# **Chapter 5 Screening and Surveillance for Promoting Population Health**

#### **Learning Outcomes**

After completing this chapter, you will be able to:

- 1. Distinguish between screening and surveillance activities.
- 2. Interpret the accuracy of a screening test.
- 3. Identify limitations associated with screening for a health problem.
- 4. Plan a surveillance system based upon known risk factors for a health problem.
- 5. Identify limitations of a surveillance system.

**Keyterms** Positive predictive value • Screening • Surveillance • Surveillance system • Syndrome surveillance

#### Introduction

In managing the health of populations, prevention measures may not be feasible or highly effective. Moreover, prevention strategies for many health conditions may not be well known. For this reason, screening and surveillance are important strategies in managing population health in communities and in populations receiving health care services. Fundamental to the success of both screening and surveillance in terms of improving population health is knowledge of the natural history of the health problem and the ability to accurately detect the problem early.

# **Screening**

The primary purpose of screening is to identify early signs and symptoms of a disease or health problem to implement early treatment or program intervention to reduce the likelihood of the emergence of disease or health problem and/or mortality from the disease in an individual. Screening in populations is only undertaken when

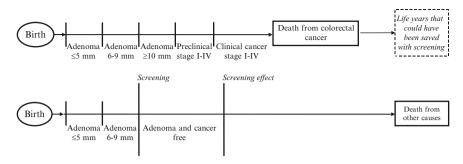


Fig. 1 Impact of screening upon the clinical course of colorectal cancer (Adapted from: Zauber et al., 2008)

Table 1 Examples of common screening tests and condition targeted for screening

Test	Targeted condition
Clinical breast exam	Breast cancer
Denver II (formerly Denver Developmental Screening Test, DDST)	Identification of children from birth to 6 years of age who may require additional evaluation to promote healthy development
Digital rectal exam	Prostate cancer
Fecal occult blood test	Colon cancer
Mammography	Breast cancer
Papanicolaou test	Invasive cervical cancer
Phenylketonuria Screening (PKU)	A rare genetic condition caused by a defect in the enzyme phenylalanine hydroxylase (PAH) which cases a build-up of phenylalanine resulting in mental retardation and behavioral abnormalities
Prostate specific antigen	Prostate cancer
Rapid HIV	Human Immunodeficiency Virus

there is proven benefit to the screening and the natural history of the disease is well established as for example with colorectal cancer (see Fig. 1). Screening may employ a technology (e.g., mammography), laboratory testing (e.g., prostatic specific antigen [PSA] blood test), a survey form (e.g., *Center for Epidemiologic Studies Short Depression Scale* [CES-D 10], Radloff, 1977), skill-based testing (e.g., *The Denver II*, Frankenburg et al., 1992), clinical assessment (e.g., digital rectal exam for prostate cancer), or a combination thereof. Table 1 lists examples of common screening tests and the condition targeted for the screening.

The value of a screening test is determined by its ability to distinguish a diseased from nondiseased state. Ideally, the screening test should have 100% specificity, 100% sensitivity, and 100% positive predictive value (PPV). Manufacturers provide information on the accuracy of screening tests produced. The computation of the values to assess a screening test was presented in chapter "Descriptive Epidemiological Methods." Criteria that should be considered when choosing a screening test follow principles presented in chapter "Epidemiological Study

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Designs for Evaluating Health Services, Programs, and Systems" for Program Evaluation and are also useful in this selection process:

- · Relatively inexpensive
- · Easy availability
- High accuracy
- Can alter the course (severity, mortality) of a disease or health problem
- Acceptable to target population
- · Convenient for staff
- · Results are quickly available

Another approach to evaluating the accuracy of a screening test is to prepare a receiver operating characteristic (ROC) curve. This graphical technique is used when test measures are ordinal and the outcome (disease) measure is nominal, a likelihood ratio (LR) for each level of the test is computed and the area under a ROC curve is used to assess criterion validity. An ROC curve is a plot of the true positive rate (sensitivity) vs. the false positive rate (1-specificity) for each level of the test. The test level where an LR of 1.0 is exceeded is defined as the threshold for positivity or the cut point at which the value for the test will significantly predict the outcome. Statistical software is available to easily construct LRs and ROC curves using statistical software such as SPSS Inc.'s Predictive Analytic Software portfolio (http:// ww.spss.com). The greater the area under the curve (AUC), the greater is the accuracy of the test measure in predicting the outcome represented by AUC = 1, perfect prediction and where AUC = 0.5 is random prediction. Figure 2 evaluates the value of the Body Mass Index (BMI) in screening for overweight in adolescents using ROC curves. Both ROC curves in Fig. 2 illustrate that use of BMI is a good method for screening for overweight in adolescents, with BMI providing a more accurate prediction of excess fatness in adolescent males than in females.

Not all screening is conducted to prevent disease. There are certain genetic conditions that are required by States for screening. It is established public health practice to screen newborns from a blood spot for selected endocrine (e.g., hypothyroidism), metabolic (e.g., phenylketonuria [PKU]), hematologic (e.g., sickle cell), and functional (e.g., hearing) disorders (Therrell et al., 2008). Although the conditions for which newborn screen is done are not currently preventable, many newborns can avoid severely disabling or fatal consequences to intervention if screening is conducted soon after delivery. Nutritional interventions, namely avoiding high protein foods in infancy, can prevent mental retardation in children with PKU. Treatment with a thyroid hormone, levo-thyroxine, can prevent mental retardation in children with congenital hypothyroidism.

Screening and screening tests can be conducted in a variety of settings, both traditional (in provider offices, clinics, health departments or hospitals) and nontraditional (schools, pharmacies, shopping malls, airports) (Boxed Example 1). Increasingly, screening tests are available for over-the-counter purchase for self-administration and at nontraditional health service settings (pharmacies offering cholesterol testing, liver function testing, diabetes screening, and hemoglobin A1C testing). Although these trends are important in engaging communities in healthy behaviors,

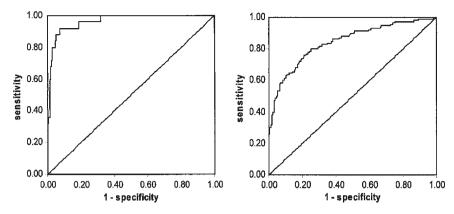


Fig. 2 (a) Receiver operating characteristics curve for male adolescents. BMI was significantly better than chance as a diagnostic test for excess fatness  $[X (0.97 \pm 0.02; n = 200]$ . The 45° represents chance as a diagnostic test (area under the curve = 0.5). Excess fatness cutoff = 25%. (b) Receiver operating characteristics curve for female adolescents. BMI was significantly better than chance as a diagnostic test for excess fatness  $[X (0.85 \pm 0.02; n = 274]$ . The 45° represents chance as a diagnostic test (area under the curve = 0.5). Excess fatness cutoff = 30% (From Neovius et al., 2004, with permission American Journal of Clinical Nutrition by Neovius, M.G., et al. Copyright 2004 by American Society for Nutrition. Reproduced with permission of American Society for Nutrition in the format textbook via Copyright Clearance Center.)

screening is not a substitute for regular contacts with a health care provider with whom the results should be shared, validated with a physical exam, and compared over time. A comprehensive review of the state of the evidence regarding screening practices for cancer in adults, cardiovascular, and respiratory diseases, infectious diseases, injury and violence, mental health and substance abuse, metabolic conditions, musculoskeletal conditions, obstetric and gynecologic conditions, vision disorders, and conditions in children is available in *The Guide to Clinical Preventive Services* (U.S. Preventive Services Task Force, 2008).

# Boxed Example 1 Mammography or MRI in Detecting Breast Cancer in Younger Women?

**Problem**: The value of detecting tumors by mammographic screening in younger women is controversial because they have denser breasts than postmenopausal women. Yet, it is important to conduct screening in women who have a family history of breast cancer or are carriers of the BRCA1 or BRCA2 or other mutations as these conditions are after associated with a diagnosis at a younger age.

**Methods and Data**: Women ages 25–70 years with a genetic risk of breast cancer (cumulative lifetime risk of 15% or more) were recruited from six cancer clinics in the Netherlands. Surveillance was conducted by means of clinical breast exam by an experienced physician every 6 months and imaging studies performed annually.

<b>Results</b> (Data from: Kriege et al., 2004):				
	Sensitivity (%)			
Screening method	Invasive breast cancer	Specificity (%)		
Clinical breast examination (CBE)	17.9	98.1		
Mammography	33.3	95.0		
MRI	79.5	89.8		

Magnetic resonance imaging (MRI) has a higher sensitivity rate than either CBE or mammography in detecting invasive breast cancer. The high sensitivity means that more True Positive cases are identified or that cases that test positive really have the disease. The False Negative rate is the lowest for MRI (100% - % Sensitivity = % False Negative; 100% - 79.5% = 20.5%). This means that fewer true positive cases are missed. The specificity is of similarly high magnitude among the three screening methods. This means there is a high percentage of cases that test negative that are truly negative.

Managerial Epidemiology Interpretation: The health care manager should understand that CBE is least likely to identify true positive cases of breast cancer, but is most likely to correctly classify true negatives. Mammography is not as effective in detecting breast cancer in young high risk women as MRI. MRI may be the screening method of choice for breast cancer in high risk young women.

The formulation of screening goals for a community, health plan membership, physician practice, or other population group should be undertaken by a health services manager practicing with epidemiologic principles. These should be crafted in consideration of national screening goals. Displayed in Table 2 are the *Healthy People 2010* screening goals for the USA.

# Challenges to the Benefit of Screening

Large scale community-based screening, such as sexually transmitted disease (STD) walk-in clinics, offers various free services, including confidential and/or anonymous testing for human immunodeficiency virus (HIV). In community-based screening, tests with high specificity and high sensitivity may yield large numbers of persons with false positive or false negative results. Test results are influenced by test-kit handling, storage conditions, clinic/laboratory quality assurance protocols, test inventory lot quality, test operator training and proficiency, external controls, and patient characteristics. Also, different testing methods for the same condition using different bodily fluids may yield different results. For example, OraQuick® oral fluid testing (OraSure Technologies, Bethlehem, Pennsylvania) was found to

**Table 2** Selected health goals from *healthy people 2010* and supporting details for screening populations, United States (Source: U.S.D.H.H.S. (2000))

populations, United States	(Source: U.S.D.H.H.S. (2000))
	Women aged 18 years and older who received a Pap test within
Goal 3-11b	the preceding 3 years
National data source:	National Health Interview Survey (NHIS), CDC, National
	Center for Health Statistics (NCHS)
State data source:	Behavioral Risk Factor Surveillance System (BRFSS), CDC,
	National Center for Chronic Disease Prevention and Health
	Promotion (NCCDPHP)
Measure:	Percent (age adjusted)
Baseline:	79 (1998)
Numerator:	Number of women aged 18 years and older who report receiving
	a Pap test within the past 3 years
Denominator:	Number of women aged 18 years and older
Population targeted:	US civilian, noninstitutionalized population
Questions used to obtain	From the 1998 National Health Interview Survey:
the national data:	Have you ever had a pap smear test?
	[If yes:]
	When did you have your most recent pap smear test? Was it a
	year ago or less, more than 1 year but not more than 2 years,
	more than 2 years but not more than 3 years, more than 3 years but not more than 5 years, or over 5 years ago?
Goal 3–12	Increase the proportion of adults who receive a colorectal cancer
Goal 3–12	screening examination
Goal 3-12a	Adults aged 50 years and older who have received a fecal occult
Godi 5 12a	blood test (FOBT) or stool blood test within the preceding 2
	years
National data source:	National Health Interview Survey (NHIS), CDC, NCHS
State data source:	Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP
Measure:	Percent (age adjusted)
Baseline:	35 (1998)
Numerator:	Number of adults aged 50 years and older who report receiving fecal occult blood testing within the preceding 2 years
Denominator:	Number of adults aged 50 years and older
Population targeted:	US civilian, noninstitutionalized population
Questions used to obtain	From the 1998 National Health Interview Survey:
the national data:	A blood stool test is when the stool is examined to determine whether it contains blood. Have you ever had a blood stool
	test?
	[If yes:]
	When did you have your most recent blood stool test? Was it a year ago or less, more than 1 but not more than 2 years, more than 2 years but not more than 3 years, more than 3 years but
Goal 3-12b	not more than 5 years, or more than 5 years ago?  Adults aged 50 years and older who have ever received a
AT 2 11.	sigmoidoscopy
National data source: State data source:	National Health Interview Survey (NHIS), CDC, NCHS Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP
Measure:	Percent (age adjusted)
Baseline:	37 (1998)
	(continued)

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Table 2 (continued)

	Women aged 18 years and older who received a Pap test within				
Goal 3-11b	the preceding 3 years				
Numerator:	Number of adults aged 50 years and older who report ever receiving a sigmoidoscopy				
Denominator:	Number of adults aged 50 years and older				
Population targeted:	US civilian, noninstitutionalized population				
Questions used to obtain	From the 1998 National Health Interview Survey:				
the national Data:	A proctoscopic examination is when a tube is inserted in the rectum to check for problems. Have you ever had a proctoscopic examination?				
Goal 3–13	Increase the proportion of women aged 40 years and older who have received a mammogram within the preceding 2 years				
National data source:	National Health Interview Survey (NHIS), CDC, NCHS				
State data source:	Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP				
Measure:	Percent (age adjusted)				
Baseline:	67 (1998)				
Numerator:	Number of women aged 40 years and older who report receiving a mammogram within the past 2 years				
Denominator:	Number of women aged 40 years and older				
Population targeted:	US civilian, noninstitutionalized population				
Questions used to obtain	From the 1998 National Health Interview Survey:				
the national data:	A mammogram is an X-ray taken only of the breasts by a machine that presses the breast against a plate. Have you ever had a mammogram?				
	[If yes:]				
	When did you have your most recent mammogram? Was it a year ago or less, more than 1 year but not more than 2 years, more than 2 years but not more than 3 years, more than 3 years but not more than 5 years, or over 5 years ago?				

have high false positive rates (or lower specificity) than finger-stick rapid testing whole-blood specimens for HIV. Out of 1,720 screened with oral fluid rapid testing, 343 false positive results occurred (Cummiskey et al., 2008). The efficacy of screening may also be mitigated by the strength of other risk factors acting upon intermediate steps in the causal pathway for a disease. Heavy cigarette smoking (≥40 pack-years) is highly associated with carcinoma in situ (Terry et al., 2000). The persistence of intermediate risk factors (e.g., heavy cigarette smoking) for an intermediate step of a disease may diminish the time-window for detecting an early phase of the disease, such as the early detection of adenomas in heavy cigarette smokers.

Some screening may not be able to be conducted anonymously or without bias. Such is the challenge with screening for obesity, particularly childhood obesity. Parental consent, overrepresentation of younger children, a lower response among adolescents, concerns over social stigma may all affect participation in screening for obesity (Crosbie et al., 2008).

Because screening may yield variability in specificity and sensitivity, either due to explained or unexplained variance, health care managers should have plans in

place if results are unacceptable. These include monthly evaluation of screening specificity and sensitivity relative to manufacturer's reported results, repeat screening testing, utilizing confirmatory testing, and selecting a different manufacturer.

#### Surveillance

Surveillance is the systematic process of identifying, collecting, orderly summarization, analysis, and evaluation of data about specific diseases or health problems with the prompt dissemination of finding to those who need to know and those who need to take action. Response by the health system includes communication of risk identified from surveillance to the public, introduction of countermeasures such as recall of products, treatment of individuals who could transmit the disease, or the administration of immunizations. Surveillance can focus on the identification of: awareness of specific medical conditions (e.g. stroke events), behavioral risk factors (factors leading to the increased risk of a health problem because of an action or task) (e.g., needlestick injury surveillance, adverse drug events), birth defects, chronic diseases, clinical syndromes clustering (because of their potential for bioterrorism), dental caries, health-related quality of life (HROoL), infectious diseases, indicators of the potential for infectious diseases in humans (e.g., surveillance of dead birds in identifying emergence of West Nile Virus), injuries, preventive service utilization, procedure utilization (e.g., assisted reproductive technology), and health problems whose prevalence is expected to markedly increase over time (e.g., epilepsy) (Centers for Disease Control, 2008; Chowdhury et al., 2007; Pelletier et al., 2005; Piriyawat et al., 2002; Wright et al., 2008; Zahran et al., 2005), and other health problems (e.g., nonfatal maltreatment of infants).

The process of surveillance begins with the definition of the "case." A case is initially defined by what is unusual about the disease, usually clinically by a set of signs and symptoms and their onset focused on unusual findings (e.g., mid-lobe lung consolidation pneumonia-like presentation on chest X-rays in SARS cases) and related to some common exposure (e.g., travel to a location where other known cases were identified). The case definition can then be further refined clinically (i.e., fewer signs and symptoms) or through expanded suspicions of a common cause or "exposure." Relevant screening laboratory tests of the cases are then followed up with confirmatory diagnostic testing. The more homogenous the clinical presentation, the more likely a common source of exposure can be identified. A Lyme disease case, one of the most rapidly increasing incidence rates of vectorborne diseases in the USA, is defined for surveillance purposes by the presence of a rash (erythema migrans), clinical signs (musculoskeletal, cardiovascular, neurologic), and laboratory determination of the presence of Borrelia burgdorferi in consideration of exposure to areas with infected ticks (Bacon et al., 2008). In addition to clinical and laboratory criteria for defining a case, epidemiologic criteria may be utilized as was with the surveillance case definition of Severe Acute Respiratory Syndrome (SARS). Epidemiologic criteria for SARS included one or more of the following exposures in the 10 days before

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onset of symptoms: Travel to a foreign or domestic location with documented or suspected recent transmission of SARS or close contact with a person with mild-to-moderate or severe respiratory illness and with history of travel in the 10 days before onset of symptoms to a foreign or domestic location with documented or suspected recent transmission of SARS (CDC, 2005).

Surveillance methodology for collecting data on confirmed or possible cases and other relating information can be accomplished through field surveys, reports of notifiable conditions from laboratories and health care providers to public health authorities, or review of existing databases or records. Table 3 describes selected surveillance systems and their target conditions. Data and trends from surveillance systems aid in planning for community- and population-based responses to emerging health problems. Data from the FoodNet consumption survey provided baseline comparisons in the general public of eating items (chicken and peanut butter) to help isolate the outbreak strain and source of a multistate outbreak of *Salmonella* infections associated with peanut butter and peanut butter-containing products (Medus et al., 2009).

Surveillance can be active or passive. The surveillance strategy selected depends upon the definition of the case, the objectives of the surveillance, and how information about risk factors for the condition is collected and also should consider the national health priorities for surveillance (Table 4). Regardless of the surveillance method used, medical and public health system resources should be prepared for action if a surveillance system identifies:

- A number of cases of an illness meeting a specific definition are larger than expected
- Unusual severe diseases or routes of transmission
- Unusual geographic presentation, seasonal occurrence, or absence of normal vector or
- Higher attack rates in persons with normal levels of exposure

It is important to note that surveillance systems or surveillance activities are not intended to support case management or referral services when cases are identified.

#### Active Surveillance

Active surveillance is the systematic, active searching for all possible events in real time using routine prospective collection of information about specific health problems and their risk factors. Cases are identified from laboratory results, admissions records to hospitals or emergency departments, radiology reports, outpatient facilities, or doctor's office's logs or billing records of presenting complaints. Active surveillance involves the process of screening, namely, locating cases with signs and symptoms that meet well-defined criteria related to a diagnosis, or proxies of human cases. Active surveillance is directed at determining if changing risk factors or more toxigenic strains are emerging which may impact communities and health care settings and to attempt to prevent through rapid case identification the spread

 Table 3 Examples of surveillance systems

Surveillance system	Purpose	Website
Behavioral Risk Factor Surveillance System (BRFSS)	On-going telephone health survey system, tracking health conditions and risk behaviors in the USA yearly since 1984.	www.cdc.gov/brfss
Foodborne Diseases Active Surveillance Network (FoodNet)	The principal foodborne disease component of CDC's Emerging Infections Program (EIP) using active surveillance of 650 clinical laboratories that test stool samples in the ten FoodNet sites	www.cdc.gov/foodnet
Illinois environmental public health tracking	Surveillance of environmental hazards, exposure to environmental hazards, and human health effects potentially related to these exposures	www.idph.state.il.us/about/ epi/epht.htm
International clearinghouse for birth defects surveillance and research	Brings together birth defect programs from around the world with the aim of conducting worldwide surveillance and research to prevent birth defects and to ameliorate their consequences	www.icbdsr.org
National child abuse and neglect data system	Compiles case-level data on as child-specific records for each report of alleged child maltreatment for which a completed investigation or assessment from a local child protective service agency has been made during the reporting period. Data collected annually from states since 1993	http://www.childwelfare.gov
National Electronic Injury Surveillance System (NEISS)	Recording of an injury associated with consumer products derived from emergency visits to a probability sample of hospitals in the USA and its territories and includes patient information	www.cpsc.gov/library/neiss. html
World Health Organization (WHO) STEPwise approach to Surveillance (STEPS)	Provides a methodology for obtaining core data on the established risk factors that determine the major chronic disease burden with a special focus on stroke	www.who.int/chp/steps/en
Surveillance, Epidemiology, and End Results (SEER)	Source of information on cancer incidence, martality and survival in the USA since 1973	www.seer.cancer.gov

Table 4	Disease sy	vndromes	targeted	for	surveillance	and	possible etiologies

Disease syndrome	Possible etiology
Gastrointestinal	Cholera, salmonella, shigella; Food poisoning due to: S. aureus,
illness	B.cereus, E.coli, ricin toxin, etc.
Hepatitis illness	Hepatitis A, yellow fever, alflatoxin, many chemical poisonings
Influenza-like illness	Influenza, RSV, rhinoviruses. Early stages of pulmonary anthrax, plague, and tularemia
Encephalitis	Eastern equine, Venezuelan equine, western equine, West Nile virus
Neuro-toxic	Botulism, shellfish toxin, chlorinated hydrocarbons, organophosphates, organic mercury, sarin, VX nerve agent, BZ, cyanide
Pulmonary disease	Pulmonary forms of anthrax, plague, tularemia, glanders, hantavirus, and chlorine gas
Rash illness	Cutaneous anthrax, smallpox, T2 mycotoxins, and mustard agents
Sepsis	Crimean-congo, ebola, lass, and marburg hemorrhagic fevers
Systemic disease	Brucellosis, typhoid, bubonic plague, Q fever, rift valley fever, tularemia
Radiation	Exposure to radioactive chemicals, X-rays, or other radiation source

of transmissible disease which has a high potential for serious illness or death such as Clostridium difficile or West Nile Virus (WVN) (Lindsey et al., 2008; Rabatsky-Ehr et al., 2008). Active surveillance for a condition similar to WNV involves collecting weekly information on the presence of this arbovirus in humans, animals, and mosquitos. Compiled data by state health departments are communicated to the CDC through a web-based system based upon reports from: (1) health care providers and clinical laboratories regarding human cases of WNV disease, (2) WNV presumption blood donors from blood collection agencies, (3) the testing of dead birds, (4) veterinarians to collect reports of WNV infection in nonhuman mammals, and (5) mosquitoes (Lindsey et al., 2008). Although typically identified as an essential component of public health practice for the control of transmissible diseases, the value of surveillance for noninfectious health problems is increasingly utilized in health services settings. For example, surveillance is an intervention utilized by nurses in the prevention of falls through the documentation of risk factors (e.g., physical impairments, cognitive impairments, inability to walk independently, incontinence, and use of certain medications such as diazepam, etc.) at admission and then monitoring these risk factors through the collection and monitoring clinical information throughout the course of the hospital stay. However, as with any active surveillance activities, the cost of the system needs to be considered relative to the resultant cost savings from the control or prevention of the outcome under surveillance (Klaucke et al., 1988; Shever et al., 2008). Thus, increasing the effectiveness of nursing intervention for surveillance for fall prevention may result in higher costs if more nursing staff would be required.

Two types of active surveillance are enhanced surveillance and syndrome surveillance. Enhanced surveillance is a type of active surveillance involving the prospective detection and simultaneous aggressive follow-up of reports of newly identified persons meeting the case definition of the disease to investigate. Enhanced surveillance: (1) focuses on the collection of accurate risk factor information, (2) guides prevention efforts, and (3) ensures referral to appropriate treatment

**Table 5** Sample national goal for surveillance and surveillance systems, United States (U.S.D.H.H.S., 2002)

Increase the number of States with an asthma surveillance system for tracking asthma 24–8. cases, illness, and disability

Target: 25 states

Baseline: 19 States had a surveillance system for tracking asthma cases, illness, and disability in 2003

Target setting method: 32% improvement

Data source: Behavioral Risk Factor Surveillance System (BRFSS), CDC

for cases and their contacts. This type of surveillance is commonly activated when clusters of disease are identified or reported emerge and rapid response by public health agencies is likely (Leuchner et al., 2008).

The early identification of epidemics of contagious diseases commonly relies on the presentation of syndrome clusters is termed syndromic surveillance (Table 5). A syndrome is the grouping of nonspecific general conditions commonly representing the early symptoms of a disease. Chief complaints of selected conditions of public health concern, upon presentation during the registration process, most commonly to the emergency room. The chief complaints are then scored or coded, typically by a software package, to be assigned and grouped to syndrome category. This is of particular importance as the detecting of these clusters of symptoms can provide an early warning of a major epidemic of transmissible diseases or bio-chemicalradiological terror attack. Thus, syndrome surveillance is viewed as a type of active surveillance. The identification of certain syndromes would trigger reporting to public health officials. Data for the identification of syndromes through active surveillance can come from emergency rooms, STD programs, lead poising prevention programs, vital records, immunization programs, ambulance calls, pharmacy medication sales of prescription and over the counter medications, and linked demographic, outpatient pharmacy claims, physician and facility claims. Syndromic surveillance can be used to estimate the burden of disease in a community, recognizing that only a limited number of persons may come in contact with the health care system to be identified. The source of the disease could be human, exposures, or from environmental sources (Cryptosporidium contamination of water). Because it is a type of active surveillance, it may be a more rapid and hence efficient and effective means of providing data to prioritize the direction of field investigations as to a potential cause. It is estimated that for every flu-like illness presenting in an emergency room, 60 illnesses may occur among residents; every visit for diarrheal illness may represent 251 illnesses in the community (Metzger et al., 2004).

#### Passive Surveillance

Passive surveillance requires that the case has already been identified through diagnosis and/or coding or databases (see Boxed Example 2). Both infectious and noninfectious conditions can be identified through passive surveillance depending if the need to identify the condition and the validity of the signs and symptoms predicting

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# Boxed Example 2 The Practice of Surveillance in a Health Plan (Source: Shatin et al., 2004)

**Problem:** The prevalence of Hepatitis C virus (HC) had increased over twofold between 1975 and 1998, particularly among individuals of working age. This presents an opportunity for managed care plans to adopt surveillance strategies to identify HCV positive individuals for the purpose of implementing effective treatment strategies.

Case Definition: At least one outpatient claim with a Current Procedural Terminology-4 (CPT-4) for one or more criteria: (1) hepatitis C antibody test (CPT-4 86803), (2) hepatitis panel (CPT-4 80059) including hepatitis A, B, and C antibody tests; (3) hepatitis C, confirmatory test (CPT-4 86804); or (4) HCV RNA test (CPT-4 87520, 87521, 87522). A physician, health facility, or pharmacy claim with at least one primary or secondary ICD-9 diagnosis for HCV (070.44 or 020.54) or at least one prescription for interferon in combination with ribavirin.

**Surveillance Strategy:** Longitudinally link computerized claims with enrollment files containing patient demographics, with patient-specific identifiers eliminated.

**Surveillance Results:** The prevalence of HCV was 6.7% among those who were tested. The likelihood of HCV was higher among males (OR = 1.8) and older ( $\geq$ 25 years, OR = 32.0). Less than 35% of those identified with chronic HCV received treatment. Follow-up testing was more likely for those on combination therapy than compared with those on interferon monotherapy (OR = 6.2).

**Managerial Epidemiology Interpretation:** The continuous surveillance of health plan members can identify early those at high risk for HCV. Aggressive follow-up for treatment among those testing positive should be promoted by the health care manager.

the condition is not urgent. The National Notifiable Diseases Surveillance System (see chapter "Health Risks from the Environment: Challenges to Health Services Delivery") is an example of passive surveillance. States provide weekly reports of notifiable disease to the Centers for Disease Control and Prevention. The specific diseases and conditions that are notifiable are determined by the states and territories and reported information includes: the date identified, the location of the diagnosis, demographics of the case, and data specifically related to the disease/condition.

Passive surveillance can be conducted using existing datasets when the data on cases within it have been validated. For example, population-based surveillance of HRQoL is conducted as a means of promoting the health and quality of life of US residents and monitoring progress toward two *Healthy People 2010* goals, (1) increase the quality and years of healthy life and (2) eliminate disparities

(Zahran et al., 2005). The HRQoL data used are from validated items collected through the Behavioral Risk Factor Surveillance System using the measures of self-rated health and within the preceding 30 days, number of physically unhealthy days, number of mentally unhealthy days, and days of activity limitation. Passive surveillance can also be conducted through mapping strategies including those using global positioning systems coupled with geographic information systems form a new epidemiologic technique called geographic surveillance. As cases occur, they are assigned a coordinate for mapping purposes. The use of spatial statistics associated with these graphical techniques adds a new dimension of identifying significantly elevated numbers of cases in geographic areas that could be useful in identifying both infectious and noninfectious cases (Blumenstock et al., 2000; Roche et al., 2002). Various spatial statistics also determine if attribute values form a clustered, uniform, or random pattern across a region. Cluster analysis determining the location of the center of the data, the shape or orientation of the data, and the dispersion of the data may be evaluated using spatial statistical software such as ArcGIS (ESRI, Inc., Redlands, CA) and Spatial Statistics Toolbox for Matlab 2.0 (MathWorks, Inc. Natick, MA).

## Evaluating the Quality of a Surveillance System

The quality of a surveillance system is measured in terms of seven dimensions, its: sensitivity, representativeness, timeliness, simplicity, flexibility, acceptability, and PPV (Klaucke et al., 1988). These criteria apply regardless of the health condition is transmissible, chronic, or another health problem (e.g., abuse). Sensitivity is the ability to accurately identify cases both in terms of diagnostic accuracy as well as the total count of the cases and their severity. Hence, sensitivity is essential to establishing the validity of the measurement of the phenomena under surveillance (see also chapter "Measurement Issues in the Use of Epidemiologic Data"). To assess if the criterion of sensitivity is met, the following questions should be asked: (1) Are reporting laboratories following appropriate protocols, including quality assurance, for testing? (2) Are providers following guidelines for the clinical spectrum for the definition of cases? (3) Can potential cases access the health care system to come to diagnostic attention, or will cases have to be identified through field surveys (e.g., contacting exposed persons by telephone)? Sensitivity of the system is also a function of the timeliness and completeness of reporting Representativeness is the assurance that all possible sources of data from which a case could be ascertained are funneled in to the surveillance system (e.g., for sexually transmitted disease [STD]: from STD clinics, prenatal clinics, prisons, etc.) and if these sources can accurately capture the projected incidence of the health event in the target population. Timeliness is defined as how quickly the cases are identified, specimens are transmitted for analysis, results transmitted to a central repository for analysis, and reports are prepared and disseminated. Increasingly, health departments are seeking to arrange for reporting through electronic means. Overhage et al. (2008) found that

automated electronic laboratory reporting identified 4.4 times more cases and 7.9 days earlier compared with traditional spontaneous, paper-based methods or by postmail. Timely identification and reporting of cases, particularly within the disease-specific incubation period, is critical to not only accurately identify all cases. but also to capture information accurately about exposures, and implementation control measures quickly. Electronic reporting can also enhance the completeness of reporting to the health department and then support more focused investigation of the cases (Kit-Powell et al., 2008). Simplicity of the system is essential in order for staff as well as the population under surveillance and is a criterion which refers to both the structure as well as the processes. Less time is spent in staff training, formatting databases for analysis, and the timely distribution of information. Less error is generated with simple forms by increasing compliance with collecting and recording (see also chapter "Advancing Patient Safety Through the Practice of Managerial Epidemiology"). Flexibility is the ability to accommodate and adapt to new and different diseases or health conditions because of variations in case definition, reporting sources, testing protocols, or exposures. Automated electronic reporting systems can also meet the criteria of simplicity and flexibility with entry of information directly onto computer screens and into computer databases which can be modified with ease. Acceptability is the level of participation individual practitioners (health care providers and public health), health care organizations, and labs are willing to engage in regarding ascertaining cases and reporting them. Concerns regarding measures to ensure confidentiality of the case, time involved in reporting, who assumes the cost of case finding, and liability may affect reporting. The reader is advised to consult and be familiar with federal and state laws and guidelines on the collection, storage, and use of protected health information which may change over time. The Centers for Disease Control (2003) is an important source of guidance regarding the HIPAA Privacy Rule and Public Health. The PPV of a surveillance system (or a screening or diagnostic test) is the proportion of individuals identified as a case who actually do have the condition under surveillance (or who are positive to screening and who have the condition targeted for screening) (see also Table 4 of chapter "Measurement Issues in the Use of Epidemiologic Data"). The value of the PPV is a function of all the preceding quality elements of a surveillance system. The higher the PPV, the less likely that there are false leads in accurately characterizing an epidemic and more efficient deployment of resources in control measures.

# Surveillance in Monitoring Progress in Disease Control

Surveillance is most effective when augmented with other surveillance activities being implemented such as electronic laboratory reporting, geographical information systems (GIS), animal health monitoring, ambulance runs, poison control data, and over-the-counter drug surveillance systems (Overhage et al., 2008). Incidence surveillance for HIV infection has been adopted as a component of the existing

national HIV/AIDS reporting system which covers 22 states. The ability to identify new from long-standing cases of HIV-infection aids in determining if there has been a shift in population subgroups at risk because of changes in risk factor patterns and if disparities in health care or access to health care. The new system confirmed that the majority of new cases (72%) continued to be among men having sex with men. The HIV incident surveillance system has identified an increasing disparity in the incidence of HIV. The rate among black males 13-29 years was found to be 7.1 times higher than comparable age white males. Among black females, the incidence rate was 14 times the rate in white females (Prejean et al., 2008). These data stress the need for both more preventive efforts as well as improving access to care for high risk groups. Syndromic surveillance has been found particularly useful in detecting and monitoring annual outbreaks of influenza, norovirus, and rotavirus (Balter et al., 2005). Syndromic surveillance systems in "high-profile" urban areas can also provide a reassurance during heightened terror or other security alert situations to provide reassurance to the public that a certain condition or exposure (e.g., anthrax) is not present. Chronic disease surveillance in the USA utilizes 92 indicators from nine data sources (Pelletier et al., 2005). With increased data capacities and cross-walks among data systems, the use of multiple indicators in surveillance to monitor progress in achieving disease control is desirable.

# Challenges Encountered with Surveillance Systems

The main challenge in implementing and maintaining a surveillance system is the cost. Cost categories include: personnel, operating costs, transportation, laboratory materials and supplies, intervention costs, communications costs, and capital equipment. The Centers for Disease Control and Prevention has developed a spreadsheet-based software, *SurvCost*, for estimating the cost resources involved operating a surveillance system. The program files and system specifications for use are available at: http://www.cdc.gov/idsr/survcost.htm.

Because of the cost, surveillance systems typically maintain the minimum amount of information required for addressing the targeted health problem and detailed clinical information may not be available. Individual-level socioeconomic information is also seldom included and population subgroups at greatest risk may not be identified. The inclusion of area-based socioeconomic indicators could provide increased sensitivity to surveillance of health disparities (Subramanian et al., 2006).

Lastly, a limitation of surveillance is that most systems rely on reporting or passive surveillance. The delay in reporting may not be sufficiently sensitive to detect a disease outbreak as a diagnosis may take days to weeks. Knowledge of the type of surveillance systems upon which decisions are made may aid in planning the timing of the deployment of system health care resources when surge capacity is needed. To address all these challenges, the next generation of surveillance

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systems for notifiable disease called the National Electronic Disease Surveillance System (NEDSS) will integrate the various reporting sources (labs, public) with clinical databases from hospitals, clinics, emergency rooms that are secured by Health Level Seven American National Standards Institute (HL7) security protocols for protected health information as well as an interface of automated grouping software (for syndromes), statistical and geospatial analysis (see Fig. 3). HL7 covers how messaging transactions regarding patient information to various data repositories are transmitted, authenticated, and determined to be complete and accurate (Edwards, 2008). This new system architecture will facilitate real-time surveillance and the early detection of outbreaks. The eventual integration of databases from outside the hospital setting, such as from pharmacies, is critical. Lack of access to health care and/or lack of health care insurance may prompt individuals to self-care/medications (e.g., purchase of over-the-counter antidiarrheals, cold remedies at pharmacies) or seek no care thereby missing and underestimating emerging diseases in some communities. The early detection of outbreaks through the integration of administrative data, public health data, laboratory data, and public/provider reporting through surveillance is an important strategy not only for preventing widespread disease outbreaks but also for combating infectious disease resistance to antibiotics through implementing control measures earlier when the first signs of increased statistical trends in diseases of public health importance emerge.

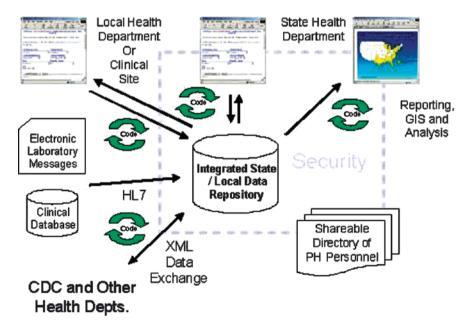


Fig. 3 Systems architecture of the National Electronic Disease Surveillance System (NEDSS) (Source: Centers for Disease Control and Prevention, http://www.cdc.gov/NEDSS (2008))

### Summary

With costs of health care, impending health manpower shortages, and the increased prevalence of chronic conditions, fewer resources may be available in the near future for disease and health problem treatment. Screening and surveillance as measures for promoting population health will become increasingly important, not only in public health, but also in every health services delivery setting as well as for payors in the USA and worldwide. The availability of many large publicly available data sets as well as the increasing use of electronic health records in the delivery of care will make surveillance of populations served a standard of care for managerial epidemiologic practice. Although different in purposes and methodologies, screening and surveillance provide opportunities for potentially more cost-effective means of promoting health in populations served, particularly if the health care organization is serving populations at high risk for chronic conditions.

## **Discussion Questions**

- Q.1. Using epidemiological measures, prioritize what population subgroups should be targeted in a screening program for cancers of the following anatomic areas: breast, cervix, colorectal, prostate, and skin (including melanoma).
- Q.2. If you were conducting a health screening in a Native American population, what conditions would you target? What would potentially be barriers to participation in this screening program?
- Q.3. How can a surveillance system be utilized to reduce health care disparities?
- Q.4. Describe the impacts of not being able to accurately estimate the incidence of a disease from a surveillance system.

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