffic Administration (NHTA);
- the Consumer Product Safety Commission (CPSC); and
- the Bureau of the Census

State health departments also routinely collect health information, some of which is not available from federal sources; and private organizations (e.g., the Public Health Foundation and the National Association of Health Data Organizations) either have health information or maintain inventories of information that can be obtained from other sources.

Information is available in other countries from similar national or local agencies (*1-4*). The United Nations and the World Health Organization (WHO) routinely publish population estimates and summary information on mortality and natality in member countries (*5-6*). Health and demographic information is also available from regional offices such as WHO/Europe (*7*).

NOTIFIABLE DISEASE AND RELATED REPORTING MECHANISMS

Overview

Reporting on notifiable diseases at the national level originated in the United States in 1878, when Congress authorized the United States Public Health Service (PHS) to collect reports on morbidity from cholera, smallpox, plague, and yellow fever, each of which was controlled through quarantine measures (*8,9*). Although initially focused on foreign ports, authority for weekly reporting was expanded in 1893 to include states and municipal authorities (*9*). To increase uniformity, the Surgeon General was authorized in 1902 to provide forms for the collection, completion, and publication of reports at the national level. Weekly telegraphic reporting was recommended for a few diseases in 1903, and by 1928, all states, the District of Columbia, Hawaii, and Puerto Rico were participating in national reporting of specified conditions (*8*). Compulsory notification for selected infectious diseases was also instituted in many other countries in the late 1800s, including Japan (1880), Scotland (1887), Italy (1888), England and Wales (1889), and Northern Ireland (1899) (*2,3,10*).

The list of diseases for which notification is recommended has changed over time, and, although there is overlap, the lists vary from jurisdiction to jurisdiction. In the

United States, for instance, 47 infectious diseases were considered notifiable at the national level in 1989 and were reported to CDC through the National Notifiable Disease Surveillance System (NNDSS) (*11*). In at least one state, however, reporting was required for over 160 infectious diseases or related conditions, 90 occupational diseases, 23 other environmental diseases, 29 congenital or related conditions, and six diseases of unknown cause. With the addition of Lyme disease and *Hemophilus* influenza in 1991, 49 infectious diseases are currently notifiable at the national level in the United States (*12*). In recent years, lists of notifiable diseases in other countries included 66 diseases in Italy (19 with rapid reporting procedures), 32 in Scotland and in Japan, 29 in England and Wales, and 26 in Northern Ireland (*2,3,10*). Procedures for modifying the list of notifiable diseases also vary from country to country. In the United States, reporting for notifiable diseases is mandated at the state level and the Council of State and Territorial Epidemiologists (CSTE), a consortium of epidemiologists from all state and territorial health departments, recommends a list of conditions to be reported each week to CDC (*12*). National reporting is required for three quarantinable diseases--plague, cholera, and yellow fever. Cases of these three diseases are also reported to the WHO by member countries.

In the United States, occupational diseases or occupation-related conditions are considered notifiable in some states, but at present, occupation-related conditions are not reported nationally (*13,14*). In 1988, at least one occupation-related condition was considered reportable in 34 states or other jurisdictions. Lead poisoning, pesticide poisoning, and occupation-related lung diseases are among the occupation-related conditions that are reportable in many states.

In recent years, notifiable-disease-reporting mechanisms have been used in some localities to collect information on conditions that are not infectious, occupation-related, or vaccine-related. In the United States, spinal-cord injuries, elevated blood lead levels for children and for occupationally exposed workers, and Alzheimer's disease are among the conditions for which reporting is required in some localities, although national reporting is not recommended by CSTE (*15-17*).

Reporting in the United States for adverse events following vaccination or in association with the administration of drugs differs from other notifiable-disease

reporting procedures in that the former types of events are reported nationally rather than to state health departments. Since 1988, all health-care providers and vaccine manufacturers have been required to report certain suspected adverse events following specific vaccinations (*18*). The Vaccine Adverse Event Reporting System (VAERS) in which all reports of suspected adverse events following any vaccination are accepted, became operational in 1990.

Adverse drug reactions are reported in the United States to the FDA (*19,20*). Drug manufacturers are required to submit post-approval reports of adverse drug reactions as well as reports from ongoing clinical trials and selected reports from foreign sources. Reports submitted to manufacturers by providers are sent to the FDA, or providers and patients can submit reports directly. Nearly 60,000 reports were submitted in 1989. Many other countries have similar adverse-drug-reaction reporting systems, and about 23 of these report data to the WHO Collaborating Center for International Drug Monitoring (*21*). In England, active surveillance for adverse drug effects in relation to specific drugs can be monitored through the Prescription Event Monitoring System, which is funded through both public and private sources (*21,22*).

Data Collection, Transmission, and Dissemination

Although information on notifiable diseases is collated and published nationally, its primary purpose is to direct local prevention and control programs. In the United States, information is generally reported by clinicians to local or state health departments. State regulations governing notifiable disease reporting are often quite specific regarding timeliness of reporting. For conditions in which an immediate public health response is needed, notification by telephone is usually mandated, either immediately or within 24 hours of a suspected case. Other conditions are generally reported on a weekly basis after the diagnosis has been confirmed.

For conditions that are reported nationally in the United States through the NNDSS, a subset of information--including the age, gender, race, and date of occurrence (or report)--is sent weekly to CDC by state health departments or other jurisdictions in a standard format, either as individual case reports or aggregate reports. Personal identifiers are not included in the NNDSS. Since 1990, all reporting states and localities have transmitted information electronically to CDC through the National

Electronic Telecommunications System for Surveillance (NETSS) (*23*). National case counts for most notifiable diseases are published the week after they are reported to CDC in the *Morbidity and Mortality Weekly Report* (*MMWR*).

Most state health departments also disseminate surveillance data and other public health information to health-care providers through weekly or monthly newsletters. For some conditions, including measles, hepatitis, syphilis, and acquired immunodeficiency syndrome (AIDS), more detailed information on risk factors and other information needed for disease-control programs is also collected by state and local health departments and, in some instances, is sent to CDC. Information is also sent to CDC through NETSS for conditions such as spinal cord injuries, giardia infection, and Reye syndrome, that are not nationally notifiable but for which information is useful at the national level. Although their use in the United States is limited primarily to influenza surveillance, networks of sentinel health-care providers in many European countries report supplemental information on notifiable diseases to local and national health officials (see below).

Surveillance for zoonotic diseases also involves monitoring animal hosts that either transmit the disease directly to humans or are also susceptible to the disease. For various types of encephalitis, for instance, detection of elevated virus titers in mosquitoes, wild birds, sentinel flocks of chickens, or horses can signal that an outbreak of human disease may occur so that mosquito-control activities can be initiated (*24*). Similarly, the potential for human cases of rabies is assessed through monitoring wild skunks, raccoons, bats, and other animal vectors (*25*); the potential for human plague is assessed by monitoring rodents in endemic areas (*26*); and Rocky Mountain spotted fever and Lyme disease are monitored through testing of ticks (*27,28*).

Although most cases of notifiable conditions are reported by clinicians, the role laboratories play in reporting notifiable conditions is becoming increasingly important. In the United States, many states have developed reporting requirements for laboratories and hospitals for conditions that need laboratory confirmation for diagnosis (*11,29,30*). In New York City, for instance, laboratories are required to report elevated blood-lead levels in children, and at least five states rely on laboratory reporting to identify workers with elevated levels of lead or other heavy

metals (*15*). Comprehensive, nationwide reporting by laboratories is not yet available in the United States, but in England, Wales, and Northern Ireland, nearly all microbiology laboratories voluntarily report positive identifications of selected conditions to the national Public Health Laboratory Service (PHLS) (*10*).

Strengths and Limitations

Although many diseases or conditions are considered notifiable, compliance is poor in most countries and sanctions are rarely enforced. As Sherman and Langmuir noted in 1952, "Our system of notification of individual case reports is a haphazard complex of interdependence, cooperation, and goodwill among physicians, nurses, and county and state health officers, school teachers, sanitarians, laboratory technicians, secretaries, and clerks. It is a rambling system with variations as numerous as the individual diseases for which reports are requested, and as numerous as the interests and individual traits of the administrative health officers, epidemiologists, and statisticians in [all] the ... States and the several federal agencies concerned with the data" (*31*). Indeed, it is remarkable--given the jerry-rigged nature of the system--that the information collected is at all useful.

Under-reporting is a consistent and well-characterized problem of notifiable-disease-reporting systems (see Chapter 12). In the United States, estimates of completeness of reporting range from 6% to 90% for many of the common notifiable diseases (*32*). Reporting is generally more complete for conditions such as plague and rabies that cause severe clinical illness with serious consequences. Among the many factors that contribute to incomplete reporting of notifiable conditions are lack of medical consultation for mild illnesses; concealment by patients or health-care providers of conditions that might cause social stigma; lack of awareness of reporting requirements; lack of interest by the medical community; incomplete etiologic definition of notifiable conditions; inadequate case definitions for surveillance purposes; variation in clinical expertise in diagnosing conditions in different areas; changes in procedures for verifying reports from providers; variation in the use of laboratory confirmation; variation in laboratory procedures; the effectiveness of control measures in effect; and priorities of health officials at local, state, and national levels (*9,30,33*). Similarly, increased concern can result in an increase in reported cases. Public health officials may actively solicit information if an

outbreak is suspected and case reports may increase in response to reports by the media.

The extent of under-reporting can vary by risk group. An evaluation of reporting for AIDS in Philadelphia found, for instance, that under-reporting was more prevalent for those who were employed in white-collar occupations and who had private health insurance (*34*). Similarly, a review of hospital-discharge data in South Carolina indicated that AIDS diagnoses were less likely to be reported for whites over 40 years of age (*35*).

Changes in case definitions and the extent to which laboratory confirmation is required for reporting can also affect reporting for notifiable conditions. In the United States, a 1984 survey of state epidemiologists found substantial variation in definitions used for communicable disease surveillance by state health departments. Since then, surveillance case definitions have been developed for many communicable diseases and occupational conditions, as well as for spinal-cord injuries (*14,17*). The degree to which standardized case definitions for notifiable-disease reporting have been adopted varies, but recent experience suggests that there will be more important changes in trends as they are more widely used. The 1987 revision of the surveillance case definition for AIDS resulted in an increase in the number of reported cases among heterosexual drug abusers (*36*). Changes in the surveillance case definition for congenital syphilis resulted in a 5-fold increase in cases in some reporting areas (*37,38*). Adoption of a uniform case definition for Lyme disease is probably reflected in the decrease in reported cases in the United States in 1990 (*39*).

The extent to which clinical reports are confirmed with laboratory findings can have a substantial impact on reporting rates. For instance, malaria was endemic in the southeastern United States in the 1930s. Epidemiologic studies in 1947 indicated that routine reporting of aggregate case counts based on clinical findings alone was not providing an accurate picture of current disease activity. When reporting of individual cases with laboratory confirmation was required, it became clear that endemic malaria had disappeared between 1935 and 1945, before malaria control programs based on drainage and indoor residential spraying of DDT were initiated (*40,41*). In recent years, the role of laboratories has been particularly important for surveillance of the numerous subtypes of *Salmonella*, legionellosis, nosocomial

infections, and detecting elevated blood-lead levels (*15,30,42*). Without laboratory-based surveillance, for instance, a large outbreak of drug-resistant *Salmonella newport* that originated from animals fed antimicrobials might not have been detected (*43*).

In spite of their limitations, surveillance systems based on reporting of notifiable conditions are a mainstay of public health surveillance. Unlike most other sources of routinely collected data, information from notifiable-disease systems is available quickly and from all jurisdictions. Knowledge of the specific characteristics of reporting for a particular condition is helpful in interpreting the findings. While long-term trends may be difficult to interpret without supplemental information, notifiable-disease systems can often detect outbreaks or other rapid changes in disease incidence in a timely manner so that control activities can be initiated. As appropriate, initial observations can be evaluated further with additional studies. Notifiable-disease systems can also detect changes in patterns of disease by demographic characteristics or risk groups. In the United States, for instance, human immunodeficiency syndrome (HIV) and AIDS surveillance systems have identified new risk groups including intravenous drug abusers and their mates and have highlighted the emerging problem of children who are born HIV-infected. Evaluation of surveillance information has also lead to changes in disease prevention and control strategies. On the basis of reports of measles among elementary school-, high school-, and college-age students, recommendations for measles vaccination in the United States were recently changed to include a two-dose schedule (*44*). Similarly, because strategies based on vaccination of high-risk groups have not been as effective as originally anticipated, recommendations for hepatitis B vaccination have recently been modified (*45*).

In the United States, reports of adverse drug reactions often result in labeling changes for new drugs (*19*). Drug withdrawals are infrequent, although two drugs (an antidepressant and a non-steroidal anti-inflammatory agent) have been withdrawn in recent years. Vaccine adverse-event-reporting systems are important for detecting potential problems following administration of vaccine, such as an increase in paralytic poliomyelitis among recently vaccinated children in the 1950s and the increase in Guillain-Barré syndrome following vaccination for swine influenza (*18,46,47*).

Notifiable-disease-reporting mechanisms have also been important for identifying unusual conditions that appear to be increasing and for obtaining a preliminary assessment of their public health impact. Among the more recent examples in the United States are AIDS, toxic-shock syndrome, legionellosis, Reye syndrome, and eosinophilia-myalgia syndrome (EMS). Following the initial report from a state health department, nationwide surveillance for EMS using a standard case definition was instituted within a few days, and, through additional studies, the putative agent was identified (*48*).

In the future, reporting of notifiable conditions may rely, in part, on computerized data bases developed for billing and other purposes. However, the utility of these systems is limited at present: first, because *International Classification of Disease (ICD)* codes are often not used to identify infectious agents on billing records and, second, because information in these large data bases is not available immediately (*49*) . In the near-term, improvements in notifiable-disease reporting in most areas are likely to be related to increased reliance on laboratory-based reporting and on the use of sentinel health-care providers or sentinel sites.

Vital Statistics

Overview

The systematic registration of vital events had its origins in the parish registers of 15th century Western Europe (*1*). One of these registers, the Bills of Mortality--a weekly tally begun in 1532 of the number of persons who died in London from plague and other causes, was used to study patterns of mortality by John Graunt, one of the first to use numerical methods to study disease (*50*).

Parish registers were superseded in the 19th century by civil registers kept for legal purposes. Registration of vital events usually remains the responsibility of local authorities, but the use of standard procedures for collecting, coding, and reporting vital events--first used systematically by William Farr in Great Britain the 1830s--allows information from different jurisdictions to be aggregated, summarized, and compared. Farr, the first medical statistician in the Office of the General Registrar of England and Wales, recognized the importance of determining death rates for different segments of the population using information collected systematically at the time of birth or death. In the first annual report to the Registrar General in 1839, Farr discussed the principles that should govern a statistical classification of

disease and urged the adoption of a uniform system (*2,51*). Nomenclature and statistical classification systems initially developed by Farr and by Marc d'Espine form the basis of the international disease classification system used today.

Information collected at the time of birth and death is one of the cornerstones of surveillance in both developed and developing countries. Today, about 80 countries or areas report statistics on vital events to WHO, which are coded and tabulated according to the ninth revision of the *International Classification of Diseases (ICD-9)* and represent about 35% of the deaths that occur each year worldwide (ICD-9) (*52*).

Vital statistics are an important source of information for surveillance because they are the only health-related data available in many countries in a standard format (*52*). Also, they are often the only source of health information available for the entire population and the only source available for estimating rates for small geographic areas. Vital statistics have been used to:

- monitor long-term trends (*53-55*);
- identify differences in health status within racial or other subgroups of the population (*56,57*);
- assess differences by geographic area (*58-62*) or occupation (*50,63*);
- monitor deaths that are generally considered preventable (*64-67*);
- generate hypotheses regarding possible causes or correlates of disease (*68,69*);
- conduct health-planning activities (*70,71*); and
- monitor progress toward achieving improved health of the population (*7,72,73*).

The usefulness of vital statistics for surveillance of a particular health event depends on the characteristics of that health event, as well as on the procedures used to collect, code, and summarize relevant information. In general, vital statistics will be more useful for conditions that can be ascertained easily at the time of birth or death. Likewise, mortality rates derived from death-certificate data will more closely approximate true incidence for conditions with a short clinical course that are easy to diagnose, are easily identified as initiating a chain of events leading to death, and are usually fatal (*52,74-76*). Although birth and death certificates are

filed shortly after the event occurs, the process of producing final vital statistics at a national level from these data can take several years. Background information on the process of producing vital statistics, outlined here for the United States, is intended to highlight some of the strengths and limitations of vital statistics for public health surveillance.

Birth and Death Certification

In the United States, responsibility for the registration of birth, death, and fetal death is vested in the individual states and certain independent registration areas (e.g., New York City) (77). States are encouraged to adopt standard certificates similar to the "model" certificate developed by NCHS in collaboration with other groups although some states modify the "model" certificate to comply with state laws or regulations or to meet their own information needs (*78*). Certificates are usually filed with a registrar within 24 hours in the jurisdiction in which the event occurred. For birth certificates, the physician or attendant certifies the date, time, and place of birth and other hospital personnel usually obtain information on the remaining items (*79*). The 1989 model birth certificate includes additional information on perinatal risk factors, such as maternal illnesses and complications of labor and delivery, that will help to improve surveillance for perinatal events (*77,80,81*).

For death certificates, the funeral director is usually responsible for including all personal information about the decedent and for assuring that medical information is provided by the physician who certifies the death (*82*). Information provided by the physician includes the cause of death (immediate, "as a consequence of," and underlying causes), the interval between onset of the condition and death, other important medical conditions, the manner of death (e.g., "accident", homicide, or suicide), whether an autopsy was performed, and whether the medical examiner or coroner was notified of the death (*78*). In most cases, information from autopsies and reports from medical examiners or coroners are not available at the time the death certificate is filed, although the certificate can be amended when this information becomes available. Local registrars assure that all vital events that occurred in the jurisdiction are registered and that required information is provided on certificates before they are sent to the state registrar. Both state and local registrars can ask

physicians or funeral directors for additional information if the certificate is considered incomplete. State registrars are usually responsible for numbering, indexing, and binding certificates for permanent safekeeping. Also, state registrars usually forward certificates for deaths of non-residents to their states of residence.

Coding, Classification, and Calculation of Rates

To calculate national death rates, the numbers of live births is used as denominators for infant and maternal mortality rates, and estimates of the population, usually derived from the censuses are used as the denominators for other death rates (*51,83*). Conditions are classified and rates are calculated according to the ninth revision of the ICD-9 developed through the WHO and in use since 1979. The ICD-9 includes a tabular list of categories and conditions with code numbers, definitions of key terms (e.g., underlying cause of death, low birth weight), rules for selecting the underlying cause of death, and lists of conditions for statistical summaries.

Age-standardized rates are usually calculated when summary rates are compared in order to control for the effects of differences in age structure between compared populations (see Chapter V). In the United States, the age distribution of the U.S. population in 1940 is usually used as the standard for vital statistics (*84,85*). Other age distributions--such as the world standard population and the European standard population--are often used for international comparisons (See Chapter 5) (*5*).

In the United States, about half the states submit both medical and demographic data from certificates to NCHS in computerized form (*84,85*). Final national mortality and natality data are generally not available from NCHS for at least 20 months after the close of the calendar year, although a written report based on a 10% sample of deaths is available within a few months. Final data are often available more quickly from individual states. Similarly, final mortality and natality data are generally available, with indices of quality and completeness, within 2-3 years for countries that routinely report data to WHO (*5*)

Comparability and Quality Control

The quality of vital-statistics information depends on various factors, including the completeness of registration, the relevance of the categories used for diseases,

injuries, and other conditions; the accuracy of demographic and medical data provided on certificates; and the translation of this information into computerized data (including its categorization and coding). When rates are calculated, estimates are also affected by the accuracy of the population estimates or other estimates used for denominators. Differences in access to medical care, diagnostic practices, and interpretation of coding rules will also affect comparability.

Registration and medical certification of deaths is virtually complete in most developed countries (*86*). Population estimates used to calculate rates in developed countries are usually derived from censuses conducted at regular intervals (usually every 10 years), in which the total population is enumerated (*6*). Inter-censal estimates are derived by adjusting census figures for birth, death, and migration patterns in the intervening years. In some countries, population estimates are derived from surveys or from continuous population registers. Through the United Nations, population estimates, including indices of the quality and completeness of these estimates, are available for about 220 countries or areas of the world.

Population under-counts can have a measurable impact on mortality rates; rates will be inflated, for instance, if population estimates used for the denominator are too small. In the United States, for instance, the 1980 age-adjusted death rate (1940 age standard) from all causes would decrease by 1.1% if the population estimate from the 1980 census was adjusted for under-counts (*85*). Effects are even greater for subgroups of the population. For homicides and deaths resulting from legal intervention in the United States in 1980, adjustment for census under-count would change the ratio of death rates for black to white men ages 35-39 years from 7.3 to 6.2--a decrease of nearly 18%.

When cause-specific rates are compared, both the extent to which information on birth and death certificates is reported completely and accurately and the precision of population estimates will affect the magnitude and the comparability of rates. The impact of these factors is likely to be of less importance for aggregated cause-of-death categories. Nonetheless, comparisons between different geographic areas or different population subgroups should be interpreted cautiously.

Mortality from "signs, symptoms, and ill-defined conditions" is often used as an indicator of the care and consideration given by medical certifiers to completing certificates (ICD-9 780-799). In recent years, countries in which "signs, symptoms, and ill-defined conditions" were coded as the underlying cause of death ranged from less than 1% for Australia, Czechoslovakia, Finland, Hungary, New Zealand, Sweden, and the United Kingdom to 5%-10% for Belgium, France, Greece, Israel, Poland, Portugal, and Yugoslavia (*86*). In the United States, 1.4% of deaths in 1988 were coded as "signs, symptoms, and ill-defined conditions," with a range among the states of 0.4% to 4.1% (*85*).

The impact of these factors on international comparisons has been assessed for cancer and for respiratory disease (*76,76*). Within the United States, differences in completeness and accuracy of certificates have also been noted within racial and ethnic subgroups (*87*).

A variety of approaches will facilitate improvement in the quality of information on birth and death certificates. These include providing physicians and funeral directors clearer instructions for completing the certificates and more effective training regarding the importance of vital statistics and the importance of following recommended procedures for completing both the medical and demographic sections of certificates (*77,88,89*). State and local registrars can increase the extent to which they contact physicians and funeral directors when information provided on certificates is not considered complete and can facilitate amendment of certificates when additional information is available from autopsies or other sources.

In spite of limitations, birth and death certificates are an important source of information for cost-efficient surveillance of a wide range of health events at local, national, and international levels. Although differences in rates may not always reflect actual differences in disease and injury burden, routine analysis of information obtained at the time of birth and death can highlight areas in which further investigation of a health event is warranted.

Examples of Surveillance Systems Based on Vital Statistics and Related Data

Weekly reports. As part of the national influenza surveillance effort in the United States, vital registrars in 121 U.S. cities report to CDC each week the number of deaths that have occurred in those jurisdictions (*90*). This 121-City Surveillance System has been operational since 1952. The total number of deaths and the number attributed to pneumonia and influenza by age group are reported, and the total number of deaths by age, city, and region are published within a week of receipt in the *MMWR*. About one-third of the deaths that occur in the United States are reported through the 121-City Surveillance System, and most are reported to CDC within 2-3 weeks of occurrence. Mortality rates based on the 121-City system cannot be directly compared with rates derived from final mortality data. However, the 121-City system does detect short-term increases in deaths from influenza and pneumonia in a timely manner as needed for public health intervention. Increases in mortality from other causes--including mortality during heat waves and increased deaths from pneumonia and influenza among young men (later linked to AIDS)-- have also been detected using the 121-City system.

Monthly or quarterly reports. In the United States, final mortality data are generally not available for nearly 2 years, although provisional estimates are published by NCHS within 3-4 months in the *Monthly Vital Statistics Report (MVSR)*. The Current Mortality Sample, a 10% systematic sample of certificates, is sent to NCHS each month by state registrars. On the basis of this sample, provisional estimates of total monthly mortality by age, race (white, black, other), gender, state, and region are published about 3 months later, and provisional rates from 72 selected causes are published the following month. Provisional rates are published by place of occurrence while final rates are published by place of residence. For the Mortality Surveillance System (MSS), time-series regression models are fitted using monthly data, and charts displaying monthly estimates and the fitted model for specific conditions are published each month in the *MVSR*.

The Current Mortality Sample and the MSS are very useful for monitoring overall trends in total mortality and for monitoring trends in relatively common causes of death that are increasing or decreasing over time (e.g., heart disease, homicide, lung cancer, HIV/AIDS). Although estimates are adjusted for under-reporting, monthly changes in mortality for conditions for which supplemental information is often needed should be interpreted with caution.

Infant mortality and other adverse reproductive outcomes. Linking information from death certificates for infants with information on maternal characteristics and other information from birth certificates is useful for assessing potentially preventable mortality by geographic area and within subgroups of the population. In England and Wales, birth and death records for infants were linked for infants born in 1949-1950 and again for infants who died from April 1964 to March 1965 (*2*). All births and deaths of infants have been linked routinely in England and Wales since 1975. In the United States, birth and death certificates have been linked for infants born from 1983 to 1986 (*91*). Approximately 40,000 infants die each year in the United States, and at least 98% of the death certificates for infants have been linked to birth certificates in these years. This information is also useful for health planning and for targeting services, since U.S. infant mortality rates vary considerably by geographic area and within demographic subgroups.

Information on birth certificates has also been used to identify high-risk mothers who need supportive services for infant care. In Michigan, for instance, information on birth certificates is transmitted electronically from hospitals to the state health department (*91*). Key information is then sent to county health departments so that public health nurses can be assigned to areas with the greatest need.

Occupational mortality. William Farr was the first to evaluate systematically the associations between occupation and cause of death (*50*). The *Decennial Supplement on Occupational Mortality for England and Wales* has been published approximately every 10 years since 1855 (*1,2*). Cause-specific rates and ratios by occupation, adjusted for social class, are estimated using information derived from death certificates and from the decennial census (*63*). Although estimates are affected by sources of error in both data sets, occupation-specific mortality rates are useful for identifying occupations for which more detailed studies may be warranted (*92*).

In the United States, usual occupation (even if retired) and industry are included on the standard death certificate (*85*). The states are not required to report this information to NCHS, but if it is submitted, it has been included since 1985 in the computerized final mortality files using the *Standard Occupational Classification* and *Standard Industry Classification* systems. In 1987, 14 states reported information on occupation and industry to NCHS and in 1989, occupation and industry during the last

year for both mother and father were added to the standard certificate for deaths of fetuses (77). Through the National Traumatic Occupational Fatalities (NTOF) surveillance system, CDC's National Institute for Occupational Safety and Health (NIOSH) obtains additional information for work-related traumatic deaths that is included on death certificates but that is not coded and computerized routinely in all states (*93*). State- and industry-specific rates are derived using estimates of the employed population from the Bureau of Labor Statistics. Analyses from the NTOF suggest that traumatic occupational fatality rates decreased in the United States between 1980 and 1985, although, in some instances, large differences were found in fatality rates by gender and by state within the same industry.

Supplemental information from other sources. Other sources of information may be available on the circumstances leading to death. In the United States, medical examiners and coroners are responsible for investigating sudden and unexpected deaths--homicides, suicides, deaths from unintentional injuries, and unanticipated deaths from natural causes--which account for about 20% of all deaths each year. Reports from medical examiners and coroners include detailed information on the circumstances surrounding death, results of laboratory analyses for alcohol and drugs, and other relevant information. These reports have been used, for instance, to investigate deaths associated with horseback riding, drug abuse, hurricanes, earthquakes, and heat waves (*94-98*). In 1990, through the Medical Examiner/Coroner Information Sharing Program, data from investigations of death were reported to CDC's National Center for Environmental Health (NCEH) in a computerized format from nine state and eight county medical-examiners' offices (R.G. Parrish, personal communication).

Additional information on fatalities is often available from other sources. In the United States, for instance, the Fatal Accident Reporting System (FARS) from the NHTA has been used to investigate the association between use of child restraints and motor-vehicle-related crashes (*99*) and the association between premature mortality and alcohol-related traffic crashes (*100*). The relationship between homicide and the prevalence of hand-gun ownership in the United States and Canada has been investigated using data from uniform crime-reporting registries of all homicides and aggravated assaults maintained by the Federal Bureau of Investigation in the United States and the Centre for Justice Statistics in Canada (*101*). Other sources--such as police,

ambulance, and fire reports--may also include information that is useful for surveillance of particular health events.

SENTINEL SURVEILLANCE

Overview

The term "sentinel surveillance" encompasses a wide range of activities focused on the monitoring of key health indicators in the general population or in special populations. Characteristics of these activities vary considerably, but, in general, their primary intent is to obtain timely information needed for public health or medical action in a relatively inexpensive manner rather than to derive precise estimates of prevalence or incidence in the general population. The term "sentinel" has been applied to key health events that may serve as an early warning or represent the tip of the iceberg; to clinics or other sites where health events are monitored; or to networks of health-care providers who agree to report information on one or more health events. A sentinel health event, according to Rutstein, is a "preventable disease, disability, or untimely death whose occurrence serves as a warning signal that the quality of preventative and/or therapeutic medical care may need to be improved" (*102*). Sentinel surveillance, according to Woodhall, represents "an attempt to find a system that would provide a measure of disease incidence in a country in the absence of good nation-wide institution-based surveillance without having to resort to large expensive surveys" (*103*). Sentinel surveillance systems are not limited to developing countries. In Europe, routine morbidity surveillance is often conducted by networks of primary care providers who routinely report information on conditions that are relatively common in general practice (*104,105*).

Sentinel Health Events

Sentinel health events are monitored for many different public health programs. In the United States, sentinel surveillance for maternal mortality, first used in New York City in the 1930s, was associated with a rapid decline in mortality associated with childbirth. For each case, medical panels reviewed pertinent records to identify missed opportunities that might have prevented a presumably unnecessary death. Similar methods have been used to monitor deaths of infants. In Massachusetts, review of records indicated that, in 1967-1968, about one-third of the deaths of infants

could have been prevented by medical intervention (*102*). Monitoring preventable conditions can also highlight more general problems. For instance, a review of deaths among infants from Rh hemolytic disease, about 90% of which are considered preventable, indicated that mothers of many affected infants did not have medical insurance coverage (*106*). Quality of care has also been evaluated using conditions for which death or disability could have been prevented including evaluation of hospital-based mortality rates after adjustment for certain patient characteristics (*107-109*).

Sentinel surveillance activities have been particularly useful for identifying health events that may be related to occupational exposures. Lists of occupation-related health events have been developed, some of which (e.g., mesothelioma and angiosarcoma of the liver) are specifically tied to environmental or occupation exposure, and some of which (e.g., lung cancer and bladder cancer) have other risk factors as well (*102*). Mesothelioma, for instance, is a rare form of cancer specifically associated with exposure to asbestos that may identify the "tip of the iceberg" of asbestos-related disease in an industry in which workers develop more common conditions, such as lung cancer and chronic obstructive pulmonary disease.

In the United States, NIOSH has developed the Sentinel Event Notification System for Occupational Risks (SENSOR) program, which focuses on surveillance of specific occupational conditions by networks of sentinel providers (*110*). Target conditions monitored by at least one of the 10 states initially included in the program include silicosis, occupational asthma, pesticide poisoning, lead poisoning, and carpal-tunnel syndrome. When cases identified by sentinel providers, (usually physicians who practice occupational medicine) are found to be occupation-related, intervention activities are undertaken by state health departments in order to prevent additional cases. Although primarily used for case identification and follow-up, information derived from SENSOR projects may augment other sources of information on trends for occupation-related disorders.

Health indicators that are monitored in many different countries could also be considered sentinel health events. Infant-mortality rates, for instance, are used in both developing and developed countries as an indicator of the availability and the quality of medical care. In Europe and the United States, additional health

indicators are monitored routinely to assess the general health of the population. In Europe, 22 key health indicators have been monitored routinely since 1986 through WHO's Health for All activity in order to compare progress toward reducing preventable morbidity and mortality in participating countries (*7*). In the United States, specific goals and objectives for improving the nation's health are monitored using key health indicators. Goals and objectives initially developed for 1990 have been revised and expanded for the Year 2000 so that progress toward attainment of specific objectives can be monitored quantitatively (*73*). A total of 226 goals and objectives for the Year 2000 has been proposed for use in monitoring health status at the national level and a subset of 18 indicators has been selected for monitoring by all levels of government (*111*). Most of these 18 community-health-status indicators are based on vital statistics and data from the NNDSS.

Sentinel Sites

Sentinel hospitals, clinics, and counties can often provide timely information on a wide range of health conditions that is not available from other sources. Although information is generally not available for the entire population, sentinel systems in both developing and developed countries can provide sufficient information for making public health decisions and for detecting long-term trends. In developing countries, the WHO Expanded Project on Immunization uses sentinel hospitals and clinics in 25 target cities to monitor the impact of vaccination on the incidence of neonatal tetanus, poliomyelitis, diphtheria, measles, pertussis, and tuberculosis (*103*). After initial contact with many hospitals and clinics, officials choose sentinel sites that serve populations as similar as possible to the general population. In developed countries, sentinel providers, hospitals, and clinics are used to monitor conditions for which information is not otherwise available. Sentinel primary-care providers report information on conditions seen in ambulatory settings, while sentinel sites--such as drug, sexually transmitted disease, and maternal and child health clinics--monitor conditions in subgroups that may be more vulnerable than the general population.

Sentinel hospitals, clinics, and counties can also provide public health information that is not readily available from other sources. In the United States, for instance, viral hepatitis is a notifiable disease, but non-A non-B hepatitis (most of which is

hepatitis C) is under-reported, and not all of the detailed information on serology, demographics, and routes of transmission needed for monitoring is routinely available. To obtain such information, patients with hepatitis reported to four county health departments are interviewed, are tested serologically at regular intervals after the onset of illness, and are followed prospectively to determine whether they have acquired hepatitis B or hepatitis C-related chronic liver disease (*112,113*). Taken together, these sentinel counties are intended to be representative of the incidence and epidemiologic characteristics of hepatitis B in the United States. Findings from these sentinel counties have highlighted the increasing importance of parenteral drug use in the transmission of both hepatitis B and C.

Surveillance from sentinel sites is also used in the United States for surveillance of HIV infection (*114*). Since the epidemic of HIV comprises multiple sub-epidemics in different population groups and different geographic areas, progression of the epidemic can be monitored by targeting surveillance efforts directed at groups who are at increased risk of HIV infection. The use of standardized survey methods and serologic testing procedures facilitates comparison of findings from the different groups. Included in the HIV family of surveys are studies of groups that receive care through publicly-funded clinics--including those for tuberculosis, drug treatment, sexually transmitted disease, family planning, and prenatal care. Other sentinel groups in which HIV prevalence is monitored include hospital patients with diagnoses that are not likely to be associated with HIV infection, women at the time of childbirth, blood donors, military recruits, Job Corps applicants, university students, prisoners, migrant farm workers, and homeless persons. Findings from HIV sentinel surveillance systems have been used to monitor progression of the epidemic in vulnerable populations and to estimate prevalence in the community at large.

Sentinel Providers

Networks of sentinel general or family practitioners and other primary care providers are active in many European countries and in the United States, Canada, Israel, Australia, New Zealand, and other countries (*115-117*). Providers in some of these networks conduct independent research projects, but many of them--particularly in Europe and Australia--report surveillance data that are used by national health agencies. Primary-care practitioners can provide timely information for surveillance

because they generally provide the first professional judgment for medical problems that are seen in early stages. In most networks, primary-care physicians report a minimum amount of information, usually at weekly intervals, on a select group of health events that are relatively common in general practice. A wide range of health events are reported by these networks including the following: infectious diseases that are and are not notifiable in that country; conditions such as dementia, gastric ulcers, multiple sclerosis, acute pesticide poisoning, and drug abuse; and requests for services, such as mammography, cervical smears, and testing for HIV (*104*). Although most systems are based on reports by primary-care practitioners, the extent to which rates can be calculated that reflect morbidity in the general population is related in large part to the manner in which medicine is organized and practiced in that country. For instance, morbidity reporting by sentinel general practitioners would more closely approximate morbidity in the general population in countries with universal health-care coverage in which patients are assigned to the same provider or group of providers, in which specialists are seen only by referral, and in which sentinel providers are selected that serve populations that are demographically similar to the general population. None of the existing networks meet all of these criteria, and the most enduring networks are usually characterized by highly motivated volunteer providers who report information consistently over time. When the population from which patients is drawn cannot be characterized, the number of cases relative to the total number of patients seen or the number of reporting physicians is usually monitored. Regardless of the strengths and limitations of each network, most are able to provide preliminary descriptive information in a timely manner for health events seen in ambulatory-care settings for which information is not otherwise available.

A recent survey by Eurosentinel, a newly-formed consortium funded by the European Economic Community to coordinate activities of sentinel general-practitioner networks, found that, as of March 1990, there were at least 39 active networks in Europe (*104*). Among the more established networks are those in Great Britain, the Netherlands, Belgium, and France. Ten of these participated in joint data-collection efforts including weekly reporting of mumps, measles, and influenza-like illness, and studies of the use of selected laboratory tests in general practice and of requests for HIV-testing (*105,118*).

The oldest sentinel-provider network in Europe, the Weekly Returns Service, was organized by the Royal College of General Practitioners in Great Britain and has been in continuous operation since 1962 (*104*). In 1990, 242 volunteer general practitioners from 66 practices in Great Britain reported weekly incidence data for 44 conditions selected collaboratively by participating practitioners, epidemiologists, and health-service providers (*119*). These sentinel providers report conditions for about 1% of the population, and rates per 100,000 population can be calculated using information from patient lists. Reported conditions range from those with official notification procedures in Great Britain (e.g., measles and whooping cough) to conditions (e.g., multiple sclerosis, rheumatoid arthritis, thyrotoxicosis, and attempted suicide) for which less information is routinely available from outpatient settings (*104,119,120*). Information from the Weekly Returns Service has been particularly useful for monitoring trends in influenza and related illnesses in Great Britain.

The Surrey University Morbidity Network, also covering about 1% of the population of Great Britain, has been operational since 1974 (*104*). In 1990, 42 infectious and non-infectious conditions were monitored by 120 practices. One of the purposes of this network is to examine seasonal and other environmental influences on morbidity. Data have been collected and transmitted electronically since 1985, and participating physicians receive reports regularly.

A network of sentinel general practitioners has reported to the Netherlands Institute of Primary Health Care (NIVEL) since 1970 (*104,121,122*). The primary purpose of this network, which covers about 1% of the population, is to gather reliable epidemiologic data on health problems, as well as on actions taken by providers to address these problems. In 1990, 45 practices involving 63 general practitioners participated in the network. Information on 16 topics was reported weekly in 1988-1989, including requests for sterilization, referrals for speech therapy and echocardiography, and newly diagnosed cases of dementia. Reasonable estimates of morbidity are possible because access to medical specialists is available only by referral, a relatively well-defined population is served by each practice, and because practitioners, although volunteers, are chosen so that the distribution of their patients is as representative of the Dutch population as possible (*121*). Many descriptive studies have been published using information provided by the Dutch network (*121-123*).

The Belgian Sentinel Practice Network has been operated by the National Health Department since 1979 (*124-126*). Each year, about 1,500 general practitioners are contacted, about 10% of them usually agree to participate, and a final group is selected so that their patients are representative of the age and sex distribution of the general population. An estimated 1.3% of the population in Belgium were seen by sentinel practitioners (*104*). In 1990, measles, acute respiratory infections, new cases of cancer, suicide attempts, and requests for HIV tests were reported by the network, in addition to five officially notifiable diseases (gonorrhea, infectious hepatitis, meningitis, syphilis, and urethritis). Dissemination of the information is one of the strengths of the Belgian network. Bimonthly and annual reports are sent to participating practitioners, to the Ministry of Public Health, to medical and public health schools, to professional organizations, and to the press.

In France, networks of sentinel primary-care providers transmit and receive information on selected conditions using computer terminals and modems available nationally at low cost (*127*). Interactive electronic systems are used by the national French Communicable Diseases Computer Network (FDCN), as well as by local and regional networks in the cities of Toulouse and St. Etienne, and in the regions of Aquitaine, France-Sud, and Lyon (*104*). The largest network, the FDCN, has been operated by the National Health Department and the National Institute of Health since 1984. In 1990, about 550 volunteer sentinel general practitioners, about 1% of the number throughout France, reported new cases of influenza, viral hepatitis, urethritis measles, and mumps each week, none of which were officially notifiable (*104,128*). Since the underlying population seen by reporting physicians is not known, trends are usually expressed as the average number of cases per reporting physician per week. Information is also transmitted directly by national, hospital, and other laboratories; and local, regional, and national health agencies are also included in the network (*127*). Electronic mail and bulletin boards are used to disseminate information, and reporting physicians can contact researchers and obtain literature searches through the network.

Tracking the spread of influenza-like illness using the FDCN has been particularly effective. Epidemic thresholds can be calculated on the basis of data from previous years and the extent of regional spread can be tracked each week (*128,129*). Unlike mortality-based surveillance systems, the FDCN was able to show that the 1988-1989

influenza epidemic occurred earlier, was of shorter duration, and affected primarily young age groups relative to epidemics in previous years (*130*). In addition to routine surveillance activities, the FDCN has been used to conduct surveys on physician attitudes regarding vaccination for measles; the use of measles, mumps, and rubella trivalent vaccine; HIV testing; and biologic testing for diarrhea (*104*). Surveys conducted before and after a nationwide AIDS campaign found that the number of tests given to women and to heterosexual men increased following the campaign that emphasized risks associated with heterosexual activity (*131*). Studies of diarrheal disease have been conducted by the Aquitaine network (*132*). Findings from the Aquitaine studies, coupled with findings on measles from the FDCN, highlight that localized outbreaks of disease for which public health action is warranted can be missed by sentinel networks that typically monitor conditions in about 1% of the population.

In the United States, a network of 139 sentinel physicians reports cases of influenza-like illness each week to CDC (*47,133*). Nasopharyngeal specimens are sent by 70 physicians to a central laboratory, which then reports findings to reporting physicians and to CDC. Physicians also report the total number of office visits per week so that the percentage of visits by patients with influenza-like illnesses can be estimated. In 1991, sentinel physicians from the Middle Atlantic and West South Central regions of the United States reported increased visits for influenza-like illness by late November, although numbers of such visits had not yet increased in other areas of the country.

Networks of family practitioners and other primary-care providers have been formed in the United States and Canada, primarily to conduct collaborative research projects, but have the potential to conduct surveillance. The descriptive and analytic studies performed by these networks have been very useful for identifying patterns of illness in outpatient settings. Unlike most networks in Europe, however, they have generally not had formal reporting relationships with state or local health agencies that are responsible for timely public health activities. The Ambulatory Sentinel Practice Network (ASPN), formed in 1981, includes 334 volunteer clinicians from 71 practices in the United States and Canada most of whom are family practitioners and many of whom practice in rural areas (*115,134*). Many studies conducted by ASPN--including studies of pelvic inflammatory disease, spontaneous abortion, chest pain, carpal tunnel

syndrome, and HIV prevalence--have increased knowledge regarding the distribution of conditions with public health impact among patients seen in private ambulatory-care settings (*135-138*).

The Pediatric Research in Office Settings (PROS) network, formed in 1985 and sponsored by the American Academy of Pediatrics, currently includes about 740 practitioners in 224 practices (*139*). The PROS network has completed a study of vision screening of young children and a pilot study of febrile illness among infants. Regional primary-care networks include the Dartmouth COOP project in northern New Hampshire and Vermont, the Upper Peninsula Research Network in Michigan, and the Wisconsin Research Network. Studies with public health impact conducted by regional networks include studies of cholesterol-, alcohol-, and cancer-screening activities; development of methods to identify functional deficits; and development of health-maintenance protocols for use in private practice.

Many of the established networks of primary-care providers participate in international collaborative organizations, such as the International Primary Care Network (IPCN), the European Electronic Adverse Drug Reaction Network (EEADRN) and Eurosentinel (*104,140*). A recent IPCN study of 3,360 children from nine countries showed that the proportion of children with otitis treated with antibiotics varied widely between countries and that antibiotic treatment did not improve the rate of recovery (*117*). In association with the British pharmaceutical industry, the EEADRN monitors adverse drug reactions in the United Kingdom, in Ireland, the Netherlands, Belgium, and Switzerland (*104*). Approximately 2,350 physicians participate in the network using hand-held computers to transfer information to the coordinator.

Establishment of a computerized European sentinel-practice network is a long-term goal of the Eurosentinel, although preliminary findings indicate that the existing networks are quite heterogeneous. Nonetheless, Eurosentinel can serve as a clearinghouse for a wide range of activities that highlight similarities and differences between countries--both in patterns of disease and in the practice of medicine and public health. Eurosentinel could also serve as a model for a broad-based international consortium of sentinel practice networks.

REGISTRIES

Overview

The use of registries for surveillance and other medical or public health activities has increased in recent years, largely because information from other sources, including notifiable disease reporting mechanisms and vital statistics, is often not adequate for monitoring the public health impact of non-acute diseases (*141*). Registries differ from other sources of surveillance data in that information from multiple sources is linked for each individual over time. Information is collected systematically from diverse sources, including hospital-discharge abstracts, treatment records, pathology reports, and death certificates. Information from these sources is then consolidated for each individual so that each new case is identified and cases are not counted more than once. Case series and hospital-based registries in which the population at risk is not known can be useful for a variety of activities, including descriptive analyses and assessment of treatment effectiveness. However, population-based registries from which incidence rates can be calculated are generally more useful. Information from registries is used primarily for research purposes, but in many instances, registries have been useful for surveillance and related activities.

The most successful registries are those where purposes are explicit and realistic, the data collected are accurate and are limited to essential information, and the registry meets needs that cannot be accommodated using simpler, less expensive methods (*142,143*). Even when data collection appears to be straightforward, the time and resources required to develop a functional registry are often underestimated. Because high-quality registries are resource intensive for long periods, they are generally not available for all geographic areas or exposed groups. Also, the complexity of the data-collection process limits the extent to which data can be made available rapidly.

Registries have been used to monitor a wide range of health events and have identified opportunities for public health prevention and control activities. For instance, analysis of data from one of the earliest registries--of blind persons in Great Britain--found that blindness among substantial proportion of the elderly was due to treatable cataracts, a finding that had not been previously recognized (*142*). Other health events that have been monitored using registries include rheumatic fever,

mental illness, Alzheimer's disease and dementia, renal disease, diabetes, heart disease, head and spinal cord injuries, child abuse, early childhood impairments, and occupation-related diseases such as berylliosis (*16,144-149*).

Registries are also used to monitor health events in groups with increased exposure to hazardous agents, including radiation and hazardous chemicals found in the work place and the environment (*150-154*). Cancer, however, is by far the most common condition for which registry information is used for surveillance.

Case Series and Hospital-Based Registries

Case series and hospital-based registries have been useful for surveillance-related activities even though population-based rates usually cannot be estimated. Changes in the descriptive epidemiology of berylliosis have been monitored using a registry, for instance (*148,155*). Cases of berylliosis increased sharply in the United States in 1939 to 1941 following an increase in the use of beryllium in large-scale manufacture of fluorescent lamps and in war industries. The number of cases, among both workers and those who lived near production facilities, declined rapidly following changes in the manufacturing process and adoption of an exposure standard. Case registries have also been used to study relatively rare conditions such as mesothelioma among those exposed to asbestos and adenocarcinoma of the vagina among women exposed prenatally to diethylstilbestrol (*156*).

For most case registries, however, the primary goal is to provide information that can be used to improve patient care. Registers of cancer patients are maintained by many hospitals, and, more recently, some hospitals have established registries of persons who have been treated for traumatic events. In the United States, hospital-based cancer registries have been promoted by the American College of Surgeons since 1931 and have been required as part of their cancer program since 1953 (*156*). Standardized software was made available to hospitals beginning in the 1980s, and development of an electronic data-transfer standard allowed information to be transmitted centrally from nearly 2,000 hospitals, beginning in 1990 (*157*). The newly formed National Cancer Data Base of the American College of Surgeons includes basic information on about 20% of all cases of cancer diagnosed each year in the United States. By highlighting the importance of histologic confirmation prior to treatment, hospital-based cancer

registries have been particularly useful in improving the overall quality of treatment for cancer.

More recently, development of regional and state systems for trauma care have prompted the development of hospital-based trauma registries. The first computerized trauma registry in the United States was developed in 1969 at Cook County Hospital in Chicago and was expanded to a statewide registry in 1971 that included information from 50 hospitals designated as trauma centers in the state (*141,143,157*). National surveys in 1987 identified 105 hospitals in 35 states with hospital-based trauma registries and 10 states with central trauma registries (*158*). The registries differed considerably, however, in the criteria used for inclusion of cases, the type of data collected, coding conventions, and the manner in which data were used. In an effort to make information in hospital-based trauma registries more comparable, standardized case criteria and a core set of recommended data items, along with supporting computer software, were developed by CDC and others in 1988 (*159*). Although data from most existing trauma registries are not population-based, they have been used to support primary prevention activities. For instance, findings from the Virginia Statewide Trauma Registry and other sources were used to support legislation regulating the use of all-terrain vehicles (*158*).

Population-Based Registries

Population-based registries are particularly useful for surveillance because, using incidence rates, the occurrence of a health event can be estimated over time in different geographic areas and subgroups of the population. For most registries, the population from which cases are identified is the general population of a specified area. Most cancer and birth defects registries, for instance, estimate rates for the general population. The population from which cases are identified can also arise from a group defined by a specific exposure that is thought to increase the risk of illness.

Descriptive analysis of incidence rates based on registry information can be used for health planning purposes and can suggest etiologic hypotheses that can be evaluated further with additional studies (*50,159-162*). For some conditions, comparisons between incidence and mortality rates can be used to estimate the effectiveness of primary

prevention, early detection, or treatment programs. Findings from studies based on registry information can also encourage physicians to abandon less-than-effective individual therapies, thus improving the standard of medical care.

Exposure Registries

Examples of exposure-based registries include the survivors of atomic bombing or Hiroshima and Nagasaki during World War II and their offspring and other groups of persons exposed to radiation (*152,163-167*). Because workers are often exposed to higher levels of physical, chemical, and biologic agents for longer periods than is the general public, follow up of cohort of workers have been used for many years to identify illnesses associated with these agents and to assess how these illnesses can be prevented.

Registries have also been been used to assess the risk of illness for general population groups exposed to specific agents. For instance, about 4,600 individuals exposed to polybrominated biphenyls through contamination of dairy cattle-food supplements in Michigan were followed to assess acute, subacute, and chronic conditions that might have been associated with this exposure (*168*). More recently, the United States Congress has mandated that the Agency for Toxic Substances and Disease Registry (ATSDR) address potential public health problems associated with environmental exposures to hazardous waste sites and chemical spills, partly through the creation of registries (*150*). ATSDR has described the rationale for a national exposure registry and methods to be used in its establishment and maintenance.

Cancer Registries

Cancer registries are used in many different countries to estimate cancer incidence and mortality rates over time. The Connecticut Tumor Registry, the oldest population-based cancer registry in the United States, has monitored cancer incidence rates for nearly 50 years (*156*). Like hospital-based registries, the Connecticut registry was developed initially to support the goals of service-oriented hospital-based cancer registries throughout the state. Through the Surveillance, Epidemiology, and End Results (SEER) program, the NCI has collected information from specific population-based cancer registries since 1973. Participant registries were selected to include a variety of population groups rather than a representative sample of United States,

although nation-wide rates can be estimated using SEER data. The four major goals of the SEER program are:

- to estimate cancer-related incidence and mortality in the United States;
- to identify unusual changes in the incidence of specific types of cancer over time in designated areas or demographic subgroups;
- to describe changes in the extent of disease at diagnosis and to estimate patient survival; and
- to foster studies of cancer risk factors, screening, and prognostic factors to allow intervention.

The SEER registry is probably the largest population-based registry in the Western world (*156*). Between 1973 and 1988, the program registered about 1.5 million incident cases of cancer. At present, about 10% of the United States population lives in one of the nine areas that includes a SEER registry, and approximately 120,000 new cases of cancer are registered from these areas each year (*169*). For all types of cancer (except certain types of skin cancer), information on selected patient demographics is recorded in addition to information on primary site, morphology, confirmation of diagnosis, extent of disease, and first course of treatment. The registries also actively follow all living patients to ascertain vital status (except those with in situ cervical cancer). Incidence rates for cancer based on SEER registry information are published regularly, and descriptive analyses of cancer incidence rates by age, race, gender, and geographic area are routinely performed. Although not part of the SEER system, many states--including New York, California, and New Jersey--maintain active, high-quality cancer registries that are used for both public health and hospital-directed activities. In 1989, there were 42 cancer registries in the United States, including 28 state-based registries that cover part or all of a state's residents (*170*).

In Europe, the first cancer registry was founded in Denmark in 1942, and there has been steady growth in the number of registries and the size of included populations since then (*171*). At present, Denmark, Belgium, England and Wales, and Scotland have nationwide registries, and most European countries have registries in certain regions. Information from cancer-incidence registries around the world is collected by the International Agency for Research on Cancer (IARC), which is part of WHO. As of 1989,

IARC had identified 238 population-based registries in 53 countries that collected information on cancer incidence, and rates were available for selected years from 106 of these registries (*170*).

Registries provide important information for a wide range of public health activities, but their usefulness for identifying new hazards has, in practice, been limited. Initial observations by astute clinicians rather than routine analysis of surveillance data have led to more extensive studies to investigate associations between angiosarcoma and vinyl chloride, mesothelioma and asbestos, and diethylstilbestrol and adenocarcinoma of the vagina (*171*). Cancer registries were essential, however, for identifying cases that were evaluated in more extensive epidemiologic investigations. Today, cancer incidence rates from population-based registries are used extensively in cancer-cluster investigations to assess whether the number of observed cases differs substantially from an expected number derived from baseline cancer incidence rates. With increased emphasis on screening activities to detect asymptomatic cancer cases at an early, more treatable stage and on behavioral-risk-factor control and possibly chemo-prevention, the public health importance of high-quality, population-based cancer registries should increase.

Birth-Defects Registries

Recognition of an epidemic of limb reduction defects among children exposed prenatally to thalidomide stimulated interest in developing population-based birth-defects registries in many countries. Some birth- defects surveillance systems (e.g., the Birth Defects Monitoring Program (BDMP) in the United States), use available sources of information including vital statistics and hospital-discharge data to monitor trends in the birth prevalence of various birth defects (*172*). This type of passive monitoring system is discussed further in the section on administrative data in this chapter.

Like most cancer-incidence registries, however, birth defects registries characterized by active case finding obtain information on individual cases from multiple sources. In the United States, the Metropolitan Atlanta Congenital Defects Program (MACDP) has been in operated by CDC's National Center for Environmental Health (NCEH) (*172-174*). All births are monitored in the five-county metropolitan Atlanta area-- about 35,000

births per year. Included in the MACDP are all live-born and stillborn infants diagnosed as having at least one major birth defect within their first year of life, with diagnoses ascertained within their first 5 years of life. Birth-defect rates and trends are monitored by quarterly reviews and analysis of data and are published regularly by CDC. Numerous investigations have been performed using MACDP data, including studies of Vietnam veterans' risk for fathering children with birth defects, the risk of bearing children with specific birth defects for women with insulin-dependent diabetes, and an apparent protective effect of peri-conceptual vitamin use on the risk of neural tube defects (*175-177*). In addition, the MACDP has served as a prototype for other birth-defects registries characterized by active case-finding (*172*).

Use of equivalent case definitions, more specific coding schemes, and a uniform set of variables has facilitated collaborative efforts between the eight birth-defects registries in the United States characterized by active case-finding (*172*). For instance, surveillance for specific birth-defects associated with first trimester exposure to isotretinoin relies on collaborative efforts by CDC and state birth-defects registries.

In Europe, population-based birth-defects registries are coordinated through EUROCAT, which is funded through the Economic Community (*178*). In 1983, birth-defects among 250,000 births were monitored by 17 birth-defects registries in 10 countries. Both active and passive birth-defects registries participate in the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS), founded in 1974 by WHO as a means of disseminating birth-defects data from surveillance systems around the world. Information is available each year on birth defects among more than 4.5 million births in 30 countries. Although methods used by various registries differ considerably, the ICBDMS provides a forum for rapid dissemination of information on teratogens. Reports from France linking valproic acid, an anti-epileptic drug, with an increase in spina bifida were disseminated rapidly though this international network (*179,180*).

More recently, some registries are being developed in some local communities to monitor preschool children for whom early intervention programs are needed. These programs can identify children with conditions such as fetal alcohol syndrome,

cerebral palsy, mental retardation, and behavioral or learning disabilities that are often detected shortly after birth. These registries will be useful for estimating the prevalence of these conditions, as well as for monitoring the effectiveness of services provided to children with special needs.

SURVEYS

Overview

Health surveys, particularly those that are conducted on a continual or a periodic basis, can provide useful information for assessing the prevalence of health conditions and potential risk factors and for monitoring changes in prevalence over time. More recently, health surveys have also been used to assess knowledge, attitudes, and health practices in relation to certain conditions such as HIV/AIDS. A survey differs from a registry in that persons surveyed are usually only queried once and are not monitored individually after that one contact. Information on respondents can be obtained through questionnaires, in-person or telephone interviews, or through record reviews. Attempts are made to assure that the survey sample is as representative of the source population as possible in order to increase the validity and reliability of estimates extrapolated to that population. Surveys are can be valuable for public health surveillance if similar information is collected over time and if findings are applied to public health activities.

In the United States, surveys such as NCHS's National Health Interview Survey (NHIS) are important sources of information for monitoring nationwide trends in the prevalence of target conditions and risk factors for which national health objectives for the year 2000 have been established (*73,181*). Nationwide surveys are costly, however, and due to their complex sample designs, specialized statistical techniques are often needed for analysis. Since information is usually not available at a local level, the usefulness of national surveys for local surveillance activities is limited.

Health Interview Surveys

In the United States, the NHIS, conducted annually since 1957, provides information on self-reported illnesses, chronic conditions, injuries, impairments, the use of health services, and other health-related topics for the civilian, non-institutionalized

population (*182,183*). Households are identified through a complex sample design involving both clustering and stratification. Households selected for interview each week are a probability sample from a primary sampling unit such as a county or metropolitan area. Respondents are interviewed in their homes with an adult family member providing information for other members of the household. Each year, information is collected on about 122,000 people from about 48,500 households (*2*). The interviews, which average about 80 minutes, include a core set of health and socio-demographic questions are repeated each year and a supplemental section in which detailed information is collected on specific health topics. In 1987, for instance, supplemental information was collected on risk factors for cancer and on knowledge and attitudes regarding AIDS. NHIS questions will be modified in the future so that progress toward meeting the year 2000 health objectives for the nation can be monitored closely.

In England, Scotland, and Wales, the General Household Survey (GHS) in which information on housing, employment, education, health, and use of social services is obtained using structured personal interviews has been in operation since 1971 (*2*). An analogous Continuous Household Survey is conducted in Northern Ireland. Electoral wards form the primary sampling units, and about 85% of households--a total of about 12,000 per year--agree to participate in the GHS. Over time, the health section of the survey has included questions on limitations in activities because of acute or chronic illnesses, smoking and drinking patterns, and contacts with health-care providers and other health-related topics. The ability to compare health-related information with extensive socio-demographic information is one of the major strengths of these surveys.

In the United States, CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) has worked with state health departments since 1981 to conduct telephone surveys about adult health behavior and use of prevention services. The primary purpose of these surveys is to support state prevention initiatives. Questionnaires used by the Behavioral Risk Factor Surveillance System (BRFSS) include a core set of questions, and, depending on a state's interest, supplemental questions developed by CDC and questions that meet state-specific needs (*184*). The 1988 BRFSS included questions on height, weight, physical activity, smoking, alcohol use, seat-belt use, and use of prevention services, such as cholesterol screening and

mammography. By 1990, 45 states and the District of Columbia were conducting these surveys. Some states have used BRFSS procedures to conduct more detailed studies. In Missouri, for instance, cholesterol awareness was compared in urban and rural areas was compared, and in California, cigarette smoking was compared among Chinese, Vietnamese, and Hispanics in three communities (*185,186*). Information from the BRFSS is timely and can reflect the particular interests of a state or local community. Use of telephones for interviewing is economical, although many persons without telephones who are not included in these surveys are generally more likely to be in need of public health services than many of the respondents.

Since 1988, NCCDPHP has developed and implemented a Youth Risk Behavior Survey (YRBS) to focus the efforts of local, state, and federal agencies that monitor the behavior of young people (*187*). In 1990, the national survey used a three-stage sample design to obtain a probability sample of 11,631 students in grades 9 through 12 in 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. From the 1990 survey, estimates are available for the prevalence of tobacco use, alcohol and drug use, exercise, diet, types of behavior that affect the risk of intentional and unintentional injuries, and sexual activity (*188-194*). The YRBS was designed to monitor changes in these types of behaviors biennially so that progress toward meeting year 2000 objectives can be monitored.

Provider-Based Surveys

In the United States, information on the use of health-care services is not available routinely. In order to estimate the use of these services nationally, NCHS has developed two complementary surveys, the National Hospital Discharge Survey (NHDS) and the National Ambulatory Medical Care Survey (NAMCS), in which characteristics of health encounters are monitored (*181, 195,196*). Through the NHDS, information has been collected since 1965 on discharges from non-federal, short-stay hospitals, including characteristics of patients, length of stay, diagnoses, surgical procedures, and hospital size and type of ownership. Beginning in 1987, computerized information for some discharges was purchased from commercial abstracting services, but, otherwise, discharges are sampled randomly from hospitals included in the survey. In 1987, information was collected on about 181,000 discharges from about 400 hospitals--about 81% of the hospitals that were asked to participate. Although hospital-discharge

information is available in many states, it is not available nationally, so that state estimates are often derived by extrapolation from the NHDS. Data from the NHDS as well as other sources have been used, for instance, to assess the public health burden of nine major chronic diseases (*197*).

The NAMCS has been conducted annually from 1973 to 1981, in 1985, and annually since 1989. The target population for the NAMCS is office visits within the continental United States to non-federal physicians who are in office-based practice and engaged in direct patient care (*9,181,196*). About 70% of all ambulatory visits occur in physicians' offices, and about 70% of selected physicians agreed to participate in the survey in 1990. Beginning in 1989, about 2,500 physicians were included in the sample, with each physician completing a short form for about 30 office visits. Information on visits to hospital out-patient departments and emergency rooms may be added to the NAMCS in the future. In addition to information on diagnoses, medications, and reason for visit, the 1990 NAMCS included information on diagnostic and screening services; counseling for drug, alcohol, and smoking cessation; and other counseling services (*198*). Estimates are published at the national level, and for some events, at the regional level. Unlike hospital-discharge data, ambulatory- care data are rarely available for routine use at the state or local level in the United States. To obtain information that could be used in their programs, however, Wisconsin conducted an ambulatory medical care survey in 1986-1987 based on the NAMCS questionnaire and study design (*199*). Proprietary data bases, such as the National Disease and Therapeutic Index (NDTI) provide ongoing data on conditions seen in ambulatory care settings. Although used primarily by the pharmaceutical industry, the NDTI has been used monitor the public health impact of recommendations to limit the use of aspirin in children with fevers (*200*).

Other Surveys

Other NCHS surveys include the National Survey of Family Growth (NSFG) and the National Health and Nutrition Examination Survey (NHANES) also contain information that is useful for public health activities. The NSFG has provided national data on demographic and social factors associated with childbearing, adoption, and maternal and child health based on household interviews of women of childbearing age. The survey has been conducted four times--in 1973,1976,1982, and 1988 (*201-203*).

The NHANES has provided extensive information on the prevalence of chronic conditions, distribution of physiologic and anthropomorphic measures, and nutritional status for representative samples of the U.S. population (204,205). The first two NHANES cycles were conducted in 1971 through 1974 and 1976 through 1980 and data collection is currently under way for the third cycle. A Hispanic Health and Nutrition Examination Survey was conducted in 1982 through 1984 in order to compare health and nutritional measures among U.S. residents of Mexican, Puerto Rican, and Cuban origin (*206*). Also, almost 4000 persons ages 55 to 74 years of ages who had been interviewed in NHANES I and were living in 1984 were enrolled in the NHANES I Follow-up Study to assess whether their characteristics in the 1970s predicted subsequent health outcomes (*207*). The NHANES studies are rich sources of information that are used primarily for epidemiologic and related analyses. They have been used, however, to provide point estimates to monitor changes over time in health outcomes, such as changes in blood-lead levels (*208*). In general, sources of information that are available for more of the population over longer periods are more useful for routine surveillance activities.

ADMINISTRATIVE DATA-COLLECTION SYSTEMS

Overview

Through the use of standard procedures and classification schemes, vital statistics are derived from birth and death certificates, completed primarily for legal reasons. Likewise, information on conditions not evident at the time of birth or death can be derived from administrative information routinely available on episodes of care (including hospitalizations, visits to emergency rooms, and visits to health-care providers in the community). In most instances, routinely collected administrative data have been computerized for billing purposes, but since diagnoses are often included, these data sets can provide useful information for public health surveillance. As computerized administrative data become increasingly available, their importance for monitoring a wide range of health outcomes is increasing.

Availability and usefulness of administrative data for surveillance depend on a number of factors including:

- the type of information that is computerized;

- the extent to which uniform classification schemes are used to categorize diagnoses, signs, symptoms, procedures, and reasons for seeking health care;
- the availability of sufficient computer capacity and user-friendly software programs to process large amounts of data;
- the extent to which supplementary information can be obtained; and
- the extent to which information for individuals from different administrative sources or time periods can be linked using a unique personal identifier;

Data that include personal identifiers are particularly useful both because statistics can be calculated on the basis of persons rather than on episodes of care and because additional information can often be obtained through linkage with other data sets. Special precautions are needed, however, to protect the confidentiality of individuals when personal identifiers are included in computerized administrative data bases. Even when personal identifiers are not included, administrative data can be very useful, however, for assessing the public health burden of various conditions based on the number of health-care visits and their costs.

Integrated health-information systems based on administrative data are available in a few countries, but in most, information may be available only for certain types of health care (e.g., hospitalizations) or for certain segments of the population (e.g., those who receive care through the public sector). Although usually incomplete, analysis of administrative data has proved useful for public health surveillance and program planning.

Integrated Health Information Systems

Integrated health-information systems, in which data on individuals are consolidated from a variety of sources are available in Sweden, Canada, and for limited groups in the United States. In Sweden, for instance, use of a unique personal identifier assigned at birth allows the linkage of computerized information on individuals from a variety of sources, including birth and death certificates, the cancer registry, hospital discharge summaries, and prescription records (*209*). In addition to etiologic studies, linked Swedish data bases have been used for a variety of

surveillance-related analyses. Examples include estimating the incidence of acute myocardial infarction; comparing methods of ascertaining myocardial infarction using community registers, hospital discharge data, and mortality data; and assessing temporal trends in the incidence of hip fracture (*144,146,210*).

In Canada, the Saskatchewan Health Plan maintains population-based billing information including diagnoses from inpatient, outpatient, and prescription records for approximately 1 million residents beginning in 1979 (*211,212*). This information, which has been used in studies of associations between nonsteroidal anti-inflammatory drugs and fatal gastrointestinal bleeding and of associations between valproic acid use and congenital malformations, could also be used for ongoing surveillance activities (*213,214*).

In the United States, integrated health-information systems have been developed for some health-maintenance organizations such as the Kaiser Permanente system or for geographic areas served by one major health care provider--such as Rochester, Minnesota. Although used frequently for research, the few integrated health-information systems in the United States are of limited use for general public health surveillance because the populations included in them are relatively small and not representative of the U.S. population. These systems are useful, however, for providing information on incidence and prevalence for conditions difficult to monitor nationally--such as the trends in incidence for specific types of primary intracranial neoplasms (*215*) and the prevalence of osteoarthritis of the knee with and without corroborative radiographic findings (*216*).

Hospital-Discharge Data Systems

Overview

The importance of collecting information on morbidity from hospital records was noted by Florence Nightingale among others, although attempts to collect and analyze this information systematically were not initiated until the 1940s in Scotland (*2,217*). Today, computerized information from hospital discharge summaries--including demographic information and discharge diagnoses--is routinely collected and computerized using standard data-set formats such as the 1981 Recommended Minimum Basic Data Set (RMBDS) for the European community and the Uniform Hospital Discharge

Data Set (UHDDS) or the Medicare Uniform Bill-82 (UB-82) formats in the United States (*218,219*). Both the UHDDS and the UB-82 formats are currently being revised in tandem.

In Scotland, for example, a standard morbidity record form is completed for each admission to a general, psychiatric, or maternity hospital and is sent to a central agency for processing and statistical analysis (*217*). Initiated in parts of Scotland in 1951, the system eventually included the entire country by 1961. Although records include a unique personal identifier, they are not linked routinely except in one area of the country. With the advent of the National Health System in 1948, a similar system based on 10% of hospital admissions was initiated in England and Wales that covered all areas by 1958.

To monitor the quality of care provided in U.S. hospitals, each acute-care hospital is required by the Joint Commission on Accreditation of Healthcare Organizations to report information on diagnoses, length of stay, and inpatient services. Hospitals often contract with private companies to abstract and computerize pertinent data from medical records, but in recent years, many hospitals are computerizing this information themselves or abstracting it from computerized treatment records. Beginning in the early 1980s, individual states began to require submission of hospital-discharge data for utilization, financial, and other health-planning studies (*219*). Thus, hospital discharge summary data are computerized for most discharges from acute-care hospitals in the United States, but data are not available nationally for all segments of the population from any one source.

Private-sector systems

In the private sector, the Commission on Professional and Hospital Activities (CPHA) has abstracted information from medical records of U.S. hospitals for over 30 years (*219,220*). Today, CPHA's Professional Activities Study (PAS) data base includes over 200 million records with diagnoses coded according to the clinical modification of the *ICD-9* (*ICD-9-CM*) in the UHDDS format; 6 million more records are being added each year (*219,221*). The PAS includes information from clinical rather than billing records, since staff from cooperating hospitals review medical charts, prepare case abstracts, and send information to CPHA. Hospital-discharge data from CPHA and more recently from the McDonnell Douglas Hospital Information System (MDHIS) have been used for the

surveillance of birth defects and related conditions (*222*). Today, the Birth Defects Monitoring Program (BDMP), initiated in 1974, includes information from newborn discharge summaries for about 1 million newborns per year--about 25% of the births in the United States. Prevalence rates are calculated using the number of live births as the denominator, and trends in rates for targeted conditions are published routinely (*223*). Information for the BDMP is abstracted from hospital discharge summaries and is not routinely verified. Although personal identifiers are not included in BDMP data sets, participating hospitals have agreed to provide hospital records for special studies using their own patient numbers to identify records (*224,225*). More recently, additional information on possible maternal exposures (e.g., infections, use of prescription or illicit drugs, or the use of alcohol) linked to birth defects or other adverse outcomes noted at birth is available for a subset of infants in the BDMP. Probabilistic matching procedures are used to link summary data without personal identifiers from newborn and maternal hospital discharge records (*222*). Validation studies indicate that about 95% of the records linked using the matching algorithm are true matches. Linked maternal and infant hospital-discharge records are particularly useful for investigating problems associated with maternal exposures. Information on birth defects surveillance systems characterized by active case-finding and integration of information from multiple sources appears in the registry section of this chapter.

In the United States, use of hospital-discharge data from CPHA, MDHIS, or other private-sector sources is more limited for surveillance of conditions other than those identified at birth. For the latter, birth-prevalence rates can be calculated using the number of live births in that hospital as the population at risk, even if the geographic areas to which these rates apply are not known. Calculation of incidence or prevalence rates for other conditions is limited by two factors: first, because the lack of complete coverage for a geographic area limits the use of census data to estimate the population at risk; and, second, because initial hospitalizations for conditions cannot usually be distinguished from subsequent hospitalizations.

In 1988, 29 states maintained hospital-discharge-data systems for acute-care hospitals: 17 in the UB-82 format, eight in the UHDDS format, and four in unique data formats (*219*). Although not currently required on the UHDDS or the UB-82, external cause-of-injury ("E codes") are required in eight states (*226*). In most states,

unique personal identifiers are not computerized, and the extent to which these data can be accessed and used for surveillance varies from state to state. When hospital discharge information is available, however, estimates of the public health burden of inpatient care--based on the number, the duration, and the cost of hospitalizations--have been useful for setting priorities for prevention or treatment efforts or for targeting interventions to specific subgroups in the community.

In California, for instance, hospital-discharge data coupled with estimates of the proportion of specific diseases attributable to smoking were used to estimate the cost of treating smoking-related diseases paid with public funds. To recoup some of these costs, California instituted a 25-cent sales tax on tobacco products in 1989 (*227*). State-based hospital discharge data systems have also been used effectively to assess the public health impact of injuries in states that require "E codes" (*226*). For instance, the effect of mandatory seat-belt laws and more stringent drunk-driving laws on motor-vehicle-related injuries has been demonstrated using hospital-discharge data that includes "E codes".

Federal data-collection systems

In the United States, health care is provided using public funds for about one-quarter of the non-institutionalized population--including the elderly (13%), the poor (9%), and the military and their dependents (4%) (*228*). In 1965, two federal health-insurance programs--a hospital insurance plan and a supplementary insurance plan--were established for persons $\geq$ age 65. Both of these Medicare health-insurance programs are administered by HCFA. All eligible recipients are enrolled in the first plan (Part A), which provides coverage for inpatient hospitalizations, stays in skilled nursing facilities, and home health services. The second plan (Part B), for which beneficiaries pay a small premium, covers physician services, outpatient hospital services, and other medical services. About 96% of the population $\geq$ 65 years is enrolled in at least the Part A program (*229*). Medicare programs were extended in 1972 to cover persons with end-stage renal disease that required dialysis or transplantation and to persons with disabilities <65 years (*230*). In Fiscal Year 1988, Medicare program payments for 31 million beneficiaries $\geq$ 65 years and an additional 3 million persons with disabilities accounted for about 18% of all personal health-care spending in the United States.

For Part A claims, computerized bills in the UB-82 format are submitted to fiscal intermediaries and then are consolidated nationally. Diagnoses included on each bill affect payment to hospitals because, since 1983, most short-stay hospitals have been paid for each case on the basis of prospectively established rates for some 475 diagnosis-related groups (DRGs) (*228*). To monitor the quality of care provided through Medicare programs, HCFA created the Medicare Provider Analysis and Review (MEDPAR) file by linking information on individuals such as age, gender, race, and residence from the eligibility files; information on diagnoses and treatment from Part A and Part B claims files; and information on health-care providers from a facilities file. A unique health-insurance number--usually the social security number--is used to link information on individuals. HCFA has created a public-use file for Part A data from the MEDPAR file and plans to add Part B files, which will includes diagnostic data in 1992 (*231*).

Although most studies using MEDPAR files have focused on quality of care and medical effectiveness these files have also been used to assess the public health impact of various conditions such as end-stage renal disease and hip fracture among the elderly (*107,230-234*) Point prevalence can be estimated because nearly all members of the general population $\geq$ 65 years are enrolled in Medicare. Incidence can also be estimated for some conditions because the first hospitalization can be identified in records for an individual linked by using the unique personal identifier. These estimated incidence rates would approximate true incidence rates more closely, however, for acute events such as hip fracture than for long-standing conditions such as Type II diabetes. Since many conditions are commonly among the elderly, rates can often be estimated for small geographic areas such as cities or counties (*235*). Recent studies indicate, for instance, that hip fracture is more common in southern states, even though weather conditions are more adverse in the north (*236,237*).

Even more useful public health surveillance information about Medicare recipients should be more available in the near future. A National Claims History File is being created for elderly Medicare recipients with information from all claims linked for individuals (*219*). To obtain additional clinical information, medical records for a random sample of beneficiaries will be abstracted using standard procedures to create a Uniform Clinical Data Set. Self-administered questionnaires will be sent to a sample of the elderly at regular intervals to obtain additional information on health

status prior to entering the Medicare program, on health-related behaviors, and on functional status. Information from all these sources will be linked in the Medicare Beneficiary Health Status Registry. Information from other sources, such as the SEER registry and other cancer-incidence registries will be linked with Medicare files when possible (*238*). An end-stage renal disease registry has been developed by linking health-claims information (*239*). As they become available, these enhanced data sets should prove useful for monitoring trends, for public health planning, and for evaluating the effectiveness of medical and preventive health services such as mammography and vaccination.

Medicaid, HCFA's other major public health-care program, provides health-care funds for the poor and medically needy through a federal-state cost-sharing program. Medicaid data had been used in for surveillance and program planning at state and local levels, particularly in the maternal and child health area. Further information on uses of Medicaid claims data for surveillance is provided in the ambulatory care and related data section of this chapter.

Hospital-discharge records from IHS hospitals have been particularly useful for developing community-specific injury profiles and targeting local public health interventions (*226*). "E codes" have been included in discharge summaries from IHS hospitals for over 20 years, and regional injury prevention coordinators are notified electronically of injury-related hospitalizations. Identification of hazardous areas identified through analysis of local data has led to brighter and more effective lighting and to installation of pedestrian walkways along hazardous stretches of road.

Data-Collection Systems in Emergency Rooms and Other Units

Administrative data from hospital emergency rooms have been used for surveillance of a variety of acute health events including non-fatal injuries, illicit drug use, poisonings, and adverse reactions to prescription drugs. Unlike inpatient hospital-discharge data, however, emergency-room data are not routinely computerized and reported from all hospitals in a standard format. Because the type of information recorded and the filing systems used to retrieve health information differ, special surveillance systems focused on specific outcomes such as injuries or illicit drug use have been developed using information obtained from cooperating hospitals.

Information from these special surveillance systems is usually not linked with other data sources. Although the scope of these systems is limited, they have provided useful information for the surveillance of acute, non-fatal health events for which admission to a hospital is not warranted.

In England and Wales, information has been provided by the Home Accident Surveillance System (HASS) since 1976 (*240*). Information is collected by trained clerks from 20 randomly sampled major emergency departments. Each hospital remains in the system for 4 years, and five hospitals are replaced each year from the pool of 270 hospitals with large emergency departments. A similar system, the European Home and Leisure Accident Surveillance System (EHLASS) is being implemented in all European Economic Community countries.

In the United States, information on injuries associated with the use of consumer products (other than automobiles) is available through CPSC's National Electronic Injury Surveillance System (NEISS). Since 1972, information on consumer-product-related injuries, poisonings, and burns has been abstracted from emergency-room records of a representative sample of hospitals (*9*). Information is sent electronically each day to CPSC, and more in-depth information can be obtained on conditions of special interest. Information on occupation-related injuries has been collected since 1982, although the number of hospitals included in NEISS was reduced from the original 73 to 62 in 1987 (*241,242*).

National estimates for a variety of conditions are derived by weighing data from reporting hospitals. NEISS has provided estimates of various consumer-product- and occupation-related injuries, including estimates of the number of work-related injuries in the United States bicycle-related injuries and poisonings among children (*241-243*). NEISS provides the only national estimates of injuries seen in emergency rooms, although the number of hospital emergency rooms on which this information is based is relatively small. NEISS data have also been used to assess the public health impact of injuries at the local level. From NEISS data from one hospital, a cluster of injuries that occurred among young girls and were related to playground merry-go-rounds was identified (*244*). Pediatric injury surveillance systems using emergency room and hospital discharge data have also been established in other areas (*245,246*).

In the United States, NIDA's Drug Abuse Warning Network (DAWN) relies on reports from about 700 hospital emergency rooms and 85 medical-examiners' or coroners' offices to detect emerging trends in the nature and severity of drug-abuse problems in the United States (*9,247*). Facilities report voluntarily to DAWN beginning in 1972, about 453 emergency rooms in 21 U.S. cities reported data consistently by 1991 (*248*). Cocaine-related deaths increased rapidly between 1985 and 1988 although recent reports suggest that cocaine-related medical emergencies began to decrease in the first half of 1989. In the same metropolitan areas, about twice as many deaths were identified through DAWN as through the vital statistics system, although time trends were similar in both types of data. The DAWN system provides timely information on medical emergencies related to drug abuse, although estimates are not population-based and are based on voluntary participation from medical facilities.

In some areas, information may be available from poison-control centers, burn units, or trauma registries. In Great Britain, poison-control centers--particularly the National Poison Information Service in London--have provided information for a variety of studies of trends in abuse of solvents and poisonings of children (*249*). In the United States, poison-control centers--covering 430 defined geographic areas--reported over 121,000 instances of exposure to suspected poisons to FDA (*243*). Reports, for instance, of childhood poisonings to FDA have declined since the introduction of child-resistant caps for medication containers, and among children < 5 years of age, flavored chewable vitamins are now the most common pharmaceutical product associated with poisoning. Information from poison-control centers has also been used to monitor acute occupation-related health events such as exposure to agricultural chemicals and corrosive chemicals (*250*). In some centers, requests for information on treatment for suspected poisonings may be collected and computerized in a standard form, although a standard format for a minimum data set has not been adopted. Exchange of information by national and international organizations--such as the American and the European Associations of Poison Control Centers and the World Federation of Poison Control Centers--facilitates identification and treatment of persons for acute conditions related to exposure to toxic substances (*249*).

Unlike hospital-discharge data, information from emergency rooms, poison-control centers, and related facilities is usually not available routinely in a standard format. Efforts are under way, however, to create standard minimum data sets and

reporting formats to aggregate and compare data. With the increase in surgical and other procedures performed on an outpatient basis, the importance of collecting core information from outpatient settings will increase.

Ambulatory Care and Related Data

With the exception of countries such as Sweden and Canada that have integrated health-information systems, ambulatory-care data are not generally available from administrative sources for all segments of the population. Information on the prevalence of signs, symptoms, and conditions not usually requiring hospitalization is usually obtained through periodic surveys of the general population or through sentinel-surveillance systems characterized by voluntary reporting of specific conditions by health-care providers. In the United States, a Uniform Ambulatory Care Data Set (UACDS), first developed in 1974 and revised in 1990, offers the possibility for standardization of ambulatory-care data (*219*), although it is not widely used at present. At present, however, diagnostic information is often not required, and when included, it is often difficult to distinguish actual diagnoses from presumptive diagnoses that are being "ruled out." Inpatient procedures are usually coded using the *ICD-9-CM*, but a universally accepted classification system is not used in outpatient settings. The *Current Procedure Terminology, fourth revision (CPT-4)* and the *HCFA Common Procedure Coding System (HPCS)* are both used, although *CPT-4* codes are not equivalent to *ICD-9-CM* codes used for the same procedures in inpatient settings. With rapid changes in medical care, it is difficult to maintain an up-to-date procedure-classification system.

In spite of these limitations, the use of claims and related data from public programs for surveillance and program planning is increasing in the United States. While data from public programs cover only a segment of the population, they are the segment to which public health interventions are most often targeted. Information from the Medicaid program, in particular, has been used by state and local health departments. About 23 million individuals were enrolled in Medicaid programs in Fiscal Year 1988, accounting for about 10% of personal health-care expenditures in the United States (*123*). The eligible population, however, changes substantially over time.

Because the states have broad discretion in administering the program under federal guidelines, benefits vary from state to state, as do the health-information systems used to track health claims. The states report aggregate expenditure and utilization data to HCFA, although about half the states voluntarily report patient-level information (*107,228*). Data from five states that report data using uniform enrollment, provider, and claims-file formats can be aggregated, but otherwise, differences in eligibility, covered services, and file structure make it difficult to aggregate data across states. Within states, however, health departments are attempting to link public health data from various sources to monitor the effectiveness of their programs, particularly in the maternal and child health area (*203*). Many states now link birth- and death-certificate data for deaths that occur within the first year of life. Some states are able to link Medicaid data with vital-record data, and a few are also able to add data from various public health programs to linked Medicaid/vital-record data sets.

Public health program data are derived from various sources: maternal- and infant-care clinics; vaccination clinics; neonatal screening programs for inborn errors of metabolism, maternal drug use, and HIV seroprevalence; lead-screening programs for schoolchildren; clinics for children with special needs; families enrolled in the Women, Infants, and Children (WIC) nutrition supplement programs; hospital discharge data; data from the Pregnancy Risk Assessment Monitoring System (PRAMS); school vaccination records; and data from Head Start programs (*203,251*). State and local health departments have met with varying levels of success in linking data sets, but the most successful have been able to target and evaluate public health interventions and to monitor outcomes. In Tennessee, for instance, adverse sequelae following vaccination were monitored using linked vaccination-clinic records, Medicaid-claims data, and vital records (*252*). Also in Tennessee, birth certificate and WIC data were linked to assess the extent to which high-risk infants were enrolled in county WIC programs (*253*). Massachusetts and Colorado are among the states that are redesigning data bases for public health programs so that the data can be linked more easily (*203,251*).

Some information derived from state and local public health programs is available nationally in the United States. CDC's Pediatric Nutrition Surveillance System and Pregnancy Nutrition Surveillance System have been operational since 1973 and 1980,

respectively (*203,251*). In both systems, key indicators of nutrition status are monitored continuously in participating states using information derived from publicly-funded health, nutrition, and food-assistance programs. Information is available from 40 states for the pediatric-nutrition system and from 16 states for the pregnancy-nutrition system. These data sets have been used to assess the prevalence of malnutrition in children < 2 years; to assess the prevalence of anemia during pregnancy among low-income women; and to monitor the decline in the prevalence of anemia among low-income children in the United States (*254-256*).

Although few countries have integrated health-information systems at present, they may become more common in the future. Although not integrated and not inclusive of most of the population, data from the patchwork of administrative systems available at present have been used successfully for public health surveillance and program planning. In the United States, computerized hospital discharge data are relatively standardized, but access is limited in some states. Because data-reporting formats are less standardized for outpatient settings, it is difficult to aggregate such data. Efforts by state health departments to create integrated data bases for public programs will help states to monitor their programs more effectively. Although eligibility may vary among states, standardization and reporting of data for at least some core variables could enhance information available nationwide on problems of public health importance.

SUMMARY

Sources of data available for public health surveillance vary considerably from country to country. Developed and many developing countries are able to monitor reproductive outcomes and mortality through vital statistics systems and many countries have notifiable disease-reporting systems for at least some infectious diseases. Otherwise, the extent of information available through administrative data systems, surveys, registries, and sentinel surveillance systems varies extensively from country to country. Although the quality and the completeness of these data sources may be limited, they often provide low-cost information that is useful for public health surveillance and related activities. Even if new data-collection efforts are needed to address specific problems, routinely collected data can provide background information that will be useful for designing these studies.

The increasing computerization of health information, the availability of powerful but relatively inexpensive computers, and the development of user-friendly software should facilitate the timely use of information from a wide range of sources. Although integrated health-information systems and computerized medical records may be on the horizon in some countries, limited information that is available quickly from notifiable-disease and sentinel-surveillance systems is often the most useful for conditions in which timely public health action is needed. Since no one source of data is usually adequate, good public health decision-making invariably requires the synthesis of data of varying quality from a wide range of sources as well as critical interpretation of findings.

Appendix III.A. Surveillance or Health Information Systems Mentioned in Chapter III

I. Notifiable diseases and related reporting mechanisms

NNDSS	National Notifiable Diseases Surveillance System, United States (CDC and state health departments)
VAERS	Vaccine Adverse Event Reporting System, United States (FDA)

II. Vital Statistics

	121-City Surveillance System, United States (CDC)
MSS	Mortality Surveillance System, United States (NCHS/CDC)
NTOF	National Traumatic Occupational Fatality surveillance system, United States (NIOSH/CDC)
	Medical Examiner/Coroner Information Sharing System, United States (NCEH/CDC)
FARS	Fatal Accident Reporting System, United States (NHTA)

III. Sentinel surveillance

SENSOR	Sentinel Event Notification System for Occupational Risks, United States (NIOSH/CDC)
EEARDN	European Electronic Adverse Drug Reaction Network, Europe

IV. Registries

	Connecticut Tumor Registry, United States
SEER	Surveillance, Epidemiology, and End Results Program, United States (NCI)

MACDP	Metropolitan Atlanta Congenital Defects Program, United States (NCEH/CDC)

V. Surveys

GHS	General Household Survey, United Kingdom
	Continuous Household Survey, Ireland
NHIS	National Health Interview Survey, United States (NCHS/CDC)
BRFSS	Behavioral Risk Factor Surveillance System, United States (NCCDPHP/CDC and state health departments)
YRBS	Youth Risk Behavior Surveillance System, United States (NCCDPHP/CDC and state health departments)
NHDS	National Hospital Discharge Survey, United States (NCHS/CDC)
NAMCS	National Ambulatory Medical Care Survey, United States (NCHS/CDC)
NDTI	National Disease and Therapeutic Index, United States (private sources)
NSFG	National Survey of Family Growth, United States (NCHS/CDC)
NHANES	National Health and Nutrition Survey, United States (NCHS/CDC)
	Hispanic Health and Nutrition Survey, United States (NCHS/CDC)
	HANES I Followp-up Study, United States (NCHS/CDC)

VI. Administrative data-collection systems

PAS	Professional Activity Studies, United States (CPHA)
MDHIS	McDonnell Douglas Hospital Information System, United States
BDMP	Birth Defects Monitoring Program, United States (NCEH/CDC)

MEDPAR	Medicare Provider Analysis and Review, United States (HCFA)
HASS	Home Accident Surveillance System, United Kingdom
EHLASS	European Home and Leisure Accident Surveillance System, Europe
NEISS	National Electronic Injury Surveillance System, United States (CPSC)
DAWN	Drug Abuse Warning Network, United States (NIDA)
PRAMS	Pregnancy Risk Assessment Monitoring System, United States (NCCDPHP/CDC and state health departments)

REFERENCES

1. Alderson M. International mortality statistics. New York: Facts on File, Inc., 1981.

2. Ashley JSA, Cole SK, Kilbane MPJ. Health information resources: United Kingdom--health and social factors. In: Holland WW, Detels R, Knox G (eds). Oxford Textbook of Public Health. 2nd edition. Vol. 2 Methods of Public Health Surveillance. Oxford, England: Oxford University Press, 1991:29-54.

3. Yanagawa H, Nagai M. Health information resources: Japan--health and social factors. In: Holland WW, Detels R, Knox G (eds.). Oxford textbook of public health. 2nd edition. Vol. 2: methods of public health surveillance. Oxford, England: Oxford University Press, 1991:55-66.

4. National Center for Health Statistics. International Health Data Reference Guide, 1991. DHHS Publication no. (PHS) 92-1007. Hyattsville, Md.: National Center for Health Statistics, 1992.

5. World Health Organization. World health statistics annual. Geneva, Switzerland: WHO, 1988.

6. United Nations. 1989 demographic yearbook. 41st issue. New York:Department of International and Social Affairs, Statistical Office, 1991.

7. World Health Organization. Targets for health for all: targets in support of the European regional strategy for health for all. Copenhagen, Denmark: WHO Regional Office for Europe, 1985.

8. National Office of Vital Statistics. Reported incidence of selected notifiable diseases, United States, each division and state, 1920-50. Vital Statistics Special Reports. Washington, D.C.:U.S. Government Printing Office, 1953;37:180.

9. Pearce N. Health information resources: United States--health and social factors. In: Holland WW, Detels R, Knox G (eds.). Oxford textbook of public health. 2nd edition. Vol. 2: Methods of public health surveillance. Oxford, England:Oxford University Press, 1991:11-28.

10. Moro ML, McCormick A. Surveillance for communicable disease. In: Eylenbosch WJ and Noah ND (eds.). Surveillance in health and disease. Oxford, England:Oxford University Press, 1988:166-82.

11. Chorba TL, Berkelman RL, Safford SK, Gibbs N, Hull HF. Mandatory reporting of infectious diseases by clinicians. *MMWR* 1990;39(RR-9):1-17.

12. Centers for Disease Control. Summary of notifiable diseases, United States, 1991. *MMWR* 1991;40.

13. Freund E, Seligman PJ, Chorba TL, Safford SK, Drachman JG, Hull HF. Mandatory reporting of occupational diseases by clinicians. *MMWR* 1990;39(RR-9):19-28.

14. Seligman PJ, Matte TD. Case definitions in public health. *Am J Public Health* 1991;81:161-2.

15. Centers for Disease Control. Childhood lead poisoning, New York City, 1988. *MMWR* 1990;39(SS-4):1-7.

16. Green LA, Lutz LJ. Notions about networks; primary care practices in pursuit of improved primary care. In: Mayfield J and Grady ML (eds.). Primary care research: agenda for the 90s. Rockville, Md.:Agency for Health Care Policy and Research, 1990:13-22.

17. Centers for Disease Control. Case definitions for public health surveillance. *MMWR* 1990;39(No. RR-13):1-43.

18. Centers for Disease Control. Vaccine adverse event reporting system--United States. *MMWR* 1990;39;730-3.

19. Faich GA. National adverse drug reaction reporting, 1984-1989. *Arch Intern Med* 1991;151:1645-7.

20. Rossi AC, Bosco L, Faich GA, Tanner A, Temple R. The importance of adverse reaction reporting by physicians: suprofen and the flank pain syndrome. *JAMA* 1988;259:1203-4.

21. Kimmel K. Surveillance for adverse reactions to drugs. In: Eylenbosch WJ and Noah ND (eds.). Surveillance in health and disease. Oxford, England:Oxford University Press, 1988: 244-54.

22. Inman WHW. Hazards of drug therapy. In: Holland WW, Detels R, Knox G (eds.). Oxford textbook of public health. 2nd edition. Vol. 2: methods of public health surveillance. Oxford, England:Oxford University Press, 1991:481-500.

23. Centers for Disease Control. National electronic telecommunications system for surveillance--United States, 1990-1991. *MMWR* 1991;40:502.

24. Tsai TF. Arboviral infections in the United States. *Infect Dis Clin North Am* 1991;5(1):73-102.

25. Fishbein D. Rabies. *Infect Dis Clin North Am* 1991;5(1):53-74.

26. Craven RB, Barnes AM. Plague and tularemia. *Infect Dis Clin North Am* 1991;5(1):165-76.

27. Buchstein SR, Gardner P. Lyme Disease. *Infect Dis Clin North Am* 1991;5(1):103-16.

28. Weber DJ, Walker DH. Rocky Mountain spotted fever. *Infect Dis Clin North Am* 1991;5(1):19-36.

29. Sacks JJ. Utilization of case definitions and laboratory reporting in the surveillance of notifiable communicable diseases in the United States. *Am J Public Health* 1985;75:1420-2.

30. Berkleman RL, Buehler JW. Surveillance. In: Holland WW, Detels R, Knox G (eds). Oxford Textbook of Public Health. 2nd edition. Vol. 2 Methods of Public Health Surveillance. Oxford, England:Oxford University Press, 1991:161-76.

31. Sherman IL, Langmuir AD. Usefulness of communicable disease reports. *Public Health Rep* 1952;67:1249-57.

32. Thacker SB, Berkleman RL. Public health surveillance in the United States. *Epidemiol Rev* 1988;10:164-90.

33. Serfling RE, Sherman IL. Problems in improving reported morbidity data as a tool for epidemiological research. CDC bulletin. Atlanta, Ga.:Public Health Service, October 1951:24-7.

34. Fife D, McAnaney, Rahman MA. Changes in AIDS case reporting after hospital site visits. *Am J Public Health* 1991;81:1648-50.

35. Conway GA, Colley-Niemeyer B, Pursley C *et al*. Underreporting of AIDS cases in South Carolina, 1986 and 1987. *JAMA* 1989;262:2859-63.

36. Selik RM, Buehler JW, Karon JM, Chamberland ME, Berkelman RL. Impact of the 1987 revision of the case definition of acquired immune deficiency in the United States. *J Acquir Immune Defic Syndr* 1990;3:73-82.

37. Cohen DA, Boyd D, Prabhudas I, Mascola L. The effects of case definition in maternal screening and reporting criteria on rates of congenital syphilis. *Am J Public Health* 1990;80:316-7.

38. Centers for Disease Control. Congenital syphilis--New York City, 1986-1988. *MMWR* 1989;38:825-9.

39. Centers for Disease Control. Lyme disease surveillance--United States, 1989-1990. *MMWR* 1991;40:417-21.

40. Andrews JM, Quinby GE, Langmuir AD. Malaria eradication in the United States. *Am J Public Health* 1950;40:1405-11.

41. Langmuir AD. The surveillance of communicable diseases of national importance. *N Engl J Med* 1963;268:182-92.

42. Noah N. Transmissible agents. In: Holland WW, Detels R, Knox G (eds.). Oxford textbook of public health. 2nd edition. Vol. 2: methods of public health surveillance. Oxford, England:Oxford University Press 1991:417-35.

43. Holmberg SD, Osterholm MT, Senger KA, Cohel ML. Drug-resistant *Salmonella* from animals fed antimicrobials. *N Engl J Med* 1984;311:617-22.

44. Centers for Disease Control. Measles prevention: recommendations of the Immunization Practices Advisory Committee (ACIP). *MMWR* 1989;38(No. S-9):1-18.

45. Centers for Disease Control. Hepatitis B virus: a comprehensive strategy for eliminating transmission in the United States through universal chilhood vaccination; recommendations of the Immunization Practices Advisory Committee (ACIP). *MMWR* 1991;40 No. RR-13.

46. Nathanson N, Langmuir AD. The Cutter incident: poliomyelitis following formaldehyde-inactivated poliovirus vaccination in the United States during the spring of 1955. I. Background. *American Journal of Hygiene* 1963;78:16-28.

47. Centers for Disease Control. Summary of 1990-1991 influenza season, United States. Influenza Branch, Division of Viral and Rickettsial Diseases. Atlanta, Ga.: 1991.

48. Centers for Disease Control. Eosinophilia-myalgia syndrome--New Mexico. *MMWR* 1989;38:765-7.

49. Watkins M, Lapham S, Hoy W. Use of a medical center's computerized health care data base for notifiable disease surveillance. *Am J Public Health* 1991;81;637-39.

50. Monson RR. Occupational epidemiology. 2nd edition. Boca Raton, Fla.:CRC Press, Inc., 1990.

51. World Health Organization. Manual of international statistical classification of diseases, injuries, and causes of death. Ninth Revision. Geneva, Switzerland: WHO, 1977.

52. Ruzicka LT, Lopez AD. The use of cause-of-death statistics for health situation assessment: national and international experiences. *World Health Stat Q* 1990;43:249-62.

53. Brzezinski ZJ. Mortality indicators and health-for-all strategies in the WHO European region. *World Health Stat Q* 1986;39:365-78.

54. Kleinman JC. The slowdown in the infant mortality decline. *Paediatr Perinat Epidemiol* 1990;4:373-81.

55. Cooper R, Sempos C, Hsieh SC, Kovar MG. Slowdown in the decline of stroke mortality in the United States, 1978-1986. *Stroke* 1990;21:1274-9.

56. Schwartz E, Kofie VY, Rivo M, Tuckson R. Black/white comparisons of deaths preventable by medical Intervention: United States and the District of Columbia 1980-1986. *Int J Epidemiol* 1990;19:591-8.

57. McCord C, Freeman HP. Excess mortality in Harlem. *N Engl J Med* 1990;322:173-7.

58. Kleinman JC, Kiely JL. Postneonatal mortality in the United States: an international perspective. *Pediatrics* 1990;86:1091-97.

59. Li J-Y. Cancer mapping as an epidemiologic research resource in China. *Recent Results Cancer Res* 1989;114:115-36.

60. Walter SD, Birnie SE. Mapping mortality and morbidity patterns: an international comparison. *Int J Epidemiol* 1991;20:678-89.

61. Fingerhut LA, Kleinman JC. International and interstate comparisons of homicide among young males. *JAMA* 1990;263:3292-5.

62. Powell-Griner E, Woolright A. Trends in infant deaths from congenital anomalies; results from England and Wales, Scotland, Sweden, and the United States. *Int J Epidemiol* 1990;19:391-8.

63. Office of Population Censuses and Surveys. The Registrar General's Decennial Supplement 1970-72, England and Wales. Occupational Mortality. Series DS No. 1. London:Her Majesty's Stationery Office, 1978.

64. New estimates of maternal mortality. *Wkly Epidemiol Rec* 1991;66:345-52.

65. Lew JF, Glass RI, Gangarosa RE, Cohen IP, Bern C, Moe CL. Diarrheal deaths in the United States, 1979 through 1987. *JAMA* 1991;265:3280-4.

66. Weiss KB, Wagener DK. Asthma surveillance in the United States: a review of current trends and knowledge gaps. *Chest* 1990;98:179S-184S.

67. Sutter RW, Cochi SL, Brink EW, Sirotkin BI. Assessment of vital statistics and surveillance data for monitoring tetanus mortality, United States, 1979-1984. *Am J Epidemiol* 1990;131:132-42.

68. Hardy RJ, Schroder GD, Cooper SP, Buffler PA, Prichard HM, Crane A. Surveillance system for assessing health effects from hazardous exposures. *Am J Epidemiol* 1990:132;S32-S42.

69. Pickle LW, Mason TJ, Howard N, Hoover R, Fraumeni JF. Atlas of U.S. cancer mortality among whites: 1950-1980. DHHS Publ No (NIH) 87-2900. Washington, D.C.:U.S. Government printing Office, 1987.

70. Brownson RC, Smith CA, Jorge NE *et al*. The role of data-driven planning and coalition development in preventing cardiovascular disease. *Public Health Rep* 1992;107:32-7.

71. Boss LP, Suarez L. Use of data to plan cancer prevention and control programs. *Public Health Rep* 1990;105:354-60.

72. Chan LS, Portnoy B, Black BL. California's use of health statistics in child health planning. *Am J Prev Med* 1985;1:24-30.

73. Department of Health and Human Services. Healthy people 2000: national health promotion and disease prevention objectives. U.S. Department of Health and Human Services. Washington, D.C.:U.S. Government Printing Office, DHHS Publication No (PHS) 91-50212, 1991.

74. Percy C, Staneck E, Gloeckler L. Accuracy of cancer death certificates and its effect on cancer mortality statistics. *Am J Public Health* 1981;71:242-50.

75. Percy C, Muir C. The international comparability of cancer mortality data: results of an international death certificate study. *Am J Epidemiol* 1989;129:934-46.

76. Kelson MC, Heller RF. The effect of death certification and coding practices on observed differences in respiratory disease mortality in 8 EEC countries. *Rev Epidemiol Sante Publique* 1983;31:423-2.

77. Vital and health statistics: the 1989 revision of the U.S. standard certificates and reports. Series 4: documents and committee reports. No. 28. DHHS Publ no (PHS) 91-1465. Hyattsville, Md.: National Center for Health Statistics, 1991.

78. National Center for Health Statistics. Physicians' handbook on medical certification of death. Hyattsville, Md.:National Center for Health Statistics, 1987.

79. National Center for Health Statistics. Hospitals' and physicians' handbook on birth registration and fetal death reporting. Hyattsville, Md.:National Center for Health Statistics, 1987.

80. Taffel SM, Ventura SJ, Gay GA. Revised U.S. certificate of birth--new opportunities for research on birth outcome. *Birth* 1989;16:188-93.

81. Freedman MA, Gay GA, Brockert JE, Potrzebowski PW, Rothwell CJ. The 1989 revision of the U.S. standard certificates of live birth and death and the U.S. standard report of fetal death. *Am J Public Health* 1988;78:168-72.

82. Funeral director's handbook on death registration and fetal death reporting. Hyattsville, Md.:National Center for Health Statistics, 1987.

83. Kleinman JC, Kiely JL. Infant mortality. *Healthy People 2000* statistical notes. Hyattsville, Md.:National Center for Health Statistics, 1991:1(no 2).

84. Vital statistics of the United States, 1988. Vol 1 - Natality. DHHS Publ No (PHS) 90-1100. Hyattsville, Md.: National Center for Health Statistics, 1990.

85. Vital statistics of the United States, 1988. Vol II - Mortality, Part A. DHHS Publ No (PHS) 90-1100. Hyattsville, Md.: National Center for Health Statistics, 1990.

86. Lopez AD. Causes of death: an assessment of global patterns of mortality around 1985. *World Health Stat Q* 1990;43:91-104.

87. Becker TM, Wiggins CL, Key CR, Samet JM. Signs, symptoms and ill-defined conditions: a leading cause of death among minorities. *Am J Epidemiol* 1990;131:664-8.

88. Report of a workshop on improving cause-of-death statistics. In: National Committee on Vital and Health Statistics, 1990. DHHS Publication no. (PHS) 91-1205. Hyattsville, Md: National Center for Health Statistics, 1991:53-77.

89. Report of the second workshop on improving cause-of-death statistics. In: National Committee on Vital and Health Statistics, 1991. DHHS Publication no. (PHS) 92-1205. Hyattsville, Md.: National Center for Health Statistics, 1992:52-83.

90. Baron RC, Dicker RC, Bussell KE, Herndon JL. Assessing trends in mortality in 121 U.S. Cities, 1970-79, from all causes and from pneumonia and influenza. *Public Health Rep* 1988;103:120-8.

91. Interagency Committee on Infant Mortality. Data and surveillance systems related to programs to reduce infant mortality: a directory of federal efforts. Atlanta, Ga.:Public Health Service, January 1992.

92. Enterline PE. Extrapolation from occupational studies: a substitute for environmental epidemiology. *Environ Health Perspect* 1981;42:39-44.

93. National Institute for Occupational Safety and Health. National traumatic occupational fatalities, 1980-1985. Atlanta, Ga.:Public Health Service, March 1989.

94. Centers for Disease Control. Injuries associated with horseback riding. *MMWR* 1990;39:329-32.

95. Centers for Disease Control. Dilaudid-related deaths--District of Columbia, 1987. *MMWR* 1988;37:425-7.

96. Centers for Disease Control. Medical examiner/coroner creports of hurricanes associated with Hurricane Hugo--Puerto Rico, 1989. *MMWR* 1989;38:680-2.

97. Centers for Disease Control. Medical examiner summer mortality surveillance system. *MMWR* 1982;31:336-43.

98. Centers for Disease Control. Earthquake-associated deaths--California, 1989. *MMWR* 1989;38:767-70.

99. Centers for Disease Control. Child passenger restraint use and motor-vehicle-related fatalities. *MMWR* 1991;40:600-2.

100. Centers for Disease Control. Premature mortality due to alcohol-related motor vehicle traffic fatalities--United States, 1987. *MMWR* 1988;37:753-5.

101. Centerwell BS. Homicide and the prevalence of handguns: Canada and the United States, 1976 to 1980. *Am J Epidemiol* 1991;11:1245-60.

102. Rutstein DD, Mullan RJ, Frazier JM, Halperin WE, Melius JM, Sesito JP. Sentinel health events (occupational); a basis for physician recognition and public health surveillance. *Am J Public Health* 1983;73:1054-62.

103. Woodall JP. Epidemiological approaches to health planning, management, and evaluation. *World Health Stat Q* 1988;41:2-10.

104. Van Casteren V. Inventory of sentinel health information systems with GPs in European countries. Eurosentinel. Brussels, Belgium:Institute of Hygiene and Epidemiology, January 1991.

105. Van Casteren V, Leurquin P. Eurosentinel: Concerted Action on Sentinel Health Information Systems with General Practitioners. Final Report. Brussels. Institute of Hygiene and Epidemiology. August 1991.

106. Chavez GF, Mulinare J, Cordero JF. Leading major congenital malformations among minority groups in the United States, 1981-1986. *JAMA* 261:1989;205-8.

107. Roper WL, Winkenwerder W, Hackbarth GM, Krakauer H. Effectiveness in health care: an initiative to evaluate and improve medical practice. *N Engl J Med* 1988;1197-202.

108. Hartz AJ, Krakauer H, Kuhn EM *et al*. Hospital characteristics and mortality rates. *N Engl J Med* 1989;321:1720-5.

109. Rutstein DD, Berenberg W, Chalmbers TC, Child CG, Fishman AP, Perdin EB. Measuring the quality of medical care. *N Engl J Med* 1976;294:582-8.

110. Baker EL. Sentinel event notification system for occupational risks (SENSOR): the concept. *Am J Public Health* 1989;79S:18-20.

111. Centers for Disease Control. Consensus set of health status indicators for general assessment of community health status--United States. *MMWR* 1991;40:449-59.

112. Alter MJ, Hadler SC, Margolis HS *et al*. The changing epidemiology of hepatitis B in the United States: need for alternative vaccinations strategies. *JAMA* 1990;262;1201-5.

113. Alter MJ, Hadler SC, Judson FN, *et al*. Risk factors for acute non-A non-B hepatitis in the United States and association with hepatitis C virus infection. *JAMA* 1990;264:2231-5.

114. Pappaioanou M, Dondero TJ, Petersen LR, Onorato IM, Sanchez CD, Curran JW. The family of HIV seroprevalence surveys: objectives, methods, and use of sentinel surveillance for HIV in the United States. *Public Health Rep* 1990;105:113-9.

115. Green LA, Wood M, Becker L *et al*. The Ambulatory Sentinel Practice Network: purposes, methods, and policies. *J Fam Pract* 1984;18:275-80.

116. Hughes JP, van Belle G, Kukull W, Larson EB, Teri L. On the uses of registries for Alzheimer disease. *Alzheimer Dis Assoc Disord* 1989;3:205-17.

117. Froom J, Culpepper J, Grob P *et al*. Diagnosis and antibiotic treatment of acute otitis media: report from International Primary Care Network. *British Medical Journal* 1990;300:582-6.

118. Van Casteren V, Leurquin P, Declercq E *et al*. Study of the use of some selected groups of laboratory tests in general practice. Summary report. Eurosentinel. Brussels, Belgium: Institute of Hygiene and Epidemiology. June 1991.

119. Fleming DM, Crombie DL. Weekly returns service report for 1990. Birmingham, England:Birmingham Research Unit of the Royal College of General Practitioners, June 1991.

120. Fleming D, Ayres JG. Diagnosis and patterns of incidence of influenza, influenza-like illness and the common cold in general practice. *Journal of the Royal College of General Practitioners* 1988;38:159-62.

121. Netherlands Institute of Primary Care. Continuous morbidity registration sentinel stations in the Netherlands. Wtrecht:NIVEL Netherlands Institute of Primary Health Care, September 1991.

122. Bartelds AIM, Fracheboud J, van der Zee J. The Dutch Sentinel Practice Network: relevance for public health policy. Utrecht:Netherlands Institute for Primary Care (NIVEL), 1989.

123. Sprenger MJW, Mulder PGH, Beyer WEP, Masurel N. Influenza: relation of mortality to morbidity parameters--Netherlands, 1970-1989. *Int J Epidemiol* 1991;20:1118-24.

124. Lobet MP, Stroobant A, Mertens R *et al*. Tool for validation of the network of sentinel general practitioners in the Belgian health care system. *Int J Epidemiol* 1987;16:612-8.

125. Stroobant A, Van Casteren V, Thiers G. Surveillance systems from primary-care data: surveillance through a network of sentinel general practitioners. In: Eylenbosch WJ, Noah ND (eds.). Surveillance in health and disease. Oxford, England:Oxford University Press, 1988:62-74.

126. Stroobant A Lamotte J, Van Casteren V. Epidemiological surveillance of measles through a network of sentinel general practitioners in Belgium. *Int J Epidemiol* 1986;15:386-91.

127. Valleron A-J, Bouvet E, Gaernerin P *et al*. A computer network for the surveillance of communicable diseases: the French experiment. *Am J Public Health* 1986;76:1289-92.

128. Costagliola D, Flauhault A, Galinec D, Garnerin P, Menares J, Valleron A-J. A routine tool for detection and assessment of epidemics of influenza-like syndromes in France. *Am J Public Health* 1991;81:97-9.

129. Garnerin P. Regional distribution of influenza-like syndrome during weeks 49-51 of 1989 (number of cases/physician/week). *British Medical Journal* 1990;300:701.

130. Surveillance of influenza-like diseases through a National Computer Network--France, 1984-1989. *MMWR* 1989;38:585-7.

131. Massari V, Brunet JB, Bouvet E, Valleron AJ. Attitudes towards HIV-antibody testing among general practitioners and their patients. *Eur J Epidemiol* 1988;4:435-8.

132. Maurice S, Megraud F, Vivares C *et al*. Telematics: a new tool for epidemiologic surveillance of diarrhoeal diseases in the Aquitaine sentinel network. *British Journal of Medicine* 1990;300:514-670.

133. Centers for Disease Control. Influenza activity -- United States, 1991-92. *MMWR* 1991;40:809-10.

134. Ambulatory Sentinel Practice Network. 1991 Convocation. Chicago, September 1991.

135. Freeman WL, Green LA, Becker LA. Pelvic Inflammatory disease in primary care: a report from ASPN. *Fam Med* 1988;20:192-6.

136. Green LA, Becker LA, Freeman WL, Iverson DC, Reed FM. Spontaneous abortion in primary care; a report from ASPM. *J Am Board Fam Pract* 1988;1:15-23.

137. Ambulatory Sentinel Practice Network. An exploratory report of chest pain in primary care. A report from ASPN. *J Am Board Fam Pract* 1990;3:143-50.

138. Peterson LR, Calonge NB, Chamberland ME, Engel R, Herring NC. Methods of surveillance for HIV infection in primary care outpatients in the United States. *Public Health Rep* 1990;105:158-62.

139. Hickner J. Practice-based primary care research networks. In: Hibbard H, Nutting PA, and Grady (eds.). Primary care research: theory and methods. Rockville, Md.:Agency for Health Care Policy and Research, 1991:13-22.

140. Culpepper L, Froom J. The International Primary Care Network: purpose, methods, and policies. *Fam Med* 1988;20:197-201.

141. Goldberg J, Gelfand HM, Levy PS. Registry evaluation methods: a review and case study. *Epidemiol Rev* 1980;2:210-20.

142. Weddell JM. Registers and registries: a review. *Int J Epidemiol* 1973;2:221-8.

143. Pollack DA, McClain PW. Trauma registries: current status and future prospects. *JAMA* 1989;262:2280-3.

144. Ahbolm A. Acute myocardial infarction in Stockholm--a medical information system as an epidemiologic tool. *Int J Epi* 1978:271-6.

145. Whiting L. The central registry for child abuse cases: rethinking basic assumptions. *Child Welfare* 1977;56:761-7.

146. Hammar N, Nervrand C, Ahlmark G *et al*. Identification of cases of myocardial infarction: hospital discharge data and mortality compared to myocardial infarction community registers. *Int J Epidemiol* 1991:114-20.

147. Brown LJ, Scott RS. A population-based register-development and applications. *Community Health Stud* 1988;12:437-43.

148. Eisnebud M, Lisson J. Epidemiological aspects of berrylium-induced nonmalignant lung disease: a 30-year update. *J Occup Med* 1983;25:196-202.

149. Johnson A, King R. A regional register of early childhood impairments: a discussion paper. *Community Medicine* 1989;11:352-63.

150. Agency for Toxic Substances and Disease Registry. Policies and procedures for establishing a national registry of persons exposed to hazardous substances. Atlanta, Ga.: Agency for Toxic Substances and Disease Registry, 1988.

151. Zack M. The pros and cons of exposure registries. In: Proceedings of the National Conference on Hazardous Wastes and Environmental Emergencies. 1985:161-64.

152. Goldhaber MK, Tokuhata GK, Digon E *et al*. The Three Mile Island population registry. *Public Health Rep* 1983;98:603-9.

153. The EUROCAT Working Group. Preliminary evaluation of the impact of the Chernobyl radiological contamination on the frequency of central nervous system malformations in 18 regions of Europe. *Paediatr Perinat Epidemiol* 1988;2:253-64.

154. Anderson RE, Key CR, Yamamoto T, Thorslund T. Aging in Hiroshima and Nagasaki atomic bomb survivors. Speculations based upon the age-specific mortality of persons with malignant neoplasms. *Am J Pathol* 1974;75:1-11.

155. Sprince NL, Kaxemi H. Beryllium disease. In: Rom WN (ed.). Environmental and occupational medicine. Boston, Massachusetts: Little, Brown, and Co., 1983:481-90.

156. Austin DF. Cancer registries: a tool in epidemiology. In: Lilienfeld AM (ed.). Reviews in cancer epidemiology. Vol 2. New York: Elsevier, 1983:119-39.

157. Menck HR, Garfinkel L, Dodd GD. Preliminary report of the National Cancer Data Base. *Cancer* 1991;41:7-8.

158. Centers for Disease Control. National survey of trauma registries--United States, 1987. *MMWR* 1989;38:857-9.

159. Centers for Disease Control. Report from the trauma registry workshop, including recommendations for hospital-based trauma registries. *J Trauma* 1989:29;827-34.

160. Blot WJ, Fraumeni JF Jr, Mason TJ, Hoover RN. Developing clues to environmental cancer: a stepwise approach with the use of cancer mortality data. *Environ Health Perspect* 1979;32:53-8.

161. MacLennan R, Muir C, Steinitz R, Winkler A (eds.). Cancer registration and its techniques. IARC scientific publications, no. 21. Lyon, France: International Agency for Research on Cancer, 1978.

162. Clemmesen J. Uses of cancer registration in the study of carcinogenesis. *J Natl Canc Inst* 1981;67:5-13.

163. Shimizu Y, Schull WJ, Kato H. Cancer risk among atomic bomb survivors. The RERF Life Span Study. Radiation Effects Research Foundation. *JAMA* 1990;264:601.

164. Tsyb AF, Dedenkov AN, Ivanov VK, Stepanenko VF, Pozhidaev VV. The development of an all-union registry of persons exposed to radiation resulting from the accident at the Chernobyl atomic power station. *Medical Radiology* 1989;34:3-6.

165. Axelson O. Occupational and environmental exposures to radon: cancer risks. *Annu Rev Public Health* 1991;12:235-55.

166. Rowland RE, Stehney AF, Lucas HF Jr. Dose-response relationships for female radium dial workers. *Radiat Res* 1978;76:368-83.

167. Archer VE. Lung cancer risks of underground miners: cohort and case-control studies. *Yale J Biol Med* 1988;61(3):183-93.

168. Landrigan PJ, Wilcox KR Jr, Silva J Jr, Humphrey HE, Kauffman C, Heath CW, Jr. Cohort study of Michigan residents exposed to polybrominated biphenyls: epidemiologic and immunologic findings. *Ann N Y Acad Sci* 1979;320:284-94.

169. Ries LAG, Hankey BF, Miller BA, Hartman AM, Edwards BK (eds.). Cancer statistics review 1973-88. NIH publication no. (NIH) 91-2789. Bethesda, Md.: National Cancer Institute, 1991.

170. Muir C, Waterhouse J, Mack T, Powell J, Whelan S (eds.). Cancer incidence in five continents. Volume V. Lyon, France: International Agency for Research on Cancer, 1987.

171. Parkin D. Surveillance of cancer. In: Eylenbosch WJ, Noah ND (eds.). Surveillance in health and disease. New York: Oxford University Press. 1988 pp 125-42.

172. Edmonds LD, Layde PM, James LM, Flynt JW, Erickson JD, Oakley GP Jr. Congenital malformations surveillance: two American systems. *Int J Epidemiol* 1981;10:247-52.

173. Lynberg MC, Edmonds LD. Surveillance of birth defects. In: Halperin WE, Baker EL, Monson RR (eds.). Public health surveillance. New York:Van Nostrand Reinhold, 1992:157-77.

174. Holtzman NA, Khoury MJ. Monitoring for congenital malformations. *Annu Rev Public Health* 1986;7:237-66.

175. Erickson JD, Mulinare J, McClain PW *et al.* Vietnam veterans' risks for fathering babies with birth defects. *JAMA* 1984;252:903-12.

176. Becerra JE, Khoury MJ, Cordero JF, Erickson JD. Insulin-dependent diabetes mellitus in pregnancy and risk for specific birth defects. *Pediatr Res* 1988;23:266A.

177. Mulinare J, Cordero JD, Erickson JD, Berry RJ. Periconceptual use of multivitamens and the occurrence of neural tube defects. *JAMA* 1988;260:3141-5.

178. Weatherall JA, de Wals P, Lechat MF. Evaluation of information systems for the surveillance of congenital malformations. *Int J Epidemiol* 1984;13:193-6.

179. Lechat MF. EUROCAT report: surveillance of congenital anomalies, years 1980-1986. Brussels: Catholic University of Louvain, 1989.

180. Lammer EJ, Sever LE, Oakley GP, Jr. Teratogen update: valproic acid. *Teratology* 1987;35(3):465-73.

181. Kovar MG. Data systems of the National Center for Health Statistics. Vital & Health Statistics. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 89-1325, (Vital & Health Statistics; series 1; no. 23), 1989.

182. Massey JT. Overview of the National Health Interview Survey and its sample design. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 89-1384 (Vital & Health Statistics; series 2; no. 110), 1987:1-5.

183. Moore TF, Tadros W. The 1985-94 NHIS sample design. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 89-1384 (Vital & Health Statistics; series 2; no. 110), 1989:18-27.

184. Centers for Disease Control. Behavior risk factor surveillance, 1988. *MMWR* 1990;39(Suppl 2):1-6.

185. Centers for Disease Control. Increased awareness in urban and rural areas--Missouri, 1988-91. *MMWR* 1992:41;323-5.

186. Centers for Disease Control. Cigarette smoking among Chinese, Vietnamese, and Hispanics, 1989-91. *MMWR* 1992;41:362-7.

187. Kolbe LJ. An epidemiological surveillance system to monitor the prevalence of youth behaviors that most affect health. *Health Education* 1990;21(6):44-4.

188. Centers for Disease Control. Participation of high school students in school physical education--United States, 1990. *MMWR* 1991;40(35):607,613-5.

189. Centers for Disease Control. Tobacco use among high school students--United States, 1990. *MMWR* 1991;40(36):617-9.

190. Centers for Disease Control. Attempted suicide among high school students--United States, 1990. *MMWR* 1991;40(37):633-5.

191. Centers for Disease Control. Weapon-carrying among high school students--United States, 1990. *MMWR* 1991;40(40):681-4.

192. Centers for Disease Control. Body-weight perception and selected weight-management goals and practices of high school students--United States, 1990. *MMWR* 1991;40(43):741,747-50.

193. Centers for Disease Control. Sexual behavior among high school students--United States, 1990. *MMWR* 1992;40(51-52):885-8.

194. Centers for Disease Control. Current tobacco, alcohol, marijuana, and cocaine use among high school students--United States, 1990. *MMWR* 1991;40(38):659-63.

195. Graves EJ. National Hospital Discharge Survey. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 89-1760 (Vital & Health Statistics; series 13;no. 99), 1989.

196. Nelson C, McLemore T. The National Ambulatory Medical Care Survey: 1975-81 and 1985. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 88-1754 (Vital & Health Statistics; series 13; no. 93), 1988.

197. Hahn RA, Teutsch SM, Rothenberg RB, Marks JS. Excessive deaths from nine chronic diseases in the United States, 1986. *JAMA* 1990;264;2654-9.

198. DeLozier JE, Gagnon RO. National Ambulatory Medical Care Survey, 1989 summary. Advance data from vital and health statistics of NCHS. Hyattsville, Md.: National Center for Health Statistics, 1991;203:1-11.

199. Schilling S, Wilson D. Wisconsin Amublatory Medical Care Survey, 1986-1987. Madison: Wisconsin Department of Health and Social Services, 1987.

200. Arrowsmith JB, Kennedy DL, Kuritsky JN, Faich GA. National patterns of aspirin use and Reye syndrome reporting, United States, 1980 to 1985. *Pediatrics* 1987;79:858-63.

201. Mathiowetz N, Northrup D, Sperry S, Waksberg J. Linking the National Survey of Family Growth with the National Health Interview Survey. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 87-1377 (Vital & Health Statistics; series 2; no. 103), 1987.

202. Dawson DA. Family structure and children's health: United States, 1988. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 91-1506, (Vital & Health Statistics; series 10; no. 178), 1991.

203. Centers for Disease Control and Health Resources and Services Administration. Health Department Profiles. Maternal Infant and Child Health Programs Data Analysis and Tracking Approaches Conference. Atlanta, Ga.:Public Health Service, January 1992.

204. McDowell A, Engel A, Massey JT, Maurer K. Plan and operation of the Second National Health and Nutrition Examination Survey, 1976-1980. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 81-1317 (Vital & Health Statistics; series 1; no. 15), 1981.

205. Miller H. Plan and operation of the health and nutrition examination survey: United States--1971-1973. Hyattsville, Maryland: National Center for Health Statistics. DHEW publication no. (HRA) 76-1310 (Vital & Health Statistics; series 1; no. 10a), 1973.

206. Maurer KR. Plan and operation of the Hispanic health and nutrition examination survey 1982-84. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 85-1321 (Vital & Health Statistics; series 1; no. 19), 1985.

207. Finucane FF, Freid VM, Madans JH *et al*. Plan and operation of the NHANES I epidemiologic followup study, 1986. Hyattsville, Maryland: National Center for Health Statistics. DHHS publication no. (PHS) 90-1307 (Vital & Health Statistics; series 1; no. 25), 1990.

208. Annest JL, Pirkle JL, Makuc D, Neese JW, Bayse DD, Kovar MG. Chronological trend in blood lead levels between 1976 and 1980. *N Engl J Med* 1983;308(23):1373-7.

209. Lunde AS, Lundeborg S, Lettenstrom GS, Thygesen L, Huebner J. The person-number systems of Sweden, Norway, Denmark, and Israel. Hyattsville, Md.: National Center for Health Statistics. DHHS publication no. (PHS) 80-1358 (Vital and Health Statistics; series 2, no. 84), 1980.

210. Naessen T, Parker R, Persson I, Zack M, Adami H-O. Time trends in incidence rates of first hip fracture in the Uppsala health care region, Sweden, 1965-1983. *Am J Epidemiol* 1989;130:289-99.

211. Strom BL, Carson JL. Use of automated data bases for pharmacoepidemiology research. *Epidemiol Rev* 1990:12;87-107.

212. West R. Saskatchewan health data bases: a developing resource. *Am J Prev Med* 1988:4 Supplement.

213. Guess HA, West R, Strand LM *et al.* Fatal upper gastrointestinal hemorrhage or perforation among users and nonusers of nonsteroidal anti-inflammatory drugs in Saskatchewan, Canada, 1983. *J Clin Epidemiol* 1988;41:35-45.

214. West R, Sherman GJ, Downey W. A record linkage study of valproate and malformations in Saskatchewan. *Can J Public Health* 1986;76:226-8.

215. Kurland LT, Schoengerg BS, Annegers JF *et al.* The incidence of primary intracranial neoplasms in Rochester, Minnesota, 1950-1977. *Ann N Y Acad Sci* 1982;381:6-16.

216. Wilson MG, Michet CJ, Ilstrup DM, Melton LJ. Idiopathic symptomatic osteoarthritis of the hip and knee; a population-based incidence study. *Mayo Clin Proc* 1990;65:1214-21.

217. Paterson JG. Surveillance systems from hospital data. In: Eylenbosch WJ, Noah ND (eds.). Surveillance in health and disease. Oxford, England:Oxford University Press, 1988:49-61.

218. Roger FH. The minimum basic data set for hospital statistics in the EEC. Luxembourg:Office for Official Publications of the European Communities, 1981.

219. Agency for Health Care Policy and Research. Report to Congress: the feasibility of linking research-related data bases to federal and non-federal medical administrative data bases. AHCPR No. 91-0003. April 1991.

220. Jick H. The Commission on Professional and Hospital Activities--professional activity study. A national resource for the study of rare illnesses. *Am J Epidemiol* 1979;109:625-7.

221. Public Health Service-Health Care Financing Administration. The international classification of diseases clinical modification, 9th revision. DHHS Publication no (PHS) 80-1260, Washington, D.C.: U.S. Government Printing Office, 1980.

222. Martin ML, Edmonds LD. Use of birth defects monitoring programs for assessing the effects of maternal substance abuse on pregnancy outcomes. In: Methodological issues in controlled studies on effects of prenatal exposure to drug abuse. National Institute on Drug Abuse Research Monograph Series. Washington D.C.:U.S. Government Printing Office, 1991:66-38.

223. Centers for Disease Control. Temporal trends in the prevalence of congenital malformations at birth based on the Birth Defects Monitoring Program, United States, 1979-1987. MMWR 1990;39 (SS-4);19-23.

224. Stroup NE, Edmonds L, O'Brien TR. Renal agenesis and dysgenesis: are they increasing? *Teratology* 1990:42;383-95.

225. Chavez GF, Mulinare J, Edmonds LD. Epidemiology of Rh hemolytic disease of the newborn in the United States. *JAMA* 1991;265:3270-4.

226. Report on the need to collect external cause-of-injury codeds in hospital discharge data systems. In: National Committee on Vital and Health Statistics, 1991. DHHS Publication no. (PHS) 92-1205. Hyattsville, Md.: National Center for Health Statistics, 1992.

227. Bal DG, Kizer KW, Felten PG, Mozar HN, Niemeyer D. Reducing tobacco consumption in California: development of a statewide anti-tobacco use campaign. *JAMA* 1990;264:1570-4.

228. Helbing C, Schieber G. Use of Medicare data in international comparisons. *Health Policy* 1990:15;45-66.

229. Fisher ES, Baron JA, Malenka DJ, Barret J, Bubolz TA. Overcoming potential pitfalls in the use of Medicare data for epidemiologic research. *Am J Public Health* 1990;80:1487-90.

230. Eggers PW, Connerton R, McMullan M. The Medicare experience with end-stage renal disease: trends in incidence, prevalence, and survival. *Health Care Financing Review* 1984;5:69-88.

231. Health Care Financing Administration. Medicare/Medicaid decision support systems: Office of Statistics and Data Management and Strategy. Baltimore, Md.:Health Care Financing Administration Publication (HCFA) 03-272, 1988.

232. Chassin MR *et al*. Variations in the use of medical and surgical services by the Medicare population. *N Engl J Med* 1986;314:285-90.

233. Centers for Disease Control. End-stage renal disease associated with diabetes--United States, 1988. *MMWR* 1989;38;546-8.

234. Kellie SE, Brody JA. Sex-specific and race-specific hip fracture rates. *Am J Public Health* 1990;80:326-8.

235. Wennberg KE, Freeman JL, Shelton RM, Bubolz TA. Hospital use and mortality among Medicare beneficiaries in Boston and New Haven. *N Engl J Med* 1989;321:1168-73.

236. Jacobson SJ, Goldberg J, Miles TP, Brody JA, Stiers W, Rimm AA. Regional variation in the incidence of hip fracture: U.S. white women aged 65 years and older. *JAMA* 1990:264;500-2.

237. Stroup NE, Freni-Titulaer LWJ, Schwartz JJ. Unexpected geographic variation in rates of hospitalization for patients who have fracture of the hip. *J Bone Joint Surg* 1990;72:1294-8.

238. Whittle J, Steinberg EP, Anderson GF, Herbert MS. Accuracy of Medicare claims data for estimation of cancer incidence and resection rates among elderly Americans. *Med Care* 1991;29:1226-36.

239. National Institute of Diabetes, Digestive, and Kidney Diseases. U.S. Renal Data System. USRDS 1991 annual data report. Bethesda, Md.:National Institutes of Health, 1991.

240. France G, Barrow M. Home accident surveillance system. In: Eylenbosch WJ, and Noah ND (eds.). Surveillance in health and disease. Oxford, England:Oxford University Press, 1988; 202-7.

241. Centers for Disease Control. Leading work-related injuries --United States. *MMWR* 1984;33:213-5.

242. Centers for Disease Control. Bicycle-related injuries: data from the National Electronic Injury Surveillance System. *MMWR* 1987;36:269-71.

243. Centers for Disease Control. Poisoning among children-- United States. *MMWR* 1986;35:149-52.

244. Hopkins RS. Consumer product-related injuries in Athens, Ohio, 1980-85: assessment of emergency room-based surveillance. *Am J Prev Med* 1989;5:104-12.

245. Gallagher SS, Finison K, Guyer B, Goodenough S. Incidence of injuries among 87,000 Massachusetts children and adolescents: results of the 1980-81 statewide childhood injury prevention program surveillance system. *Am J Public Health* 1984:74;1340-6.

246. Pollack DA, Holmgreen P, Lui K-J, Kirk ML. Discrepancies in the reported frequency of cocaine-related deaths, United States, 1983 through 1988. *JAMA* 1991;266:2233-7.

247. King WD. Pediatric injury surveillance: use of a hospital discharge data base. *South Med J* 1991:84;342-8.

248. Colliver JD, Kopstein AN. Trends in cocaine abuse reflected in emergency room episodes reported to DAWN. *Public Health Rep* 1991;106:59-68.

249. Volans GN, Wiseman HM. Surveillance of poisoning -- the role of poison control centers. In: Eylenbosch WJ and Noah ND (eds.). Surveillance in health and disease. Oxford, England: Oxford University Press, 1988:255-72.

250. Blanc PD, Rempel D, Maizlish N, Hiatt P, Olson KR. Occupational illness: case detection by poison control surveillance. *Ann Intern Med* 1989;111:238-44.

251. Adams MM, Shulman HB Bruc C, Hogue C, Brogan D, the PRAMS Working Group. The pregnancy risk assessment monitoring system: design, questionnaire, data collection and response rates. *Paediatric and Perinatal Epidemiology* 1991:5;333-46.

252. Griffin MR, Ray WA, Livengood JR et al. Risk of sudden infant death syndrome after immunization with the dipteria-tetanus-pertussis vaccine. *N Engl J Med* 1988:319;618-23.

253. Yip R, Fleshood L, Spillman TC, Binkin NJ, Wong PL, Trowbridge FW. Using linked program and birth records to evaluate coverage and targeting in Tennessee's WIC program. *Public Health Rep* 1991;106:176-80.

254. Centers for Disease Control. Anemia during pregnancy in low-income women. *MMWR* 1990;39:73-6.

255. Yip R, Binkin NJU, Fleshood L, Trowbridge FL. Declining prevalence of anemia among low income children in the United States. *JAMA* 1987;258;1619-23.

256. Gayle HD, Dibley MJ, Marks JS, Trowbridge FL. Malnutrition in the first two years of life. *Am J Dis Child* 1987:141;531-4.

1. U.S. Department of Health and Human Services, Public Health Service. Healthy People 2000. National Health Promotion and Disease Prevention Objectives. 1991. DHHS Pub. No. (PHS) 91-50212.

2. Centers for Disease Control. Consensus set of health status indicators for the general assessment of community health status - United States. MMWR 1991;40:449-451.

3. Chorba TL, Berkelman RL, Saffod SK, Gibbs NP, Hull HF. Mandatory reporting of infectious diseases by clinicians. JAMA 1989;262:3018-3026.

4. American Cancer Society. Cancer Facts and Figures - 1991. American Cancer Society. 1991.

5. Teutsch SM, Herman WH, Dwyer DM, Lane JM. Mortality among diabetic patients using continuous subcutaneous insulin infusion pumps. N Engl J Med 1984;310:361-368.

6. Ellwood PM. Outcomes management. A technology of patient experience. N Engl J Med 1988;318:1549-1556.

Chapter IV

Management of the Surveillance System and Quality Control of Data

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Norma P. Gibbs
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"It is possible to fail in many ways...while to succeed is possible only in one way (for which reason also one is easy and the other difficult--to miss the mark easy, to hit it difficult)."

Aristotle

INTRODUCTION

This chapter provides a description of practical management and quality control of a disease-reporting system for notifiable diseases, at the disease- and injury-report-gathering stage--as in a city/county health department, state health department, or within the federal government. It focuses on disease-reporting systems for notifiable diseases. It is important to note that in most health jurisdictions there are laws that specify which diseases and injuries are reportable, who is responsible for reporting, and what method and timing of reporting are to be used (e.g., by telephone within 24 hours of diagnosis or by mail within 1 week of diagnosis) (*1*). Because these reporting laws differ by geographic locale and municipal unit, the material in this chapter is restricted to a general overview of a disease-surveillance system, recognizing that aspects may not be applicable to all areas and that issues specific to jurisdictions are not covered completely. The term "state" is used in this discussion; although "state" is a geographic designation in the United States, analogous geographic units have similar functions in other countries.

Types of Reports and Surveillance Systems

There are three categories of notifiable disease reports: a) those in which information is collected on each individual with the disease or injury; b) conditions for which only the total number of patients seen is reported; and c) conditions for which the total number of cases is reported if, and only if, there is judged to be an epidemic. Each category generally requires specific forms. Once a report has been received, for many conditions a nurse or other disease investigator may request that the reporting unit provide information for additional disease/injury-investigation forms.

A traditional way of classifying a surveillance system is as passive or active (*2*). A passive surveillance system can be described as one with which the health jurisdiction **receives** disease/injury reports from physicians or other individuals or institutions as mandated by state law. In contrast, an active surveillance system is established when the health department regularly **contacts** reporting sources (e.g., once per week) to elicit reports, including negative reports (no cases). An active surveillance system is likely to provide more complete reporting but is much more labor intensive and is therefore more costly to operate than a passive system.

In most surveillance systems, any health worker who has knowledge of an individual with a reportable condition may be required to report that case to the health department. In a sentinel surveillance system, only selected physicians or institutions report disease or injury. Proponents of sentinel systems maintain that it is preferable to receive disease/injury reports of high quality from a few sources than to receive data of unknown quality from (in theory) all potential reporting sources in a population. This, of course, presupposes that the reporters in a sentinel system will, in fact, provide high-quality information on a reliable basis. It should also be noted that sentinel systems are inadequate when every case of a particular condition needs to be identified.

Most states have comprehensive, passive disease surveillance systems. For example, "as required by law in all 50 U.S. states," any health worker having knowledge of a person with a reportable condition is obligated to report that case to the local/state health department (*1*). Regular contact initiated by the health department and

directed to all possible reporting sources is not feasible or required.

Collection of Data

Laws for reporting disease and injury at the state and local levels not only specify who is responsible for reporting, but to whom the reports are to be directed. In the least complicated reporting situation, a physician diagnoses a reportable condition and sends the appropriate report form to the local health department, where the data on that case are added to the appropriate disease/injury-surveillance system. Summaries of reports are reviewed regularly and analyzed by staff at the local health department to identify any conditions that are being reported more frequently than expected on the basis of past experience. After disease/injury reports have been processed at the local level, the information is forwarded to the state health department to be consolidated with reports from other local health departments, and the composite data are examined for trends. Each state health department then voluntarily reports these cases to the Centers for Disease Control (CDC) on a weekly basis (*3*).

This reporting scheme can be reasonably effective, but problems can arise. For example, how does one notify health-care professionals about the requirements and procedures for reporting to the health department? Who is responsible for such notification? How are new practitioners in the jurisdiction identified and notified of their responsibility to report? Who provides quality assurance for the process? How? At what frequency? Other issues include reporting of suspected cases while laboratory results are pending, the desired routing of reports, the mechanism for updating/completing reports as additional information is received, reporting of disease/injury among transients (e.g., military personnel or migrant workers), and defining appropriate time frames for reporting a case of a specific disease/injury (Table IV.1).

There may not be one correct answer to each of the questions formulated in Table IV.1 that applies in all situations; the answers are often situation dependent. However, a disease- or injury-surveillance system should document how to respond to each of the above questions so that disease reporting is performed in a consistent manner for each disease.

Entry of Data into the Surveillance System

With the availability of microcomputers, many health departments enter disease/injury reports into computerized data bases. It is essential that one person be responsible for management of the surveillance data base (i.e., to be designated and to act as the data-base manager (DBM) (*4*). A primary responsibility of the DBM is maintaining the integrity and completeness of the data base. Concerns of the DBM are summarized in Table IV.2.

Checklist for Data-Base Manager

With any surveillance system for disease/injury, there is a need to establish procedures for maintenance and retention of paper disease-report forms (called "source documents"). In general, the individual disease reports are filed by year of report (or onset), by disease, and in alphabetical order by the patient's last name. If not already specified by disease-reporting laws, retention periods should be designated for maintaining these files for reference purposes. Electronic reporting may obviate the need for redundant paper records. (See Chapter XI for more information on computerized surveillance systems.)

Documentation and Training

Documentation is a critical step in the development of a computerized system--but one that is often neglected. A users' manual if needed and should provide both general and detailed descriptions of the system, including the following topics (*4*):

- General description of the entire system
- Detailed procedures for installing the system
- Detailed procedures for operating the system
- Detailed procedures for maintaining the system

The DBM should maintain contact with the programmer for the system so that modifications to record formats and programs can be documented by the manager; the programmer should also maintain a file of all such changes. Thorough, clear documentation facilitates the addition of new programs and modifications in equipment or operations (*4*).

A formal training program should be established for persons involved in the daily operation of the surveillance system. These staff members must feel that they can participate in shaping the system, and their ideas and comments should be elicited as part of the training process (4). The DBM should schedule a series of training classes that include hands-on experience with the data-base software. Written operational procedures--including guidelines for interpreting information contained in the disease/injury report forms--should be distributed and explained at this time. Software tutorial packages and videotapes (interactive or presentational) can also be useful tools for training.

Management of the organization responsible for the surveillance system should also be oriented to the system in one or several briefing sessions.

Analysis and Standard Reports

An effective surveillance system must be designed to cover all the following areas in its reporting process:

- Determining whether a condition is being reported more frequently than expected (see Chapter V)
- Responding appropriately to reports of individual cases
- Detecting clusters of cases
- Notifying public health practitioners of the presence of specific conditions in their areas
- Reinforcing the importance of reporting through facilitating effective control/prevention activities

The completeness and timeliness of case reports in the surveillance system should be assessed regularly. This assessment should include both the proportion of the reports with each variable, such as age of patient or date of onset of the condition, date

completed, and time between onset of condition and receipt of report. At the local health department, this information can be analyzed by reporting source (e.g., clinicians or hospital or diagnostic laboratory staff) or, at the state level, by health jurisdiction. These analyses should identify groups or institutions in need of additional information or training on disease reporting.

Most surveillance systems for infectious disease rely primarily on receipt of case reports from physicians and other health-care providers. To encourage reporting by these health professionals, many local health departments and most state health departments publish newsletters containing data and other information of interest to the contributors to the data base (*1*). Such newsletters may include standard tabular reports of the occurrence of a reportable condition by week or month, with a year-to-date summary. They may also include narrative reports about conditions of interest or about other topics relevant to public health. Such feedback is important to demonstrate to those involved with the system that the data are being used, as well as to accomplish communications goals (see Chapter VII).

The information needs of management and operations personnel should be considered as programs are developed for standard reports from the data base. Standard reports should include information on time, place, and person, and should be produced in a form that can be easily interpreted by epidemiologists and management. The purpose of each report should dictate the appearance of the output, e.g., a table, map, or graph. Most types of reports should be produced on a regular basis and according to a set schedule, but others may be created only on an as-needed basis.

Data Sharing

In some situations disease and injury reports may be shared by various local or state health departments, particularly with conditions that require additional investigation or follow-up. For example, when a resident of one county/state is examined and given a particular diagnosis at a hospital in a neighboring county/state, health authorities need to be able to track the condition back to its source in order to respond appropriately.

Occasionally, disease and injury reports are sent directly to the state health

department, bypassing the local health department. If that happens, the state needs to notify the appropriate local health department so that the reports can be added to the disease/injury reporting system at the local level. Additional data that the state may collect should also be shared with the local health department.

The DBM should be aware of other sources of information that may need to be accessed and compared with or added to the data collected in his or her own system--e.g., laboratory results, epidemiologic information for specific conditions, population estimates, and mortality records. Through careful planning and coordination on the part of managers of reporting systems, standard coding schemes can be adopted as data systems evolve. These actions facilitate the sharing and use of data.

System Maintenance and Security

Maintenance of a system should be directed first toward reducing errors introduced through flaws in design and through content changes (e.g., changes in the list of notifiable conditions) and second toward improving the system's scope and services. Related activities can be categorized as routine maintenance, emergency maintenance, requests for special reports, and system improvements. Maintenance should not be performed on an informal or first-come, first-served basis. An effective maintenance program includes the following steps (4):

- Back up data and system files according to an established schedule, and maintain records in a secure environment.
- Require that requests for emergency maintenance be made in writing and entered into a log.
- Assign priorities to special requests on the basis of urgency of need and time and resources required.
- Institutionalize routine maintenance, such as procedures associated with changing to a new reporting year.
- Document maintenance as it is conducted.

In order to maintain the integrity of a computer system, only one person should have the authority to access the system and assign and change passwords. The DBM should be the only staff member with authority to install or modify production software. This same rule should apply to access to the physical computer files. Authority to add or delete files from subdirectories or environments of computers should be delegated to only one individual who is then held accountable for all modifications. A second computer should be available for testing changes to the system so that the computer used for the surveillance system can be reserved for production only. The second computer could also serve as a back-up computer should the primary machine fail.

The numerous risks to the security of a data base include mechanical failure, human carelessness, malicious damage, crime, and invasion of privacy. Therefore, back-up copies of the data base should be kept off-site to ensure that the system cannot be deliberately or unintentionally destroyed. Updating of the off-site copies should be done on a routine basis, and new diskettes should be used to make back-up copies at least once each year.

A monthly, total system back-up is recommended, if a valid copy of the current system is available. Data files that are changed during the day should be backed up at the end of the day.

Computer viruses have become a threat to data-base and computer-system security. These programs can be highly sophisticated and are capable of attaching themselves to software or data being loaded on the computer or data being sent from one computer to another. Software is available to scan entire systems or diskettes for virus infections; such software should be updated periodically because of the addition of new viruses. Data received via telecommunications channels or on diskettes from other sources should always be scanned before data files and programs are copied to the computer's disk. Software retrieved from electronic bulletin boards should be carefully examined before being incorporated into a system.

In the event of extended mechanical failure, a contingency plan should be in place for shifting the base of operations to another computer.

Surveillance data on disease/injury are generally received by a local health

department, forwarded through a regional health center, and eventually directed to the state health department. The complete reporting form, which includes confidential information on patients, is usually shared by local and state health departments for purposes of follow-up (if necessary) and for identifying and deleting any redundant (duplicate) reports.

Persons who report disease/injury should be familiar with the types of activities that may follow the receipt of a report. For example, for purposes of prevention or treatment, all cases of syphilis may be investigated to determine the source of the infection and potential spread of the infection to others. Disease-reporting laws may specify who has access to the confidential portions of a disease/injury report, and it is important to assure that the confidentiality of the report is maintained. Failure to keep the reports confidential is likely to lead to an unwillingness to report on the part of physicians and other health-care providers. Reports and files that do not require personal identifiers should not contain them. In the United States, notifiable-disease reports received from states by CDC do not include personal identifiers (such as name, address, and telephone number).

Modification of Reporting Systems

The basic steps shown below are intended to ensure that a computer-based surveillance system will meet current and future needs. A systems analyst, an epidemiologist, and the final users of information from the system should work together to produce a system that is user-friendly and functional (5).

1. Review current methods of processing disease/injury information. Obtain copies of paper forms or computer-screen forms or reports. Determine whether suggested report forms or screens are available from state or national agencies. Often, ready-to-use surveillance software is available. Use of such systems facilitates standardization, quality control, and comparability of data.

2. Review with management and users any problems with the current method for processing data and any desired future enhancements.

3. Document the current system and proposed future system. Allow concerned parties

to review and comment on their understanding of objectives for the system.

4. Limit access to the confidential portion of a disease/injury report as much as possible. Store the original report forms containing confidential data in locked cabinets or a locked room. Secure electronic data bases by limiting access to the computer, and obtain additional security through the required use of passwords (pre-approved for access to the protected portion of the data base).

5. Document developmental specifications to meet the objectives above. In addition, document proposed testing schedules and methodology for implementing the system when it is completed.

6. Develop prototypic screens and reports for management and end users to review, so that misunderstandings and problems can be identified and resolved during development.

7. Once all parties are in agreement, establish self-contained modules of development that can be completed, and proceed to the testing stage while other modules are being developed.

8. Begin development in a test environment separate from any current computer-based production system. Document any changes to developmental specifications that become necessary during actual development.

9. Produce processing manuals for users (to include not only the operation of the computerized system but also proper handling of paper forms, storage of electronic and paper data, and distribution of final reports). This documentation should be as thoroughly tested as the actual computer system.

10. Establish training sessions or develop tutorial manuals for users. If such manuals are to be effective, a development/test system for users must be in place during their training stage.

11. Finalize specification documents to include all current stages of the system, as

well as all expected future enhancements. This documentation should include a schedule and methodology for maintaining and troubleshooting the system.

12. Establish and document proper back-up and data-recovery techniques. This step includes selecting a data-base manager.

SUMMARY

A surveillance system of high quality and integrity can only be developed through careful planning, documentation, implementation, training, and long-term support. Because of the changing nature of disease/injury reporting (e.g., new conditions being added or case definitions being modified), useful surveillance systems must be flexible enough to allow for such changes with a minimal amount of disruption.

Also important is the coordination of disease and injury-reporting activities among local health departments, from local health departments to their appropriate state health departments, and among state health departments. The Council of State and Territorial Epidemiologists has played an important role in the state-to-state coordination of disease and injury reporting, as well as in reporting practices from states to CDC.

While there are many complicated aspects of disease/injury-surveillance systems, it is important to remember that the overall purposes of such systems are to provide information on preventing disease and injury and to improve the quality of the public health.

REFERENCES

1. Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. Mandatory reporting of infectious diseases by clinicians. *MMWR* 1990;39(RR-9):1-17.

2. Mausner JS, Kramer S. Epidemiology---an introductory text. Philadelphia, Pa.: W.B. Saunders Co., 1985.

3. Wharton M, Chorba TL, Vogt RL, Morse DL, Buehler JW. Case definitions for public health surveillance. *MMWR* 1990;39(RR-13):1-43.

4. Murdick, RG. MIS concepts and design. Englewood Cliffs, N.J: Prentice-Hall, 1980.

5. Klaucke DN, Buehler JW, Thacker SB, Parrish RG, Trowbridge FL, Berkelman RL *et al.* Guidelines for evaluating surveillance systems. *MMWR* 1988;37(S-5):1-18.

Chapter V

Analyzing and Interpreting Surveillance Data

Willard Cates, Jr.

G. David Williamson

"Where is the wisdom we have lost in knowledge? Where is the knowledge we have lost in information?"

T.S. Eliot

["Where is the information we have lost in data?"

Editors]

INTRODUCTION

Historically, the core processes of public health surveillance have involved using appropriate methods to aggregate the units of data being collected--namely, analysis--and also creative approaches to assess the emerging data patterns--namely, interpretation (*1*).

For these reasons, the ability to analyze and interpret surveillance data determines the mettle of the epidemiologist. Viewed as basic to observational studies (*2*), surveillance is at the forefront of the spectrum of descriptive epidemiology. Surveillance has a myriad of uses (*3,4*), each of which requires careful analysis and interpretation. Whether surveillance is used to detect epidemics, suggest hypotheses, characterize trends in disease or injury, evaluate prevention programs, or project future public health needs, data from a surveillance system must be analyzed carefully and interpreted prudently. In this chapter we address practical and methodologic approaches to surveillance analysis; the presentation of surveillance data by time, place, and person; the concept of rates and standardization of rates; approaches to exploratory data analysis; the use of graphics and maps; and, finally, the systematic interpretation of surveillance data.

APPROACH TO SURVEILLANCE ANALYSIS

Practical Approach

The fundamental approach to analyzing surveillance data is relatively straightforward. Because of their descriptive nature, surveillance data cannot be used for formal hypothesis testing (*5*). Rather, the regular scrutiny of systematically collected information allows epidemiologists to describe patterns of disease and injury in human populations, organized by a variety of sub-measures. Moreover, the analysis (and subsequent interpretation) proceeds from the specific elements of the data themselves. Thus, surveillance analysis represents an inductive reasoning process in which the assembly of individual units eventually produces a more general picture of health-related problems in a population.

Frequently, the time-consuming problems of collecting, managing, and storing

surveillance data leave little energy for the analysis itself. Nonetheless, analyzing surveillance data must be afforded a high priority by those in charge of surveillance systems (3). Approaches to analyzing surveillance data include the following steps:

1. Know the inherent idiosyncracies of the surveillance data set. It is tempting to begin immediately to examine trends over time. However, intimate knowledge of the day-to-day strengths and weaknesses of the data-collection methods and the reporting process can provide a "real world" sense of the trends that emerge.

2. Proceed from the simplest to the most complex. Examine each condition separately, both by numbers and crude trends. How many cases were reported each year? How many cases were reported in each age group each year? What are the variable-specific rates? Only after looking separately at each variable should one examine the relationships among these variables.

3. Realize when inaccuracies in the data preclude more sophisticated analyses. Erratically collected or incomplete data cannot be corrected by complex analytic techniques. Differential reporting (see representativeness Chapter VIII) by different regions or by different health facilities render the resulting surveillance data set liable to misinterpretation.

Methodologic Considerations

Analysis of surveillance information depends on the accuracy of that information (Chapter VIII). Attempts to analyze data that are haphazardly collected or have varying case definitions waste valuable time and resources. The two key concepts which determine the accuracy of surveillance data are reliability and validity (5). Reliability refers to whether a particular condition is reported consistently by different observers, whereas validity refers to whether the condition as reported reflects the true condition as it occurs. Ideally, both reliability and validity can be achieved, but in practice, reliability (e.g., reproducibility) is easier than validity to assess. In situations involving conditions, such as laboratory testing

for infectious diseases, when biologic measures complement clinical case definitions, the accuracy of the data can be more completely assured. However, in the context of more subjective behavioral aspects, such as those associated with lifestyles, accuracy is more difficult to confirm.

The application of standard statistical techniques to the analysis of surveillance data is dictated by the limitations of the data themselves and the flexibility of the epidemiologist/statistician (*5*). In a sense, because the essentials of sampling theory have not been satisfied, no statistical testing is possible with the often incomplete surveillance data set. However, if the information is viewed as samples over time, apparent clusters of health events can be evaluated for their statistical "significance." Applying 95% confidence limits or other standard statistical tests to these "samples over time" can allow a determination of whether any differences are unlikely to have occurred by chance alone.

Surveillance analyses are often ecologic, since they describe trends in groups of individuals. Thus, the use of surveillance data may be especially prone to the problem of the "ecological fallacy" (*6,7*). In brief, this type of bias may occur when health officials interpreting observations about groups (e.g., aggregated surveillance data) make causal inferences about individual phenomena (*8*). These population-level analyses may suffer from two separate problems (*7*): a) aggregation bias---due to loss of information when individuals are grouped and b) specification bias---due to the definition of the "group" itself (*8*). The chances of the ecological fallacy can be reduced by analyzing subsets of surveillance data to reveal trends in the individual characteristics. However, when describing bodies of surveillance data, public health officials usually synthesize the populations trends, thus opening the possibility for fallacious interpretation.

Time, Place, and Person

Surveillance data allow public health officials to describe health problems in terms of the basic epidemiologic parameters of time, place, and person. In addition, surveillance data permit comparisons among these different parameters (e.g., what are the patterns of disease/injury at one time compared with another, in one place compared with another, or among one population compared with another). Use of

appropriate census data as denominators allows calculation of rates, which then facilitates comparison of the risks of disease or injury in terms of the parameters of time, place, and person. Moreover, use of these fundamental variables permits the epidemics to be detected, long-term trends to be monitored, seasonal patterns to be assessed and future occurrence of disease/injury to be projected, thus possibly facilitating a more timely public health response.

Time

Analysis of surveillance data by time can reveal trends in disease/injury. For all health conditions, a measurable delay occurs between the exposure and the problem. In the case of disease, an interval exists between exposure and expression of symptoms, as well as an interval between a) onset of symptoms and diagnosis of the problem, and b) eventual reporting of the illness to public health authorities so that it can be included in the surveillance data set. For an infectious disease, this last interval may represent days or weeks, whereas for chronic disease it may be measured in years. Thus, choosing the appropriate interval for analysis must involve a consideration of the health condition being assessed.

Analysis of surveillance data by time can be conducted in several different ways to detect changes in incidence of disease/injury. The easiest analysis is usually a comparison of the number of case reports received during a particular interval (e.g., weeks or months) (see Figure I.1). Such data can be organized into a table or graph to assess whether an abrupt increase has occurred, whether the trends are stable, or whether a gradual rise or fall in the numbers occurs. Another simple method of analysis compares the number of cases for a current time period (e.g., a given month) with the number reported during the same interval for the past several years. Similarly, the cumulative number of cases reported in the period representing the year-to-date can be compared with the appropriate cumulative number for previous years.

Analyzing long-term (secular) trends is facilitated by graphing surveillance data over time. The watershed events that influence secular trends--such as changes in the case definition used for surveillance, new diagnostic criteria, changes in reporting requirements or practices, publicity about a particular condition, or new intervention programs--can be indicated on the graph. Changes in the surveillance system itself

also influence long-term trends, particularly when the intensity of active case detection increases (e.g., screening programs in particular communities).

Finally, additional epidemiologic measures enhance the analysis of surveillance data by time. Using denominators to calculate rates becomes especially important if changes occur in the community, such as the immigration of a new population. As the size of a population changes over time, so will the expected number of cases of diseases and injuries. In addition, analysis by date of onset rather than date of report more clearly defines the condition. Because of delays between diagnosis and reporting, using date of onset when practical and possible provides a better representation of actual disease incidence. The longer the interval between the occurrence of symptoms, the seeking of health care, and the reporting of events, the greater the need for a surveillance system based on date of onset.

Place

Analysis by the place where the condition occurred is the next step. (see Figure I.2). The location from which the condition was reported (such as a hospital) may not be the place where the exposure actually occurred (in the community). Similarly, for medical procedures, the place an operation took place may not be the place of residence of the patient. For example, the District of Columbia has the highest rate of legal abortions in the United States, but more than 50% of this figure reflects women who reside outside the District (*9*).

Locating the geographic area with the highest rates can facilitate efforts to identify cause(s) and allow appropriate interventions to be applied. John Snow's removing the Broad Street pump handle remains the classic example of intervention by location (*10*). Even in situations in which the numbers of a particular problem are decreasing, focal areas with high levels of the condition may remain, and the identification of these areas allows prevention resources to be targeted effectively. Finally, the size of the unit for geographic analysis is determined by the type of condition involved. For some rare conditions, large areas such as states may be appropriate, whereas for events that occur at relatively high frequency or for outbreak situations, areas defined by postal codes or other geographic boundaries may be the most desirable size of the measure.

The availability of computers, as well as software for spatial mapping, allow more sophisticated analysis of surveillance data by place. Public health officials are now able to use surveillance data to follow the geographic course of a particular condition, thus assisting in their efforts to plan intervention strategies (see "Maps" below).

Person

Analyzing surveillance data by the characteristics of persons who have the condition provides further specification. The demographic variables most frequently used are age, gender, and race/ethnicity. Other variables such as marital status, occupation, and levels of income and education may also be helpful, even though most surveillance systems do not routinely collect such information.

Analysis of trends in disease/injury by age depends on the specific health condition of interest. For childhood diseases, relatively narrow age categories (e.g., by single years), can identify the age group associated with the peak incidence of a particular health condition. Conversely, for conditions that primarily affect older populations, broader 10-year age intervals are frequently used. In general, the typical age distribution associated with the health condition provides the best guide to deciding which age categories to use, with several narrower categories for the ages associated with peak incidence and broader categories covering the remainder of the age spectrum.

Surveillance systems have also been used to analyze behavioral characteristics of populations. Such systems generally depend on self-reported behavior and may be based on repeated surveys of representative groups, trends in markers for specific types of behavior (e.g., sales of a particular product), or active surveillance of a particular behavioral characteristic or indicator in a defined group (e.g., testing urine for drugs in school or work settings).

If possible, the characteristics of persons included in any surveillance system should be related to denominators. While assessing the number of cases alone can be sufficient, variable-specific rates are more helpful in allowing comparisons of the risk involved. Thus, even if the number of cases of a particular condition is higher in one part of a population, the rate may be lower if that group represents a large

proportion of the population. In this way, comparing the rates within surveillance data of certain populations is analogous to calculating relative risks within observational cohort studies.

Interactions among Time, Place, and Person

By proceeding from the simple (e.g., crude rates) to the more complex (e.g., variable-specific rates), meaningful trends may be revealed. This is because interactions among the time-place-person parameters of surveillance data can obscure important patterns of disease/injury in specific populations. For example, in the United States in the 1980s, the overall number of syphilis cases fell during the first two-thirds of the decade but rose beginning in 1987 (Figure V.1, Panel A). When analyzed by gender (Figure V.1, Panel B), the decline in syphilis occurred primarily among men; cases among women were low for the first 5 years, increased slightly in 1986, and rose more rapidly for the rest of the decade. Finally, when stratified by both gender and race (Figure V.1, Panel C), the decrease in numbers of cases of syphilis was seen only among white males--presumably among men who have sex with other men and who had changed their sexual practices in response to human immunodeficiency virus (HIV) prevention activities (*12*). Conversely, the increase in syphilis occurred among black men and women, with both trends beginning in 1986, and being linked to unsafe sexual behavior associated with use of crack cocaine (*13*). If more specific analysis by person had not occurred, the offsetting trends in the mid-1980s of declines among white males might have delayed recognition by public health officials of the syphilis epidemic among minorities.

RATES AND RATE STANDARDIZATION

Overview

A rate measures the frequency of an event. It comprises a numerator (i.e., the upper portion of a fraction denoting the number of occurrences of an event during a specified time) and a denominator (i.e., the lower portion of a fraction denoting the size of the population in which the events occur). A crucial aspect of a rate is the specification of the time period under consideration. An optional component is a multiplier, a power of 10 that is used to convert awkward fractions to more workable numbers (*14*). The general form of a rate is shown below:

$$\text{rate} = \frac{\text{number of occurrences of event in specified time}}{\text{average or mid-interval population}} \times 10^n,$$

where the denominator represents the size of the population during the specified period in which the events occur and the power of n usually ranges from 2 to 6 (i.e., the number at risk varies between 100 and 1,000,000). The selection of n depends on the incidence or prevalence of the event.

Although surveillance often provides numerator data only, the use of raw numbers such as cases of a disease or injury has limitations. Raw numbers quantify occurrences of an event during a specified time without regard to population size and dynamics, or other demographic characteristics such as distribution by race and gender. Rates enable one to make more appropriate, informative comparisons of occurrences in a population over time, among different sub-populations, or among different populations at the same or different times, since the size of the population and the period of time specified are accounted for in the calculation of rates.

A wide variety of "rates" are employed in standard public health practice (Table V.1). These measures are calculated in numerous ways and may have different connotations. Special distinction should be made among the terms "rate," "ratio," and "proportion." A *ratio* is any quotient obtained by dividing one quantity by another. The numerator and denominator are generally distinct quantities, neither of which is a subset of the other. No restrictions exist on the value or dimension of a ratio. A *proportion* is a special type of ratio for which the numerator is a subset of the denominator population, thus requiring the resulting quotient to be dimensionless, positive, and less than one, or less than 100 if expressed as a percentage. Although all rates are ratios, in epidemiology a *rate* may be a proportion (e.g., prevalence rate) or may be limited in scope by further restrictions such as representing the number of occurrences of a health event in a specified time and population per unit time (e.g., hazard or incidence rate). This latter definition is most restrictive and is the definition generally used for rates in chemistry and physics.

Use of Rates in Epidemiology

Calculation and analysis of rates is critical in epidemiologic investigations, not only for formulating and testing hypotheses about cause(s), but also for identifying

risk factors for disease and injury. Rates also allow valid comparisons within or among populations for specific times. To determine rates, one must have reliable numerator and denominator data, the latter being generally more difficult to obtain in most epidemiologic investigations, particularly if the data to be analyzed (i.e, the number of occurrences of an event) have been collected from public health surveillance systems.

Crude, Specific, and Standardized Rates

Crude and specific rates

Rates can be calculated either for the entire population or for certain subpopulations within the larger group. Rates describing a complete population are termed "crude." The computation of crude rates is performed as the initial step in analysis since they are important in obtaining information about and contrasting entire populations.

Within a population, the rate at which a particular health event occurs may not be constant throughout the entire population. To examine the differences, the population is partitioned into relevant "specific" subpopulations, and a "specific" rate is calculated for each subset. For example, if one calculates death rates by age group (because death rate is not constant for all age categories), the resulting rates are termed "age-specific death rates."

Variation of rates among population subgroups results from several factors: natural history of the health problem, differential distribution of susceptibility or cause(s), or genetic differences among subpopulations. For example, mortality rates are higher among men than women and blacks than whites (*15*). The distribution of subgroups within the population may also be so disparate that a summary rate may not convey useful information. Therefore, the magnitude of a crude rate depends on the magnitude of the rates of the subpopulations as well as on the demographics of the entire population (*16*). These variations in rates across a population would remain unknown if only crude rates were calculated.

Standardized rates

When rates are compared across different populations or for the same population over

time, crude rates are appropriate only if the populations are similar with respect to factors that are associated with the health event being investigated (*17*). Such factors could include age, race, gender, socioeconomic status, or risk factors (e.g., number of cigarettes smoked). If the populations are dissimilar, variable-specific rates should be computed and compared. Alternatively, the rates can be adjusted for the effect of a confounding variable in order to obtain an undistorted view of the effect that other variables have on risk. This adjustment of rates when comparing populations is called standardization and yields "standardized" or "adjusted" rates. The two techniques of standardization are direct and indirect.

Direct standardization

A directly standardized rate is obtained for a study population by averaging the specific rates for the population, using the distribution of a selected standard population as the averaging weights. This adjusted rate represents "what the crude rate would have been in the study population if that population had the same distribution as the standard population with respect to the variable(s) for which the adjustment or standardization was carried out" (*14*). The rate is termed "directly standardized" because specific rates are used directly in the calculation. If data for the same standard population are used to calculate directly standardized rates for two or more study populations, those standardized rates can be appropriately compared. Any difference among the standardized rates cannot be attributed to differential population distributions of the standardized variable because the calculations have been adjusted for that variable (*18*). The following data must be available in order to use direct adjustment:

- Specific rates for the study population and
- Distribution for the selected standard population across the same strata as those used in determining the specific rates.

Indirect Standardization

An indirectly standardized rate is calculated for a study population by averaging the specific rates for a select standard population, using the distribution of the study population as weights. One should use indirect adjustment when any of the specific rates in the study population are unavailable or when such small numbers exist in the categories of strata that the data are unreliable (i.e., the resulting rates are

unstable). This commonly occurs in occupational mortality or in small geographic areas. For these reasons, indirect standardization is used more often than direct standardization. Indirectly standardized rates for two or more populations of interest can be appropriately compared if the same standard population is used in the computations. The following data are required to make an indirect adjustment to a rate:

- Specific rates for the selected standard population,
- Distribution for the study population across the same strata as those used in calculating the specific rates,
- Crude rate for the study population, and
- Crude rate for the standard population.

A special application of the indirect standardized rate, when the health event of interest is death, is the standardized mortality ratio (SMR). It is the number of deaths occurring in a study population or subpopulation, expressed as a percentage of the number of deaths expected to occur if the given population and the selected standard population had the same specific rates (*19*). Explicitly, the SMR is an indirect, age-adjusted ratio calculated as the indirect standardized mortality rate for the study population, divided by the crude mortality rate for the standard population. Additional information is available on the use of the SMR, as well as on computation of variance and confidence intervals for direct and indirect measures (*18*).

Choice of Standard Population

If crude rates are to be adjusted, an appropriate standardized population needs to be chosen. In extreme cases, the choice of different standardized populations can lead to different results. For example, use of one standardized population may yield an adjusted rate higher for population A than for population B, while choice of another standard population may yield a higher rate for population B (*18*).

Two factors should be considered when choosing a standard population:

- Select a population that is representative of the study populations being compared and
- Understand how choice of a standard population affects directly

standardized rates (e.g., if the age-specific rates for population A are greater than for population B at young ages and the opposite is true at older ages, a standard population with distribution skewed to younger ages will yield a higher directly standardized rate for population A than for population B).

Generally the choice of standard population makes little difference in comparing adjusted rates. Although magnitudes of the adjusted rates depend upon choice of standard population, no meaning is attached to those magnitudes; only relative differences in the adjusted rates can be assessed.

Various choices are available for a standard population. Customary selections include the combined or pooled population of the overall population to be studied, the population of one of the study groups, a large population (such as the 1940 or 1980 United States population), or a hypothetical population. Calculating standardized rates using different standard populations allows comparisons of different distributions (*20*).

To Standardize or Not To Standardize. The decision to standardize is not always straightforward. Several factors, most of which are data-driven, must be considered in the decision process. Reasons to present standardized rates include the following (*17*):

- Standardization adjusts for confounding variables to yield a more realistic view of the effect of other variables on risk,
- A summary measure for a population is easier to compare with similar summary measures than are sets of specific rates,
- A standardized rate has a smaller standard error than any of the specific rates (this is important when comparing sub-populations or geographic areas),
- Specific rates may be imprecise or unstable because of sparse data in the strata, and
- Specific rates may be unavailable for certain groups of interest (e.g., small populations or those designated by specific geographic areas).

The major disadvantage of standardization is evident when the specific rates vary differently across strata, such as when they move in different directions or at different magnitudes, in individual age groups. In this case the trend in the standardized rate is a weighted average of the trends in the specific rates, where the weights depend on the standard population selected. When this occurs, the standardized rate tends to mask the differences, and no single summary measure will reveal these differences.

Another unfavorable characteristic of standardized rates is that their magnitude is arbitrary and depends entirely on the standard population. Although generally not the case, relative rankings of summary measures from different study populations may change if a different standard population is selected.

Regardless of the decision made regarding standardization, it is crucial to evaluate the specific rates to characterize accurately and to understand more fully the variation among study populations. Standardized rates should never be used as a substitute for specific rates, nor should they be the basis of inferences when specific rates can be computed. A compromise to the use of a summary measure versus a set of specific measures is to use the specific rates but to eliminate or combine categories to minimize the number of rates required for comparison. Additional discussion is available on advantages and disadvantages of standardization and on analyzing crude and specific rates (*21*).

Rate standardization: practical example

To demonstrate how crude, specific, and standardized rates are obtained, we compare death rates in two Florida counties. This example shows how standardized rates can be misleading if they are not properly scrutinized.

We will use population and death totals for Pinellas and Dade Counties in Florida for 1980 (Table V.2). The crude death rate for Pinellas County is about 60% higher than that for Dade County. When the age distributions of each county are used, the resulting age-specific death rates are generally slightly higher in Dade County (Table V.3), even though the crude death rate is substantially higher for Pinellas County. This seeming anomaly in the data results from the different age distributions of each county. Specifically, the population in Pinellas is older.

Directly standardizing the Pinellas and Dade County rates to the United States 1980 population corrects for the differences in population (Table V.4). Once differences in age-related distributions in the two counties have been taken into account, the adjusted death rate for Pinellas County is lower than that for Dade County (7.7 and 7.9, respectively).

The indirect method of adjustment increases the relative difference between death rates for the two counties (Table V.5). The adjusting factor is computed as the 1980 death rate for the total U.S. population divided by the expected death rate. Then, adjusted death rate is calculated as the adjusting factor multiplied by the crude death rate. In this example, indirect adjustment reinforces and accentuates the results of direct adjustment by yielding rates of 7.5 and 7.8 deaths per 1,000 population for Pinellas and Dade Counties, respectively.

This example illustrates the importance of being thoroughly familiar with the data. Comparison of crude death rates alone can be misleading. However, calculating age-specific and adjusted rates permits an accurate understanding of death rates in these counties and shows that the high crude rate in Pinellas County reflects its older population. The example also illustrates how the magnitude of adjusted rates depends on the choice of standard population.

Analysis of Rates

When numerator and denominator data are available, analysis of rates should always begin with calculation of crude rates and proceed to subsequent computation of relevant specific rates. If appropriate, a standard population can be chosen to determine standardized rates. Tables and especially maps are important means of presenting rates at different times and/or locations. (See "Tables," "Graphs," and "Maps" below).

Several statistical procedures are available to analyze data. Inference on a single proportion is performed using a z test, and assessing the difference between two proportions can be accomplished with a z or χ^2 test (17).* Use of Poisson parameters

*Note that Fleiss does not distinguish between rates and proportions or the analysis of them.

is helpful in comparing two rates (*22*). A series of χ^2 tests can be used to compare proportions from several independent samples (*16*), and Poisson regression is frequently used for comparing several rates (*23*). Other modeling procedures that can be used to analyze rates include smoothing, Box-Jenkins, and Kalman filter approaches, all of which are time-series methods discussed in Chapter VI. Space-time cluster techniques and small-area estimation methods are also discussed in Chapter VI.

EXPLORATORY DATA ANALYSIS

Overview

Exploratory data analysis (EDA) is enumerative, numeric, or graphic detective work (*24*). It is the application of a set of techniques to a body of data to make the data more understandable. EDA is a philosophy that minimizes assumptions, allows the data to motivate the analysis, and combines ease of description with quantitative knowledge. EDA leads the analyst to uncover characteristics often hidden within the data.

Practice of EDA involves four fundamental steps (*24-25*):

1. Using visual displays to convey the structure of the data and analyses,
2. Transforming the data mathematically to simplify their distribution and to clarify their analysis,
3. Investigating the influence that unusual observations (outliers) have on the results of analysis, and
4. Examining the residuals (the difference between the observed data and a fitted model) to provide additional insight into the data.

EDA is the initial step in any analysis. It allows the investigator to become familiar with the data and forms the foundation for further analysis. Although most public health surveillance systems are established for specific topics, proper EDA of the data can provide insight into demographic, temporal, and spatial patterns otherwise overlooked in the collection of numbers. EDA may additionally contribute to more timely detection of unusual observations, which may, in turn, facilitate a quicker public health response to factors that cause increased morbidity and/or mortality.

Data Displays

A first step in any analysis of data is a visual examination of the data. A few of the techniques that should be used initially are described below for application to a single set of numbers, for exploration of relationships between two factors, and for comparisons among several populations.

Dot plots

A dot plot is a one-dimensional plot (Figure V.2) of the individual values of a set of numbers. The x-axis represents one or more categories of a non-continuous variable, and the y-axis represents the range of values displayed by the observations. Observations with identical values are plotted side by side on the same horizontal plane.

Stem-and-Leaf Displays

A stem-and-leaf display is a graphic (Figure V.3) that allows the digits of the observation values to sort the numbers into numerical order for display. This is a variation of the conventional histogram. The basic principle used in constructing a stem-and-leaf display is the splitting of each data value between a suitable pair of adjacent digits to form a set of leading digits and a set of trailing digits. The set of leading digits forms the stems, and the set of the first trailing digit from the data forms the leaves. Remaining trailing digits are ignored for the purpose of the graphic. Variations to the stem-and-leaf display are possible (*24*).

Many investigators begin an evaluation of data with a histogram (see below), but the stem-and-leaf display has several advantages over the histogram. Because every observation is plotted in the stem-and-leaf display, it contains more detail than the histogram and allows computation of percentages points. Moreover, transformations can be applied directly to stem-and-leaf data.

Scatter plots

The scatter plot or scatter diagram is a plot (Figure V.4) that reveals the relationship between two variables. Each observation comprises a pair of values, one for each variable. The observation is plotted by measuring the value of one variable on the horizontal axis and the value of the other on the vertical axis.

Data summaries

One can summarize a data set by calculating a few numbers which are relatively easy to interpret. For example, measures of central tendency and variability are frequently used to describe data. In particular, two types of summary displays have proven useful in characterizing data, i.e., the five-number summary and the box plot.

Five-number summaries

The five-number summary of a data set is a simple display (Table V.6) involving the median, hinge, and extreme values. The median is a measure of the central tendency of the data that splits an ordered data set in half. The hinges are a measure of the variability of the data and are the values in the middle of each half. Therefore, the hinges are the data values that are approximately 1/4 and 3/4 from the beginning of the ordered data set. They are determined by formulas (*25*) and are similar to quartiles that are defined so that 1/4 of the observations lie below the lower quartile and 1/4 lie above the upper quartile. The extremes also reflect the variability of the data and are the smallest and largest values in the data.

Box plots

The box plot is a graphic representation (Figure V.5) of the five-number summary with the two ends of the box representing the hinges and the line through the box representing the median. A line runs from each end of the box (i.e., from each hinge) to the corresponding lower and upper extreme values. This plot allows the reader to see quickly the median level, the variability, and the symmetry of the data. Variations of the box plot, including identification of outlier values, are possible (*25*).

Transformations

Transformation or re-expression of data is a powerful tool that facilitates understanding their implications. If numbers are collected in a manner that renders them hard to grasp, the data analyst should use a transformation method, while preserving as much of the original information as can be used. When used appropriately, transformed data can be readily analyzed and interpreted.

Raw data are transformed for a number of reasons--including the achievement of

symmetry--to produce a straight-line relationship, to allow use of an additive model, to reduce variability, and to attain normally distributed data. Symmetry is highly desirable when analyzing a single data set, since it ensures that a "typical" value (such as the mean or median) more nearly summarizes the data. When analyzing pairs of data, a straight-line relationship is important because linear associations are simple, both in form and in interpretation. One or both variables can be transformed to achieve linearity. Additive models have the desirable feature that data in multi-way tables can be typically decomposed into additive effects and analyzed accordingly. Reduced variability of the data is crucial when comparing several data sets. If the data spread varies with the data set, then "typical" values are obtained more accurately in the data with smaller spread. Finally, normally distributed data are needed so that normal theory statistics can be applied to test hypotheses and draw inferences.

Not all data sets can be transformed. The ratio of the largest to smallest value in the original data set is a simple indicator of whether a group of numbers will be affected substantially by transforming. If the ratio is near 1, a transformation will not severely alter the appearance of the data. Since transformations affect larger values and smaller values differently, the further the ratio is from 1, the greater the need is for transformation to display and understand the data most simply.

Transformations are generally accomplished by raising each value of the data set to some power p. Different values of p yield different effects on a data set, but those effects are ordered if the values of p are ordered. Some transformations are especially effective in certain instances (Table V.7). For example, the square root transformation is particularly capable of reducing variability in count data. Guidelines are available to assist in selecting appropriate transformations (*24,25*).

Smoothing

Smoothing refers to EDA techniques that summarize consecutive, overlapping segments of a series of data to produce a smoother curve. Its goal is to represent patterns in the data more clearly without becoming encumbered with any detailed peaks and valleys. Variations in the data set caused by irregular components are smoothed so that the overall trend can be determined more readily. Thus, smoothing allows investigators to

search for patterns in data that may otherwise be masked.

Smoothing is used on data series to explore the relationship between two variables. The values along the x-axis should be equally spaced. The y values are called a time series if they are collected over successive time intervals, although these values need not be defined by time (e.g., in a data sequence of birth rates by mother's age). As long as the x-axis defines an order and the order is not too irregular, the y sequence can be called a time series, and smoothing techniques can be applied. In time-series analysis, models are frequently developed on the smoothed data because these data are generally easier to model.

Numerous smoothing approaches exist, each having its own assets and liabilities. The simplest example of smoothing is a moving average of three intervals in which observation y_i in the data sequence is replaced with the mean of y_{i-1}, y_i, and y_{i+1}. Discussions of smoothing functions, including suggestions on how to overcome the problem of obtaining end points for the smoothed series, appear elsewhere (*25-26*).

DATA GRAPHICS

Overview

Visual tools play a critical role in public health surveillance. Data graphics visually display measured quantities using points, lines, a coordinate system, numbers, symbols, words, shading, and color (*27*). Graphics allow researchers to mesh presentation and analysis. Data graphics are essential to organizing, summarizing, and displaying information clearly and effectively. The design and quality of such graphics largely determine how effectively scientists can present their information.

Many visual tools are available to assist in analysis and presentation of results. The data to be presented and the purpose for the presentation are the key factors in deciding which visual tools should be used (Table V.8). Further discussion and guidance in producing effective, high-quality data graphics are available from several sources (*27-32*).

Tables

A table arranges data in rows and columns and is used to demonstrate data patterns and relationships among variables and to serve as a source of information for other types of data graphics (*28*). Table entries can be counts, means, rates, or other analytic measures.

A table should be simple; two or three small tables are simpler to understand than one large one. A table should be self-explanatory so that if taken out of context readers can still understand the data. The guidelines below should be used to increase effectiveness of a table and ensure that it is self-explanatory (*29*).

- Describe what, when, and where in a clear, concise table title.
- Label each row and column clearly and concisely.
- Provide units of measure for the data.
- Provide row and column totals.
- Define abbreviations and symbols.
- Note data exclusions.
- If the data are not original, reference the source.

One-variable tables

One of the most basic tables is a frequency distribution by category for a single variable. For example, the first column of the table contains the categories of the factor of interest, and the second column lists the number of persons or events that appear in each category and gives the total count. Often a third column contains percentages of total events in each category (Table V.9).

Multi-variable tables

Most phenomena monitored by public health surveillance systems are complex and require analysis of the interrelationships of several factors. When data are available on more than one variable, multi-variable cross-classified tables can elucidate associations. These tables are also called contingency tables when all the primary table entries (e.g., frequencies, persons, or events) are classified by each of the variables in the table (Table V.10).

The most frequently used type of table in epidemiologic analysis is the two-by-two contingency table, which is appropriate when two variables, each having two categories, are studied. This special case is particularly suited for analyzing case-control and cohort studies for which the categories of the variables are *case* and *control* (or *ill* and *well*) and *exposed* and *unexposed*.

Graphs

A graph is a visual display of quantitative information involving a system of coordinates. Two-dimensional graphs are generally depicted along an x-axis (horizontal orientation) and y-axis (vertical orientation) coordinate system. Graphs are primary analytic tools used to assist the reader to visualize patterns, trends, aberrations, similarities, and differences in data.

Simplicity is key to designing graphs. Simple, uncluttered graphs are more likely than complicated presentations to convey information effectively. Several specific principles should be observed when constructing graphs (*29*).

- Ensure that a graph is self-explanatory by clear, concise labeling of title, source, axes, scales, and legends,
- Clearly differentiate variables by legends or keys.
- Minimize the number of coordinate lines.
- Portray frequency on the vertical scale, starting at zero, and the method of classification on the horizontal scale.
- Assure that scales for each axis are appropriate for the data.
- Clearly indicate scale division, any scale breaks, and units of measure.
- Define abbreviations and symbols.
- Note data exclusions.
- If the data are not original, reference the source.

Several commonly used graphs are described below. The scatter plot, an extremely helpful graph for detecting the relationship between two variables, has already been described (see "Data Displays").

Arithmetic-scale line graphs

An arithmetic-scale line graph is one in which equal distances along the x and/or y axes represent equal quantities along that axis. This type of graph is typically used to demonstrate an overall trend over time rather than focusing on particular observation values. It is most helpful for examining long series of data or for comparing several data sets (see Figure I.1).

The scale of the x-axis is usually presented in the same increments as the data are collected (e.g., weekly or monthly). Several factors should be considered when selecting a scale for the y-axis (*28*).

- Choose a length for the y-axis that is suitably proportional to that of the x-axis. (A common recommendation is a 5:3 x:y-axis ratio.)
- Identify the maximum y-axis value and round the value up slightly.
- Select an interval size that provides enough detail for the purpose of the graph.

Scale breaks can be used for either or both axes if the range of the data is excessive. However, care should be taken to avoid misrepresentation and misinterpretation of the data when scale breaks are used.

Semi-logarithmic-scale line graphs

A semi-logarithmic-scale line or semi-log graph is characterized by one axis being measured on an arithmetic scale (usually the x-axis) and the other being measured on a logarithmic scale. A logarithm is the exponent expressing the power to which a base number is raised (e.g., log 100 = log 10^2 = 2 for base 10). The axis portraying the logarithmic scale on semi-log graph paper is divided into several cycles, with each cycle representing an order of magnitude and values 10 times greater than the preceding cycle (e.g., a 3-cycle semi-log graph could represent 1 to 10 in the first cycle, 10 to 100 in the second cycle, and 100 to 1,000 in the third cycle).

A semi-logarithmic-scale line graph is particularly valuable when examining the *rate* of change in surveillance data, because a straight line represents a constant rate of change. For absolute changes, an arithmetic-scale line graph would be more appropriate. The semi-log scale is also useful when large differences in magnitude or outliers occur because this type of graph allows the plotting of wide ranges of values

(see Figure I.6). With semi-log graphs, the slope of the line indicates the rate of increase or decrease; thus a horizontal line indicates no change in rate. Also, parallel lines for two conditions demonstrate identical rates of change (*29*).

Histograms

A histogram is a graph in which a frequency distribution is represented by adjoining vertical bars. The area represented by each bar is proportional to the frequency for that interval (i.e., the height multiplied by the width of each bar yields the number of events for that interval). Thus, scale breaks should never be used in histograms because they misrepresent the data.

Histograms can be constructed with equal- and unequal-class intervals. Equal-class intervals occur when the height of each bar is proportional to the frequency of the events in that interval. We do not recommend using histograms with unequal class intervals because they are difficult to construct and interpret correctly.

The epidemic curve is a special type of a histogram in which *time* is the variable plotted on the x-axis. The epidemic curve represents the occurrence of cases of a health problem by date of onset during an epidemic, (e.g., an outbreak of paralytic poliomyelitis in Oman [see Figure V.6]). Usually the class intervals on the x-axis should be less than one-fourth of the incubation period of the disease, and the intervals should begin before the first reported case during the epidemic in order to portray any identified background cases of the condition being graphed.

Cumulative frequency and survival curves

A cumulative frequency curve is used for both continuous and categorical data. It plots the cumulative frequency on the y-axis and the value of the variable on the x-axis. Cumulative frequencies can be expressed either as the number of cases or as a percentage of total cases. For categorical data, the cumulative frequency is plotted at the right-most end of each class interval (rather than at the mid point) to depict more realistically the number or percentage of cases above and below the x-axis value (Figure V.7). When percentages are graphed, the cumulative frequency curve allows easy identification of medians, quartiles, and other percentiles of interest.

A survival curve (Figure V.8) is useful in a follow-up study for graphing the

percentage of subjects remaining until an event occurs in the study. The x-axis represents time, and the y-axis is percentage surviving. A difference in orientation exists between cumulative frequency and survival curves (Figures V.7, V.8).

Frequency polygons

A frequency polygon is constructed from a histogram by connecting the midpoints of the class intervals with a straight line. A frequency polygon is useful for comparing frequency distributions from different data sets (Figure V.9). Detailed instructions for constructing frequency polygons are presented elsewhere (*28,29*).

Charts

Charts are useful graphics for illustrating statistical information. Many types of charts can be used (*28-30*). They are most suited and helpful for comparing magnitudes of events in categories of a variable. In the paragraphs below, we describe several of the most frequently used types of charts.

Bar charts

Bar charts are one of the simplest and most effective ways to present comparative data. A bar chart uses bars of the same width to represent different categories of a factor. Comparison of the categories is based on linear values since the length of a bar is proportional to the frequency of the event in that category. Therefore, scale breaks could cause the data to be misinterpreted and should not be used in bar charts. Bars from different categories are separated by spaces (unlike the bars in a histogram). Although most bars are vertical, they may be depicted horizontally. They are usually arranged in ascending or descending length, or in some other systematic order.

Several variations of the bar chart are commonly used. The **grouped** or multiple-unit bar chart compares units within categories (Figure V.10). Generally the number of units within a category is limited to three for effective presentation and understanding.

A **stacked** bar chart is also used to compare different groups within each category of a variable. However, it differs from the grouped bar chart in that the different groups

are differentiated not with separate bars, but with different segments within a single bar for each category. The distinct segments are illustrated by different types of shading, hatching, or coloring, which are defined in a legend (Figure V.11).

The **deviation** bar chart illustrates differences in either direction from a baseline. This type of chart is especially useful for demonstrating positive-negative and profit-loss data or comparisons of data at different times (Figure V.12). The incorporation of a confidence interval-like portion in the bars provides additional useful information.

Pie charts

A pie chart represents the different percentages of categories of a variable by proportionally sized pieces of pie (Figure V.13). The pieces are usually denoted with different colors or shading, and the percentages are written inside or outside the pieces to allow the reader to make accurate comparisons.

Maps

Maps are the graphic representation of data using location and geographic coordinates (*33*). A map generally provides a clear, quick method for grasping data and is particularly effective for readers who are familiar with the physical area being portrayed. A few popular types of maps that depict incidence or distribution of health conditions are described below.

Spot maps

A spot map is produced by placing a dot or other symbol on the map where the health condition occurred or exists (Figure V.14). Different symbols can be used for multiple events at a single location. Although a spot map is beneficial for displaying geographic distribution of an event, it does not provide a measure of risk since population size is not taken into account.

Chloropleth maps

A chloropleth map is a frequently used statistical map involving different types of shading, hatching, or coloring to portray range-graded values (Figure V.15). It is also called a shaded or area map. Chloropleth maps are useful for depicting rates of

a health condition in specific areas.

Care must be taken in interpreting chloropleth maps because each area is shaded uniformly regardless of any demographic differences within an area. For example, most of a county may be relatively sparsely populated by low-income persons, where as a small portion of that county may be densely inhabited by persons with higher incomes; and the rate at which a particular health condition occurs may falsely appear to be evenly distributed by location and by socioeconomic status throughout the county. Chloropleth maps can also give the false impression of abrupt change in number or rate of a condition across area boundaries when, in fact, a gradual change may have occurred from one area to the next.

Density-equalizing maps

A density-equalizing or rubber map (Figure V.16) transforms actual geographic coordinates to produce an artificial figure in which area or population density is equal throughout the map (*34*). Density-equalizing maps correct for the confounding effect of population density and thus are particularly useful in analyzing geographic clusters of public health events.

Several algorithms exist to transform coordinates of maps. Any transformation routine should define a continuous transformation over the map domain, solve for the unique solution that minimizes map distortion, accept optional constraints, and avoid overlapping of transformed areas (*35*).

INTERPRETATION OF SURVEILLANCE DATA

The real art of conducting surveillance lies in interpreting what the data say. Data need to be interpreted in the context of our understanding of the etiology, epidemiology, and natural history of the disease or injury. The interpretation should focus on aspects which might lead to improved control of the condition. By proceeding from the simple to the complex, investigators can use surveillance as a basis for taking appropriate public health action. Epidemics can be recognized, preventive strategies applied, and the effect of such actions can be assessed. The key to interpretation lies in knowing the limitations of the data and being meticulous in describing them. One axiom to be kept in mind always is that, because of the

descriptive nature of surveillance data, **correlation does not equal causation**.

Limitations in Data

No surveillance system is perfect; however, most can be useful. Several problems inherent in data obtained through surveillance must be recognized if the data are to be interpreted correctly.

Underreporting

Because most surveillance systems are based on conditions reported by health-care providers, underreporting is inevitable. Depending on the condition, 5%-80% of cases that actually occur will be reported (*36-39*). However, the need for completeness of reporting--particularly for common health problems--may be exaggerated. Disease trends by time, place, and person can frequently be detected even with incomplete data. So long as the underreporting is relatively consistent, incomplete data can still be applied to derive useful inferences. For problems that occur infrequently, the need for completeness becomes more important.

Unrepresentativeness of reported cases

Health conditions are not reported randomly. For example, illnesses dealt with in a public health facility are reported disproportionatelly more frequently than those diagnosed by private practitioners. A health problem that leads to hospitalization is more likely to be reported than problems dealt with on an outpatient basis. Thus, reporting biases can distort interpretation. When it is possible, adjusting for skewed reporting will allow investigators to obtain a more accurate picture of the occurrence of a health problem. Collecting data from multiple sources may help provide ways to improve the representativeness of the information.

Inconsistent case definitions

Different practitioners frequently use different case definitions for health problems. The more complex the diagnostic syndrome, the greater the difficulty in reaching consensus on a case definition. Moreover, with newly emerging problems, as understanding of their natural history progresses, we frequently adjust the case definition to allow greater accuracy of diagnosis. Persons who interpret surveillance data must be aware of any changes in case definitions and must adjust their

interpretations accordingly.

Approach to Interpretation

Creative interpretation of surveillance data requires more common sense than sophisticated reasoning. The data can speak for themselves. Brainstorm and test, if possible, all potential explanations for an observed pattern. Has the nature of reporting changed? Have providers or new geographic areas entered the surveillance system? Has the case definition changed? Has a new intervention, such as screening or therapy, been introduced?

Consistency among different surveillance systems is probably the most crucial factor affecting interpretation. If different surveillance data sets from different locations show similar trends, the likelihood that the effect is real increases. Examine trends in different age groups. Finally, choose the surveillance system you think represents the highest quality local information. If the trends of the health problem are evident there, you can be more confident about your interpretations.

To facilitate interpretation of surveillance data, formats can be designed to determine whether the number of reported cases of a health problem for a specified reporting period differs from that of a previous period. An example of such a "user-friendly" format has been published in CDC's *Morbidity and Mortality Weekly Report (MMWR)* since 1990 (*40,41*). Known simply as "Figure 1," the graph uses horizontal bars to indicate the ratio of the current level of disease to the previous 5-year average (Figure V.12). Striping in the bars shows whether the number of reported cases during the most recent 4-week interval are higher or lower than the expected based on the mean and two standard deviations of the 4-week totals. A change in the occurrence of disease identified by this approach indicates the need for more detailed examination of the data--and may indicate an epidemic. Other diverse statistical techniques can be used to detect aberrations in surveillance data (*42*; see Chapter VI).

INTERPRETIVE USES FOR SURVEILLANCE DATA

Identifying Epidemics

An important use of surveillance data is in determining whether increases in numbers

of cases of a health condition at the local or national level represent outbreak (i.e., epidemic) situations that require immediate investigation and intervention. Thus, a surveillance system can function as an early warning signal for public health officials. For example, increases in numbers of cases of hepatitis B among military recruits provided the stimulus to intervene with drug-prevention programs (*43*). CDC's Birth Defects Monitoring System identified increases in renal agenesis (*44*) during the 1970s and 1980s, which prompted an investigation. Monitoring of regional trends in rubella and congenital rubella identified outbreaks among the Amish in 1989-1990 (*45*). A national registry of anti-abortion-associated violence clearly documented an "epidemic" of attacks in the mid-1980s, which decreased after vigorous prosecution was initiated by the Federal Bureau of Investigation (*46*).

The utility of surveillance data in detecting epidemics is highest in situations in which cases of the health condition occur over a wide geographic area or gradually over time. In such situations, the time-place-person links among cases probably would not be recognized by individual practitioners (*3*). Typical examples occur with infectious diseases, when laboratory monitoring of unusual serotypes or antibiotic-resistance patterns identify outbreaks of specific microorganisms that might otherwise have gone unnoticed. Nationwide epidemics of *Salmonella newport* (*47*), *S. enteritidis* (*48*), and *Shigella sonnei* (*49*) have been detected through surveillance.

Identifying New Syndromes

The most dramatic use of surveillance data occurs when a "new" syndrome emerges from an ongoing monitoring system. Legionnaire's disease was detected and subsequently characterized as the result of an outbreak of non-influenza pneumonia within a specific place and population (*50*). Acquired immunodeficiency syndrome (AIDS) was recognized both because of rapid increases in requests for CDC's pentamidine supply and because it occurred in a special time (early 1981), place (California, New York), and person (men having sex with men) setting (*51*). Finally, the national scope of the epidemic of eosinophilia myalgia syndrome (EMS) was noticed because its unique features were like those of toxic oil syndrome (*52*).

Monitoring Trends

Even if specific outbreaks or new syndromes cannot be identified by tracking

surveillance data, the baseline level of the health condition being monitored reflects any variation in its occurrence over time. This purpose is especially relevant to assessing events associated with reproductive health (e.g., ectopic pregnancy or neonatal mortality), chronic disease, or infections with a long latency. The progressive decline--until recently--of tuberculosis in the 20th century and the constant increase in numbers of cases of AIDS throughout the 1980s reflect this monitoring function (*53,54*).

Evaluating Public Policy

Surveillance data can assess the health impact--pro or con--of specific interventions or of public policy. The rapid fall in numbers of cases of poliomyelitis and measles after national vaccination campaigns were instituted is a classic example of the usefulness of surveillance data (*55,56*). Creative interpretation of surveillance data has also been applied to non-infectious-conditions; the impact, in such situations, is somewhat more difficult to assess. For example, in Washington, D.C., the adoption of a gun-licensing law coincided with an abrupt decline in firearm-related homicides and suicides (*57*). No similar reductions occurred in the number of homicides or suicides committed by other means, nor did states adjacent to the District experience any reductions in their rates of firearm-related homicides or suicides. Also, surveillance of legal abortions and of deaths associated with illegal abortion has helped trace the public health impact of this controversial health problem (*8,58,59*). After legal abortion became widely available, deaths from illegal abortion decreased markedly; however, restriction of federal funds for abortion had a negligible effect on health parameters (*60*).

Though it is tempting to use trends in disease and injury to monitor the impact of community interventions, such evaluation becomes increasingly suspect when several factors contribute to the occurrence of disease or health condition being monitored. In addition, if only a portion of the population accepts an intervention, analysis and interpretation of surveillance data are made even more difficult. Frequently, surveillance of process measures or other health problems can act as proxies for the intended outcome. Moreover, finding comparability in data from several populations that have attempted similar public health programs strengthens evidence that the interpretation is correct. For example, to evaluate the effectiveness of allowing

people to exchange used hypodermic needles for new ones as a means of preventing AIDS, epidemiologists could simultaneously examine trends in numbers of needles distributed, surveys of needle use, and incidence of higher-prevalence infections such as hepatitis B.

Projecting Future Needs

Mathematical models based on surveillance data can be used to project future trends. This tool helps health officials determine the eventual need for preventive and curative services. Recently such modelling assisted in estimating the impact of AIDS on the United States health-care system in the 1990s (*61*). Not only did such projections address the demand for AZT by HIV-infected persons with low CD-4 lymphocyte counts, but also the requirements for hospital care for persons with life-threatening superinfections later in the course of HIV-related disease. In addition, models based on surveillance data can predict the decline of morbidity and/or mortality when there are changes in risk factors among the population at risk. Examples of this application include projecting the decline in cardiovascular disease on the basis of decreased smoking of cigarettes (*62*), the decline in cirrhosis-related mortality in the presence of lower levels of alcohol use (*63*), and decreased rates of mortality from cervical cancer associated with an increase in the prevalence of hysterectomy (*64*).

REFERENCES

1. Thacker SB, Berkelman RL. Public health surveillance in the United States. *Epidemiol Rev* 1988;10:164-90.

2. Doll R. Surveillance and monitoring. *Int J Epidemiol* 1974;3:305-13.

3. Berkelman RL, Buehler JW. Surveillance. In: Holland WW, Detels R, Knox G, eds. Oxford textbook of public health, second edition. Vol 2: Methods of public health. Oxford: Oxford University Press, 1991:161-76.

4. Hinman AR. Analysis, interpretation, use and dissemination of surveillance information. *PAHO Bull* 1977;11:338-43.

5. Thacker SB, Berkelman RL, Stroup DF. The science of public health surveillance. *J Pub Health Pol* 1989;10:187-203.

6. Morgenstern H. Uses of ecologic analysis in epidemiologic research. *Am J Public Health* 1982;72:1336-44.

7. Piantadosi S, Byar DP, Green SB. The ecological fallacy. *Am J Epidemiol* 1988;127:893-904.

8. Robinson WS. Ecological correlations and the behavior of individuals. *Am Sociol Rev* 1950;15:351-7.

9. Koonin LM, Kochanek KD, Smith JC, Ramick M. Abortion surveillance, United States, 1988. In: CDC surveillance summaries, July 1991. *MMWR* 1991;40(No. SS-2):15-42.

10. Snow J. Snow of cholera. New York: Hafner Press, 1965.

11. Firebaugh G. A rule for inferring individual relationships from aggregate data. *Am Sociol Rev* 1978;43:557-72.

12. Rolfs RT, Nakashima AK. Epidemiology of primary and secondary syphilis in the United States, 1981-1989. *JAMA* 1990;254:1432-7.

13. Marx R, Aral SO, Rolfs RT, Sterk CE, Kahn JG. Crack, sex, and STD. *Sex Transm Dis* 1991;18:92-101.

14. Last JM, ed. A dictionary of epidemiology. 2nd ed. New York: Oxford University Press, 1988:141.

15. Health United States 1990. DHHS publication no. (PHS) 91-1232. Hyattsville, Maryland: Centers for Disease Control, 1991.

16. Ahlbom A, Norell S. Introduction to modern epidemiology. Chestnut Hill, Massachusetts: Epidemiology Resources Inc, 1984:97.

17. Fleiss JL. Statistical methods for rates and proportions. 2nd ed. New York: John Wiley & Sons, Inc, 1981:321.

18. Kahn HA, Sempos CT. Statistical methods in epidemiology. In: MacMahon B, ed. Monographs in epidemiology and biostatistics. Vol 12. New York: Oxford University Press, 1989:292.

19. Lilienfeld AM, Lilienfeld DE. Foundations of epidemiology. 2nd ed. New York: Oxford University Press, 1980:375.

20. Peavy JV. Adjusted rates. DHHS publication No. (PHS) 00-1833. Atlanta: Centers for Disease Control, 1988.

21. Mausner JS, Bahn AK. Epidemiology: an introductory text. Philadelphia: WB Saunders, 1974:377.

22. Haight F. Handbook of the Poisson distribution. New York: John Wiley & Sons, Inc, 1967.

23. Kleinbaum DG, Kupper LL, Muller KE. Applied regression analysis and other

multivariable methods. 2nd ed. Boston: PWS-Kent Publishing Co, 1988:718.

24. Tukey JW. Exploratory data analysis. Reading, Massachusetts: Addison-Wesley Publishing Company, 1977:688.

25. Velleman PF, Hoaglin DC. Applications, basics, and computing of exploratory data analysis. Boston: Duxbury Press, 1981:354.

26. McNeil DR. Interactive data analysis. New York: John Wiley & Sons, Inc, 1977:186.

27. Tufte ER. The visual display of quantitative information. Cheshire, Connecticut: Graphics Press, 1987:197.

28. Principles of epidemiology. 2nd ed (field test version 11/91). Atlanta: Centers for Disease Control, 1991.

29. Peavy JV, Dyal WW, Eddins DL. Descriptive statistics: tables, graphs, & charts. DHHS publication no. (PHS) 00-1834. Atlanta: Centers for Disease Control, 1986.

30. Schmid CF. Statistical graphics design principles and practices. New York: John Wiley & Sons, Inc, 1983:212.

31. Chambers JM, Cleveland WS, Kleiner B, Tukey PA. Graphical methods for data analysis. Boston: Duxbury Press, 1983:395.

32. Tufte ER. Envisioning information. Cheshire, Connecticut: Graphics Press, 1990:126.

33. Haggett P, Cliff AD, Frey A. Locational analysis in human geography. 2nd ed. Bristol: JW Arrowsmith Ltd, 1977:605.

34. Gillihan AF. Population maps. *Am J Public Health* 1927;17:316-9.

35. Merrill DW, Selvin S, Mohr MS. Analyzing geographic clustered response. In: American Statistical Association 1991 Proceedings of the Section on Statistics and the Environment. Alexandria, Virginia: American Statistical Association (in press).

36. Eylenbosch WJ, Noah ND. Surveillance in health and disease. Oxford: Oxford University Press, 1988:15-23,32-5.

37. Vogt RL, LaRue D, Klaucke DN, Jillson DA. Comparison of active and passive surveillance systems of primary care providers for hepatitis, measles, rubella and salmonellosis in Vermont. *Am J Public Health* 1983;73:795-7.

38. Levy BS, Mature J, Washburn JW. Intensive hepatitis surveillance in Minnesota: methods and results. *Am J Epidemiol* 1977;105:127-34.

39. Marier R. The reporting of communicable diseases. *Am J Epidemiol* 1977;105:587-90.

40. Centers for Disease Control. Proposed changes in format for presentation of notifiable disease report data. *MMWR* 1989;38:805-9.

41. Centers for Disease Control. Changes in format for presentation of notifiable disease report data. *MMWR* 1990;39:234-5.

42. Stroup DF, Williamson GD, Herndon JL, Karon JM. Detection of aberrations in the occurrence of notifiable diseases surveillance data. *Stat Med* 1989;8:323-9.

43. Cowan DN, Prier RE. Changes in hepatitis morbidity in the United States Army, Europe. *Milit Med* 1984;149:260-5.

44. Edmonds LD, James LM. Temporal trends in the prevalence of congenital malformations at birth based on the Birth Defects Monitoring Program, United States, 1979-1987. In: CDC surveillance summaries, December 1990. *MMWR* 1990;39(No. SS-4):19-23.

45. Centers for Disease Control. Outbreak of rubella among the Amish--United States, 1991. *MMWR* 1991;40:264.

46. Grimes DA, Forrest JD, Kirkman AL, Radford B. An epidemic of anti-abortion violence in the United States. *Am J Obstet Gynecol* 1991;165:1263-8.

47. Holmberg SD, Osterholm MT, Senger KA, Cohen ML. Drug-resistant *Salmonella* from animals fed antimicrobials. *N Engl J Med* 1984;311:617-22.

48. St Louis ME, Morse DL, Potter ME, et al. The emergence of grade A eggs as a major source of *Salmonella enteritidis* infections: new implications for the control of salmonellosis. *JAMA* 1988;259:2103-7.

49. Centers for Disease Control. Nationwide dissemination of multiply resistant *Shigella sonnei* following a common-source outbreak. *MMWR* 1987;36:633-4.

50. Fraser DW, Tsai TR, Orenstein W, et al. Legionnaires' disease: description of an epidemic of pneumonia. *N Engl J Med* 1977;297:1189-97.

51. Centers for Disease Control. Pneumocystic pneumonia--Los Angeles. *MMWR* 1981;30:250-2.

52. Swygert LA, Maes EF, Sewell LE, Miller L, Falk H, Kilbourne EM. Eosinophilia-myalgia syndrome: results of national surveillance. *JAMA* 1990;264:1698-703.

53. Reider HL, Cauthen GM, Kelly GD, et al. Tuberculosis in the United States. *JAMA* 1989;262:385-90.

54. Centers for Disease Control. Update: acquired immunodeficiency syndrome--United States, 1981-1990. *MMWR* 1991;40:358-69.

55. Centers for Disease Control. Measles prevention: recommendations of the Immunization Practices Advisory Committee (ACIP). *MMWR* 1989;38(no. S-9):1-18.

56. Centers for Disease Control. Progress toward eradicating poliomyelitis from the

Americas. *MMWR* 1989;38:532-5.

57. Loftin C, McDowall D, Wiersema B, Cottey TJ. Effects of restrictive licensing of handguns on homicide and suicide in the District of Columbia. *N Engl J Med* 1991;325:1615-20.

58. Cates W Jr, Rochat RW, Grimes DA, Tyler CW Jr. Legalized abortion: effect on national trends of maternal and abortion-related mortality (1940-1976). *Am J Obstet Gynecol* 1978;132:211-4.

59. Cates W Jr. Legal abortion: the public health record. *Science* 1982;215:1586-90.

60. Cates W Jr. The Hyde amendment in action: how did the restriction of federal funds for abortion affect low-income women. *JAMA* 1981;246:1109-12.

61. Centers for Disease Control. HIV prevalence estimates and AIDS case projections for the United States: report based upon a workshop. *MMWR* 1990;39:(No. RR-16).

62. Kullback S, Cornfield J. An information theoretic contingency table analysis of the Dorn study of smoking and mortality. *Comput Biomed Res* 1976;9:409-37.

63. Skog O. The risk function for liver cirrhosis from lifetime alcohol consumption. *J Stud Alcohol* 1984;45:199-208.

64. Centers for Disease Control. Hysterectomy prevalence and death rates for cervical cancer--United States, 1965-1988. *MMWR* 1992;41:17-20.

Chapter VI

Special Analytic Issues

Donna F. Stroup

"There is only one good, that is knowledge. There is only one evil, that is ignorance."

Socrates

NATURE OF PUBLIC HEALTH SURVEILLANCE DATA

Data obtained in a public health surveillance system have several characteristics that affect analyses. Most fundamentally, data from most surveillance systems are not generated from a designed study or randomized trial. Although this departure has been

addressed in the context of epidemiologic studies and field investigations (*1*), the effect in the surveillance setting has specific consequences.

First, for a surveillance system, data are reported regularly, and may be updated after the initial report. Since the lag time between first report and subsequent updating may vary by health event or reporting location, methods developed for early detection of aberrations in the data should be applied as soon as provisional data are available. If the analyses are implemented as part of a routine surveillance program, results can be monitored as data are updated.

Second, surveillance data are generated by a spatial as well as a temporal process. For example, at a given point in time, cases of a disease for a given area may not appear excessive; however, when compared with other times or other areas at a given time, an excess may become apparent (*2*).

Third, when only aggregated data are available (e.g., from regions, counties, or states), the distribution of cases in the underlying population cannot be assessed directly. This problem is compounded because the areas of aggregation are usually arbitrarily defined and case definitions are not consistent within areas. As a result, statistical inferences concerning the properties of individuals are confounded by the properties of the aggregated system.

Finally, the surveillance process is generally a multivariate one (*3*). Multiple health events under surveillance may be related for a given point in time for the same area, or the relationship may be delayed in time for the same or nearby areas if diagnosis is uncertain or confirmation is delayed. The multivariate nature of this process should be used to improve the ability of any method to detect aberrations from a baseline.

CLUSTERING OF HEALTH EVENTS

One foundation of the science of epidemiology is the study of the departure of the observed patterns of the occurrence of disease from the expected pattern of occurrence (*4*). Variations in the usual incidence of health events in different geographic areas or different time periods may provide important clues to specific risk factors or even

to the etiology of the problem. The expected numbers of reported health events are generated by a process involving human behavior and transmission of disease, and patterns of occurrence within human populations may lead to hypotheses about the determinants of the health problem (5).

The public health community continues to struggle with nomenclature for such variations. The term *"cluster"* can be defined as "a set of events occurring unusually close together to each other in time or space, in both time and space, or within the limits of demographic characteristics (e.g. persons in the same occupation)." "Cluster" is usually used to describe uncommon events (e.g., leukemia, suicide) and tends to evoke emotional response from members of the public or from the media.

A related term is *"epidemic"*, historically used to describe aggregation of infectious diseases: "an outbreak of a disease spreading rapidly from person to person" (*6*). More recently, the concept has broadened to the following: "the occurrence in a community or region of cases of an illness, specific health-related behavior, or other health-related events clearly in excess of normal expectancy . . . . The number of cases indicating the presence of an epidemic will vary according to agent, size and type of population exposed, previous experience or lack of exposure to the disease and time and place of occurrence; thus, epidemicity is relative to the usual frequency of the disease in the same area, among the specified population, at the same season of the year" (7). It is prudent to be conscious of the fact that the term *"epidemic"* evokes responses beyond these definitions. In late 1988, the British Public Health Laboratory Service used *"epidemic"* to describe an increase in reported numbers of cases of *Salmonella enteritidis* associated with contaminated chicken and eggs. The country's Chief Medical Officer, Sir Donald Acheson, advised caution "...in using the word epidemic when addressing the public because of its connotations with terrifying diseases such as cholera and smallpox" (*8*). The term *"outbreak"* has less evocative connotations. With all such definitions, a critical concept is the comparison of an observed number with what is usual or normal. The distinction made here is that "aberration" will be used to denote changes in the occurrence of health events that are statistically significant when compared with usual or normal history. The definition of an epidemic may require the existence of an aberration; e.g., the Centers for Disease Control (CDC) declares that an epidemic of a specific strain of influenza is occurring only if the number of reported deaths exceeds a 95% confidence

limit in the forecast for two or more consecutive periods. In general, application of the term "epidemic" may require epidemiologic conditions beyond the statistical ones, e.g., laboratory isolates or resistance to vaccine.

In this chapter, *"aberration"* is used to describe statistical departures from a usual distribution. It is important to understand that such departures do not necessarily signal the "onset of an epidemic" or the "presence of a cluster." Conversely, one can have an epidemic even in the absence of a statistical increase, such as when infant mortality is "low" but still higher than expected. The methods developed here are intended for routine use by the public health analyst, in conjunction with epidemiologic investigation and close communication with the source of the surveillance reports.

ABERRATIONS IN TIME

Since the definition of surveillance implies ongoing data collection, perhaps the most fundamental question suggested by the analysis of a surveillance system is the following: When does the value of reported events signal a change in the process from past patterns? Although fundamental, the analysis required to address this question suggests additional questions. How are "past patterns" defined? If an outbreak occurred in the past, should this affect the definition of a change? Other than the disease or injury process itself, what other factors could cause a change?

In the paragraph below, we use the terms "baseline" to denote historical data and "current report" to denote the recent data on which the assessment is based.

Graph of Current and Past Experience

State health departments report the numbers of cases of about 50 notifiable diseases each week to CDC's National Notifiable Diseases Surveillance System (NNDSS). The list of health events is determined collaboratively by the Council of State and Territorial Epidemiologists and CDC (*9,10*). Each week provisional reports are published in the *Morbidity and Mortality Weekly Report* (*MMWR*) and are made available to epidemiologists, clinicians, and other public health professionals in a timely manner. Although the tables of the *MMWR* continue to provide important information, the volume of data and the need for ease of interpretation encouraged the development of a

graphic display to highlight unusually high or low numbers of reported cases.

A new analytic and graphical method was adopted for this system to achieve the following objectives: a) to portray in a single comprehensible figure the weekly reports of data for approximately 20 diseases and to compare those data with past results b) to highlight for further analysis the results most likely to reflect either long-term trends or epidemics. These objectives were formulated to reflect most recent behavior in as short a time period as possible for weekly publication, but a long enough period to assure stable results. To facilitate comprehension, the same method is used for all diseases portrayed.

The analytic method currently used for constructing Figure I in the *MMWR* (see Figure VI.12), called the "*CDC MMWR Current/Past Experience Graph (CPEG)*," compares the number of reported cases in the current 4-week period for a given health event with historical data on the same condition from the preceding 5 years (*11,12*). Numbers of cases in the current month are listed to facilitate interpretation of instability caused by small numbers.

The choice of 4 weeks as the "current period" was based on evidence that weekly fluctuation in data from disease reports usually reflects irregular reporting practices rather than actual incidence of disease. The use of 5 years of history achieves the objective of using the same model for all conditions portrayed, since some health events were made notifiable only recently (e.g., acquired immunodeficiency syndrome (AIDS) and legionellosis).

Also, modelling of reported influenza incidence has shown that more accurate forecasts are based on more recent data (*13*). To increase the historical sample size and to account for any seasonal effect, the baseline is taken to be the average of the reported number of cases for the preceding 4-week period, the corresponding 4-week period, and the following 4-week period, for the previous 5 years. This yields 15 correlated observations, referred to as the historical observations, or "baseline" (Figure VI.1).

The deviation from unity of the ratio of the current 4-week total to the historical average is indicative of a departure from past patterns. We plot this ratio on a

logarithmic scale so that an n-fold increase projects to the right the same distance as an n-fold decrease projects to the left, and no change from past patterns (1:1) produces a bar of zero length (*14*). To distinguish the conditions that may require further investigation, the hatching on the bars begins at a point based on the mean and standard deviation of the historical observations.*

An evaluation of this method shows that it has good statistical robustness to patterns in the data and high sensitivity and predictive value positive for epidemiologically confirmed outbreaks (*15*). An outbreak of rubella detected by this method proved to be of substantial public health importance (*16*). Recent increases beyond historical limits in reporting of aseptic meningitis reflected increased disease activity primarily in the northeastern United States (*17*).

TIME-SERIES METHODS

The method used by CDC to estimate excess mortality associated with influenza was developed from a 1932 study that defined the expected number of weekly deaths from pneumonia and influenza, or from all causes, as the median number of deaths for a given week during non-epidemic years (*18*). "Excess deaths," then, was defined as the difference between the observed and the conditional expected numbers, a one-period-ahead forecast. Later, a regression model was fitted to weekly pneumonia and influenza data from U.S. cities to calculate an expected number of deaths (*19*). In 1979, CDC proposed a new method to estimate expected deaths using a body of methods called time-series (*20*). More recently, a method forecasting separate expected numbers by age group has been investigated (*13*).

The methodology of time series is appropriate for data available sequentially over time. A time-series model generally comprises components estimating the effect of secular trend, cycles, or year-to-year seasonal patterns. The process of model fitting consists of identification, estimation, and diagnostic validation. One then evaluates competing models on the basis of the fit of the models to the observed data and of the accuracy of the forecasts.

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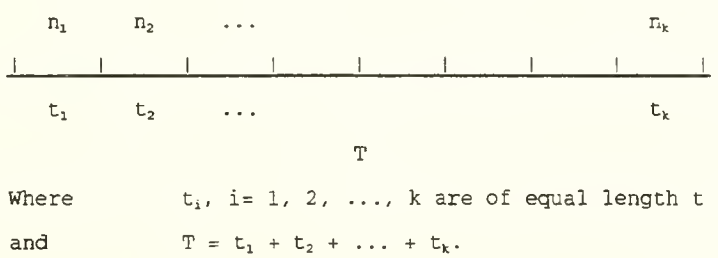
*Historical limits of the ratio of current reports to the historical mean are calculated as 1 plus or minus 2 times the standard deviation divided by the mean, where the mean and the standard deviation are calculated from the 15 historical 4-week periods.

Most common methods of time-series analysis, such as the Auto Regressive Integrated Moving Average (ARIMA) models (*21*), are appropriate for relatively long series of data that exhibit certain regular properties over the entire series. Differencing, or forming a new series by subtracting adjacent observations, is generally used to create a series with a stationary mean, that is without trend. An additional property, stationarity of the variance, is generally required, so that the process does not become more or less variable over time. An autoregressive model includes terms that model the data at one point in time as a function of previous data. A moving-average term creates a series from averages of adjacent observations and is used to model cycles in the data.

The advantage of time-series models for surveillance over other modeling methods, such as regression, is that the estimation process accounts for period-to-period correlations and seasonality, as well as long-term secular trends. A more detailed description of the concepts used in time series has been described (*21*).

Scan Statistic

Consider this surveillance question: Is the number of cases reported for a certain time period excessive? While ARIMA time-series methods provide one approach to the answer, often the mechanics of this analysis are complex. The scan statistic (*22*) offers a relatively simple alternative in this situation. The scan statistic is the maximum number of reported cases (i.e., events) in an interval of predetermined length over the time frame of interest. It is used to test the null hypothesis of uniformity of reporting against an alternative of temporal clustering. Consider the following setting. Surveillance data are reported over a time period T, containing k intervals of equal length:



Where t_i, i= 1, 2, ..., k are of equal length t

and $T = t_1 + t_2 + \ldots + t_k$.

The total number of events reported in the entire time period is called N and is the

sum of the numbers of events in each of the intervals $n_1 + n_2 + \ldots + n_k$. Let n = max $\{n_i\}$, i= 1,2, ..., k, or the largest report in any of the intervals. Then compute L = T/t, or the number of intervals in the entire time period.

The statistical question addressed by the scan statistic is: What is the probability that the maximum number of cases in any interval of length t is equal to or exceeds n?

For example if the frequency of trisomies among karyotyped spontaneous abortions for a defined geographic area by calendar month of last menstrual period in 1992 are as follows:

Month	Number of cases	Month	Number of cases
January	1	July	2
February	3	August	4
March	2	September	4
April	2	October	2
May	4	November	3
June	3	December	10

What is the probability of 10 or more trisomies in December given there were a total of 40 in 1992? Using the notation defined above, N = 40, T = 12; L = 12/1 = 12; n = 10; and t= 1. Then from tabulated values (*23*) the probability of 10 or more trisomies in December, given 40 for the year, is 0.083.

	L= 8		L= 12		L= 15	
N	n	p	n	p	n	p
35	14	0.002	11	0.007	10	0.007
40	13	0.040	10	**0.083**	9	0.082
40	14	0.012	11	0.024	10	0.021
40	15	0.003	12	0.006	11	0.005
45	14	0.042	11	0.064	10	0.053

If the results of the scan statistic are to be useful, the lengths of the entire time frame and the scanning interval must be determined a *priori*. The lack of extensive tabulated values and the computer-intensive calculations for large sample sizes limit the usefulness of the method. Approximations to the exact distribution are described elsewhere (*23-25*).

ABERRATIONS IN SPACE AND TIME

Given cases of a health event reported from a defined geographic area over a defined time period, can we say that the cases occur unusually close together in both space and time? That is, do they form a spatial-temporal cluster? Traditional approaches to the analysis of health-event aggregation in geographic areas have been based on randomization arguments (*26-27*). A representative discussion follows.

One proposed method divides the study area into subareas (e.g., counties or census tracts) and the study time period into intervals of constant length (e.g., month or year) (*28*). The cases of the health event for each time-space "cell" are then calculated. The maximum count within any time interval is summed across all subareas to obtain a test statistic. This method assumes equal population density across all area cells and has limitations (*29*).

In Knox's method, all possible pairs of cases are examined, and each pair is classified according to whether the case-patients in the pair lived "close" together and had onset of the health problem (or report) "close" in time, resulting in the 2-by-2 table:

		Reports close in time?	
		Yes	No
Reports close in space?	Yes	a	b
	No	c	d

Under the hypothesis of no clustering, the expected number may be calculated in the usual way, with an adjustment in the significance test, since the statistic is based on pairs of cases (*30*). A brief example follows.

Consider cases of a disease with the following spatial and temporal relationships:

		Close in space?		
		Yes	No	All
Close in time?	Yes	1		5
	No			23
	All	6	22	28

The test statistic to be computed is X = number of pairs close in space and time, 1 in this example. We use row and column marginal totals to compute an expected value for

this cell: (6 x 5) / 28 = 1.07. Now use the Poisson distribution to compute the probability of seeing one (or more) cases close in space and time, given that we expect 1.07; this value is at least 0.63. Therefore, we conclude that these data provide no evidence for space/time clustering.

A criticism of Knox's method is that the choice of the critical time and space distances is arbitrary. This problem was addressed for the question of spatial clustering (*31*), and the method does not require spatial boundaries or assessment of the entire population base. An alternative approach is demonstrated by Williams (*32*), with a sensitivity analysis of the time and space critical values.

A second criticism of Knox's method is that it makes no allowance for edge effects which arise either from natural geographic boundaries (e.g., coastlines) or because there are unrecorded cases outside the designated study region. A new method (*33*) addresses this, by altering the interpretation of expected pairs of close cases and replacing the simple count of close pairs by a weighted sum. Recently, this new method has been applied to test the hypothesis that many non-outbreak cases of Legionnaires' disease in Scotland and not sporadic and to attempt to pinpoint cases clustering in space and time (*34*).

It is important to emphasize that because of the diverse and complicated nature of clusters, there is no single test to assess them. The statistical sources suggested here are intended only to augment other epidemiologic methods in a systematic, integrated approach (*35*), coupled with flexibility in methods of analysis and interpretation of significance levels.

COMPLETENESS OF COVERAGE

Statistical methods are the basis of many aspects of evaluating a public health surveillance system (*36*). For example, the question of completeness of a surveillance system is fundamental to the system's usefulness. One approach to the assessment of completeness involves a capture-mark-recapture technique, developed for the enumeration of wildlife populations (*37*) and used by the U. S. Census Bureau (*38*). The method requires two parallel surveillance systems, or a surveillance system and a survey, measuring the incidence of a single health event, and provides an estimate of

true total number of cases of that health event and the completeness of coverage of the two systems.

The Chandra Sekar-Deming (CSD) and Lincoln-Peterson Capture-Recapture (LPCR) Methods suggest the following structure for the analysis. Suppose two surveillance systems for the same health event report *R* and *S* totals respectively for some time period. In addition, suppose it is possible to match the cases so that we know which *C* of the cases are reported to both surveillance systems. This structure suggests the following 2-by-2 table:

	Surveillance system 1		
Surveillance system 2	Cases reported	Cases not reported	All cases
Cases reported	C	N_2	S
Cases not reported	N_1	X	
All cases	R		N

The CSD and LPCR methods estimate N, the total number of cases from the combined information, and provide a confidence interval for that estimate. Using the notation suggested in the table above,

$$N = [\ (R+1)\ (S+1)\ /\ (C+1)\ ]\ -\ 1$$

$$Var(N) = (R+1)\ (S+1)\ N_1\ N_2\ /\ [\ (C+1)^2\ (C+2)\ ]$$

$$95\%\ CI\ (N) = N \pm 1.96\ \sqrt{Var\ (N)}.$$

Thus the completeness of each surveillance system can be calculated as follows:

$$\text{Completeness of \#1} = R\ /\ N$$

$$\text{Completeness of \#2} = S\ /\ N.$$

Consider the following example. There exist two independent surveillance systems for hepatitis A for a location with stable population. Suppose that the events identified in either of the two systems are true events, that the matching procedure identifies all true matches, and only true matches are identified.

	Surveillance system 1		
Surveillance system 2	Cases reported	Cases not reported	All cases

Cases reported	790	60	850
Cases not reported	50	X	
All cases	840		N

The estimated number of cases missed by both systems is

$$X = (50 \cdot 60) / 790 = 3.8 \rightarrow 4.$$

So, the estimated number of cases in the population under surveillance is:

$$N = 790 + 50 + 60 + 4 = 904.$$

The formulas above yield a 95% confidence interval for N of 904 ± 4. The completeness of surveillance system #1 is 840/904 or 0.93, and that of surveillance system #2 is 0.94.

The usefulness of results from this capture-recapture calculation is based on four assumptions:

- Surveillance is done for a closed population.
- The matching procedure successfully identifies all true matches and, conversely, only true matches are identified.
- All events identified in either of the two systems are true events.
- The two systems are independent.

Clearly, these are seldom if ever satisfied for public health surveillance systems; however, this should not preclude the method as an investigative tool. For example, at the national level, the lack of personal identifiers precludes exact matching of cases between surveillance systems. However, other information (age, gender, county, date of onset) may allow probability matching or estimates of the overlap. Application of the LPCR method with more stringent or relaxed matching criteria will yield bounds on the completeness of coverage still useful for surveillance evaluation. For example, if we relax the matching criteria in the table above so that 820 cases are reported to both systems, analogous calculations show that the completeness of system #1 is 0.96, and that of system #2 is 0.98.

SELECTION OF ANALYTIC METHODS

No single method can be used to detect all epidemics or all types of aberrations. Several questions provide a framework for choosing an analytic method.

What is the purpose of the surveillance system? The data used for the *CPEG* analyses are reported weekly by state health departments. Although each state analyzes its own data, patterns may be apparent from the aggregated national picture that may facilitate prevention and intervention efforts. Additionally, the data are maintained historically for the archival purposes of measuring trends and assessing the effects of interventions.

What is the purpose of the analytic method? Since a single method cannot be expected to distinguish between a change in historical trend and a one-time outbreak with unsustained increases, the analyst must identify the purpose of the analysis before choosing an analytic method. If the nature of the data is determined and the questions are well-defined, the results of the analytic method can be used to augment other sources of information.

The purpose of *CPEG* is to facilitate the routine analysis of surveillance data and to supplement other sources of information. The method is not useful for conditions with long-term historical trends. When the data have complex patterns, it may be helpful to remove (simplify) some of this pattern by modeling. The classical methods of time-series analysis are appropriate for this situation, but these may not be accessible to the practicing public health official.

Which conditions should be monitored? Routine analysis should be reserved and adapted for conditions for which there are public health interventions. The *CPEG* methodology is most appropriate for conditions with historical trends that do not exhibit frequent changes in trend or level and that occur often enough so that a single case or two does not constitute a significant flag. If the raw data are not already analyzed for trend and period effects, and the variance of the numerator (present cases) cannot be assumed to have the same variance as the observations in the denominator (historical data), and if the series exhibits considerable correlation for first-order (adjacent) observations and beyond, the **CPEG** method may be less powerful.

For rare conditions, the instability caused by small numbers of reported cases may make the results unsuitable for repeated use.

What is the (person, place, or time) unit of analysis? We chose national data for presentation of *CPEG*. The objective was to use as short and recent a time period as possible for weekly publication, thus making the results useful for timely intervention. However, variability in weekly reports reflecting factors other than the disease process--e.g., delayed reports due to outbreaks--made the results unstable. We then chose a 4-week window.

Because of the interest in analytic techniques for the analysis of aberrations in surveillance data at the state level, six state health departments evaluated the usefulness of the *"CPEG"* (*39*). During the 4-month period of study, a total of 210 episodes were observed, of which 27 episodes were flagged as exceeding historical limits; one state had no episodes of unusual reporting. Overall, 14 episodes (52%) represented epidemiologically confirmed outbreaks. Many were small, and none were detected when aggregated with other state data for the national analyses. Each disease exceeded historical limits at least twice during the study period, and for all but meningococcal disease, at least one incident represented an outbreak. Although the numbers are clearly small, the proportion of episodes that represented outbreaks varies. This is expected for conditions with different epidemiology.

The five outbreaks that the health department knew about but that were not detected by the *CPEG* method highlight some of its limitations. In three outbreaks, cases were not reported nationally as current reports; thus, they were not included with the data used for the calculation. The other two outbreaks were not detected because of concurrent increases in the corresponding baseline.

What provision is there for updating or correcting the data using later reports? In the NNDSS, cases are reported as early as possible and then later confirmed or modified. The methodology of *CPEG* is applied to the provisional (earliest reported) data. In our study of six states, two of the five outbreaks that were not detected reflected late reports not included in the current reporting period.

How is the baseline determined? The choice of 5 years as a baseline period was based on a consideration of appropriate sample size balanced by a desire to use the same method for all conditions. Although a longer baseline might be used for some conditions with a long reporting history, epidemics or changes in trend in the baseline will increase the variance of the baseline and thus offset any benefit of additional data. An additional source of variation may be increases in reporting due to intensive investigation. In these cases, the analyst may choose to omit or adjust the increased baseline data.

How are outbreaks in the baseline handled? *CPEG* as presented here does not adjust for epidemics in the baseline. The result of this is a progressive decline in sensitivity--when an outbreak moves in and then out of the baseline window. To address this point, one could use a median of the baseline reports (rather than a mean). Unfortunately, this replacement invalidates the technique used to compute the point for signalling aberrations, and the alternative methods for calculating this are not as accessible to the practicing epidemiologist as the *CPEG* methodology.

What are the sensitivity and, predictive value positive of the method? Applying *CPEG* by states detected 14 of 19 (74%) of outbreaks and 14 of 27 (52%) of the episodes exceeded historical levels were actually outbreaks by sensitivity (74%) and predictive value positive (52%) of *CPEG* in states is therefore quite high. Partly because of the use of provisional data, we use the mean of the historical baseline in the calculation. We investigated the predictive value positive of the *CPEG* from six state health departments by asking each department to follow up on aberrations detected by this system. In addition, we asked that outbreaks that came to their attention through other sources but had not been identified by *CPEG* be noted.

What are the mechanics of operation? For any analytic method to be useful, it must be easily implemented in the routine work of the practicing epidemiologist. In evaluating the states use of *CPEG* at the national level, an epidemiologist routinely evaluated each aberration, analyzed state distributions, and conveyed results to each CDC program responsible for the control of the condition. Additional information was provided by epidemiologists in state health departments. Investigation was based on this evidence in addition to that obtained through other analysis. Eventually, state

health departments will have the software to generate *CPEG* locally.

Emergent methods provide opportunities for the future of surveillance analysis. Many methods of pattern recognition are based on Bayesian concepts, in which a different approach is taken to the process that generates the data--in this context, reports of a health event.

Classical statistical theory regards the data as arising from a process with unknown but constant parameters. The objective of classical methods, then, is to use the observed data to estimate or make inferences about the unknown values. Bayesian methods regard the parameters as having prior distributions, independent of the data, and the data are used to update or refine our idea of this distribution. "The gain in introducing the prior [distribution] is partly that it provides a way of injecting additional information into the analysis and partly that there is a gain in logical clarity" (*40*).

In the application to data generated over time and space as public health surveillance reports, the Bayesian approach recognizes the value of information beyond the mere data history (e.g., a change in the definition of a reportable case of AIDS (*41*). In such circumstances, no statistical model can be expected to predict such occurrences using historical data only. "There is a tendency to overfit [sic] a particular past realization at the expense of the unrealized future" (*42*). It is necessary to have a system in which people can convey their information to the method and have the method convey this uncertainty in a way that is useful for intervention and control.

One important application of Bayesian methodology is to increase the stability of observed rates of health events on the basis of data for small populations. For example, county-level mapping may provide the resolution necessary to identify regions with potentially elevated risk, but the high variability of observed rates in counties with small populations may mask any underlying patterns. A two-stage empirical Bayes procedure (*43*) addresses this problem by augmenting information for one county with that of all other counties. Devine (*44*) applied this method to mapping of injury-related mortality rates for the United States from 1979 through 1987. This work represents an important step towards producing meaningful maps for small areas. However, sensitivity to model assumptions and consideration of spatial dependence

remain areas for investigation.

REFERENCES

1. Goodman RA, Buehler JW, Koplan JP. The epidemiologic field investigation: science and judgment in public health practice. *Am J Epidemiol* 1990;132:9-16.

2. Openshaw S, Taylor PJ. The modifiable areal unit problem. In: Wrigley N and Bennett RJ, (ed.). Quantitative geography: a British view. London: Routledge and Kegan, Paul 1981.

3. Thacker SB, Berkelman RL, Stroup DF. The science of public health surveillance. *J Publ Hlth Pol* 1989;10:187-203.

4. Lilienfeld AE, Lilienfeld DE. Foundations of epidemiology. 2nd edition. Oxford, England: Oxford University Press, 1980.

5. Macmahon B, Pugh TF. Epidemiology: principles and methods. Boston, Ma.: Little Brown and Co., 1970.

6. Baker AD, Margerison FM. New medical dictionary. London, England: Northcliff, 1935.

7. Last JM. a dictionary of epidemiology, 2nd edition. Oxford, England: Oxford University Press, 1988.

8. London Times, January 11, 1989.

9. Thacker SB. The surveillance of infectious diseases. *JAMA* 1983;249:1181-5.

10. Centers for Disease Control. summary of notifiable diseases United States 1990. *MMWR* 1990;39:(53).

11. Stroup DF, Williamson GD, Herndon JL, Karon JM. Detection of aberrations in the occurrence of notifiable diseases surveillance data. *Stat Med* 1989;8:323-32.

12. Centers for Disease Control. Proposed changes in format for presentation of notifiable disease report data. *MMWR* 1989;38(47):805-9.

13. Stroup DF, Thacker SB, Herndon JL. Application of multiple time series analysis to the estimation of pneumonia and influenza mortality, by age, 1962-1983. *Stat Med* 1989;7:1045-59.

14. Morgenstern H, Greenland S. Graphing ratio measures of effect. *J Clin Epidemiol* 1990;43:539-42.

15. Stroup DF, Wharton M, Kafadar K, Dean AG. An evaluation of a method for detecting aberrations in public health surveillance data. In press: *Stat Med.*

16. Centers for Disease Control. Increase in rubella and congenital rubella syndrome--United States, 1988-1990. *MMWR* 1991;40:93-9.

17. Centers for Disease Control. Aseptic meningitis--New York State and United States, weeks 1-36, 1991. *MMWR* 1991;40(45):773-5.

18. Collins SD. Excess mortality from causes other than influenza and pneumonia during influenza epidemics. *Publ Health Rep* 1932;47:2159-80.

19. Serfling RE. Methods for current statistical analysis of excess pneumonia-influenza deaths. *Public Health Rep* 1963;78:494-505.

20. Choi K, Thacker SB. An evaluation of influenza mortality surveillance, 1962-1979. I. Time series forecasts of expected pneumonia and influenza deaths. *Amer J Epidemiol* 192;113:215-26.

21. Box GEP, Jenkins G. Time series analysis: forecasting control. San Francisco, Ca.: Holden-Day, 1976.

22. Wallenstein S. A test for detection of clustering over time. *Am J epidemiol* 1980;111:367-72.

23. Naus JI. Approximations for distributions of scan statistics. *J Amer Stat Assn* 1982;77:177-83.

24. Wallenstein S, Neff N. An approximation for the distribution of the scan statistic. *Stat Med* 1987;6:197-207.

25. Glaz J. Approximations and bounds for the distribution of the scan statistic. *J Amer Stat Assn* 1989;84:560-6.

26. Mantel N. The detection of disease clustering and a generalized regression approach. *Cancer Res* 1967;27:209-20.

27. Aldrich TE, Wilson CC, Warner SS, Easterly CE. Studying case clusters: a primer for disease surveillance. *Am J Epidemiol* 1989;120:223-30.

28. Ederer F, Myers MH, Mantel N. A statistical problem in space and time: do leukaemia cases come in clusters? *Biometrics* 1964;20:626-39.

29. Knox EG. The detection of space-time interaction. *Appl Statist* 1964;13:25-9.

30. David FN, Barton DE. Two space time interaction tests for epidemicity. *Brit J Prev Soc Med* 1966;20:44-8.

31. Cuzick J, Edwards R. Spatial clustering for in for inhomogeneous populations. *J R Statist Soc* 1990;652:73-104.

32. Williams EH, Smith PG, Day NE, *et al*. Space-time clustering of Burkitt's lymphoma in the west Nile district of Uganda: 1961-1975. *Brit J cancer* 1978;37:109-22.

33. Diggle PJ, Chetwynd AG, Haggkvist R. Second order analysis of space-time clustering. Lancaster, Pa.: Lancaster University, 1991. (Department of Mathematics technical report).

34. Bhopal RS, Diggle PJ, Rowlingson B. Pinpointing clusters of apparently sporadic cases of legionnaire's disease. *BMJ* 1992;304:1022-7.

35. Centers for Disease Control. Guidelines for investigating clusters of health events. *MMWR* 1990;39(No. RR-11).

36. Centers for Disease Control. Guidelines for the evaluation of surveillance systems. *MMWR* 1988;37(S-5).

37. Eberhardt LL. Appraising variability in wildlife populations. *J Wildlife Management* 1978;42:207-38.

38. Wolter KM. Accounting for America's uncounted and miscounted. *Science* 1991;253:12-5.

39. Wharton M, Price W, Hoesly F *et al*. Evaluation of a method for outbreak detection in six states. *Am J Prev Med* (in press).

40. Cox DR, Hinkley DV. *Theoretical Statistics*. London, England: Chapman and Hall, 1974.

41. Selik RM, Buehler JW, Karon JM *et al*. Impact of the 1987 revision of the case definition of acquired immune deficiency syndrome in the United States. *J Acquired Immune Deficiency Syndromes* 1990;3:73-82.

42. Harrison PJ, Stevens CF. Bayesian forecasting (with discussion). *J Royal Stat Soc* 1976;38:205-47B.

43. Tsutakawa RK. Mixed model for analyzing geographic variability in mortality rates. *J Am Stat Assoc* 1988;83:37-42.

44. Devine OJ. A modified empirical bayes approach for stabilizing mortality rates in areas with small populations. Proceedings of the National Meeting of the American Statistical Association, Atlanta, Ga., August, 1991.

Chapter VII

COMMUNICATING INFORMATION FOR ACTION

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"All I know is just what I read in the papers."

Will Rogers

DEFINITION OF THE PROBLEM: COMMUNICATING SURVEILLANCE DATA

Standard definitions for public health surveillance specify the requirement for the timely dissemination of findings to those who have contributed and others who need to know (*1-3*). In the United States, surveillance findings have been disseminated through the *Morbidity and Mortality Weekly Report (MMWR)* series of publications, public health bulletins in states, and special reports in peer-reviewed journals. However, even though new technologies and epidemiologic methodologies have dramatically improved the collection and analysis of surveillance data, public health programs have lagged in developing effective approaches to the dissemination of surveillance findings--and to the ultimate successful communication of those findings.

As recently as the 1970s, public health surveillance in the United States focused almost exclusively on the detection and monitoring of cases of specific communicable diseases, and surveillance data were disseminated primarily in a basic tabular format. However, surveillance efforts have expanded rapidly and now include chronic diseases, injuries, occupationally acquired conditions, and other problems. In addition, surveillance encompasses problems as diverse as personal behavior (e.g., cigarette

smoking and seat-belt use); environmental insults (e.g., hazardous materials incidents); and preventive practices (e.g., Pap smears and mammographic screening).

Because of the fundamental changes in public health programs and priorities, programs at all levels require innovative approaches to convey surveillance findings to new and more diverse constituencies. This chapter provides a practical framework for optimizing dissemination and communication of information developed through public health surveillance efforts.

BASIC CONCEPTS FOR DISSEMINATING AND COMMUNICATING SURVEILLANCE INFORMATION

Surveillance has been characterized as a process that provides "information for action." This concept is inherently consistent with one definition that described communications as "...a process, which is a series of actions or operations, always in motion, directed toward a particular goal" (5). On the basis of this definition, then, public health programs must ensure more than the mere transmission or dissemination of surveillance results to others; rather, surveillance data should be presented in a manner that facilitates their consequent use for public health actions. One fundamental concept is that the terms "dissemination" and "communication" cannot be used interchangeably. Dissemination is a one-way process through which information is conveyed from one point to another. In comparison, communications is a loop--involving at least a sender and a recipient and is a collaborative process. The communicator's job is completed when the targeted recipient of the information acknowledges receipt and comprehension of that information.

A basic framework for disseminating the results of public health surveillance with the intent of communicating can be adapted from fundamental models for communications. One such model--which emphasizes the effect of communications-includes the sender, the message, the receiver, the channel, and the impact (3). The sender is the person responsible for surveillance of each health condition being monitored. For applications in public health practice, this model can be modified (See Table VII.1).

Each of these steps is discussed in greater detail in the paragraphs below. They

should all be read with the understanding that one should never disseminate more information than s/he can evaluate and revise, as needed, during the communications process.

Establish Message

The primary message or communications objective for the findings of any public health surveillance effort should reflect the basic purposes of the surveillance system. In this textbook, the purposes of surveillance systems have been described (Chapters I and II). For each of these categories, the findings and interpretation of surveillance data may necessitate a different type of public health response. In addition to disseminating data to those who may have contributed, the communications objectives should also dictate the delivery of the information to the relevant target groups and the stimulation of appropriate public health action, as illustrated below.

To detect and control outbreaks

When the purpose of a surveillance system is to detect outbreaks or other occurrences of disease in excess of predicted levels, the primary communications objective should be to inform two groups: a) the population at risk of exposure or disease, and b) persons and organizations responsible for immediate control measures and other interventions. For example, when surveillance efforts detect influenza activity in a specific locality, public health agencies can promptly disseminate this information to health-care providers who may, in turn, intensify efforts to vaccinate or provide amantadine chemoprophylaxis to persons at high risk of complications from influenza. The release and timing of such messages should be carefully considered and coordinated with appropriate agencies.

In the context of this example, the impact of releasing a message recommending the use of amantadine or influenza vaccine may be enhanced if the release has been coordinated with public health units, local pharmaceutical suppliers, and medical organizations.

To determine etiology and natural history of disease

Public health surveillance for newly recognized or detected problems may be initiated to assist in determining the epidemiology, etiology, and natural history of such conditions. In such circumstances, the communications objective may simply be to

provide information which is sufficient to initiate surveillance.

For example, when eosinophilia-myalgia syndrome (EMS) was recognized in the United States in October 1989, a case definition was developed and disseminated to the public health community to enable the immediate implementation of national surveillance for EMS (*4*). Surveillance efforts were critical in characterizing the epidemiology and natural history of EMS, as well as in assisting in the development of hypotheses regarding its cause.

Evaluate control measures

For many public health conditions, surveillance is the principal means for assessing the impact of control measures. Epidemiologic trends and patterns that are based on surveillance findings must be conveyed to persons involved in control efforts in order to refine control activities and guide the allocation of resources in support of those activities.

Following a period of relative quiescence, as of the mid-1980s the incidence of measles in the United States surged. When surveillance indicated that vaccination coverage had declined substantially in some groups (e.g., children residing in inner-city locations), key findings were conveyed to and used by public health programs and primary care providers in targeting measles vaccination efforts.

To detect changes in disease agents

In addition to monitoring trends in the occurrence of public health problems, surveillance systems may be fundamental to the process of detecting changes in disease agents and the impact of these changes on public health. For example, in the late 1980s in the United States, surveillance documented an increase in the incidence of tuberculosis--an increase substantially in excess of predicted levels. In addition to this overall trend, transmission of multi-drug-resistant tuberculosis (MDR-TB) was detected in health-care and prison settings (*5*). The public health implications of these findings are similar to the basic considerations outlined above for detecting and controlling outbreaks: specifically, there is need for timely and effective notification of populations at risk and of organizations responsible for control/prevention measures. Therefore, in the case of MDR-TB, the communications objectives would include immediate notification of the public health community about

the problem with the intent of facilitating implementation of proper diagnostic, therapeutic, and preventive measures.

To detect changes in health practices

Some surveillance systems monitor changes in health practices and behaviors in the population rather than changes in patterns of disease (*6*). This "life-style" information is particularly important for problems such as chronic disease, for which trends in risk behavior often precede changes in health outcome by years or even decades. The communications objective in this context is often to increase awareness regarding the role of behavior in causing disease or injury. In addition, this information may be used to identify high risk groups in the population.

For example, surveillance data regarding trends in cigarette smoking indicate that smoking rates have not declined among persons with lower educational attainment. Accordingly, surveillance data which characterize risk factors (such as smoking), outcomes, health services, and other related factors may guide public health programs and decision makers in the implementation of targeted communitywide or statewide intervention strategies (*7*).

Facilitate planning of health policies

For some conditions, the most appropriate control measure is promulgation of a public health policy. In this context, surveillance information about the public health impact of different conditions and problems must be effectively communicated to legislators and public health policy makers.

For example, in California, surveillance information about smoking-attributable mortality, morbidity, and economic costs helped in enacting Proposition 99. This legislation provided for a 25-cent increase in the state cigarette tax which, in turn, funded statewide initiatives to prevent and control the use of tobacco. Subsequently, surveillance data regarding trends in the prevalence of smoking and the impact of this initiative assisted in ensuring the application of state funds to control tobacco use. Similarly, data for the United States have confirmed that increases in cigarette taxes have helped in reducing cigarette smoking (*8*).

Define the Audience

Identification of target groups is an essential part of the process of developing strategies for communicating surveillance results. Typically, public health surveillance information and reports have been disseminated in a standard format with only limited consideration of the target audiences and, more importantly, the techniques to communicate effectively to these groups. In general, key target groups may include public health practitioners, health care providers, professional and voluntary organizations, policy makers (e.g., from the executive and legislative branches of government), the press, or the public.

In some instances, surveillance information should be disseminated widely, in which case communication strategies should be tailored to subgroups of greater interest. For example, information regarding trends in injecting drug use (IDU)-related risks for HIV is often communicated to the general public through the newspapers; however, this strategy may be suboptimal for reaching the groups at highest risk, who use alternative media such as radio and television (*9*).

Select the Channel

Specification of the messages and audiences for surveillance results enable selection of the most suitable channels of communication for this information. Traditionally, surveillance information has been disseminated through published surveillance reports. However, in addition to conventional means for communicating with traditional audiences, the advent of new methods and technologies have made possible improved communications with both old and new audiences. This spectrum of communications options includes professional and trade publications, electronic channels, broadcast media, print media, and public forums:

- Publications: government public health bulletins and surveillance reports, peer-reviewed public health and biomedical journals, newsletters.

- Electronic: telecommunications systems (e.g., National Electronic Telecommunications Surveillance System [see Chapter IV], Public Health Net), fax and batch fax, audioconferences, videoconferences.

- Media: news releases, news conferences, fact sheets, video releases.

- Public forums: briefings, hearings and testimony, conferences and other planned meetings.

Market the Information

Once the message has been defined and the target audience and channel selected, it is critical to assure that the information is communicated and marketed--not merely disseminated--to those who need to know. In the decade of the 1990s, enormous quantities of information concerning public health are communicated through professional channels, as well as the print and electronic media. Because of the volume of essential information, as well as time constraints, surveillance information must be carefully tailored for presentation to each targeted audience, including public health and health care professionals, policy makers, and the public.

To ensure that surveillance information is readily communicated to target audiences, public health agencies should use those techniques that are most effective for marketing information. First, as a general principal, graphic formats and other visual displays are likely to be more effective in conveying information than conventional tabular presentations. Such formats include maps, bar graphs, histograms, diagrams, or other ways of visually depicting data which may not be readily comprehended through tabular presentation. For example, in December 1989, the Centers for Disease Control introduced a graphic format for displaying national notifiable disease surveillance data in the *Morbidity and Mortality Weekly Report* (*10*). This bar graph (Figure V.12), which replaced a standard table, was designed both to facilitate interpretation of routine notifiable disease data and to enable timely public health responses to changes in disease patterns.

Second, the principal components of the message can be focused by selecting the most important point, then stating that point as a simple declarative sentence. This message, termed the "single over-riding communication objective (SOCO)", should consider three questions:

- What is new?
- Who is affected?

- What works best?

For example, chronic disease surveillance information data indicate that compared with younger women, older women are less likely to have received a Pap test in the past, are more likely to have cervical cancer diagnosed at a late stage, and have higher mortality rates due to cervical cancer. Traditionally, this information might be disseminated to health care and public health providers through vital statistics reports and other published accounts about cervical cancer. However, if these findings are to be used as a basis for action, they first must be synthesized, then effectively communicated. Thus, in addition to presenting these findings in detailed reports, they also may be expressed through a single message, the SOCO: "Older women need to get regular Pap tests."

Third, techniques must be used which present (or "package") the surveillance information in a manner which captures an audience's interest and focuses attention on a specific issue. Examples of these techniques are the use of introductory terms such as: "A new study . . ."; "Recent findings . . ."; and "Information recently released . . . ." These terms are likely to appeal more to a target audience than a presentation which begins with a conventional preface, such as "Based on recent surveillance findings, ..."

Fourth, the method and forum of release of surveillance information may be critical--particularly when a timely release is required, or when the target audiences include the media, the public, or policy makers. Under such circumstances, news conferences or other news releases may be considered, and should be held when they are likely to be attended. Foremost, the presenter should involve reporters in the public health surveillance process by "walking them through it", and should recognize opportunities to articulate the SOCO on camera or in print. Important adjuncts for presenting the information include readily available handouts and effective, but simple, visuals.

Evaluate the Effect

Because public health surveillance is, by definition, oriented toward action, evaluation efforts should address two considerations: first, whether surveillance information has been communicated to those who need to know; and second, whether the

information has had a beneficial effect upon the public health problem/condition of interest.

Assessment of whether surveillance information has been communicated to those who need to know may be accomplished through a process evaluation, such as by monitoring the distribution of the information or a user survey. In particular, the effectiveness of communication through newspapers can be evaluated by using clipping services which determine the number of published reports, the geographic distribution of the reports, and the proportion of the total audience to which the reports have been circulated. In addition, process evaluation efforts should include a review of the content of articles to assess both the accuracy and appropriateness of the communicated message.

The second consideration--the impact of the communications effort on the public health problem--requires an evaluation of outcomes (e.g., knowledge or practices) within specific target audiences.

Under ideal circumstances, this type of evaluation requires surveys of the target audiences both before and after the surveillance information has been communicated to detect changes in levels of outcomes. The potential for such evaluation is constrained, however, by technical and methodologic challenges, as well as substantial resource requirements.

SUMMARY

Effective communication of public health surveillance results represents the critical link in the translation of science information section. Recognition of the key components in this process--including the medium, the message, the audience, the response, and the evaluation of the process--is the first step in completing the communications loop.

REFERENCES

1. Langmuir AD. The surveillance of communicable diseases of national importance. *N Engl J Med* 1963;288:182-92.

2. Thacker SB, Berkelman RL. Public health surveillance in the United States. *Epidemiologic Rev* 1988;10:164-90.

3. Hiebert RE, Ungurait DE, Bohn TW. the process of communication. In: Mass media: An introduction to modern communication III. Longman Inc., New York, 1982, pp 15-29.

4. Centers for Disease Control. Eosinophilia-myalgia syndrome--New Mexico. *MMWR* 1989;38:765-7.

5. Centers for Disease Control. Nosocomial transmission of multidrug-resistant tuberculosis among HIV-infected persons--Florida and New York, 1988-1991. *MMWR* 1991;40:585-91.

6. Remington PL, Smith MY, Williamson DF, Anda RF, Gentry EM, Hogelin GC. Design, characteristics, and usefulness of state-based risk factor surveillance 1981-1986. *Public Health Rep* 1988 July-August;103(4):366-75.

7. Boss LP, Suarez L. Uses of data to plan cancer prevention and control programs. *Public Health Rep* 1990;105:354-60.

8. Peterson DE, Zeger SL, Remington PL, Anderson HA. The effect of state cigarette tax increases on cigarette sales, 1955 to 1988. *Am J Public Health* 1992;82:94-6.

9. Centers for Disease Control. HIV-prevention messages for injecting drug users: sources of information and use of mass media--Baltimore, 1989. *MMWR* 1991;40:465-9.

10. Centers for Disease Control. Proposed changes in format for presentation of notifiable disease report data. *MMWR* 1989;38:805-9.

Chapter VIII

Evaluating Public Health Surveillance

Douglas N. Klaucke

"The best way to escape from a problem is to solve it."

Brandon Francis

OVERVIEW

The overall purpose of evaluating public health surveillance is to promote the most effective use of health resources. The highest-priority public health events should be under surveillance, and surveillance systems should meet their objectives as efficiently as possible. Meeting each of these objectives involves evaluating surveillance from two different perspectives; in turn, each perspective has a slightly different emphasis in the application of the elements of surveillance evaluation.

TYPES OF EVALUATION

The first level of evaluation answers the question, "Should this health event be under surveillance?" This question should be answered from a perspective external to the surveillance system itself. It is the first question that should be asked when deciding whether to start a new system or before conducting a detailed evaluation of an existing one. This "external" evaluation is primarily an assessment of the public health importance of a health event and how its importance compares with that of other health events. Once a health event is identified as being of high priority, it is important to consider both the feasibility and cost of conducting surveillance for that event. If this first-level evaluation leads to a decision to discontinue a surveillance system, a detailed evaluation of that system is superfluous.

The second level evaluates an operating surveillance system for a high-priority health event to increase the system's utility and efficiency. This type of evaluation may also compare two or more systems involving the same health event. This type of evaluation will determine whether the system is meeting its objectives, serving a useful public health function, and operating as efficiently as possible. It should include at least the following steps:

- An explicit statement of the purposes and objectives of the system
- A description of its operation
- Documentation of how the surveillance system has been useful
- An assessment of the different quantitative and qualitative attributes, and
- Estimates of the cost of the system.

The goal is to maximize the system's usefulness and to achieve the simplest, least expensive system that meets its objectives.

ADAPTING THE EVALUATION

Although all systems should be assessed for their purpose and usefulness, specific attributes described below that are critical to one system may be less important to another. Efforts to improve certain attributes--such as the ability of a system to detect a health event--may detract from other attributes--such as simplicity or timeliness. Thus, the success of an individual surveillance system depends on the proper balance of characteristics, and the strength of an evaluation depends on the

ability of the evaluator to assess these characteristics with respect to the system's objectives. Any approach to evaluation must therefore be flexible.

Determining the most efficient approach to surveillance for a given health event is an art. There is room for creativity and opportunity to combine scientific rigor with practical realities. The methods discussed in this chapter should be used as a guide to the types of questions that need to be answered about the system. Each evaluation should be individually tailored. Few evaluations address fully all of the methods outlined in this chapter, and many profitably focus on only one or two major attributes, such as sensitivity and timeliness (*1-3*). Some of these elements may also be useful for evaluating other health-information systems or evaluating the value of secondary data sources for surveillance.

Each of the listed aspects of a surveillance evaluation will be discussed in the sections that follow: public health importance, objectives and usefulness, operation of the system and qualitative attributes (simplicity, flexibility, and acceptability), quantitative attributes (sensitivity, predictive value positive, representativeness, and timeliness), and cost. This chapter continues the process through which methods for evaluating public health surveillance systems evolve (*4,5*).

PUBLIC HEALTH IMPORTANCE

The public health importance of a health event and the need for surveillance of that health event can be described in a variety of ways. Health events that affect many people or require large expenditures of resources are clearly important in a public health context. However, health events that affect relatively few persons may also be important, especially if the events cluster in time and place--e.g., a limited outbreak of a severe disease. At other times, public concerns may focus attention on a particular health event, creating or heightening the sense of importance associated with it. Health problems that are now rare because of successful control measures may be perceived as "unimportant," but their level of importance should be assessed on the basis of their potential to reemerge. Finally, the public health importance of a health event is influenced by its preventability and the ability of public health action to influence it.

Some measures of the importance of a health event, and, therefore, the surveillance system that monitors it, include the following:

- Magnitude of the problem: Total number of cases, incidence, and prevalence.
- Severity: Mortality rate and case-fatality ratio.
- Morbidity: physician visits, hospital days.
- Premature mortality: Years of potential life lost (YPLL).
- Economic cost: Costs of medical care, lost productivity.
- Preventability: Prevented fraction.

Measures of importance used should take into account the effect of existing control measures. For example, the number of cases of vaccine-preventable illness has declined following the implementation of school immunization laws, and the public health importance of diseases in this category is underestimated by case counts alone. In such instances, it may be possible to estimate the number of cases that would be expected in the absence of control programs (*6*).

Preventability can be defined at several levels--from preventing the occurrence of disease (primary prevention), through early detection and treatment, (secondary prevention), to minimizing the effects of the health problem among those already ill (tertiary prevention). From the perspective of surveillance, preventability reflects the potential for effective public health interventions at any of these levels.

The need for surveillance may also be affected by factors other than those mentioned above. Political and public pressure may affect whether surveillance is undertaken--or, at the other extreme, forbidden--for a specific health event. Regulations, laws, and public health programs may be implemented on the basis of considerations other than those listed above. However, it is still important to make the scientific criteria as clear and explicit at possible.

Even when using quantitative measures, judgment is necessary to decide which criteria are most relevant for each condition. It is important to make these judgments as explicit--and as early--as possible.

Attempts have been made to quantify the public health importance of health conditions. Dean described such an approach that involved using a score that accommodated for age-specific mortality and morbidity rates and health-care costs (7). The Canadian Laboratory Centre for Disease Control has used explicit criteria in setting national surveillance priorities for communicable diseases. Their criteria include the parameters listed above, plus several others such as interest on the part of the World Health Organization, or the Department of Agriculture (Canada), potential for outbreaks, public perception of risk, and necessity for immediate public health response. Their ratings for 60 communicable diseases can be useful in setting priorities for initiating a surveillance system (*8*).

SYSTEM OBJECTIVES AND USEFULNESS

The most important steps in evaluating a surveillance system are a) describing the health event(s) under surveillance, b) stating explicitly the objectives of the system, and c) describing how the system has actually been used to help prevent and/or control disease or injury. These three steps alone often sufficiently indicate how the system can be improved.

Case definition(s) should be specified, which include symptoms, signs, laboratory results, and epidemiologic information; a scale of severity; and the different levels of confidence in the diagnosis for each case, such as "suspected," "probable," and "confirmed." Case definitions for nationally notifiable diseases have been published for Canada and the United States (*9,10*). Table VIII.1 outlines a case definition developed by the Centers for Disease Control (CDC) and the U.S. Council of State and Territorial Epidemiologists.

The possible objectives of surveillance systems and the uses of surveillance information are very similar and have been reviewed in Chapter I.

A surveillance system might also meet a statutory requirement based on political necessity or public pressure or might identify cases for additional studies. There may also be objectives, such as meeting the reporting requirements of the World Health Organization, that might not be of immediate or direct benefit to the agency operating the surveillance system.

The usefulness of a system should be described specifically, including the actions that have been taken as a result of the data and analysis from the surveillance system, and who used the data to make decisions and take actions. Other anticipated uses of the data should be noted and their feasibility determined.

A surveillance system should contribute to the control and prevention of adverse health events. This process may include an improved understanding of the public health consequences of the events. A surveillance system can also be useful if it determines that an adverse health event previously thought to have public health importance actually does not.

An assessment of the usefulness of a surveillance system begins with a review of the objectives of the system and should consider the dependence of policy decisions and control measures on the surveillance system. Depending on the objectives of a particular surveillance system, the system may be considered useful if it satisfactorily addresses one or more of the following questions. Does the system, e.g.,

- detect trends signaling changes in the occurrence of the health problem in question?
- detect epidemics?
- provide estimates of the magnitude of morbidity and mortality related to the health problem being monitored?
- stimulate epidemiologic research likely to lead to control or prevention?
- identify risk factors involved in the occurrence of the health problem?
- permit assessment of the effects of control measures?
- lead to improved clinical practice by the health-care providers who are the constituents of the surveillance system?

Usefulness may be affected by all the attributes of surveillance described below. Increased sensitivity may afford a greater opportunity for identifying epidemics and understanding the natural course of an adverse health event in a community. More rapid reporting allows more timely control and prevention activities. Increased specificity enables public health officials to focus on productive activities. A

representative surveillance system will characterize more accurately the epidemiologic features of a health event in the population.

OPERATION OF THE SYSTEM

To evaluate a surveillance system, one must know how it operates (see Chapter IV). The system description should include the following:

- The people and organizations involved,
- The flow of information (up and down),
- Mechanisms of information transfer,
- Frequency of reporting and feedback, and
- Quality control.

The evaluation should address the following questions. What is the population being monitored? Who is responsible for reporting a case (and to which public health agency)? What information is collected on each case, and who is responsible for collecting it? If there are multiple administrative levels represented in the system, how are the data transferred from one level to another? How is information stored? Who analyzes the data? How are they analyzed, and how often? Are there preliminary and final tabulations, analyses, and reports? How often are reports disseminated? To whom? By what mechanisms/media are the reports distributed? Are there any "automatic" responses to case reports, (e.g., follow-up of individual cases of rabies, botulism, or poliomyelitis)?

A diagram is often useful to summarize the relationship between the various components of a system (Figure VIII.1).

ATTRIBUTES OF THE SYSTEM

Each surveillance system has characteristics or attributes that contribute directly to its ability to meet its specific objectives. The combination of these attributes determines the strengths and weaknesses of the system. The attributes must be balanced against each other, (e.g., high sensitivity may only be possible with a complex reporting system from a wide array of providers).

QUALITATIVE ATTRIBUTES:

Simplicity and Flexibility

In describing a surveillance system, three desirable qualitative attributes should be addressed: simplicity, flexibility, and acceptability.

Simplicity of a surveillance system refers both to its structure and to its ease of operation. Surveillance systems should be as simple as possible, while still meeting their objectives. It may be useful to think of the simplicity of a surveillance system from two perspectives: the design of the system and the size of the system. The following measures might be considered in evaluating the simplicity of a system:

- Amount and type of information necessary to establish a diagnosis,
- Number and type of reporting sources,
- Method(s) of transmitting case information/data,
- Staff training requirements,
- Type and extent of data analysis,
- Amount of computerization,
- Methods of distributing reports, and
- Amount of time spent operating the system.

The cost estimates for a system are also an indirect indicator of simplicity. Simple systems usually cost less that complex ones. Another consideration is the ability of the system to adapt to changing needs such as the addition of new conditions or data-collection elements. This characteristic is termed "flexibility."

Acceptability

Acceptability reflects the willingness of individuals and organizations to participate in the surveillance system. This attribute refers to the acceptability of the system to health department staff and at least equally importantly to persons outside the sponsoring agency, (e.g., doctors or laboratory staff) who are asked to report cases of certain kinds of health problems. To assess acceptability, one must consider the points of interaction between the system and its participants, including subjects (persons identified as having cases) and reporters. Indicators of acceptability

include the following: a) subject or agency participation rates; b) interview completion rates and question refusal rates, if the system involves case interviews; c) completeness of report forms; d) physician, laboratory, or hospital/facility reporting rates; and e) timeliness of reporting.

QUANTITATIVE ATTRIBUTES

The four quantitative attributes of a surveillance system include sensitivity, predictive value positive, representativeness, and timeliness. These are often difficult to measure precisely, but even indirect estimates can be useful in helping to improve the efficiency of a system and in comparing it with other systems.

Sensitivity

The sensitivity of a surveillance system can be considered on two levels. First, the completeness of case reporting--i.e., the proportion of cases of a disease or health condition that are detected by the surveillance system (Table VIII.2)--can be evaluated. Second, the system can be evaluated for its ability to detect epidemics (*11*). (see Chapters V & VI).

The sensitivity of a surveillance system is affected by the likelihood that

- persons with certain health conditions seek medical care;
- the condition is correctly diagnosed which reflects the skill of care providers and the accuracy of diagnostic tests; and
- the case is reported to the system, once it has been diagnosed.

These factors also apply to surveillance systems that do not fit the traditional disease/care-provider model. For example, the sensitivity of a telephone-based surveillance system of morbidity or risk factors would be affected by

- the number of people who have telephones, who are at home when the surveyor calls, and who agree to participate;
- the ability of persons to understand and correctly answer the questions; and
- the willingness of respondents to report their status.

The extent to which these questions are explored depends on the system and on the resources available for the evaluation. The measurement of sensitivity in a surveillance system requires the validation of information collected through the system, so as to distinguish accurate from inaccurate case reports, and the collection of information external to the system, so as to determine the frequency of the condition in a community, (i.e. a "gold standard.") (*12*). From a practical standpoint, the primary emphasis in assessing sensitivity--assuming that most reported cases are correctly classified--is estimating what proportion of the total number of cases in the community are being detected by the system. If this proportion is estimated using methods that compare two or more surveillance systems, none of which is a "gold standard," then this proportion should be called an estimate of "completeness of coverage" rather than of sensitivity. (See also Chapter VI on capture recapture).

A surveillance system that does not have high sensitivity can still be useful in monitoring trends, as long as the sensitivity and predictive value positive remain reasonably constant. Questions concerning sensitivity in surveillance systems most commonly arise when changes in patterns of occurrence of the health problem are noted. Changes in sensitivity can be precipitated by heightened awareness of a health problem, introduction of new diagnostic tests, or changes in the method of conducting surveillance.***** A search for such surveillance "artifacts" is often an initial step in investigating an outbreak.

Several evaluations have looked at the sensitivity or completeness of coverage of surveillance systems (*13-15*).

Predictive value positive

Predictive value positive (PVP) is defined as the proportion of persons identified as case-patients who actually have the condition being monitored (*11*). In Table VIII.2 above this is represented by A/(A+B).

In assessing PVP, primary emphasis is placed on the confirmation of cases reported through the surveillance system. Its effect on the use of public health resources can be considered on two levels. At the level of an individual case, PVP affects the amount of resources required for investigation of cases. For example, where every

reported case of hepatitis A is promptly investigated by a public health nurse, and family members at risk are referred for a prophylactic immune globulin injection each reported case generates a requirement for follow-up. A surveillance system with low PVP and therefore frequent "false-positive" case reports would lead to resources being wasted on cases that do not, in fact, exist.

The other level is that of detection of epidemics. A high rate of erroneous case reports over the short term might trigger an inappropriate outbreak investigation, and conversely, a constant high level of "false-positive" reports might mask a true outbreak. In assessing this attribute, we want to know what proportion of epidemics identified by the surveillance system are "true epidemics."

Calculating the PVP requires confirmation of all cases. Interventions initiated on the basis of information obtained from the surveillance system should be documented and kept on file. Personnel activity reports, travel records, and telephone logbooks may all be useful in estimating the impact of the PVP on the detection of epidemics.

A low PVP means that a) non-cases are being investigated, and b) there may be mistaken reports of epidemics. "False-positive" reports to surveillance systems lead to unnecessary interventions, and falsely detected "epidemics" lead to costly investigations. A surveillance system with high PVP will lead to fewer "less unnecessary and inappropriate expenditure of resources (*16*).

The PVP for a health event may be enhanced by clear and specific case definitions. Good communication between the persons who report cases and staff operating the surveillance system can also improve PVP. The sensitivity and specificity of the case definition, as well as the prevalence of the condition in the population contribute to the PVP; (Table VIII.2) the PVP increases with increasing specificity and prevalence.

Sensitivity and predictive value positive are inversely related. The balance between assuring that all (or almost all) cases are identified (high sensitivity) and few false positives are identified (high PVP) must be based on the level of importance accorded to identifying all cases (e.g., for rabies or meningococcal meningitis) and the ability to use an indicator of the disease in the community (e.g., use of *Salmonella* laboratory isolates).

Representativeness

A truly representative surveillance system accurately describes the occurrence of a health event over time and its distribution in the population by place and person.

Representativeness is assessed by comparing the characteristics of reported events with those of all such events that occurred. Although this information is not generally available in specific detail, some judgment of the representativeness of surveillance data is possible, on the basis of knowledge of the following factors:

- characteristics of the population--e.g., age, socioeconomic status, and geographic location (*17*);
- natural history of the condition--e.g., latency period, fatal outcome;
- prevailing medical practices--e.g., sites performing diagnostic tests, and physician-referral patterns (*18,19*);
- multiple sources of data--e.g., mortality rates for comparison with data on incidence, laboratory reports for comparison with physician reports.

Representativeness can also be examined through special studies of a representative sample of the population (*16*).

The points at which bias can enter a surveillance system and decrease representativeness are illustrated in Figure VIII.2.

Case ascertainment bias (Representativeness)

This might also be called "sampling bias" and is the differential identification and/or reporting of cases from different populations or over time.

In order to generalize findings from surveillance data to the population at large, the data from a surveillance system should reflect the population characteristics that are important to the goals and objectives of that system. These characteristics generally relate to time, place, and person. An important result of evaluating the representativeness of a surveillance system is the identification of subgroups in the population that may be systematically excluded from the reporting system. This will

enable appropriate modification of data-collection practices and more accurate projections of incidence of the health event in the target population.

Changes in reporting practices over **time** can introduce bias into the system and make it difficult to follow long-term trends or establish baseline rates to be used for the recognition of outbreaks. For example, switching from a passive to an active system or changing reporting sources may change the sensitivity of the system. Publicity can also increase rates of reporting in passive systems (*20*). While more complete reporting is desirable in principle, it is difficult to predict how a change in reporting practices or in publicity associated with the reportable condition will change the proportion of cases reported.

Differences in reporting practices by geographic location can bias the representativeness of the system. For example, the National Notifiable Diseases Surveillance System (NNDSS) aggregates data collected independently by the 50 states, Washington, D.C. and several territories. For some infectious diseases, some states collect data only from laboratories, whereas other states also accept cases reported by health practitioners (*21*). Also, despite efforts to achieve consistency, case definitions are not standardized across state and territorial boundaries (*10*).

Differential reporting rates of cases may occur in association with different characteristics of the person, so that cases among certain subpopulations may be less likely to be reported than those among other groups. For example, an evaluation of reporting on viral hepatitis in a county in Washington State suggested that cases of hepatitis B were underreported among homosexual men and that cases of hepatitis nonA-nonB were underreported among persons exposed to blood transfusions. The importance of these risk factors as contributors to the occurrence of these diseases was apparently underestimated, as indicated by the selective underreporting of certain hepatitis cases (*22*).

Bias in descriptive information about a reported case

Given that a case of a reportable health condition has been identified and reported, there may be errors in the collection and recording of descriptive information about the case, or "information bias."

Most surveillance systems collect more than simple case counts. Information commonly collected includes the demographic characteristics of affected persons, details about the health event, and the presence or absence of defined potential risk factors. The quality, usefulness, and representativeness of this information depends on its completeness and validity.

Quality of data is influenced by the clarity of the information forms, the training and supervision of persons who complete surveillance forms, and the care exercised in management of data. A review of these facets of a surveillance system provides an indirect measure of quality of data. An examination of the percentage of "unknown" or "blank" responses to items on surveillance forms or questionnaires is straightforward. Assessing the validity of responses requires special studies, such as chart reviews or re-interviews of respondents.

Errors and bias can make their way into a surveillance system at any stage in the reporting and assessment process. Because surveillance data are used to identify high-risk groups, to target interventions, and to evaluate interventions, it is important to be aware of the strengths and limitations of the information in the system.

So far, the discussion of attributes has been aimed at the information collected for cases, but many surveillance systems also involve calculating morbidity and mortality rates. The denominators for these rate calculations are often obtained from a separate data system maintained by another agency, such as the Bureau of the Census or the National Center for Health Statistics of CDC. Although these data are regularly evaluated, thought should be given to the comparability of categories (e.g., race, age, or residence) used in the numerator and denominator of rate calculations.

Several studies have looked at quality-assurance problems associated with surveillance data. A sample of National Electronic Injury Surveillance System (NEISS) records were compared with emergency-room records to assess the quality of data recorded in the surveillance system (*23*). A study of quality of national malaria surveillance reports was carried out in the United Kingdom (*24*). The quality of Behavioral Risk Factor Surveillance System (BRFSS) data, which are obtained through monthly telephone surveys, for behavioral risks associated with cardiovascular problems has been

examined in California (*25*). And CDC examined the completeness of race-ethnicity reporting in the NNDSS (*26*).

Timeliness

Timeliness reflects the delay between any two (or more) steps in a surveillance system. The timeliness of the system can best be assessed by the ability of the system to take appropriate action based on the urgency of the problem and the nature of the public health response. Four points of time in the surveillance process are most often considered when measuring timeliness: a) time of onset of disease or occurrence of an injury, b) time of diagnosis, c) time the report of case received by public health agency responsible for control activities, and d) time of implementation of control activities. Usually one of the first two points of time (a or b) is used as the starting point, and each of the other two points (c, d) is used as an end point.

Timeliness is usually measured in days or weeks, but in hospital settings it might be measured in hours; for diseases that do not necessitate an immediate response, it might be measured in months or even years.

Evaluations of the timeliness with which shigellosis is reported in two different surveillance systems in the United States found median delays of 11 and 12.5 days from time of onset of illness to receipt of report by the public health agency responsible for control measures. This delay did not allow public health officials to intervene in a timely manner to prevent the occurrence of secondary or tertiary cases. However, such a time frame might still allow for effective intervention in settings, such as day-care facilities, in which outbreaks may persist for weeks or months (*27*). Another study of timeliness in the reporting of salmonellosis, shigellosis, hepatitis A, and bacterial meningitis looked at the reporting delay between date of onset and date of report to the CDC (*3*). Median reporting delays ranged from 20 days for bacterial meningitis to 33 days for hepatitis A. Wide variations in reporting delays were found between states as well. A study in Australia showed that reports of infectious diseases from laboratories were received by the Medical Officer of Health in a substantially shorter time than those received from medical practitioners (13).

In contrast, if there is a long latency between exposure and appearance of disease, the rapid identification of cases of illness may not be as important as the rapid availability of data to interrupt and prevent exposures that lead to disease.

The need for a rapid reporting to a surveillance system depends on the nature of the public health problem under surveillance and the objectives of the system. Recently, computer technology has been integrated into surveillance systems and may promote timeliness of reporting (*28,29*).

COST

The final descriptive element is an estimation of the resources used to operate the system. The estimates generally are limited to direct costs and include the costs of personnel and resources required for collecting, processing, and analyzing surveillance data, as well as for the dissemination of information resulting from the system.

Personnel costs may be determined from an estimate of the time it takes to operate the system for different personnel. While this can be expressed as person-time expended per year of operation, it is preferable to convert the estimate to dollar costs by multiplying the person-time by appropriate salary and benefit figures.

Other costs may include those associated with travel, training, supplies, equipment, and services such as mail, telephone, rent, and computer time.

The resources required at all relevant levels of the public health system--from the local health-care provider to municipal, county, state, and federal health agencies--should be included.

The approach to resources described here includes only those personnel and material resources required for the direct operation of surveillance. A more comprehensive evaluation of costs should examine consequential or indirect costs, such as follow-up laboratory testing or treatment, case investigations or outbreak control resulting from surveillance, costs of secondary data sources (e.g., vital statistics or survey data), and costs averted (benefits) by surveillance.

Costs are judged relative to benefits, but few evaluations of surveillance systems have included a formal cost-benefit analysis, and such analyses are beyond the scope of this chapter. Estimating benefits, such as savings resulting from morbidity prevented through surveillance, may be possible in some instances, although this approach does not take into account the less tangible benefits that may result from surveillance systems. More realistically and in most instances, costs should be judged with respect to the objectives and usefulness of a surveillance system.

Alternative data collections may be compared based on their costs and number of cases identified (See also Chapter XII). For example, in Vermont, two methods of collecting surveillance data were compared. The "passive" system was already in place and comprised unsolicited reports of notifiable diseases to the district offices or the state health department. The "active" system was implemented to involve in a probability sample of physicians' practices. Each week a health department employee called these practices to solicit reports of selected notifiable diseases. In comparing the two systems, an attempt was made to estimate associated costs. The resources estimates directly applied to the surveillance systems are shown in Table VIII.3. The active system identified on additional 23 cases at an average cost of $861 per case.

RECOMMENDATIONS

On the basis of the evaluation, an assessment of how well the surveillance system is meeting its current objectives should be made (Table VIII.4). Modifications to the system to enhance its usefulness and improve its attributes should be considered. A regular review of each surveillance system should assure that systems remain responsive to contemporary public health needs.

REFERENCES

1. Harkess JR, Gildon BA, Archer PW, Istre GR. Is passive surveillance always insensitive? An evaluation of shigellosis surveillance in Oklahoma. *Am J epidemiol* 1988;128:878-81.

2. Modesitt SK, Hulman S, Fleming D. Evaluation of active versus passive AIDS surveillance in Oregon. *Am J Public Health* 1990;80:463-4.

3. Birkhead G, Chorba TL, Root S, Klaucke DN, Gibbs NJ. Timeliness of national reporting of communicable diseases: the experience of the National Electronic Telecommunications System for Surveillance. *Am J Public Health* 1991;81:1313-5.

4. Klaucke DN, Buehler JW, Thacker SB, *et al*. Guidelines for evaluating surveillance systems. *MMWR* 1988;37(SS-5):1-18.

5. Thacker SB, Parrish RG, Trowbridge FL. A method for evaluating systems of epidemiological surveillance. *World Health Statistics Quarterly* 1988;41:11-18.

6. Hinman AR, Koplan JP. Pertussis and pertussis vaccine: reanalysis of benefits, risks, and costs. *JAMA* 1984;251:3109-13.

7. Dean AG, West DJ, Weir WM. Measuring loss of life, health, and income due to disease and injury. *Public Health Rep* 1982;97:38-47.

8. Laboratory Centre for Disease Control. Establishing goals, techniques and priorities for national communicable disease surveillance. *Canada Diseases Weekly Report* 1991;17:79-84.

9. Laboratory Centre for Disease Control. Canadian communicable disease surveillance system. Disease-specific case definitions and surveillance methods. *Canada Diseases Weekly Report* 1991;17(Suppl 3):1-35.

10. Wharton M, Chorba TL, Vogt RL, *et al*. Case definitions for public health surveillance. *MMWR* 1990;39(RR-13):1-43.

11. Weinstein MC, Fineberg HV. Clinical decision analysis. Philadelphia: W.B. Saunders Co., 1980.

12. Chandra Sekar C, Demine WE. On a method of estimating birth and death rates and the extent of registration. *J Am Stat Assoc* 1949;44:101-15.

13. Murphy DJ, Seltzer BL, Yesalis CE. Comparison of two methodologies to measure agricultural occupational fatalities. *Am J Public Health* 1990;80:198-200.

14. Rosenman KD, Trimbath L, Stanbury M. Surveillance of occupational lung disease: comparison of hospital discharge data to physician reporting. *Am J Public Health* 1990;80:1257-8.

15. Rushworth RL, Bell SM, Rubin GL, *et al*. Improving surveillance of infectious diseases in New South Wales. *Med J Australia* 1991;154(12):828-1.

16. Barker WH, Feldt KS, Feibel J, *et al*. Assessment of hospital admission surveillance of stroke in a metropolitan community. *Am J Chron Dis* 1984;37:609-15.

17. Kimball AM, Thacker SB, Levy ME. *Shigella* surveillance in a large metropolitan area: assessment of a passive reporting system. *Am J Public Health* 1980;70:164-6.

18. Vogt RL, Larue D, Klaucke DN, Jillson DA. Comparison of active and passive surveillance systems of primary care providers for hepatitis, measles, rubella and salmonellosis in Vermont. *Am J Public Health* 1983;73:795-7.

19. Thacker SB, Redmond S, Rothenberg R, *et al*. A controlled trial of disease surveillance strategies. *Am J Prev Med* 1986;2:345-50.

20. Davis JP, Vergeront JM. The effect of publicity on the reporting of toxic-shock syndrome in Wisconsin. *J Infect Dis* 1982;145:449-57.

21. Sacks JJ. Utilization of case definitions and laboratory reporting in the

surveillance of notifiable communicable diseases in the United States. *Am J Public Health* 1985;75:1420-2.

22. Alter MJ, Mares A, Hadler SC, *et al*. The effect of under reporting on the apparent incidence and epidemiology of acute viral hepatitis. *Am J Epidemiol* 1987;125:133-9.

23. Hopkins Rs. Consumer product-related injuries in Athens, Ohio, 1980-85: assessment of emergency room-based surveillance. *Am J Prev Med* 1989;5(2):104-12.

24. Phillips-Howard PA, Mitchell J, Bradley DJ. Validation of malaria surveillance case reports: implications for studies of malaria risk. *Journal of Epidemiology and Community Health-London* 1990;44(2):155-61.

25. Jackson C, Jatulis DE, Fortmann SP. The behavioral risk factor survey and the Stanford Five-city project survey: a comparison of cardiovascular risk behavior estimates. *Am J Public Health* 1991;82:412-6.

26. Buehler JW, Stroup DF, Klaucke DN, Berkelman RL. The reporting of race and ethnicity in the national notifiable disease surveillance system. *Pub Health Rep* 1989;104:457-65.

27. Rosenberg ML. *Shigella* surveillance in the United States, 1975. *J Infect Dis* 1977;136:458-9.

28. Marks JS, Hogelin GC, Gentry EM, *et al*. The behavioral risk factor surveys: I. State-specific prevalence estimates of behavioral risk factors. *Am J Prev Med* 1985;1:1-8.

29. Graitcer FL, Burton AH. The epidemiologic surveillance project: a computer-based system for disease surveillance. *Am J Prev Med* 1987;3:123-7.

Chapter IX

Ethical Issues

Robert A. Hahn

"Epidemiologists [and surveillance investigators] should be cognizant that many competing values may have moral weight equal to or greater than the freedom of scientific inquiry....there are many clearly appropriate social restraints on epidemiologic research [and surveillance]."

Beauchamp

INTRODUCTION

Webster defines ethics as "the discipline dealing with what is good and bad or right and wrong or with moral duty and obligation." A professional code of ethics provides a guide to right and wrong behavior. An ethical code is not a **description** of what practitioners (and others) actually do, but rather a **prescription** for what they **should** do. Ethical obligations derive principally from moral values--such as the "Golden Rule," presumably shared by the broader society--rather than from scientific principles, such as "formulate a hypothesis and a method before collecting data." However, ethical decisions require an understanding of the objectives, current issues, and methods of the scientific disciplines to which they refer.

OVERVIEW

Over the past several decades, much ethical discussion in health--i.e., "bioethics"--has focused on clinical medicine and medical research, and thus on physicians and their patients and on researchers and research subjects. Because public health is concerned with the public, specific principles of bioethics may not apply directly to public health, although underlying moral values may be shared. Ethical principles associated with surveillance are perhaps closer to those of the social sciences than to those of clinical

medicine or medical research (*1*).

Indeed, public health ethics may conflict with the ethics of clinical medicine insofar as clinical ethics--represented by such issues as patient confidentiality--compromise public health (e.g., when the patient's condition threatens the health of others); or when the demands of public health compromise the rights of individuals (e.g., in quarantine); or when mass vaccination is required for public health despite the personal objections of individual patients (*2*). The practice of public health generally assumes that individual rights may be ethically superseded in the pursuit of public well-being and a greater public good (*2*). Epidemiologists and ethicists have recently collaborated in the formulation of ethical principles for epidemiology (*3*).

Although characteristics may distinguish surveillance-related ethical issues from ethical issues in other areas of epidemiology and public health, many of the ethical issues confronting public health surveillance are similar to those of epidemiology. Consequently, much of the discussion in this chapter draws heavily on experience in epidemiologic research, where these issues have been more fully discussed. Public health surveillance may affect the public in several ways. Surveillance is the principal means by which the health status of the population is assessed; it can be used to identify problems, indicate solutions, plan interventions, and monitor change. As such, public health surveillance commonly requires widespread and repeated contact with the public it serves regarding basic and often personal matters of health and exposures to risk factors. In addition, surveillance systems may be linked with other systems, requiring compatible identifiers of individual records; and systems may be shared among researchers or public health officials, thus increasing chances of public disclosure. Many facets of surveillance may infringe on individual privacy and therefore may increase the risk of breaches of confidentiality.

Several theories have been proposed to account for the basic principles underlying sound ethical decisions. Such theories are relevant in public health decisions about resource allocation, intervention, surveillance, and other issues, but are only briefly mentioned here.

Some ethicists dispute the possibility of formulating general ethical principles, because they believe that correct ethics are specific to each situation (i.e., "situation ethics")

(4). In contrast, most ethicists assume that ethical principles apply to different situations; these ethicists commonly adopt one of two positions about the nature of ethical rules. **Utilitarians** believe that ethical actions are those that most effectively distribute valued goods within the population; this position is sometimes equated with the epithet, "the end justifies the means." In contrast, **deontologists** believe that certain principles, such as honesty, are fundamental, and that ends, such as the distribution of goods in a population, do not justify the violation of fundamental principles. Public health intervention programs commonly combine utilitarian and deontological approaches. They attempt to maximize the distribution of health benefits, while maintaining a satisfactory level of morality in the means of distribution.

MORAL PRINCIPLES IN CLINICAL MEDICINE AND RESEARCH

Ethicists have formulated several basic moral principles that they believe underlie clinical medicine and research (5). Some of these basic principles apply to public health surveillance:

Respect for autonomy asserts that "autonomous actions and choices should not be constrained by others" (5). Basic to the notion of autonomy is self-determination and voluntary action.

Beneficence is the principle that one should act to enhance the welfare of others. Although **non-maleficence**, or avoiding acts that might harm others, is sometimes viewed as a principle separate from beneficence, it may also be regarded as the first tenet of beneficence. That is, in order to benefit others, one must at least avoid doing them harm.

Paternalism is the active pursuit of another person's well-being (as perceived by the pursuer), independent of--and sometimes contrary to--that person's express wishes. Paternalism may be regarded as a form of beneficence. While paternalism is generally thought of as protection of a person against harm to himself/herself, the notion may be broadened to include threatened harm to others. Paternalism commonly conflicts with respect for autonomy and, perhaps for this reason, is not a popular concept in the United States. It becomes useful when a person's capacity for autonomy is compromised (as may occur in sickness) or when personal autonomy may seriously compromise the well-being of others.

Justice is the principle promoting the equitable distribution of burdens and benefits in society. Unfortunately, there is no agreed-upon definition of equity;

the range includes an equal share for each person, each according to need, each according to effort, each according to societal contribution, or each according to presumed merit (*5*).

Other ethical principles are regarded by some ethicists as independent and by others as derivative from more basic principles (*5*):

Veracity is the duty of full disclosure of relevant information. Veracity is often considered a duty of clinicians or researchers but may also be a duty of patients or subjects.

Privacy is the duty to respect a person's right "...of determining, ordinarily, to what extent his thoughts, sentiments, and emotions shall be communicated to others" (*6*). Privacy includes protection from unwanted intrusions, and from the divulgence of personal information to others. The right to privacy may derive from respect for autonomy.

Confidentiality is the duty not to disclose information about individuals without their consent. Confidentiality may be seen as a principle following privacy.

Fidelity, commonly applied to the relationship between physician and patient, is the duty to keep promises and maintain contracts.

CONFLICTS AND SANCTIONS

While conflicts among ethical principles are common--e.g., paternalism versus respect for autonomy--there is no simple prescription for resolving such conflicts. Utilitarians might choose one alternative and deontologists, another. Attempts to prescribe principles of conflict resolution emphasize that decisions should be accompanied by justification of the choice (*7*).

In contrast to medical institutions, institutions of public health and epidemiology do not license practitioners and do not maintain official sanctions against violations of professional ethical standards (even insofar as such standards exist and are codified). Public health practitioners are not sued for malpractice. Informal sanctions (e.g., the avoidance of unscrupulous colleagues or loss of one's job) occur, but have not been systematically described. Some epidemiologists have recently proposed an ethical duty to monitor and address the unethical practices of their colleagues (*7*). In contrast to the absence of collegial sanctions in public health, some aspects of epidemiology and

surveillance are governed by law (e.g., violations of confidentiality by surveillance personnel) (*8*).

Varying degrees of contact are involved in different forms of surveillance. Environmental surveillance (e.g., of environmental lead or rates of Lyme disease infection of ticks), may involve contact with animals or the physical environment rather than with humans; surveillance using hospital records or death certificates involves indirect human contact; surveillance by household interviews and/or physical examinations requires face-to-face and/or physical contact. Ethical principles may vary from situation to situation and are likely to be more stringent as more human contact is involved.

This chapter focuses on surveillance involving face-to-face human contact. Also considered are surveys such as the Health Interview Survey, the National Health and Nutrition Examination Survey, and the Vital Statistics System of the Centers for Disease Control's National Center for Health Statistics. These surveys or statistical systems may not meet the stringent objectives of public health surveillance, but because they entail the collecting personal information on individuals and are widely used for surveillance they provide examples surrounding data collection. The U.S. Census is also considered, because census information plays an essential role in providing denominators for surveillance data.

The collection of public health information may involve the participation of many individuals and institutions. Potential participants include not only the investigator and subjects of surveillance but persons in the immediate social environment of study subjects, the investigator's colleagues, the broader public health community, clinicians, and society at large. Explicit and implicit relations among these parties delineate their ethical obligations to one another (Table IX.1). Ethical issues are reviewed below by focusing on several of these relationships.

RELATIONSHIPS IN SURVEILLANCE AND THEIR ASSOCIATED ETHICAL OBLIGATIONS

Surveillance practitioners and society at large. The practice of public health may

be regarded as one means by which a society addresses issues of well-being in the population. Public health practitioners retain an essential connection with society at large; ultimately, they are supported by and act at the behest of their public constituency. The assumption is that, as they pursue and achieve public interests, they should be supported by society in their work.

As agents of public welfare, public health practitioners have several ethical responsibilities as outlined below:

Choice of surveillance topics. In pursuit of beneficence, as well as in upholding public fidelity, practitioners should conduct surveillance on priority issues with potential public health benefit (7). "As a parallel in a research study, it would be unethical to ask anyone to participate that has little likelihood of producing meaningful results or furthering scientific knowledge for the good of society" (*9*). Insofar as surveillance findings are basic indicators of health inequities and trends, (e.g., in risk or exposure, health-care access, morbidity, or mortality), the pursuit of justice is also a primary moral rationale for surveillance.

Judgments of priority and potential benefit should be based on explicit criteria, such as the criteria for the strength of scientific evidence used by the Preventive Services Task Force (10). Perhaps paradoxically, surveillance results themselves facilitate the determination of priority issues, (e.g., the magnitude and location of health problems in the population).

Avoidance of conflicts of interest. As with other epidemiologic activities, surveillance may be prone to conflict of interest. "Virtually all epidemiologic research is sponsored, and few if any research sponsors, public or private, are disinterested in the outcome of their epidemiologic research" (*11*). In their commitment to public well-being, practitioners of surveillance must assure that data are conducted to answer scientific or public health questions effectively, rather than to serve the interests of financial and institutional sponsors or to "prove" personal preconceptions. For example, practitioners must assure that populations surveyed and questions asked are appropriate to assess the issues considered and not to find "results" desired by a sponsor. Epidemiologists have presented guidelines for avoiding conflicts of interest (*12*); the guidelines apply to surveillance activities as well.

- The investigator's independence from the sponsor must be maintained in the design, conduct, and reporting of epidemiologic (and surveillance) results. Written agreement between investigator and sponsor may increase the likelihood of independence.
- Investigations should not be conducted in secrecy, and results should be published in a timely fashion.
- Decisions on release and publication of results should not be influenced by the interests of sponsors.
- All sponsorship should be acknowledged.
- Decisions regarding the dissemination and publication of results should be made by the investigator rather than the sponsor.

Bond (*13*) has suggested that certain private industries may have an ethical obligation to monitor the effects of their activities for instance the exposures and health of these employees. Rothman (*11*) has argued that it is unethical to judge the results of investigations simply on the basis of sponsorship, e.g., private industry. Rather, investigations should be judged by the quality of the work involved.

Methodologic and analytic scrutiny. The principle of beneficence requires that one choose the best feasible method of investigation and that one appropriately analyze results--thus requiring knowledge of scientific methods (7).

Interpretation and recommendation. The principle of beneficence also requires (as does the concept of surveillance itself) that surveillance data be interpreted and used to assess and address public health problems.

Report of findings. Finally, the principle of beneficence requires that surveillance results be reported understandably, sensitively, and responsibly, in a timely fashion, with scientific objectivity and caution, appropriate confidence, and appropriate doubt. "Epidemiologists should carefully avoid being placed in a situation in which their results might be suppressed or inappropriately edited by either internal or external influences" (7). Some (*14*) have argued that epidemiologists should be advocates for the positions

firmly supported by their data. Others (*15*) have asserted that epidemiologists are legitimate expert witnesses. Practitioners of surveillance must also be free of internal or external constraints and must be able to present the results of their work objectively.

INVESTIGATORS AND SUBJECTS

Beneficence

Surveillance subjects do not usually benefit directly from surveillance, though some benefit to them may accrue as a side-effect (e.g., when surveillance subjects are given physical examinations or when a discovery made by surveillance serves a health need of a surveillance subject). When an adverse health condition is determined in the course of surveillance, it is the responsibility of the investigator to provide the surveillance subject with timely information about the discovered condition; if the condition is complex or sensitive, such information may be best conveyed by the subject's physician, trained counselors, or local public health officials (*9*).

Non-Maleficence

A more common ethical issue in surveillance is non-maleficence. Surveillance subjects must not be harmed in the course of the surveillance program. When invasive procedures are deemed necessary to the surveillance system--including psychologically as well as physically invasive procedures--care must be taken that subjects do not suffer undue reactions (*9*).

Epidemiologists have recognized a need to be culturally sensitive to the populations they are studying. Cultural sensitivity may be a component of beneficence, non-maleficence, and autonomy, and may also enhance the effectiveness of the investigation. Cultural sensitivity is important not only during the course of surveillance but also in the appropriate reporting of results.

Non-maleficence may also require that survey participants be compensated for their participation. Compensation should at least cover the costs of participation--e.g., transportation, lost work time, and child care. While altruism and the personal contribution to potential public health benefits may motivate some prospective participants in a data collection system, additional compensation may increase the

participation of others--a pragmatic rather than an ethical justification for payment.

Protection of Privacy

Non-maleficence may also underlie respect for privacy. Protection of privacy requires not only restraint in intrusion and in the disturbance of persons in their private lives but assurance that once information (or a specimen) has been collected, it will not be distributed to others in a form that identifies the surveillance subject (see Chapter X)(*16*).

Beauchamp *et al.* propose three situations in which the invasion of privacy by epidemiologists (and surveillance investigators) is justified (*7*):

- The invasion of privacy is a necessary aspect of the investigation.
- There is no reason to suspect that subjects of the investigation will be placed at substantial risk (e.g., of being fired or divorced).
- The research must have potential social benefit.

In Public Law 93-579 (*17*), the Congress states the following:

> "(*1*) the privacy of an individual is directly affected by the collection, maintenance, use, and dissemination of personal information by Federal agencies;...
>
> (*4*)the right to privacy is a personal and fundamental right protected by the Constitution of the United States; and
>
> (*5*)in order to protect the privacy of individuals identified in information systems maintained by Federal agencies, it is necessary and proper for the Congress to regulate the collection, maintenance, use, and dissemination of information by such agencies."

In the United States, public health surveillance activities conducted under the auspices of the Executive Branch (thus including the Department of Health and Human Services and the Bureau of the Census) are regulated by the Public Health Service Act and by the Privacy Act of 1974 (*17*). Both acts regulate contractors of federal agencies as well as

the agencies themselves. Regulations apply to "establishments"--i.e., institutions--as well as to individuals surveyed. They address "systems of records" ". . . from which information is retrieved by the name of the individual or by some identifying number, symbol or other identifying particular assigned to the individual" (*17*). Thus, records without identifiers are exempt from these regulations.

While the Privacy Act focuses on the disclosure and dissemination of information already collected, the act also restricts surveillance information that may be collected by stipulating that records may contain only "such information about an individual as is relevant and necessary to accomplish a purpose of the agency...." This enforces the ethical obligation to conduct surveillance on issues with potential public health benefit. In addition, the Privacy Act prohibits use of surveillance (or other information) "for any purpose other than the purpose for which it was supplied unless such establishment or person has consented...to its use for such other purpose . . . ."(*18*).

The Privacy Act gives individuals the right to obtain their own records, to correct errors in the record, and to receive an accounting of how the record has been disseminated. Exemptions to individual access include the use of records maintained for statistical purposes only (rather than for administrative use). Census information, for example, is exempt. Exemptions must meet specific criteria and must be published in the *Federal Register*.

The Privacy Act requires that federal agencies train and regulate personnel with access to record systems and that agencies maintain physical means of protecting records from unwarranted access. Agencies are also required to describe their record systems and to report procedures used to comply with requirements in the *Federal Register*. Criminal penalties and fines may be imposed on persons who violate the stipulations of the act.

Informed Consent

The Privacy Act regulates not only the collection and maintenance of record systems, but the informed consent procedures by which they are collected and matters of confidentiality involved in the dissemination of records that have been collected. Informed consent is a requirement based on respect for autonomy. Informed consent must be attained primarily in the context of surveys and studies. Administrative, medical-care, and legally mandated

information-collection systems should also consider obtaining informed consent. The Privacy Act requires that potential participants in record systems be a) informed of the authority under which the data are collected, b) explained the purposes of the information, c) explained routine uses of the information, and d) described the consequences of not participating. Informed consent is required for "establishments" (through their representatives) as well as for individuals.

Epidemiologists and philosophers have proposed several elements to be included in comprehensive informed consent:

- Reasonable disclosure of the goals and uses of the study (or surveillance activity).
- Evidence of comprehension on the part of prospective participants. The response of potential respondents to surveys following appropriate information is sometimes regarded as evidence of consent, despite the lack of evidence of respondent comprehension (*19*).
- Voluntariness on the part of prospective participants. "All forms of duress or undue influence are to be scrupulously avoided" (*7*).
- Competence on the part of prospective participants.
- Consent of prospective participants.

Possible harm of the surveillance--e.g., from some physical test--should also be explained to prospective participants. To guarantee autonomy, comprehensive informed consent should also be receptive to **informed dissent** and non-participation or to withdrawal at any point in the research or surveillance activity.

Feinlieb (*9*) argues that, "the first responsibility of the epidemiologist to the subject is to be clear about the objectives of the study." He also allows that, when the goals of epidemiologic investigations (or surveillance) are complex or when full disclosure might bias responses, comprehensive disclosure may not be required, so long as the respondent is "...not deliberately misled into participating in a study that the investigator knows is against the respondent's interests" (*9*). This paternalistic principle may compromise the participant's autonomy.

Disclosure, Dissemination, and Confidentiality

The Privacy Act forbids the disclosure of information in which individual identity is ascertainable, unless the subject has agreed to disclosure. This principle thus protects the confidentiality of individuals and affects the dissemination of surveillance findings (see Chapter X).

Records protected by the Privacy Act are exempt from Freedom of Information Act (FOIA) requests. FOIA specifically exempts "personal and medical files and similar files the disclosure of which would constitute a clearly unwarranted invasion of personal privacy" and matters "specifically exempted from disclosure by statute" (*19*). Federal surveillance data are also commonly exempt from subpoena and may be explicitly exempted by authorization of the Secretary of Health and Human Services (*18*). Census data, too, are exempt from FOIA access.

There are several dimensions of disclosure (*19*):

***** • Exact disclosure, which indicates a precise (numerical) value of some characteristic, (e.g., precise income or age, associated with an individual), versus approximate disclosure, which indicates a range of values associated with an individual.

- Probability-based disclosure indicates the likelihood (<100%) that some characteristic is associated with an individual, while certainty disclosure indicates (with 100% likelihood) that the characteristic is associated with the individual.
- Internal disclosure associates an individual with a characteristic on the basis of evidence found within one particular study or survey, while external disclosure associates individuals and characteristics by linking studies or surveys.

Since the absolute protection of disclosure might make the use of surveillance information impossible and would severely hamper programs of disease control and prevention, non-disclosure requirements have been interpreted as protecting individuals from harm while allowing appropriate use of surveillance information. For example, publication of analyses or tables with small numbers of conditions such as fetal or infant deaths or deaths from rabies in a county--allowing the identification of individuals--is said to

be reasonable because these exceptions "...have been accepted traditionally and because they rarely, if ever, reveal any information about individuals that is not known socially" (*20*). Also exempt is publication of small numbers if the identifying characteristics are judged not to be "sensitive."

Two kinds of breaches of confidentiality should be differentiated. In the first, information collected in confidence by a clinician or public health practitioner should be divulged if the information substantially threatens the welfare of another person (*21,22*). Divulging information need not reveal the identity of the first individual, but such revelation may be unavoidable. This is a common occurrence associated with "contact tracing" for sexually transmitted diseases. The public health responsibilities of clinicians and public health practitioners may override duties of confidentiality to individual patients and surveillance subjects, even though their actions abrogate privacy, autonomy, and even beneficence. In the second kind of breach of confidentiality, revelation of information and the identity of an individual serves no public health purpose and is therefore unethical.

Several techniques may mitigate the likelihood of disclosure and may legitimate the publication of otherwise protected data: a) small samples (e.g., <10% of the data) hamper efforts to identify which individual in the population a sampled individual represents, b) the deliberate creation of errors or imputations of missing data allows that any given datum may be an error or an imputation rather than a true observation, c) incompleteness of reporting allows that an individual may not have been included in the survey, and d) lack of sensitivity of the information in question (because of prior publication or historical time frame), so that publication reveals no harmful information.

In the United States, individual states use surveillance information for their own disease-control programs. As major surveillance agencies, the states have been critically concerned with issues of confidentiality (*23*). While all states have provisions for complying with freedom of information requests and maintaining confidentiality of information, they vary in specific regulations and their enforcement. Twenty-five states have general confidentiality requirements with little specific definition; seven states require written consent for release of information; five states exclude surveillance information from subpoena; and 10 states have penalties for unlawful disclosure of information on some or all reported infectious diseases (*23*). The states are concerned

with the protection of the confidentiality of data released for federal surveillance systems and, in collaboration with CDC, have established confidentiality guidelines (*23*).

Several procedures are commonly used to protect the confidentiality of records in surveillance investigation settings, disseminated data sets, and published tabulations and analyses:

a. Names or other personal identifiers are necessary in public health surveillance for two principal, related purposes: to follow up individuals for the determination of subsequent health events and to link data systems for additional information on individuals. Surveillance functions which require neither follow-up nor linkage may avoid problems of confidentiality by **not using names or other identifiers.** It should be noted, however, that the absence of identifiers, as in "blinded" studies, may preclude informing surveillance subjects of adverse surveillance findings.

b. When names or other identifiers are justified, problems of disclosure may be minimized with use of protected or "scrambled" identifiers, which make association between records and individuals difficult. The **use of identifiers in record systems and separate files relating identifiers and individuals maintained in separate, secure areas** is a common means of minimizing disclosure.

c. **Identifying information can be destroyed once it has served its designated follow-up or linkage function.**

d. **Avoiding the collection of data that will not be used and that might serve to identify individuals.**

e. Precise data--e.g., dates of birth or death or income in exact dollar amounts, residence by block or street or address--are rarely essential; data-range specifications are most often adequate for surveillance purposes. Since precise data facilitate identification of individuals, the **use of data ranges is preferable if surveillance goals can be achieved with such information.**

f. In some surveillance investigations, linkage with other surveillance sources is necessary to determine additional information. In this case, the Privacy Act requires that **federal agencies and personnel involved be trained in and comply with common regulations of privacy and confidentiality.**

g. **Suppression of analyses or tables with cells with small numbers in publications** (*19*):

h. i) no table should include a row or column in which all cases are found in one cell,

ii) the marginal total of any row or column should not be fewer than three,
iii) no estimate should be based on fewer than three cases,
iv) no estimates should be published if one case contributes more than 60% to that estimate,
v & vi) no characteristics of individuals should be identifiable by calculation from other tabulated data in the same or other data sets. Solutions to the problem of small numbers may be the aggregation of rows or columns or the suppression of data in cells and marginal totals.

Veracity

In the ethics of public health surveillance, the principle of veracity is usually considered in the disclosure by investigators of the goals and uses of surveillance information. However, veracity may also be an ethical duty of surveillance subjects (to the investigator as well as to society) once they participate. Deception by subjects may contribute to erroneous results and public health harm.

Investigators and Persons in Subjects' Social Environments

During the course of surveillance, it may be discovered that some condition of the surveillance subject (e.g., an infectious disease or violent intentions) might severely affect or might have affected the well-being of other persons in the subject's social environment. In this case, it may be the ethical duty of investigators to inform appropriate authorities (e.g., public health officials or law enforcement agents) of these circumstances (*9*). Paternalistic social beneficence might justify the breach of confidentiality.

Surveillance and the Public Health Community

Public health surveillance practitioners have the duty of having their work reviewed by colleagues for ethical as well as scientific integrity; they also have the responsibility of reviewing the work of others. The review process requires the sharing of methods and findings. Ethical--as well as scientific--critiques must be balanced. "Epidemiologists and many research scientists often search in detective-like fashion for flaws in the studies of those they review, even though the studies may contain substantial merit" (7).

While some agencies have policies to protect researchers' primary use and control of the data they collect (*24*), others have favored broader access (*25*). Ethical principles justifying broad access are detailed below.

- Enhancing the quality of science by allowing reanalysis and confirmatory studies--thus potentially contributing to public welfare
- Expanding knowledge by facilitating additional analyses--thus also potentially contributing to public welfare
- Reducing the burden of surveillance on subjects
- Reducing the burden of surveillance on practitioners

Epidemiologists and ethicists have also argued that practitioners have the obligation to promote ethical behavior in the public health community and to confront ethically unacceptable behavior of colleagues (*7*).

CLINICIANS AND THE PUBLIC HEALTH COMMUNITY

Physicians, laboratorians, and other health-care practitioners play a critical role in reporting infectious diseases to local and state health departments. Reporting traumatic events (e.g., gunshot wounds and child abuse) is also required in some states (*26*). Fulfilling these duties may prevent further infection or trauma. While reporting selected diseases and injuries is mandatory for physicians and others in all states, completeness of reporting is said to range from 6% to 90% for many notifiable diseases (*27*); reporting laws are seldom enforced.

Investigators and Clinicians

Investigators have a duty to report findings to clinicians. Findings may concern the welfare of a clinician's patients who have been surveillance subjects. Findings from surveillance investigations may also have implications for patients in general or patients with certain conditions.

The scale and significance of public health surveillance demand scrupulous and ongoing attention to ethics as well as to science (Table IX.2). Ethics should not be regarded as an afterthought, or worse, an obstacle, to professional practice, but as an element

vital to its foundation and goals.

REFERENCES

1. Cassel J. Ethical principles for conducting fieldwork. *Am Anthropologist* 1980;82:28-41.

2. Lappe M. Ethics and public health. Maxcy-Rosenau Public Health and Preventive Medicine 12th ed. Norwalk, Connecticut: Appleton-Century-Crofts, 1986:1867-77.

3. Soskolne CL. Ethical decision-making in epidemiology: The case study approach. *J Clin Epidemiol* 1991;44(Suppl 1):125S-30S.

4. Fletcher J. Morals and medicine. Boston: Beacon Press, 1960.

5. Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 3rd ed. New York: Oxford University Press, 1989.

6. Warren SD, Brandeis LD. The right to privacy. *Harvard Law Review* 1890;4:193-220.

7. Beauchamp TL, Cook RR, Fayerweather WE, Raabe GK, Thar WE, Cowles SR, Spivey GH. Ethical guidelines for epidemiologists. *J Clin Epidemiol* 1991;44(Suppl 1):151S-69S.

8. Lako CJ. Privacy protection and population-based health research. *Soc Sci Med* 1986;23:293-5.

9. Feinleib M. The epidemiologists responsibilities to study participants. *J Clin Epidemiol* 1991;44(Suppl 1):73S-9S.

10. U.S. Preventive Services Task Force. Guide to clinical preventive services: An assessment of the effectiveness of 169 interventions. Baltimore: Williams & Wilkins, 1989.

11. Rothman KJ. The ethics of research sponsorship. *J Clin Epidemiol* 1991; 44(Suppl 1):25S-8S.

12. Stolley PD. Ethical issues involving conflicts of interest for epidemiologic investigators. A report of the committee on ethical guidelines of the society for epidemiologic research. *J Clin Epidemiol* 1991:44(Suppl 1).

13. Bond GG. Ethical issues relating to the conduct and interpretation of epidemiologic research in private industry. *J Clin Epidemiol* 1991;44(Suppl 1):29S-34S.

14. Last JM. Obligations and responsibilities of epidemiologists to research subjects. *J Clin Epidemiol* 1991;44(Suppl 1):95S-101S.

15. Cole P. The epidemiologist as an expert witness. *J Clin Epidemiol* 1991;44(Suppl 1):35S-9S.

16. Greenawalt K. Privacy. in Reich, WT., ed., Encyclopedia of bioethics. New York: Free Press, pp. 1356-63.

17. The Privacy Act, Washington, D.C.: U.S. Government Printing Office, 1974.

18. Public Health Service Act, Washington, D.C.: U.S. Government Printing Office, 1944, as amended.

19. Centers for Disease Control (CDC). Staff manual on confidentiality. 1984.

20. National Center for Health Statistics. NCHS staff manual on confidentiality. 1984.

21. Vernon TM. Confidential reporting by physicians. *Am J Public Hlth* 1991;81:931-2.

22. Teutsch S, Berkelman RL, Toomey KE, Vogt RL. Reporting for disease control activities. *Am J Public Hlth* 1991;81.

23. Vogt RL. Confidentiality: Perspectives from state epidemiologist. in Challenge for Public Health Statistics in the 1990's (sic). Proceedings of the 1989 Public Health Conference on Records and Statistics, National Center for Health Statistics,

July 17-19, Washington, D.C.

24. Sharing Research Data. Washington, D.C.: National Academy Press, 1985.

25. Hogue CJR. Ethical issues in sharing epidemiologic data. *J Clin Epidemiol* 1991;44(Suppl 1):103S-7S.

26. Smith GR. Health care information confidentiality and privacy: A review and analysis of state and federal law. Emory University School of Law, unpublished ms, 1987.

27. Thacker SB, Berkelman RL. Public health surveillance in the United States. *Epidemiol Rev* 1988;10:164-90.

CHAPTER X

Public Health Surveillance and the Law

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"The people's good is the highest law."

Marcus Tullius Cicero

INTRODUCTION

Public health surveillance and the law are joined by so many interconnecting links that virtually every aspect of a surveillance program is associated with one or more legal issues. In the United States, and throughout the world, many surveillance efforts have been effected through mandates enforced by statutes or regulations. By the same token, reports derived from the interpretation and application of data from surveillance programs have been used to drive legislation relating to public health.

Public health surveillance involves the collection, analysis, interpretation, and dissemination of data. It may be useful to have a working definition of the law to meld with this description of surveillance. In essence, as Wing observes, the law

is "the sum or set or conglomerate of all of the laws in all of the jurisdictions: the constitutions, the statutes and the regulations that interpret them, the traditional principles known as common law, and the judicial opinions that apply and interpret all these legal rules and principles" (*1*). However, that is by no means all. The law is also the legal profession, and, in order to understand the law, we must try to understand the lawyers--how they think, how they speak, and what roles they play in the legal process. In addition, from a very practical point of view, the law is also the legal process--legislatures and their politics, as well as the time, efforts, and costs associated with changes in legislation. Finally, the law is what it is interpreted to be. This takes us back to the lawyers, as well as to the judges in the legal system.

We cannot avoid what Wing describes as "the traditional barrier" between the legal profession and the rest of the world. He continues with the observation that "the legal profession has for centuries done many things to surround the practice of law with a quasi-mystical aura. Much as the medical profession would have us believe that there is something almost sacred about medical judgment and that only a physician can understand it, lawyers have perpetuated the only partially justified myth that there is something called legal judgment that only someone with the proper mix of formal education, practical experience, and appropriate vocabulary can make" (*1*).

"The basic function of the law is to establish legal rights, and the basic purpose of the legal system is to define and enforce those rights . . . . Legal rights" are the "relationships that establish privileges and responsibilities among those governed by the legal system" (*1*). This concept of "legal rights" does not purport to cover freedoms or interests given unconditional, global protection, but rather it covers the protection of carefully specified interests against the effects of other carefully specified interests. Finally, some rights are protected, not by statute or regulation, but by an understanding and application of the prevailing ethics in an area. In general, ethics are regulated through whatever sanctions are imposed against censured behavior by peers or colleagues (see Chapter IX).

This orientation is pivotal in our discussion of legal issues associated with surveillance because the reader must continue to be alert to the fact that everything in this chapter is subject, first of all, to different interpretations in different legal settings, and, second, to amendment of both statute and practice.

The task of surveillance as an applied science could be simplified considerably by avoiding any discussion of legal issues. Although this observation is probably valid, we have already pointed out that surveillance very often takes place under statute. Beyond this fact, the relevance of the definition of the police powers of a state must be acknowledged, i.e., "powers inherent in the state to prescribe, within the limits of state and federal constitutions, reasonable laws necessary to preserve the public order, health, safety, welfare, and morals" (*2*). That describes a sweeping scope of authority and certainly covers anything that would be dealt with under the heading of "public health surveillance."

In other words, one cannot look at surveillance and claim to have created an accurate picture without considering the legal constraints and processes that accompany it--particularly since, for public health surveillance, we have added the component of "timely dissemination of the findings" to our definition of surveillance. How information is collected, from and about whom it is collected, how it is interpreted, and how and to whom the results are disseminated all must be scrutinized under the umbrella of "accepted practice" and "the law." The sections that follow contain information specific to the United States, but for an international orientation, the issues and concerns remain basically constant, while the written body of the law and the process through which the law is enacted and enforced vary widely.

If the reporting component of public health surveillance is treated as a requirement, one can assert that such surveillance began in the United States in 1874 in Massachusetts, when the State Board of Health instituted the first statewide voluntary plan for weekly reporting of prevalent diseases by physicians. By the turn of the century, the forerunner of the Public Health Service had been established, and laws in all states required that certain communicable diseases be reported to local authorities (*3*).

SURVEILLANCE IN THE EARLY YEARS (1900-1930)

With the development and growth of surveillance in the United States in the early 1900s came the inevitable conflicts created when the interests of one human being conflict with those of another individual or political unit. Much of the debate took place because of the problem the United States was experiencing with sexually transmitted diseases--which became even more acute with the participation of American troops in World War I. The issues were basically

- the moral dilemma created by not reaching consensus on the purpose of information obtained through surveillance (i.e., whether to direct control efforts toward sexual behavior of the individual or toward the disease agents),
- the debate surrounding the duty of the physician to his/her patient and to society, and
- the disagreement about whether government provision of health services comprised unfair competition to the private practitioner.

Since these concerns still have not been completely resolved in the United States as of the 1990s, they are examined in more detail.

Social Hygiene Versus the Scientific Approach

By the early 1900s, the epidemiology of syphilis was reasonably well-documented. This understanding did not constitute an unmixed blessing. As William Osler told his students at the Johns Hopkins Medical School in 1909, "In one direction our knowledge was widened greatly. It added terror to an already terrible disorder" (4). Aside from the scope of the destructive powers of syphilis, physicians were just beginning to appreciate the fact that many "innocent victims" were contracting this disease. The prevailing wisdom of earlier years of "reaping what one sowed," as well as other statements of poetic and moral justice, was no longer adequate when women of "good family" and unblemished reputation were known to have contracted syphilis from their spouses and when children suffered severe effects from congenital syphilis.

What the medical and public health officials apparently had the most difficulty reconciling was how to direct their efforts to deal with the growing problem of syphilis.

Both surveillance and treatment efforts could be directed toward a) people, a focus on behavior modification through education as a control strategy or b) the disease vector, a focus on the organism that caused the disease and how to eradicate it from individuals and society at large. Neither approach to syphilis control was ever agreed to be the ideal, and, in fact, the two in combination have still not proved totally effective. The tensions represented by the "moralistic" and the "scientific" approaches are, moreover, still quite evident in public health practice and surveillance in the 1990s.

One only has to review the popular press for the past several years to see how the "moral versus scientific" dilemma relates to public health in the context of such currently serious problems as human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) and the reemergence of multidrug-resistant strains of tuberculosis.

Duty of Physicians

The concept of the confidential nature of communication between patient and physician is clearly stated in the Hippocratic Oath and has continued to be emphasized in legal and social settings. In the context of the syphilis epidemic in the United States in the early years of the 20th century, this concept became a crucial point of debate in efforts to control the spread of the disease. Physicians did not wish to breach the confidence relied on by their patients by reporting cases of syphilis to the authorities; by the same token, if they did not report the occurrence of syphilis--if not to the authorities at least to the patients' spouses--they were tacitly participating in the continued transmission of the disease to "innocent victims." The entire issue boils down to primary responsibility to an individual or to society. It clearly has not been resolved but constitutes an important component of the success or failure of present-day surveillance efforts.

Economic Competition

Also as yet unresolved is the problem created for public health officials and for practicing physicians in the early 1900s by the need, on the one hand, to have physicians report all cases of sexually transmitted disease and to establish public health clinics to provide prompt treatment and education to patients and, on the other hand, the need for public health officials to protect the financial interests of physicians by not infringing on their turf and removing paying customers to free or financially subsidized

facilities. At the same time, it did not seem reasonable to expect the physicians to make such reports and refer such patients for treatment elsewhere when it would mean, in essence, taking money out of their own pockets. For surveillance efforts, this dilemma guaranteed underreporting of cases, with the selective reporting of cases representing patients who could not pay and the withholding of reports of cases representing patients who could pay.

Of concern to the 1990s surveillance effort, and again in the context of HIV/AIDS, physicians might choose not to report cases of HIV positivity for fear their patients might be discriminated against in a work or social setting. Problems with insurance coverage might also lead to such underreporting.

ERA OF GRADUAL GROWTH IN MANDATED SURVEILLANCE (1940s-1970s)

During the period of the 1940s-1970s, states added many diseases to their mandatory reporting lists. Even in states that did not enact legislation to require additional reporting, surveillance/reporting efforts were broadened during this period through state regulation or directive from the state health commissioners (5).

In contrast, surveillance and reporting to agencies in the federal government were--and continue to be--voluntary. The resulting discrepancy in data obtained on a particular disease at the state and federal levels leads to problems in analysis and interpretation. However, several professional organizations, including the Association of State and Territorial Health Officers (ASTHO) and the Council of State and Territorial Epidemiologists (CSTE), have been instrumental in setting up a patchwork system to coordinate and improve the quality and completeness of surveillance data.

A major factor in the development of surveillance planning and implementation during this period is represented by the institution in 1976 of the Federal Protection for Human Subjects Regulations. One of the most well-known of the regulations states the requirement that "informed consent" be obtained from any person who is asked to participate in a medical research project. In addition, the regulation covers compensation for persons injured during the course of the project and confirmation of the

ethics of the research being conducted.

CURRENT LEGAL ISSUES (1980 to the Present)

There is little dispute that biomedical research and surveillance activities of the 1980s were greatly affected by concerns and reactions associated with the HIV/AIDS epidemic. All the old issues from early in the 20th century reemerged at critical levels: Do we want to treat persons for the disease, or do we want to modify their behavior in control/prevention efforts? Is the physician's primary duty to protecting a patient's privacy or to the greater good of society? Is the public health machine treading on the physician's turf by advertising and providing medical treatment more inexpensively than the physician can?

Although these questions still need to be answered fully, public health action cannot wait until consensus is reached before constructing and applying interventions. The sections below examine four key legal issues that relate to these questions and have a major impact on surveillance in the 1990s.

Personal Privacy

The right of an individual to have his/her privacy protected under the law is a vast gray area. The U.S. Constitution does not specify a right to privacy, although particulars relating to the protection of privacy under particular circumstances are included in the Bill of Rights (protection from "search and seizure," etc.). As noted earlier in this chapter, the issue of right to privacy and the physician's role in protecting that privacy through the concept of privileged communication emerged as a hotly debated issue during the war on sexually transmitted diseases in the United States in the early years of the 20th century. The concept of the so-called "medical secret" (*6*) involved the dilemma that faced a physician whose male patient had a sexually transmitted disease (for which there was no sure cure), whose reputation the physician wished to spare, but whose spouse or future spouse was at risk of having the disease if the physician did not step forward and report it. Many physicians opted to remain within the accepted double standard of behavior of the day and, according to Prince Morrow, became "accomplices" in the further transmission of infection (7). The medical secret was described by one physician as a "blind policy of protecting the guilty at the expense of the innocent," and a New York attorney ventured the opinion that "a physician who knows that an infected patient is

about to carry his contagion to a pure person, and perhaps to persons unborn, is justified both in law and in morals, in preventing the proposed wrong by disclosing his knowledge if no other way is open" (7).

Unfortunately, the right to privacy issue was no more resolved in the early 20th century United States than was the public health problem created by the nationwide problem of sexually transmitted diseases. Public health officials continue to struggle with questions associated with privacy and the rights of the individual versus the good of society to this day.

The landmark case relating to the right of an individual to privacy was *Griswold vs. Connecticut*, 381 U.S. 479 (1965), which resulted from the arrest of the director of the Planned Parenthood League of Connecticut (Griswold) on the grounds that she had provided information, instruction, and medical advice about contraception to married people. In Connecticut at the time, the law stated that the **use** of contraceptives was punishable by law. Subsequently, the U.S. Supreme Court declared the Connecticut law to be unconstitutional and reversed the criminal convictions in the case. In the majority opinion written for the Court by Justice William Douglas, there are references to the so-called "penumbras" or auras of privacy that radiate out from the specific rights to privacy stated in the Bill of Rights. He observed that "various guarantees create zones of privacy" (*8*). He went on to say that the Connecticut law exceeded its bounds by seeking to regulate the **use** of contraceptive devices rather than their manufacture and/or sale. The only means he could postulate for enforcing the law as written involved the invasion of the clearly defined zone of privacy represented by marriage. Lest anyone misunderstand his meaning, he observed: "Would we allow the police to search to sacred precincts of marital bedrooms for tell tale signs of the use of contraceptives? The very idea is repulsive to the notions of privacy surrounding the marriage relationship" (*8*).

Later courts would refer to this constitutionally recognized right of the individual to privacy in certain contexts as a "fundamental interest." In the precedent-setting abortion case of *Roe v. Wade*, 410 U.S. 113 (1973), a single woman challenged the constitutionality of a Texas law forbidding abortion (except when the pregnant woman's life was in jeopardy). She claimed that this law denied her constitutional right to privacy and cited the earlier opinions of the Supreme Court relating to birth control. Justice Blackmun observed that "the state does have an important and legitimate interest

in preserving and protecting the health of the pregnant woman...[and] it has still another important and legitimate interest in protecting the potentiality of human life. These interests are separate and distinct. Each grows in substantiality as the woman approaches term and, at a point during pregnancy, each becomes 'compelling'" (*9*).

The link between the right to privacy and surveillance is also related to The Freedom of Information Act (amended 1986). In essence, the latter act spells out the situations and conditions pertaining to the right of the U.S. taxpayer to obtain information s/he has paid for from agencies within the Federal Government. Clearly, there is the potential for conflicting interests in such situations, if information about taxpayer A is released to taxpayer B. The act takes this point into consideration in its statement that "to the extent required to prevent a clearly unwarranted invasion of personal privacy, an agency may delete identifying details when it makes available or publishes an opinion, statement of policy, interpretation, or staff manual or instruction" (*10*).

An essential aspect in designing a surveillance program is the assurance to the persons (agencies) who report and those being reported upon that the privacy rights of the persons whose health information is of interest will not be violated. The conflict created by the "right to privacy" and the "need to know" represents an area that must be monitored by the managers of a surveillance program as diligently as they monitor the health conditions to be reported. To illustrate: One of the most important court decisions the Centers for Disease Control (CDC) has obtained in recent years related to litigation arising out of the epidemic of toxic-shock syndrome of the late 1970s and early 1980s. The attorneys representing the manufacturer of the tampon that had been strongly statistically associated with the occurrence of toxic shock syndrome wanted to obtain not only data about women who had had toxic shock syndrome and from whom CDC had collected information but the names of the women as well. The agency argued (through district court and up to the Federal Court of Appeals) that participation in federal surveillance is voluntary and that participants in such programs have a reasonable expectation that their confidentiality will be protected by the Federal Government. The Appeals Court ruled in CDC's favor, but this position will continue to be challenged on a "need to know" basis, and persons who are designing and operating surveillance systems should always keep in mind the specter of the forced divulgence of information they have assured participants would be confidential. This is particularly likely in situations involving litigation, because of the courts' strong bias to make available the same information to legal

representatives for both plaintiffs and defendants.

The final observation in this section is that the manager of a surveillance program, at least within a federal agency, is always in danger of being accused by the popular media or the legal community of hiding something deliberately--not to protect the privacy of individuals, but for sinister reasons that are usually hinted at but not stated. This sort of accusation may have no basis in fact, but must be taken seriously and generally requires, at a minimum, an undesirable outlay of energy and worry on the part of the surveillance program manager.

Right of Access

If the taxpayers support the gathering of information, they have a right to that information (*11*). This statement forms one basis for the "right to access" position. Both the Privacy Act and the Freedom of Information Act reflect the post-Watergate era, with its focused concern on the potential for the government to keep secret files containing information on individuals. Beyond that is the "reasonable man" position, which maintains that a person has a right to any information that is about him/her. Unfortunately, giving information to an individual about himself/herself can sometimes have the effect of providing information that assigns liability to another person (or organization) in the data set. So even the process of providing personal information to the person in question is not without its hazards.

In addition to the individuals who wish to obtain information about themselves, there are the so-called "third-party" inquirers. These individuals call for information on a need-to-know basis and may range from members of the U.S. Congress through attorneys and special-interest groups (e.g., "right to life" or "pro-choice" groups) to representatives of the news media.

A major point for the surveillance program manager to ponder is when to make a public-use data set. Although there is no legal precedent to be followed here, once the first paper has been published about a data set, it is prudent to place that data set in the public domain if there is a reasonable expectation of its further use. Although this creates the risk of extra work and having others preempt publication, it obviates accusations about willful withholding of information or the danger that forced release of data before

they are properly prepared for public use will allow some subjects to be identified.

Product Liability

This heading could be "Research Institution Discovers Corporate America--and Vice Versa." The issue has been around for many years but seemed to rise to prominence in the United States with the emergence of toxic-shock syndrome in the late 1970s and early 1980s. It is not unusual for investigations to show that a product is contaminated, that someone used a machine incorrectly, or even that someone deliberately tampered with a medication or device and caused illness or death. What was not familiar was that a "good" product, one that meets all its quality-control specifications and does what it is advertised to do, can also have effects that are less than desirable. Thus, no one was ready to deal with the situation in which an efficiently designed tampon apparently led to a life-threatening illness. The scientists had to accept the findings because scientists deal in fact (probability), and the media had grist for their mills, but the manufacturer of the tampon (and its employees and stockholders and legal representatives) did not have an easy time coping with "the facts." In fact, they underwent a classic grief reaction--which the staff at CDC and other health science agencies have since learned to anticipate and to recognize--involving the stages of denial, anger, depression, acceptance, and resolution. Human nature was applied with a vengeance, and the first three stages were immediate, intense, and enduring. The last two stages took some time and extensive effort to induce.

Ideally, one should assure that surveillance programs are flawless and that all the information reported is unassailable. In the world of public health practice, such utopian standards can rarely be met. And public health practitioners must continue to be prepared to deal with issues on a mixture of levels--including public health, legal, ethical, socio-cultural, and emotional components.

Litigation Demands

Under litigation demands, the issue is to what extent an agency is responsible for providing its staff to testify in litigation relating to findings it obtained through surveillance or research. Of course, there is no simple answer, just as there have not been any simple answers to the other questions posed in this chapter. Clearly, it is not responsible to refuse to provide expert testimony in any instance in which it is

solicited. In some cases, agency scientists may be the only ones who have worked in the area in question and have facts to cite. By the same token, in situations in which there are massive numbers of suits being conducted over a period of several years (as with toxic-shock syndrome or transfusion-associated HIV infection), all of the scientific resources of an agency could be expended on time in court and, therefore, none of them on the science that is their primary business. Somewhere, there is a correct answer for each agency and each health issue, and this problem may need to be faced when planning surveillance activities.

CONCLUSION

For those who set up and run surveillance programs, it is important to note the following summary comments. Public health surveillance systems operate in the massive goldfish bowl that encompasses both public health practice and the law.

- Plan and design surveillance systems so that they are most likely to provide all the information and only the information actually needed.
- Include as few personal identifiers as feasible.
- Analyze and publish data in a responsible and timely fashion.
- Be prepared to stand behind the results (and hope your agency will stand behind you).
- Be prepared to place each data set in the public domain as soon as the first results are published.
- If the findings are revolutionary, be prepared for a hostile reaction rather than a medal.
- Finally, remember that the individual has rights (to privacy, to access information, to participate or not to participate in surveillance programs, and the like). The public health practitioner, at least in the role of public health practitioner, has no rights--only responsibilities.

Public surveillance constitutes one of the bridges between what we think is happening and what is actually happening. As such, it is one of the most valuable tools of the public health practitioner. With surveillance data as the light bulb and the law as a rheostat that stimulates change and regulates behavior, the two areas can work in concert to improve the quality of the public's health.

REFERENCES

1. Wing KR. The law and the public's health. Ann Arbor, Michigan: Health Administration Press, 1990:1-50.
2. Friedman LM. A history of American law. New York, New York: Norton Press, 1986:1-8.
3. Thacker SB, Berkelman RL. Public health surveillance in the United States. *Epidemiologic Reviews* 1988;10:165.
4. Osler W. Internal medicine as a vocation. In: Aequanimitas: with other addresses to medical students, nurses and practitioners of medicine. 3rd edition. Philadelphia, Pennsylvania: W.B. Saunders, 1932:131-46.
5. Hogue LL. Public health and the law: issues and trends. Rockville, Maryland: Aspen Systems Corporation, 1980:10.
6. Brandt AM. No magic bullet: a social history of venereal disease in the United States since 1880, 1985:157-8.
7. Parran T. The next great plague to go. *Survey Graphic* 1936:405-11.
8. 381 U.S. at 484-86.
9. 410 U.S. at 162-64.
10. The Freedom of Information Act (As Amended). Washington, D.C.: Government Printing Office, 1986.
11. Abraham HJ. Freedom and the court: civil rights and liberties in the United States. New York, New York: Oxford University Press, 1988;23.

Chapter XI

Computerizing Public Health Surveillance Systems

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"We only conquer what we wholly assimilate."

André Gide

In this chapter on informatics or computerization of surveillance systems, we will first explore what is technically possible in computerization of surveillance, finding

an enormous gap between this and the best of today's actual systems. The barriers to optimal use of computers in surveillance---mostly social, organization, and legal---are explored. The remainder of the chapter explores some of the problems that must be confronted in thinking about microcomputer-based surveillance, leaning heavily on examples from the notifiable disease system in the United States.

OVERVIEW OF A SURVEILLANCE SYSTEM IN THE FUTURE

An Ideal Surveillance System

Ideally the epidemiologist of the future will have a computer and communications system capable of providing management information on all these phases and also capable of being connected to individual households and medical facilities to obtain additional information.

Suppose that the epidemiologist of the future has a computer with automatic input from all inpatient and outpatient medical facilities, with standard records for each office or clinic visit and each hospital admission. S/he chooses to compare today or this week with a desired period, perhaps the past 5 years, and the computer displays or prints a series of maps for all conditions with unusual patterns. One of the maps seems interesting, and the epidemiologist may point to a particular area and request more information. A more detailed map of the area appears, showing the data sources that might provide the desired information, with estimates of the cost of obtaining the items desired. A few clicks of the mouse button select the sources, types of data, and format for a display, and the computer spends a few minutes interacting with computers in the medical facilities involved--extracting information and paying the necessary charges from the epidemiology division's budget. Soon the more detailed information is displayed on the epidemiologist's computer screen.

The pattern of hospitalizations and outpatient visits for asthma stands out, and the epidemiologist requests a random sample of specified size of persons who have ever had asthma in the same area, matched by age and gender, to serve as controls for a case-control study. The video-cable addresses of these "controls" and of the case-patients are quickly produced through queries to appropriate local medical-information sources. The epidemiologist formulates several questions about recent experiences, types of air conditioning, visits to various public facilities, and the like, adapts these to a

previously tested video questionnaire format, and requests that video interviews be performed for case-patients and controls. Each household is contacted or left a FAX-like request to tune to a particular channel and answer a 5-minute query from the state health department on a matter of importance to public health. Eighty-five percent of the subjects respond to the first query, and the computer automatically follows up with the rest, bringing the response to 92%, with half of the remainder reported to be absent from their homes for at least 2 days.

The odds ratio for persons with recent hospitalizations for asthma who work in or visit in a particular neighborhood is considerably higher than 1.0, and the epidemiologist connects by local-area network to the state occupational surveillance system and requests a display of all factories in the relevant area. Selecting those that deal with possibly allergenic materials, s/he issues a request for more detailed investigation of activities at the plants in a selected time interval. The epidemiologist also requests information from the weather bureau on wind direction and velocity, temperature, and rainfall.

Within a few hours, a plant is identified that is in the process of moving a large pile of by-products with a bulldozer. A request is issued that the by-product be sprayed with water to prevent its particles from becoming airborne, and the plant manager readily agrees when shown the maps that depict hospitalization rates for asthma downwind from the plant. To monitor progress and widen the investigation, the epidemiologist asks the computer to do similar studies for conjunctivitis and for coryza or hay fever over the previous and next 2 weeks. Selecting several maps and tables to include in the report, s/he asks the computer to write a description of the studies performed and the findings, and then dictates a brief summary of the problem and several follow-up notes to the voice port of the computer. At the end of 2 weeks, the number of cases of asthma has fallen to normal for the area, and the computer calculates on the basis of the number of medical visits during the outbreak that $55,000 has been saved at a total cost of a few hours of the epidemiologist's effort, a site visit to the plant, and charges of $9,500 for the data and the communication facilities used to perform the interviews.

Barriers to the Ideal Surveillance System

Obviously, we are a long way from implementing the system described above. It may be helpful in thinking about the future to explore what barriers must be surmounted before this scenario can be enacted. Strangely enough, few of them are technical; all of the necessary systems could be built today with fairly conventional equipment and software, with the exception of the two-way interactive video connection with each household. This hook-up with the individual household is more likely to be available within the next 10 years than is the connection between the physician's record files and the health department. In fact, the two-way interactive video link between the household and the outside world is simply awaiting the government's or the marketplace's decision on what format will be used and on the realization of the benefits of such a connection on the part of the entrepreneurs and the public.

However, there are some difficult problems to be solved before the "ideal system" can be implemented. They include the following:

a) *The rapid availability of standardized, computerized medical records.* Several issues need to be addressed before such a system is possible. In the United States, for example, a profusion of computerized medical-record systems for inpatient and outpatient records as well as insurance and other purposes have been developed These systems contain a plethora of different variables and use many different formats. Until a simple core public health record of age, gender, geographic location, diagnosis, and a few other items is created for each outpatient visit and each hospitalization--and is available in a standard format without delay--the responsive interactive system above remains an unrealistic pipe dream. An additional problem is that most medical records are still not more than partially computerized.

   The barriers to establishing standardized public health output from computerized medical records are primarily political and administrative; most large retail organizations create records of similar size for each item sold, and the items carry on average, a much lower price than the cost of a visit for medical care. Once there is the will to establish a national computerized medical record system, the technical hurdles will be readily overcome. The needs include standard but suitably flexible

record formats, solutions to problems associated with confidentiality, incentives to create the records (including the assurance of appropriate and cost effective use of the records), and voice output.

b) Another problem is the lack of recognition that information about patients, except for legally designated "reportable diseases," is useful in public health and should be available to public health agencies. The level of awareness could be heightened if technical solutions to problems of confidentiality were publicized and understood by the public and their legislative representatives. Such solutions as one-way encoding algorithms could provide partial solutions to matching and follow up problems, if properly used without turning public health agencies into carbon copies of dreaded "big brother."

c) A pervasive feeling among those in charge of data that their data base must be "clean" before anyone else can use it. Months or even years are consumed while corrections and updates are made to make the data as accurate as possible. Although from one perspective this quality control is necessary and important, the concept of "surveillance" includes rapid turnaround, a realization on the part of everyone concerned (even the media and the public) that the data are preliminary, and the understanding that in order to look at today's data today, one must be willing to accept today's imperfections. This mental shift, as well as corresponding technical developments, will be necessary before a computerized system can be used to examine automatically a "time slice" of disease and injury records that originate in clinics and hospitals. Imperfections will be everywhere, and methods must be found to cope with reality--even if it includes warts--on an immediate basis.

The Technology of the Future

As stated above, today's technology, given enough social and organizational development, is adequate to allow the creation of miracles in public health information and communication. Nevertheless, it seems likely that development in technology will continue to reflect more of a driving force in public health computing

than progress in political and social organization.

Technologic developments over the next decade will probably include the areas shown below:

High capacity storage devices

CD ROM's (compact disk read only memory) similar to those used for music make it possible to have access to large bibliographic data bases anywhere there is electricity. The MEDLARS data base of the U.S. National Library of Medicine can be searched from a clinic in Africa; (once there are lower prices for books on CD ROM and they include needed illustrations), it will be possible to take a medical library anywhere in a briefcase. Past data bases from the United States and elsewhere will become available on CD ROM, although the process of cleaning them up for this purpose often reveals gaps and inconsistencies that reflect changing definitions and diminish their value as consistent anchors for comparison.

Networks

A local area network (LAN) is a system linking microcomputers, terminals, workstations with each other and/or a mainframe computer to facilitate sharing of equipment (e.g., printers) programs, data, or other information. LANs are transforming the way many agencies do business. The most noticeable effect is the transmission of written memoranda that could or would not have been typed, packaged, and sent through a paper system. The cost of installing and supporting a LAN is not small, particularly in terms of support personnel. Uses for surveillance include entering data at multiple computers connected by a LAN. This requires special software to protect against errors. Special precautions to protect confidentiality are necessary in a network, if several people enter data in the same file at the same time.

New user interfaces

The parts of programs that interact with users have become easier to understand, and more attractive, with pull-down menus, windows, and pointing devices such as the "mouse." This elegance has its cost in terms of requirements for faster computers, for more memory, and particularly for greater skill to produce such programs. Some new programs cause unexpected problems when run with older programs or on older

computers. All in all, the trend is toward a standard set of screen "controls," like those in modern cars, but the path in that direction is replete with experiment and minor failures.

New programming tools

It is widely recognized that software production is the narrow point in the implementation of new ideas in computing. Useful software still requires hundreds of thousands of lines of hand-written and highly personal "coding." Many new trends such as "fourth-generation data bases," computer-assisted software design (CASE) tools, and "object-oriented design" have made programming more productive, but this area of new tools is one in which major advances would create revolutionary changes.

Higher-capacity processors and more memory

The almost miraculous advances in computer speed and memory capacity in the last decade have removed many of the limits that required use of mainframe computers or minicomputers rather than microcomputers. Now almost any project can be done on a microcomputer or several microcomputers connected by a LAN if there is sufficient motivation.

Video and computer integration

Photographs and fully functional video will soon be appearing on our computer screens. Although this may have greatest impact in pathology and radiology, and education, it also alters on opportunities to use color and three-dimensional dynamic displays for epidemiologic data. The possibilities for computer interaction via ordinary television sets are exciting, because every epidemiologist (and market researcher) can savor the possibility of interviewing citizens via cable television with the results captured immediately in computerized form. The medium offers new challenges in identifying responses that result from the various stages of humor, exasperation, or intoxication that citizens may undergo in the privacy of their homes.

Voice and pen input

System are available now that identify thousands of spoken words (for tens of thousands of dollars) and allow for a crude interaction between voice and computer. Computers that recognize handwritten text of reasonably structured type are being sold

currently. Presumably the rather elementary state of computerization of medical records will undergo a quantum leap once such systems allow medical staff to dictate to the computer without typing and preferably without being near a computer. When medical handwriting is replaced by voice dictation into a lapel microphone, real progress may occur in the use of computers in both clinical medicine and public health settings. As stated above, however, realizing real public-health benefit from such technology will require dramatic social and legal changes.

BACK TO THE PRESENT: COMPUTERIZED PUBLIC HEALTH SURVEILLANCE IN 1992

Since 1985, Centers for Disease Control (CDC) staff have installed and maintained customized disease-surveillance software in 36 state health departments and a number of county, district, and territorial departments. The software has been based on *Epi Info*, a public-domain word-processing, database, and statistics package for IBM-compatible microcomputers that is a joint product of CDC and the Global Programme on AIDS, World Health Organization (*1,2*). These systems have made possible the participation of all 50 states in the National Electronic Telecommunications Surveillance System (*3,4*). Benefits cited in a recent evaluation include improved access to data and improvement in both quality of data and access associated with decentralized entry of data (*5*).

Although reportable-disease systems are a specific kind of surveillance system and *Epi Info* is only one type of data-base/statistics program around which a system can be built, many of the principles of computerization apply to other systems. To avoid empty generalization, much of the rest of this chapter is based on CDC's experience with reportable-disease surveillance using *Epi Info*. The information is directed to those considering computerization of a disease-surveillance or similar system of records, whether they wish to do their own system design or will be working with a professional computer-systems designer. Computerizing a surveillance system for disease is not easy. Since the success of computerization depends as much on the administrative and epidemiologic environment as on the software, it is vital that public health practitioners understand the details of a new system and participate in its design. The most important step in developing a computerized surveillance system

is identifying the public health objective for the system. In some cases, the objective(s) will have been clear for decades in a manual system ("Identify and treat or isolate cases of X and evaluate results," or "Assess results of immunization programs and identify new cases for special control efforts"). Computerization can then be directed toward accomplishing the same task more efficiently or in greater volume or detail.

The most successful computer systems, however, are those that change methods by which an agency operates rather than those that merely automate a manual task (*6*). In establishing a new surveillance system or reexamining an existing system, it may be useful to address the following question: "What key pieces of information do I want to see on my desk (or computer screen) every day, week, month, or year that will make my work easier or more effective?" The same question can be asked at several levels of management--from epidemiologic technician to epidemiologist to director of a public health agency.

Given a surveillance system that has a public health goal and to some extent achieves the goal, why computerize? Sometimes the answer is obvious--because the annual report takes a herd of clerks 2 years to process," or "we like the graphs health department A turns out so easily with their computer." Potential benefits relate to quality of data or of reports, quantity of data that can be processed, and speed of processing. Dissemination (copying) of surveillance records to another site is one reason disease reports in all 50 U.S. states are computerized.

We were unable to find systematic studies on the benefits of computerizing public health surveillance systems, although numerous articles describe individual systems that have been computerized (*7-10*), and Gaynes *et al.* (*11*) describe methods for evaluating a computerized surveillance system. In literature about the commercial world, benefits of computerization have been examined from the viewpoint of financial savings. Savings by automating a manual information process may amount to 20% or so, but the real benefits are achieved if computerization transforms the entire process concerned, giving a competitive advantage in the commercial world--which would correspond to a new order of service in the public health world (*6*). So far, most public health applications have automated manual systems, although some--such as the spreadsheet calculation of the impact of smoking on populations--verge on establishing

new and previously unknown styles of doing business (*12*).

One problem cited in other "vertical markets" (industries with specialized practitioners) such as the construction, meat-packing, and real estate industries. With only 7,000 epidemiologists in the United States, relatively few commercial developers feel that it is financially worthwhile to develop software for this market alone, since applications such as spreadsheets, languages, and word processors may sell millions of copies to the general public (*13*).

Basic Needs

The first requisite for computerization is a paper system or operational design that works reasonably well or would do so if the process were speedier and more accurate. Chaos computerized is not necessarily an improvement over what is already in place, although the process of computerization offers a chance to rethink some of the features of a system and to make improvements. If the surveillance system is a new one, it may be desirable to evolve the computer facilities in small stages with minimal investment until the system proves to be useful and well-conceived. This requires a careful plan (including provision for changing the plan if necessary) but will minimize the expense of adaptation as the epidemiologic design of the system undergoes the inevitable adaptation to external reality. After the "bare bones" system has proven its worth and the probability of expensive changes is lower, the "bells and whistles" can be added later.

Personnel to do the collection of data, data entry, analysis, and system maintenance are important contributors to the system. Many of the tasks can be learned by current employees, particularly if they find this challenge welcome. If possible, those chosen should be long-term employees to assure stability of the system, although they may be aided by students and other temporary employees. The epidemiologist who will use the results should participate in the planning of the system and should understand how it is constructed. A staff member with some programming skills and/or aptitude for microcomputing should be involved in designing and setting up the system, even if an outside consultant does the actual programming.

If several computers are to interact and share data, a set of standards is necessary

(e.g., just as humans carrying on a conversation need a common language). In the United States, the states and CDC chose a standard record format so that computers of different types could reformat data to a set of standard records and send these to the central agency. This standard, first devised in 1984 and revised in 1991, has served the purpose well, without placing unnecessary restrictions on the type of hardware or the format of records kept within each state. One state maintains 20 times more information for local use than do other states, but all export the same standard record formats to the national level. The new standard record format allows for standard demographic and diagnostic information, attachment of variable-length detailed reports for selected diseases, mixture of summary with individual records, and automatic comparison of state and national data bases with each transmission.

Most government settings have an organization in charge of computer programming, approval of new systems, and purchasing of computers and software. It is important to maintain liaison with this organization and to arrange its assistance ahead of time with difficult areas such as purchasing computers. In some organizations, purchases are limited to particular types of computers--occasionally with unique characteristics--or to centrally administered systems. We recently encountered a network of "diskless" workstations that presented numerous problems in trying to load or run software or back-up files from a particular station without a removable storage device. If such problems are present, it is prudent to discover and, if possible, to surmount them at an early stage through patient negotiation and collaboration or other methods if necessary. The technical difficulties that arise in setting up a computer system are usually the easy problems; the difficulties that lead to months and years of delay and unhappiness usually reflect misunderstanding and miscommunication among individuals or organizational entities.

Some Key Concepts: Files, Records, and Fields

Computerized records are stored in files. A file is a collection of records, usually one record per case, that has a name (e.g., GEPI.REC, for General EPIdemiology) and can be manipulated as a unit. Files, like books, can be opened, closed, read, written to, or discarded. They are stored on nonvolatile media such as hard or floppy disks or magnetic tape.

Records correspond to one copy of a completed questionnaire or form, such as a disease-report card. Usually, one disease report or questionnaire is stored in a file as a single record. Records can be displayed on the screen, searched for by name or some other characteristic, saved (written) to a disk, or marked as deleted. Many records can be stored in each file.

A field is one item of information within a record. NAME, AGE, and DATEONSET might be fields within a disease-report record. Records in a particular file all have the same fields. Each field has a name, a type (text, upper-case text, numeric, date, etc.), and a length, such as 22 characters for NAME or 3 for AGE. During analysis, fields may be called variables, and commands such as "TABLES DISEASE COUNTY" are used to instruct the system to process a particular file and construct the desired table by tabulating the fields or variables called DISEASE and COUNTY. In this case, the result in *Epi Info* would be a table that lists DISEASE down the left side and COUNTY across the top, with numbers of reports by county indicated in the cells of the table.

Hardware: What Size Computer is Appropriate?

With microcomputers being available for much less than $5000, it is possible to process more than 100,000 records in reasonable time periods. Processing time tends to reflect the record length as well as the number of records, however, and the size of each record should be kept short if large numbers will be processed. Since the total number of disease reports for the United States is several hundred thousand per year, states and counties should find it possible to build most systems on a microcomputer if desired.

Minicomputers and mainframes can serve as the basis for surveillance systems if available at reasonable cost and if programming and support staff are available to work creatively with staff of the surveillance system. The greater technical skill required to run and program such computers often resides in an organization other than the one running the surveillance system, and close coordination becomes much more important than in the do-it-yourself situation with a microcomputer.

Systems that seem to require processing of millions of records, such as hospital discharge or Medicare records for a state, can be reduced by sampling to a manageable

size for the microcomputer. The mainframe can be used to select a sample of records (e.g., particular age groups, diseases, every tenth record, or persons born in decade years). Files are then exported for processing on a microcomputer that is more responsive to the epidemiologist's wishes. Epidemiologists are usually acutely conscious of sample size when performing interviews but sometimes fail to recognize how unnecessary it is to process 6 million records to estimate a simple proportion.

Software

The type of software used to perform the computerization is often less crucial than the skills of those who will program and run it. Usually, there are several types of data-base or statistical packages that will do a given task well if properly programmed. Beware of the "indispensable programmer" syndrome, in which a single expert programmer writes a system in his or her favorite language and then departs for greener pastures, leaving the users without resources for further maintenance.

Data-base packages such as dBase, Paradox, Foxbase, and Clipper are designed to allow data input, storage, retrieval, and editing. Most will count records but do not easily do such statistics as odds ratios. They require a skilled programmer to produce a customized system.

Statistics packages, such as Statistical Analysis System (SAS) and Statistical Package for the Social Sciences (SPSS), focus on producing statistical reports, usually from single files of data. They are less convenient for data entry. Both SAS and SPSS now have mainframe and microcomputer versions. They contain many routines rarely used by epidemiologists and occupy large amounts of disk space (tens of megabytes for SAS).

Epi Info provides a combination of data-base and statistical functions, allowing relational linking of several files during data entry or analysis. Questionnaires or forms may be up to 500 lines, with hundreds of numeric or text fields, and the number of records is limited only by disk storage space. Frequencies, cross tabulations, customized reports, and graphs can be produced through commands contained in a program file or interactively from the keyboard. Commonly used epidemiologic statistics are part of the statistical output. Although it takes little experience to use *Epi Info* for investigating outbreaks, producing a complete surveillance system from the

beginning takes both skill and time. It may, however, be much simpler to modify software supplied with the program.

It is important to realize the limitations of software packages before they are used. Both statistical and data-base packages typically cost at least several hundred dollars and therefore are not likely to be feasible for classes of students or large numbers of remote computers.

Some data-base packages limit the number of fields in a record or the number of records in a file, and few will do statistics without advanced programming or purchase of a supplementary package. Statistics packages, on the other hand, may have limitations in handling textual ("alpha") data, and most allow processing of only one file at a time. A complete surveillance system may require the functions of both data-base and statistical programs.

The current version of *Epi Info* has limitations on the number of records that can be sorted or linked at one time (tens of thousands), however, and since text fields are limited to 80 characters, *Epi Info* would not be a good choice if large amounts of text are to be stored, as in a complete clinical system containing dictated notes.

Designing Entry Forms

In a surveillance system, data items are usually entered in a standard format (e.g., a questionnaire or report form). The information is stored in files containing one record per individual. In *Epi Info*, the format of the data-base file is specified by typing a questionnaire or form in the word processor. The result resembles a paper form, with entry blanks indicated by special symbols (e.g., underlined characters for text fields and number signs for numeric fields). The computer reads the form and constructs a file in the proper format.

In designing a form, it is useful to include a unique case identifier as a number of combination of letters and digits. This may include meaningful information, such as the year, but should not include any item that may need to be changed, such as a disease code. It must be designed so that a new and unique number will always be available for each record.

The amount of data entry and computer storage required may be minimized by computerizing only information that will actually be used. If follow-up information such as name, address, and telephone number can be used from the paper form, there may be no need to enter it into the computer. If contact tracing is recorded, the computer record may summarize the number of contacts named and the number found or treated, with the details on each and progress of the follow-up efforts relegated to the paper forms used by field investigators. When including an item on the input form, it is helpful to ask, "how will this be analyzed?" and "how would the result look after processing?" Computers around the world are full of data items that someone entered "just in case we need it." Most are never needed.

Textual material can be printed from a computer file, but it is usually difficult or impossible to process such entries as "Pen, Strep, and Ampicillin," to produce meaningful tabulations. For serious analysis a more usable format would be

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Penicillin          <Y>
Streptomycin        <Y>
Ampicillin          <Y>
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in which "<Y>" represents a blank for a "Y" or "N" response.

A common problem in designing entry forms is that several data items may be similar. Suppose you want to record name and treatment (RX) status for up to 12 contacts of each case-patient. One possible approach is to create fields called NAME1 through NAME12 and RX1 through RX12. This approach allows the data to be entered, although it creates a very large data-entry record (say 12 x 22 characters for NAMEs and 12 x 1 characters for RX=276 characters, even if no information about contacts is entered). However, analyzing the information becomes a programming nightmare, as determining the number of contacts or their treatment status requires examining at least 12 different fields in each record to see whether they have been filled in and keeping a running tally of the results. In computer data-base jargon, the record is not "normalized." These repeating groups of fields should be placed in separate records--one for each contact--linked to the main file as described below in the section on linking special-purpose records. Then a case-patient with one contact has one record in the case file and one record in the contact file rather than the equivalent of these plus 11 empty records in a single file.

This problem is resolved by rethinking what is really the best unit around which to build an individual record. The simple answer is that if you intend to tabulate cases, build a case record; if you will tabulate contacts or follow-up visits, then you need a contact or follow-up record. If both are necessary and the system is large or permanent, records should be placed in separate files and linked using relational data-base features as described below.

Data Entry

The details of data entry should be determined and documented, including who will prepare the paper records (if needed) for entry, who will enter them, and at what intervals. The status of the report as "suspected" or "confirmed" may determine whether it is entered, and this must be determined at the outset. Most disease reports are entered in batches--once a week, for example--and in many states not more than an hour or two is needed to enter the data for a week, although the quantity of records varies sixfold in size in different states and correspondingly in time required to enter data.

Records linked to more extensive specialized forms can be sent as partial submissions and revised later to avoid delays in reporting caused by the slower progress of data collection for the more detailed forms. This issue needs to be considered and resolved in advance.

Cleaning and Editing the Data

Errors or duplications inevitably occur during data entry, and additional information may arrive that requires changes or additions. The data can be "cleaned" during data entry or with the help of analytic programs that display "outliers," and data can be checked visually by browsing through records in the ENTER program or by scanning a list printed by the ENTER or ANALYSIS programs. Records can be viewed and corrected in a spreadsheet format in ANALYSIS. Finally, a program called VALIDATE can be used to compare files entered in duplicate by different operators. Records showing different entries are printed out for reconciliation.

Epi Info allows extensive programming of error checks on data entry. Each field can be set to accept only specified codes, and, if necessary, multiple fields can be

checked for inconsistencies such as gynecologic conditions recorded for males. Unfortunately, many errors cannot be caught by such systems, and one can still enter the wrong code for a less gender-specific disease.

Regardless of the method used, errors should be caught and corrected near the time of data entry if possible, since they can create much larger problems if left for the end of the year. The choice depends largely on orientation and number of personnel available and perhaps on their preferences after trying different methods.

Analysis of Data

The type of output desired should be planned in advance, since the inputs and outputs usually specify fairly precisely what kind of processing is needed to achieve the result. Dummy tables and graphs should be sketched on paper. *Epi Info* and many other data-base programs can be programmed to print a table or mixture of text and tables in almost any format, using a feature called the "report generator."

It is not necessary to design reports to cover all possible needs, since ad hoc queries are an important part of any system, and additional reports can be added later if they are deemed useful. In *Epi Info*, an epidemiologist can learn to do simple queries (READ GEPI; TABLES RACE COUNTY) in a short time and to limit these to particular time periods (SELECT REPORTWK = 34) almost as easily.

Sometimes a simple report such as a listing this week's reports, sorted by disease, may be as useful as a number of tables with very small numbers in each cell. The number of records available should be considered in designing reports and in determining how often they will be produced.

Distributed Data Base

So far, we have described a surveillance system housed in a single microcomputer. As more community health departments obtain computers, however, the trend is toward networks of computers within a state, connected by modem in ways analogous to those used in the National Electronic Telecommunications Surveillance System (NETSS), with its 50+ state and territorial participants. Each participating site enters data and sends them periodically to a computer at the next level up.

This process would be simple to do if all data were entered at the local level and sent to the state level, and if no changes were made later. However, in practice, not only are changes made, but in some states records are entered at both state and local levels, and some method must be in place to see that both levels of staff eventually have the same records.

Ideally, only one copy of the records would be considered the "master" copy, and each user would know its location and provide updates only at the designated time. The best way to accomplish this objective is still being worked out, and experiments of several types are likely. Designating only one of the sources as the "owner" and rightful editor of the data is one possibility. At present, we favor indicating on each record the site at which it was created and allowing only that site to make changes that are transmitted weekly to the other sites to update their copies of the records.

State health departments use the latest software to transmit year-to-date summary information on the state data base to the national level each week. These data are compared automatically with the contents of the national data base, and any discrepancies are reported.

Transmitting Data

In NETSS, most states transmit reports each week through a commercial telecommunications network. The 50+ reports stay in the network computer until they are picked up on Tuesday morning by CDC staff, stripped of comments and address material, and joined together in a single file for processing on the CDC mainframe. Error checking is done to test for invalid codes and other problems, and error notices are sent back to the states.

Another method that eliminates errors caused by telephone noise involves transmission directly from computer to computer by means of modems and software that retransmits if errors are caused by noise. Several states are using this method to connect with CDC microcomputers that, in turn, send the files to the CDC mainframe.

A third less elegant but often practical solution is physical transfer of floppy

diskettes by mail or messenger at intervals. This allows large files to be transferred with minimal inconvenience, and may be appropriate if the additional trouble of setting up modems and software is not yet warranted or in developing countries where telephones are unreliable or unavailable.

In any case, the result is that a copy of a file of records from the peripheral site arrives at the central site. The records must then be merged into the main data base. If all are new records, this task is straightforward. If the incoming records contain updates for records previously transmitted, the process is more complex.

Correcting and Updating Records from Another Site

In NETSS, only state participants are allowed to update records; CDC staff do not do so, although they may enter temporary telephone reports. Updates are sent as records with the same identification number as that for the original record. If a new record has the same identification number as a record in the data base, the existing record is updated so that all non-blank fields of the new record prevail. To change an age, for example, a state would send a record containing the case identification number and the new age. To delete a record, the state, year, and identification numbers are sent in a special "Delete" record. When errors are found at CDC, the information is transmitted to the state staff, who then corrects the errors and transmit update records the following week.

Individual and Summary Records

Many systems function with a record for each individual case report. In some, however, there is a need for summary records, each of which represents a number of case reports. This is helpful if large numbers of similar records (e.g., cases of gonorrhea in a big city) are processed, or if only summary numbers are available. It also allows records from entire years to be summarized in condensed format, so that a 5-year trend can be calculated without reading and processing each record for the previous 5 years.

A summary record is similar to a case record, but it contains an additional field called "COUNT," which contains a number. The number indicates how many records with the same information are represented by the summary record. *Epi Info* contains

commands called SUMTABLES and SUMFREQ to process summary records. These commands sum the contents of the count field rather than counting individual records. Since a record with COUNT equal to 1 is an individual case record, files that are mixtures of summary and individual records can be processed as a single unit.

Linking Special-Purpose Records to the Main Data Base

As mentioned above, sometimes it is necessary to link related records in different files together in order to allow easy processing of, for example case-patients and contacts who are related to case-patients. This requires that a common case identification number be included in each record. *Epi Info* and other data-base programs, such as dBASE, allow automatic linking of records through such a common identifier. On data entry, answering "Y" to the question "Contacts (Y/N)?" might cause another form, representing the contact file, to appear on the screen. The operator can then enter one or many contact forms for this case, pressing a function key (F10) to return to the main form. A separate record is created for each contact.

In *Epi Info*'s ANALYSIS program, the CONTACT file is READ, and the CASE file is linked ("related") to it. Each contact record then contains information about the case-patient as well as about the contact, and questions such as "how many contacts of female case-patients were treated?" can be answered easily. The CASE file can also be processed alone to answer questions such as "how many cases of syphilis were there?"

We also link disease-specific forms to the main data base of reports. Hepatitis, for example, requires a full page of extra information used to define further the epidemiology of a report. By linking a hepatitis file to the main case file, records are created only if the disease is hepatitis, thus saving a great deal of storage space over the single-file method, in which all the questions on hepatitis would be left blank in a nonhepatitis record. Current systems, including the one distributed as an example on the *Epi Info* disks, contain related files for hepatitis, meningitis, and enteric disease, each of which only appears if a relevant disease code is entered.

Dissemination of Data

Dissemination of results is an important element of the surveillance cycle. Computerization can assist by making new methods of analysis or presentation

practical. Use of tabular or graphics software in conjunction with desk-top publishing technology can make the preparation of results not only faster but more accurate and meaningful. A graphic method for comparison of current results with those for the past 5 years has been introduced to the *Morbidity and Mortality Weekly Report* in the United States (Figure V.12) (*14*). This method would have been too cumbersome for manual processing.

Computer software greatly simplifies and improves the production of maps and graphs. *Epi Map*, a public domain companion to *Epi Info*, to be released in 1993 will make mapping available to anyone with an IBM-compatible microcomputer.

Tables, maps, graphs, text, and data files may be made available either on-line via modem connections or by distributing floppy or CD-ROM disks. The latter are particularly useful in remote areas or for large volumes of data than can be easily sent over low-speed modems.

Data Disasters

Destruction or damage or data on hard disks should be expected and planned for. During the first 4 years of NETSS (and during the 3 year tenure of its predecessor, the Epidemiologic Surveillance Project), a number of hard disks have "crashed." In most cases, back-up files on floppy diskettes had been properly prepared and stored, and they were used to restore the data once the disk had been replaced.

Recently, some state programs began to reuse case-identification numbers from several years ago, not realizing that the new records would overwrite the old records in the national data base. It is important to be clear about the time period for which updates will be accepted.

Upgrading either hardware or software is a frequent cause of problems, when the new items have unexpected features, occupy more memory space, or require that protocols for functions, such as communications, be changed.

Computer viruses are an increasing cause of problems. They can cause a variety of difficulties ranging from erratic behavior of software to complete loss of files.

They may be introduced from networks, by accessing other computer bulletin boards, or by loading copied software from unknown sources.

Programs to detect and eradicate computer viruses are available commercially. It is essential to install one of these and to be sure that any disk from an external source is scanned for viruses before it is copied or used as a source of new programs.

Backup Methods

Methods for disaster prevention center around regular backup of data files onto floppy diskettes (or tape if available, but beware of tape backups with only one compatible tape drive in the same institution). The back up copies should be rotated so that several circulate in turn and so that the one overwritten has at least two more recent relatives. To protect against fire, water damage, and damage by panic-stricken personnel, it is wise to keep at least one backup in a site remote from the computer. Setting the write-protection feature on the diskettes after making the backup is an additional protection.

Upgrading hardware or software should be done at a time when use of the system is least critical, and care should be taken to allow for replacing the old system exactly as it was if problems occur with the new one. Thus, before installing a new version of software, the old one should be thoroughly backed up or preferably left in place in another directory so that it can be used if necessary.

Training of Staff and Transition Techniques

We have found that the most effective staff training occurs by having potential operators participate in the design of the system and receive short demonstrations and hands-on lessons at the time the system is installed. Usually installation of a system takes two or three days for planning and decision making, two or three days for programming, and a similar period for staff training, trial runs, and revisions.

National meetings and training sessions for operators of state surveillance systems have been helpful in providing extra training and motivation and in surfacing problems that need to be addressed and new ideas for software improvements.

During the transition from a paper to a computerized system, both systems are run in

parallel for a period until the results are satisfactory and staff feel comfortable with the new system.

DISCUSSION

The old image of the computer expert in an expensive suit handing the client the keys to the new "turn-key" system perfectly adapted to his or her needs was probably always a fantasy, but with modest budgets, small data bases, and a desire for "hands-on" access to data, it certainly has little relevance to public health needs. Although in some ways centralized computers and instant interactivity for updating records would present fewer problems than the distributed systems we have described, public health workers usually do not require and cannot financially afford the instant updates needed for law enforcement, banking, or airline reservations. Microcomputers and local data bases can maintain the data and analytic results closer to the professionals primarily responsible for prevention and control.

We are convinced that participation of all 50 state health departments in the national computerized system would have been impossible without a) software for states that allowed customization for use of local forms and procedures, b) participation of each state epidemiologist's staff in designing a system unique to the state, and c) a standardized record format. Each state has a different input form, although the records sent to CDC are restructured and variable values are recoded by *Epi Info* programs so that they are in the uniform national format.

As systems become more complex, however, it is important to standardize as many features as possible from state to state so that a thoroughly debugged core system can be used by all. We are gradually achieving this with a new *Epi-Info* based system that has a series of standard modules, accompanied by other modules that are highly customizable.

As pointed out in this chapter, there is an enormous gap between what is technologically possible with the use of computers in public health and what is actually going on at the grass-roots level of public health practice. Until the keeping of medical records in clinical practice is computerized to a much greater extent, it would be difficult to imagine that our scenario of the future will actually

move closer to reality.

Other key issues remaining to be resolved include a) the balance between confidentiality and free access to clinical records for public health purposes, b) the cost of data access and of programming and processing, and c) the ability of both professionals and the public to deal with "dirty" and preliminary data.

Many of these issues have both technical and social solutions. A great deal of work in both realms remains to be done before computerized public health surveillance can be said to have achieved its full potential.

REFERENCES

1. Dean AD, Dean JA, Burton AH, Dicker RC. Epi Info, version 5: a word processing, database, and statistics program for epidemiology on microcomputers. Atlanta, GA.: Centers for Disease Control, Atlanta, 1990.

2. Dean AD, Dean JA, Burton AH, Dicker RC. Epi Info: a general-purpose microcomputer program for public health information systems. *Am J Prev Med* 1991;7:178-82.

3. Graitcer PL, Burton AH. The epidemiologic surveillance project: a computer-based system for disease surveillance. *Am J Prev Med* 1987;3:123-7.

4. Centers for Disease Control. National Electronic Telecommunications System for Surveillance--United States, 1990-1991. *MMWR* 1991;40(29):502-3.

5. Odell-Butler ME, Ellis B, Hersey JC. Final report for task 8, an evaluation of the National Electronic Telecommunications System for Surveillance (NETSS). Arlington, Va.: Battelle, June 1991:49-50.

6. The big pay-off (benefits of computerizing a business) (node supplement). *IBM System User* March 1990:S20.

7. Mary M, Garnerin P, Roure C, *et al*. Six years of public health surveillance of measles in France. *Int J Epidemiol* 1992;21:163-8.

8. Centers for Disease Control. Surveillance of influenza-like diseases through a national computer network--France, 1984-1989. *MMWR* 1989;38(49):855-7.

9. Watkins M, Lapham S, Hoy W. Use of a medical center's computerized health care database for notifiable disease surveillance. *Am J Public Health* 1991;81(5):637-9.

10. Bernard KW, Graitcer PL, van der Vlugt T, Moran JS, Pulley KM. Epidemiological

surveillance in Peace Corps volunteers: a model for monitoring health in temporary residents of developing countries. *Int J Epidemiol* 1989;18(1):220-6.

11. Gaynes R, Friedman C Copeland TA, Thiele GH. Methodology to evaluate a computer-based system for surveillance of hospital-acquired infections. *Am J Infec Control* 1990;18:40-6.

12. Shultz JM, Novotny TE, Rice DP. Quantifying the disease impact of cigarette smoking with SAMMEC II software. *Public Health Rep* 1991;106(3):326-33.

13. Call B. The ones that got away: why some industries have not yet computerized. *PC Week* June 24, 1986;3:(25).

14. Centers for Disease Control. Proposed changes in format for presentation of notifiable disease report data. *MMWR* 1988;38(47):805-9.

Chapter XII

State and Local Issues in Surveillance

Melinda Wharton

Richard L. Vogt

"The government is very keen on amassing statistics. They collect them, add them, raise them to the nth power, take the cube root and prepare wonderful diagrams. But you must never forget that every one of these figures comes in the first instance from the village watchman, who just puts down what he damn well pleases."

Josiah Stamp

INTRODUCTION

In a recent report, the Institute of Medicine defined assessment as a core function of

public health agencies at the state and local level. "An understanding of the determinants of health and the nature and extent of community need is a fundamental prerequisite to sound decision-making about health. Accurate information serves the interests both of justice and the efficient use of available resources. Assessment is therefore a core governmental obligation in public health." State responsibilities include "assessment of health needs within the state based on statewide data collection" as well as "establishment of statewide health objectives, delegating power to localities and holding them accountable." Responsibilities of local public health units include "assessment, monitoring, and surveillance of local health problems and needs and resources for dealing with them" (*1*).

AUTHORITY FOR REPORTING SURVEILLANCE DATA

Although much of this book focuses on surveillance at the national level, the legal and regulatory authority for public health surveillance activities in the United States derives from state and local law (see Chapter X). Both the vital records and morbidity reporting systems were developed initially at the state level, and only later were national systems developed, with the participation of all states being voluntary. Indeed, in the United States, state and local governments have both the authority and the responsibility for almost all public health actions. This decentralization of power is outlined in the Constitution of the United States. Therefore, although most of the issues discussed in this chapter are relevant to other countries, some are unique to the practice of surveillance in the United States.

Although the objectives of surveillance at the state and local level do not differ substantially from those at the national level, the link to action--whether it be outbreak control, vector-control activities, legislation requiring use of child-restraint devices, or community mobilization--is most explicit at the state and local level. The objectives of state as well as national surveillance must be considered as systems are developed or redesigned, to assure that the information needed for public health action is obtained in the most efficient and cost-effective manner. The focus of the objectives may vary somewhat by condition (see Chapters I and II).

SOURCES OF SURVEILLANCE DATA

Only two data sources--vital records and notifiable-disease reports--are available at the local level in all states in the United States. Although other data sources discussed in Chapter III may be available at the state and local levels in some areas, alternate data sources may be needed in some states or localities to assess the impact of specific public health problems. Innovative solutions to particular data-related problems have been developed in many communities; some issues related to data sources at the state and local level are summarized below. For more information regarding other data sources, see Chapter III.

Notifiable Diseases

All 50 states require that physicians report cases of specified notifiable diseases to the appropriate state or local health department. The legal authority for the collection of this information rests with state statutes that are promulgated in state regulation; the diseases that are reportable vary by state (*2,3*). The notifiable-diseases reporting system was initially developed for reporting epidemic diseases such as smallpox and yellow fever, and this mechanism is still most commonly used for surveillance of infectious diseases. For noninfectious conditions, reporting by physicians is less uniformly required. In many states, however, reporting of specific occupational or chronic diseases is required by statute.

Sentinel Systems

State and local health departments may supplement information available through the notifiable-disease reporting system by creating sentinel reporting systems. State-based sentinel systems in Maine and Rhode Island relied on reporting by physicians, who were recruited by the state health department and were paid small amounts of money for participation. Both systems were subsequently discontinued because of budgetary cutbacks (*4,5*).

More recently, a sentinel active surveillance system developed in Missouri has been organized to ensure representation of the six public health districts in the state. Over 500 sites were recruited for participation, including schools, hospitals, day-care centers, preschools, and nursing homes; fewer than 30% of the participating individuals or institutions were physicians or clinics. Each participating site is telephoned weekly by local health departments to solicit reports (*6*). A similar

system, including universities, has been operated by the Los Angeles County Department of Health Services since 1981. In addition to providing timely information about reportable diseases, the system also has provided data on a variety of nonreportable conditions (*7*).

Such sentinel systems may be particularly useful for following trends in common conditions--e.g., varicella or influenza--when precise counts of cases are not needed and when a public health response is not necessary for individual case reports. However, if the reporting units selected for the sentinel system are unrepresentative of the overall reporting population, findings may not be generalizable to the wider population. Sentinel surveillance systems may be used to facilitate collection of additional risk-factor and other information on a subset of case reports, thus limiting the overall burden of data collection (*8*).

Hospital-Based Surveillance

Hospital-based surveillance systems, drawing on emergency room visits or hospital-discharge data, have most commonly been developed at the state and local level for surveillance of injuries (*9-15*). Other uses have included assessment of unmet health needs by identification of preventable disease (sentinel health events) (*16*). Aside from nosocomial infections, such systems are likely to have limited usefulness for surveillance for communicable disease (*17*).

In areas in which hospital-discharge diagnoses are coded using external cause of injury and poisoning codes (E-codes), hospital-discharge data are useful for surveillance of injuries. Currently 28 states have uniform hospital-discharge reporting systems, and addition of E-coding is a high priority for state and local injury-surveillance programs (*18*). The recent experience of New York State demonstrated the feasibility of such an addition, particularly when care was taken to develop a constituency to support the proposed change. Review of clinical records demonstrated that 93% of charts contained information necessary to allow proper coding. Since E-coding has begun, 95% of records of injured persons contain a valid E-code (*19*).

Other hospital-based data sources may be useful for surveillance at the state and local level. For example, trauma registries are a potential source of data for injury

surveillance (*20*), despite the lack of representativeness of patients referred to trauma centers for care (*21*).

School-Based Surveillance

School-based surveillance systems have been developed in some states to monitor disease trends among children of school age. This approach has been used for surveillance of influenza and varicella (*22,23*). Absenteeism is an excellent marker for influenza and is almost always available for administrative reasons. In Michigan, schools provide reports of cases of notifiable diseases among their students--along with counts of number of cases of influenza-like illness and varicella--to local health departments on a weekly basis. In many states, notifiable-disease regulations mandate reporting of specified diseases by school authorities.

Surveys at the State and Local Level

Information on certain issues, such as seat-belt use or nonutilization of health-care services, cannot be obtained readily without the use of surveys. Although national surveys may provide national estimates, data at the state or even local level are needed for health planning or to support legislative initiatives. Since 1981, state health departments have collaborated with the Centers for Disease Control (CDC) to conduct telephone surveys of adults to obtain information on health practices and behavior. In 1990, 45 states and the District of Columbia participated in the Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS allows estimation of age- and gender-specific prevalence of various risk factors by state (*24,25*). Likewise, behavioral risk factors among young people are periodically measured through state and local school-based surveys in the Youth Risk Behavior Surveillance System (*26*). County or community surveys may be particularly useful in areas with small populations, in instances in which morbidity or mortality data may be of limited usefulness to monitor the impact of interventions (*27*).

National Mortality Registration System

State law requires filing a death certificate for every death that occurs in the state, and death registration is virtually complete in the United States. At the

state level, mortality data are available before national data are compiled and released. Although the underlying cause of death is determined using standard computerized algorithms in all states, not all states use E-coding.

Such data are useful at the local level to identify preventable mortality and to set health priorities in the community. These efforts may be particularly important in developing community-based prevention programs for chronic disease (*28*).

Other Data Sources

Surveillance responsibilities of state and local health departments extend into many other areas, and in some jurisdictions may include monitoring of environmental quality, illnesses of domestic and wild animals, and vector populations. Although outside the scope of this book, these types of surveillance provide important information at the state and local level. For example, management of persons exposed to possibly rabid animals is influenced by the epidemiology of rabies in the area of exposure (*29*).

Arbovirus surveillance includes monitoring of vectors, vertebrate hosts, human cases, weather, and other factors in order to detect or predict changes in the transmission dynamics of arboviral infections. Guidelines for arbovirus surveillance programs in the United States have recently been developed (*30*).

Provider-Based Reporting: Special Issues

Mandatory reporting of communicable diseases by physicians has a long history in the United States, and there is an equally long history of failure on the part of physicians to comply. During the yellow fever epidemic of 1795, the New York City Health Committee quarantined patients with yellow fever at Bellevue Hospital. Many physicians refused to report cases, and the New York Medical Society went on record opposing the Committee's action, on grounds that the disease was not contagious (*31*). Physicians fought early efforts to make tuberculosis reportable, arguing that compulsory reporting constituted an invasion of the doctor-patient relationship and a violation of confidentiality (*32*). By 1913, five states had enacted regulations requiring reporting of venereal disease. Dr. Herman Biggs, director of the New York City Board of Health, stated that "the ten year long opposition to the reporting of

tuberculosis will doubtless appear a mild breeze compared with the stormy protest against the sanitary surveillance of the venereal diseases" (*33*).

The completeness of reporting of communicable diseases is variable, but for most diseases in most locations, it is thought to range from low to very low (*34,35*). Of course, factors other than the failure of physicians to report cases contribute to the low level of reporting of incident cases. Persons with asymptomatic infections or mild disease are unlikely to seek medical care. Of those persons who do seek care, not all will receive a specific diagnosis. Nationally, only 5% of cases of varicella are reported in the United States (*36*), and estimates of completeness of reporting are similar for shigellosis (*37*). Studies of outpatient-based or hospital-based reporting in some areas suggest somewhat higher levels of reporting of diagnosed cases of notifiable diseases, with substantial variation by disease (*38-40*). Reporting rates are higher for inpatients than outpatients (*17*).

Given the historic reluctance of physicians to participate in reporting disease, it is fortunate that reports of disease are available to most state health departments from other sources. Almost all states mandate reporting by clinical laboratories of at least some notifiable diseases (*41*). Laboratory reporting is often more readily available and reliable than reports from physicians. In Vermont, 71% of initial reports of confirmed cases of notifiable diseases in the period 1986-1987 originated from clinical laboratories; only 10% originated from physicians' offices (*42*). In Oklahoma, approximately 85% of cases of shigellosis are reported, but laboratories account for almost all of the reports received. Laboratories reported 77% of all reported cases, compared with only 6% for physicians (*43*).

Although laboratory-based reporting may be a valuable adjunct to physician-based reporting, it cannot replace reporting by physicians for all diseases. Some reportable diseases are clinical syndromes, requiring clinical judgment, and no specific laboratory diagnostic procedures exist (*44*). In other situations, laboratory diagnosis may play an important role, but may not be routinely available in a timely enough manner to replace reporting by physicians. Finally, physicians may have additional information that is epidemiologically important but is not known to the laboratory; a timely report by a physician may allow early institution of control measures, without waiting for the health department to follow up on laboratory reports.

A number of studies have attempted to identify reasons for physicians' failure to report notifiable diseases (*42,45-47*). In recent years, physicians have cited many of the same objections that have been raised historically, as noted above, although it is at least reassuring that the noncontagiousness of diseases that are actually communicable is no longer invoked. Commonly cited reasons, in approximate order of importance, are summarized in Table XII.1.

In an effort to improve reporting of notifiable diseases by physicians, local and state health departments have tried a number of different strategies. Although many of them have not been formally evaluated, enough information is available to reach some conclusions about possible successful approaches.

Projects aimed at improving reporting by physicians have included many interventions (e.g., revised reporting procedures, improved dissemination of findings and feedback to participants, and informational campaigns regarding the importance of reporting and outlining procedures for reporting). Even relatively intensive efforts may not produce major increases in reporting, although they may be effective in increasing awareness of reporting procedures among physicians (*7,48*).

Efforts to increase reporting through specific projects provide some clues on the most effective approaches. Active surveillance projects, in which health department personnel contact physicians' offices on a regular basis, have demonstrated 2- to 5-fold increases in the reporting of specified diseases, as well as increases in reporting of other conditions not subject to active surveillance (*49-51*). The consistency of these findings demonstrates that under some circumstances physicians are willing to report cases of notifiable disease. In these studies, reporting was a simple matter, and that may be important; equally important may be the message conveyed by the substantial investment by the health department in active surveillance--that disease reporting is an important activity.

The need for surveillance data on notifiable disease and the usefulness of such data are so obvious to workers in state and local health departments that we often believe that all physicians would report if they only understood the importance of reporting. Efforts to educate physicians have included a) lectures to medical students, house officers, and local medical groups on the importance of reporting; b) health depart-

ment newsletters; c) educational mailings; and conjunction with licensure. Although all of these may be useful, and lectures and newsletters are important forms of feedback to the medical community, evaluation of single presentations to clinical groups, newsletters, and mailings have not been found, in isolation, to increase reporting. Intensive efforts to market the concept of reporting may be more useful but will be accompanied by an obvious increase in cost (*52*).

If sending an occasional speaker to the local medical society and mass mailings are not effective, what is? The active surveillance projects and other studies of interventions demonstrate the usefulness of telephone contact (*49-51,53*). In fact, the efforts that work all target individual physicians--rather than groups of physicians--and make limited use of mailings and more use of personal visits and telephone contact. Some approaches that appear to be successful include a) providing physicians with feedback on the health department's disposition of individual cases (*54*); b) matching laboratory reports with physicians' reports, and for those cases reported only by laboratories, notifying physicians that a specific case should have been reported to the health department; and c) conducting in-person site visits to review reporting procedures (*55*). The latter intervention may be quite effective in enhancing laboratory- and hospital-based reporting, especially if accompanied by a review of medical records. The relevant factors may be less the mode of contact than the need to remind physicians on a regular basis that there is a health department that wants the information and that the health department actually does something with the data that are provided.

Exhortation and pleading for reports is no substitute for a state or local health department that responds promptly to reported public health problems, provides useful responses to inquiries from physicians and the public, and gives feedback on its activities and on the health status of the community to the medical community and the public. Nonetheless, a few specific steps that state and local health departments can take to improve reporting of notifiable diseases can be identified (Table XII.2).

Active surveillance works, but it is generally too costly to maintain as a routine health department activity. Less costly alternatives include sentinel active surveillance, in which certain physicians and institutions are identified and are targeted for active surveillance. Although this approach has been successful in some areas, it

is also costly and may detract from collection of surveillance data from non-sentinel sites. Another approach is what has been called "stimulated passive surveillance," in which the health department uses any contact with the medical community to solicit reports and provide feedback on community health status and health department activities. It may not be feasible to contact every physician, or even a systematic sample of physicians, every week, but every week physicians **are** contacted, for a variety of purposes, and those contacts can be used to exchange information.

Administrative barriers to reporting should be identified and eliminated. Physicians should be provided readable and up-to-date copies of lists of notifiable diseases, reporting forms, and telephone and facsimile numbers for local and state health departments. Reporting procedures should be as simple as possible. Some health departments have used toll-free numbers for telephone reporting (*46,56*). Answering machines can answer telephones at night, but people can answer questions and provide--and solicit--additional information. Reporting forms should be simple, clear, and printed in colors that allow photocopying or transmission by facsimile machine. Self-addressed, postage-paid cards or envelopes may be helpful. Although these tools may make reporting easier, without the other components of effective surveillance they are unlikely to have substantial impact on reporting behavior of physicians.

State licensing boards may penalize physicians for failing to report, although such actions are rarely taken. In California, a physician who failed to report on a patient with hepatitis A who subsequently transmitted infection to others had his license suspended for a year, and was placed on probation for 5 years (*57*). The medicolegal implications of failure to report are well-established in law, where the physician's obligation has been found to extend beyond the patient under his/her care (*58*). Although no single approach--be it improved communications, improved procedures, education, or fear--is necessarily successful in improving reporting by physicians, effective presentations have been developed using case studies that include the medicolegal implications of failure to report (Hendricks K, personal communication).

MAINTENANCE OF A LIST OF NOTIFIABLE DISEASES

Although the mechanisms vary, it is important that lists of notifiable diseases

undergo periodic revision. Public health priorities, epidemiology of specific conditions, and available public health interventions all change over time, with the result that last year's list of notifiable diseases no longer meets this year's needs. Additions and deletions must be made on an as-needed basis in order to maintain the usefulness of a notifiable-disease system. In particular, care must be exercised to assure that data on all notifiable conditions are actually needed and are used for public health purposes. "Diseases are often made reportable but the information gathered is put to no practical use, and with no feed-back to those who provided the data. This leads to deterioration in the general level of reporting, even for diseases of much importance. Better case reporting results when official reporting is restricted to those diseases for which control services are provided or potential control procedures are under evaluation, or epidemiologic information is needed for a definite purpose" (*59*).

In Canada, specific criteria have been developed for determining which diseases or conditions should be reported at the national level (Table XII.3) (*60*). In practice, these criteria have not resulted in the removal of any diseases from the list of nationally notifiable diseases, but they have at least provided a systematic basis for deciding among diseases proposed for addition.

ANALYSIS OF DATA

Most of the analytic issues relevant at the state and local level have been addressed elsewhere in this book (chapters V and VI), but some problems encountered in analyses at the state and local level are rarely faced at the national level.

Comparison of rates in different geographic areas poses particular and difficult problems when the number of events is small and/or the population of the areas is small. When analyzing data drawn from a small population, particularly for an uncommon event or from a subset of the population (e.g., when calculating age- or race-specific rates), calculated rates may be difficult to interpret. Unfortunately, it is difficult to say with certainty what population size, or number of events, is "too small" for meaningful analysis.

Issues involved in assessing the stability of rates and changes in rates when numbers

are small have been well summarized for the nonstatistician (*61*). For example, confidence intervals for rates can be calculated as shown in Table XII.4. In general, rates calculated based on $\leq$20 events will have a 95% confidence interval approximately as wide as the rate itself.

Two methods for comparing independent rates (that is, rates from different, non-overlapping geographic areas or from a single area at two different nonoverlapping time intervals) have been suggested. The 95% confidence interval for the ratio of two independent rates can be calculated using the formula shown in Table XII.5. The two rates differ significantly at the 5% level if the 95% confidence level for the ratio of the two rates does not include 1. This method produces valid results if the rate in the denominator is calculated from more than 100 events. The 95% confidence interval for the difference between two independent rates can be calculated using the formula shown in Table XII.6. The rates differ significantly at the 5% level if the 95% confidence interval of the difference between the two rates does not include zero. Sometimes the two methods provide contradictory results; if that occurs, one should conclude that the rates being compared are not significantly different (*61*).

In another report, four age-adjusted mortality indexes were compared, using 1969-1971 U.S. mortality data by county, for counties with populations of >5,000. On the basis of coefficients of variation, the standardized mortality ratio has produced stable results for mortality data from all counties studied, while unacceptable instability was found when the relative mortality index was applied to data from counties with populations of <50,000. Calculation of years of life lost from all causes produced stable results when applied to data from counties with populations of $\geq$25,000 (*62*). The stability of rates for specific causes of death remains a problem for small geographic areas. Methods for stabilization of rates have been developed, specifically for mapping of uncommon events such as suicide or specific types of cancer by county (*63,64*).

As an initial step, before a more complicated method for stabilization of rates is applied, aggregated rates should be compared with disaggregated rates (i.e., multiple years versus a single year; state-wide versus county-wide; and entire population versus age-, gender-, or race-specific rates). High rates in geographic areas with small populations--or in subsets of the population--may be due to chance, particularly

if the elevated rate is based on a small number of observed cases. Alternatively, if increases are consistent over time--or across some population subgroups--it is more likely that they represent important differences rather than chance occurrences.

Other events deserve attention, even if only a single case occurs; the occurrence of a sentinel health event represents a failure somewhere in the system of public health or of health-care delivery and warrants careful attention. Such sentinel events include maternal and infant deaths and a wide variety of infectious and noninfectious conditions (*65*).

Intercensal population estimates for small areas are available from a variety of sources. Because of limited availability of age-, gender-, and race-specific estimates from the U.S. Bureau of the Census for small areas, often, state governments have developed their own estimates (*66*). Methods for interpolating census data for estimation of small area populations have been developed (*67*).

Methods have also been developed for defining hospital service areas in metropolitan areas (*68*). Although these methods have most commonly been used in studies of health-services utilization in different geographic areas, they are potentially of value in analyses of data generated by hospital-based surveillance at the state or local level. Small-area analyses in health-services research have recently been reviewed (*69*). The statistical issues raised by these studies are also relevant to analyses of surveillance data (*70*).

Although more elaborate techniques have been described, most analyses of surveillance data are quite simple--frequencies, proportions, and rates--which may be conveniently presented in tabular form, graphs or as maps. Indeed, the simplest analyses--the number of births to teenagers by census tract, or crude death rates by county--may be the most useful for documenting the need for services. Simple analyses should be done and their results thoughtfully considered before more complicated procedures are undertaken. By far the most common error made in analysis of surveillance data is failure to look at the data.

DISSEMINATION OF SURVEILLANCE: STATE AND LOCAL

PERSPECTIVES

Most of the issues relevant to the dissemination of surveillance data at the state and local level have been addressed in Chapter VII. The role of newsletters, annual reports, and press releases has already been addressed, as has the importance of clear presentation and use of graphics. Mapping is a powerful technique for presenting data. Electronic mail systems have been developed in some states to facilitate the dissemination of information between state and local health departments.

RESOURCES FOR SURVEILLANCE AT THE STATE AND LOCAL LEVEL

No model system for surveillance at the state or local level exists. There is great variation in organizational structure of state and local health departments, and surveillance activities are usually closely linked to disease-control programs. Although this linkage helps assure that the data collected will indeed be used, it complicates efforts to document the resources, personnel and other, needed for surveillance; surveillance cannot be readily separated from other related activities.

There are only a few published reports that address the cost of routine surveillance systems for communicable disease in state health departments. The cost of a newly established active surveillance system that surveyed half the primary-care physicians in Vermont was estimated to be $20,000 annually, compared with $3,000 for passive surveillance (*50*). A study of the sentinel active surveillance system in Los Angeles County estimated that the additional cost of weekly contacts made with selected hospitals, physicians, schools, day-care centers, and university health centers was approximately $7,000 per year, compared with an estimated $10,000 per year for passive surveillance. The California costs reflected student instead of professional staff time and did not include time expended in recording reports at the health department (*7*). In 1985, the Kentucky Department for Health conducted active surveillance for hepatitis A infections among one-half of primary-care practitioners in 45 of 120 counties in the state. The 22-week active surveillance program was estimated to cost $5,616. Although the system was cost-effective overall, because the administration of immune globulin to contacts averted an estimated $14,021 in direct medical and indirect costs of potential subsequent cases, the health department itself, of course,

incurred increased cost. The system was not continued after the study was completed (*71*).

Higher quality data on cost are available for some more recently developed surveillance systems at the state level. A survey of 24 state and metropolitan health departments that conducted surveillance for nutrition in 1981 found that an average of 16.6 hours of work by a nutritionist was required each month for the surveillance system. Eight and one-half hours of clerical time were needed, along with support from statisticians, computer technicians, and others (*72*).

Data collection, coding, and entry for 2,000 persons with injuries seen at a single hospital participating in the National Electronic Injuries Surveillance System cost approximately $7,000 in 1989 (*11*).

Costs of the BRFSS are shared by CDC and participating state health departments through cooperative agreements. In 1987, the cost per state was approximately $50,000, or approximately $25-$30 per completed telephone interview (*24*).

Part of the Statewide Childhood Injury Prevention Project (SCIPP) in Massachusetts involved conducting a random-digit telephone survey. Information on injuries in the previous 2 months was obtained; because of the relative infrequency of these events, a large sample size was needed. Twelve hundred households were contacted at a cost of $25,000, yielding reports of only 80 injuries, most of which were falls (*73*).

More complete and accurate documentation of the costs of surveillance--including data analysis and dissemination--may facilitate funding, particularly in the current era of tight constraints on state budgets. Explicit discussion of costs and benefits may help, both in terms of protecting (if not increasing) funding levels and assuring that existing surveillance systems are necessary and make the best possible use of personnel time.

SUMMARY

Public health surveillance--the systematic and ongoing collection of data pertinent to public health, and the subsequent analysis and dissemination of these data--is the

first step toward action in public health, but it is only the first step. A number of approaches to translation of data into action have been developed, with emphasis on the local level. The Assessment Protocol for Excellence in Public Health (APEXPH), developed in collaboration with the National Association of County Health Officers, guides local health department officials through identification of health problems that require priority attention and through building of community coalitions for action (*74*). Such an approach provides a good foundation for adopting community health objectives (*75*). These methods have been very successful in communities that have undertaken them, and they provide useful outlines for translating information into action at the community level. For example, in Tucson, Arizona, a community coalition targeted for action the high rate of infant mortality, with the result that a new program to provide prenatal care was established.

Other examples, at the state level, are readily available. National studies that found that residents of Delaware died at high rates of preventable chronic disease resulted in a statewide cancer control plan, including a mobile mammography unit for inner-city neighborhoods. Widespread measles outbreaks occurred in New York State in 1989 among high school and college students who had been previously vaccinated. Surveillance data led New York officials to reconsider the state's vaccination strategy, with the result that in April 1989 New York became the first state in the United States to adopt a two-dose schedule for routine measles vaccination (*76*). Similarly, surveillance data in Tennessee led to the adoption of a statewide vaccination requirement for children who attend school in the state (Figure XII.1).

The competition for limited dollars and for the attention of policy makers and the public is intense. The challenge is to identify problems, set priorities, and to work with communities to develop solutions. More than ever, it is important to use data to decide among competing priorities and allocate limited resources--the most important of which are the time and energy of the public health practitioner and the best interests of the public.

REFERENCES

1. Institute of Medicine. The future of public health. Washington, D.C.: National Academy Press, 1988.
2. Chorba TL, Berkelman RL, Safford SK, Gibbs NP, Hull HF. Mandatory reporting of infectious diseases by clinicians. *JAMA* 1989;262:301-826.
3. Freund E, Seligman JP, Chorba TL, Safford SK, Drachman JB, Hull HF. Mandatory reporting of occupational diseases by clinicians. *JAMA* 1989;262:3041-4.
4. Feagin OT. Maine's sentinel physician system. *Journal of the Maine Medical Association* 1971;62:187,201.
5. Schaffner W, Scott HD, Rosenstein BJ, Byrne EB. Innovative communicable disease reporting: the Rhode Island experiment. *HSMHA Health Rep* 1971;86:431-6.
6. Dodson DR, Bright MF. Sentinel active surveillance system. *Missouri Epidemiologist* July 1989:1-2.
7. Weiss BP, Strassburg MA, Fannin SL. Improving disease reporting in Los Angeles County: trial and results. *Pub Health Rep* 1988;103:415-21.
8. Laboratory Centre for Disease Control. Canadian communicable disease surveillance system: disease-specific case definitions and surveillance methods. *Can Dis Wkly Rep* 1991;17(Suppl 3):1-35.
9. Gallagher SS, Guyer B, Motelchuck M, Bass J, Lovejoy FH, McLoughlin E, Mehta K. A strategy for the reduction of childhood injuries in Massachusetts: SCIPP. *N Engl J Med* 1982;307:1015-8.
10. Runyan CW, Kotch JB, Margolis LH, Buescher PA. Childhood injuries in North Carolina: a statewide analysis of hospitalizations and deaths. *Am J Public Health* 1985;75:1429-32.
11. Hopkins RS. Consumer product-related injuries in Athens, Ohio, 1980-85: assessment of emergency room-based surveillance. *Am J Prev Med* 1989;2:104-12.
12. Grisso JA, Wishner AR, Schwarz DF, Weene BA, Holmes JH, Sutton RL. A population-based study of injuries in inner-city women. *Am J Epidemiol* 1991;134:59-68.
13. King WD. Pediatric injury surveillance: use of a hospital discharge data base. *South Med J* 1991;84:342-8.
14. Goebert DA, Ng MY, Varney JM, Sheetz DA. Traumatic spinal cord injury in Hawaii. *Hawaii Medical Journal* 1991;50(2):44,47-48,50

15. Smith GS, Langlois JA, Buechner JS. Methodological issues in using hospital discharge data to determine the incidence of hospitalized injuries. *Am J Epidemiol* 1991;134:1146-58.

16. Carr W, Szapiro N, Heisler T, Krasner MI. Sentinel health events as indicators of unmet needs. *Soc Sci Med* 1989;29:705-11.

17. Watkins M, Lapham S, Hoy W. Use of a medical center's computerized health care database for notifiable disease surveillance. *Am J Public Health* 1991;81:637-9.

18. Graitcer PL. The development of state and local injury surveillance systems. *J Safety Res* 1987;18:191-8.

19. Feck G, Relethford JH. The addition of E-codes to the hospital discharge reporting system in New York. Abstracts of the 119th Annual Meeting of the American Public Health Association, November 10-14, 1991, Atlanta, Ga., 1991:1-38.

20. Lloyd LE, Graitcer PL. The potential for using a trauma registry for injury surveillance and prevention. *Am J Prev Med* 1989;1:34-7.

21. Patetta M, Cole T, Bowling JM, Watkins S. Evaluation of the representativeness of the North Carolina Trauma Registry. Abstracts of the 119th Annual Meeting of the American Public Health Association, November 10-14, 1991, Atlanta, Ga., 1991:139.

22. Peterson D, Andrews JS, Levy BS, Mitchell B. An effective school-based influenza surveillance system. *Public Health Rep* 1979;94:88-92.

23. Finger R, Stapleton M, Pelletier A. Reportable diseases in Kentucky: a five-year surveillance summary 1986-1990. Kentucky Cabinet for Human Resources, Department for Health Services, Division of Epidemiology.

24. Remington PL, Smith MY, Williamson DF, Anda RF, Gentry EM, Hogelin GC. Design, characteristics, and usefulness of state-based behavioral risk factor surveillance: 1981-87. *Public Health Rep* 1988;103:266-375.

25. Anda RF, Waller MN, Wooten KG, *et al*. Behavioral risk factor surveillance, 1988. In: *CDC Surveillance Summaries*, June 1990. *MMWR* 1990;39(no. SS-2):1-21.

26. Kolbe LJ. An epidemiological surveillance system to monitor the prevalence of youth behavior. *Health Education* 1990;21:44-8.

27. Aday LAA, Sellers C, Andersen RM. Potentials of local health surveys: a state-of-the-art summary. *Am J Public Health* 1981;71:835-40.

28. Remington PL, Anderson DE, Manering MC, Peterson EA, Anderson H. The PRECEDES Project: background and materials. *Wisconsin Medical Journal* 1990;89:695-6.

29. Fishbein DB. Rabies. *Infect Dis Clin North Am* 1991;5:53-71.

30. Moore CG, McLean RG, Mitchell CJ, *et al*. Guidelines for arbovirus surveillance programs in the United States. Atlanta, Ga.: Public Health Service (in press).

31. Duffy J. The sanitarians: a history of American public health. Urbana, Illinois: University of Illinois Press, 1990.

32. Starr R. The social transformation of American medicine. New York: Basic Books, 1982:187.

33. Brandt AM. No magic bullet: a social history of venereal disease in the United States since 1880. New York: Oxford University Press, 1987:42-3.

34. Haward RA. Scale of undernotification of infectious diseases by general practitioners. *Lancet* 1973;1:873-4.

35. Thacker SB, Choi K, Brachman PS. The surveillance of infectious diseases. *JAMA* 1983;249:1181-5.

36. Wharton M, Fehrs L, Stroup N, Cochi SL. Health impact of varicella in the 1980s. Abstracts of the 30th Interscience Conference on Antimicrobial Agents and Chemotherapy, October 21-24, 1990, Atlanta, Ga., 1990:276.

37. Rosenberg ML, Gangarosa EJ, Pollard RA, *et al*. *Shigella* surveillance in the United States, 1975. *J Infect Dis* 1977;136:458-60.

38. Marier R. The reporting of communicable diseases. *Am J Epidemiol* 1977;105:587-90.

39. Vogt RL, Clark SW, Kappel S. Evaluation of the state surveillance system using hospital discharge diagnoses, 1982-1983. *Am J Epidemiol* 1986;123:197-8.

40. Campos-Outcalt D, England R, Porter B. Reporting of communicable diseases by university physicians. *Pub Health Rep* 1991;106:579-83.

41. Sacks JJ. Utilization of case definitions and laboratory reporting in the surveillance of notifiable communicable diseases in the United States. *Am J Pub Health* 1985;75:1420-22.

42. Shramm M, Vogt RL, Mamolen M. Disease surveillance in Vermont: who reports? *Pub Health Rep* 1991;106:95-7.

43. Harkess JR, Gildon BA, Archer PW, Istre GR. Is passive surveillance always insensitive? An evaluation of shigellosis surveillance in Oklahoma. *Am J Pub Health* 1988;128:878-81.

44. Centers for Disease Control. Case definitions for public health surveillance. *MMWR* 1990;39(No.RR-13):1-43.

45. Konowitz PM, Petrossian GA, Rose DN. The underreporting of disease and physici-

an's knowledge of reporting requirements. *Pub Health Rep* 1984;99:31-5.

46. Do physicians report diseases? *Louisiana Morbidity Report* 1990;1(4):1-2.

47. Jones JL, Meyer P, Garrison C, *et al*. Physician and infection control practitioner HIV/AIDS reporting characteristics. *Am J Pub Health* 1992;82:889-91.

48. Seixas NS, Rosenman KD. Voluntary reporting system for occupational disease: pilot project, evaluation. *Public Health Rep* 1986;101:278-82.

49. Brachott D, Mosley JW. Viral hepatitis in Israel: the effect of canvassing physicians on notifications and the apparent epidemiological pattern. *Bull Wld Health Org* 1972;46:457-64.

50. Vogt RL, LaRue D, Klaucke DN, Jillson DA. Comparison of an active and passive surveillance system of primary care providers for hepatitis, measles, rubella and salmonellosis in Vermont. *Am J Pub Health* 1983;73:795-7.

51. Thacker SB, Redmond S, Rothenberg RB, et al. A controlled trial of disease surveillance strategies. *Am J Prev Med* 1986;2:345-50.

52. Scott HD, Thacher-Renshaw A, Rosenbaum SE, *et al*. Physician reporting of adverse drug reactions: results of the Rhode Island Adverse Drug Reaction Reporting Project. *JAMA* 1990;263:1785-8.

53. Rothenberg R, Bross DC, Vernon TM. Reporting of gonorrhea by private physicians: a behavioral study. *Am J Public Health* 1980;70:983-6.

54. Spencer L, Wren GR. New reporting system aids epidemiologists. *Hospitals* 1979;53:105-6.

55. Fife D, McAnaney, Rahman MA. Changes in AIDS case reporting after hospital site visits. *Am J Public Health* 1991;81:1648-50.

56. Tizes R, Pravda D. Proposed toll-free telephone reporting of notifiable diseases. *Health Serv Rep* 1972;87:633-7.

57. Disease reporting--a health professional's responsibility. *Public Health Letter* (Los Angeles County Department of Health Services) 2[10]. September 1980.

58. Isaacman SH. Significance of disease reporting requirements. *Infectious Disease News* 1990;3(10):23.

59. Benenson AS, (ed). Control of communicable diseases in man. Fifteenth Edition. Washington, D.C.: *American Public Health Association* 1990:xxvi.

60. Laboratory Centre for Disease Control. Establishing goals, techniques, and priorities for national communicable disease surveillance. *Can Dis Wkly Rep* 1991;17:79-84.

61. Kleinman JC, Kiely JL. Infant mortality. *NCHS Statistical Notes* 1991;1:7-10.

62. Kleinman JC. Age-adjusted mortality indexes for small areas: applications to health planning. *Am J Public Health* 1977;67:834-40.

63. Manton KG, Woodbury MA, Stallard E, *et al*. Empirical Bayes procedures for stabilizing maps of U.S. cancer mortality rates. *J Am Stat Assn* 1989;84:637-50.

64. Lui KJ, Martinez B, Mercy J. An application of the empirical Bayes approach to directly adjusted rates: a note on suicide mapping in California. *Suicide and Life-Threatening Behavior* 1990;20:240-53.

65. Rutstein DD, Berenberg W, Chalmers TC, *et al*. Measuring the quality of medical care: a clinical method. *N Engl J Med* 1976;294:582-8.

66. Balachandran M, Balachandran S (eds.). State and local statistics sources. Detroit, Michigan: Gale Research Inc., 1990.

67. Aickin M, Dunn CN, Flood TJ. Estimation of population denominators for public health studies at the tract, gender, and age-specific level. *Am J Public Health* 1991;81:918-20.

68. Thomas JW, Griffith JR, Durance P. Defining hospital clusters and associated service communities in metropolitan areas. *Socio-Economic Plan Sci* 1981;15:45-51.

69. Paul-Shaheen P, Clark JD, Williams D. Small area analysis: a review and analysis of the North American literature. *J Health Politics Policy Law* 1987;12:741-809.

70. Diehr P. Small area statistics: large statistical problems. *Am J Public Health* 1984;74:313-4.

71. Hinds MW, Skaggs JW, Gershon HB. Benefit-cost analysis of active surveillance of primary care physicians for hepatitis A. *Am J Public Health* 1985;75:176-7.

72. Scheer JC, Sims LS. Status of nutritional surveillance activities in 24 state and metropolitan health departments. *Public Health Rep* 1983;98:349-55.

73. Guyer B. The application of morbidity data in the Massachusetts Statewide Childhood Injury Prevention Program. *Can J Public Health* 1989;80:432-4.

74. APEX*PH*: Assessment protocol for excellence in public health. Washington, D.C.: National Association of County Health Officials, 1991.

75. Healthy communities 2000: model standards. Washington, D.C.: American Public Health Association, 1991.

76. Birkhead GS, Morse DL, Mills IJ, Novick LF. New York State's two-dose schedule for measles immunization. *Public Health Rep* 1991;106:338-44.

Chapter XIII

Important Surveillance Issues in Developing Countries

Mac Otten

"The health of the people is really the foundation upon which all their happiness and all their powers as a state depend."

Benjamin Disraeli

INTRODUCTION

Previous chapters in this book have discussed surveillance largely from the perspective of developed countries. Although the issues they address are relevant to all nations, developing countries have unique needs and opportunities. The health conditions typically associated with the developing world--diarrhea, malaria, pneumonia, and malnutrition--occur in settings with only rudimentary health care. This chapter highlights a number of surveillance issues relevant to developing countries, including resource constraints.

Although conducting surveillance in developing countries is complex, it also presents unique opportunities. Because the formal health-care system is often an integral part of organized government services, there are fewer impediments to implementing surveillance systems. The limited number of health-care providers and diagnostic laboratories reduces the number of data sources, which can facilitate quality assurance. Moreover, acute diseases and injuries still represent major causes of morbidity and mortality in many of these countries; these are conditions for which surveillance techniques are well-developed. Finally, communities often have well-defined health systems that can be used for surveillance purposes. These opportunities should be taken when feasible--despite such obstacles as rudimentary record-keeping systems and limited resources, numbers of diagnostic laboratories, demographic and vital information, and infrastructure.

Four issues relating to surveillance are covered in this chapter: a) planning, b) data

sources (e.g., vital statistics, surveys, and sentinel surveillance), c) surveillance at the local level, and d) development of integrated surveillance systems. In this chapter, the term "local" refers to the health station (which we assume to be the lowest level of the formal health system), where health assistants work. In addition, "population-based" is used to describe information for **all** persons in a certain geographic unit as opposed to facility-based information, which may represent only persons from the catchment area of a given health facility.

PLANNING

Identifying Health Objectives and Linkage to Surveillance

Identifying measurable health objectives, assigning them priority, and then linking surveillance to those objectives is a high-priority activity both for the surveillance system and for health-system development in general (*1-3*). Linking surveillance to these ordered health objectives alleviates the pitfall of thinking of surveillance as just the reporting of disease rather than as a system that uses information from multiple sources (such as sentinel sites, exit interviews, and regular surveys). Linking surveillance to objectives will help planners of the surveillance system to think creatively in efforts to build a surveillance system to measure all priority health objectives. Table XIII.1 lists data sources that could be used in building a surveillance system in a developing country.

Throughout the world, health objectives should be based on health impact, feasibility of intervention, and cost-effectiveness of the intervention. In developing countries, measurable health objectives often cannot be identified because high-quality, population-based mortality data are often missing. As a result, estimates of mortality and health outcome from such international organizations as United Nations International Children's Emergency Fund (UNICEF) and the World Health Organization (WHO), international conferences, and population laboratories (e.g., International Center for Diarrheal Disease Research, Bangladesh) are used. Although health problems are similar in most developing

countries (Table XIII.2), relying on data from other countries can create major problems, especially for conditions for which impact is not clearly known (e.g., hepatitis B, iodine deficiency, or malaria) or for emerging health problems (e.g., human immunodeficiency virus [HIV] infection, tobacco use, and motor-vehicle injuries).

The need for country-specific data is illustrated by the finding of World Bank analysts that oral-rehydration therapy (ORT) in low-mortality environments is much less cost-effective than passive case detection and short-course chemotherapy for tuberculosis, whereas ORT in high-mortality environments is very cost-effective (*1*). The cost-effectiveness varies by a factor of 2 to 10, depending on the local situation.

Health objectives should focus both on current health status and on anticipated health needs. It may be more cost-effective to address preventive strategies (e.g., early bottle feeding, cessation of tobacco use, use of seat belts, and sanitation) now rather than when the impact of adverse events becomes more apparent.

For each health objective, the surveillance method for evaluating that objective and its sub-objectives should be listed (Table XIII.3). Once such a list is made, a surveillance grid can be constructed to show which component of the surveillance system will measure which objective (Table XIII.4). Completing a surveillance grid helps one visualize the overall structure and function of the surveillance system.

The process of defining objectives, linking objectives to surveillance components, and constructing surveillance grids will highlight surveillance needs. The process provides a basis for strengthening existing components, for identifying existing information that could measure objectives, and for developing innovative new surveillance system components. For example, in many countries, the process of linking surveillance to objectives highlights the need for mortality data and the absence of vital statistics.

Often, the most important objectives--the reductions in mortality associated with diarrhea and measles--are measured in sentinel areas, since in many countries vital events are not registered for the entire country (Table XIII.4). Risk factors, health-related behavior, and health interventions--such as ORT and use of fluids at home, feeding during diarrhea, use of contraception, use of condoms, use of chloroquine, missed opportunities for vaccinations--can be measured nationally with regularly scheduled surveys. Risk factors and interventions can also be identified through exit interviews at the district, health-center, health-station, or village level.

Using a surveillance grid developed for a hypothetical country, one sees that surveillance for HIV is not as straightforward as for measles and diarrhea (Table XIII.4). The primary health-status outcome chosen by this country's ministry of health was not HIV-related mortality or acquired immunodeficiency syndrome (AIDS), but HIV seroprevalence in selected areas and selected populations. Therefore, sentinel vital-event registration areas will not be used to measure the HIV-related objectives. In addition, the objectives for HIV-related risk factors and health interventions are targeted at certain areas (areas in which HIV seroprevalence of patients with sexually transmitted diseases [STDs] is >10%). Since national surveys provide estimates only for the country as a whole, national surveys will not be the primary method for measuring progress of objectives related to risk HIV factors, behavior, and health interventions at a state or local level.

Examining the surveillance system as a whole is important for assigning resources. For diseases such as measles, diarrhea, pneumonia, and pertussis, surveillance traditionally includes measurement of mortality in vital registration and measurement of risk factors and health interventions nationally with surveys and locally with exit interviews (*4*). However, conditions such as HIV, malaria, malnutrition, tuberculosis (TB), vitamin A deficiency, and hepatitis B can be difficult to measure.

Use of a surveillance grid facilitates the integration of some aspects of

surveillance and may increase cost-efficiency. For example, a laboratory team may go to 12 sentinel sites in a year and test blood for HIV from pregnant women and patients with sexually transmitted diseases (STDs), blood for syphilis serology from 20- to 24-year-old pregnant women, sputum from 50 patients with cough for at least 1 month, and blood smears from 50 children with fever. Efficiency can be gained by constructing surveys--cluster surveys or exit interviews--that integrate questions about priority topics such as diarrhea, measles, HIV, tobacco use, and birth spacing.

Surveillance of Measures of "Outcome" Versus "Process"

Currently, at national and global levels, much emphasis is being placed on measurement of processes (e.g., coverage with vaccinations) versus the measurement of health outcomes (e.g., cases of measles) as the primary focus(*5*). Emphasis is placed on process measures, in part, because systems for efficient measurement of population-based health outcomes do not exist.

There are two major problems with process measures. First, process measures do not directly measure primary events of interest--death and disease--or the effectiveness of the processes (interventions). In contrast, the health outcome is the measure of interest, and what is measured is the effectiveness (i.e., the combined effect of the coverage and the efficacy of the intervention).

The usefulness of a process measure for surveillance depends on the true and consistent effectiveness of the intervention being measured. Focusing on the measurement of processes is most suitable when the intervention is documented to have consistent, high effectiveness. For example, measles vaccine administered to a 9-month-old infant is thought to be 90% effective in preventing subsequent measles (*6*). Therefore, if a child receives measles vaccine before being exposed to measles virus, the probability that s/he will have clinical measles is very low.

The difficulty with process measurements, however, exists even with an intervention as highly effective as measles vaccine (e.g., children infected with measles virus before vaccination are not protected by vaccine). The effectiveness of most interventions is often less than that of measles vaccine, and the effectiveness of the delivery of such interventions varies substantially from setting to setting. For example, on the basis of the industrialized-country experience, three doses of OPV were thought to have an effectiveness of at least 95% in all settings (*7,8*). Yet, recent evaluations of field vaccine efficacy, reviews of serologic efficacy, and outbreaks in countries with high coverage with OPV have shown that the effectiveness of OPV in developing countries is not as high as in industrialized countries, and that process measures of OPV coverage can lead to a false sense of security (*9-12*).

In programs in which an intervention has high and consistent effectiveness, the magnitude of the problem of using process measures also depends on the stage of development of a program. If an intervention is reliably 70%-90% effective, as are measles vaccine and OPV, one can be relatively confident that health outcomes will be positively affected if coverage increases from 20% to 80%. However, one cannot be at all confident of any change in health outcome if coverage increases from 80% to 90% or 95%. In fact, statistically significant changes in coverage from 80% to 90% or 90% to 95% cannot be detected by current methods of measurement.

A second major problem with process measures is measurement accuracy. Intervention activities are often measured by administrative methods and population-based surveys. An example of the administrative method of estimating the percentage coverage of an intervention is counting the number of vaccinations administered and then dividing by some denominator, such as the population in the catchment area <1 year of age.

The administrative method is relatively easy and cheap to perform and is available locally. On the other hand, both the numerator and the denominator are often unavailable. For example, to estimate the percentage of persons who have received

a complete series of OPV, one must know the number of third doses of OPV administered; this number is often not recorded.

To overcome the limitations of administrative data, population-based surveys are used to provide process measures (e.g., the percentage of persons who received ORT during the most recent episode of diarrhea and the percentage of reproductive-age women who use modern methods of family planning), especially at the national level. Yet, there are increased costs associated with surveys and numerous potential inaccuracies from current survey tools (see section on surveys below).

Using Outcome To Measure Process

In any international setting, surveillance for both outcomes and processes is desirable, but the focus of surveillance should be on outcome measures. Outcome-based programs have been extremely successful for global progress to eradicate smallpox, guinea worm, and poliomyelitis. The smallpox program, which started out as a process-based (coverage-driven) program, switched to an outcome-based program, which led to improved program effectiveness (*13*). An outcome-based program in the Americas has decreased the number of cases of poliomyelitis from nearly 3,000 in 1980 to a handful by 1990 (*14*). See Appendix XIII.A for a more detailed discussion.

POPULATION-BASED SURVEILLANCE

Population-based surveillance is especially important in many developing countries because of the disparities of access to health facilities and health status in urban centers versus rural areas. A single hospital in the capital city often consumes 25%-50% of the health budget for an entire country. Since surveillance from sentinel sites and health facilities is often concentrated in urban areas, public health needs in rural areas may not be well-represented by policy makers at

the national level unless population-based surveillance systems are used.

Vital-Event Registration

The measurement of vital events is the most important single addition that developing countries can make to their existing surveillance system (See Chapter III). Death and birth rates--along with cause-specific, age-specific, and gender-specific rates--are very useful. In the United States, for example, 13 of the 18 status indicators chosen to measure the health status of the population as part of the health objectives for the nation will be measured using vital records (*15*).

Why so little emphasis has been placed by developing countries on establishing vital-event registration is not clear. Registration could begin in small sentinel areas, could be evaluated for problems, and then could be expanded. The vital-registration system in the United States started in 1900 in 10 sentinel states, and it took 23 years for all states to be admitted into the system (*16*). Obviously, in the early stages of setting up a registry, some births and deaths would be missed. As late as 1974-1977, 21% of neonatal deaths were not registered in Georgia (*17*); despite this underregistration, vital data have been extremely useful.

In areas in which routine mortality data are not available, the verbal autopsy, in which trained or untrained workers take histories from family members to classify deaths by cause is a useful technique (*18*). In 1978, WHO published a monograph called *Lay Reporting of Health Information* (*19*). It contained a detailed list of approximately 150 causes of death and a minimal list of 30 causes that could be used by non-physicians to classify deaths by cause.

In establishing vital-event systems, consideration should be given to including the registration of pregnancy. This is especially needed to measure the number of neonatal deaths, which in turn is needed to allow accurate infant-mortality rates

to be calculated. Registration of pregnancies would allow measurement of prenatal care, fetal death associated with syphilis, family planning, and other important health concerns.

Regular, Periodic Surveys

Regular, periodic surveys can be an important component of a surveillance system. In particular, cluster surveys--multi-stage surveys with primary sampling units--are important surveillance tools in many developing countries because they are the only feasible method of collecting population-based information (*20*).

Cluster surveys have not been thought of as an essential and regularly performed surveillance activity. Surveys have generally been single-purpose and have been conducted intermittently on an as-needed basis, often at the request of international organizations. However, because the survey is the only method of gathering population-based information in many countries and surveys can be used to collect information on a variety of health topics, regularly scheduled surveys can constitute an excellent surveillance tool (see Behavioral Risk Factor Surveillance in Chapter III).

To assure the development of a useful national surveillance system in a developing country, a survey unit or survey person should be assigned the task of coordinating all national health surveys. The coordinator first works with program staff to develop surveillance questions in high-priority areas (e.g., diarrhea, vaccinations, HIV/AIDS, family planning, child survival, malaria, and tuberculosis). Two to five questions are often adequate for some conditions. The questions should be assigned priority so that the survey coordinator has some flexibility to shorten the overall questionnaire if needed.

Previously conducted surveys can serve as models for adaptation to local situations. For example, for vaccination-related questions, the Expanded Programme on Immunization (EPI) at WHO has a useful module. WHO also has useful

questionnaires for diarrhea; acute respiratory-tract infections; and knowledge, attitude, and behavior associated with HIV infection. The Centers for Disease Control (CDC) has questionnaires on child mortality, health-station practices, nutrition, HIV risk behavior among youths, and others.

Once questionnaire modules have been developed, each module should be field tested for readiness for implementation. Advance preparation and testing are very important; it is both difficult and time-consuming to develop an effective questionnaire.

A small set (10 or so) of core questions measuring the highest-priority objectives should be included in every survey. Some space should be reserved for last-minute questions on information desired by high-level policy makers. Not only will this demonstrate the timeliness of this surveillance component, but it might facilitate political and financial support for its continuation. Finally, when the time comes for a survey, the survey coordinator puts together the core questions, the last-minute questions from the policy makers, and the appropriate survey modules.

Data collection desired by international organizations can be integrated into the ministry of health's schedule of surveys. The survey coordinator can provide the international organization that wishes to have a survey conducted with the schedule and proposed modules to be used. The two groups can then collaborate to determine how the needs of both groups could be met. The international group can help train survey-unit staff and can help maintain a training manual on designing and conducting a survey, including interviewing techniques. This method is a cost-effective way to build local capacity and facilitate sustainability. See Appendix XIII.B for a discussion of some statistical issues in cluster surveys.

Sentinel Surveillance

Sentinel surveillance at health facilities can play a critical role in

surveillance in developing countries. Sentinel sites are used to a) collect important information not collected at all sites and b) pilot collection of new information in order to be able to assess the usefulness of the data and the method of collection. Since routinely reported information from all sites must be restricted to high-priority items and must be easy to collect, much important information is unlikely to be collected from all health facilities.

At sentinel sites, more resources and more experienced and dedicated personnel can often be used to collect information on more diseases, more detailed information about each case, and more difficult-to-collect information such as sexual behavior. Also, sentinel sites can often serve as sources of information about new conditions and can be used to determine the most effective methods for inserting newly required data into the routine collection system.

There are several potential problems in interpreting data from sentinel sites. Sentinel sites are often hospitals or other sophisticated facilities and tend to serve urban patients. Such data will not reflect rural, small, non-urban health stations where the majority of the population may live. Consequently, rural and small health stations should be in the sentinel-site system.

Nevertheless, for several reasons, hospitals as sentinel sites and hospitals in urban areas can yield important information in a timely manner at a relatively low cost: first, cause-of-death data are available, permitting timely data collection and analysis; second, because the number of visits and deaths is large, they yield more precise estimates and allowing subgroup analysis by age, gender, or other important variables. Also, data are currently available, whereas systems of vital events and regular, periodic surveys are not generally established. For example, in Kinshasa, Zaire, the Ministry of Health used a hospital-based sentinel surveillance system to establish that measles remained an important cause of death for children <9 months old. The spread of clinically important resistance to chloroquine was detected because of increasing mortality from malaria in sentinel hospitals in numerous African countries (*21*).

Surveillance at the Local Level

Integrated, well-thought-out surveillance at the health-station and health-center level warrants more focused attention; especially, data-collection, analysis, and dissemination of results as a basis for public health action. Surveillance responsibilities should be specified in employee work plans and completion of surveillance duties used to assess health-worker performance.

WHO has surveillance and evaluation training modules for vertical programs such as EPI and Control of Diarrheal Diseases (CDD) (*20,22,23*), but there are no general surveillance training modules for district or health-station levels. Local surveillance is critical because major health problems in developing countries require innovative public health action at the local level. Local surveillance and public health action based on surveillance may be less urgent for programs with high effectiveness and ease of administration, (e.g., vaccinations), or for programs that depend solely on the formal health-care system (e.g., acute respiratory infections or tuberculosis). However, local surveillance and linked public health action will be essential for most of the priority diseases (e.g., diarrhea, malaria, and HIV) and related prevention activities (oral-rehydration solutions, chloroquine for all cases of fever, and condoms). In general, these interventions require extensive behavior change on the part of clients and also require local problem-solving, surveillance of objectives, strategy reformulation, and creative intervention by health workers to be successful.

Collection, Display, and Analysis of Local Surveillance Data

Analysis of surveillance data and action based on that surveillance information at the local level have several benefits. If collected data are prominently displayed as tables and graphs in the local health office, public health personnel (and patients) can see the results of data-collection efforts. Through the analysis and interpretation of the displayed surveillance data, local staff can be

involved in the process of devising strategies to solve health problems and at the same time, can help attain national and local health objectives. Such involvement gives health staff a sense of participation and professionalism.

The process of designing a surveillance system for a district or a health-station is the same as for the national level. First, health priorities are determined on the basis of the impact of the health problem and the feasibility and cost-effectiveness of intervention. Second, objectives are determined and assigned priority. Third, surveillance components to measure high-priority objectives are identified and implemented.

Four differences between national and local surveillance sometimes emerge. First, many health stations will not have mortality surveillance based on vital-event registration, whereas national surveillance systems may include at least a sentinel-registration component. However, health stations can begin sentinel population-based mortality surveillance by starting vital-event registration in one or two villages.

Second, 30-cluster surveys conducted regularly every 1-3 years are not feasible for district and health-station surveillance of risk factors and health interventions.

Third, resource constraints at the local level limit the number of sentinel sites. However, both health stations and districts can conduct a form of sentinel surveillance by limiting data collection on some health problems to a small sample of sites at infrequent intervals. For example, although children have their growth monitored throughout the year, the percentage with weight-for-age of <80% of standard might be calculated only once every 3 months on a consecutive sample of 30 children.

Fourth, limited resources require integration of surveillance and non-surveillance health information by local health workers.

Data collected routinely by health stations should be limited to high priority conditions. For example, mandatory reporting could be limited to 10 selected diseases on the basis of established priorities or reporting laws. In addition, the health station should meet certain standards before reporting requirements are expanded: the health station staff should be a) reporting regularly, b) displaying information collected, c) thinking about the meaning of the data, d) using the data to solve health problems, and e) using the data to evaluate programs targeted at certain health problems. If these are all being done, the staff is likely to become enthusiastic about the public health aspect of the station's job and initiate the idea of collecting more information. For example, information for each case-patient (e.g., age and date of onset of disease) can be collected for selected health problems instead of just reporting the number of cases of disease (i.e., summary-count data). Additional diseases can be added on the basis of priority setting (e.g., AIDS or moderate and severe malnutrition). The practice of collecting data intermittently for special purposes can be expanded, and data items found to be useful at sentinel sites can be added to reportable conditions from all health stations or at least can be expanded to a larger number of sentinel sites.

Display and interpretation of surveillance data and planned action based on the interpretation can be integrated into assigned duties of health workers and into the duties of their supervisors. Each health worker should have a detailed task analysis or job description, with the task analysis linked to national and local health objectives.

Employee and project work plans, based on supervisory visits and on input from members of the community, should also reflect health objectives and ongoing analysis and interpretation of surveillance data. For example, if one of the high-priority health objectives is the reduction of measles cases by 50% as of 1995 (compared with the 1989-1991 baseline) and the graphs of measles cases by year and measles cases by month in 1993 show no decline, the work plan for the next 6 months might include conducting exit interviews, collecting additional information on cases, and convening focus groups.

Through focus groups, health workers can determine from groups of mothers why children are not being vaccinated and what might be done to solve this problem. Exit interviews can be used to determine measles coverage. Additional information about the ages of persons with measles can be recorded for the next 6 months, and then the health worker and supervisor can determine whether measles is a disease primarily among infants or among older persons as well. Using the vaccination status of persons with measles, health workers can estimate measles coverage. The effectiveness of a work plan should then be evaluated both through continued surveillance of measles cases and through exit interviews.

In addition, the 6-month work plan could include teaching mothers about appropriate preparation and use of oral-rehydration fluids at home. During a supervisory visit, the supervisor can do exit interviews of 30 consecutive women seen at the health station and record whether and what they have been taught about using fluids at home, possibly asking for demonstration of what they have been taught. At the same exit interviews, receipt of measles vaccine can be recorded as a measure of coverage. This will integrate surveillance for measles coverage with direct health-worker-performance assessment of a diarrhea-related task.

Exit Interviews and Focus Groups

Interviews of patients who have finished their visits at health facilities, which can be called "exit interviews," can be a flexible, easy, and cost-effective method of collecting information. Exit interviews are ideal for measuring progress toward local health objectives. They can be used to collect data for emergent problems or for routine surveillance, as well as to evaluate the performance of health workers. For surveillance purposes, exit interviews can be used to collect information about "process" health objectives, health risks, health behavior, and health interventions. Unlike surveys, exit interviews can be conducted frequently. Supervisory visits provide an excellent opportunity to involve the supervisor in the conduct of exit interviews.

Focus groups can make important contributions to the design of a surveillance system. As complex issues such as changes in behavior are assigned higher health priorities (e.g., HIV-related behavior, diet, home fluids, treatment practices, and reasons for not being vaccinated), focus groups are often used to gain new information.

Focus groups often provide an appropriate first step in generating ideas about why events and behavior occur. After ideas or hypotheses are available, surveys, exit interviews, and special studies (case-control studies) can be used to identify specific factors that should be incorporated into surveillance systems. Health-station staff can use focus groups, along with exit interviews, to measure health objectives of local importance.

BUILDING INTEGRATED SURVEILLANCE SYSTEMS

Over the last 15 years, the sophistication of public health in developing countries has increased greatly. EPI provided one model for surveillance. However, surveillance for measles was relatively easy--the intervention was consistently and highly effective, and almost all infections caused a distinct, noticeable condition. However, the EPI surveillance model was not as successful for problems such as diarrhea, pneumonia, family planning, and malaria, where the interventions were less effective or less consistently effective and where the outcome of interest was more difficult to measure.

Then, HIV appeared. Reporting of cases of AIDS was inadequate for immediate prevention because of the lengthy incubation period for this condition. Accurate surveillance for HIV had to rely on expensive laboratory testing.

Of the top 10 priority diseases in developing countries, only tuberculosis and malaria require any laboratory testing (at least sentinel testing) for surveillance, and the diagnostic tests for malaria and tuberculosis (though not

the tests for antimicrobial resistance) are relatively simple and inexpensive. In addition, the appearance of HIV put new emphasis on the need for surveillance of types of health behavior, the main prevention focus for HIV. Previously, surveillance had been considered to be adequate in developing countries if it covered disease reporting and vaccination coverage.

Now, surveillance data are expected to be available on risk factors and health behavior (e.g., age at marriage and age at first sexual intercourse for family-planning purposes), as well as on such newly important diseases as hepatitis B, genital ulcer disease, urethritis, use of tobacco, and injuries associated with motor vehicles.

As public health programs become more sophisticated and public health workers need access to more information on more and more conditions, the complexity of the structure of surveillance systems will increase. The integration of surveillance and evaluation for vertical programs such as EPI, diarrhea, acute respiratory infections, HIV/STD, and family planning into a coherent, rational surveillance system will depend on the actions taken by ministries of health.

There are several advantages to integration:

- surveillance information can be gathered with greater cost-efficacy,
- requirements for health-station staff will be simplified and their training will be less duplicative.

Although international organizations, often supporting vertical programs, control a substantial proportion of the resources being spent on public health in developing countries, these organizations are likely to respond favorably to the implementation of logical, well-crafted, integrated surveillance systems that are linked to written national health priorities.

Surveillance systems must continually focus on outcomes (cases of the health problem) in order to adjust strategies and interventions for control and prevention. Many countries are trying to reach low levels of vaccine-preventable

diseases by the year 1995 (measles and neonatal tetanus) or eradication by the year 2000 (poliomyelitis)(*24*). The poliomyelitis eradication initiative attempted to demonstrate that outcome-based surveillance intimately linked to intervention can be the "leading wedge" in disease reduction.

The sophistication of the tools available in developing countries to analyze surveillance data has also increased. Surveillance data have been analyzed with computers at the national level for the past several years. As the prices of computer hardware have continued to decrease, computers have been moved to zonal, state, and provincial levels. *Epi Info*, an inexpensive and freely copyable epidemiology computer program, is now available in English, French, Spanish, and Arabic (*25*); also, manuals are available in Czech and Italian. Mapping of surveillance data has been underutilized because inexpensive mapping programs that can display maps by district, health station, and village and can be linked to surveillance data bases have not been available. However, a mapping program called *Epi Map* is compatible with *Epi Info* and can create maps of surveillance data automatically.

SUMMARY

The vision for surveillance systems in developing countries as described above involves systems that are linked to health objectives, ordered by priority, limited in scope, and not burdensome at the health-station level. These systems should also contain an extensive sentinel network and have strong elements of population-based data gathering from surveys and vital event registration. Surveillance data need to be collected routinely. Sentinel sites will provide the information required to monitor health objectives, but such surveillance should also be flexible enough to collect new data needed for emerging problems, and for changing priorities.

Health objectives provide national politicians and health leaders a plan to ensure the public's health. With a surveillance system that is linked to these

objectives, leaders will be able to monitor progress made toward meeting national objectives. With analysis and action at the district and health-station level, local health staff can take rapid and appropriate action. Population-based vital statistics can show whether enough emphasis is being placed on health in rural and remote areas of a country. Health surveys can be conducted as a regular part of the surveillance system. Expertise and funding provided by international organizations can help train and maintain a survey coordinator and surveyors.

In implementing surveillance and health systems, developing counties can avoid the mistakes that industrialized countries have already made--poorly planned and fragmented surveillance systems, surveillance systems not linked to objectives, health objectives that are not explicit and often politicized, large divisions between curative and preventive medicine, and differences in health care in rural versus urban areas.

As noted at the beginning of this chapter, surveillance in developing countries is accompanied by numerous logistic problems but also presents unique opportunities. The careful setting of health priorities and the meticulous allocation of limited resources to the interests of the public's health can be the results of surveillance in such settings.

Appendix XIII.A. Using Outcome To Measure Process

This appendix describes a method to estimate process measures from outcome measures. Some process measures such as percentage coverage of an intervention (e.g., percentage using chloroquine, percentage having received vaccine, percentage using ORT) may be cost-effectively assessed by outcome data (e.g., number of cases of malaria, cases of measles, deaths from diarrhea). There is a relationship between the proportion of persons with a disease that has "received" an intervention, the effectiveness of the intervention, and the "coverage" of the intervention in the population. The relationship is as follows:

$$PCI = \frac{PPI-(PPI*Eff)}{1-(PPI*Eff)}$$

where PCI is the percentage of the cases of disease exposed to the intervention, where PPI is the percentage of the population exposed to the intervention, and where Eff is the efficacy of the intervention.

This formula is derived from the formula for program (vaccine) efficacy, where efficacy equals the attack rate among persons not exposed to the program or intervention minus the attack rate among persons exposed, divided by the attack rate among those unexposed (*26*), i.e., for vaccine efficacy, Eff = VE or vaccine efficacy; PCI = PCV or percentage of case-patients who are vaccinated; and PPI = PPV or percentage of the population vaccinated.

The graphic representation of this formula is known in immunization programs as the vaccine-efficacy curve (Figure XIII.A.1)(*26*). As an example, if the percentage of case-patients with disease that have been exposed to the intervention (PCI) is $\leq$20%, the coverage of the intervention in the population (PPI) is poor (i.e., the efficacy of the intervention is 90% or less). If the proportion of case-patients who have received the intervention is >50%, either the percentage coverage is high or the efficacy of the intervention is low. To estimate from surveillance the coverage of cases, one needs to determine whether

persons with the disease were or were not exposed to a particular intervention (e.g., whether case-patients used condoms, whether case-patients received appropriate home fluids, or whether case-patients received vaccine).

To use the formula or the curve, the exposure to the intervention must be dichotomized into a "yes/no" format. For example, for poliomyelitis, exposure is categorized into "fully vaccinated" with >3 doses of vaccine and "not fully vaccinated" with <3 doses of vaccine. This method has several advantages. It allows estimates of coverage at the health-station level, which allows local action to solve local health problems. It is much simpler and cheaper than conducting surveys, it provides information about effectiveness as well as coverage, and it is more difficult to falsify than coverage-survey and administrative method estimates. However, this method provides only a crude estimate and should be used with other sources of data. For example, if the survey or administrative estimate of OPV3 coverage is 95%, and only 20% of confirmed poliomyelitis case-patients received 3 doses of OPV, then the survey or administrative estimates should be questioned.

Appendix XIII.B. 30-Cluster EPI Survey Design

In the absence of an internationally funded survey to attach modules or questions desired by a ministry of health, a 30-cluster EPI survey can be performed (*20*). The EPI survey was designed to provide a crude estimate of vaccination coverage (±10%) (*27*); it provided information about whether vaccination coverage was low (20%-40%) or relatively high (70%-90%). Other programs have adapted the design for other purposes (e.g., mortality from neonatal tetanus, mortality and practices associated with diarrhea, and changes in vaccination coverage over time) (*22,23*).

However, results have often been misleading because appropriate confidence intervals were not calculated. Many health professionals did not realize that the confidence interval for each survey was not fixed at ±10% but varied depending on the results (inter-cluster correlation and the point estimate) of each survey. Often confidence intervals were not calculated and appropriate analyses of subgroups (males, females) were not done because easy-to-use computer programs were not available. Fortunately, such computer programs as (COSAS; Lotus spreadsheet for diarrhea cluster surveys; and CLUSTER, which runs within *Epi Info*) are now available to calculate appropriate confidence intervals. However, if an analysis by age, by gender, or some other specific characteristic is desired, a more complicated program (e.g., SUDAAN or CARP) still must be used to obtain **valid point estimates** and valid confidence intervals (*28*). For example, one cannot get a valid estimate of coverage for males and females in a typical EPI coverage survey without the use of SUDAAN.

As the use of the cluster survey becomes more sophisticated and as greater accuracy and precision is desired, use of the EPI cluster-survey design is complicated by the potential for bias in both selection of the first house and subsequent selection of additional houses (*29*). Despite being designed and analyzed as a survey with equal probability of selection, selection of the starting house from a randomly selected direction yields a higher probability of

selection for houses near the middle of the cluster. If occupants near the middle of the cluster have some characteristic associated with the outcome (e.g., have higher incomes), a biased estimate will result.

An alternative method of selecting the first and additional houses in a cluster is by segmenting and subsegmenting the cluster until a small number of houses can be mapped (e.g., 30 houses). Then, the first and additional houses can be chosen at random. If one assumes that the number of target-group persons per household is similar in all clusters, valid point estimates and approximate confidence intervals can be calculated using less-complicated programs (CLUSTER and COSAS). The use of subsegmenting in the absence of being able to select the first house randomly has also been described.

An easy-to-use program that appropriately analyzes cluster surveys (including appropriate analysis of subgroups and comparison of two independent surveys done at two different times) operating within *Epi Info* is being prepared.

REFERENCES

1. Jamison DT, Mosley WH. Disease control priorities in developing countries: health policy responses to epidemiological change. *Am J Public Health* 1991;81:15-22.

2. Jamison DT, Mosley WH (eds.). Disease control priorities in developing countries. Oxford and New York: Oxford University Press. In press.

3. Walsh JA, Warren KS. Selective primary health care: an interim strategy for disease control in developing countries. *N Engl J Med* 1979;301:967-74.

4. Frerichs RR. Epidemiologic surveillance in developing countries. *Ann Rev Pub Health* 1991;12:80-257.

5. Lemeshow S, Robinson D. Surveys to measure programme coverage and impact: a review of the methodology used by the Expanded Programme on Immunization. *World Health Stat Q* 1985;38:65-75.

6. Markowitz LE, Sepulveda J, Diaz-Ortega JL *et al.* Immunization of 6-month-old infants with different doses of Edmonton-Zagreb and Schwarz measles vaccines. *N Engl J Med* 1990;322:580-7.

7. Hardy GE, Hopkins CC, Linnemann CC *et al.* Trivalent oral polio vaccine: a comparison of two infant immunization schedules. *Pediatrics* 1970;45:444-8.

8. McBean AM, Thoms ML, Albrecht P *et al.* Serologic response to oral polio vaccine and enhanced-potency inactivated poliovaccines. *Am J Epidemiol* 1988;128:615-28.

9. Deming MS, Jaiteh KO, Otten MW *et al.* Epidemic poliomyelitis in The Gambia following the control of poliomyelitis as an endemic disease. II. Clinical efficacy of trivalent oral polio vaccine. *Am J Epidemiol* 1992;135:393-408.

10. Patriarca PA, Wright PF, John JT. Factors affecting the immunogenicity of oral poliovirus vaccine in developing countries: review. *Review of Infectious Diseases* 1991;13:926-39.

11. Sutter RW, Patriarca PA, Brogan S *et al.* Outbreak of paralytic poliomyelitis in Oman: evidence for widespread transmission among fully vaccinated children. *Lancet* 1991;338:715-20.

12. Otten MW, Deming MD, Jaiteh KO *et al.* Epidemic poliomyelitis in The Gambia following the control of poliomyelitis as an endemic disease. I. Descriptive findings. *Am J Epidemiol* 1992;135:381-92.

13. Fenner F, Henderson DA, Arita I *et al.* Smallpox and its eradication. Geneva, Switzerland: World Health Organization, 1988:475-6.

14. Pan American Health Organization. Health Information System for EPI. Washington, D.C.: Pan American Health Organization, 1992.

15. Centers for Disease Control. National Center for Health Statistics. Health status indicators for the year 2000. *Statistical Notes* 1991;1:1-4.

16. U.S. Bureau of the Census. Historical statistics of the United States, Colonial times to 1970, Bicentennial edition, Part 1. Washington, D.C.:

Government Printing Office, 1975.

17. McCarthy BJ, Terry J, Rochat R, Quave S, Tyler CW. The underregistration of neonatal deaths: Georgia 1974-1977. *Am J Public Health* 1980:977-82.

18. Kielmann AA, Taylor CE, DeSweemer C *et al.* Child and maternal health services in rural India: the Narangwal experiment. Baltimore: Johns Hopkins University Press, 1983.

19. World Health Organization. Lay reporting of health information. Geneva, Switzerland: World Health Organization, 1978.

20. Expanded Programme on Immunization. The EPI coverage survey. Training for mid-level managers. Geneva, Switzerland: World Health Organization, 1988.

21. U.S. Agency for International Development, Centers for Disease Control. African child survival initiative, 1989-90. Bilingual annual report. Washington, D. C.: Government Printing Office, 1990.

22. Galazka A, Stroh G. Guidelines on the community-based survey of neonatal tetanus mortality. Geneva, Switzerland: World Health Organization, WHO/EPI/GEN/86/8, 1986.

23. Programme for Control of Diarrhoeal Diseases. Household survey manual: diarrhea case management, morbidity, and mortality. Geneva, Switzerland: World Health Organization, CDD/SER/86.2/Rev.1, 1989.

24. World Health Organization. Global Advisory Group. Part II. Expanded Programme on Immunization. *Weekly Epidemiological Record* 1992;67:17-19.

25. Dean AG, Dean JA, Burton AH *et al.* **EPI INFO.** Version 5.A. Word-processing, data-base, and statistics program for epidemiology on microcomputers. Atlanta, Ga.: Centers for Disease Control, 1990.

26. Orenstein WA, Bernier RH, Dondero TJ *et al.* Field evaluation of vaccine efficacy. *Bull World Health Organization* 1985;63:1055-68.

27. Henderson RH, Sundaresan T. Cluster sampling to assess immunization coverage: a review of experience with simplified sampling methods. *Bull World Health Organization* 1982;60:253-60.

28. Shah B, Barnwell BG, Hunt P *et al.* SUDAAN user's manual. Release 5.50. Raleigh, N.C.: Research Triangle Institute, 1989.

29. Lemeshow S, Stroh G. Sampling techniques for evaluating health parameters in developing countries. Washington, D.C.: National Academy Press, 1988.

Reference Material for Principles and Practice of Public Health Surveillance

TABLES

FIGURES

Table I.1. The uses of surveillance (*23*)

- Quantitative estimates of the magnitude of a health problem.
- Portrayal of the natural history of disease.
- Detection of epidemics.
- Documentation of the distribution and spread of a health event.
- Facilitating epidemiologic and laboratory research.
- Testing of hypotheses.
- Evaluation of control and prevention measures.
- Monitoring of changes in infectious agents.
- Monitoring of isolation activities.
- Detection of changes in health practice.
- and planning

TABLE II.1. Steps in planning a surveillance system

1. Establish objectives.
2. Develop case definitions.
3. Determine data source or data-collection mechanism (type of system)
4. Develop data-collection instruments.
5. Field test methods.
6. Develop and test analytic approach.
7. Develop dissemination mechanism.
8. Assure use of analysis and interpretation.

TABLE II.2. Criteria for identifying high-priority health events for surveillance

- Frequency:
  - Incidence
  - Prevalence
  - Mortality
  - Years of potential life lost
- Severity:
  - Case-fatality ratio
  - Hospitalization rate
  - Disability
- Cost
  - Direct and indirect costs
- Preventability
- Communicability
- Public interest

TABLE IV.1. Essential questions for the practice of effective disease/injury reporting

Initiation/sources of reports

* How and by whom are health-care practitioners (existing and newly practicing) entered into the reporting network?

* By what agency are conditions reported for such temporary residents as college students, military personnel, and migrant workers?

Routing/timing of reports

* How should "suspected case, laboratory results pending" be handled?

* Should the local or the state health department update a case report when additional information is received?

* Should case reports arise from the health jurisdiction in which the patient resides? In which the patient became infected (injured)? In which the patient became ill (and/or received treatment)?

* Should a diagnostic laboratory send data on reportable conditions to the requester, or should it be responsible for reporting to appropriate local/state health departments? (If "yes" to the latter, in what order?)

* If a case occurs one calendar year, but is not reported until early in the next calendar year, what is the year of report? What is the cut-off date for reports from the previous year? How are reports treated that are for the previous year but are received after the established deadline?

* Is there a mechanism for reporting disease/injury across state lines, as appropriate?

Policy issues in reporting disease/injury

* What items on the reporting form **must** be completed before a report can be forwarded?

* If a reportable condition has a specific case definition (such as measles and AIDS), should the case be reported before confirmation by a disease investigator? (3)

* What mechanism will be (has been) established to deal with situations in which cases must be reported in batches rather than individually because the number of reports is overwhelmingly large?

* If case reports are held pending laboratory confirmation, should the "date of report" reflect the **original date** of report or the date laboratory confirmation **was received** or some other date associated with this health event?

* Are reports generated to identify records with incomplete/unconfirmed data so that follow-up can be initiated?

* How does one avoid duplicate reports of the same case?

* How are discrepancies in the information on duplicate reports resolved?

TABLE IV.2. Concerns of the data-base manager

1. Who will enter the data? What credentials must this person have? Who is this person's back-up? Who will update records? Back-up the computer file?

2. Will data be entered on an as-received basis or according to an established schedule?

3. Does the data-entry screen replicate the paper form from which data are to be entered?

4. Does the data-entry program allow for certain data items to be entered automatically on subsequent screens until the data recorder makes a change? (For example, the county initially entered will appear on each subsequent screen until the recorder types in a different county. This allows the recorder to batch records for more efficient entry).

5. Does the data-entry program effectively validate the data being entered for completeness by use of "must-enter" fields and "look-up" files?

6. Does the data-entry program have the ability to do range checking on values entered? If so, does the system allow for acceptable ranges to change, reflecting values entered in the data base over a time? Is there a logic audit procedure in the system---to locate such errors as misspelled names or addresses, incorrectly coded race, gender, or code for disease/injury?

7. At what level (state or local) will records be changed or deleted? Who owns the data records?

8. If the data base is distributed to other users as an electronic file or on floppy diskette, are there safeguards to prevent overwriting another user's data? Safeguards against computer viruses?

9. Are the data-entry programs flexible enough to allow variables to be modified as prescribed by changes in state regulations and national recommendations?

10. Are production reports automatically generated for quality assurance of data entry?

11. How and with what frequency are data copied and stored for back-up purposes? Are paper/film copies maintained (in the event of computer failure)?

12. Are double-entry systems used for quality assurance?

TABLE V.1. Rates and quantities involving rates commonly used in epidemiology

Measure	Numerator	Denominator	Expressed per number at risk
Measures of morbidity:			
Incidence rate	Number of new cases of specified condition/given time	Population at start of time interval	variable: 10^x where x = 2,3,4,5,6
Attack rate	Number of new cases of specified condition/epidemic period	Population at start of epidemic period	variable: 10^x where x = 2,3,4,5,6
Secondary attack rate	Number of new cases of specified condition among contacts of known patients	Size of contact population at risk	variable: 10^x where x = 2,3,4,5,6
Point prevalence	Number of current cases of specified condition at given time	Estimated population at same point in time	variable: 10^x where x = 2,3,4,5,6
Period prevalence	Number of old cases plus new cases of specified condition identified in given time interval	Estimated mid-interval population	variable: 10^x where x = 2,3,4,5,6
Measures of mortality:			
Crude death rate	Total number of deaths reported in given time interval	Estimated mid-interval population	1,000 or 100,000
Cause-specific death rate	Number of deaths from specific cause in given time interval	Estimated mid-interval population	100,000
Proportionate mortality	Number of deaths from specific cause in given time interval	Total number of deaths from all causes in same interval	100 or 1,000

Measure	Numerator	Denominator	Expressed per number at risk
Measures of mortality: (continued)			
Death-to-case ratio (Case-fatality rate, case-fatality ratio)	Number of deaths from specific condition in given time interval	Number of new cases of that condition in same time interval	100
Neonatal mortality rate	Number of deaths (<28 days of age) in given time interval	Number of live births in same time interval	1,000
Infant mortality rate	Number of deaths (<1 year of age) in given time interval	Number of live births reported in same time interval	1,000
Maternal mortality rate	Number of deaths from pregnancy related causes in given time interval	Number of live births in same time interval	100,000
Measures of natality:			
Crude birth rate	Number of live births reported in given time interval	Estimated total mid-interval population	1,000
Crude fertility rate	Number of live births reported in given time interval	Estimated number of women ages 15-44 years at mid-interval	1,000
Crude rate of natural increase	Number of live births minus number of deaths in given time interval	Estimated total mid-interval population	1,000
Low birth weight ratio	Number of live births (<2,500 grams) in given time interval	Number of live births reported in same time interval	100

TABLE V.2. Crude death rates--Dade and Pinellas counties, Florida, 1980

	Population	Deaths	Crude death rate (per 1,000 population)
Dade County	1,706,097	16,859	9.9
Pinellas County	732,685	11,531	15.7

Sources: Bureau of the Census, 1983.
National Center for Health Statistics, Centers for Disease Control.

TABLE V.3. Age-specific death rates--Dade and Pinellas counties, Florida, 1980

Age group (years)	Dade County			Pinellas County		
	Population	Deaths	Rate (per 1,000 pop.)	Population	Deaths	Rate (per 1,000 pop.)
0-4	97,870	383	3.9	31,005	101	3.3
5-14	221,452	75	0.3	77,991	20	0.3
15-24	284,956	440	1.5	95,456	80	0.8
25-34	265,885	529	2.0	90,435	129	1.4
35-44	207,564	538	2.6	65,519	168	2.6
45-54	193,505	1,107	5.7	69,572	460	6.6
55-64	175,579	2,164	12.3	98,132	1,198	12.2
65-74	152,172	3,789	24.9	114,686	2,746	23.9
>75	107,114	7,834*	73.1	89,889	6,629*	73.7
Total	1,706,097	16,859	9.9	732,685	11,531	15.7

Sources: Bureau of the Census, 1983.
National Center for Health Statistics, Centers for Disease Control.

*Deaths >75 include six persons of unknown age for Dade and one of unknown age for Pinellas counties.

TABLE V.4. Directly standardized death rates--Dade and Pinellas counties, Florida, 1980*

Age group (years)	(A) 1980 U.S. population (percentage distribution)	(B) Age-specific death rates (per 1,000 pop.)		(C) Expected deaths in 1980 U.S. population using county age-specific rates†	
		Dade County	Pinellas County	Dade County	Pinellas County
0-4	7.2	3.9	3.3	28	24
5-14	15.3	0.3	0.3	5	5
15-24	18.7	1.5	0.8	28	15
25-34	16.5	2.0	1.4	33	23
35-44	11.4	2.6	2.6	30	30
45-54	10.0	5.7	6.6	57	66
55-64	9.6	12.3	12.2	118	117
65-74	6.9	24.9	23.9	172	165
>75	4.4	73.1	73.7	322	324
Totals	100.0	9.9	15.7	793	769
Directly adjusted death rates (per 1,000 pop.)§				7.9	7.7

*United States population, 1980, used as standard.

†$C_{ij} = A_i x B_{ij}$ where i=1,...,9 age groups and j=1,2 counties.

§$\sum_i C_{ij} /100$.

TABLE V.5. Indirectly standardized death rates–Dade and Pinellas counties, Florida, 1980*

Age group (years)	(A) Death rates (per 1,000 pop.) U.S. 1980	(B) 1980 population		(C) Expected number of deaths in county based on U.S.-specific rates†	
		Dade	Pinellas	Dade	Pinellas
0-4	3.3	97,870	31,005	323	102
5-14	0.3	221,452	77,991	66	23
15-24	1.2	284,956	95,456	342	115
25-34	1.3	265,885	90,435	346	118
35-44	2.3	207,564	65,519	477	151
45-54	5.9	193,505	69,572	1,142	410
55-64	13.4	175,579	98,132	2,353	1,315
65-74	29.8	152,172	114,686	4,535	3,418
>75	87.2§	107,114	89,889	9,340	7,838
Totals	8.8	1,706,097	732,685	18,924	13,490
Expected death rates (per 1,000 pop.)¶				11.1	18.4
Adjusting factors**				0.79	0.48
Crude death rates (per 1,000 pop.)				9.9	15.7
Indirectly adjusted death rates (per 1,000 pop.)††				7.8	7.5

*United States age specific death rates, 1980, used as standard.

†$C_{ij} = A_i x B_{ij}$ where i=1,...,9 age groups and j=1,2 counties.

§Deaths >75 include 568 of unknown age for United States.

¶$\sum_i C_{ij} / \sum_i B_{ij}$ for j=1,2.

**U.S. total death rate/expected death rate.

††Crude death rate x adjusting factor.

TABLE V.6. Five-number summary of 39 4-week totals of reported cases of meningococcal infections--United States, 1987-1989

Median	190	
Hinges	151	237
Extremes	102	350

TABLE V.7. Common power transformations ($y \rightarrow y^p$)

p	Transformation	Name	Notes
•			
•			Higher powers
•			
2	y^2	Square	
1	y	Raw	No transformation
½	$\sqrt{y}$	Square root	Appropriate for count data
0	log(y)	Logarithm	Generally logarithm to base 10; widely used
-½	$-1/\sqrt{y}$	Reciprocal root	Minus sign preserves order
-1	-1/y	Reciprocal	
-2	$-1/y^2$	Reciprocal square	
•			
•			Lower powers
•			

TABLE V.8. Guide for selecting data graphics

Type of graph or chart	When to use
Arithmetic-scale line graph	Trends in numbers or rates over time
Semilogarithmic-scale line graph	1. Emphasize rate of change over time 2. Display values ranging >2 orders of magnitude
Histogram	1. Frequency distribution of continuous variable 2. Number of cases during epidemic (i.e., epidemic curve) or over time
Frequency polygon	Frequency distribution of continuous variable, especially to show components
Cumulative frequency	Cumulative frequency
Scatter diagram	Plot association between two variables
Simple bar chart	Compare size or frequency of different categories of single variable
Grouped bar chart	Compare size or frequency of different categories of 2-4 series of data
Stacked bar chart	Compare totals and illustrate component parts of the total among different groups
Deviation bar chart	Illustrate differences, both positive and negative, from baseline
Pie chart	Show components of a whole
Spot map	Show location of cases or events
Chloropleth map	Display events or rates geographically
Box plot	Visualize statistical characteristics (e.g., median, range, skewness) of variable

TABLE V.9. Primary and secondary morbidity from syphilis, by age category--United States, 1989

Age group (years)	Cases	
	Number	Percentage*
≤14	230	0.5
15-19	4,378	10.0
20-24	10,405	23.6
25-29	9,610	21.8
30-34	8,648	19.6
35-44	6,901	15.7
45-54	2,631	6.0
>55	1,278	2.9
Total	44,081	100.0

*Percentages do not add to 100.0 due to rounding.

TABLE V.10. Primary and secondary morbidity from syphilis, by age category, race, and gender--United States, 1989

Age (years)	White			Black			Other			Total		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
<15	2	14	16	31	165	196	7	11	18	40	190	230
15-19	88	253	341	1,412	2,257	3,669	210	158	368	1,710	2,668	4,378
20-24	407	475	883	4,059	4,503	8,562	654	307	961	5,120	5,285	10,405
25-29	550	433	983	4,121	3,590	7,711	633	283	916	5,304	4,306	9,610
30-34	564	316	880	4,453	2,628	7,081	520	167	687	5,537	3,111	8,648
35-44	654	243	897	3,858	1,505	5,363	492	149	641	5,004	1,897	6,901
45-54	323	55	378	1,619	392	2,011	202	40	242	2,144	487	2,631
>55	216	24	240	823	92	915	108	15	123	1,147	131	1,278
Total	2,804	1,813	4,617	20,376	15,132	35,508	2,826	1,130	3,956	26,006	18,075	44,081

TABLE VII.1. Controlling and directing information dissemination

Steps	Questions to be Answered
Establish communications message	What should be said?
Define audience	To whom should it be said?
Select the channel	Through what communication medium?
Market the message	How should the message be stated?
Evaluate the impact	What effect did the message create?

TABLE VIII.1. Sample case definition developed by the Centers for Disease Control and the U.S. Council of State and Territorial Epidemiologists

Measles

Clinical case definition

An illness characterized by all of the following clinical features:

- A generalized rash lasting ≥3 days
- A temperature ≥38.3 C (101 F)
- Cough or coryza or conjunctivitis

Laborstory criteria for diagnosis

- Isolation of measles virus from a clinical specimen

  or
- Significant rise in measles antibody level by any standard serologic assay

  or
- Positive serologic test for IgM antibody (to measles)

Case classification

Suspected: any rash illness with fever.

Probable: meets the clinical case definition, has no or noncontributory serologic or virologic testing, and is not epidemiologically linked to a probable or confirmed case.

Confirmed: a case that is laboratory confirmed or that meets the clinical case definition and is epidemiologically linked to a confirmed or probable case. A laboratory-confirmed case does not need to meet the clinical case definition.

Comment

Two probable cases that are epidemiologically linked would be considered confirmed, even in the absence of laboratory confirmation.

TABLE VIII.2. The detection of health conditions with a surveillance system.*

		'Condition' present		
		Yes	No	
Detected by surveillance	Yes	True positive A	False positive B	A+B
	No	False negative C	True negative D	C+D
		A+C	B+D	TOTAL

*Sensitivity = A/(A+C).

TABLE VIII.3. Comparison of estimated costs for active and passive surveillance systems in a health department, Vermont, June 1, 1980, to May 31, 1981

	Type of surveillance system	
	Active*	Passive†
Paper	$ 114	$ 80
Mailing	185	48
Telephone	1,947	175
Personnel		
Secretary	3,000	2,000
Public health nurses	14,025	0
TOTAL	$19,271	$2,203

*Active = Weekly calls from health department to request reports.
†Passive = Provider-initiated reporting.

TABLE VIII.4. Outline of sample surveillance evaluation report

1. **Public Health Importance**
   Describe the public health importance of the health event. The three most important categories to consider are the following:
   - Total number of cases, incidence, and prevalence.
   - Indices of severity such as the mortality rate and case-fatality ratio.
   - Preventability.

2. Objectives and Usefulness
   Explicitly state the objectives of the system and the health event(s) being monitored (case definitions). Describe the actions that have been taken as a result of the data from the surveillance system. Describe who has used the data to make decisions and take actions. List other anticipated uses of the data.

3. **System Operation**
   Describe the following: the population under surveillance, the period of time of the data collection, the information that is collected, who provides the information, how the information transferred and how often, how the data are analyzed (by whom and how often), how often reports are disseminated, and how reports are distributed (to whom and in what media). Include an assessment of the simplicity, flexibility, and acceptability of the system.

4. **Quantitative Attributes:** Include assessments of the sensitivity, predictive value positive, representativeness, and timeliness of the system.

5. **Cost of Operating the Surveillance System.** Estimate direct costs and, if possible, assess cost-benefit issues.

6. **Conclusions and Recommendations**
   These should state whether the system is meeting its objectives and should address issue of whether to continue and/or modify the surveillance system.

TABLE IX.1. Ethical responsibilities in surveillance--participants and duties

Responsibility of ↓ to →	Investigator	Subject	Subject's social environment	Public health community	Clinicians	Society at large
Investigator	X	Beneficence Cultural sensitivity Informed consent Privacy Confidentiality	Beneficence Warning on threats to health	Sharing findings Sharing data Critique, peer review	Sharing findings	Enhance, protect, restore public health Conduct priority research Careful research Report findings clearly, sensitively Advocacy
Study subject	Veracity	X				
Subject's Social Environment			X			
Public health community	Critique, peer review		Mandatory notifiable disease reporting Partner notification	X		Mandatory notifiable disease reporting
Clinicians	Confidentiality		Partner notification	Mandatory notifiable disease reporting	X	Mandatory notifiable disease reporting
Society at large	Support			Support		X

TABLE IX.2. An ethical checklist for public health surveillance

1. Justify the surveillance system in terms of maximizing potential public health benefits and minimizing public harm.
2. Justify use of identifiers and the maintenance of records with identifiers.
3. Have surveillance protocols and analytic research reviewed by colleagues, and share data and findings with colleagues and the public health community at large.
4. Elicit informed consent from potential surveillance subjects.
5. Assure the protection of confidentiality of subjects.
6. Inform health-care providers of conditions germane to their patients.
7. Inform the public, the public health community, and clinicians of findings of surveillance.

TABLE XII.1. Reasons cited by physicians for failure to report notifiable diseases (*42,45-47*)

1. Assumed that the case would be reported by someone else.
2. Unaware that disease reporting was required.
3. Do not have notifiable disease reporting form/telephone number.
4. Do not know how to report notifiable diseases.
5. Do not have copy of list of notifiable diseases.
6. Concerned about confidentiality.
7. Concerned about violation of doctor-patient relationship.
8. Reporting is too time-consuming.
9. Absence of incentives to report.

TABLE XII.2. What local and state health departments can do to improve reporting by physicians

Local health departments

- Express an interest in disease reporting to those responsible for reporting.
- Maximize contact with the local medical community.
  - Presentations
  - Mailings
  - Newsletters
  - Telephone contact
  - Mass media
- Use the data.

State health departments

- Express an interest in disease reporting to those responsible for reporting.
- Maintain a reasonable list of reportable conditions.
- Maximize contact with the state medical community.
  - Presentations
  - Mailings
  - Newsletters
  - Telephone contact
  - Mass media
- Use the data.

TABLE XII.3. Criteria used to set priorities for national disease surveillance, Canada (*60*)

1. Surveillance by the World Health Organization
2. Importance to agriculture in Canada
3. Disease incidence
4. Morbidity (hospital days and short-term disability)
5. Mortality.
6. Case-fatality ratio
7. Communicability
8. Potential for outbreaks
9. Socioeconomic impact
10. Public perception of risk
11. Vaccine preventability
12. Necessity for an immediate public health response

TABLE XII.4. Confidence intervals for rates (*61*).

Let r = rate per 1,000

n = denominator upon which rate is based

The limits of the 95-percent confidence interval are:

$$\text{upper limit: } r + 61.981\sqrt{r / n}$$

$$\text{lower limit: } r - 61.981\sqrt{r / n}$$

TABLE XII.5. Formula for calculating the 95% confidence interval for the ratio of two independent rates (*61*)

Let r_1 = rate for period 1 (or area 1)

d_1 = number of events for period 1 (or area 1)

r_2 = rate for period 2 (or area 2)

d_2 = number of events for period 2 (or area 2)

$R = r_1/r_2$

The limits of the 95% confidence interval are:

$$\text{upper limit: } R + 1.96R \sqrt{1/d_1 + 1/d_2}$$

$$\text{lower limit: } R - 1.96R \sqrt{1/d_1 + 1/d_2}$$

TABLE XII.6. Formula for calculating the 95% confidence interval for the difference between two independent rates

Let r_1 = rate for period 1 (or area 1)

n_1 = denominator upon which r_1 is based

r_2 = rate for period 2 (or area 2)

d_2 = denominator upon which r_2 is based

$D = r_1 - r_2$

The limits of the 95% confidence interval are:

$$\text{upper limit: } D + 61.981 \sqrt{r_1/n_1 + r_2/n_2}$$

$$\text{lower limit: } D - 61.981 \sqrt{r_1/n_1 + r_2/n_2}$$

Table XIII.1. Examples of data sources for surveillance in developing countries

I. Case reports
   a. from health stations or hospitals
   b. from sentinel sites

II. Births and deaths
   a. from hospitals
   b. from sentinel sites
   c. complete ascertainment

III. Laboratory reports (usually from hospitals)

IV. Sample surveys (particularly cluster surveys)

Table XIII.2. Health problems ranked according to preventability and treatability, Thailand, 1987

Rank	Disease	Total score (4-16)*	Prevent-ability (H-M-L)**	Disease	Total score (4-16)	Treat-ability (H-M-L)
1.	Tetanus	7	H	Malaria	12	H
2.	Poliomyelitis	7	H	Pneumonia	11	H
3.	Measles	7	H	Dengue (hemorrhagic)	10	H
4.	Diphtheria	6	H	Acute diarrhea	10	H
5.	Rabies	6	H	Tuberculosis	9	H
6.	Rubella	5	H	Veneral Disease	9	H
7.	Traffic injury	16	M	Dysentery	8	H
8.	Stroke	15	M	Conjunctivitis	7	H
9.	Malaria	12	M	Influenza	7	H
10.	Peptic Ulcer	11	M	Measles	7	H

Source: "Review of the Health Situation in Thailand: Priority Ranking of Diseases."

* Rated on a scale of 4 (low) to 16 (high)
**H=high, M=medium, L=low

Table XIII.3. Examples of objectives linked to surveillance components that will measure objectives

Surveillance-linked objectives

Objective	Surveillance component that measures objective
Priority area #1--Diarrhea	
• Health status--Reduce diarrhea mortality by 25% by 1995	• Vital-event registration in five sentinel areas
• Risk factor--Increase female literacy of 10- to 14-year-olds to 80% by 1995	• Regularly conducted survey
• Health activity--Increase to 90% the proportion of 0- to 4-year-olds given appropriate home fluids by 1995	• Regularly conducted health survey • Local--exit interviews
Priority area #2--Measles	
• Health status--Reduce measles mortality by 25% by 1995	• Vital-event registration in five sentinel areas
• Health status--Reduce number of reported measles cases by 50% by 1995 compared with 1990	• National disease-reporting system
• Health activity--Increase percentage of 12- to 23-month-olds with one dose of measles vaccine to 90% nationwide	• Regularly conducted health survey
• Health activity--Increase to 80% the percentage of districts with one-dose measle vaccination coverage of 12- to 23-month-olds of 90%	• Exit interviews of mothers of 50 12- to 23-month-olds at all health facilities in district twice a year

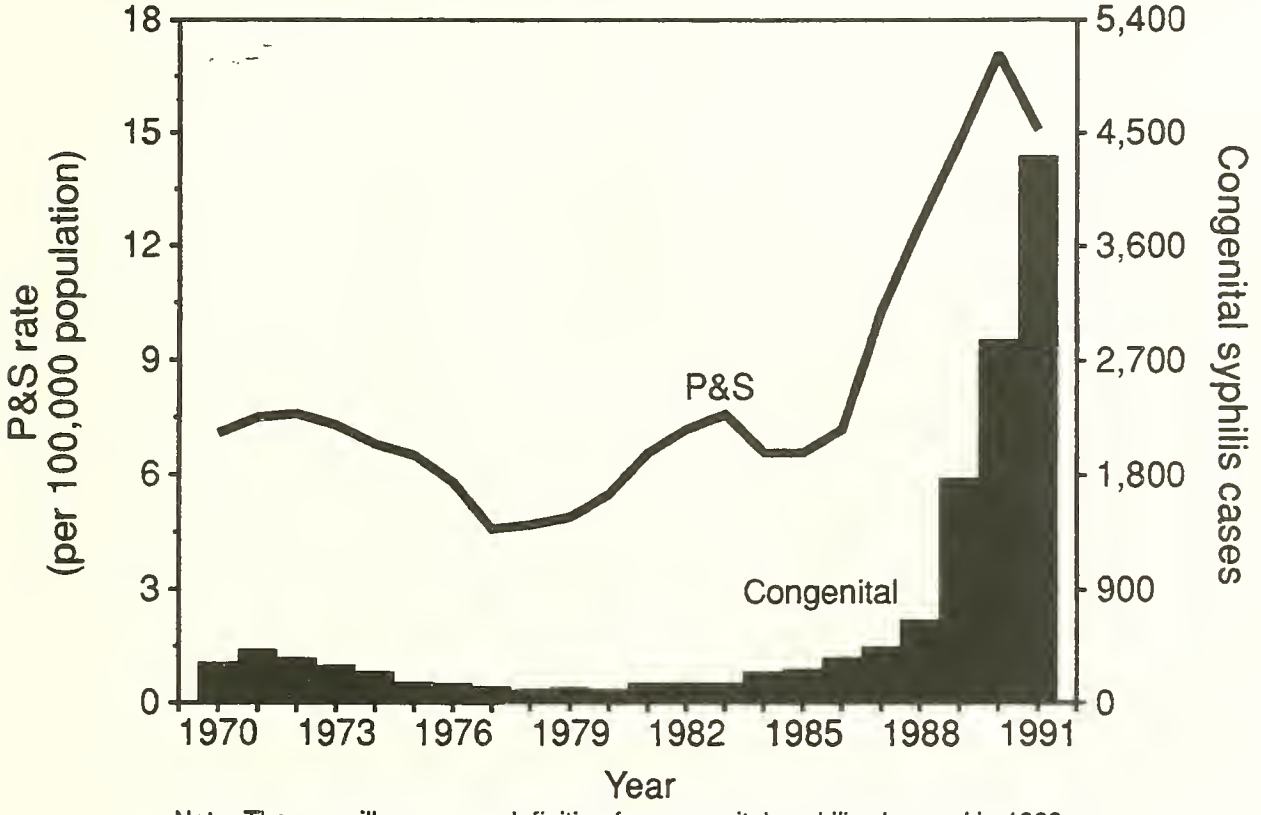
Priority area #5--HIV/AIDS	
• Health status--Stabilize at 10% the proportion of 20- to 25-year-old women who have babies at the capital city hospital and who are HIV-positive by 1993	• Sentinel HIV testing of 20- to 25-year old women who have babies in capital city
• Health status--No increase in the 2% HIV seroprevalence of rural women who have babies that are HIV-positive by 1993	• Sentinel HIV testing of women having babies in capital city
• Risk factor--Reduction of HIV-risk taking behavior by 50% in 1994 in areas with HIV seroprevalence of STD patients >10% (an indicator of entrance of HIV into community)	• Reporting of clinical chancroid through the national disease-reporting system • Laboratory--Syphilis serology testing of 20- to 25-year-old women having babies in affected areas • Exit interviews in affected areas • Nationwide only--Regularly-conducted health survey
• Health activity--Increase to 75% the percentage of sexual contacts whose partners are not spouses who also use condoms by 1995 in areas with HIV seroprevalence of STD patients >10%	• Exit interviews in affected areas • Nationwide only--Regularly-conducted health survey

Table XIII.4. Grid to identify which surveillance component will measure a health objective in a hypothetical developing country

Objectives	Not population-based							Population-based			Local surveillance
	Disease reporting	Deaths/births from health facilities	Laboratory			Sentinel sites	Exit interviews	Vital events		National surveys	Exit interviews
			HIV test	Syphilis test	Other test			Sentinel areas	Entire population		
Priority area #1--Diarrhea Reduce diarrhea mortality by 25% by 1995		2°						1°			
Increase female literacy of 10- to 14-year-olds to 80% by 1995										1°	x
Increase percentage of 0- to 4-year-olds given appropriate home fluids to 90% by 1995							2°			1°	x
Priority area #2--Measles Reduce measles mortality by 25% by 1995		2°						1°			
Reduce number of reported cases of measles by 50% by 1995 compared with 1990	1°										
Increase percentage of 12- to 23- month-olds with one dose of measles vaccine to 90% nationwide										1°	x
Increase to 80% the percentage of districts with one-dose measle vaccination coverage for 12- to 23-month-olds of 90%							1°				x
Priority area #5--HIV/AIDS Stabilize HIV seroprevalence of 20- to 25-year-olds who have babies in the capital city at 10% by 1993			1°			1°					
No increase in HIV seroprevalence of rural women who have babies by 1993 (compared with 1989-1990)						1°					
Reduce HIV-risk behavior by 50% by 1994 in areas with HIV seroprevalence of STD patients >10% • Reduce reported chancroid in designated areas by 50% by 1995	1°										
• Reduce RPR positivity of 20- to 25-year-olds who have babies in designated areas by 50% by 1995				1°							
Increase to 75% the percentage of condom use among sexual contacts with partners that are not spouses by 1995 in areas with HIV seroprevalence of STD patients >10%						1°	1°				x

"1°" indicates primary surveillance component measuring objective; "2°" means a secondary means of measuring.

FIGURE I.1. Reported cases of congenital syphilis among infants <1 year of age and rates of primary and secondary (P&S) syphilis among women---United States, 1970-1991



Note: The surveillance case definition for congenital syphilis changed in 1989.
Source: Centers for Disease Control.

FIGURE I.2. *Salmonella* rates in New Hampshire and contiguous states, by county

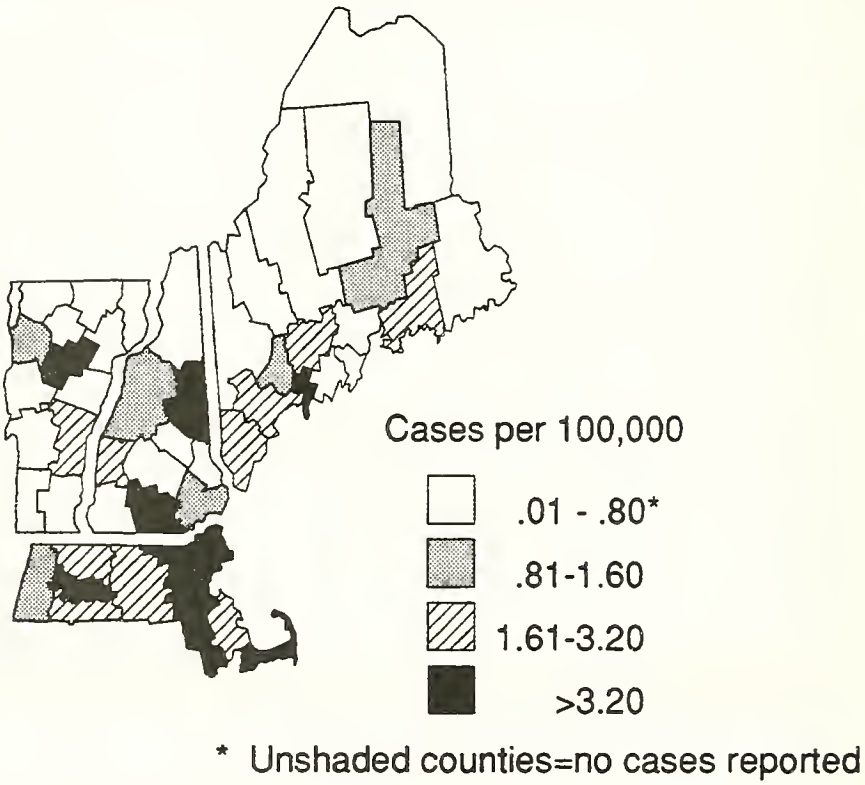


FIGURE I.3. Homicide rate, by age and gender of victim, United States, 1986

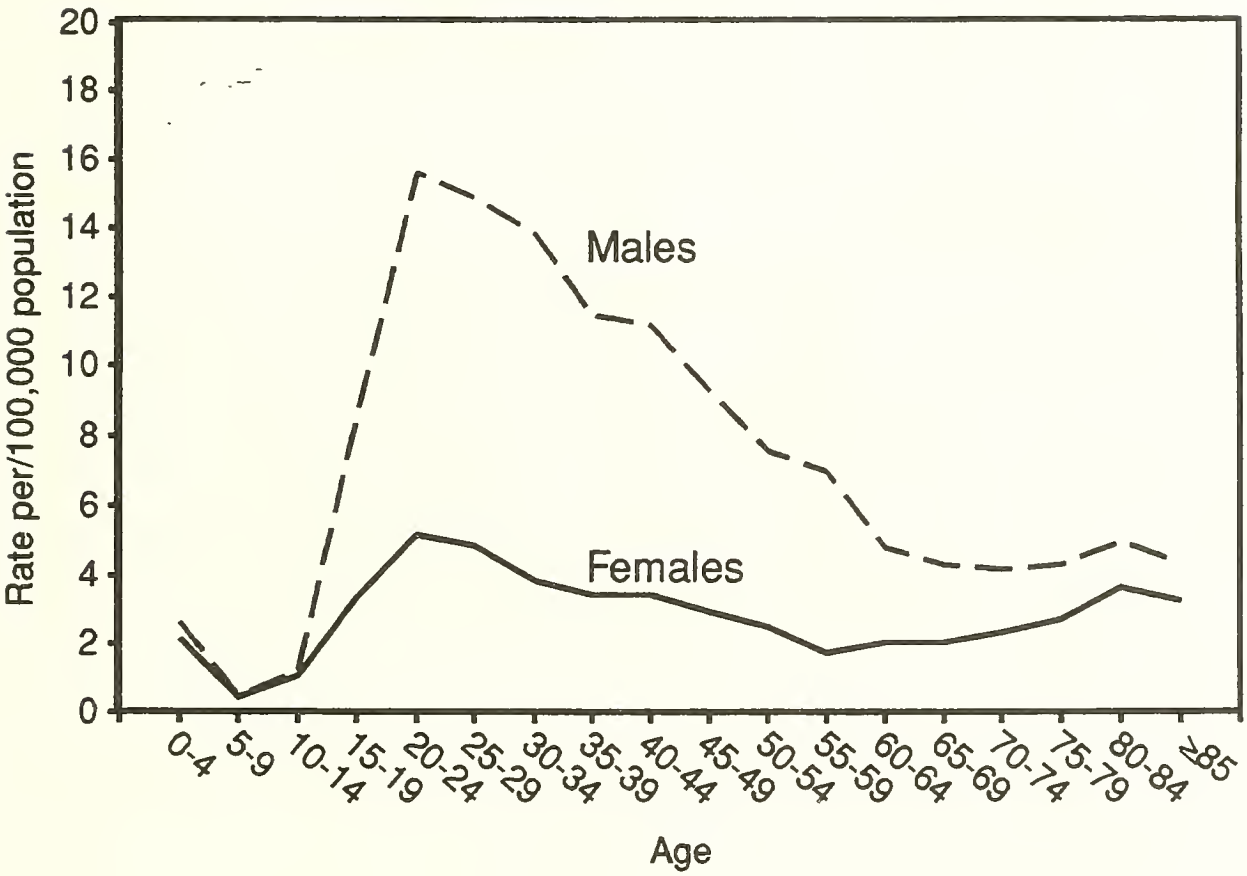


FIGURE I.4. Malaria rates, by year---United States, 1930-1988

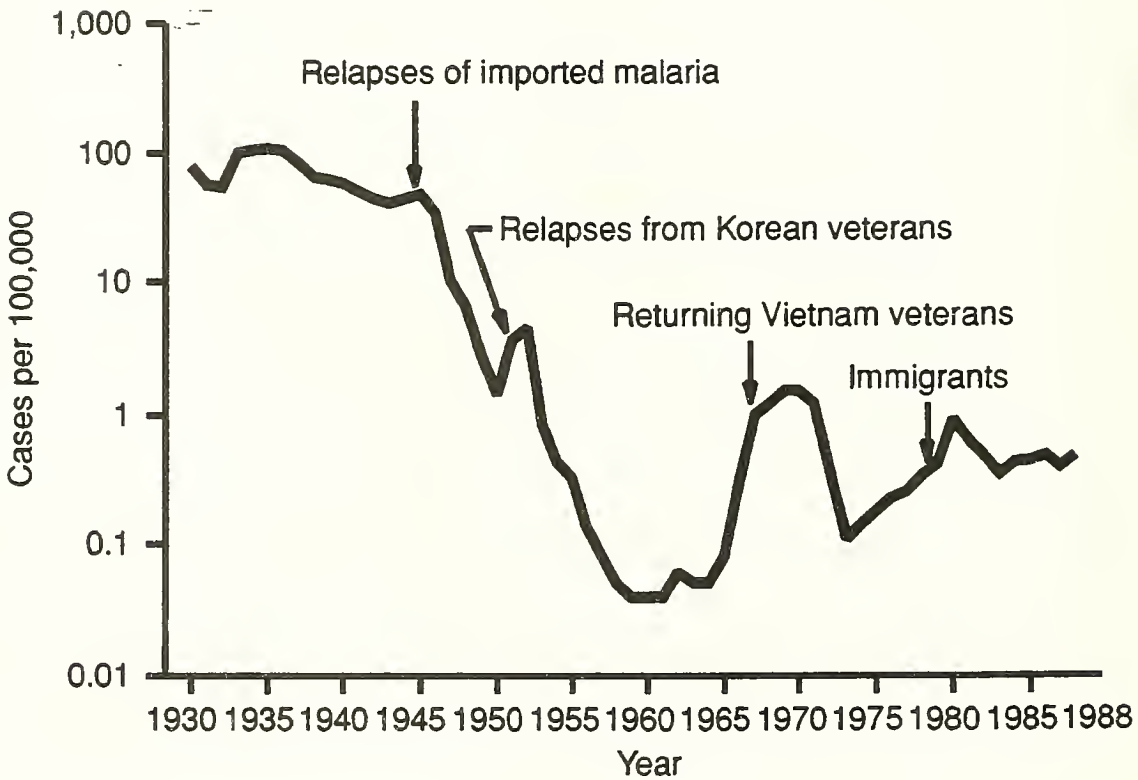
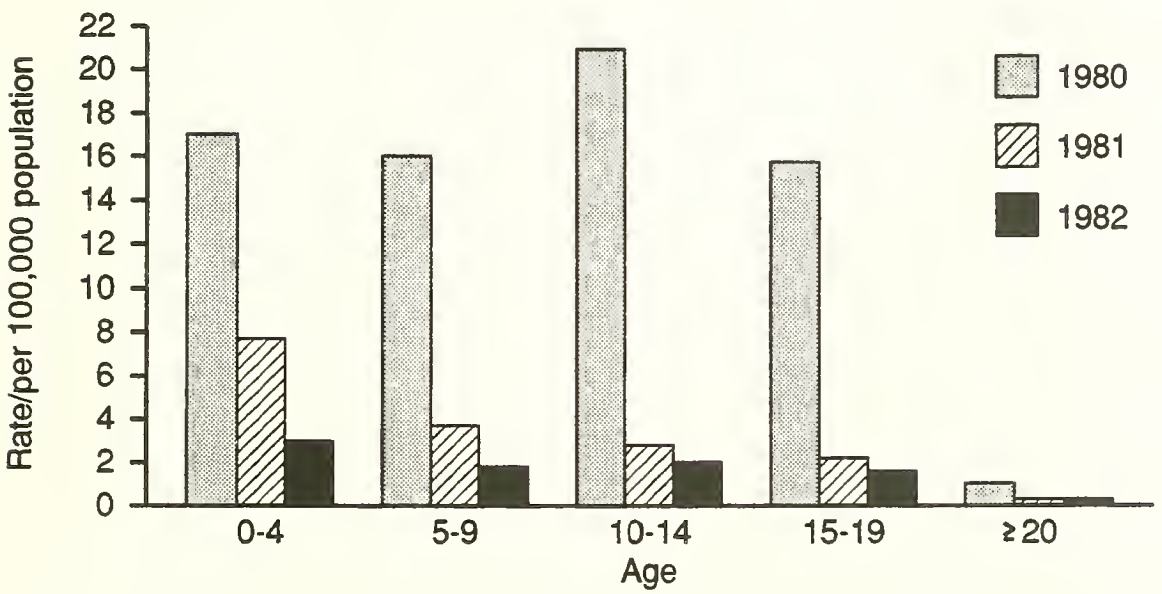


FIGURE I.5. Reported cases of measles, by age group, United States, 1980-1982*



* Rates estimated by extrapolating age, from reported case-patients with known age.

FIGURE I.6. Semi-logarithmic-scale line graph of reported cases of paralytic poliomyelitis---United States, 1951-1989

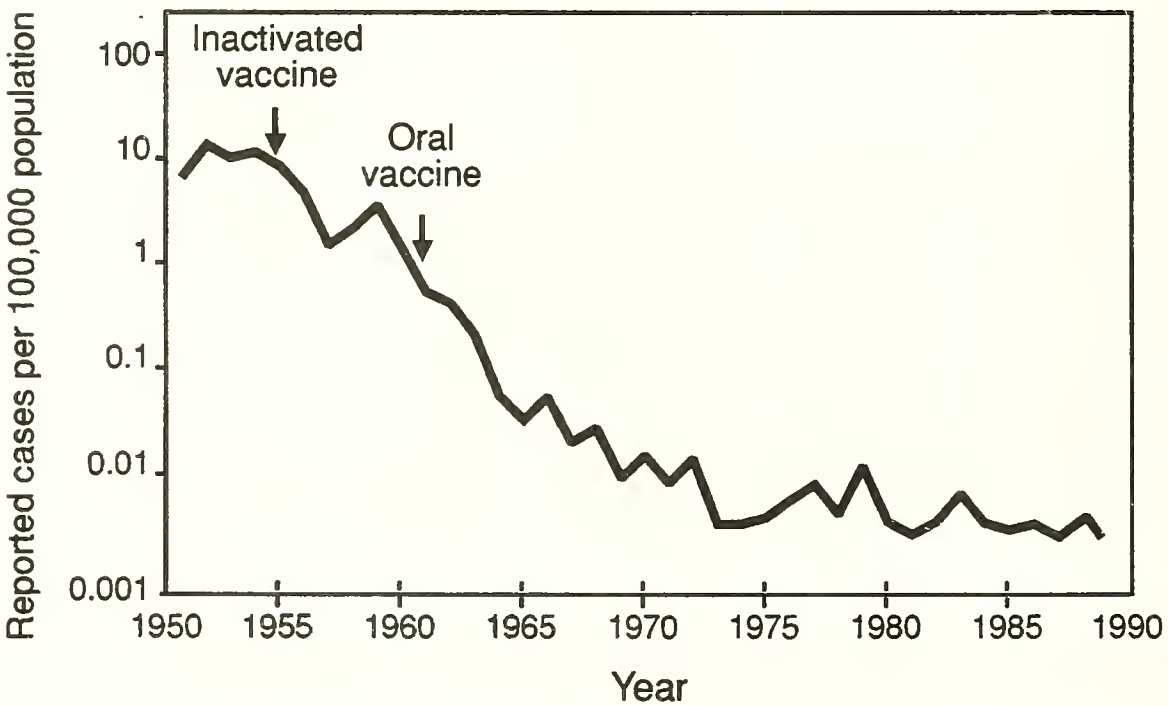


FIGURE I.7. Percentage of reported cases of gonorrhea caused by antibiotic-resistant strains---United States, 1980-1990

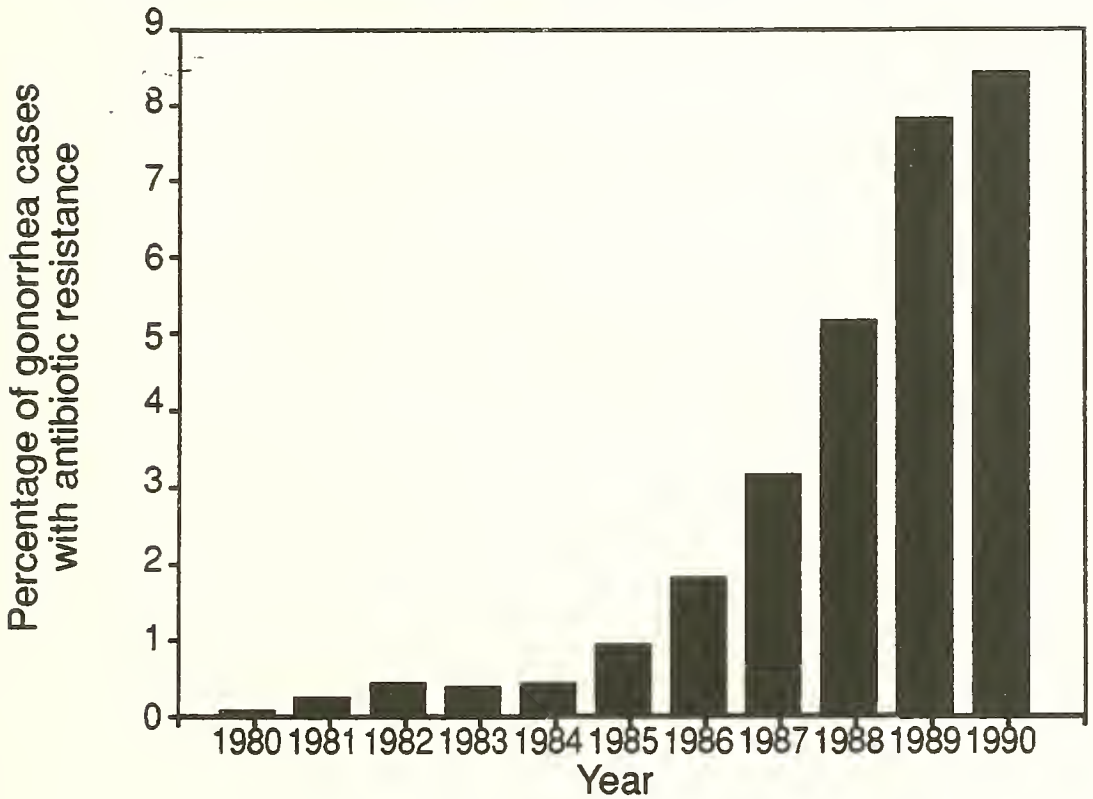


FIGURE I.8. Cesarean deliveries as a percentage of all deliveries in U.S. hospitals, by year, 1970--1990

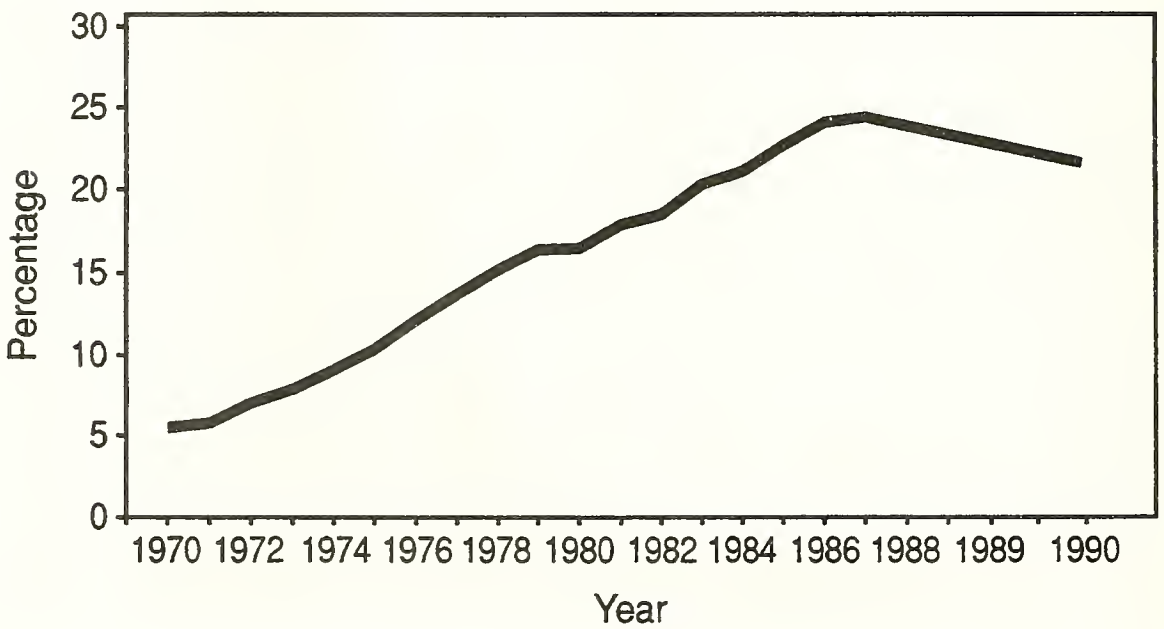
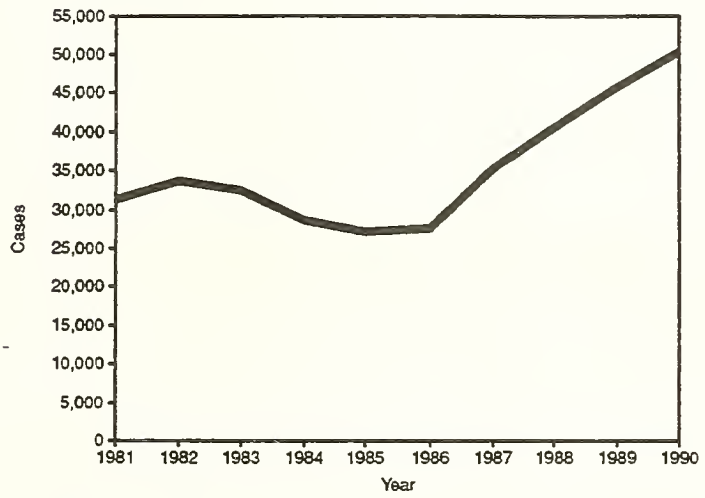
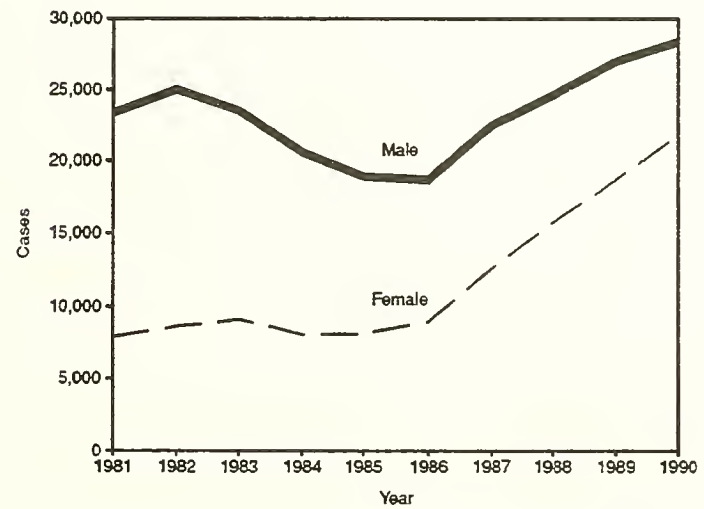


FIGURE V.1. Crude, gender-specific and gender-race-specific cases of primary and secondary syphilis---United States, 1981-1990, comparison of differential trends





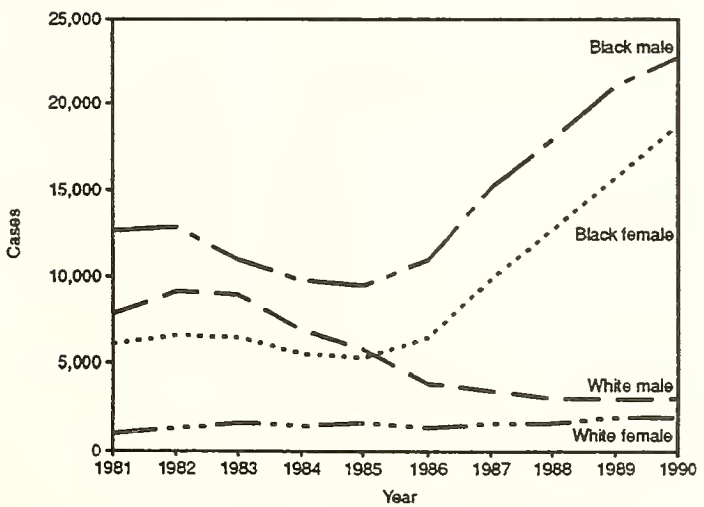


FIGURE V.2. Dot plot of results of swine influenza virus (SIV) hemagglutination-inhibition (HI) antibody testing among exposed and unexposed swine exhibitors---Wisconsin, 1988

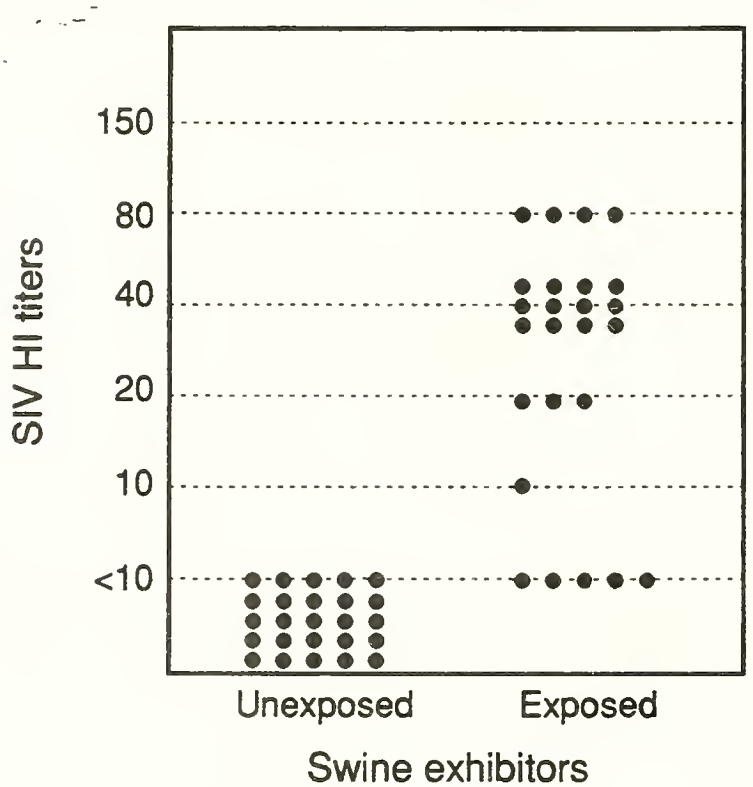


FIGURE V.3. Ordered data series and stem-and-leaf display of 39 4-week totals of reported cases of meningococcal infections--United States, 1987-1989

1987: 226, 307, 350, 236, 222, 258, 197, 167, 138, 108, 191, 190, 201

1988: 216, 238, 331, 270, 265, 156, 164, 142, 112, 111, 153, 138, 159

1989: 145, 306, 314, 264, 222, 195, 155, 149, 102, 117, 174, 158, 159

Stem	Leaf
34	0
32	1
30	674
28	
26	450
24	8
22	22668
20	16
18	0157
16	474
14	259356899
12	88
10	28127
	- - - -+- - - - -+

In this example the first two digits of each datum serve as the stem and the third digit serves as a leaf, e.g., for the numbers 264 and 265, the stem and leaves appear as 26 (stem) and 45 (leaves). Since further division of the stems would result in an attenuated distributional shape, each stem represents a range of 20 numbers, e.g., the stem 26 represents any number from 260 to 279 so that for the number 270, the stem and leaf appear as 26 (stem) and 0 (leaf).

FIGURE V.4. Scatter plot of 39 4-week totals of reported cases of meningococcal infections---United States, 1987-1989

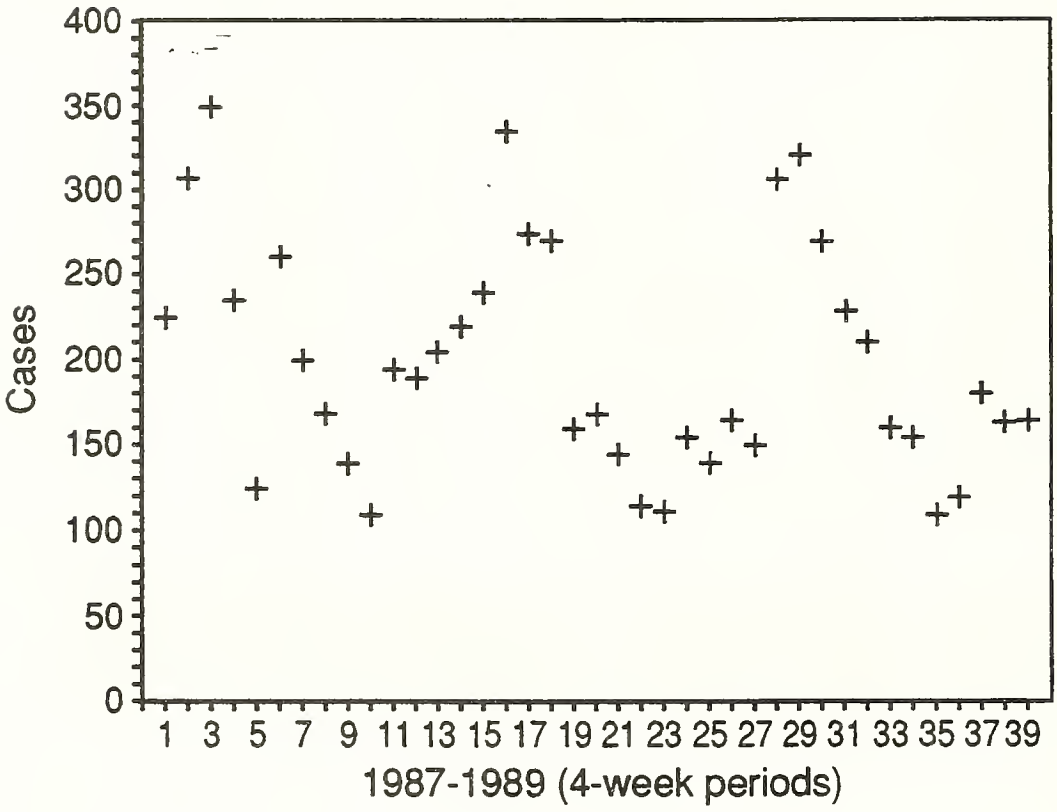


FIGURE V.5. Box plot of 39 4-week totals of reported cases of meningococcal infections--United States, 1987-1989

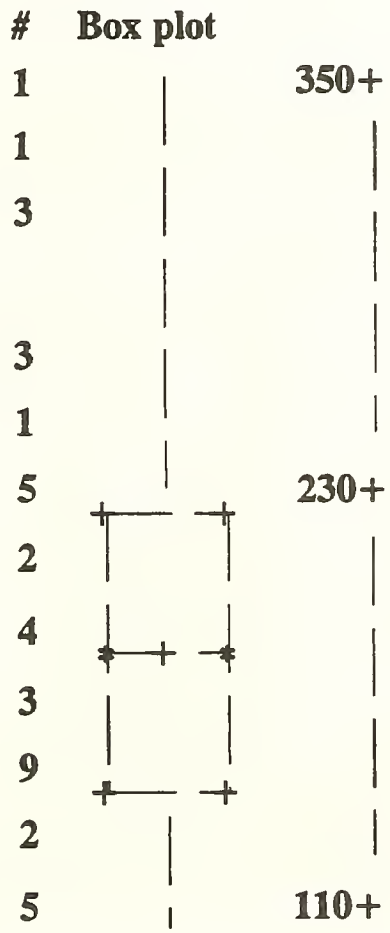


FIGURE V.6. Histogram (epidemic curve) of reported cases of paralytic poliomyelitis---Oman, January 1988-March 1989

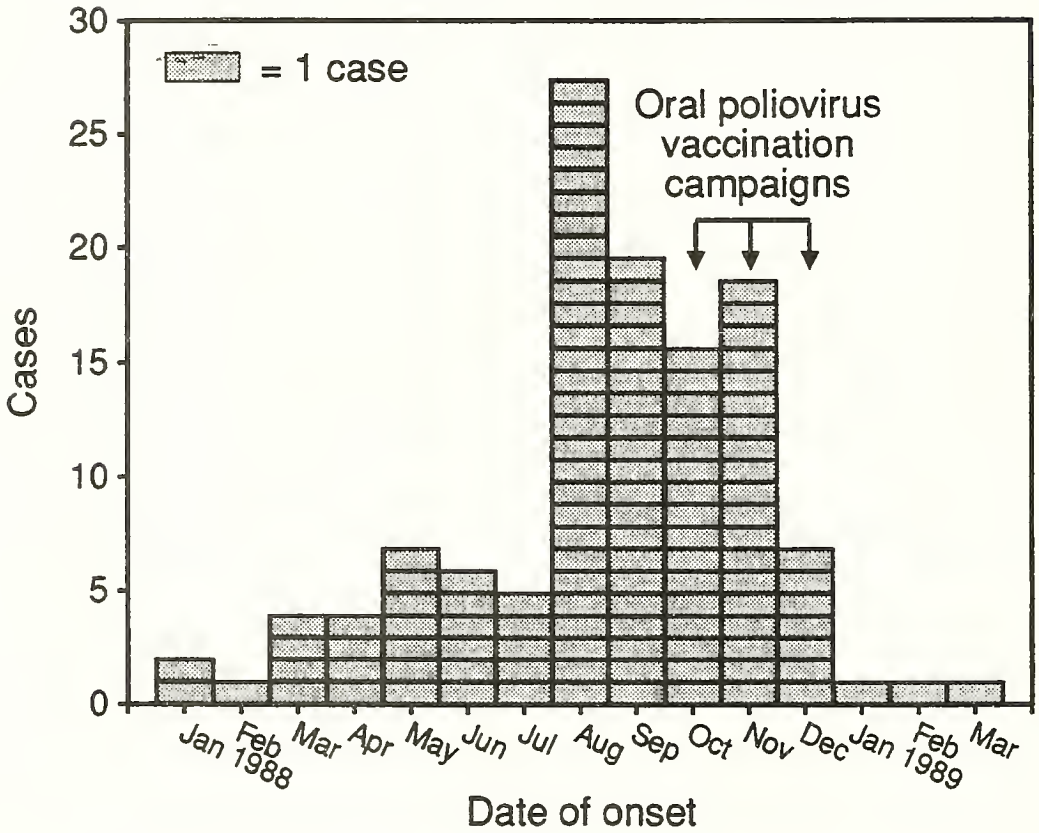


FIGURE V.7. Sample cumulative attack rate, by grade in school and time of onset --- North Carolina, 1985

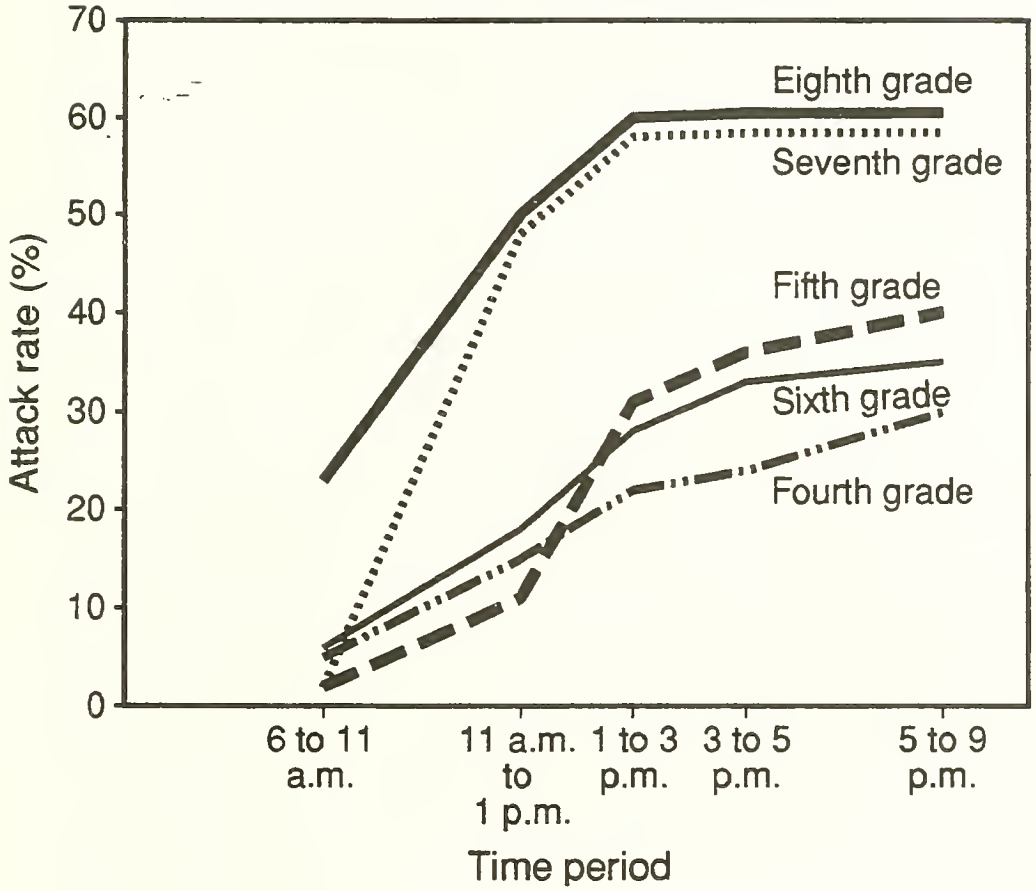


FIGURE V.8. Survival curves over time, based on serum testosterone level, Eastern Cooperative Oncology Group

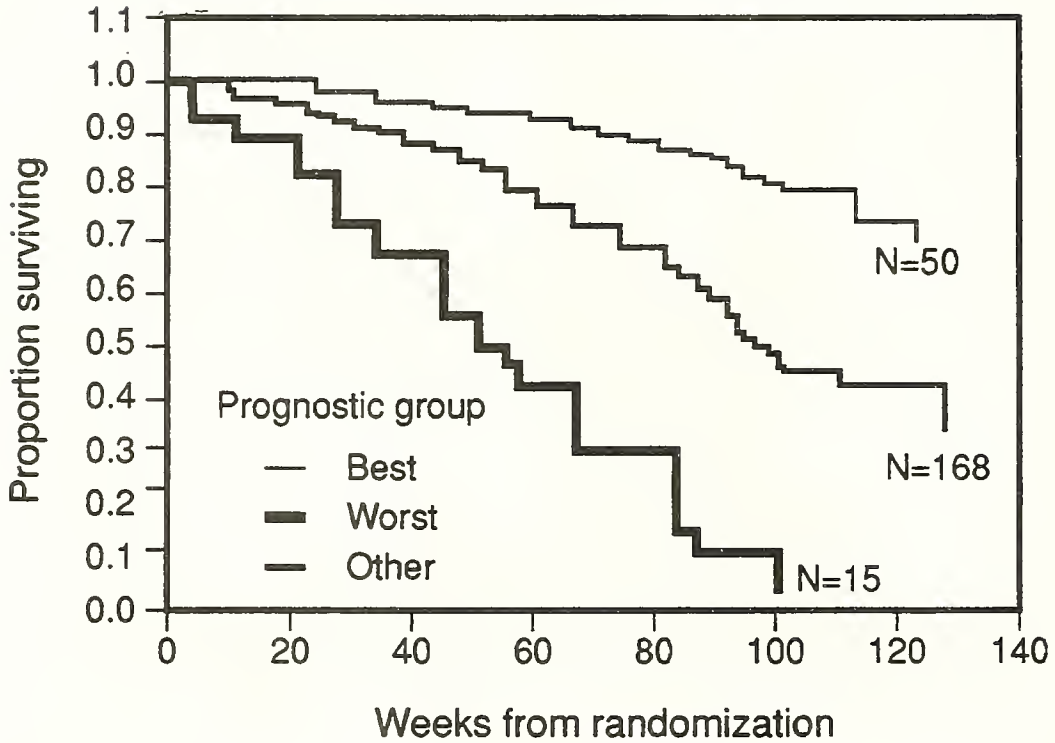


FIGURE V.9. Frequency polygon of reported cases of encephalitis---United States, 1965

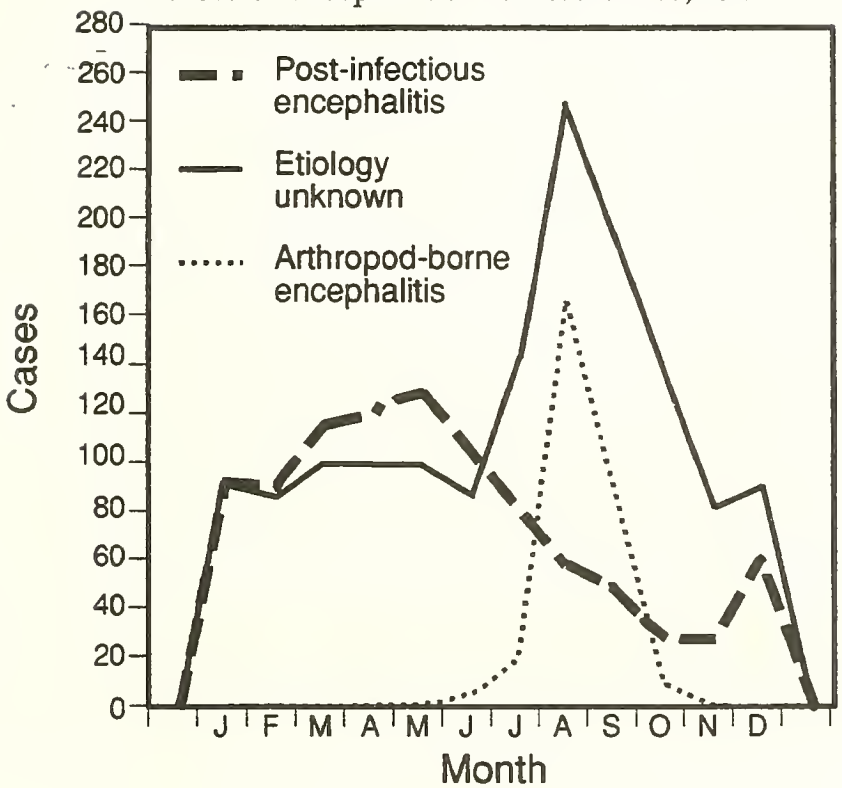


FIGURE V.10. Group bar chart of case-fatality rates from ectopic pregnancy, by age group and race---United States, 1970-1987

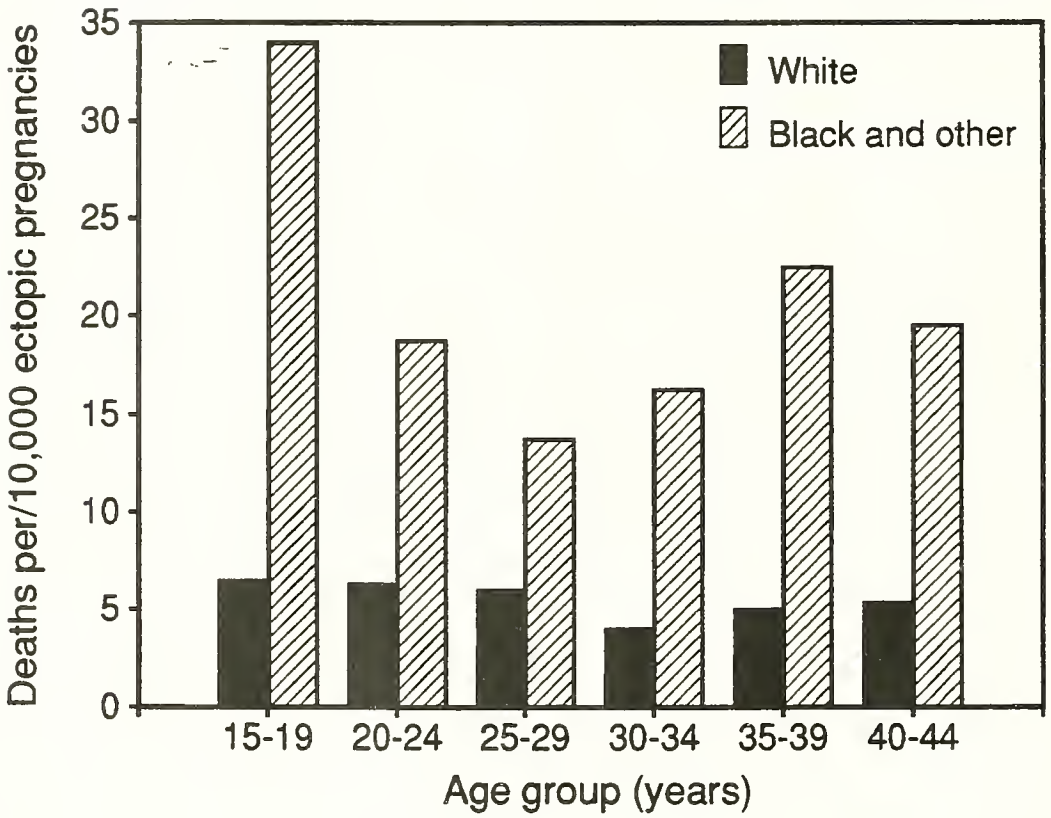


FIGURE V.11. Stacked bar chart of underlying causes of infant mortality, by racial/ethnic group and age at death---United States, 1983

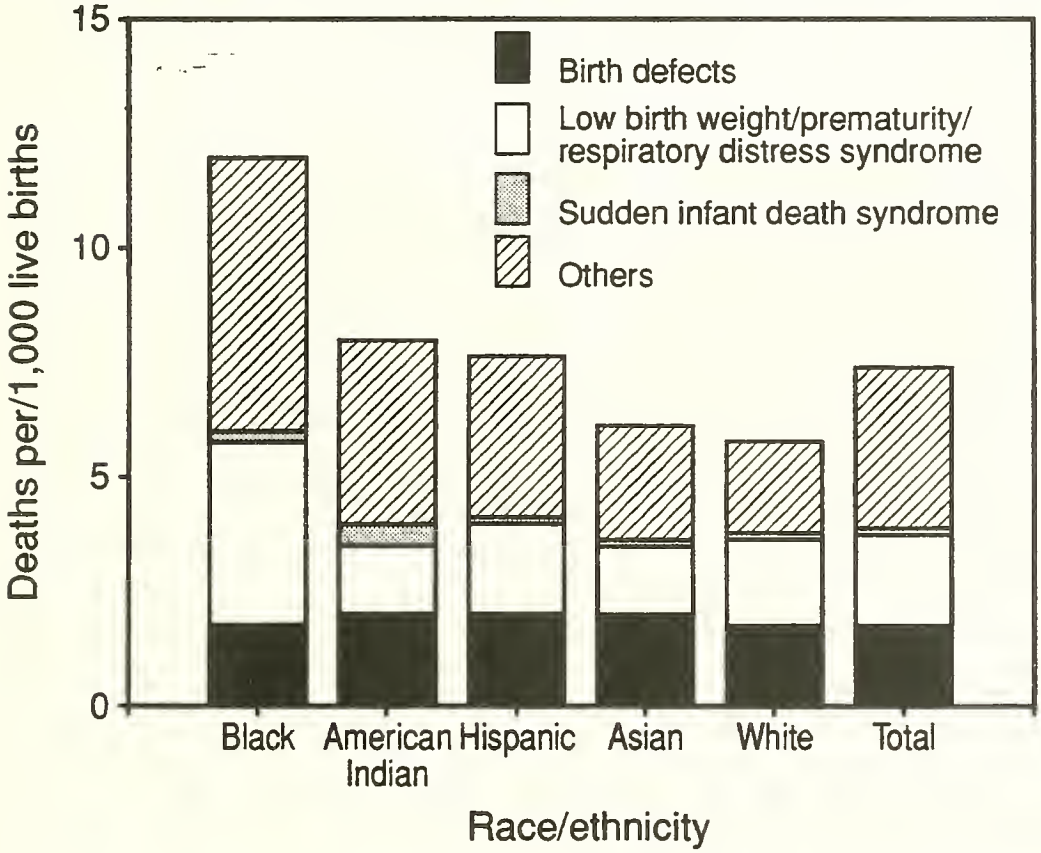
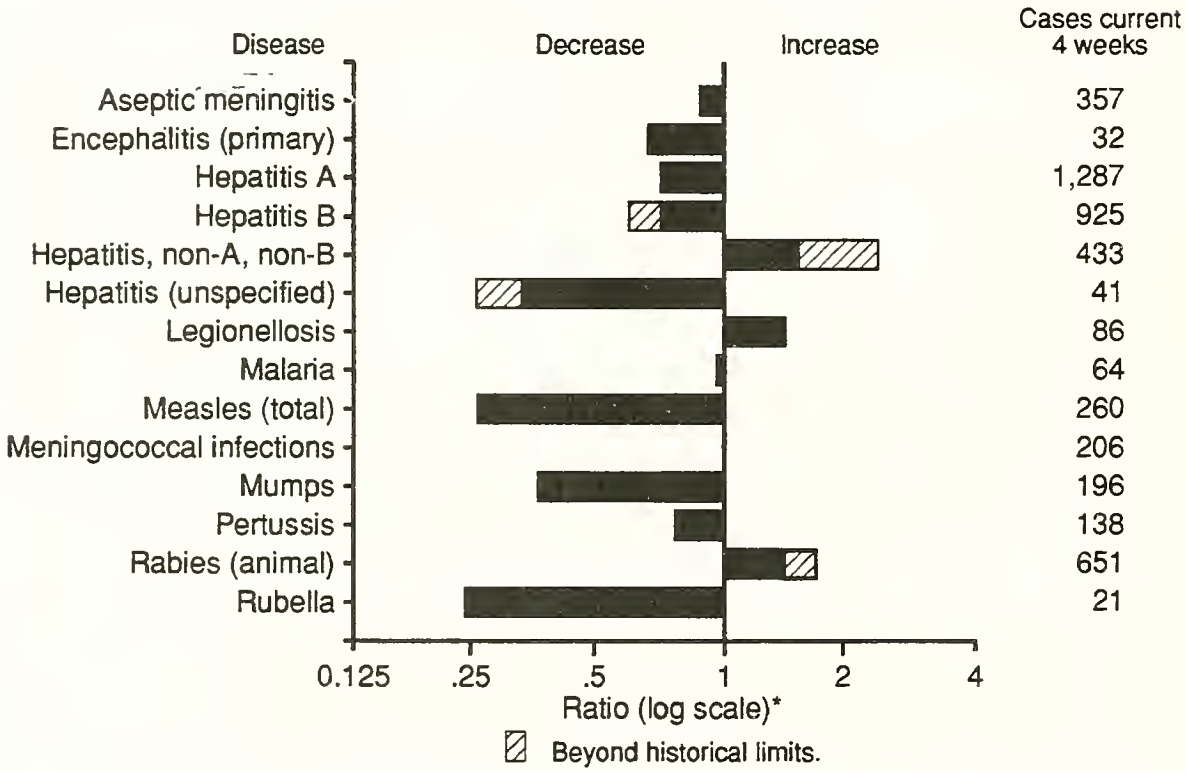
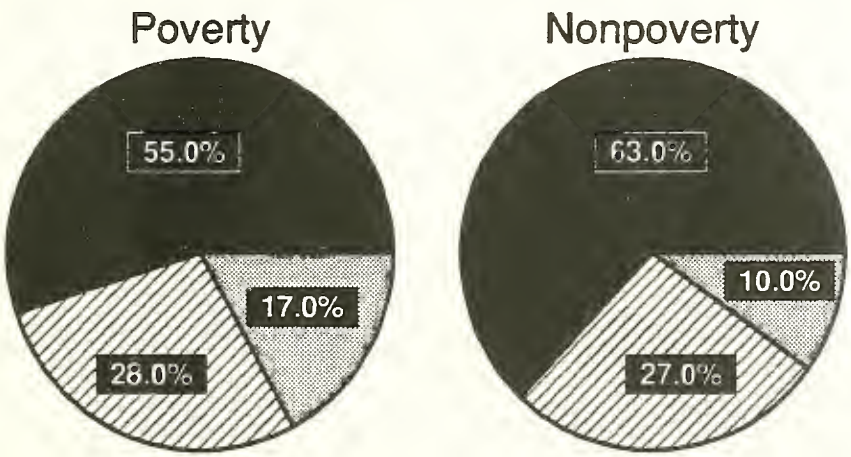


FIGURE V.12. Deviation bar chart of notifiable disease reports, comparison of 4-week totals ending May 23, 1992, with historical data---United States



* Ratio of current 4-week total to the mean of 15 4-week totals (from previous, comparable, and subsequent 4-week periods for the past 5 years). The point where the hatched area begins is based on the mean and two standard deviations of these 4-week totals.

FIGURE V.13. Pie charts of poliomyelitis vaccination status of children ages 1-4 years in cities with populations ≥250,000, by financial status---United States, 1969



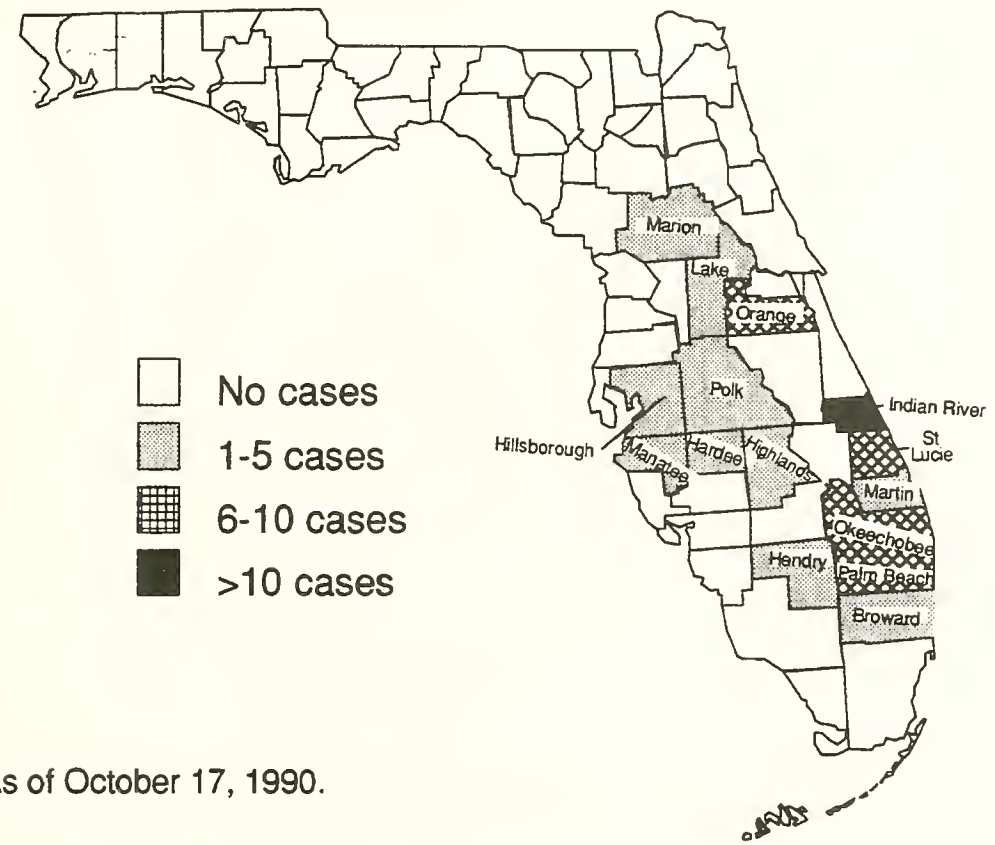
Adequately vaccinated: 3+ doses inactivated poliovirus vaccine (IPV) and/or 3 doses oral poliovirus vaccine (OPV).

Inadequately vaccinated: Some poliovirus vaccine, but < 3 doses of IPV and/or < 3 doses of OPV.

Not vaccinated: No vaccine given.

FIGURE V.14. Spot map of deaths from smallpox---California, 1915-1924

FIGURE V.15. Chloropleth map of confirmed and presumptive cases of St. Louis encephalitis, by county---Florida, 1990*



* As of October 17, 1990.

FIGURE V.16. Density-equalizing map of California (based upon population density), depicting deaths from smallpox, 1915-1924

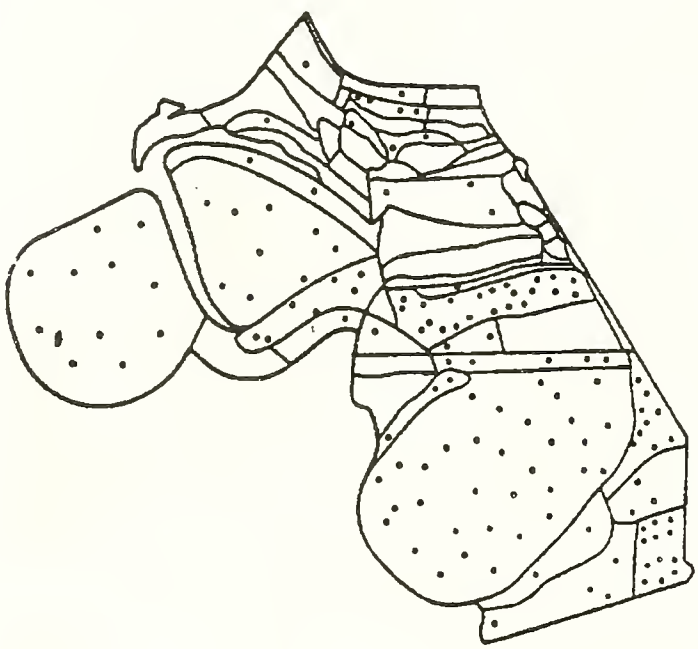
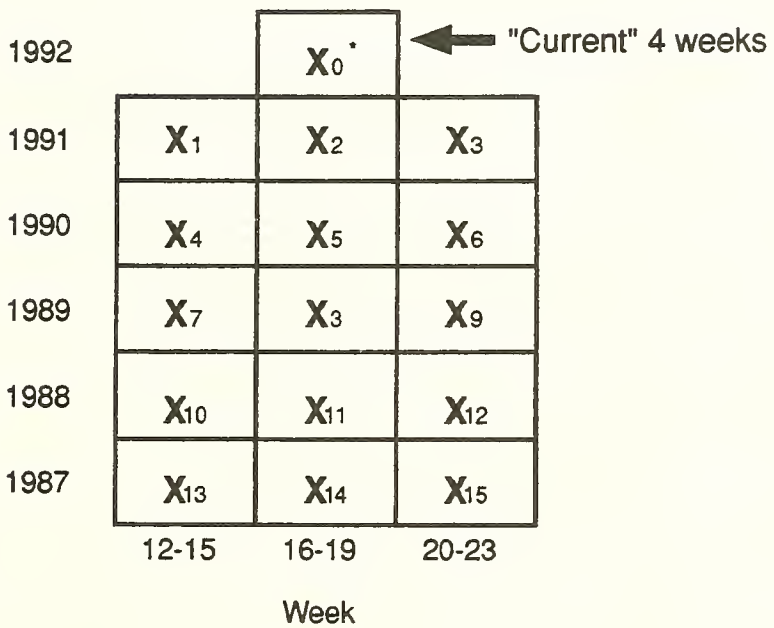


FIGURE VI.1. Example: Data used for report published during week 20 (May 23, 1992)



* For example, X_0 is total of cases reported for weeks 16-19, 1992.

FIGURE VIII.1. National Notifiable Diseases Surveillance System

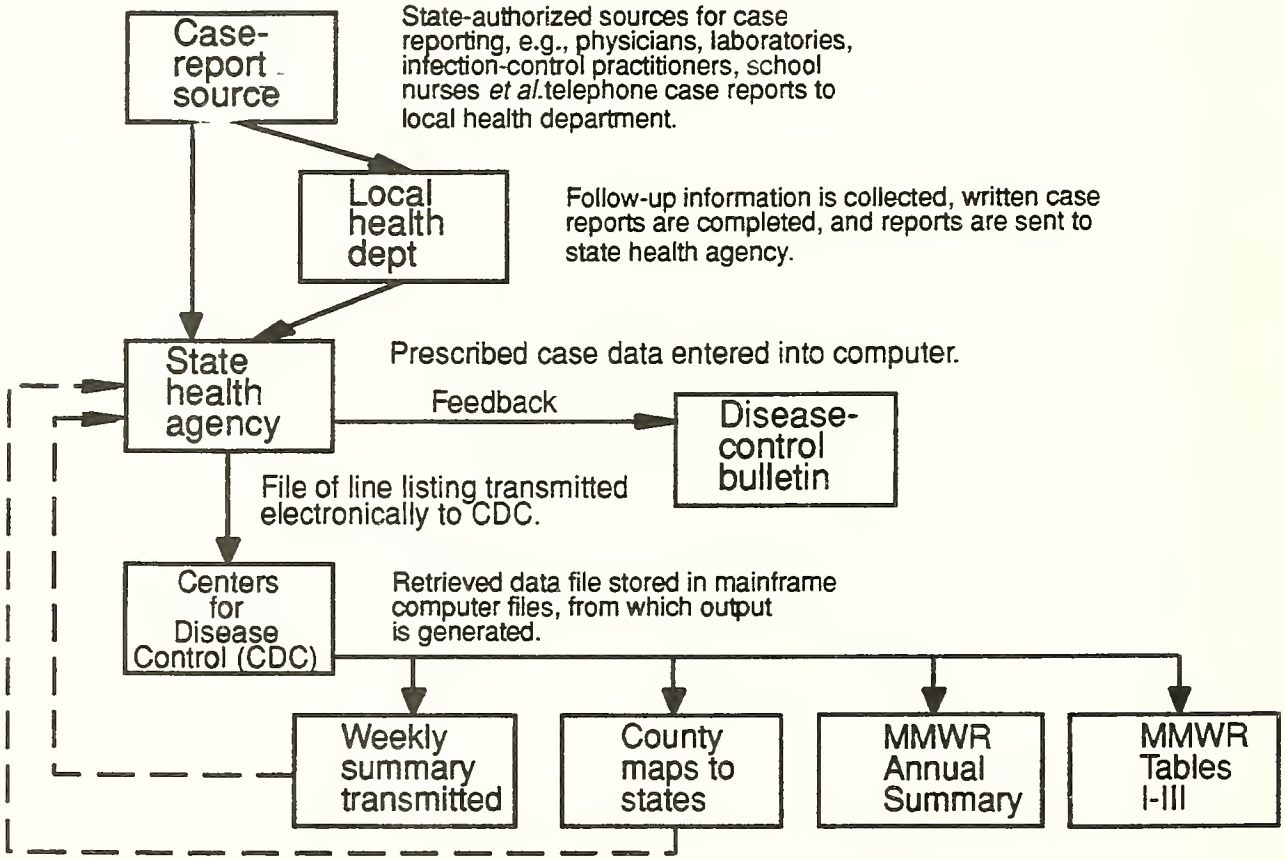


FIGURE VIII.2. Biases in surveillance

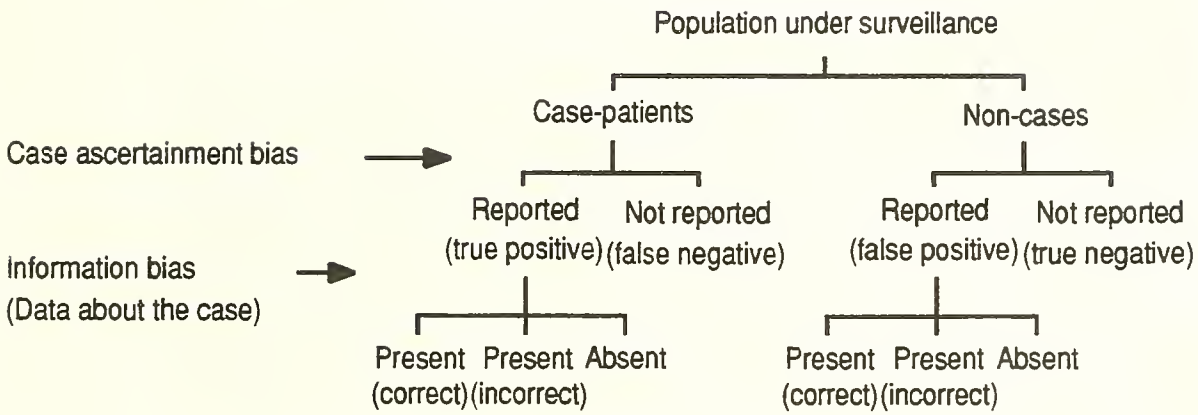


FIGURE XII.1. Cartoon depicting mumps as a public health problem, Tennessee

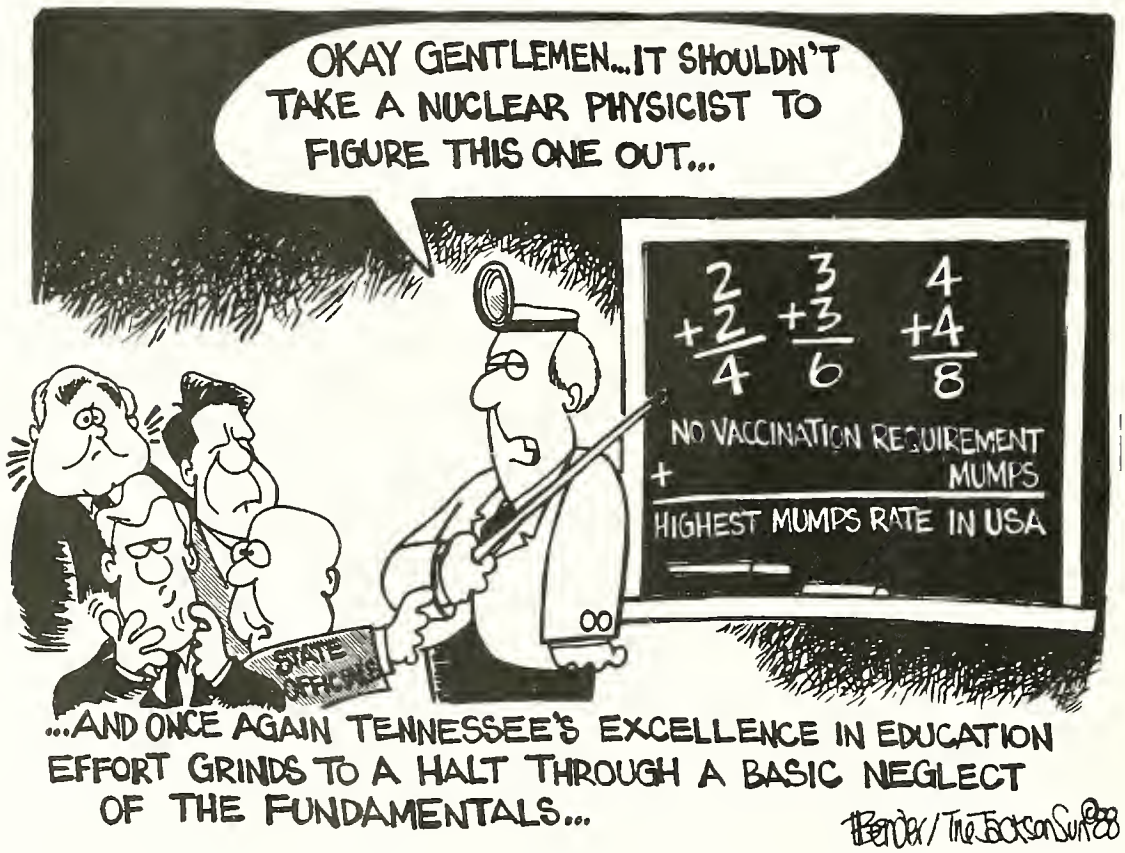
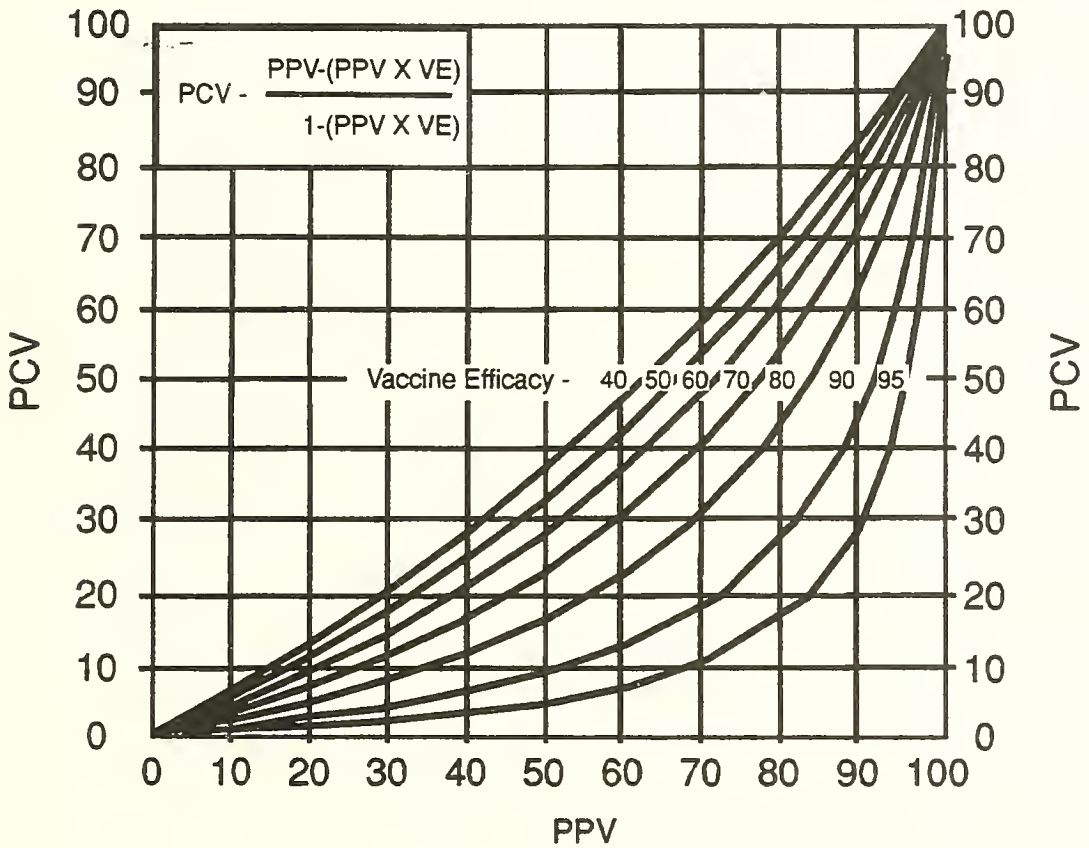


FIGURE XIII.A.1. Percentage of case-patients vaccinated (PCV) per percentage of population vaccinated (PPV) for seven values of vaccine efficacy (VE)



Principles and practice of public health surveillance