Introduction
Welcome! My name is Jim Gale. I am professor emeritus in the Department of Epidemiology at the University of Washington School of Public Health and Community Medicine. I spent 12 years as a local health officer in Kittitas County, Washington, where I have used surveillance while investigating several foodborne outbreaks.

I used surveillance as a United States public health service epidemic intelligence service officer and as a research tool in evaluating vaccine efficacy in Taiwan. I have also evaluated the uses of national surveillance data at 15 local and state health jurisdictions in the Western United States.

This online training provides a basic introduction to Public Health Surveillance. The module should take about an hour to complete. It includes several interactive exercises designed to help you remember the material.

Module Overview
This module gives an overview of surveillance systems in local, state, and national public health practice. Examples of these systems include: establishing systematic identification of cases during an outbreak, usually limited to a period of weeks or months; the monitoring of teen suicides within a state to pinpoint populations where intervention programs might be most effectively used, and the tracking of influenza virus types as they occur throughout the United States, in order to plan for the make up of future vaccines.

Objectives
By the end of this module you should be able to:
• Define surveillance and discuss its importance to public health.
• Describe at least two different types of surveillance systems.
• Discuss the legal bases for disease reporting and surveillance, which differ by state.
• List the steps in establishing a surveillance system.
• And, finally, you should be able to list the steps in establishing a surveillance system and explain the process used for evaluating these systems.

What Is Surveillance?
The Centers for Disease Control and Prevention, or CDC, defines public health surveillance as the ongoing, systematic collection, analysis, interpretation, and dissemination of data about a health-related event for use in public health action to reduce morbidity and mortality and to improve health.

Who Uses Surveillance?
Data from surveillance is used in many contexts. For example, public health practitioners, health-care providers, data providers and users, representatives of affected communities, governments at the local, state, and federal levels, and professional and private nonprofit organizations all use surveillance.

Surveillance Systems and Applications
The four essential elements of a surveillance system are the collection of data, the analysis of those data, dissemination of these analyses back to the reporting sources and to others who need to know, and application of these results to control disease and/or improve health.

Surveillance was initially used as part of the process to control communicable diseases. More recently, these methods have been applied to other conditions, including non-communicable diseases, occupational hazards, highway crashes, and a long list of other conditions and behaviors.
Surveillance vs. Data Collection Systems

What are the differences between a surveillance system and a data collection system? Data collection systems can be useful, but, by themselves, they do not constitute surveillance systems because they are not directly linked to disease control activities. For example, collection of vital records information (such as birth and death data) and disease registries are not full surveillance systems.

Food establishment inspections routinely are conducted by local health department personnel as part of foodborne illness outbreaks. Inspections can identify contributing factors that may account for spread of infection and may be used to change policy, but again, they do not constitute a surveillance system by themselves.

By contrast, the Behavioral Risk Factor Surveillance System (sometimes called by its acronym BRFSS), which is a periodic telephone survey of a weighted sample of the United States population to identify risky health behaviors, is considered a surveillance system because it is tied to control measures. The BRFSS is integral to state and local health department planning functions.

Surveillance may be established during an outbreak investigation, depending on whether the extent of the population at risk and possibly affected is known. Interviews with all persons attending a single banquet could be considered case finding, that is, finding cases of the outbreak disease. This activity might also be considered active surveillance, which we will discuss later. Alternatively, extending an alert for hepatitis cases during a community-wide hepatitis outbreak would be considered surveillance. In both instances, the information gathered would be linked to disease control activities.

Exercise 1

Ongoing Versus Limited

The duration of surveillance activity varies depending on the circumstances. Surveillance systems may be ongoing for years for diseases such as hepatitis or influenza. Or they may be limited to monitor people exposed to acute events such as a fire in a pesticide

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warehouse or a one-time common source outbreak such as a Norwalk-like virus outbreak due to exposure to an ill food handler.

We will describe ongoing reportable disease systems next. These systems include reporting and feedback loops, which lead to actions to promote health and prevent disease.

Passive Surveillance
Passive surveillance is a traditional provider-based approach that many people are familiar with. It is based on each state’s official list of reportable diseases. States mandate reporting of cases or data, usually to local health jurisdictions, by the providers, or directly to the state, by the laboratories. In this fashion, local jurisdictions get to see their own patterns of disease occurrence immediately and can follow up with providers directly for clarification. Although passive systems have traditionally underestimated the true burden of disease, their relative increase or decrease can be useful in identifying trends. Interpretation of such trends requires experience to distinguish true changes in disease occurrence from other causes of such change.

Passive Surveillance Information Flow
This diagram illustrates information flow with ongoing, passive reporting systems. Physicians and other health providers report mostly to the local health department, and laboratories report mostly to the state health department. The local and state health departments and the CDC all exchange data with each other. The local health jurisdiction is usually the primary responder if any action is needed. Local health jurisdictions may also call for more assistance when necessary from the state, which in turn, can request assistance from the CDC.
Active Surveillance
Active surveillance involves active outreach, such as personal visits or telephone calls to providers and laboratories, to collect specific disease reports from reporting sources. Active surveillance is similar to case finding in an outbreak situation.

Active Surveillance Information Flow
In this diagram of active surveillance information movement, the solid yellow arrows indicate that the local or state health department takes the initiative in contacting the laboratory, hospital, or other health care provider seeking information on cases or conditions of interest.

Sentinel Surveillance
Another widely used system is called sentinel surveillance. Sentinel surveillance systems are on the “look-out” for certain health events. In an active sentinel system, reporting units are asked to report periodically. For example, the World Health Organization, or WHO, uses sentinel influenza laboratories for advanced detection of influenza activity. These isolates confirm the presence of the virus and allow for identification of the particular strain isolated. Because sentinel surveillance reports come from only a sample of all potential reporting sites it is possible that the system will miss disease activities occurring in a region not covered by the reporting entity.
Sentinel Surveillance (cont.)

Sentinel surveillance can also refer to a reporting system where disease occurrence is identified indirectly.

For example, dead crows are tested for West Nile Virus, because these deaths often precede human cases in a community by a number of weeks. Appearance of the virus in crows then alerts public health authorities to step up prevention activities.

In some areas, sentinel chickens are set out and periodically tested for antibody conversion to arthropod-borne viruses such as St. Louis Encephalitis virus or Western Equine Encephalitis virus. Detection of antibodies prior to the occurrence of human cases documents that the virus is present in that community at that time and may suggest further prevention activities.

Exercise 2

Syndromic Surveillance

Syndromic surveillance is the collection and analysis of pre-diagnosis information that leads to an estimation of the health status of the community that signal a sufficient probability of a case or an outbreak to warrant further public health response. Its utility for detecting outbreaks associated with bioterrorism is increasingly being explored by public health. It has not a fully developed system and not cost-effective at this point in time.

Surveillance Legal Issues

What is the legal authority for surveillance? State laws and regulations define each state’s authority, reporting requirements, and practices. Although they have the potential for great diversity, the CDC exerts a strong coordinating function as to which conditions will be made reportable and the format of the reporting. However, the CDC has no constitutional authority to mandate such practices, and instead must work through consensus with the states.
Surveillance Legal Issues (cont.)

Although state public health regulations can require the gathering of personal health information, states must consider privacy concerns in exerting this authority. The need to conduct surveillance and collect sensitive information on HIV infection and AIDS, for example, has drawn attention to issues of authority and confidentiality in public health. States vary in how they balance the rights of the individual versus the needs of the public health system to keep people healthy.

Enforcement of reporting regulations needs to be handled carefully. Cooperating with reporting sources and educating them has usually been the most effective way to increase reporting. Coercion through legal action is rarely used, although it is often useful to inform reporting sources that health departments have the authority to collect the information. In some states legislatures have passed regulations providing authority to collect information for specific conditions, such as HIV-AIDS.

Providers are more eager to participate if they believe that their patients will benefit. Activities with a clear benefit include the interviewing of contacts of patients with sexually transmitted diseases, or the administration of gamma globulin to contacts of reported persons with hepatitis A. Respondents are not always so conscientious if they feel that data are to be archived and yearly totals compiled without action.

Why Does Public Health Need Surveillance?

Surveillance systems are used to accomplish several objectives. One primary use is to determine the distribution and spread of disease in different population groups. An example of this is the work that was done nationally as the HIV-AIDS outbreak unfolded.

Another use is to detect outbreaks and support public health interventions that follow from the continued monitoring of these data.

Ongoing surveillance can be used to estimate the natural history and often the impact of a condition over time.

Knowing what to expect in terms of natural history aids in planning where to allocate resources.
Continuing surveillance after an intervention can be used to evaluate prevention and control measures.

Finally, surveillance is used in certain research situations. Field testing of new vaccines requires surveillance for disease occurrence in both the vaccinated and the non-vaccinated group to determine the efficacy of the vaccine.

**Attributes of an Ideal Surveillance System**

A surveillance system should be as simple as possible in both its structural design and its ease of use. It should be easy to apply, even before a causative agent can be identified.

A system should justify the effort required by its participants. Its acceptability to stakeholders will be reflected in their completeness and accuracy in reporting.

A system should be at least moderately sensitive. Sensitivity is defined as the system’s ability to detect all or most of the cases. As a practical matter, sensitivity may need to be traded off for simplicity, timeliness, or economy. A surveillance system that is not highly sensitive can still be useful in monitoring trends, as long as the sensitivity remains reasonably constant from one time period to the next.

The system should also be specific—that is, confined to the conditions of interest. Some misclassification can be tolerated, as when monitoring for influenza-like illness in schools, or influenza in nursing homes.

**Attributes of an Ideal Surveillance System (cont.)**

Another attribute, timeliness, is always desirable, especially for conditions where prompt intervention can prevent further disease spread, as in active tuberculosis, or pertussis.

For other conditions, such as Sudden Infant Death Syndrome (or SIDS), surveillance is important in assessing recommendations for infant sleeping position, but there is less urgency in gathering and analyzing information than with, say, TB or pertussis.

A flexible system will adapt to changing information needs. These might include a modification of the...
case definition, as in the case of HIV-AIDS, new reporting forms or procedures, new reportable diseases or conditions (such as SARS), or changes in workload.

Generally, simpler systems will be more flexible—fewer components will need to be modified and integrated with other systems.

Representativeness of a surveillance system refers to the accurate description of both groups that are included (such as the STD clinic population) and excluded (such as undocumented migrant workers, or prison populations).

Finally, costs will influence many of these factors, especially sensitivity, specificity, and timeliness.

Exercise 3

Setting Up a Surveillance System

Now we will consider steps in setting up a surveillance system in a state or a community. The public health importance of the event under surveillance should be considered. While pandemic flu has considerable public health importance, so do other less frequent conditions such as meningitis or rabies. The cost in resources and goodwill involved in setting up and maintaining new surveillance should be assessed against the cost and need to maintain existing systems and the potential for rare but dangerous threats to re-emerge. In all instances, the local context must be considered. In setting up your system, be clear as to your purposes, and be ready to explain them. The system should lead to action steps such as detecting outbreaks, describing the natural history of a disease, and evaluating an intervention.

Setting Up a Surveillance System (cont.)

Stakeholders should be invested in the system. They should understand its purpose and receive regular feedback. If the system is not perceived by the stakeholders to offer public health value, participation will lag, if not disappear.

The case definition, that is, the criteria used to identify cases of disease, should be as simple as possible, consistent with the goals. For example, laboratory
confirmation may not be required early in an outbreak situation, but may be added later if increased specificity is needed.

Data should be analyzed in a timely fashion. Do not collect more data than you are actually going to use. File cabinets are full of unanalyzed data, which not only increases the length of time of data collection, but could actually discourage participation.

Developing a Case Definition

In order to set up a surveillance system, a case definition must be developed. As we mentioned earlier, simplicity is often preferable at the beginning of an outbreak to increase the sensitivity for finding cases. For example, early definitions of SARS included clinical symptoms of fever and an influenza-like illness occurring at a certain time in a certain place. Undoubtedly, many illnesses which were similar but not identical to SARS were included. Nevertheless, public health officials were able to make an estimate of the extent and severity of the outbreak, even with such a non-specific definition.

Developing a case definition requires careful consideration. The definition may evolve as knowledge about the disease or outbreak increases. All definitions should include attributes of persons, place, and time.

When laboratory criteria become available, they can be added to the definition. For example, persons meeting the definition of a case of gastroenteritis during a foodborne outbreak could have the positive stool culture added at a later time.

Sensitivity, or the ability to discover all of the cases occurring, is usually increased with a broader definition, such as all cases of respiratory disease with fever, but it is usually at the expense of specificity, added by laboratory criteria, or shorter periods of exposure. For example, if a positive stool culture is part of a definition, persons who are actually cases may not be counted if their stool culture is no longer positive, or the specimen is mishandled. These trade-offs need to be carefully considered.

Data Collection

Surveillance involves all levels of public health, yet the routes for collecting and exchanging disease information vary. Traditionally, surveillance systems have relied on individual disease report cards filled out by clinical providers.
and sent to the local health department. There, more comprehensive surveillance forms may be filled out and/or entered into a computer. The forms and the report card may then be mailed or sent electronically to the state health department, where they are entered into a computer and electronically transmitted to the CDC.

There is a push to make all reporting electronic, but this is not yet feasible. Issues of completeness of data forms, timeliness, data confidentiality, system security, and right of access to data among people at the federal, state, and local level are among the issues to be resolved. Resources for analyzing and interpreting data are not always timely or available.

**Limitations of Surveillance Systems**

Surveillance system limitations include diagnostic accuracy, completeness, and timeliness of reporting. However, surveillance data can be very useful whenever there is a change in the level of reported cases based on what is expected from past reports. As long as we have an idea of the quality of these three characteristics, having some data is usually better than having none at all. We have spoken of accuracy and completeness of our data, and we have noted that there are usually trade-offs in time and resources to increasing these two characteristics beyond a certain point.

In some instances, such as salmonellosis, reported cases underestimate what is happening in the community because only a small percentage of affected individuals seek out medical care. On the other hand, more severe diseases, like encephalitis or meningitis, are fairly well reported because of their severity and likelihood of being seen and recognized by a clinician.

For any condition, omissions along the reporting path may occur. These can range from omissions caused by ill persons not seeking care, on up to omissions at the CDC itself.
Limitations of Surveillance Systems (cont.)

In summary, despite incompleteness and some misclassification of reported cases, relative increases or decreases can indicate useful trends. Experience is needed in interpreting data, but inferences can be used to suggest the need for active intervention and to evaluate the effectiveness of each intervention as it is put in place. For instance, West Nile Virus reporting is not complete, but has been useful in identifying the east-to-west progression of disease across the United States and the spectrum of associated illness.

Exercise 4

Analyzing Surveillance Data

The analysis of surveillance data often depends upon its intended use.

Ongoing passive surveillance data are usually used to monitor trends over time by person and place. These are usually descriptive analyses and often depicted graphically. The simplest analyses will often return the majority of the benefit from passive surveillance data. Analysis by person, place, and time is always the place to start.

Knowledge of each condition will often determine why prevalence or incidence data should be used. Rates are sometimes preferable to simple counts, but often require more resources to gather them. The additional benefit may not be justified by the additional cost. Please see our other modules for further discussion of rates, incidence, and prevalence.

West Nile Virus Activity

This map shows 2005 West Nile virus activity in human, avian, animal, or mosquito infections reported to the CDC. That these reported cases in all likelihood do not constitute all cases that occurred does not diminish the usefulness of this map. A semi-quantitative sense of the distribution of West Nile virus
activity is well conveyed by the numbers of cases, and especially by those few states where no human cases have been reported. The additional information conveyed by rates would probably not justify the additional expense and effort required to get the information to calculate them.

**Hepatitis A**

Here is another map showing surveillance information, this time for reported Hepatitis A case rates by state and U.S. territory. Differences in the completeness of reporting over time and by different states must be taken into consideration in drawing inferences from these data. That can be done by experienced personnel, and plans for resource allocation can be made accordingly.

**Anthrax Cases**

In the fall of 2001, an investigation conducted by local, state, and federal public health and law enforcement authorities identified letters intentionally contaminated with *Bacillus anthracis* spores. This graph shows the location and date of onset of anthrax cases. When such an outbreak occurs, it is important to enhance existing surveillance activities and/or to install new systems to meet the needs of a given outbreak.

**Surveillance: Anthrax Outbreak (2001)**

Several different surveillance strategies were employed by states in response to the intentional release of anthrax in 2001. These strategies were developed with the goals of improving case finding, describing the spectrum of clinical signs and symptoms of possible anthrax illness, characterizing the population at risk, and determining the magnitude of the outbreak.

One strategy initiated in response to the outbreak was the implementation of a hospital-based surveillance system to monitor conditions potentially related to anthrax or other bioterrorism-associated agents.
Other health indicators monitored for anthrax activity included: a review of death certificates from a specified period of time prior to and during the anthrax outbreak to determine whether any of the deaths could have been anthrax-related, review of laboratory data by contacting hospital-associated laboratories to collect information on detection of the bacterium that causes anthrax as well as other similar species of bacteria, and review of postal worker attendance records.

AIDS Reported Cases 1982–2002
This figure shows the number of cases of AIDS reported from 1982 through 2002. Note the sharp spike in the curve that occurs when the case definition of AIDS was changed in the early 1990s, increasing the sensitivity of the definition. As long as the viewer knows of this change, the rise in the graph at this point can be properly interpreted. The absolute number of cases before or after the case definition was changed cannot be known.

Exercise 5
Evaluation of Surveillance Systems
Evaluation is an important component of the ongoing surveillance process. The approach must be flexible, since characteristics of each system will vary by condition.

For example, all cases of rabies probably will be reported if rabies is diagnosed, for two reasons: intervention must be prompt, first to prevent rabies in persons exposed (by administration of rabies immune globulin, or vaccine), and second, to prevent additional exposures in unexposed persons (by confiscations of animals, bats, and so on). By contrast, the consequences of an unreported case of influenza are usually not so dire. Completeness of reporting takes on different levels of value for these two conditions.
Evaluation (cont.)

Engaging stakeholders is as important during the evaluation process as when a surveillance system is being developed. Stakeholders include those who provide data for the system, those who operate it, and those who use the information generated. Since they are invested in the system, they provide context for, and recommendations following, the evaluation results. Weighing the system’s importance must be ongoing, and is as important during the evaluation as when the system was established.

The system operation evaluation process should include the population under surveillance, time for data collection, information collected, information providers, information transfer and data analysis, and report distribution.

It should include an assessment of the simplicity, flexibility, and acceptability of the system.

It is also necessary to assess quantitative attributes of the system, including its sensitivity, representativeness, and timeliness. Evaluation of the costs and benefits is critical.

Finally, the conclusions should state whether the system is meeting its objectives, and whether it should be continued, modified, or discontinued.

CDC’s Role in Surveillance

CDC provides important leadership for surveillance activities in several ways.

As mentioned earlier, their leadership is by consensus with the states, as they have no constitutional authority to force states to comply. Without the involvement of local health providers and local health departments, routine surveillance would not even exist. On the other hand, without CDC’s participation, there would be no standardization of public health information. Furthermore, data might not be analyzable across state borders.

CDC provides a national perspective for controlling disease conditions and improving the public’s health in general. They often respond to requests from states if assistance with these activities is needed.

CDC supports the state’s efforts to perform routine surveillance by providing...
training and consultation. They also distribute and oversee the funding to help support many nationally reportable conditions.

Operationally, the CDC receives, collates, and analyzes the data that flow into the various centers and programs. From the analysis of these surveillance data, they may suggest interventions in cooperation with states to improve disease prevention and control activities. In addition, in conjunction with current research, they may suggest changes to improve public health surveillance activities.

And finally, CDC reports disease information of global importance to the World Health Organization.

**National Notifiable Disease Surveillance System (NNDSS)**

The CDC maintains many surveillance systems. One is the National Notifiable Disease Surveillance System, or the NNDSS. The NNDSS provides communicable disease data at the national level. It publicizes the list of reportable diseases and laboratory findings of public health interest, publishes case definitions for the system, and maintains a system for passing case reports from local health jurisdictions to the states and then to the CDC. The NNDSS produces local, state, and national disease incidence and trends to guide public health activities at all three levels. The system collects information on 61 conditions, primarily infectious conditions. The Council of State and Territorial Epidemiologists, along with representatives from the CDC, review this list annually.

**Federal Surveillance Systems**

The CDC maintains over 100 other surveillance systems, in addition to the NNDSS. Some of these include international collaborators. These systems address over 200 infectious and non-infectious diseases. Examples include:

- The National West Nile Virus Surveillance System, which monitors West Nile Virus activity and triggers control activities when indicated.

As we mentioned before, the Behavioral Risk Factor Surveillance System is a telephone survey of a
weighted sample of the United States population. It gathers behavioral data affecting preventable chronic diseases, injuries, and infectious diseases. The data are used by states to track health problems and evaluate public health programs.

Influenza surveillance involves sentinel care providers reporting the overall number of patient visits and the number of visits for influenza-like illness by age group to their facilities each week. These data are combined with other surveillance data in order to describe the national and regional activity of influenza and influenza-like illness.

The Vaccine Adverse Event Reporting System, or VAERS, is a post-marketing surveillance program, which collects information about adverse effects occurring after the administration of licensed vaccines in the United States. It is a cooperative program of the CDC and the Food and Drug Administration. Although not particularly sensitive, since many adverse effects are either not recognized or do not get reported, under the correct circumstances it can indicate a problem.

State Surveillance Systems

Many states are implementing projects that improve the public health system by computerizing public health information and providing secure 24 hour, 7 day a week means for urgent communications during public health emergencies. For instance, laboratory data are now being reported automatically in some states. Like the National Center for Health Statistics, states also collect and publish critical information that is needed to help guide actions and policies to improve the health of their citizens. State health statistics programs provide access to data that cover injuries, hospitalizations, deaths, births, pregnancy rates, abortion rates, and behavioral risk factors. Data may be distributed as raw data sets, statistical tabulations, Web pages, and through printed reports. These data are also used by policy makers, health professionals, community-based organizations, and researchers to understand trends, identify high-risk populations and geographic areas, set prevention priorities, and plan targeted health promotion strategies.
Summary

In summary, public health surveillance is a core public health activity directly linked with assessment. Originally used to control infectious diseases, surveillance has expanded to include environmental hazards and illnesses, injuries, chronic diseases, health behaviors, and maternal and child health activities. Legal authority for surveillance activities is spelled out in state-specific statutes and varies among states. Data sources and surveillance methods must be carefully selected to match the available resources and specified goals of surveillance. Surveillance systems should be evaluated regularly to ensure that problems of public health importance are being monitored efficiently and effectively. Each system is unique and must balance benefits versus personnel, resources, and cost allocated to each of its components to achieve its intended purpose and objectives.

Web Resources

Here are some links that provide further information about surveillance.

Final Assessment