



## **Public Health Surveillance:**

- Focus and characteristics of public health surveillance
- Identifying and prioritizing health problems for surveillance
- Collecting data for surveillance
- Analysis and interpretation of data
- Dissemination of data
- Evaluating and improving surveillance
- Characteristics of well-conducted surveillance
- Examples of surveillance
- Major health data systems in the United States
- Limitations of notifiable disease surveillance
- Recommendations for improvement

Christopher W. Blackwell, Ph.D., ARNP-C  
*Assistant Professor*, College of Nursing  
University of Central Florida

NGR 7642: Epidemiology Principles in Advanced Practice Nursing

# Public Health Surveillance

- Introduction:
  - Surveillance: The continued watchfulness over the distribution and trends of incidence of a disease through the systematic collection, consolidation, and evaluation of morbidity and mortality reports and other relevant data
  - Public Health Surveillance now includes diseases and injuries (including risk factors) of public health problems
  - Real essence is to monitor health problems to facilitate prevention and control
  - Essential in setting priorities, planning, and conducting disease control programs and assessing control efforts (does not control the problem)
  - 5 main functions for those conducting surveillance:
    - ID, define, and measure the health problem of interest
    - Collect and compile data about the problem
    - Analyze and interpret these data
    - Provide these data and their interpretation to those responsible for controlling the health problem
    - Monitor and evaluate the usefulness and quality of surveillance to improve it for future use



# Purpose and Characteristics of Public Health Surveillance

- To help interpret data and control disease, it is essential for surveillance to have clear objectives
- Need to have a clear description of how data are collected, consolidated, and analyzed
- After objectives are determined, critical characteristics of surveillance are apparent:
  - Timeliness: to implement effective control measures
  - Representation: to provide an accurate picture of the temporal trend of the disease
  - Sensitivity: to allow ID of persons w/ disease to facilitate Tx, quarantine, or other measures
  - Specificity: to exclude persons not having disease



# Purpose and Characteristics of Public Health Surveillance

- Essential ?'s to ask when deciding surveillance objectives and methods for study:

- What is the **health-related event** under surveillance? What is its **case definition**?
- What is the **purpose** and what are the **objectives** of surveillance?
- What are the **planned uses** of the surveillance data?
- What is the **legal authority** for any data collection?
- Where is the **organizational home** of the surveillance?
- Is the system **integrated** with other surveillance and health information systems?
- What is the **population** under surveillance?
- What is the **frequency** of data collection (weekly, monthly, annually)?
- What **data** are collected and **how**? Would a **sentinel** approach or **sampling** be more effective?
- What are the **data sources**? What **approach** is used to obtain data?
- During what **period** should surveillance be conducted? Does it need to be continuous, or can it be intermittent or short-term?
- How are the data **processed** and **managed**? How are they routed, transferred, stored? Does the system comply with applicable standards for data formats and coding schemes? How is **confidentiality** maintained?
- How are the data **analyzed**? By whom? How often? How thoroughly?
- How is the information **disseminated**? How often are reports distributed? To whom? Does it get to all those who need to know, including the medical and public health communities and policymakers?<sup>9,10</sup>



# ID Health Problems for Surveillance

- You must first determine:  
Is this problem acute and life-threatening or more chronic? Is it truly a problem for this population?
- Selecting a Health Problem for Surveillance:
  - What is its importance?
  - Ability to prevent, control, or Tx the health problem
  - Capacity of health system to implement control measures for the health problem

## Public health importance of the problem —

- incidence, prevalence,
- severity, sequela, disabilities,
- mortality caused by the problem,
- socioeconomic impact,
- communicability,
- potential for an outbreak,
- public perception and concern, and
- international requirements.

## Ability to prevent, control, or treat the health problem —

- preventability and
- control measures and treatment.

## Capacity of health system to implement control measures for the health problem —

- speed of response,
- economics,
- availability of resources, and
- what surveillance of this event requires.



# ID Health Problems for Surveillance

- In the US, CDC and Council of State and Territorial Epidemiologists (CSTE) review communicable diseases and other health conditions to determine which ones should be reported to federal authorities by the states
- Because of their immediate threat, communicable diseases are usually the ones reported
- The *MMWR (Morbidity and Mortality Weekly Reports)* provides a weekly and annual summary of nationally notifiable infectious diseases in the US
- Table 5.1 provides a list of the Nationally Notifiable Diseases– United States 2006



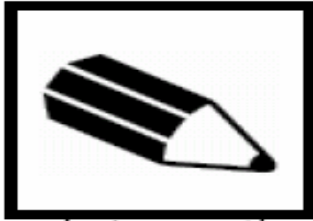
# ID Health Problems for Surveillance

**Table 5.1 Nationally Notifiable Infectious Diseases — United States, 2006**

Acquired immunodeficiency syndrome (AIDS)	Hantavirus pulmonary syndrome	Shiga toxin-producing <i>Escherichia coli</i> (STEC)
Anthrax	Hemolytic uremic syndrome, postdiarrheal	Shigellosis
Arboviral neuroinvasive and nonneuroinvasive diseases	Hepatitis, viral, acute	Smallpox
• California serogroup virus disease	• Hepatitis A, acute	Streptococcal disease, invasive, Group A
• Eastern equine encephalitis virus disease	• Hepatitis B, acute	Streptococcal toxic-shock syndrome
• Powassan virus disease	• Hepatitis B virus, perinatal infection	<i>Streptococcus pneumoniae</i> , drug resistant, invasive disease
• St. Louis encephalitis virus disease	• Hepatitis, C, acute	<i>Streptococcus pneumoniae</i> , invasive in children aged <5 years
• West Nile virus disease	Hepatitis, viral, chronic	Syphilis
• Western equine encephalitis virus disease	• Chronic Hepatitis B	• Syphilis, primary
Botulism	• Hepatitis C Virus Infection (past or present)	• Syphilis, secondary
• Botulism, foodborne	HIV infection	• Syphilis, latent
• Botulism, infant	• HIV infection, adult (aged ≥13 years)	• Syphilis, early latent
• Botulism, other (wound and unspecified)	• HIV infection, pediatric (aged <13 years)	• Syphilis, late latent
Brucellosis	Influenza-associated pediatric mortality	• Syphilis, latent, unknown duration
Chancroid	Legionellosis	• Neurosyphilis
<i>Chlamydia trachomatis</i> , genital infections	Listeriosis	• Syphilis, latent, nonneurological
Cholera	Lyme disease	Syphilis, congenital
Coccidioidomycosis	Malaria	• Syphilitic stillbirth
Cryptosporidiosis	Measles	Tetanus
Cyclosporiasis	Meningococcal disease	Toxic-shock syndrome (other than streptococcal)
Diphtheria	Mumps	Trichinellosis (trichinosis)
Ehrlichiosis	Pertussis	Tuberculosis
• Ehrlichiosis, human granulocytic	Plague	Tularemia
• Ehrlichiosis, human monocytic	Poliomyelitis, paralytic	Typhoid fever
• Ehrlichiosis, human, other or unspecified agent	Psittacosis	Vancomycin — intermediate
Giardiasis	Q Fever	<i>Staphylococcus aureus</i> (VISA)
Gonorrhea	Rabies	Vancomycin-resistant <i>Staphylococcus aureus</i> (VRSA)
<i>Haemophilus influenzae</i> , invasive disease	• Rabies, animal	Varicella (morbidity)
Hansen disease (leprosy)	• Rabies, human	Varicella (deaths only)
	Rocky Mountain spotted fever	Yellow fever
	Rubella	
	Rubella, congenital syndrome	
	Salmonellosis	
	Severe acute respiratory syndrome-associated coronavirus (SARS-CoV) disease	



# ID Health Problems for Surveillance



## Exercise 5.1

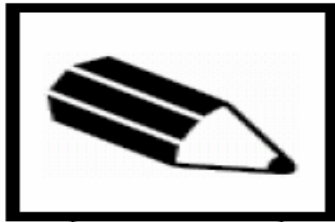
*A researcher at the state university's medical center is urging the state health department to add chlamydial infections to the state's list of diseases for which surveillance is required. On the basis of the information about chlamydial infections provided in Appendix B, draw conclusions on the table below and discuss the advantages and disadvantages of adding chlamydia infections to the state's list of notifiable diseases.*

### *Public health importance of chlamydia*

Incidence	Estimated to be 2.8 million new cases each year in the United States.
Severity	Approximately 40% of infected, untreated women experience pelvic inflammatory disease. Five-fold increase in risk among women of experiencing HIV infection, if exposed.
Mortality caused by chlamydia	Ectopic pregnancy, a potential complication of chlamydial infection, can cause death, but frequency is unknown.
Socioeconomic impact	Complications of chlamydial infections among women have impact on their reproductive ability and can cause chronic illness among certain women, resulting in an undue burden on them, their families, and the health-care system.
Communicability	Passed person to person through sexual contact or from mother to baby during birth.
Potential for an outbreak	Varies with population sexual activity and practices, as well as underlying prevalence.
Public perception and concern	Not described in fact sheet provided. Different readers might have differing perceptions of the level of public concern.
International requirements	None.



# ID Health Problems for Surveillance



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### *Ability to prevent, control, or treat chlamydia*

Preventability

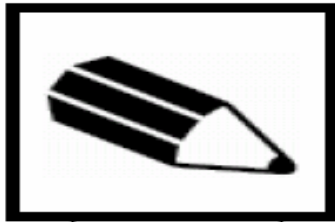
Preventable by sexual abstinence, sexual contact with uninfected partners, and use of latex male condoms.

Control measures and treatment

Secondary prevention through annual screening for chlamydia, which is recommended for all sexually active women aged  $\leq 25$  years. An annual screening test is also recommended for women aged  $\geq 25$  years who have risk factors for chlamydia (e.g., a new sex partner or multiple sex partners). All pregnant women should have a screening test for chlamydia. Chlamydia is highly responsive to antibiotic treatment. Sexual partners should be evaluated, tested, and treated, if infected.



# ID Health Problems for Surveillance



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### *Capacity of health-care system to implement control measures for Chlamydia*

Speed of response

Disease is often asymptomatic, resulting in delayed diagnosis. Annual screening for chlamydia is recommended for all sexually active women aged  $\leq 25$  years and for women aged  $\geq 25$  years who have risk factors for chlamydia.

Economics

Treatment is typically through the health-care system, and the costs are paid by insurers, employers, or the government. Follow-up of patients to identify contacts is the responsibility of the health department. Given the frequency of the disease, this might require substantial resources that are not be available in certain places.

Availability of resources

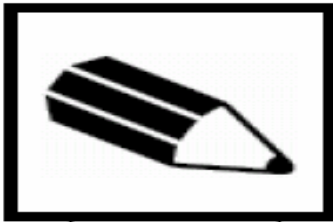
Dependent on location.

What does surveillance for this event require?

Screening and diagnosis of men and women with chlamydial disease and then reporting of disease by health-care providers to the state health department by using a standard form. The percentage of women who actually receive recommended screening is unknown. Surveillance can also be conducted by using reporting of positive diagnostic tests by laboratory facilities.



# ID Health Problems for Surveillance



## Exercise 5.1

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### Advantages

- Surveillance provides an estimate of the true prevalence of this important but often overlooked condition.
- Infection is treatable, and transmission is preventable.
- Untreated chlamydial infection is a major cause of pelvic inflammatory disease and infertility.
- Surveillance can be conducted through routine laboratory reporting of all positive tests for chlamydia, which might reduce the reporting burden on health-care providers.

### Disadvantages

- Clinicians might ignore the requirement to report chlamydia, even if it is added to the list of notifiable diseases, if they believe the list is already too long. They might believe they should only be required to report communicable diseases with statistically significant morbidity or mortality that can lead to immediate intervention by the health department.
- Clinicians might not adhere to screening recommendations, and therefore, recognition of disease might be low.
- Adding chlamydia to the list will not lead to better diagnosis and treatment, because the majority of infections are asymptomatic.



# ID Health Problems for Surveillance

- Defining the Health Problem, ID Needed Information, and establishing the Scope for Surveillance:
  - After ID the need to undertake surveillance, we must then operationalize the definition to ensure the problem is accurately and reliably recognized and counted; this is known as the Case Definition:

## Case Definition of Listeriosis for Surveillance Purposes

### *Clinical description*

Infection caused by *Listeria monocytogenes*, which can produce any of multiple clinical syndromes, including stillbirth, listeriosis of the newborn, meningitis, bacteremia, or localized infections.

### *Laboratory criteria for diagnosis*

Isolation of *L. monocytogenes* from a normally sterile site (e.g., blood or cerebrospinal fluid or, less commonly, joint, pleural, or pericardial fluid).

### *Case classification*

*Confirmed:* A clinically compatible case that is laboratory-confirmed.

*Source: Centers for Disease Control and Prevention. Case definitions for infectious conditions under public health surveillance. MMWR 1997;46(No.RR-10):p. 43.*



# ID Health Problems for Surveillance

- Defining a case isn't always “cut and dry”
- Often, it becomes necessary to ID and count occurrence of a disease based on a constellation of s/s, CC, or presumptive Dx; this is known as Syndromic Surveillance
- A good clinical example of this is the WTC attacks:

For example, a syndromic surveillance system was put in place in New York City after the World Trade Center (WTC) attacks in 2001. Here, the objectives were to detect illness related to either a bioterrorist event or an outbreak because of concern that the WTC attack could be followed by terrorists' use of biological or chemical agents in the city. One example of non-bioterrorist syndromic surveillance is surveillance for acute flaccid paralysis (syndrome) in order to capture possible cases of poliomyelitis. This is an example where the syndrome is monitored as a proxy for the disease, and the syndrome is infrequent and severe enough to warrant investigation of each identified case.



# ID Health Problems for Surveillance

- The goal of syndromic surveillance is to provide an earlier indication of an unusual inc. in illnesses than traditional surveillance might to facilitate earlier intervention
- The advantage of syndromic surveillance is that persons can be ID when they first seek medical attention, often 1-2 days before a Dx is made
- Because the emphasis is based on s/s instead of confirmed diagnoses, we're more likely to "capture" possible cases
- However, this results in a multitude of complex data collection and analysis; computers are utilized to assess for space-time clusters

You might use syndromic surveillance when:

- Timeliness is key either for naturally occurring infectious diseases (e.g., severe acute respiratory syndrome [SARS]), or a terrorism event;
- Making a diagnosis is difficult or time-consuming (e.g., a new, emerging, or rare pathogen);
- Trying to detect outbreaks (e.g., when syndromic surveillance identified an increase in gastroenteritis after a widespread electrical blackout, probably from consuming spoiled food); or
- Defining the scope of an outbreak (e.g., investigators quickly having information on the age breakdown of patients or being able to determine geographic clustering).



# ID Health Problems for Surveillance

- Syndromic Surveillance is an important adjunct not intended to replace traditional surveillance; it's effective at detecting possible bioterrorist events early
- However, it's not a proven science—fortunately we haven't had to test it
- Critics cite possible high implementation costs & likelihood of “false alarms”

## Possible Scenario for Syndromic Surveillance

Consider the time sequence of an unsuspecting person exposed to an aerosolized agent (e.g., anthrax).

- Two days after exposure, the person experiences a prodrome of headache and fever and visits a local pharmacy to buy acetaminophen or another over-the-counter medicine.
- On day 3, he develops a cough and calls his health-care provider.
- On day 4, feeling worse, he visits his physician's office and receives a diagnosis of influenza.
- On day 5, he feels weaker, calls 9-1-1, and is taken by ambulance to his local hospital's emergency department, but is then sent home.
- By day 6, he is admitted to the hospital with a diagnosis of pneumonia.
- The following day, the radiologist identifies the characteristic feature of pulmonary anthrax on the chest radiograph and indicates a diagnosis. Laboratory tests are also positive. The infection-control practitioner, familiar with notifiable disease reporting, immediately calls the health department, which is on day 7 after exposure.

Thus, the health department learns about this case and perhaps others a full 7 days after exposure. However, if enough persons had been exposed on day 0, the health department might have detected an increase days earlier by using a syndromic surveillance system that tracks pharmacy over-the-counter medicine sales, nurses' hotlines, managed care office visits, school or work absenteeism, ambulance dispatches, emergency medical system or 9-1-1 calls, or emergency room visits.



# ID Health Problems for Surveillance

- After defining the case, determine what information is needed from surveillance data to implement control measures
- For example, local control measures might be needed if the problem affects only a county
- Or, obtaining the names and addresses of sexual contacts might be effective at controlling an outbreak of syphilis
- Knowing new cases of HIV over the course of a year might be a good gauge at prevention efforts
- Also essential is establishing geographic boundaries and timelines for the surveillance



# ID or Collecting Data for Surveillance

- After ID the problem and its definition, scope, and needs, available reports and other relevant data should be located that can be used to conduct surveillance
- Before describing available local and national data resources for surveillance, understanding the principal sources and methods of obtaining data about health problems is helpful
- It is essential for practitioners to know and recognize the natural Hx of a disease in order for it to be “caught” and counted
- Diseases with readily apparent s/s are more easily recognized and counted than those without them
- Some diseases are in-between these extremes



# ID or Collecting Data for Surveillance

- Sources and Methods for Gathering Data:
  - Data collected for health-related purposes typically come from 3 sources:
    - Individual persons; the environment; and providers/facilities
  - Data collected for non health-related purposes can also be used for disease surveillance

## Examples of documentation of financial, legal, and administrative activities that might be used for surveillance

- Receipts for cigarette and other tobacco product sales.
- Automated reports of pharmaceutical sales.
- Electronic records of billing and payment for health-care services.
- Laws and regulations related to drug use.

**Table 5.2 Typical Sources of Data**

Individual Persons
Health-care providers, facilities, and records
— Physician offices
— Hospitals
— Outpatient departments
— Emergency departments
— Inpatient settings
— Laboratories
Environmental conditions
— Air
— Water
— Animal vectors
Administrative actions
Financial transactions
— Sales of goods and services
— Taxation
Legal actions
Laws and regulations



# ID or Collecting Data for Surveillance

- Environmental monitoring, surveys, notifications, and registries are useful in collecting the majority of health-related data
- Depending on the situation, these methods might be used to obtain information about a sample of a population or events or about all members of the population or all occurrences of a specific event
- Data might be collected continuously, periodically, etc. depending on the need
- Consideration of the objectives of the surveillance and the dis/advantages of different collection sources is essential when deciding the most appropriate sources and methods for obtaining it
- Environmental Monitoring:
  - Multiple qualitative and quantitative approaches are used to monitor the environment

## **Examples of environmental monitoring**

- Cities and states monitor air pollutants.
- Cities and towns monitor public water supplies for bacterial and chemical contaminants.
- State and local health authorities monitor beaches, lakes, and swimming pools for increased levels of harmful bacteria and other biologic and chemical hazards.
- Health agencies monitor animal and insect vectors for the presence of viruses and parasites that are harmful to humans.
- National, state, and local departments of transportation monitor roads, highways, and bridges to ensure that they are safe for traffic; they also monitor traffic to ensure that speed limits and other traffic laws are observed.
- Public safety and health departments periodically monitor compliance with laws requiring seat belt use.
- Occupational health authorities monitor noise levels in the workplace to prevent hearing loss among employees.



# ID or Collecting Data for Surveillance

## – Survey:

- Uses a structural and systematic gathering of information from a sample of a population of interest to describe the population in quantitative terms
- Vast majority of surveys collect data from a sample with the intention of generalizing it to the total of that entire population
- Most often used data collection tool

## – Notification:

- Reporting of certain (Notifiable) diseases or other health-related conditions by a specific group, as specified by law, regulation, or agreement
- Usually notify state or local health agencies
- Often used for surveillance, aid in control of specific health problems
- Considered confidential and not available for public inspection
- Physicians office/ clinic → County Health Dept. → State Health Dept. → Federal Data Collectors (CDC)
- This is called Passive Surveillance (provider-initiated notification)
- The reverse is Active Surveillance, where the health dept. solicits providers for information; this is typically see in outbreaks or community exposures



# ID or Collecting Data for Surveillance

- Underreporting is common; this makes Sentinel reporting (reporting from samples of providers within a community) essential
- Sentinel reporting is consistent because the sample is stable and the participants committed to providing the data

**Table 5.3 Types of Notification and Examples**

1. Disease or hazard-specific notifications
  - a. Communicable diseases
    - i. World Health Organization: International health regulations require reporting of cholera, plague, and yellow fever
    - ii. National: United States and Canada specify diseases that require notification by all states and provinces, respectively
    - iii. Provincial, state, or subnational: for example, coccidioidomycosis in California
  - b. Chemical and physical hazards in the environment
    - i. Childhood lead poisoning
    - ii. Occupational hazards
    - iii. Firearm-related injury
    - iv. Consumer product-related injury
2. Notifications related to treatment administration
  - a. Adverse effect of drugs or medical products
  - b. Adverse effect from vaccines
3. Notifications related to persons at risk
  - a. Elevated blood lead among adults
  - b. Elevated blood lead among children

*Adapted from: Koo D, Wingo P, Rothwell C. Health Statistics from Notifications, Registration Systems, and Registries. In: Friedman D, Parrish RG, Hunter E (editors). Health Statistics: Shaping Policy and Practice to Improve the Population's Health. New York: Oxford University Press; 2005, p. 82.*



# ID or Collecting Data for Surveillance

- Registries:
  - Method of documenting or tracking events or persons over time
  - Intended to be a permanent record of persons or events (birth/ death registries)
  - Tracks a person with a disease over time and usually includes diagnostic, Tx, and outcome information
  - Usually requires health facilities to provide information of pts. w/ a disease; but sometimes, registry managers will update this information through review of health, vital, or other records
- Reanalysis or Secondary Data Use:
  - Surveillance based on data originally collected for other purposes
  - Suffers from a lack of timeliness, or lack sufficient detail to address the problem under surveillance
  - Undertaking primary collection for data surveillance is time and resource intensive; thus, attempt to collect secondary data whenever possible



# ID or Collecting Data for Surveillance

**Table 5.4 Types of Registries and Examples of Selected Types**

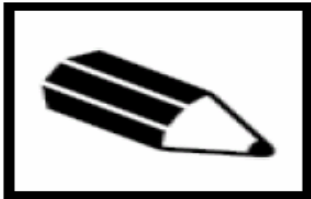
1. Vital event registration
  - a. Birth registration
  - b. Marriage and divorce registration
  - c. Death registration
2. Registries used in preventive medicine
  - a. Immunization registries
  - b. Registries of persons at risk for selected conditions
  - c. Registries of persons positive for genetic conditions
3. Disease-specific registries
  - a. Blind registries
  - b. Birth defects registries
  - c. Cancer registries
  - d. Psychiatric case registries
  - e. Ischemic heart disease registries
4. Treatment registries
  - a. Radiotherapy registries
  - b. Follow-up registries for detection of iatrogenic thyroid disease
5. After-treatment registries
  - a. Handicapped children
  - b. Disabled persons
6. Registries of persons at risk or exposed
  - a. Children at high risk for developing a health problem
  - b. Occupational hazards registries
  - c. Medical hazards registries
  - d. Older persons or chronically ill registries
  - e. Atomic bomb survivors (Japan)
  - f. World Trade Center survivors (New York City)
7. Skills and resources registries
8. Prospective research studies
9. Specific information registries

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



# ID or Collecting Data for Surveillance



## Exercise 5.2

*State funding for a childhood asthma program has just become available. To initiate surveillance for childhood asthma, the staff is reviewing different sources of data on asthma. Discuss the advantages and disadvantages of the following sources of data and methods for conducting surveillance for asthma. (Figure 5.12 in Appendix C indicates national data for these different sources.)*

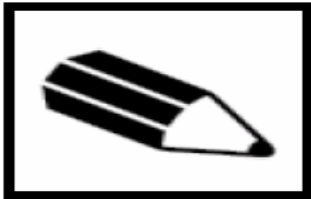
- Self-reported asthma prevalence and asthmatic attacks obtained by a telephone survey of the general population.
- Asthma-associated outpatient visits obtained from periodic surveys of local health-care providers, including emergency departments and hospital outpatient clinics.

Asthma is a chronic illness that can vary in severity. Using just one source of data or just one dataset to monitor it provides limited knowledge of its extent and the potential effect of treatment and other interventions on it. Thus, using multiple sources of data with information on asthma's incidence, prevalence, morbidity, and mortality is the best way to conduct surveillance for this illness.

- Self-reported asthma prevalence or attacks provides information on its occurrence among the entire population, even those who might not seek or receive medical care for it.
- The majority of cases of asthma requiring medical attention are observed in physician offices, emergency departments, or outpatient clinics. Thus, obtaining information from these sources provides optimal knowledge of its occurrence and morbidity among the majority of persons.
- Severe episodes of illness can require hospitalization and be an indicator that routine treatment in outpatient settings is not being delivered effectively to the whole population. Thus, data on hospitalizations caused by asthma is helpful in monitoring effectiveness of interventions.
- Deaths from asthma are similar to hospitalizations and might represent a failure of the health-care system to deal effectively with the illness.



# ID or Collecting Data for Surveillance



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### Surveys

#### *Advantages*

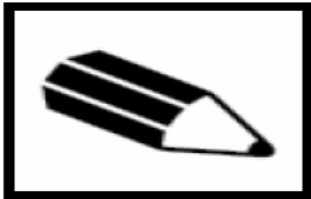
- More control over the quality of the data.
- More in-depth data possibly collected on each case than is usually possible with notifications.
- Can identify the spectrum of illness, including cases that do not warrant medical care.
- More accurate assessment of true incidence and prevalence.

#### *Disadvantages*

- More costly to perform because surveys usually require development of de-novo data-collection systems and hiring of interviewers who require training and supervision.
- Might represent only a single point in time ("snapshot"), if survey is not periodically repeated; might miss seasonal trends, rare diseases, or rapidly fatal diseases.
- Recall bias more likely to affect results because data collected retrospectively (notifications are usually prospective).



# ID or Collecting Data for Surveillance



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### **Notifications (Reporting of illness by health-care providers)**

#### *Advantages*

- Cheaper (for the health department).
- Typically use existing systems and health-care personnel for collecting data.
- Allows monitoring of trends over time.
- Ongoing data collection might allow collection of an adequate number of cases to study those at risk. With surveys, an event might be too infrequent to gather enough cases for study; with notifications, the observation period can be extended until sufficient numbers of cases are collected.

#### *Disadvantages*

- Might not provide a representative picture of the incidence or prevalence unless care is taken in selecting reporting sites and ensuring complete reporting.
- Data that can be collected are limited by the skill, time, and willingness of the data collectors, who usually have other responsibilities.
- Quality control might be a major problem in data collection.
- The quality of data might vary among collection sites.
- As a result, notifications usually provide a substandard estimate of the true incidence and prevalence.

An alternative to notification might be to enroll interested and appropriate health-care providers and clinics in a sentinel system to gather case numbers of asthma.



# Major Health Data Systems

- Systems exist at the national, state, or local levels– these data (characteristics of disease and injury) are critical for guiding efforts for preventing and controlling those diseases
- Surveillance for communicable disease principally relies upon reports of notifiable diseases from health providers, labs, and the registration of deaths
- Local departments are concerned with preventing or controlling cases of disease; thus, local surveillance relies on finding individual cases through notifications, or where more complete reporting required, actively contacting health facilities or providers on a regular basis
- At the state and national level, the principal notification is the National Notifiable Disease Surveillance System (NNDSS)
- State and local vital registries provide data for monitoring deaths from certain infectious diseases (influenza/ AIDS)

## More About the National Notifiable Disease Surveillance System

A notifiable disease is one for which regular, frequent, and timely information regarding individual cases is considered necessary for preventing and controlling the disease.

The list of nationally notifiable diseases is revised periodically. For example, a disease might be added to the list as a new pathogen emerges, and diseases are deleted as incidence declines. Public health officials at state health departments and CDC collaborate in determining which diseases should be nationally notifiable. The Council of State and Territorial Epidemiologists, with input from CDC, makes recommendations annually for additions and deletions. However, reporting of nationally notifiable diseases to CDC by the states is voluntary. Reporting is mandated (i.e., by legislation or regulation) only at the state and local levels. Thus, the list of diseases considered notifiable varies slightly by state. All states typically report diseases for which the patients must be quarantined (i.e., cholera, plague, and yellow fever) in compliance with the World Health Organization's International Health Regulations.

Data in the National Notifiable Disease Surveillance System (NNDSS) are derived primarily from reports transmitted to CDC by the 50 states, two cities, and five territorial health departments.

*Source: National Notifiable Diseases Surveillance System [Internet]. Atlanta: CDC [updated 2006 Jan 13]. Available from: <http://www.cdc.gov/epo/dphsi/nndsshis.htm>*



*College of Nursing*



# Major Health Data Systems

- Surveillance for chronic diseases usually relies upon healthcare-related data (hospital DCs, surveys of the public, and mortality data from the vital statistics system)
- Surveillance for chronic conditions need not be as timely as those for acute infectious diseases due to their steady incidence and prevalence
- Surveillance for behaviors that influence health and for other markers for health (smoking, BP, and serum cholesterol) is accomplished via population surveys:
  - Behavioral Risk Factor Surveillance System (BRFSS)
  - Youth Risk Behavior Surveillance System (YRBSS)
  - National Health Interview Survey (NHIS)
  - National Household Survey on Drug Abuse
  - National Health and Nutrition Examination Survey (NHANES) most comprehensive survey in the US of health and factors that influence it
    - Data from NHANES includes physiologic and biochemical markers of the population and on the presence of chemical exposures among the population (Fe- poisoning; pesticides; nicotine from 3rd hand smoke)



# Major Health Data Systems



## Exercise 5.3

*Assume you work in a state in which none of the following conditions is on the state list of notifiable diseases. For each condition, list at least one existing source of data that you need for conducting surveillance on the condition. What factors make the selected source or data system more appropriate than another?*

**Listeriosis:** A serious infection can result from eating food contaminated with the bacterium *Listeria monocytogenes*. The disease affects primarily pregnant women, newborns, and adults with weakened immune systems. A person with listeriosis has fever, muscle aches, and sometimes gastrointestinal symptoms (e.g., nausea or diarrhea). If infection spreads to the nervous system, such symptoms as headache, stiff neck, confusion, loss of balance, or convulsions can occur. Infected pregnant women might experience only a mild influenza-like illness; however, infections during pregnancy can lead to miscarriage or stillbirth, premature delivery, or infection of the newborn. In the United States, approximately 800 cases of listeriosis are reported each year. Of those with serious illness, 15% die; newborns and immunocompromised persons are at greatest risk for serious illness and death.

**Listeriosis:** A wide spectrum of nonspecific clinical illness and a low case fatality rate exists (except among newborns and immunocompromised persons). Therefore, surveillance should be based on morbidity rather than mortality data; diagnoses should be confirmed in the laboratory. Possible sources of surveillance data include laboratory reports, hospital discharge data (although patients with listeriosis are often not hospitalized), or adding listeriosis to the notifiable disease list.



# Major Health Data Systems



## Exercise 5.3

*Assume you work in a state in which none of the following conditions is on the state list of notifiable diseases. For each condition, list at least one existing source of data that you need for conducting surveillance on the condition. What factors make the selected source or data system more appropriate than another?*

**Spinal cord injury:** Approximately 11,000 persons sustain a spinal cord injury (SCI) each year in the United States, and 200,000 persons in the United States live with a disability related to an SCI. More than half of the persons who sustain SCIs are aged 15-29 years. The leading cause of SCI varies by age. Motor vehicle crashes are the leading cause of SCIs among persons aged <65 years. Among persons aged  $\geq 65$  years, falls cause the majority of spinal cord injuries. Sports and recreation activities cause an estimated 18% of spinal cord injuries.

**Spinal cord injury:** This is a severe health event with substantial mortality; almost all persons who sustain a spinal cord injury are brought to a hospital. Therefore, surveillance would most logically be based on hospital records and mortality data (e.g., death certificates or medical examiner data). Special efforts might be directed to obtaining data from regional trauma centers. Using data from emergency medical services and rehabilitation centers might also be explored.



# Major Health Data Systems



## Exercise 5.3

*Assume you work in a state in which none of the following conditions is on the state list of notifiable diseases. For each condition, list at least one existing source of data that you need for conducting surveillance on the condition. What factors make the selected source or data system more appropriate than another?*

**Lung cancer among nonsmokers:** A usually fatal cancer of the lung can occur in a person who has never smoked. An estimated 10%-15% of lung cancer cases occur among nonsmokers, and this type of cancer appears to be more common among women and persons of East Asian ancestry.

**Lung cancer among nonsmokers:** Similar to spinal cord injury, lung cancer is a severe health event with high morbidity and mortality. Unfortunately, hospital discharge records and vital records do not routinely provide smoking information. For this condition, cancer registries might provide the best opportunity for surveillance, if smoking information is routinely collected. Alternatively, surveillance might be established by using interested internists, oncologists, and other health-care providers likely to interact with lung cancer patients.



# Analyzing and Interpreting Data

- After relevant data about a health problem have been gathered and compiled, they should be analyzed by time, person, and place
- Data from individual cases are analyzed differently than those from multiple records; text data must be sorted, categorized, and coded for stats. analysis; and data from surveys might need to provide valid estimates for sampled populations
- Descriptive methods are appropriate for the majority of surveillance data
- Frequencies (counts) or rates of the health problem in simple tables and graphs are most common
- Rates frequently preferred for comparing occurrence of disease for different geographic areas or periods because they take into account the size of the population from which they arise
- Before calculating a rate, first decide on an appropriate denominator:
  - For state- or country- wide data, general population data from the US Census or from a state planning agency are used
  - Other times, the population at risk can dictate and alternative denominator (for example: infant mortality rates would use # of live-born infants; # of surgical wound infections would be in-terms of total procedures performed, etc.
- To determine if prevalence or incidence has  $\uparrow$ , data must be compared over the SAME time or across areas of known prevalence:
  - Eg: We would want to compare outbreaks of seasonal-related diseases during the same seasons across a given period of time



# Analyzing and Interpreting Data

- Surveillance for chronic diseases usually requires data covering multiple years
- Data for acute infectious diseases might only require data covering weeks or months; data over a period of years might be helpful in the analysis of the natural history of disease
- Analyzing by Time:
  - Usually conducted to detect trends and changes in disease incidence
  - For notifiable diseases, the first analysis is usually a comparison of case reports for the current week with those of the preceding weeks
  - This is highly effective when new cases are reported promptly
  - In this example, Hep A cases are ↑ in Clark County in Week 4

Table 5.5 Reported Cases of Hepatitis A, by County and Week of Report, 1991

County	Week of report								
	1	2	3	4	5	6	7	8	9
Adams	–	–	–	1	–	–	1	–	–
Asotin	–	–	–	–	–	–	–	–	–
Benton	–	–	–	2	1	–	2	–	3
Chelan	–	–	1	3	1	1	–	–	1
Clallam	–	–	1	–	–	–	–	2	–
Clark	–	–	3	8	14	13	11	6	–
Columbia	–	–	–	–	–	–	–	–	–
Cowlitz	2	–	3	–	–	6	4	9	–
Douglas	–	–	–	–	–	–	–	–	–
Ferry	–	–	–	–	–	–	–	–	–
Franklin	–	–	3	2	3	–	5	–	4
Garfield	–	–	–	–	–	–	–	1	–
Etc.									



# Analyzing and Interpreting Data

- Another common time analysis is comparing the # of cases during the current period to the # reported during the same period for the last 2-10 years (Table 5.6)
- A related method is comparing the cumulative # of cases reported to date during the current year (or during the previous 52 weeks) to the cumulative # reported to the same date during previous years

Table 5.6 Reported Cases of Hepatitis A, by County for Weeks 1–4, 1988–1991

County	Year			
	1988	1989	1990	1991
Adams	—	—	—	1
Asotin	—	—	—	—
Benton	—	—	3	2
Chelen	—	1	2	4
Clallam	—	1	1	1
Clark	6	3	—	11
Columbia	—	—	—	—
Cowlitz	—	5	—	5
Douglas	—	—	2	—
Ferry	1	—	—	—
Franklin	—	2	3	5
Garfield	—	—	—	—
Etc.				



# Analyzing and Interpreting Data

- Analysis of long-term trends (secular trends) involves graphing occurrences of disease by year– Figure 5.1
- This can also highlight events that have an impact on the secular trend (control programs, outbreaks, etc.)– Figure 5.2

Figure 5.1 Rate (per 100,000 Persons) of Reported Cases of Malaria, By Year, United States, 1932–2003

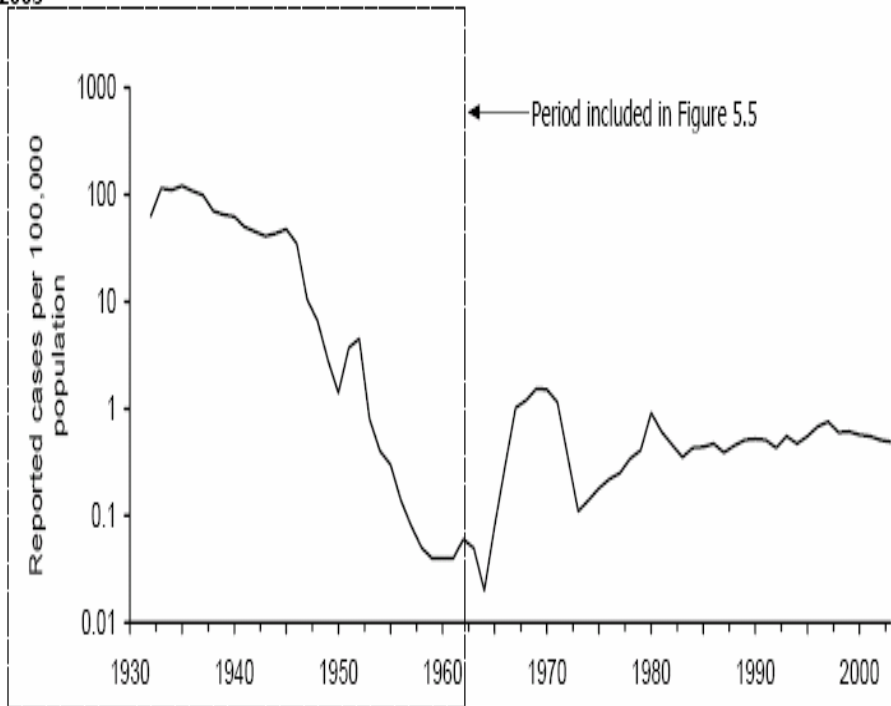
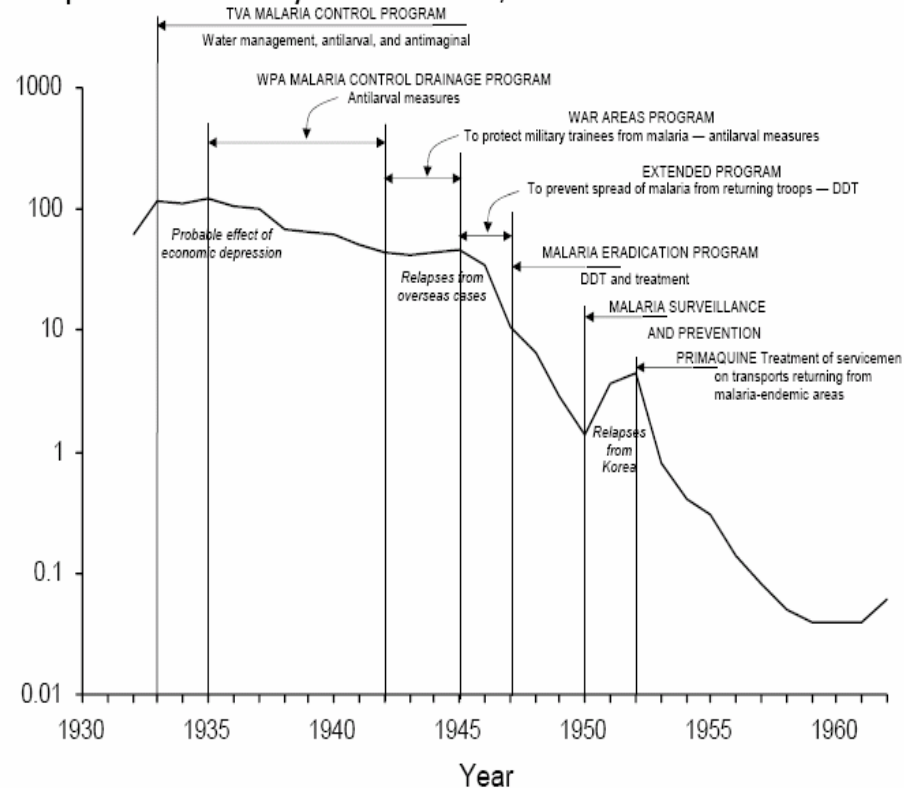


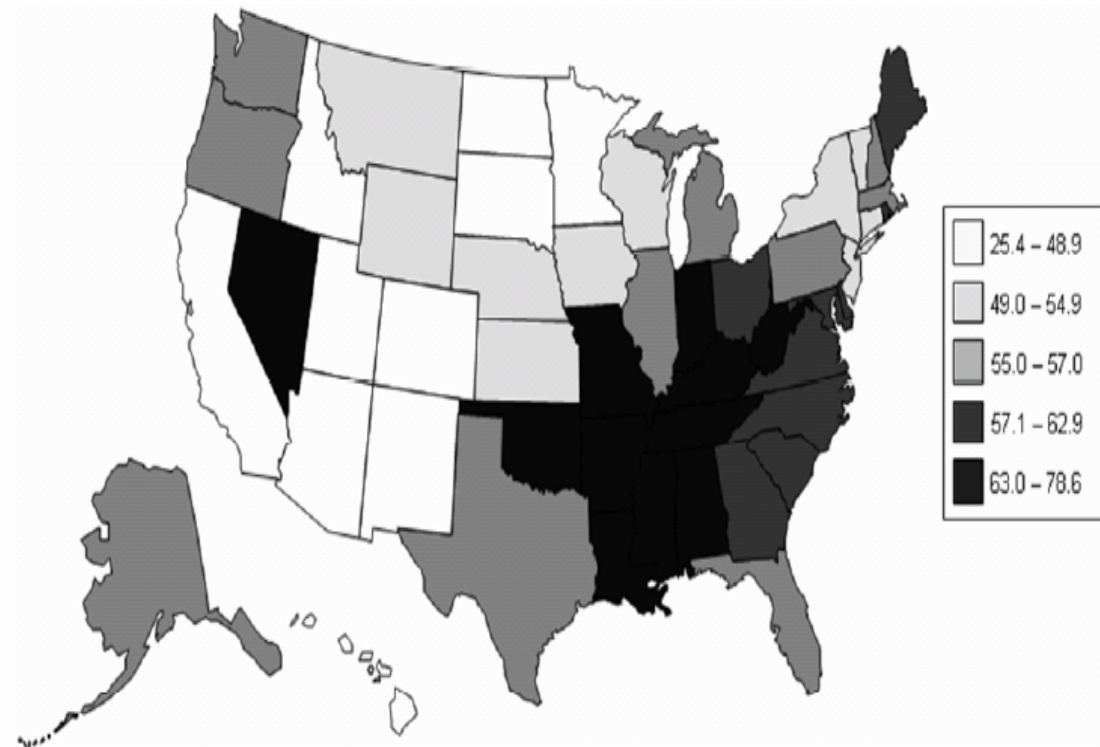
Figure 5.2 Reported Malaria Morbidity in the United States, 1932–1962



# Analyzing and Interpreting Data

- Statistical programs can also be employed to track aberrations (deviations) from the baseline, by using either long-term (3-5 yrs) or short-term (1-6 days) baseline—Early Aberration Detection System (EARS) is one such system
- Analyzing by Place:
  - Usually accomplished via a table or map
  - State and local officials usually analyze by neighborhood or county
  - CDC usually analyzes per state
  - Rates are often calculated by adjusting for the size of the population of counties, states, and geographic areas
  - Geographic Information Systems (GIS) has led to more robust/sophisticated data, particularly when clarifying geographic relationships

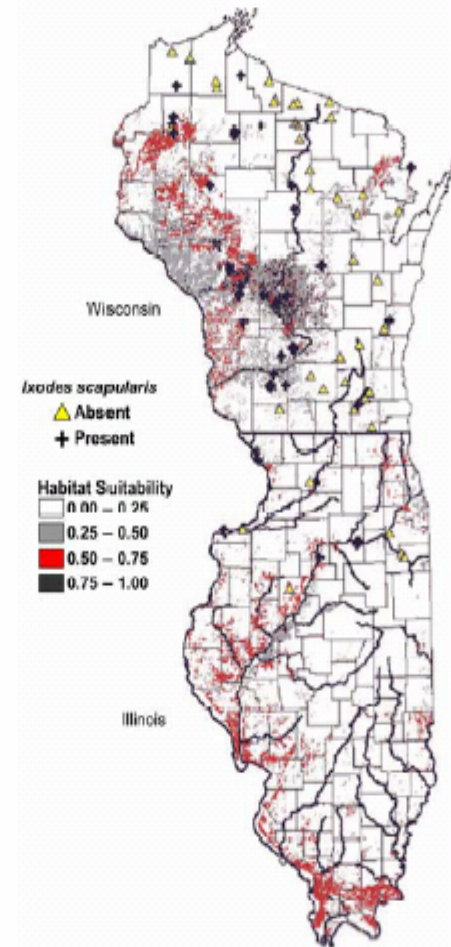
Figure 5.3 Age-Adjusted Lung and Bronchus Cancer Mortality Rates (per 100,000 Population) By State — United States, 1998–2002



# Analyzing and Interpreting Data

Figure 5.4 Predictive Risk Map of Habitat Suitability for *Ixodes scapularis* in Wisconsin and Illinois

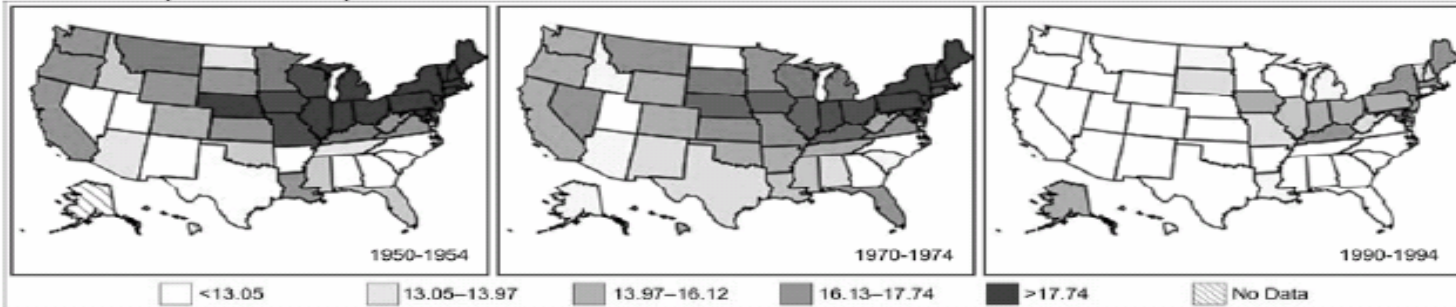
For example, in Figure 5.4, the absence or presence of the tick that transmits Lyme disease, *Ixodes scapularis*, are illustrated superimposed over habitat suitability.<sup>18</sup> Such software packages as SatScan™ (Martin Kulldorff, Harvard University and Information Management System, Inc., Silver Spring, Maryland), EpiInfo™ (CDC, Atlanta, Georgia), and Health Mapper (World Health Organization, Geneva, Switzerland) provide GIS functionality and can be useful when analyzing surveillance data.<sup>19-21</sup>



# Analyzing and Interpreting Data

- Analyzing by Time and Place:
  - Often analyzed simultaneously
  - Maps or tables highlighting different periods or populations:

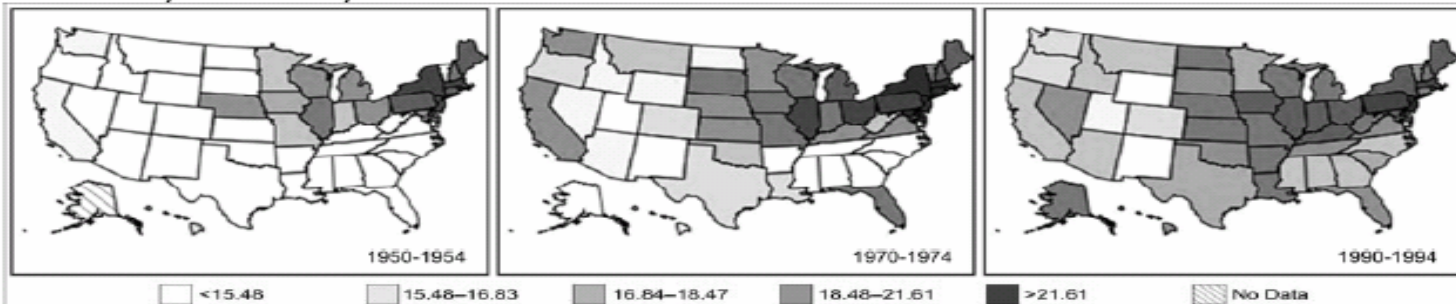
**Figure 5.5 Age-Adjusted Colon Cancer Mortality Rates\* for White Females by State — United States, 1950–1954, 1970–1974, and 1990–1994**



*\*Scale based on 1950–1994 rates (per 100,000 person years).*

*Data Source: Customizable Mortality Maps [Internet] Bethesda: National Cancer Institute [cited 2006 Mar 22]. Available from: <http://cancercontrolplanet.cancer.gov/atlas/index.jsp>.*

**Figure 5.6 Age-Adjusted Colon Cancer Mortality Rates\* for White Males by State — United States, 1950–1954, 1970–1974, and 1990–1994**



*\*Scale based on 1950–1994 rates (per 100,000 person years).*



# Analyzing and Interpreting Data

- Analyzing by Person:
  - Most common “person” characteristics assessed are age and sex
  - Age:
    - Categorization depends on the disease of interest; categories might be all-inclusive (including extremes  $< 1$  yr. or  $\geq 84$  yrs.) or mutually exclusive (allowing no overlap)
    - The characteristic age distribution of a disease should be used in deciding the age categories

Standard age categories for childhood illnesses are usually  $<1$  year and ages 1–4, 5–9, 10–14, 15–19, and  $\geq 20$  years. For pneumonia and influenza mortality, which usually disproportionately affects older persons, the standard categories are  $<1$  year and 1–24, 25–44, 45–64, and  $\geq 65$  years. Because two-thirds of all deaths in the United States occur among persons aged  $\geq 65$  years, researchers often divide the last category into ages 65–74, 75–84, and  $\geq 85$  years.

To use data in the calculation of rates, the age categories must be consistent with the age categories available for the population at risk. For example, census data are usually published as  $<5$  years, 5–9, 10–14, and so on in 5-year age groups. These denominators could not be used if the surveillance data had been categorized in different 5-year age groups (e.g., 1–5 years, 6–10, 11–15, and so forth).



# Analyzing and Interpreting Data

- Other Person-or Disease-Related Risk Factor:
  - For some diseases, other data are collected and analyzed
  - For example:
    - Any reported cases of Hep A among food-handlers who might have exposed patrons?
    - Same dentist among those exposed with Hep B?
    - What's the vaccination status of those w/ varicella?
    - Data regarding risk factors are not often available for analysis, particularly if a generic form or secondary data are used
- Interpreting Results of Analyses:
  - When the incidence of a disease  $\uparrow$  or its pattern among a specific population at a particular time and place varies from expected, further investigation is warranted; and control measures are usually indicated
  - The amt. of  $\uparrow$  required for action is usually determined from:
    - Local agents and priorities to various diseases
    - Local health dept.'s capabilities and responsive resources
    - Public, political, or media pressures
  - With certain diseases (like botulism), only two or more case is required to warrant investigation
  - Suspicion is also aroused with findings of shared characteristics (race, place of residence, school, occupation, time of onset of illness)
  - Clinicians often report odd occurrences of diseases, which sparks further investigation



# Analyzing and Interpreting Data

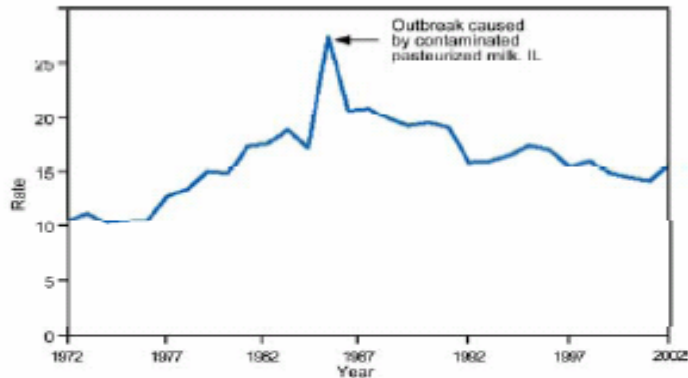
- $\uparrow/\downarrow$  in a disease doesn't always indicate a true  $\uparrow/\downarrow$ ; this can often result from the ways in which surveillance was conducted
- Examples of artifactual changes include:

- Changes in local reporting procedures or policies (e.g., a change from passive to active surveillance).
- Changes in case definition (e.g., AIDS in 1993).
- Increased health-seeking behavior (e.g., media publicity prompts persons with symptoms to seek medical care).
- Increase in diagnosis.
- New laboratory test or diagnostic procedure.
- Increased physician awareness of the condition, or a new physician is in town.
- Increase in reporting (i.e., improved awareness of requirement to report).
- Outbreak of similar disease, misdiagnosed as disease of interest.
- Laboratory error.
- Batch reporting in which reports from previous periods are held and reported all at once during another reporting period (e.g., reporting all cases received during December and the first week of January during the second week of January).



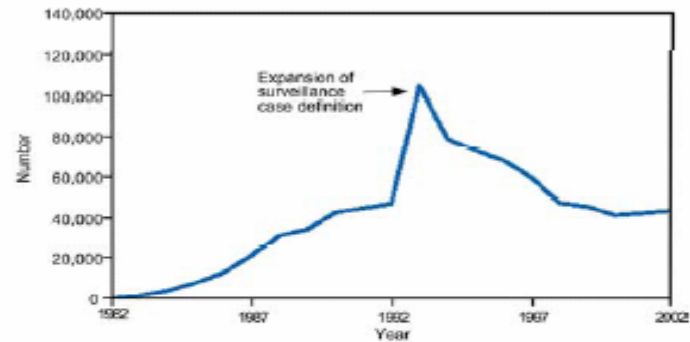
# Analyzing and Interpreting Data

**Figure 5.7 Reported Cases of Salmonellosis per 100,000 Population, By Year — United States, 1972–2002**



Source: Centers for Disease Control and Prevention. *Summary of notifiable diseases—United States, 2002*. Published April 30, 2004, for *MMWR* 2002;51(No. 53): p. 59.

**Figure 5.8 Reported Cases of AIDS, by Year — United States\* and U.S. Territories, 1982–2002**



\* Total number of AIDS cases includes all cases reported to CDC as of December 31, 2002. Total includes cases among residents in the U.S. territories and 94 cases among persons with unknown state of residence.

Source: Centers for Disease Control and Prevention. *Summary of notifiable diseases—United States, 2002*. Published April 30, 2004, for *MMWR* 2002;51(No. 53): p. 59.



# Analyzing and Interpreting Data



## Exercise 5.4

*During the previous 6 years, one to three cases per year of tuberculosis had been reported to a state health department. During the past 3 months, 17 cases have been reported. All but two of these cases have been reported from one county. The local newspaper published an article about one of the first reported cases, which occurred in a girl aged 3 years. Describe the possible causes of the increase in reported cases.*

## Exercise 5.4

Possible explanations for the sudden increase include those listed in the following. Each possibility should be investigated before deciding that the increase is a true increase in incidence.

1. Change in surveillance system or policy of reporting.
2. Change in case definition.
3. Improved or incorrect diagnosis.
  - New laboratory test.
  - Increased physician awareness of the need to test for tuberculosis, new physician in town, and so forth.
  - Increase in publicity or public awareness that might have prompted persons or parents to seek medical attention for compatible illness.
  - New population subgroup (e.g., refugees) in state A who have previous recent vaccination against tuberculosis using the bacille de Calmette-Guérin (BCG) vaccine.
  - New or untrained staff conducting testing for tuberculosis and incorrect interpretation of skin reaction to tuberculin.
4. Increase in reporting (i.e., improved awareness of requirement to report).
5. Batch reporting (unlikely in this scenario).
6. True increase in incidence.



# Disseminating Data and Interpretations

- The timely, regular dissemination of basic data and their interpretations is a critical component of surveillance
- Data and interpretations should be sent to those who provided reports or other data (providers or lab directors) and those who use them for planning and managing control measures, administrative purposes, or decision-making
- The most common dissemination method is via summary or report (serves to inform and motivate)
- Information based on time, person, and place informs providers about their risk for encountering the problem in pts.
- Summaries/reports can also provide control strategies and summaries of investigations
- These reports can be dispersed quickly via the mail or E-Mail; or be Posted to Internet Sites for public access
- These reports are also motivational: Reporting clinicians receive assurance that the data they are providing are being utilized appropriately
- Weekly or monthly newsletters, distributed to providers in a given area, detailing disease occurrence, rate comparisons, and other data like Tx and diagnostic information are powerful tools for clinicians and makes them aware
- At the national level, the CDC provides this information through *MMWR*, *MMWR Surveillance Summaries*, and *MMWR Annual Summary of Notifiable Diseases*
- You can access the *MMWR* On-Line: <http://www.cdc.gov/mmwr/>



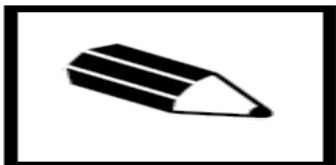
# Disseminating Data and Interpretations

When faced with a health problem of immediate public concern, whether it is a rapid increase in the number of heroin-related deaths in a city or the appearance of a new disease (e.g., AIDS in the early 1980s or West Nile Virus in the United States in 1999), a health department might need to disseminate information more quickly and to a wider audience than is possible with routine reports, summaries, or newsletters. Following the appearance of West Nile Virus in New York City in late August 1999, the following measures were taken:

*“Emergency telephone hotlines were established in New York City on September 3 and in Westchester County on September 21 to address public inquiries about the encephalitis outbreak and pesticide application. As of September 28, approximately 130,000 calls [had] been received by the New York City hotline and 12,000 by the WCDH [Westchester County Health Department] hotline. Approximately 300,000 cans of DEET-based mosquito repellent were distributed citywide through local firehouses, and 750,000 public health leaflets were distributed with information about personal protection against mosquito bites. Recurring public messages were announced on radio, television, on the New York City and WCDH World-Wide Web sites, and in newspapers, urging personal protection against mosquito bites, including limiting outdoor activity during peak hours of mosquito activity, wearing long-sleeved shirts and long pants, using DEET-based insect repellents, and eliminating any potential mosquito breeding niches. Spraying schedules also were publicized with recommendations for persons to remain indoors while spraying occurred to reduce pesticide exposure.”<sup>26</sup>*



# Disseminating Data and Interpretations



## Exercise 5.5

*You have recently been hired by a state health department to direct surveillance activities for notifiable diseases, among other tasks. All notifiable disease surveillance data are entered and stored in computer files at the state and transmitted to CDC once each week. CDC publishes these data for all states in the MMWR each week, but health*

*department staff do not routinely review these data in the MMWR. The state has never generated its own set of tables for analysis and dissemination, and you believe that it would be valuable to do so to educate and increase interest among health department staff.*

- A. What three tables might you want to generate by computer each week for use by health department staff?
- B. You next decide that it would be a good idea to share these data with health-care providers, as well. What tables or figures might you generate for distribution to health-care providers, and how frequently would you distribute them?

## **Exercise 5.5**

No right answer exists, but one set of tables for health department staff might be as follows:

**Table 1.** Number of reported cases of each notifiable disease this week for each county in the state.

**Table 2.** Number of reported cases of each notifiable disease by week for the entire state for the current and the previous 6–8 weeks for comparison.

**Table 3.** Number of reported cases of each notifiable disease for the past 4 weeks (current week and previous 3 weeks) and for comparison, the number of cases during the same period during the previous 5 years.

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

A report for health-care providers does not need to be distributed as frequently and does not need to include all of the notifiable diseases. One approach might be to distribute a report every 6 months and include notifiable diseases that have demonstrated substantial change since the last report, with a discussion of possible causes for the change. Maps of the geographic distribution and figures illustrating the trends over time of selected diseases might be more appealing and informative to health-care providers than tables of frequencies. Information on the diagnosis and treatment of highlighted diseases might also be of interest to health-care providers.

Reports for the media and public typically should be issued to inform them of outbreaks, of new diseases, or of diseases of particular concern. These reports should include basic information about the diseases, the location and frequency of their occurrence, and information on recognition, prevention, and treatment of the diseases.



# Disseminating Data and Interpretations



## Exercise 5.6

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

### **Exercise 5.6**

State health department newsletters do not always go to all those who have a need to know. Even among those who receive the newsletter, some do not read it, and many others skim the articles and ignore the tables. In addition, depending on the timing of the laboratory report and publication deadlines, the information might be delayed by weeks or months.

This information about finding rabid raccoons in a residential area is important for those who might be affected and for those who might be able to take preventive measures, including the following:

- Other public health agencies (e.g., neighboring local health departments or animal control staff) — Contact and inform by telephone or e-mail message.
- Health-care providers serving the population in the affected area — Contact and inform through a special mailing.
- Veterinarians — Inform through a mailing so that they can be on alert for pets that might have come into contact with rabid wildlife; veterinarians can provide specimens, as appropriate, of both wild animals and pets to the state laboratory for testing for rabies.
- The public — Inform by issuing press release to the media asking the public to avoid wild animals and to have their pets vaccinated.



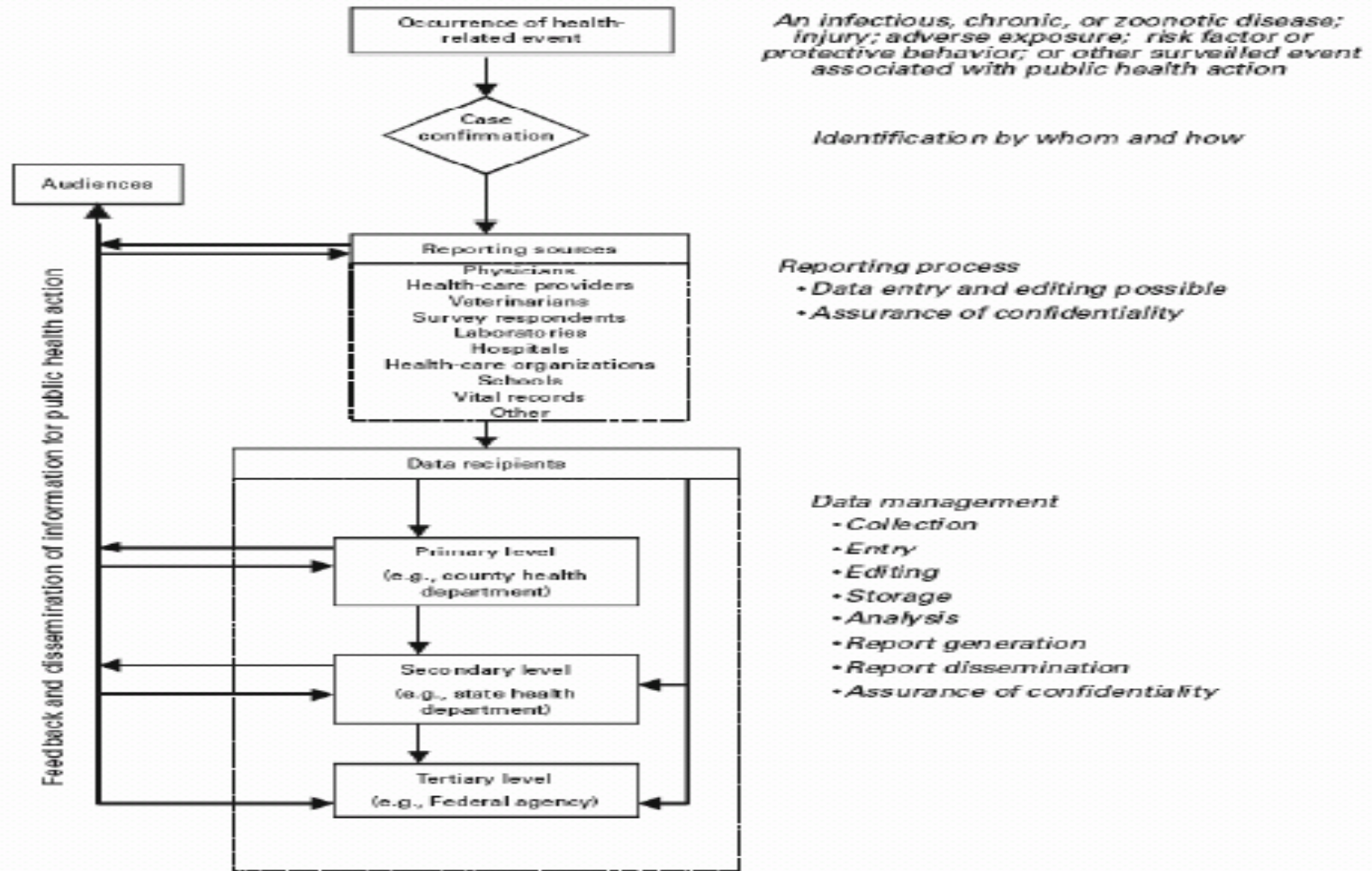
# Evaluating and Improving Surveillance

- Evaluating and Improving Surveillance:
  - Evaluation of surveillance should include:
    - ID elements of surveillance that should be enhanced to improve its attributes
    - Assess how surveillance findings control efforts
    - Improves the quality of data and interpretations provided by surveillance
    - Process:
      - ID/interview stakeholders and collect background docs, forms, and reports
      - Address: surveillance purpose, objectives, and mechanics for conduction of surveillance; usefulness of surveillance; and the presence or absence of characteristics of optimal surveillance
      - Finally, always provide recommendations for improvement
  - Stakeholders:
    - Persons and organizations who contribute to, use, and benefit from surveillance
    - Ex: Public health officials/staff, providers, data providers/users, community reps, government officials, and others interested in the condition under surveillance
    - Important to involve stakeholders in evaluation because they can both provide and utilize information
    - If not ID and involved early, can often be viewed as being an unimportant outsider and will not provide input into evaluation
  - Purpose, Objectives, and Operations:
    - Starts with a clearly written statement identifying the purpose of prevention or control of a health-related problem
    - Next, clearly state objectives describing how surveillance data and their interpretations should be used
    - Sketching a flow chart of the method of conducting surveillance is recommended



# Evaluating and Improving Surveillance

Figure 5.9 Simplified Diagram of Surveillance for a Health Problem



Source: Centers for Disease Control and Prevention. Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. *MMWR* 2001;50(No. RR-13): p. 8.



# Evaluating and Improving Surveillance

## – Usefulness:

- Whether surveillance contributes to prevention and control of a health-related problem
- Can include improved understanding of the public health implications of the health problem
- Usually used to determine if surveillance meets its objectives
- For example, if the primary objective of surveillance is to ID individual disease cases to facilitate timely and effective control measures, does it allow for timely and accurate ID, Dx, Tx, or other handling of contacts when appropriate?
- Influenced greatly by its operation, including its feedback mechanisms to those who need to know, and by the presence or absence of the characteristics of optimal surveillance
- Evaluation of surveillance requires either quantitative or qualitative assessment of each characteristic



# Evaluating and Improving Surveillance

- Resource Requirements (Personnel and other Costs):
  - Refers to finances, personnel, and other direct costs needed to operate all phases of surveillance, including any collection, analysis, and dissemination of data
  - ID and quantify the following:
    - Funding sources and budget
    - Personnel requirements to collect, compile, edit, analyze, interpret, or disseminate data
    - Other resources (training, travel supplies, and PCs and related equipment)
- Recommendations:
  - The purpose of evaluating surveillance for a specific disease is to draw conclusions and make recommendations about its present state and future potential
  - The finding should conclude if surveillance is meeting its objectives as is and if it's operating efficiently
  - If not, recommendations should address what modifications need to be made and:
  - Recommendations must recognize that characteristics and costs of conducting surveillance are interrelated and potentially conflicting
  - For example: In syndromic surveillance, timeliness and sensitivity are, but high sensitivity increases false alarms, which can drain limited public health resources
  - Each characteristic must be considered and balanced to ensure that the objectives of the surveillance are met
  - Recommendations should be realistic, feasible, and clearly explained
  - Don't neglect to provide feedback to facilities and stakeholders; certain feedbacks may be negative and require convincing and justification
  - When possible, conclude an estimate of the time and resources needed to implement the changes
  - Ensuring that improvements are initiated in a timely fashion is critical to the evaluation's ultimate success



# Evaluating and Improving Surveillance

- Summary:
  - Surveillance has a long-standing Hx in public health—continues to evolve as new health-related problems arise
  - Surveillance is the continued watchfulness over health-related problems through systemic collection, consolidation, and evaluation of relevant data
  - Data and interpretations from surveillance are useful in setting priorities, planning and conducting disease control programs, and assessing the effectiveness of control efforts
  - Sources of data are often available and used for surveillance at the national, state, and local levels
  - Time, place, and person are the foundation for characterizing a health-related problem through surveillance
  - Timely, regular dissemination of basic data and their interpretation is a critical component of surveillance
  - Reports of findings must be shared with those who supplied the data and those responsible for controlling health problems
  - Critical to maintaining useful, cost-effective surveillance is periodic evaluation and implementation of recommended improvements
  - Stakeholders should be ID and included in the evaluation process; a clear description and diagram of surveillance activities should be developed ; and the usefulness, resource requirement, resource requirements, an characteristics of optimal surveillance should be individually assessed



# Characteristics of Well-Conducted Surveillance

**Acceptability** reflects the willingness of individual persons and organizations to participate in surveillance. Acceptability is influenced substantially by the time and effort required to complete and submit reports or perform other surveillance tasks.

**Flexibility** refers to the ability of the method used for surveillance to accommodate changes in operating conditions or information needs with little additional cost in time, personnel, or funds. Flexibility might include the ability of an information system, whose data are used for surveillance of a particular health condition, to be used for surveillance of a new health problem.

**Predictive Value Positive** is the proportion of reported or identified cases that truly are cases, or the proportion of reported or identified epidemics that were actual epidemics. Conducting surveillance that has poor predictive value positive is wasteful, because the unsubstantiated or false-positive reports result in unnecessary investigations, wasteful allocation of resources, and especially for false reports of epidemics, unwarranted public anxiety (see Figure 5.10 for how to calculate predictive value positive.)

**Quality** reflects the completeness and validity of the data used for surveillance. One simple measure is the percentage of unknown or blank values for a particular variable (e.g., age) in the data used for surveillance.

**Representativeness** is the extent to which the findings of surveillance accurately portray the incidence of a health event among a population by person, place, or time. Representativeness is influenced by the acceptability and sensitivity (see the following) of the method used to obtain data for surveillance. Too often, epidemiologists who calculate incidence rates from surveillance data incorrectly assume that those data are representative of the population.

**Sensitivity** is the ability of surveillance to detect the health problem that it is intended to detect. (see Figure 5.10 for how to calculate sensitivity.) Surveillance for the majority of health problems might detect a relatively limited proportion of those that actually occur. The critical question is whether surveillance is sufficiently sensitive to be useful in preventing or controlling the health problem.



# Characteristics of Well-Conducted Surveillance

*Simplicity* refers to the ease of operation of surveillance as a whole and of each of its components (e.g., how easily case definitions can be applied or how easily data for surveillance can be obtained). The method for conducting surveillance typically should be as simple as possible while still meeting its objectives.

*Stability* refers to the reliability of the methods for obtaining and managing surveillance data and to the availability of those data. This characteristic is usually related to the reliability of computer systems that support surveillance but might also reflect the availability of resources and personnel for conducting surveillance.

*Timeliness* refers to the availability of data rapidly enough for public health authorities to take appropriate action. Any unnecessary delay in the collection, management, analysis, interpretation, or dissemination of data for surveillance might affect a public health agency's ability to initiate prompt intervention or provide timely feedback.

*Validity* refers to whether surveillance data are measuring what they are intended to measure. As such, validity is related to sensitivity and predictive value positive: Is surveillance detecting the outbreaks it should? Is it detecting any nonoutbreaks?



# Characteristics of Well-Conducted Surveillance

**Figure 5.10 Calculation of Predictive Value Positive, Sensitivity, and Specificity for Surveillance**

		True case or outbreak		Total
		Yes	No	
Detected by surveillance?	Yes	True positive (A)	False positive (B)	Total detected by surveillance (A + B)
	No	False negative (C)	True negative (D)	Total missed by surveillance (C + D)
Total		Total true cases or outbreaks (A + C)	Total noncases or non-outbreaks (B + D)	Total (A + B + C + D)

Predictive value positive =  $A / (A+B)$

Sensitivity =  $A / (A+C)$

Specificity =  $D / (B+D)$

**Table 5.7 Relative Importance of Selected Surveillance Characteristics By Use of Surveillance Findings**

Characteristic	Use of surveillance		
	Managing individual cases of disease	Detecting outbreaks of disease	Planning and evaluating health programs
Flexibility	***	****	*
Predictive value positive	****	***	****
Quality	*****	***	****
Representativeness	**	**	****
Sensitivity	****	****	***
Stability	****	*****	***
Timeliness	****	*****	*

The number of asterisks reflects the relative importance of each characteristic with more asterisks signifying greater importance.

*Adapted from: Sosin DM, Hopkins RS. Monitoring disease and risk factors: surveillance. In: Pencheon D, Melzer D, Gray M, Guest C (editors). Oxford Handbook of Public Health, 2<sup>nd</sup> ed. Oxford: Oxford University Press; 2006 (in Press).*



# Examples of Surveillance

## Surveillance for Consumer Product-Related Injuries

The U.S. Consumer Product Safety Commission's (CPSC) National Electronic Injury Surveillance System (NEISS) is a national probability sample of hospitals in the United States and its territories (Figure 5.11). Patient information is collected from each NEISS hospital for every emergency department (ED) visit involving an injury associated with consumer products. From this sample, the total number of product-related injuries treated in hospital EDs nationwide can be estimated.

**Figure 5.11 U.S. Consumer Product Safety Commission NEISS Hospitals, 2003**

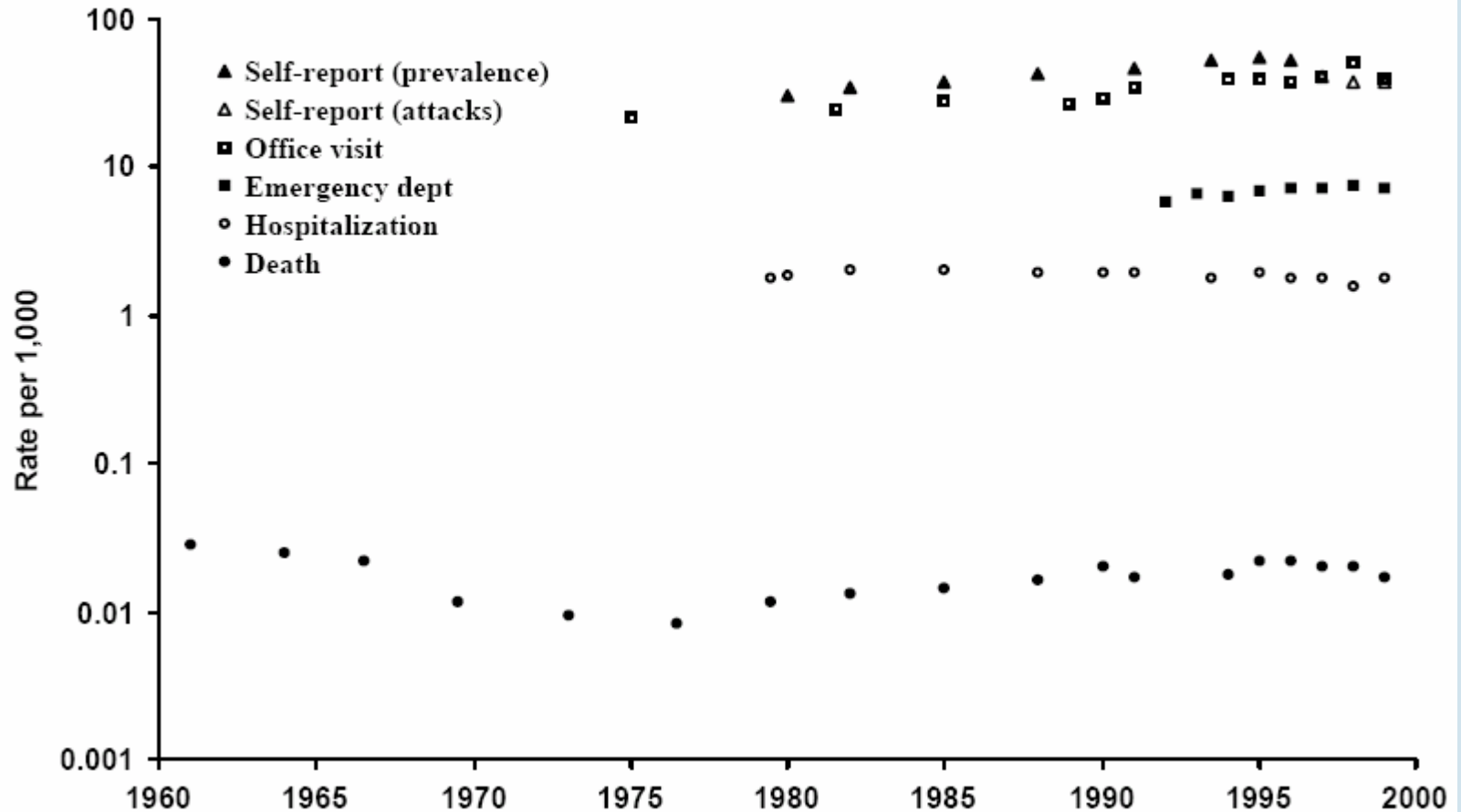


*Source: NEISS: The National Electronic Injury Surveillance System - A Tool for Researchers [monograph on the Internet]. Washington (DC): U.S. Consumer Product Safety Commission, Division of Hazard and Injury Data Systems [updated 2000 Mar; cited 2005 Dec 2]. Available from: <http://www.cpsc.gov/neiss/2000d015.pdf>.*



# Surveillance for Asthma

Figure 5.12. Asthma Prevalence, Morbidity, and Mortality Rates, United States, 1960–1999



# Surveillance for Influenza

- Reporting from states to the Centers for Disease Control and Prevention (CDC) is not limited to notifiable diseases.; surveillance for influenza is one such example.
- Because influenza can be widespread during the winter but its diagnosis is rarely confirmed by laboratory test
- Has presented challenges that have been met by using a combination of different sources of data
- At the state and local levels, health authorities receive reports of outbreaks of influenza-like illness, laboratory identification of influenza virus from nasopharyngeal swabs, and reports from schools of excess absenteeism (e.g., >10% of a school's student body)
- In addition, certain local systems monitor death certificates for pneumonia and influenza, arrange for selected physicians to report the number of patients they examine with influenza-like illness each week, and ask selected businesses and schools to report excessive employee absenteeism
- At least one type of surveillance for influenza includes pharmacy reports of the number of prescriptions of antiviral drugs used to treat influenza
- Another health department monitors the number of chest radiographs a mobile radiology group performs of nursing home patients; >50% of the total chest radiographs ordered is used as a marker of increased influenza activity
- At the national level, CDC collects and analyzes data weekly from seven different data systems to assess influenza activity
- The laboratory-based system receives reports of the number of percentage of influenza isolates from approximately 125 laboratories located throughout the United States
- Selected isolates are sent to CDC for additional testing



# Surveillance for Influenza

- The U.S. Influenza Sentinel Providers Surveillance Network receives reports of the number and percentage of patients examined with influenza-like illness by age group from a network of approximately 1,000 health-care providers
- The 122 City Mortality Reporting System receives counts of deaths and the proportion of those deaths attributable to pneumonia and influenza from 122 cities and counties across the country.
- Each state and territorial health department provides an assessment of influenza activity in the state as either “No Activity,” “Sporadic,” “Local,” “Regional,” or “Widespread.”
- Influenza-associated pediatric mortality (defined as laboratory-confirmed influenza associated death among children aged <18 years) is now a nationally notifiable condition and is reported through the National Notifiable Disease Surveillance System.
- Emerging Infections Program conducts surveillance for laboratory-confirmed influenza-related hospitalizations among persons aged <18 years in 11 metropolitan areas in 10 states
- By using multiple data sources at all levels — local, state, and national — public health officials are able to assess influenza activity reliably throughout the United States without asking every health-care provider to report each individual case.



# Limitations of Surveillance and

## Recommendations for Improvement

- Surveillance might have limitations, particularly as a result of underreporting, lack of representativeness, and lack of timeliness, that compromise its usefulness
- For rare, serious diseases of public health importance (e.g., rabies, plague, or botulism), the percentage of cases actually reported might approach 100% of diagnosed cases
- Reporting completeness for diseases that have local programs that specifically look for cases of the disease to aid in their prevention or control (e.g., AIDS, tuberculosis, and sexually transmitted diseases [STDs]) has been identified as being higher than for other, nonlife-threatening diseases
- For other diseases, reporting has been reported to be as low as 9%

Table 5.8. Rosenberg's Shigellosis Cascade

Event	Percentage of Patients	Cumulative Days Elapsed from Onset of Symptoms
Infected	100	—
Symptomatic	76	—
Consulted physician	28	—
Culture obtained	9	7
Culture positive	7	10
<b>Reported to local health department</b>	<b>6</b>	<b>11</b>
Reported to CDC	6	29
Patient contacted	6	—
Negative follow-up culture obtained	2	39

Adapted from: Rosenberg MJ, Marr JS, Gangarosa EJ, Pollard RA, Wallace M, Brolnitsky O. *Shigella* surveillance in the United States, 1975. *J Infect Dis* 1977;136:458–60.



# Limitations of Surveillance and Recommendations for Improvement

- Limitations

**Underreporting.** For the majority of notifiable diseases, data for surveillance are based on passive reporting by physicians and other health-care providers. Studies have demonstrated that in the majority of jurisdictions, only a fraction of cases of the notifiable diseases overall are ever reported.<sup>37-39</sup> The most obvious result of such underreporting is that effective action is delayed, and cases occur that might have been prevented by prompt reporting and prompt initiation of control measures. For example, if a case of hepatitis A in a food handler goes unreported, the opportunity to provide protective immune globulin to restaurant patrons will be missed, and cases or an outbreak of hepatitis A that should have been prevented will instead occur. However, underreported data might still be useful for assessing trends or other patterns reflecting the occurrence or burden of disease.



# Limitations of Surveillance and Recommendations for Improvement

- Barriers to Reporting from Providers' Perspective:

Lack of knowledge of reporting requirements —

- Lack of awareness of responsibility to report.
- Lack of awareness of which diseases must be reported.
- Lack of awareness of how or to whom to report.
- Assumption that someone else (e.g., the laboratory) will report.

Negative attitude toward reporting —

- Time consuming.
- Hassle (e.g., a lengthy or complex report form or procedure).
- Lack of incentive.
- Lack of feedback.
- Distrust of government.

Misconceptions that result from lack of knowledge or negative attitude —

- Compromises patient-physician relationship.
- Concern that report might result in a breach of confidentiality (e.g., HIPAA concerns).
- Disagreement with need to report.
- Judgment that the disease is not that serious.
- Belief that no effective public health measures exist.
- Perception that health department does not act on the reports.



# Limitations of Surveillance and Recommendations for Improvement

**Lack of representativeness of reported cases.** Underreporting is not uniform or random. Two important biases distort the completeness of reporting. First, health-care providers are more likely to report a case that results in severe illness and hospitalization than a mild case, even though a person with mild illness might be more likely to transmit infection to others because the person might not be confined at home or in the hospital. This bias results in an inflated estimate of disease severity in such measures as the death-to-case ratio. Second, health-care providers are more likely to report cases when the disease is receiving media attention. This bias results in an underestimate of the baseline incidence of disease after media attention wanes.

Both biases were operating in 1981 during the national epidemic of tampon-associated toxic shock syndrome. Early reports indicated a death-to-case ratio much higher than the ratio determined by subsequent studies, and reported cases declined more than incident cases after the publicity waned.<sup>41</sup>

**Lack of timeliness.** Lack of timeliness can occur at almost any step in the collection, analysis, and dissemination of data on notifiable diseases. The reasons for the delays vary. Certain delays are disease-dependent. For example, physicians cannot diagnose certain diseases until confirmatory laboratory and other tests have been completed. Certain delays are caused by cumbersome or inefficient reporting procedures. Delays in analysis are common when surveillance is believed to be a rote function rather than as one that provides information for action. Finally, delays at any step might culminate in delays in dissemination, with the result that the medical and public health communities do not have the information they need to take prompt action.



# Limitations of Surveillance and Recommendations for Improvement

- Recommendations for Improvement of Surveillance

**Improving awareness of practitioners.** Most important, all persons who have a responsibility to report must be aware of this responsibility. The health department should actively publicize the list of notifiable diseases and the reporting mechanisms. Certain states send the reporting requirements in a packet when a physician becomes licensed to practice in the state. Other state health officials visit hospitals and speak at medical presentations or seminars to increase the visibility of surveillance.

**Incentives.** Health-care providers might need services or therapeutic agents that are only available from the health department, which might be able to use this need to obtain reports of certain diseases. Services can include laboratory testing and consultation on diagnosis and treatment of certain diseases. Agents might include immune globulin for human rabies and hepatitis B and antitoxin for diphtheria and botulism. These services and agents might be particularly effective incentives if they are available promptly and delivered in a professional, authoritative manner.<sup>10</sup>

**Simplify reporting.** Reporting should be as simple as possible. Health departments often accept telephone reports or have toll-free telephone numbers. If paper forms are used, they should be widely available and easy to complete, and they should ask only for relevant information. Certain state health departments have arranged for electronic transfer of laboratory or other patient- or case-related data; therefore, reporting is accomplished automatically at scheduled times or at the push of a computer key.



# Limitations of Surveillance and Recommendations for Improvement

**Frequent feedback.** The role of feedback cannot be overemphasized. Feedback can be written (e.g., a monthly newsletter) or oral (e.g., updates at regular meetings of medical staff or at rounds). The feedback should be timely, informative, interesting, and relevant to each reporter's practice. Feedback should include information about disease patterns and control activities to increase awareness and to reinforce the importance of participating in a meaningful public health activity.

**Widening the net.** Traditionally, surveillance for notifiable diseases has relied on reporting by physicians. Almost every state now requires reporting of positive cultures or diagnostic tests for notifiable diseases by commercial and hospital laboratories. For certain states, the number of laboratory reports exceeds the number of reports from physicians, hospitals, clinics, and other sources. Other health-care staff (e.g., infection control personnel and school nurses) can be used as sources of data for surveillance. Another way to widen the net is to develop alternative methods for conducting surveillance (e.g., using secondary sources of data). This method has been used effectively for surveillance of influenza and certain injuries.

**Shifting the burden.** Another effective approach is to shift the burden for gathering data from the health-care provider to the health department. In essence, this approach involves ongoing surveys of providers to more completely identify cases of disease, and it has been demonstrated to increase the number of cases and the proportion of identified-to-incident cases. Because health department staff contact health-care providers regularly, this approach also promotes closer personal ties among providers and health department staff. As with surveys in general, this approach is relatively expensive, and its cost-effectiveness is not entirely clear. In practice, it is usually limited to disease elimination programs, short-term intensive investigation and control activities, or seasonal problems (e.g., certain arboviral diseases).



# Chlamydia

**What is chlamydia?** Chlamydia is a common sexually transmitted disease (STD) caused by the bacterium, *Chlamydia trachomatis*, which can damage a woman's reproductive organs. Even though symptoms of chlamydia are usually mild or absent, serious complications that can cause irreversible damage, including infertility, can occur without notice before a woman ever recognizes a problem. Chlamydia also can cause discharge from the penis of an infected man.

**How common is chlamydia?** Chlamydia is the most frequently reported bacterial STD in the United States. In 2002, a total of 834,555 chlamydial infections were reported to CDC from 50 states and the District of Columbia. Underreporting is substantial because the majority of persons with chlamydia are not aware of their infections and do not seek testing. Also, testing is not often performed if patients are treated for their symptoms. An estimated 2.8 million Americans are infected with chlamydia each year. Women are frequently re-infected if their sex partners are not treated.

**How do people contract chlamydia?** Chlamydia can be transmitted during vaginal, anal, or oral sex. Chlamydia can also be passed from an infected mother to her baby during vaginal childbirth. Any sexually active person can be infected with chlamydia. The greater the number of sex partners, the greater the risk for infection. Because the cervix (opening to the uterus) of teenage females and young women is not fully matured, they are at particularly high risk for infection if sexually active. Because chlamydia can be transmitted by oral or anal sex, men who have sex with men are also at risk for chlamydial infection.



# Chlamydia

**What are the symptoms of chlamydia?** Chlamydia is known as a "silent" disease because approximately three quarters of infected women and half of infected men have no symptoms. If symptoms do occur, they usually appear within 1–3 weeks after exposure.

Among women, the bacteria initially infect the cervix and the urethra (urine canal). Women who have symptoms might have an abnormal vaginal discharge or a burning sensation when urinating. When the infection spreads from the cervix to the fallopian tubes (the tubes that carry eggs from the ovaries to the uterus), certain women still have no signs or symptoms; others have lower abdominal pain, low back pain, nausea, fever, pain during intercourse, or bleeding between menstrual periods. Chlamydial infection of the cervix can spread to the rectum.

Men with signs or symptoms might have a discharge from their penis or a burning sensation when urinating. Men might also have burning and itching around the opening of the penis. Pain and swelling in the testicles are uncommon symptoms.

Men or women who have receptive anal intercourse might acquire chlamydial infection in the rectum, causing rectal pain, discharge, or bleeding. Chlamydia has also been identified in the throats of women and men having oral sex with an infected partner.



# Chlamydia

**What complications can result from untreated chlamydia?** If untreated, chlamydial infections can progress to serious reproductive and other health problems with both short- and long-term consequences. Similar to the disease itself, the damage that chlamydia causes is often asymptomatic.

Among women, untreated infection can spread into the uterus or fallopian tubes and cause pelvic inflammatory disease (PID). This happens among  $\leq 40\%$  of women with untreated chlamydia. PID can cause permanent damage to the fallopian tubes, uterus, and surrounding tissues. The damage can lead to chronic pelvic pain, infertility, and potentially fatal ectopic pregnancy (pregnancy outside the uterus). Women infected with chlamydia are  $\leq 5$  times more likely to become infected with HIV, if exposed.

To help prevent the serious consequences of chlamydia, screening at least annually for chlamydia is recommended for all sexually active women aged  $\leq 25$  years. An annual screening test also is recommended for women aged  $\geq 25$  years who have risk factors for chlamydia (a new sex partner or multiple sex partners). All pregnant women should have a screening test for chlamydia.

Complications among men are rare. Infection sometimes spreads to the epididymis (a tube that carries sperm from the testis), causing pain, fever, and, rarely, sterility. Rarely, genital chlamydial infection can cause arthritis that can be accompanied by skin lesions and inflammation of the eye and urethra (Reiter syndrome).

**How does chlamydia affect a pregnant woman and her baby?** Among pregnant women, evidence exists that untreated chlamydial infections can lead to premature delivery. Babies who are born to infected mothers can contract chlamydial infections in their eyes and respiratory tracts. Chlamydia is a leading cause of early infant pneumonia and conjunctivitis (pink eye) among newborns.

**How is chlamydia diagnosed?** Laboratory tests are used to diagnose chlamydia. Diagnostic tests can be performed on urine; other tests require that a specimen be collected from such sites as the penis or cervix.



# Chlamydia

**What is the treatment for chlamydia?** Chlamydia can be easily treated and cured with antibiotics. A single dose of azithromycin or a week of doxycycline (twice daily) are the most commonly used treatments. HIV-positive persons with chlamydia should receive the same treatment as those who are HIV-negative.

All sex partners should be evaluated, tested, and treated. Persons with chlamydia should abstain from sexual intercourse until they and their sex partners have completed treatment; otherwise re-infection is possible.

Women whose sex partners have not been appropriately treated are at high risk for re-infection. Having multiple infections increases a woman's risk for serious reproductive health complications, including infertility. Retesting should be considered for females, especially adolescents, 3–4 months after treatment. This is especially true if a woman does not know if her sex partner has received treatment.

**How can chlamydia be prevented?** The surest way to avoid transmission of STDs is to abstain from sexual contact or to be in a long-term mutually monogamous relationship with a partner who has been tested and is known to be uninfected. Latex male condoms, when used consistently and correctly, can reduce the risk of transmission of chlamydia.

Chlamydia screening is recommended annually for all sexually active women aged  $\leq 25$  years. An annual screening test also is recommended for older women with risk factors for chlamydia (a new sex partner or multiple sex partners). All pregnant women should have a screening test for chlamydia.

Any genital symptoms (e.g., discharge or burning during urination or unusual sores or rashes) should be a signal to stop having sex and to consult a health-care provider immediately. If a person has been treated for chlamydia (or any other STD), he or she should notify all recent sex partners so they can see a health-care provider and be treated. This will reduce the risk that the sex partners will experience serious complications from chlamydia and will also reduce the person's risk for becoming re-infected. The person and all of his or her sex partners should avoid sex until they have completed their treatment for chlamydia.

