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# Reviews/Analyses

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## Public health surveillance: historical origins, methods and evaluation

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*In the last three decades, disease surveillance has grown into a complete discipline, quite distinct from epidemiology. This expansion into a separate scientific area within public health has not been accompanied by parallel growth in the literature about its principles and methods. The development of the fundamental concepts of surveillance systems provides a basis on which to build a better understanding of the subject. In addition, the concepts have practical value as they can be used in designing new systems as well as understanding or evaluating currently operating systems.*

*This article reviews the principles of surveillance, beginning with a historical survey of the roots and evolution of surveillance, and discusses the goals of public health surveillance. Methods for data collection, data analysis, interpretation, and dissemination are presented, together with proposed procedures for evaluating and improving a surveillance system. Finally, some points to be considered in establishing a new surveillance system are presented.*

Surveillance, which for long was considered a branch of epidemiology, has in the last thirty years developed into a complete discipline within public health, with its own objectives, data sources, methodologies and evaluation procedures. Full descriptions of its principles and methods, however, have not been covered in the literature except for some articles and chapters in books which are mostly focused on specific issues (1-9).

This article reviews the origins, principles and methods of surveillance, and proposes several points for establishing a surveillance system (10).

### Historical origins

The concept of using mortality and morbidity data as a basis for public health action arose in Europe some 600 years ago with the emergence of scientific thought during the Renaissance, and subsequently spread to the Americas with the European settlers.

**Fourteenth and fifteenth centuries.** The occurrence of the Black Death or pneumonic plague about 1348 resulted in the appointment of three guardians of public health by the Venetian Republic to detect and exclude ships which had infected people aboard. This detection was a primitive form of surveillance which led to the first public health measure taken by a government in Europe (11). The detention of travellers from plague-infected areas for 40 days in Marseilles (1377) and in Venice (1403) resulted in quarantine as a means to control the spread of infectious diseases (3).

**Sixteenth century.** Records of vital events were preserved in numerous European towns beginning in the sixteenth century. The first London Bills of Mortality were prepared by an unknown person in 1532 although their use for health and scientific purposes did not begin until a hundred years later (4).

**Seventeenth century.** One of the earliest examples of surveillance was that of plague in London in the seventeenth century. At first, the data were collected centrally and only sporadically in the plague years, but beginning in the seventeenth century the parish clerks of London made regular weekly reports of the number of burials, with the causes of death, to the Hall of the Parish Clerks' Company. The Clerk of the Hall was responsible for compiling the statistics of deaths for the City of London and adjoining parishes and then interpreting them to provide informa-

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tion on the extent of plague in the capital. This information was disseminated in a weekly "Bill of Mortality" to those who required it so that appropriate action could be taken. This early surveillance system illustrates the main principles of surveillance which are still used—data collection and analysis, interpretation to provide information, and dissemination of that information for action (12).

Detailed analyses of the weekly Bills of Mortality were made by John Graunt (1662), who was the first to estimate the population of London and to count the number that died from specific causes. He was also the first to conceptualize and quantify the patterns of disease and to understand that numerical data on a population could be used to study the cause of disease (4).

**Eighteenth century.** During the eighteenth century, surveillance was recognized as an integral part of the provision of population health. At the same time, Mirabeau and other leaders of the French Revolution claimed that the health of the people was the responsibility of the State (13).

In 1766, Johann Peter Frank advocated a comprehensive form of public health surveillance as part of his system of police medicine<sup>a</sup> in Germany. This system dealt with school health, injury prevention, maternal and child health, and public water and sewage treatment (6). Frank formulated and presented a coherent, comprehensive, and very detailed health policy which had considerable impact both within Germany and in countries such as Hungary, Italy, Denmark and Russia that had close cultural contact with Germany (13).

In the same period, the basic elements of surveillance were developed in some colonies in America. In 1741 Rhode Island passed an act requiring tavern-keepers to report contagious disease among their patrons. Two years later, the colony passed a law requiring the reporting of smallpox, yellow fever and cholera (6).

**Nineteenth century.** Surveillance, involving the collection and interpretation of health-related data for the purpose of identifying appropriate actions, became fully developed in the nineteenth century.

Sir Edwin Chadwick (1800–90), Secretary of the Poor Law Commission in England, was the first health administrator to demonstrate, through surveillance, that poverty and disease were closely related (4). In the USA, Lemuel Shattuck's "Report of the Massachusetts Sanitary Commission" (1850) related

living conditions to rates of infant and maternal mortality and morbidity. He recommended a decennial census, standardization of nomenclature for diseases and causes of death, and the collection of health data by age, sex, occupation, socioeconomic level and locality (4).

The need for more accurate and complete mortality data in the United Kingdom led to the establishment of the General Register Office in 1836 and the introduction of medical certification of death and universal death registration in 1837 (12). William Farr became the first Compiler of Abstract (medical statistician), who during his 41 years (starting in 1838) at the General Register Office created a modern surveillance system (12). He is recognized as the founder of the modern concept of surveillance (14).

**Twentieth century.** The twentieth century saw the expansion of the concept of surveillance and the development of many different surveillance systems. Methods of collection, analysis and dissemination of data have diversified and methodological issues were emphasized (4).

Table 1 gives some of the more important events related to the development of surveillance in the last 100 years.

## Definitions and concepts

### *Modern concepts of population and individual surveillance*

The concept of public health surveillance has evolved over time and is still confused with other uses of the word surveillance. The Oxford English Dictionary defines the term surveillance as "watch or guard

Table 1: Development of surveillance in the last 100 years

1888: Mandatory reporting of eleven communicable diseases and death certificates, in Italy
1893: Publication of international list of causes of death by the International Statistical Institute (founded in London in 1885)
1911: Use of surveillance data from National Health Insurance, in the United Kingdom
1935: First National Health Survey, in the USA
1943: First registry, the Danish Cancer Registry First Sickness Survey, in the United Kingdom
1965: Establishment of an Epidemiological Surveillance Unit in the Division of Communicable Diseases at WHO headquarters, Geneva
1966: First publication of Communicable Disease Surveillance Reports by WHO
1967: Development of General Practitioners' Sentinel Systems, in the United Kingdom and the Netherlands

<sup>a</sup> See Sigerist HE. *Landmarks in the history of hygiene*. New York/London, Staples Press, 1956. Cited in ref. 13.

kept over a person, especially over a suspected person" (15).

Prior to 1950, in fact, surveillance meant the close observation of persons exposed to a communicable disease to detect early symptoms and institute prompt isolation and control measures. The current concept of surveillance as the monitoring of disease occurrence in populations was promoted by Alexander D. Langmuir in the USA as a function of the newly created Communicable Diseases Center—now the Centers for Disease Control and Prevention (CDC)—around 1950.

"Surveillance, when applied to a disease, means the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data. Intrinsic in the concept is the regular dissemination of the basic data and interpretations to all who have contributed and to all others who need to know" (16, pp. 182–183).

To distinguish these two surveillance activities, 'surveillance' is used to describe health events in populations, while the term 'personal surveillance' is now used to describe monitoring of potentially exposed individuals for the detection of early symptoms. During the 1960s, under the leadership of Karel Raška, this new concept of surveillance was recognized first in Czechoslovakia, and then internationally through the World Health Organization (17). In 1968, the Technical Discussions of the 21st World Health Assembly made a full examination of surveillance as an established and essential function of public health practice. The concept of population surveillance was adopted and its three basic characteristics were listed: systematic collection of data; consolidation and analysis of the collected data; and dissemination of information by means of narrative epidemiological reports (18).

### **Surveillance and control activities**

During the past 20 years the concept of surveillance was expanded further. At the 1968 World Health Assembly Technical Discussions, surveillance was said to imply the responsibility of following up to see that effective action had been taken.<sup>b</sup> Examples can be seen in several WHO programmes: in malaria eradication, surveillance embraced active measures of control, namely chemotherapy and insecticiding; in smallpox eradication, surveillance became synonymous with containment including active vaccination of large numbers of people (14).

<sup>b</sup> World Health Organization. *Report of the Technical Discussions at the Twenty-first World Health Assembly on "National and global surveillance of communicable diseases"*. Geneva, May 1968. (Unpublished document A21/Technical Discussion/5).

However, Langmuir stated on more than one occasion that the concept of surveillance did not encompass direct responsibility for control activities (16), and that "the surveillance officer should be the alert eyes and ears of the health officer and he should advise regarding control measures needed, but the decision and the performance of the actual control operations must remain with the properly constituted health authority" (20, p. 684).

The 1986 CDC definition of surveillance reflects this view and avoids the use of the term surveillance for control activities, although it states that the final link in the surveillance chain is the application of these data to prevention and control (21).

### **Epidemiological surveillance or public health surveillance**

Some epidemiologists have tended to define surveillance as synonymous with epidemiology in its broadest aspects, including investigation and research. The use of "epidemiological" to describe surveillance first appeared in the mid-1960s, in association with the establishment of a WHO unit of Epidemiological Surveillance. At the 21st World Health Assembly in 1968, the Organization adopted Raška's definition of surveillance, meaning "the epidemiological study of a disease as a dynamic process involving the ecology of the infectious agent, the host, the reservoirs, and the vectors, as well as the complex mechanisms concerned in the spread of infection and the extent to which this spread occurs" (17, p. 316; 18, p. 440).

Langmuir did not agree with a definition of surveillance that included the general practice of epidemiology or epidemiological intelligence. Although he acknowledged that surveillance data may provide interesting leads for research investigations, he warned that the actual performance of the research study should be recognized as a function separate from surveillance (20).

Thacker & Berkelman agreed with Langmuir that surveillance did not encompass research or services, and stressed the problem of terminology: "the use of the term epidemiologic to modify surveillance is misleading... We propose that a more appropriate term is 'public health surveillance', because its use retains the original benefits of the term epidemiologic and removes some of the confusion surrounding current practice" (6, p. 168).

This is reflected in the new CDC definition, very similar to the one used in 1986 (21), apart from the words qualifying surveillance.

"Public health surveillance is the ongoing systematic collection, analysis, interpretation and dissemination of health data... The concept of public

health surveillance does not include administration of the prevention and control programs, but does include an intended link with those programs” (8, pp. 338–339).

It seems that the term public health surveillance is gradually entering into common use, even within WHO (22). The *Dictionary of epidemiology*, on the other hand, focuses on surveillance methods, which are “distinguished by their practicability, uniformity, and frequently their rapidity, rather than by complete accuracy” (23, p. 125).

**Surveillance and monitoring**

The terms surveillance and monitoring are often used interchangeably, but are in fact distinct. Eylenbosh & Noah warned that the use of the term “monitoring” should be confined to the continuous assessment of an intervention–change relationship. Monitoring evaluates intervention or action (4).

The *Dictionary of epidemiology* approaches this idea when it states that “monitoring is the ongoing measurement of performance of a health service or a health professional, or of the extent to which patients comply with or adhere to advice from health professionals” (23, p. 83).

Surveillance and monitoring have in common the routine and ongoing collection of data, and the methods of both tend to be pragmatic and rapid. Surveillance would be used to assess the impact of an infectious disease in a population, both before and after the introduction of a vaccine, and the extent of vaccine usage, whereas monitoring would describe the process of measuring the effect of vaccination programmes on the disease. Monitoring implies a constant adjustment of performance in relation to the results and is an important management tool (4).

Another distinction can be made with regard to the target group. Surveillance, by definition, concerns populations, whereas monitoring applies to specific groups (e.g., vaccination of travellers) or individuals.

**Health events under surveillance**

The communicable diseases were the first to be put under surveillance. However, in recent years surveillance has also been applied to a wide variety of other conditions. Table 2 gives some examples but is not exhaustive.

**Objectives of surveillance**

The objectives of surveillance are determined by the definition of surveillance being used. For the remainder of this article, “surveillance” will refer to public health surveillance, as defined above.

(1) *To describe the ongoing pattern of disease occurrence and to link with public health action*

According to the 1968 World Health Assembly Technical Discussions, the purpose of surveillance is “to use all appropriate epidemiologic and other methods as a guide to the control of disease” (18, p. 440). This function of surveillance is also described in the *Dictionary of epidemiology*: “its main purpose is to detect change in trend or distribution in order to initiate investigation or control measures” (23, p. 125). Galbraith enlarged the objective to include the evaluation of disease control measures and the provision of data for health service planning (12).

The first part of this objective is about describing the ongoing pattern of disease occurrence and disease potential, as in the following examples (8):

- (a) detecting acute changes in disease occurrence and distribution (e.g., epidemics);
- (b) identifying and quantifying trends and patterns of disease (e.g., recent increase in sexually transmitted diseases);
- (c) observing changes in agents and host factors to assess the potential for future disease occurrence (e.g., the laboratory surveillance of influenza virus);
- (d) detecting changes in health practices (e.g., increasing caesarean delivery).

The second part of this first objective is about using the collected data to facilitate and evaluate the investigation and control and prevention measures. The following are among the possible uses (8).

- (a) Disease investigation and control: reports of many of the notifiable diseases stimulate action, such

Table 2: **Examples of health events under surveillance**

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Mortality
Communicable diseases
Chronic diseases
Birth defects
Abortions and other pregnancy outcomes
Environmental hazards
Environmental air and water quality
Injuries
Behavioural risk factors
Health practices
Animal reservoirs and vector distribution
Vaccine and drug utilization and adverse reactions
Growth, development and nutritional status
Occupational safety
Animal health
Nosocomial infections
Mental illness

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as searching for the source, which may prompt further action (withdrawal of a product, warning to the public, closure of restaurant, or identification and care of a susceptible exposed people).

(b) Health services planning: surveillance provides a factual basis for rational decision-making (e.g., allocating resources, choosing priorities, predicting future needs); Langmuir said in 1963 that "good surveillance does not necessarily ensure the making of the right decisions, but it reduces the chances of wrong ones" (16, p. 191).

(c) Evaluation of prevention and control measures (e.g., the measles resurgence in the late 1980s led to a revision in vaccination policy in the USA).

### (2) *To study the natural history and epidemiology of the disease*

Public health surveillance is not limited to those diseases for which effective control measures are available. Surveillance is justifiable for another important purpose: to increase knowledge about the natural history and epidemiology of the disease. In time, this knowledge may lead to development of prevention and control measures (8).

Surveillance data can be used to measure the extent and limits of a disease in a population by establishing its incidence and prevalence, to describe this occurrence by place and time, and to determine the population at risk, the critical exposures and risk factors. Moreover it can be used to help define the natural history of the disease and the spectrum of illness (4). Surveillance of the acquired immunodeficiency syndrome (AIDS) recently has added significantly to knowledge about this disease.

Questions and hypotheses are often generated by the analysis of surveillance data. For example, the upsurge in pentamidine requests noted by the CDC in the USA in 1981 quickly led to the recognition of a nationwide AIDS epidemic (8).

Surveillance data can sometimes be used to test hypotheses. For example, in 1973 an insecticide spray was suspected of being related to birth defects but the 1970–73 surveillance data showed a decrease in total birth defects, even though there was a five-fold increase in spray sales during the same period (8).

### (3) *To provide information and baseline data*

The Laboratory Centre for Disease Control in Canada added the following objective for the Canadian Communicable Disease Surveillance System: "to satisfy the needs of government, health care professionals, voluntary agencies and the public for information on risk patterns and trends in the occurrence of communicable diseases" (24, p. 1).

Baseline data are potentially useful in assessing prevention and control measures when they have

been developed and implemented. Archival records of disease activity can also have important uses (e.g., historical surveillance data were used to develop models for predicting the effectiveness of proposed policies for the eradication of measles and poliomyelitis) (8).

## Legal and ethical issues

### *Principle of medical confidentiality*

The principle of medical confidentiality is one of the most venerable obligations of medical ethics. Doctors are bound by the Hippocratic Oath not to use the information they acquire for any purpose other than the continuing care of the patient, and not to release it without the patient's consent to anyone who is not directly involved in that care (4).

The general principles of the Hippocratic tradition were endorsed in 1948 by the Declaration of Geneva and have been substantially incorporated into the legal codes of most countries, so that tradition and law operate in concert. The Hippocratic tradition, however, does not address the doctor's responsibility to the community as a whole, and "although the Declaration of Geneva starts with a solemn pledge of consecration to the service of humanity, for centuries codes of medical ethics have been concerned with proper behavior toward individual patients and almost ignored the doctor's responsibilities to society" (25, p. 583).

At present, there is common recognition that the public interest may on certain occasion justify a breach of the principle of confidentiality, especially when the objective is to protect the health of the public (e.g., public health surveillance) (4). For example, the medical profession in the countries of the European Economic Community generally accepts the following exceptions to the principle of confidentiality:

- when there is a clear overriding duty to society;
- when the information is required by law;
- when the information is required for purposes of medical research and it is impractical or undesirable to seek explicit consent;
- when the patient gives full, free and informed consent to disclosure (4).

In Canada, the USA and many other countries, the public health laws provide similar exemptions to the principle of confidentiality—for such purposes as disease notification and certain public health interventions.

### *General ethical principles*

Confidentiality is not the only ethical principle in medical investigation. There is widespread agree-

ment that three principles form the ethical basis of biomedical studies and research.

- Respect for human subjects, which incorporates the principles of autonomy and protection of those with impaired or diminished autonomy.
- Beneficence, which includes the precept to do no harm, and the principle of non-maleficence, which is not limited to physical injury and pain, but also loss of confidentiality, public reputation, and faith in others.
- Justice, which includes the rule of distributive justice and the right to be adequately informed (26).

### **Principles of ethical epidemiology**

Surveillance and epidemiological studies should be undertaken in accordance with ethical principles. However, the modern concept of surveillance involves 'populations' rather than 'individuals', so that the ethical principles that govern clinical medicine and experimentation may not always be applicable to public health and surveillance activities.

The application of ethical principles to public health and epidemiology is a difficult challenge. Existing codes and guidelines tend not to expressly address the special features related to these fields. Recently efforts have been made to apply the three ethical principles to epidemiological studies, surveillance systems, and investigations of outbreaks of diseases.

The Council for International Organizations of the Medical Sciences (CIOMS) has developed guidelines to consider ethical principles and procedures governing surveillance and research in human populations. When epidemiological or public health studies directly involve human subjects, the general body of rules is applicable. When epidemiological studies concern population groups as opposed to individuals, however, refinements of these rules may be applicable. Issues such as individual consent, community involvement, feedback to the communities, confidentiality, and respect for human rights are among those most related to surveillance (26).

At the same time, most countries have enacted legislation concerning the release of information for surveillance and for processes concerned with the protection of the public. For persons working in surveillance units it may be necessary to sign a statement to ensure that data are treated in confidence. Names should be deleted if not required and raw data must be kept secure (4). To be sure that the patient's identity cannot be traced from surveillance reports a category with less than five cases should be aggregated with another.

The recent debate on ethical issues regarding surveillance of AIDS and human immunodeficiency

virus (HIV) indicates that the field of ethics applied to surveillance is underdeveloped and problematic. One issue balances the protection of society from HIV infection and the protection of seropositive persons and AIDS patients from unjust discrimination and against unnecessary constraints on their human rights and civil liberties. "The commanding values, beliefs and perceptions of a community, at any given period in its history, will greatly affect how the balance is struck between the individual's interest in liberty and privacy and the public's interest in health and safety" (27).

Another issue concerns the ethics of identifying groups. The presentation of surveillance information in terms of race, socioeconomic status or sexual preferences can label a group of people in an unethical way. On the other hand, it can lead to special interventions that prevent disease and therefore benefit the group.

## **Sources of data**

### **Traditional sources of data**

Many sources of data can be used for public health surveillance. In 1968, WHO listed ten key sources of surveillance data (18).

Data may be obtained from routinely collected reports, or by special efforts on the part of the investigator, or from collections for other purposes which may be used for surveillance.

The sources of data vary from country to country depending on the stage of development and sophistication of public health services, the quality and extent of laboratory facilities, the available resources, the characteristics of the local diseases (3), and the availability of computers and computer networks.

**Mortality data.** Mortality registration is the oldest form of disease reporting.

#### **• Advantages:**

- Death certificates are legally required in most countries.
- Most infectious diseases of sufficient severity to cause death exhibit unique enough clinical characteristics to permit accurate diagnosis (3).

#### **• Disadvantages:**

- Mortality data reflect incidence only when there is some relatively constant ratio between deaths and cases. When the case fatality rate is too low, mortality statistics may not provide an accurate assessment of the occurrence of the disease (2). For diseases with a long latency period, mortality reports reflect the incidence from many years previously.

- When there are multiple causes of death, the one of greatest public health significance may be lost when causes are recorded on the death certificate (3). There are international rules for the hierarchy of importance when choosing, from the three causes of death on the death certificate, the single cause allowed in the electronic record in most parts of the world; infectious diseases are often at a low level in the hierarchy.
- There is often a long delay in the tabulation and publication of mortality data (3).
- There is wide variation in the accuracy with which death certificates are filled out (2).

**Morbidity data: case reporting.** The notification of cases for specified diseases is the backbone of surveillance.

- **Advantages:**
  - Case reporting is legally required in most countries and is well established.
  - It gives local information for local public health action.
  - The quality of the data is usually good for severe or rare diseases.
- **Disadvantages:**
  - Reportable diseases are, of necessity, mainly acute, infectious diseases. Many diseases are not suitable for this form of surveillance.
  - The system can be quite slow and depends upon the diagnostic accuracy of many different health care providers.
  - Failure to report is common and can vary giving false trends.

**Epidemic reporting.** The identification of epidemics often involves public health officials and laboratory facilities.

- **Advantages:**
  - Most countries require some form of reporting of epidemics.
  - Certain diseases cannot be readily distinguished as sporadic cases, nor do they present a serious health hazard before they occur in epidemic form. Examples are influenza, rubella, and certain types of diarrhoea and food poisoning (18).
  - Frequently, there is a quantitative improvement of reporting when clusters of cases occur (2).
- **Disadvantages:**
  - A cluster of false cases can occur raising expectations of more cases. This can bias reporting for a period of time.

- If the reporting of epidemics leads to severe restrictive measures (e.g., with tuberculosis or leprosy), there may be suppression of information (18).

**Laboratory reporting.** Disease reports can originate in laboratory facilities.

- **Advantages:**
  - There are diseases for which laboratory identification of the etiological agent is essential for accurate diagnosis and treatment. For these diseases, laboratory surveillance works very well and can prevent burdening the case reporting system with the requirement to report.
  - The laboratory can provide important information concerning specific characteristics of microorganisms. For example, the antigenic characteristics of influenza strains that are important in the formulation of vaccine or the identification of the serotype of salmonellae isolated from different patients that may be part of a single outbreak (2, 3).
  - Laboratory notification of certain diseases is relatively easy to implement and inexpensive to run. It is required by law in several countries.
- **Disadvantages:**
  - Laboratory reports may not be representative of the disease in the community because there are selection biases that determine which patients have samples sent to the laboratory, and multiple tests can be ordered on a single individual.
  - The accuracy of information can be influenced by differences in diagnostic techniques.
  - Epidemiological information on cases is limited.

**Individual case reports.** Individual case investigation is more likely to be performed in rare diseases or unusual cases of a common disease. If a disease of public health importance occurs in an area previously free of disease or if the disease is approaching control (or eradication) status, then intensive investigation of each reported case is important. For diseases of high frequency, individual case investigations may be conducted as a check on the validity of morbidity or mortality reporting (2, 3).

Currently individual case investigations are carried out for diseases such as smallpox, yellow fever, certain types of viral encephalitis, haemorrhagic fevers, rabies, and paralytic poliomyelitis.

**Epidemic field investigation.** When there is an increase in the number of cases or deaths from a disease of public health significance, a team sometimes is dispatched to investigate the epidemic. The decision to do this is based on the specific disease, the

seriousness of the outbreak, the anticipated need for more specific information concerning the occurrence of the epidemic, the availability of resources, research potential, and possibly political pressures (2).

• *Advantages:*

- Epidemic field investigation may uncover more cases of the disease than would have been reported without the investigation (2).
- It may add scientific information on sources, transmission modes and characteristics of disease and lead to measures that prevent similar outbreaks in future.

• *Disadvantages:*

- Usually only outbreaks of cases closely related in time and place are identified.
- It can be costly.

**Surveys.** Many types of surveys have been used in public health, particularly for infectious disease markers. Some epidemiological markers that are useful for surveys are: physical examination (splenomegaly for malaria, scars due to smallpox or its vaccine); diagnostic testing (positive blood smears for malaria, positive skin test for tuberculosis). For many viral diseases, major reliance must be placed on serological surveys because the clinical picture is not diagnostic (2, 3).

• *Advantages:*

- Surveys use standardized methods, usually produce high quality data and can be carried out rapidly.

• *Disadvantages:*

- Surveys are usually costly.
- Considerable controversy exists as to the correct interpretation of serological tests for many diseases. This has led to confusion about the meaning of the results of some serological surveys (e.g., HIV antibody testing in populations with low prevalence).
- A survey gives information only for a single point in time.

**Animal reservoir and vector distribution studies.**

Surveillance of human diseases acquired from animals or arthropod vectors requires the collection of data on the presence of animal cases or appropriate vectors in the area. The surveillance of these infections requires a multidisciplinary investigation team or close cooperation between epidemiological, veterinary and entomological services (3, 18).

**Demographic data.** Demographic data are necessary in order to effectively analyse disease occurrence

data. Incidence rates cannot be determined without denominator data on population size. Such data may include age, sex, occupation, residence or other personal information (2).

**Environmental data.** Environmental background information that may be valuable includes sanitary conditions, food and water supplies, housing, insect vectors of disease, nutrition and cultural habits. The accessibility, utilization and quality of medical care must be known in order to evaluate the potential efficacy of case-reporting, mortality data and other indices of the health of the population (3). Data about air pollution and weather conditions may be important for certain diseases (e.g., respiratory diseases).

**Other sources of data**

Since 1968, additional sources of data have become available and may be used besides the traditional sources listed above. Most of these data are collected for other purposes, but may be utilized in supplementing routine surveillance data or in evaluating special disease situations.

**Hospital and medical care statistics.** The existence of national health plans in many countries and the extension of prepaid health-insurance schemes make computerized accounting necessary. This generates large databases that can be used for surveillance.

Hospital discharge data include information on diagnosis, surgical procedures, complications, length of stay, laboratory data and other factors (3, 28, 29). These data are valuable in providing information on the severest stages and types of illness.

For less severe illness, information on hospital emergency and outpatient visits has been used (12), as well as records of health insurance payments. Data from special clinics, such as child health clinics, sexually transmitted disease clinics, tuberculosis clinics, can also be used.

**General practitioners.** In some areas, networks have been established by groups of cooperating physicians to record morbidity and medical care data (3, 30). This source of data includes less severe illnesses not necessarily in hospital records.

**Public health laboratory reports.** Public health laboratories provide a wide range of diagnostic facilities for communicable diseases and today many are computerized, making their data bases easily accessible. Utilization of information from these laboratories is valuable for surveillance of viral infections since many are not reportable diseases and accurate diagnosis is often dependent on laboratory identification of the viral agent (3).



**Disease registries.** Registries are designed to collect information on a specific topic and are usually limited in scope. They are not surveillance systems, but data from registries can be used for public health surveillance (6).

**Drug and biologics utilization and sales data.** The utilization or sale of drugs and biologics for treatment or prophylaxis of a disease may be used to monitor disease occurrence (8).

**Absenteeism from school or work.** A sensitive barometer of any major epidemic is an increase in school or work absenteeism. The most valuable venue depends on the usual age affected by the disease. Sickness-benefit or insurance claims can also be utilized (3).

**Health and general population surveys.** Data from health and general population surveys, carried out for other purposes, can be used for surveillance. They are not helpful in providing immediate surveillance, but repeated surveys can reveal long-term trends of importance (3).

**Newspaper and news broadcasting reports.** The news media often report outbreaks of disease before they have been detected by the slower process of most health reporting mechanisms. Furthermore, there may be epidemics of non-reportable diseases picked up by the news media that may be missed or never officially reported to the public health authorities (3).

## Methods: data collection and surveillance systems

### Collection of data

The collection of data is the most costly and difficult component of a surveillance system. The quality of a surveillance system is only as good as the quality of the data collected. Moreover, it is essential to establish denominator data for the target population (4).

**General methods.** Application of the following methods should ensure the quality, uniformity, and reliability of surveillance data. Any bias in the surveillance system should remain consistent over time to be more easily dealt with at the analysis stage.

- **Motivation.** The diligence with which case information is collected reflects the motivation of the person responsible for collecting it. This can be encouraged by legal requirements, education, participation in projects, dissemination of data back to the people who collected them, and by making important clinical and therapeutic information available to those

who report. Other methods have also been used, such as making specific drugs or biologics available to physicians on notification, and non-monetary or monetary rewards (2).

- **Ease of collecting.** Any collection mechanism that is complex or that demands excessive expenditure of time is unlikely to succeed, even when ingenious ways to encourage reporting are used (2).

The data collectors have to be trained or at least provided with clear and strict guidelines for data collecting. Ideally data collection should be made on standard forms, with the following characteristics: (a) clarity; (b) simplicity; (c) requirement for only important information; and (d) no ambiguity (4).

- **Definitions.** It is important in developing a surveillance programme that standard and specific definitions, including case definitions, be developed and publicized so that all participants can collect accurate information.

The case definition must be simple, acceptable, and understandable and not incorporate diagnostic criteria that are difficult to comprehend or obtain. If laboratory test results are part of the definition, they must be readily available, inexpensive, and not demand a great deal of the patient. It is also important to consider whether only confirmed cases should be reported or whether reporting should also include presumptive or suspect cases of disease (2). Other terms that often require definition include race, immigrant, immunization status, and sexual preference.

- **Timeliness.** Reporters and collectors should be required to return the forms at regular intervals, e.g., daily, weekly or monthly. Timeliness has been improved by linking reporting to payment systems (4).

- **Completeness.** The need for completeness of case ascertainment varies according to the incidence of the disease under surveillance. For those diseases that normally do not occur in an area or occur at a very low incidence, it is essential that all cases should be reported.

On the other hand, for the surveillance of diseases that occur commonly it is not necessary for all cases to be reported. The fact that all cases are not reported should not reduce the effectiveness of surveillance, since it is generally the trends of disease occurrence that are important for decision-making on control and preventive measures. However, if a change in the ascertainment fraction occurs for any reason (change in the case definition, improvement in diagnostic techniques, etc.), it will be followed by a change in the reported occurrence of the disease. This should be recognized in the analysis of the data and not falsely interpreted as a real change (2). It is

sometimes necessary to sacrifice a measure of completeness to ensure regular and systematic reporting (4).

**Collection procedures.** Although the above-mentioned general methods for data collection are always applicable, different needs, diseases, and sources may require different systems for collecting the data.

- *Passive surveillance.* In a passive surveillance system, the data recipient may have initiated the system, but essentially has to wait for the data providers to report. Sometimes the providers are required by law to produce the information, as in a notification system, or in other ways are obliged to do so (4).

- *Active surveillance.* In certain circumstances data must be obtained by searching for cases and, perhaps, periodically contacting those who may know of cases: this is known as active surveillance. For some, usually rare, diseases (where completeness becomes more important) or during outbreaks active surveillance is necessary so that cases that may otherwise be missed are sought using any available source. For this type of surveillance, reminders may have to be sent to possible providers of information. Because of the large amount of effort and low return, active surveillance is expensive (4) and usually limited to specific diseases over a limited period of time, e.g., after exposure of a community or during an epidemic (8).

- *Sentinel surveillance.* Sentinel surveillance relies on a pre-arranged sample of reporting sources who agree to report all the cases (or a sample) of one or more conditions (8). With sentinel surveillance, completeness is sacrificed for greater reliability, speed, and sometimes cost containment. This type of surveillance is usually only worthwhile for common diseases (4).

- *Surveillance based on secondary data analysis.* Increasingly, health agencies are making creative use of available data sets for surveillance purposes. This approach is the primary one for chronic disease surveillance, but is also being applied to infectious diseases, particularly those that do not have established surveillance systems.

Using the available data sets for surveillance differs from traditional surveillance in several ways. First, most data sets lack personal identifiers, so that the level of surveillance is necessarily the community rather than the individual. Second, the data are collected, compiled, edited, packaged, and made available sometimes months if not years after the events occurred. Therefore, secondary data analysis is usually more appropriate for guiding long-term rather than short-term intervention. Third, because the data are often collected for other reasons, they

may not be of high quality and important epidemiological items may be missed (8).

- *Special surveillance surveys and investigations.* Two of the sources of data listed by WHO, namely epidemic field investigations and surveys, could be considered as data collection methods rather than as sources of data.

### **Surveillance systems**

A surveillance system for a specific disease or health-related condition will not include all the data sources or collecting procedures discussed previously. One or any combination of the different sources and methods can be used to develop a system. Those that provide the most accurate information that can be collected in a practical and efficient manner and that satisfy the goals and objectives of the surveillance system should be used.

The specific sources and methods used in any surveillance system depend on the disease or condition under surveillance, the methods used for identifying the disease, the goal of the system, the personnel and material resources available, the population involved, and the characteristics of the disease's occurrence. At times, one source of data may be used regularly and others utilized as necessary to improve the primary source (2). Moreover, if more information is needed concerning the occurrence of the disease or if there is a need to validate surveillance data, a second method can be introduced to improve or check the sensitivity and specificity of the first.

Table 3 gives some examples of surveillance systems, which use different data sources and methods. The list is not exhaustive, but includes a wide variety.

## **Methods: data analysis, interpretation, dissemination and link with public health action**

### **Analysis of data**

Surveillance data initially should be analysed in terms of time, place and person. Simple tabular and graphic techniques are traditionally used to display the data.

Analysis of surveillance data primarily involves comparing current data with some "expected" value, identifying differences between them, and assessing the importance of these differences. Most commonly the expected value is based on figures for recent reporting periods, or for corresponding periods from previous years. In addition, current data from one reporting area (e.g., a country) can be compared with

Table 3: Examples of surveillance systems

Accident surveillance (31–33) <sup>a</sup>
Adverse reaction surveillance (34, 35)
Cancer surveillance (36, 37)
Child growth and nutrition surveillance (38–40)
Cholera surveillance (41)
Chronic disease surveillance (42–44)
Communicable disease surveillance (11, 24, 45–49)
Congenital malformation and birth defect surveillance (50, 51)
Environmental surveillance (52)
Epidemic surveillance (53)
Injury surveillance (54, 55)
Mental illness surveillance (56)
Nosocomial infection surveillance (57)
Occupational health surveillance (58, 59)
Poliomyelitis surveillance (60)
Sexually transmitted disease surveillance (61)
Smallpox surveillance (62)
Tuberculosis surveillance (63)
Vaccine surveillance (64)

<sup>a</sup> Figures in parentheses indicate a publication in the list of references.

data from neighbouring areas or a larger area to which it belongs (8, 65).

**Time.** There are four trends to consider in the time analysis: secular trend, cyclic trend (e.g., five-year patterns), seasonal patterns, and epidemic occurrence of the disease (2, 65).

Time analysis is usually conducted in several different ways to detect changes in disease incidence. Some examples follow.

- The number of case reports received in one week compared with the previous four weeks may show an abrupt increase or a gradual rise in the number of cases. This method works well when new cases are reported promptly.
- The reporting rates during the current period may be compared with the reporting rates during the same period of the last four years. A related method involves a comparison of the cumulative number of cases reported to date this year with the cumulative number reported up to the same date in previous years.
- Analysis of long-term (secular) trends is usually presented in graphs indicating the occurrence of disease, by year. The graphs may include the occurrence of events which are thought to have an impact on the secular trend, such as a change in diagnostic criteria or reporting requirements, or the implementation or cessation of an intervention programme. Changes in the level of

emphasis on active case detection should also be noted.

The analysis should be based on the disease rates, taking into account the size of the population from which the cases arose. This is important particularly when analysing secular trends.

If delay occurs between diagnosis and reporting, a better representation of disease incidence over time can be obtained by analysing by the date of onset rather than by the date of the report. Unfortunately, because of variation in reporting delays, this method is not practical for short-term analysis (8).

**Place.** If the time analysis reveals an increase in disease incidence, it is important to determine where the cases are occurring. Even if time analysis is unrevealing, geographical analysis may identify a localized outbreak (8).

Analysing the data by place refers both to the location of the source of the disease and to the location of the patient at the time infection occurred and at the time of onset of clinical disease. The development of effective control measures depends on carefully defining each of these areas (2). Use of rates is essential for separating high incidence from high case numbers due to high population density.

**Person.** The analysis of surveillance data by the affected persons' characteristics is valuable for identifying risk groups. Age and sex are provided in most reporting systems. Other variables such as nationality, level of immunity, nutrition, lifestyle, school or workplace, hospitalization, risk factors, and socioeconomic status may be studied if available.

Meaningful age categories depend on the disease of interest. In general, the characteristic age distribution of a disease should be used in deciding the age categories. Categories chosen for the surveillance (numerator) data should be consistent with the available population (denominator) data (8).

### Interpretation of data

Data analysis must be followed by interpretation. Interpretation involves consideration of whether the apparent increases in disease occurrence, within a specific population at a particular time and place, represent true increases. The amount of variation required for action depends on the priorities assigned to the disease, as well as the interests, capabilities and resources of responsible agencies and sometimes the public, and also political or media attention and pressure.

Other possibilities for variation include an increase in population size, improvement in diagnostic procedures, enhanced reporting, duplicate reporting, and other changes in the system (8). In many

instances it may be difficult to decide if the change detected is real or artificial, but this question must be answered before action can be contemplated (4). Suspicion of a common source of infection, arising from apparent similarities in the sex, age, and place of residence or occupation of cases may be sufficient to initiate an investigation (8).

### **Dissemination of data**

Dissemination of surveillance data to those who need to know is a critical component of a surveillance system. Recipients should include those who provide (or should provide) reports, those who collect the data, and those who need to know for administrative or programme planning and decision-making purposes (8). Appropriate research workers, members of the public, and the media may also be target groups (4).

A surveillance report serves two primary purposes: information and motivation (8). A summary of the current situation, appropriate analysis, and presentation of data (with meaningful interpretation and discussion of trends or other important features) are the basic elements (4, 66). Reports are usually prepared at regular intervals such as weekly, monthly, quarterly or annually. The frequency should reflect the interest in the data as well as the need for distribution of the data for control actions (2).

Most health agencies produce a periodic newsletter for the medical and public health community. Usually these newsletters also contain information on prevention, diagnosis, and treatment of selected diseases and summaries of epidemiological investigations in progress or recently completed (8).

### **Link with public health action**

The link between problem identification and public health response is well established for many of the communicable diseases. An outbreak of a communicable disease usually leads to an investigation and appropriate public health action (e.g., removal of food product, exclusion from school, vaccination, treatment of water supply). Surveillance data may also be used to target or modify education, immunization, and other risk-reduction programmes.

The link between chronic disease surveillance and public health programmes is less well characterized. In part, this reflects the immaturity of most chronic disease surveillance efforts. In part, it also reflects the nature of chronic diseases and the time frame in which a response is appropriate. Rather than warranting an acute response, changes in chronic disease occurrence are more likely to result in initiation of new community intervention programmes which may affect disease occurrence in 10 or even 20 years (8).

## **Evaluation of a surveillance system**

Every surveillance system should be evaluated periodically to ensure that it is serving a useful public health function and is meeting its objectives. A systematic evaluation should address the following five aspects (5, 8, 67).

### *(1) Importance*

The importance of a health event and the need to have that health event under surveillance can be described in several ways. Health events that affect many people or are costly clearly have public health importance. However, health events that affect relatively few people may also be important, if the events cluster in time and place or if the event has a potential to re-emerge. Elements to evaluate importance could be the total number of cases, severity of the illness, mortality, hospitalization, disability, potential for spread, and preventability (68).

### *(2) Objectives and components*

Describing the objectives of the system allows the development of a framework for evaluating its specific parts, such as:

- case definition of the health events;
- population under surveillance;
- data collected—time period and information collected;
- data sources, reporters and collectors;
- data handling—transferring and storing;
- data analysis—by whom, how, and how often;
- data dissemination—to whom, how, and how often.

It can be helpful to draw a flow-chart of the system.

### *(3) Usefulness*

An assessment of the usefulness of a surveillance system should begin with a review of the objectives of the system. The usefulness is measured by whether it meets the objectives and whether this leads to positive health outcomes.

The assessment can be qualitative, in terms of the subjective views of those using the system, or quantitative in terms of the impact of the system on policies, interventions or the occurrence of a health event.

### *(4) Cost*

The cost of a system includes indirect as well direct costs, and should be measured in relation to the benefits obtained. All elements of the system should be included in the cost: data collection, analysis and dissemination. Since this task is quite difficult and

often cannot be accomplished, at least a description of the resources that are used to operate the system (direct costs) should be done. This includes the personnel and financial resources expended by the public health community to maintain all phases of the system (69, 70).

##### (5) *Quality of surveillance system*

A surveillance system has several features that affect the quality of the system. These are discussed below.

- *Simplicity.* Simplicity should be inherent in the system as a whole, as well as each component (case definition, reporting procedures, etc.), to make it easy to understand and implement. In general, a surveillance system should be as simple as possible while still meeting its objectives. A simple system is usually more flexible, and is more likely to provide timely data with fewer resource needs than a complex system.

- *Flexibility.* Flexibility refers to the ability of the surveillance system to accommodate changes in operating conditions or information needs. A flexible system adapts easily to the addition of new notifiable diseases or situations or more population groups. Flexibility is probably best judged retrospectively, by observing how a system responded to a new demand.

- *Acceptability.* Acceptability reflects the willingness of individuals and organizations to participate in the system. The acceptability of a system depends on the perceived public health importance of the event under surveillance, the recognition of the contribution of individuals to the system, and how much time is needed to make the reports. The surveillance method must be acceptable not only to the collectors of the data, but also to the subjects who will want assurances on the confidentiality of the data (71).

Acceptability of reporting may be gauged by the proportion of persons who report cases compared with the number who should report and by the completeness of report forms. For systems that involve interviews with subjects, acceptability may also be measured by interview completeness rates. Acceptability may also be considered in terms of the intended linkage to programmes, determining whether action occurs based on the information provided by the surveillance system.

- *Sensitivity.* Sensitivity is the ability to detect health events which the surveillance system is intended to detect. The measurement of sensitivity requires validation of the findings of the system (outbreaks, trends, change in disease occurrence, etc.), verification of the quality of the data (in terms of accuracy and completeness of each case reported), and the estimate of the proportion of the total num-

ber of cases in the community being detected by the system (reporting fraction). Sensitivity may be measured by conducting a representative survey and comparing the results with those from the surveillance system (72).

Sensitivity has often been viewed as completeness of reporting, especially for notifiable diseases (73–75). In fact, the need for completeness is often considered so important that considerable cost, time, and energy are expended in attaining this goal. However, a surveillance system that does not have high completeness can be sensitive, as long as the reporting fraction remains reasonably constant (76). Indeed, for relatively common conditions, achieving high completeness of reporting may be expensive and accomplishes little.

Completeness becomes a more important consideration for very uncommon diseases (e.g., Reye syndrome) or when, as a control measure progresses, a common disease becomes rare (4, 77). In these situations, one purpose of surveillance is case-finding and completeness becomes synonymous with sensitivity.

The people responsible for a surveillance system should be aware of and know why underreporting occurs (e.g., asymptomatic cases, inadequate data sources, case definition requirements). For notifiable diseases, the reasons for underreporting that can be corrected include: lack of knowledge of the reporting requirement (e.g., unaware of which disease must be reported, or how or to whom to report); negative attitude towards reporting (time-consuming, too difficult, lack of incentive, lack of feedback, or distrust of the government); and misconceptions that result from lack of knowledge or a negative attitude (concern about confidentiality, or the disease is not regarded as serious, or the perception that the health department does not use or value reports) (8, 69, 73, 78).

- *Predictive value positive.* Predictive value positive is useful in the case of rare notifiable diseases. It is the proportion of reported cases which truly are cases, or the proportion of reported epidemics which are actual epidemics. Assessment requires confirmation of cases reported through the system. When the main purpose of a surveillance system is case-finding, a low predictive value positive, and therefore frequent false-positive case reports, would lead to waste of resources. However, in circumstances where it is extremely important not to miss a single true case, a certain level of false positive reports may have to be accepted.

- *Representativeness.* Representativeness reflects the extent to which the surveillance system accurately portrays the incidence of the health event in the population by person, time and place (75, 79). Rep-

representativeness is important for the generalizability of the information.

Representativeness can be measured by comparing the surveillance data with data from another source (e.g., random sample survey). It is related to underreporting, when this is not uniform or random. Some examples are:

- a case which results in severe illness and hospitalization is more likely to be reported than a mild case; this bias results in an inflated estimate of disease severity such as death-to-case ratio;
- a case that occurs during periods of local publicity about the disease is more likely to be reported than at other times; this bias results in an underestimate of the baseline incidence of disease;
- a case with particular characteristics is less likely or more likely to be reported; this bias results in the systematic exclusion or inclusion of a high-risk group (80);
- some types of health care settings tend to have a higher reporting fraction than others.

Assessing the representativeness of the system may help identify important biases in terms of sub-populations systematically excluded by the system.

• *Timeliness.* Timeliness reflects the delay between steps in a surveillance system. It involves not only the interval between the occurrence of the event and the receipt of the report (data collection) (75), but also the time subsequently required for identifying a problem or epidemic (analysis, interpretation of data) and the feedback (dissemination) for control measures.

Timeliness is related to the simplicity of the system and of the case definition (e.g., whether a laboratory test is required), and it depends to some extent on the resources available. Timeliness must be considered in relation to the event concerned; for most infectious diseases, the response should be quick, whereas for a chronic disease much slower reporting may be adequate.

## Ways to improve the system

Evaluation of a surveillance system may suggest a number of steps that could be taken to improve it. Attributes and costs of a surveillance system are interdependent, and the attributes within themselves are interdependent. The improvement of one may improve or compromise another. Recommendations for changes in the system need to consider these interactions. Some ways to improve a system are described below.

### (1) *Improve the awareness of providers*

All persons who have a responsibility to report must be aware of this responsibility. This can be accom-

plished by publicizing the list of reportable diseases and the mechanism by which to report a case (69), and giving greater emphasis to the legal requirement and importance of reporting at every level of the health care providers' training (73, 80, 81).

### (2) *Simplify reporting*

Reporting should be as simple as possible for the reporter. This can be accomplished in several ways: telephone reports and toll-free numbers, wide availability of forms, and automatic reporting (8).

### (3) *Frequent feedback*

Feedback should be timely, informative, interesting, and relevant to practice. Apart from providing information, feedback about disease patterns and control activities, based on surveillance, increases and reinforces the importance of participation in a meaningful public health activity (8).

### (4) *Use multiple sources and methods*

Any relevant data source can be considered as a supplement to the primary source (73). Sources are chosen according to the disease characteristics (77). Supplemental methods such as an active system may be used as well (82).

### (5) *Active surveillance*

Active surveillance shifts the burden for report generation from the health care provider to the data collector. Active surveillance has been shown to increase the number and proportion of reported cases, and to promote closer personal ties between the providers and the collectors. However, active surveillance is relatively expensive, and its cost-effectiveness is not entirely clear (8, 70).

### (6) *Sentinel surveillance*

It has been proposed that notification of all cases is only necessary for the very limited group of diseases which are rare or for which case-finding may be necessary. Information for epidemiological purposes is required for a very wide range of relatively common infectious diseases, and could best be obtained from a small number of sentinels. This would give a more accurate picture of a sample of the population, from which extrapolation for national and international comparisons could be done (74, 83).

### (7) *Computerization*

The introduction of computer hardware and software has provided public health professionals with the capability of performing surveillance more efficiently (6). Among the advantages of routinely using computers are better management of large databases; record linkage of separate sets of health statistics (84); increased timeliness of data collection; increased ability to organize, tabulate and analyse

data; increased ability to carry out epidemic investigation through software developed for this purpose; and reduction in human resource requirements.

### **Computer-linked telecommunication networks**

The introduction of computer networks is opening a completely new way of performing traditional surveillance activities. The main advantage of networking is improved data timeliness that allows better monitoring of diseases and rapid identification of epidemics and changing epidemiological patterns. The quick return of information to the data collectors, together with access to on-line information, can stimulate participation.

There are two well-described experiences with computer networks: one in the USA, the Epidemiologic Surveillance Project which links weekly reporting of notifiable infectious diseases from State Health Departments to the CDC via computer (85, 86); and one in France, the French Communicable Disease Network, initiated in November 1984, which includes the National Department of Health and local health offices with part of the transmission from the local to the national level occurring through the network (87, 88).

### **New methods of analysis**

The increased sophistication of statistical methods, the availability of computers, and the development of statistical software for analysis have broadened the potential for statistical analysis in day-to-day public health practice and led to new methods for analysing surveillance data (89).

**Detecting time and place clusters.** Although detecting clusters of disease has always been a goal of public health surveillance, formal statistical testing for clusters has rarely been applied to routinely collected surveillance data. In February 1988 a United States National Conference on Clustering of Health Events provided a public forum for reviewing this subject and for presenting new information and approaches (90). A guideline on this topic has since been developed by the CDC (91). The importance of these new methods is based on the fact that often, particularly for non-infectious events, standard approaches cannot be used in an investigation of clusters because the number of events is too small, data on the population at risk are unavailable, and stimulated reporting may occur.

**Time-series analysis.** Time-series analysis has been applied to surveillance data to examine oscillatory trends in the incidence of infectious disease and the impact of mass vaccination programmes on these well-documented phenomena (92, 93).

**Mathematical models.** There is increasing use of mathematical models to study the dynamics of infection within communities of people and the impact of various vaccination policies (94, 95), and to forecast epidemics based on surveillance data (19, 96, 97).

## **Establishing a surveillance system**

Occasionally there is a need for the establishment of a new surveillance system. This can be because of an emergency, a serious new disease, or an increased need for information on a known disease. Since running a surveillance system is a very complex, difficult and expensive task, the justification, objectives and processes for a system should be clearly identified and considered before starting up.

The tasks involved in establishing a surveillance system are outlined below (10), with a summary of some topics described earlier in this paper.

### **Justification**

The first consideration is related to whether a new system is really needed. The following criteria should be considered:

- importance of the disease (it causes serious illness, death or disability, or it has potential for spread);
- prevention and/or control measures are available and surveillance is necessary to guide, monitor, and evaluate them;
- there is a need to study the disease, its patterns of occurrence and the populations at risk;
- there is a need for baseline data (e.g., when control measures are anticipated);
- available data and alternative sources of data will not suffice.

Often there are many health events to put under surveillance, either in the same or in different systems. On the other hand, the resources available for surveillance purposes are limited. In this case, it is necessary to select criteria to set the priorities for surveillance among the health events (68).

### **Objectives**

The next step is to describe the objectives. This is a particularly crucial step because it creates the general framework for designing, implementing and evaluating the system. The objectives should be as clear as possible to provide a common understanding among participants in the system.

### **Definitions**

The health event or events to be included in the surveillance system, any other crucial terms, and the population under surveillance must be clearly defined.

The case definition follows from the objectives stated for the system. It should reflect them in its characteristics (e.g., specificity/sensitivity, confirmed/suspected cases, symptomatic/asymptomatic cases, laboratory confirmation, etc.). It must be standardized, simple, acceptable and understandable to all who use it.

### **Data collection**

A description of the characteristics of the disease, what is known about its cause, epidemiology, and clinical features can help in choosing and defining the components, data sources and procedures of the system. All must reflect the objectives of the system and the characteristics of the condition under surveillance.

Numerous details must be addressed. Some examples are:

(1) Data to be collected:

- data sources (available, feasible and suitable);
- information to be collected and time period;
- confidentiality and ethical issues;
- collection form, medium;
- information and source for denominator.

(2) Process of collecting:

- collection procedure (passive, active, sentinel, etc.);
- reporters, collectors;
- motivation (legal requirement, voluntary service, etc.);
- lines of data transmission (mail, fax, phone);
- flow of data (local health authorities, central agency);
- coding, entering and storing;
- frequency of collection/transmission;
- computers and networks;
- guidelines for data collection staff;
- staff training.

Before implementing a new system it is essential to evaluate future support and cooperation by those who will be required to provide/collect/report the data. This can include information about their concern or interest in the health event, their availability, and their need in terms of feedback.

### **Data analysis and interpretation**

The planning should include how the data will be analysed (e.g., software, statistical analysis, tables, graphs, maps), as well as the frequency of analysis and those responsible for it.

### **Dissemination and link to public health action**

The dissemination of the data should be planned in advance. This should include how the data will be communicated, how frequently, and to whom. Since the primary objective of most surveillance systems is to lead to appropriate action, it is critical that the system should have a link with those who are responsible for action. This should be addressed in the planning phase, through various considerations:

- Have they been included in the decision making?
- Do they support the surveillance system?
- Will it provide the information they want?
- Will they use the data to make decisions?

### **Personnel and other resources**

Resources must be adequate to allow the system to meet its objectives.

Personnel resources, recruitment, and training should be considered carefully for both the central and local level. The cost of the system should be accurately detailed. This can help in balancing the estimated costs against the resources available, and in evaluation of the system.

### **Evaluation**

Once established, surveillance systems should be evaluated periodically to ensure that surveillance systems meet their objectives and operate efficiently. The evaluation should determine the extent to which objectives are met, decide on the need to continue or modify the system, and give suggestions for improving quality and efficiency.

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### **Résumé**

#### **Surveillance de la santé publique: origines historiques, méthodes et évaluation**

Au cours des trois dernières décennies, la surveillance des maladies s'est transformée en une discipline complète, distincte de l'épidémiologie. Cet élargissement en un domaine scientifique spécial s'inscrivant dans la santé publique n'est



pas reflété dans la littérature consacrée à ses principes et à ses méthodes. Le présent article passe en revue les notions fondamentales de surveillance dont on peut s'inspirer pour mettre au point des systèmes nouveaux et aussi pour comprendre ou évaluer les systèmes qui fonctionnent actuellement.

Les données relatives à la mortalité et à la morbidité ont été conservées et exploitées en vue de l'action de santé publique depuis le XIV<sup>e</sup> siècle et on peut trouver un exemple primitif de système de surveillance lors de l'épidémie de peste à Londres au XVII<sup>e</sup> siècle. Toutefois, ce n'est qu'au XIX<sup>e</sup> siècle que s'est pleinement développé le rôle de la surveillance pour contrôler l'apparition des maladies et décider des mesures de lutte. Cette notion de surveillance a évolué au cours des âges, impliquant au début l'observation des personnes exposées en vue de déceler les symptômes et d'appliquer les mesures individuelles d'isolement et de lutte contre la maladie puis, à l'époque moderne, la surveillance de l'apparition des maladies dans la population.

La surveillance a principalement pour objectif de décrire à tout moment le tableau de morbidité pour guider les mesures de lutte, faciliter la planification des services de santé et évaluer l'action de prévention et de maîtrise de la maladie. Les autres objectifs consistent à étudier l'histoire naturelle et l'épidémiologie de la maladie et à fournir des informations et des données de référence.

Les principes de la déontologie médicale, tels que la confidentialité des renseignements, le consentement individuel, l'engagement communautaire et le respect des droits de l'homme, sont en cause dans la surveillance où il faut équilibrer d'une part le désir de l'individu de jouir de sa liberté et de faire respecter sa vie privée et, d'autre part, la nécessité pour la société de protéger la santé du public.

De nombreuses sources de données peuvent être exploitées pour la surveillance de la santé publique, depuis les rapports établis d'une manière systématique jusqu'aux études spéciales entreprises par des chercheurs ou aux données recueillies pour d'autres raisons. Les méthodes de collecte des données doivent garantir la qualité, l'uniformité et la fiabilité des informations, différentes procédures (par exemple, surveillance passive, active ou par sentinelles) pouvant être appliquées par ailleurs en fonction des objectifs particuliers et des ressources du système. L'analyse descriptive des données selon l'époque, le lieu et l'individu doit être suivie de leur interprétation puis de leur communication à ceux qui ont besoin de connaître les résultats. Les personnes

qui ont la responsabilité d'entreprendre une action basée sur les conclusions des enquêtes doivent avoir un lien étroit avec le système et être disposées à se servir de ses résultats en prenant leurs décisions.

L'évaluation périodique est un élément essentiel de tout système de surveillance. Ce processus doit prendre en considération les composantes, l'utilité, le coût et la qualité du système (simplicité, souplesse, acceptabilité, sensibilité, valeur prédictive, représentativité et opportunité) selon l'importance de la maladie et les objectifs visés. Les recommandations en matière de changements et d'améliorations doivent tenir compte de l'interaction de ces facteurs.

Quand il est nécessaire d'instaurer la surveillance d'un état morbide, il faut prendre en considération l'ampleur de ses effets sur la santé de la collectivité, la possibilité de prendre des mesures de lutte et la nécessité de recueillir des données pertinentes. Des objectifs clairement énoncés créent la structure voulue pour mettre au point, appliquer et évaluer un système de surveillance. Par ailleurs, les définitions, les ressources et les méthodes de collecte, d'analyse, d'interprétation et de diffusion des données doivent être nettement établies avant le démarrage et elles doivent refléter les objectifs du système et les caractéristiques de l'état pathologique faisant l'objet de la surveillance.

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