PARTICIPANT WORKBOOK

Evaluating an NCD-Related Surveillance System

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Evaluating an NCD-Related Surveillance System

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Section 1: Introduction

BACKGROUND

The purpose of evaluating public health surveillance systems is to ensure that problems of public health importance are being monitored efficiently and effectively. In this module, the process of evaluating a noncommunicable disease (NCD) surveillance system is presented. The workbooks in this module are based primarily on the CDC Guidelines for Evaluating Surveillance Systems, published in 1988[1] and the updated guidelines, published in 2001[2]. The reports describe each of the tasks involved in evaluating a public health surveillance system, which have been adapted from the steps in program evaluation in the *Framework for Program Evaluation in Public Health.*[3] Sections of the updated guidelines have been used with permission in this module.

LEARNING OBJECTIVES

1. At the end of the classroom training, you will be able to:
    - Plan for evaluating a surveillance system in your country; and
    - Assess the attributes, conclusions and recommendations of a sample surveillance system evaluation.

2. When you return to your job, you will be able to:
    - Complete the six steps to evaluating a surveillance system
    - Follow the Field Guidelines to write an evaluation report
    - Create a PowerPoint presentation

ESTIMATED COMPLETION TIME

The module should take approximately 12 hours to complete. Additional time should be set aside to complete the final skill assessment – evaluating a surveillance system – when you return to your job.

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[1] *Centers for Disease Control and Prevention. Guidelines for Evaluating Surveillance Systems. MMWR 1988;37(S-5);1-18*
[2] *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)*
[3] *CDC. Framework for program evaluation in public health. MMWR 1999;48(RR-11)*

TARGET AUDIENCE

The module is designed for Field Epidemiology Training Program (FETP) residents who specialize in NCDs; however, you can also complete the module if you are tasked to evaluate a communicable disease surveillance system.

PRE-WORK AND PREREQUISITES

Before participating in this training module, **you must complete the pre-work assignment**. The activities for the assignment include:

- Select an NCD-related surveillance system in your country to evaluate.
- Bring to class all the information you gathered about the surveillance system, including:
    - Purpose and objectives of the system
    - Health-related event under surveillance
    - Components of the system (e.g., population under surveillance, what data are collected and how they are collected)

In addition, you should have completed training on the following topics:

- NCD Data Sources
- NCD Surveillance in Public Health

ABOUT THE WORKBOOKS

To meet the learning objectives, you will use three documents:

The **Participant Workbook** consists of an overview section and six sections that correspond to the six-step evaluation process. You will read information about evaluating an NCD surveillance system and complete 11 practice exercises. These exercises allow you to practice the skills learned so that you can successfully complete the skill assessments.

Throughout the training module, you will also be asked to complete 6 skill assessments located in the **Activity Workbook**. These assessments measure how well you have achieved the module's learning objectives.

The last skill assessment – evaluating an NCD surveillance system, writing a report and preparing a presentation --should be completed in the field. You will use the **Field Guidelines** for this exercise.

ICON GLOSSARY

The following icons are used in this workbook:

Image Type	Image Meaning
 Activity Icon	Activity, exercise, assessment or case study that you will complete
 Stop Icon	Stop and consult with your facilitator/mentor for further instruction
 Tip Icon	Supplemental information, or key idea to note and remember

ACKNOWLEDGEMENTS

Many thanks to two colleagues from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Office on Smoking and Health (OSH): Italia Rolle, PhD, RD and Eugene Lam, MD, MSPH for providing detailed feedback and guidance.

And many thanks to the following Epidemic Intelligence Service (EIS) officers who have allowed the use of their NCD surveillance system evaluations and provided additional information for this module:

- *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*, 2011, by Eugene K.K. Lam, MD, MSPH
- *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity,* 2010, by Zewditu Demissie, PhD, MPH
- *Evaluation of National Surveillance of Arthritis in the U.S.: The National Health Interview Survey (NHIS),* 2010, by Kamil Barbour, PhD, MPH

Copies of the above mentioned surveillance system evaluations are located in Appendix

Section 2: Overview of Evaluating Surveillance Systems

You should evaluate a new surveillance system to ensure that it functions as it was planned and envisioned. The operation or maintenance of the system may encounter unforeseen problems, and some of these problems may not be noticed unless the system is carefully evaluated.

Established surveillance systems should also be evaluated to determine whether the system is meeting its purpose and objectives. Additionally, the epidemiologic context for the health problem being monitored may change, so that data collection methods or sources may no longer be efficient or appropriate.

In this section, you will discuss the definition and purpose of public health surveillance systems and read an overview of the steps for evaluating surveillance systems.

When to Conduct a Surveillance System Evaluation

Surveillance systems can and should be evaluated periodically. Evaluation takes place as the system is still functioning. Therefore, data will continue to be collected, and analysis will continue to occur, even as the system is being evaluated.

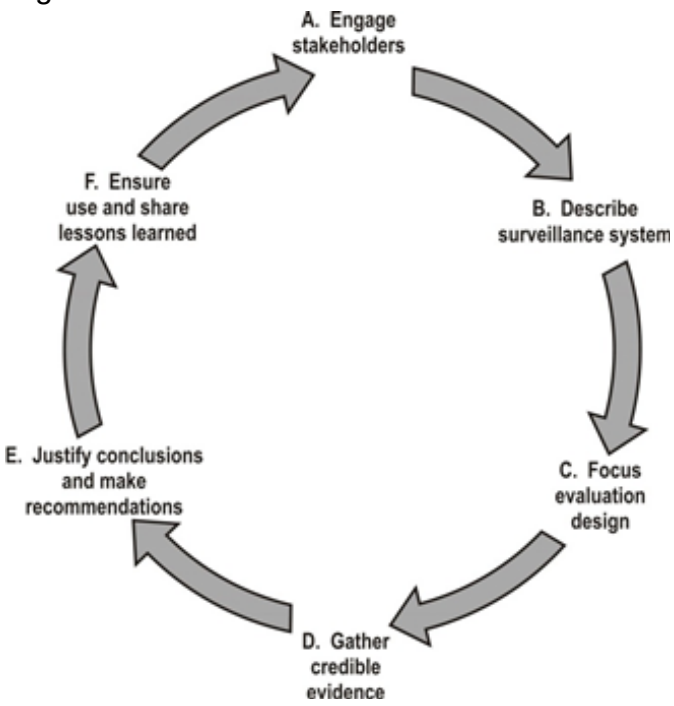
The “right” time to analyze a surveillance system may be at critical moments, for example when funding needs to be renewed, or when the disease under surveillance is receiving particular attention or scrutiny from the public or from policymakers.

It may be convenient to establish regular intervals at which to evaluate aspects of a surveillance system. The intervals could be months or years, and would depend on how surveillance system data are used and the importance of having the system function effectively compared to other uses of time and money.

Note, a surveillance system evaluation may not always be a formal ritual that is done only at certain times. In fact, any time that surveillance system data are analyzed, it presents an opportunity to evaluate aspects of the surveillance system.

TASKS FOR EVALUATING A PUBLIC HEALTH SURVEILLANCE SYSTEM

The main tasks (or steps) for evaluating a public health surveillance system are shown in the following diagram. Notice that the tasks are very similar to those of evaluating a public health program; however, in task B, you describe the *surveillance system* to be evaluated rather than the public health program.



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In this module, you will learn how to perform each task for an NCD-related surveillance system as outlined in the CDC guidelines for all surveillance evaluations:

A. Engage the stakeholders in the evaluation

B. Describe the surveillance system to be evaluated

   B1. Describe the public health importance of the health-related event under surveillance

   B2. Describe the purpose and operation of the surveillance system

   B3. Describe the resources used to operate the system

C. Focus the evaluation design

D. Gather credible evidence regarding the performance of the surveillance system

   D1. Indicate level of usefulness

   D2. Describe each system attribute

E. Justify and state conclusions, and make recommendations

F. Ensure use and share lessons learned

Section 3: Task A. Engage Stakeholders

This section will define stakeholders, explain the benefits of engaging them, and discuss how to determine which stakeholders to involve in the evaluation process.

WHO ARE STAKEHOLDERS AND WHY THEY SHOULD BE ENGAGED

Stakeholders are those persons or organizations who use data for the promotion of healthy lifestyles and the prevention and control of disease, injury, or adverse exposure. For a public health surveillance system evaluation, stakeholders might include:

- public health practitioners,
- health-care providers,
- members of affected communities,
- data providers and users (e.g., statisticians),
- members of professional and private organizations, and/or
- representatives from governmental agencies (e.g., the Ministry of Health or Finance).

Tip

Engaging stakeholders during the evaluation helps to ensure that the evaluation:

- *addresses appropriate questions*
- *assesses pertinent attributes*
- *produces acceptable and useful findings*

The scope, level, and form of stakeholder involvement will vary for each evaluation.

For example, if the potential effect of changes recommended by the evaluation will be **limited**, involvement might be minimal. If the potential effect of recommended changes will be **substantial**, engaging a diverse range of stakeholders becomes more important. Engaging stakeholders will also provide a more transparent process for the surveillance evaluation.

DECIDING WHICH STAKEHOLDERS TO INVOLVE

To determine which stakeholders to involve, determine the following information:

- Who is funding the surveillance system,
- Who uses the information derived from the system, and
- Whether the political/organizational environment will support changes to the surveillance system evaluation.

The following is an example of stakeholders engaged from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

Stakeholders:
The stakeholders of the Global Youth Tobacco Survey (GYTS) include the World Health Organization (WHO) headquarters, its Tobacco Free Initiative (TFI) and all six WHO regional offices (AFRO, AMRO, EMRO, EURO, SEARO, WPRO[1]), the U.S. Centers for Disease Control and Prevention (CDC), national entities such as local governments (ministries of health and education), local schools and educators, academia and researchers, and the general public.

[1] The author of this report would have spelled out each of these acronyms for the WHO regional offices the first time that they were used in the document.

The following is an example of stakeholders engaged from an *Evaluation of National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity):*

Stakeholders:
NYRBS stakeholders include CDC, ICF Macro (the data collection contractor), data users from governmental and nongovernmental agencies, schools, parents, and students.

Stop

Activity

Take out the Activity Workbook and complete Skill Assessment 1.

Section 4: Task B. Describe the Surveillance System to be Evaluated

This section will discuss the three sub-tasks of Task B (Describe the Surveillance System to be Evaluated):

1. Describe the public health importance of the health-related event under surveillance.
2. Describe the purpose and operation of the system.
3. Describe the resources used to operate the system.

Tip

To develop a reliable system description, you may need multiple sources of information. You can improve the system description by consulting with the people who are involved with the surveillance system and by checking reported descriptions against direct observation.

B.1 Describe the Public Health Importance of the Health-Related Event Under Surveillance

You can describe the public health importance of the health-related event under surveillance in several ways, such as:

a. **Indices of frequency**: this can include incidence rates, prevalence, and/or mortality rates and/or summary measures of population health status (e.g., quality-adjusted life years [QALYs]).

b. **Indices of severity**: this can include bed-disability days, case-fatality ratio, hospitalization rates, disability rates, disability-adjusted life years (DALYs), and years of potential life lost (YPLLs).

c. **Disparities or inequities associated with the health-related event (social determinants of health)**. For example, this could include disparities related to socioeconomic status (e.g., education, income), geographic location (e.g., rural vs. urban), or differences based on sex or ethnicity.

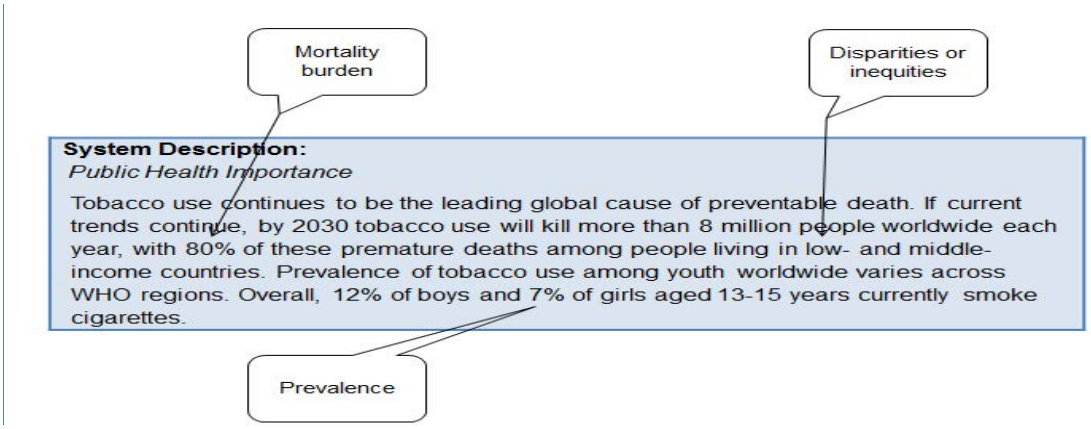
d. **Costs associated with the health-related event**

e. **Preventability:** this can be defined at several levels, including primary prevention (the occurrence of disease or other health-related event is prevented), secondary prevention (disease progression or recurrence is prevented), and tertiary prevention (minimizing the effects of disease and disability among persons already ill). From the perspective of surveillance, preventability reflects the potential for effective public health intervention at any of these levels.

f. **Potential clinical course of action in the absence of an intervention (i.e., treatment of disease).**

g. **Public interest.**

Refer to the following example of a **System Description – Public Health Importance** section from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS).*



Activity

Practice Exercise #1 (Estimated Time: 20 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following **System Description – Public Health Importance** from the *Evaluation of National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity:*

System Description:

Public Health Importance

Childhood obesity rates have tripled during the past 30 years. Unhealthy dietary behaviors and physical inactivity contribute to the obesity epidemic and are associated with increased risk for some cancers, cardiovascular disease, and diabetes. Obesity prevention through improved physical activity and nutrition is one of CDC's "winnable battles."[4]

3. Answer the questions on the following page:

[4] *4 http://www.cdc.gov/winnablebattles/*

a. What parameters did the evaluator use to describe the public health importance of dietary and physical activity behaviors and obesity in the United States? Fill out the table below.

Parameter	Is it included? Y or N	If yes, how is it described?
Indices of frequency		
Indices of severity		
Disparities or inequities associated with the health-related event		
Costs associated with the health-related event		
Preventability		
Potential clinical course of action in the absence of an intervention		
Public interest		

b. Are there other parameters you would include in the description of public health importance for dietary and physical activity behaviors and obesity?

4. Check your answers with those in Appendix B.

B.2 Describe the Purpose And Operation of the Surveillance System

The methods to describe the purpose and operation of the surveillance system can include the following:

- **List the purpose and objectives of the system**: The purpose of the system indicates why the system exists/was developed to address an important public health program. The objectives explain how the data are used for public health action. Public health surveillance system objectives, for example, might address immediate public health action, program planning and evaluation, and formation of research hypotheses.
- **Describe the planned uses of the data from the system**: Explain how the data from the evaluation system will be used to improve public health. This description, along with the purpose and objectives of the system, establish a frame of reference for evaluating specific components.
- **Describe the health-related event under surveillance, including the case definition for each specific condition.** A public health surveillance system is dependent on a clear case definition for the health-related event under surveillance, which can include clinical manifestations (i.e., symptoms), laboratory results, epidemiologic information (e.g., person, place, and time), and/or specified behaviors, as well as levels of certainty (e.g., confirmed/definite, probable/presumptive, or possible/suspected).

Tip

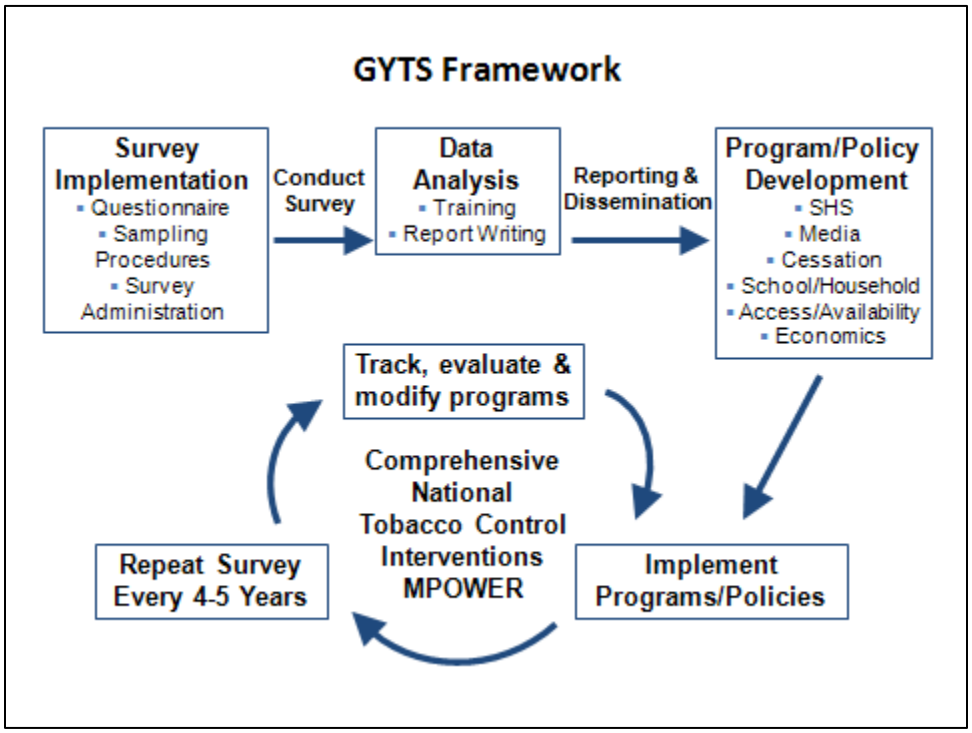
Using a standard case definition increases the specificity of reporting and improves the comparability of the health-related event reported from different sources of data, including geographic areas.

- **Cite any legal and political authority for the data collection (e.g. Ministry of Health).**
- **Describe where in the organization(s) the surveillance system resides, including the context (e.g., the political, administrative, geographic, or social climate).**

- **Describe the level of integration with other systems, if appropriate.** The evaluation should assess how well the public health surveillance system is integrated with other surveillance and health information systems (e.g., data exchange and sharing in multiple formats, transformation of data, linkage to other databases/surveillance systems). Streamlining related systems into an integrated public health surveillance network enables individual systems to meet specific data collection needs while avoiding the duplication of efforts and lack of standardization that can arise from independent systems.[5]
- **Draw a flow chart of the system.** Listing the discrete steps to process health-event reports by the system and depicting these steps in a flow chart can be useful. A chart of data flow should be sufficiently detailed to explain all of the system functions, including average times between steps and data transfers.

  The following example of a flow chart is shown below and was used in a PowerPoint presentation for *An Evaluation of Surveillance for Tobacco Use Among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

[5] *Morris G, Snider D, Katz M. Integrating public health information and surveillance systems. J Public Health Management Practice 1996;2:24--7.*



- **Describe the components of the system**. Consider the following questions:
  - What is the population under surveillance?
  - What is the period of time of the data collection?
  - What data are collected and how are they collected?
  - What are the reporting sources of data for the system?
  - How are the system's data managed (e.g., the transfer, entry, editing, storage, and back up of data)? Does the system comply with applicable standards for data formats and coding schemes? If not, why?
  - How are the system's data analyzed and disseminated? This might include who analyzes the data, how they are analyzed, and how often. This description could also address how the system ensures that appropriate scientific methods are used to analyze the data.

Tip

The public health surveillance system should operate in a manner that allows effective dissemination of health data in a timely manner

so that decision makers at all levels can readily understand the implications of the information.

Options for disseminating data and/or information from the system include electronic data interchange; public-use data files; the Internet; press releases; newsletters; bulletins; annual and other types of reports; publication in scientific, peer-reviewed journals; and poster and oral presentations, including those at individual, community, and professional meetings. The audiences for health data and information can include public health practitioners, health-care providers, members of affected communities, professional and voluntary organizations, policymakers, the press, and the general public.

- What policies and procedures are in place to ensure patient privacy, data confidentiality, and system security? What is the policy and procedure for releasing data? Do these procedures comply with applicable government statutes and regulations? If not, why?

  In conducting surveillance, public health agencies are authorized to collect personal health data about persons and thus have an obligation to protect against inappropriate use or release of that data.

  Physical, administrative, operational, and computer safeguards for securing the system and protecting its data must allow authorized access while denying access by unauthorized users.

Tip

The protection of patient privacy (recognition of a person's right not to share information about him or herself), data confidentiality (assurance of authorized data sharing), and system security (assurance of authorized system access) is essential to maintaining the credibility of any surveillance system. This protection must ensure that data in a surveillance system regarding a person's health status are shared only with authorized persons. Examples of physical safeguards might include locking information in a secure filing cabinet and in a room that only certain people can enter, while administrative/operational safeguards could mean that only certain

authorized personnel are allowed to access the information. Technical safeguards can include protecting the database with a strong password or storing it on a secure server.

- Does the system comply with an applicable records management program? For example, are the system's records properly archived and/or disposed of?

  A related concern in protecting health data is data release, including procedures for releasing record-level data; aggregate tabular data; and data in computer-based, interactive query systems. Even though personal identifiers should be removed before data are released, it may not be a sufficient safeguard for sharing health data. For example, including demographic information in a line-listed data file for a small number of cases could lead to indirectly identifying a person even though there were no personal identifiers.

  A public health surveillance system might be legally required to participate in a records management program. Records can consist of a variety of materials (e.g., completed forms, electronic files, documents, and reports) that are connected with operating the surveillance system. Properly managing these records prevents a "loss of memory" or "cluttered memory" for the agency that operates the system, and enhances the system's ability to meet its objectives.

  Refer to the following example of a **System Description – Purpose & Operation** section from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

Purpose/ Objectives

How data are collected

Planned

opulation under rveillance

System Description:

Purpose & Operation

In 1998, WHO and CDC initiated the GYTS to enhance the capacity of countries to monitor tobacco use among youth; guide national tobacco prevention and control programs; and facilitate comparison of tobacco-related data at the national, regional and global levels. The GYTS targets non-institutionalized students in grades associated with ages 13-15 years. Participants are selected through a 2 stage cluster sample design. Schools are selected proportional to enrollment size and classrooms were chosen randomly within selected schools. In smaller countries, a census is conducted of students within the target grades. All students in selected classes are eligible for participation. Since 1999, the GYTS has been conducted in 167 countries across all 6 WHO Regions. Over 2 million students and 11,000 schools have participated in GYTS.

Activity

Practice Exercise #2 (Estimated Time: 20 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of a **System Description – Purpose & Operation** section from *Evaluation of National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity:*

System Description:

Purpose and Objectives: The NYRBS is part of the Youth Risk Behavior Surveillance System and is designed to monitor six categories of priority health-risk behaviors that contribute to death, disease, disability, and social problems in the U.S. The objectives are to assess the distribution and co-occurrence of these behaviors among subgroups of youth and how the prevalence of these behaviors changes over time.

Operation: The NYRBS is a cross-sectional survey conducted biennially since 1991 among nationally representative samples of public and private school students in grades 9-12. A 3-stage cluster sampling method with oversampling of black and Hispanic students is used. Participation is anonymous and voluntary. One class period is needed to complete the 97-item self-administered questionnaire, which includes 9 dietary behavior questions, 6 physical activity questions, and self-reported height and weight. Macro has been contracted to coordinate sample design/selection, standardized data collection, and data weighting. The Division of Adolescent and School Health (DASH) is responsible for data cleaning, analysis, and dissemination. Extensive data security measures are utilized.

3. Answer the questions below:

    a. What methods were used to describe the purpose and operation of the surveillance system? Fill out the table on the next page.

Method	Is it included? Y or N	If yes, how is it described?
Describe purpose and objectives of the surveillance system		
Describe planned uses of the data from the system		
Describe health-related event under surveillance, including case definition		
Cite legal authority for the data collection		
Describe where in the organization the system resides		
Describe level of integration with other systems		
Draw a flowchart of the system		
Describe the components of the system (e.g., population under surveillance, what data are collected)		

b. Are there any other methods you would use to describe the purpose and operation of the National Youth Risk Behavior Surveillance System?

4. Check your answers with those in Appendix B.

B.3 Describe the Resources Used to Operate the System

To assess resources, consider only those resources directly required to operate a public health surveillance system. These resources are sometimes referred to as “direct costs” and include the personnel and financial resources expended in operating the surveillance system.

In describing these resources, consider the following:

- **Funding source(s):** Specify the source of funding for the surveillance system.
- **Personnel requirements:** Estimate the time it takes to operate the system, including the collection, editing, analysis, and dissemination of data.
- **Other resources:** Determine the cost of other resources, including travel, training, supplies, computer and other equipment, and related services (e.g., mail, telephone, computer support, Internet connections, laboratory support, and hardware and software maintenance).

When appropriate, assess all levels of the public health system, from the local healthcare provider to district, regional and national health agencies.

Refer to the following example of a **System Description – Resources** section from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

Cost

Funding Source

System Description:

Resources

GYTS is funded by the U.S. government and managed through CDC/ Office on Smoking and Health (OSH), in collaboration with WHO Headquarters in Geneva, and its 6 regional offices. Total estimated operating cost for GYTS averages approximately $1 million (U.S.) annually for an average of 29 surveys conducted internationally each year.

Refer to the following example of a **System Description – Resources** section from *Evaluation of National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity:*

Funding Source

Cost

System Description:

Resources

CDC funds the NYRBS. The cost for each NYRBS cycle is approximately $1,500,000.

Stop

Activity

Take out the Activity Workbook and complete Skill Assessment 2.

Section 5: Task C. Focus the Evaluation Design

This section briefly discusses how to focus the evaluation design, and in particular, how to identify standards for the performance of the surveillance system.

OVERVIEW

Focus the evaluation design to ensure that time and resources are used efficiently. This involves:

- determining the specific purpose of the evaluation
- identifying stakeholders (from Task A) who will receive the findings and recommendations of the evaluation (i.e., the intended users)
- considering what will be done with the evaluation findings and recommendations
- determining standards for assessing the performance of the surveillance system

Depending on the specific purpose of the evaluation, its design could be straightforward or complex.

Tip

An effective evaluation design is contingent upon:

a. *its specific purpose being understood by all of the stakeholders in the evaluation, and*
b. *persons who need to know the findings and recommendations of the design are committed to using the information generated from it.*

In addition, when there are multiple stakeholders, those who are implementing the evaluation might need to establish agreed upon roles and responsibilities.

STANDARDS

To establish what the surveillance system must accomplish to successfully meet its objectives, the performance of the public health surveillance system will be compared to existing standards/guidelines relevant for that system and health event under surveillance.

These standards specify, for example, what levels of usefulness and simplicity are relevant for the system, given its objectives. Approaches to setting useful standards for assessing the system's performance include a review of current scientific literature on the health-related event under surveillance and/or consultation with appropriate specialists, including users of the data.

In the following example of the **Evaluation Design** section from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS),* only the purpose of the evaluation is described.

Evaluation Design:

The purpose of this evaluation is to assess the performance of GYTS as a surveillance system for tobacco use.

In this example of **Evaluation Design** from the *Evaluation of National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity,* the EIS officer described the goal of the evaluation and the sources used:

Evaluation Design:

The goal of this evaluation was to determine the strengths and weaknesses of the NYRBS dietary and physical activity behavior and obesity questions. I reviewed NYRBS documentation, published manuscripts, and nutrition and physical activity guidelines, and interviewed DASH staff.

Stop

Activity

Take out the Activity Workbook and complete Skill Assessment 3.

Section 6: Task D. Gather Credible Evidence Regarding the Performance of the Surveillance System

Tip

Stakeholders must view evidence of the system's performance as being credible. For example, the gathered evidence must be reliable, valid, and informative for its intended use.

In this section, you will learn how to assess the surveillance system's **usefulness** and the following **system attributes**:

- Simplicity
- Flexibility
- Data quality
- Acceptability
- Sensitivity
- Predictive value positive
- Representativeness
- Timeliness
- Stability

D.1. Indicate the Level of Usefulness

A public health surveillance system is useful if it contributes to the prevention and control of adverse health-related events, including an improved understanding of the public health implications of such events. A public health surveillance system can also be useful if it helps to determine that an adverse health-related event previously thought to be unimportant is actually important.

Measures and Methods

Assessing the usefulness of a public health surveillance system begins with reviewing the objectives of the surveillance system and considering the system's effect on policy decisions and disease-control programs. Depending on its objectives, you might determine the system to be useful if it satisfactorily addresses *at least one* of the following questions.

Does the system:

- detect diseases, injuries, or adverse or protective exposures of public importance in a timely way to permit accurate diagnosis or identification, prevention or treatment, and handling of contacts when appropriate?
- provide estimates of the magnitude of morbidity and mortality related to the health-related event under surveillance, including the identification of factors associated with the event?
- detect trends that signal changes in the occurrence of disease, injury, or adverse or protective exposure, including detection of epidemics (or outbreaks)?
- permit assessment of the effect of prevention and control programs?
- lead to improved clinical, behavioral, social, policy, or environmental practices?
- stimulate research intended to lead to prevention or control?

To gather evidence about usefulness, you can formally or informally survey people who use the system data. It is important to document how you gathered the information whether formally or informally and provide the details in your report.

All of the attributes of a public health surveillance system may affect usefulness. For example, if you improve timeliness, prevention and control activities may be initiated earlier. Public health surveillance systems that are simple, flexible, acceptable, and stable will likely have greater user compliance and more complete and accurate data. Such systems will therefore be of greater use for public health action.

Read the example on the following page of how **usefulness** was assessed in *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS).*

The example contains the following sections:

- **measures and methods used:** the data collection processes used to assess usefulness,
- **key results:** main findings from the assessment,
- **conclusions:** whether the surveillance system is addressing an important public health problem and is meeting its objectives, and,
- **recommendations:** how the surveillance system should be modified and/or continued (See Task E).

Measures and methods used: Review of 2011 evaluation expert panel meeting report, previously published country survey reports, key informants reports, published manuscripts, global tobacco surveillance system website, and number of surveys conducted.

Key Results: GYTS has been used to provide tobacco use prevalence estimates on a subset of youth ages 13-15 years to provide cross country and regional comparisons. Based on key informants, GYTS data has been used previously for policy change in the following ways: promotion of smoke-free legislation, advocacy for tobacco control policy, training of teachers on tobacco control and the planning of anti-tobacco campaign strategies in schools.

Conclusions: Data from GYTS surveillance system have the potential to be utilized in a variety of ways by key stakeholders.

Recommendations: No changes in terms of usefulness are recommended.

Activity

Practice Exercise #3 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.
2. Refer to the following example of how **usefulness** was assessed in the *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.
3. Based on what you have read, complete the conclusions and recommendations sections below.

Measures and methods used:

- Review of documents, products and records- DASH provides a summary slide set on the Healthy Youth webpage that includes information on the uses of YRBS. This document points to other resources regarding the uses of YRBS data.
- Interview of stakeholders- DASH staff were able to provide manuscripts (both published and in press) that discussed the uses of YRBS data.

Key Results:

- Users can download datasets from the CDC DASH website and/or use an online public data query system called Youth Online
- NYRBS data are used to describe the national prevalence of dietary behavior and physical activity behaviors among high school students.
- The data also are used to create awareness about unhealthy dietary behaviors and physical inactivity; evaluate CDC's Performance Plan; monitor the nations' progress towards meeting national public health goals/recommendations; and support policies, legislation, programs, and funding initiatives.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2. Describe Each System Attribute

Tip

In this next section, you will learn how to assess nine system attributes: simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability.

You must examine **all** system **attributes** because they are relevant to surveillance systems. If there is no available data on a specific attribute, note this limitation in your evaluation report.

There are many potential sources of evidence you can use to assess a system's performance, including consultations with physicians, epidemiologists, statisticians, behavioral scientists, public health practitioners, laboratory directors, program managers, data providers, review of surveillance reports and records, and data users.

D.2.a. Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation. A surveillance system should be as simple as possible while still meeting its objectives. Simplicity is closely related to acceptance and timeliness. Simplicity also affects the amount of resources required to operate the system.

Measures and Methods

A chart describing the flow of data and the lines of response in a surveillance system can help assess the simplicity or complexity of a surveillance system. A simplified flowchart for a generic surveillance system is shown on the following page.

You may use the following measures to evaluate the simplicity of a system:

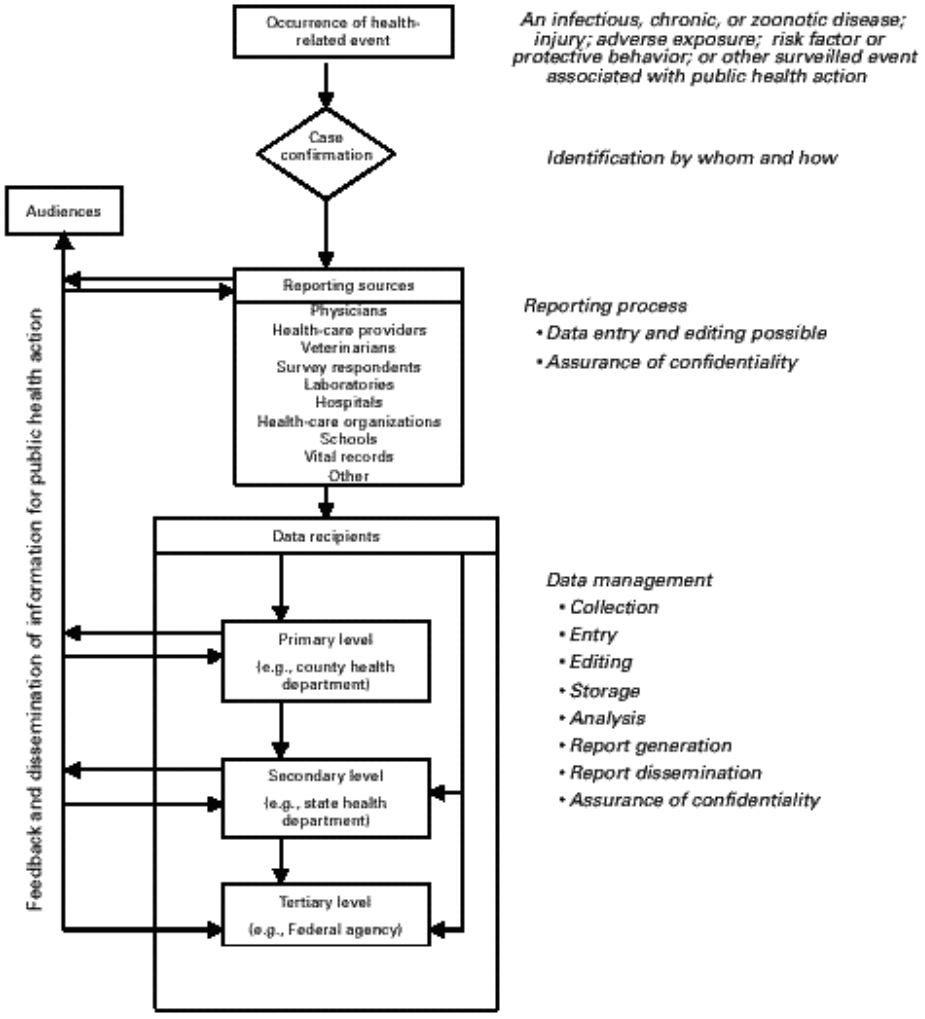
- amount and type of data necessary to establish that the health-related event has occurred (i.e., the case definition has been met);
- amount and type of other factors on cases (e.g., demographic, behavioral, and exposure information for the health-related event);

- number of organizations involved in receiving case reports;
- level of integration with other systems;
- method of collecting the data, including number and types of reporting sources, and time spent on collecting data;
- amount of follow-up that is necessary to update data on the case;
- method of managing the data, including time spent on transferring, entering, editing, storing, and backing up data;
- methods for analyzing and disseminating the data, including time spent on preparing the data for dissemination;
- staff training requirements; and
- time spent on maintaining the system.

Refer to the sample flow chart for a surveillance system on the following page:[6]

[6] *Adapted from: CDC. Framework for program evaluation in public health. MMWR 1999;48(RR-11)*

FIGURE 1. Simplified flow chart for a generic surveillance system



The methods of data collection to use to obtain the abovementioned information may include:

- review of documents,
- review of products/ outputs,
- qualitative interviews of key informants, and
- quantitative interviews of participants.

Thinking of the simplicity of a public health surveillance system from the design perspective might be useful. An example of a system that is simple in design is one that:

- has a case definition that is easily understood by the person who will be using it,

- has a case definition that is easy to apply (i.e., the case is easily established), and/or
- where the person identifying the case will also be the one analyzing and using the information.

A more *complex* system might involve some of the following:

- investigation of the case, including telephone contact or a home visit by public health personnel to collect detailed information;
- integration of related systems whereby special training is required to collect and/or interpret data;
- multiple levels of reporting. For example, surveillance for cancer in the United States involves collecting data from medical records in clinics, hospitals, cancer-specific treatment facilities, and pathology laboratories. This information is analyzed and used by clinical staff, county and state health departments, as well as the federal government. The analysis may be different for each organization due to their needs (i.e. clinical staff need to know about treatment regimens and survival times vs. state/federal staff need to understand the regional cancer rates in order to work on efficiently allocating treatment resources).

  Read the following example of how **simplicity** was assessed in *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

Measures and Methods used: Review of survey implementation records, training of country survey coordinators, key informants evaluation, data collection, data management, and survey handbook.

Key results:

- Addresses only tobacco indicators, compared to NHANES which addresses multiple health indicators.
- GYTS consists of a single school-based questionnaire comprised of 55-100 questions, while NHANES uses an in-person interview, comprised of nearly 325 questions, followed by a physical exam.

Conclusions: The survey has considerably fewer questions than NHANES and uses less time for it to be completed.

Recommendations: None

Activity

Practice Exercise #4 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **simplicity** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

3. Based on what you have read, complete the conclusions and recommendations sections below.

Measures and Methods used:

- Review of documents, products and records- NYRBSS surveillance summary report, Macro plan
- Interview of stakeholders- particularly the NYRBS lead in DASH

Key Results:

- Data collection involves 16,460 students from 158 schools across the U.S.
- Considerable manpower and expertise are needed in areas such as drawing national probability samples, survey instrumentation and design, and data management and analysis.
- A complex 3-stage cluster, proportional probability sampling design is used
- Data collection training is short
- No participant follow-up is needed.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.b. Flexibility

A flexible public health surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds. Flexible systems can accommodate, for example, new health-related events, changes in case definitions or technology, and variations in funding or reporting sources. In addition, systems that use standard data formats (e.g., in electronic data interchange) can be easily integrated with other systems and thus might be considered flexible.

Measures and Methods

It is best to evaluate flexibility *retrospectively* by observing how a system has responded to a new demand. For example, an important characteristic of CDC's Behavioral Risk Factor Surveillance System (BRFSS) is its flexibility. Conducted in collaboration with state health departments, BRFSS is an ongoing sample survey that gathers and reports state-level prevalence data on health behaviors related to the leading preventable causes of death as well as data on preventive health practices. The system permits states to add questions of their own design to the BRFSS questionnaire but is uniform enough to allow state-to-state comparisons for certain questions. These state-specific questions can address emergent and locally important health concerns. In addition, states can stratify their BRFSS samples to estimate prevalence data for regions or counties within their respective states.

Read the following example of how **flexibility** was assessed in the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS):*

Measures and methods used: Review of survey implementation, training of country survey coordinators, key informants evaluation, data collection, data management, survey handbook

Key results:

- The structure of the GYTS is stratified by topic area and restricted to tobacco outcomes which allows for ease of revision.
- Countries in each region can insert optional questions for country-specific adaption with little additional resources.

Conclusions: The system is flexible as countries are able to insert optional questions for country-specific adaptation with little additional resources.

Recommendations: None

Activity

Practice Exercise #5 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.
2. Refer to the following example of how **flexibility** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.
3. Based on what you have read, complete the conclusions and recommendations sections.

Measures and Methods used:

- Review of DASH documents, products and records
- Interview of stakeholders- NYRBS lead in DASH

Key results:

- Survey modifications are considered each cycle.
- Some reasons for modifications include policy changes, results from methods studies, changes in health priorities, the emergence of new public health problems, changes in public health objectives and indicators, and expert opinion.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.c. Data Quality

Most surveillance systems rely on more than simple case counts. Data commonly collected include the demographic characteristics of affected persons, details about the health-related event, and the presence or absence of potential risk factors. The quality of these data depends on their completeness and validity.

The acceptability (see Task D.2.d) and representativeness (Task D.2.g) of a public health surveillance system are related to data quality. With data of high quality, the system can be accepted by those who participate in it. In addition, the system can accurately represent the health-related event under surveillance.

Measures and Methods

Examining the percentage of "unknown" or "blank" responses to items on surveillance forms is a straightforward and easy measure of data quality. High quality data will have low percentages of such responses. However, fully assessing the completeness and validity of the system's data might require a special study. You can compare data values recorded in the surveillance system to "true" values by reviewing sampled data, a special record linkage with other databases, or interviewing patients. In addition, calculating sensitivity (Task D.2.e) and predictive value positive (Task D.2.f) for the system's data fields might be useful in assessing data quality.

Quality of data can be influenced by:

- Performance of the screening and diagnostic tests for the health-related event (i.e., the case definition)
- Clarity of hardcopy or electronic surveillance forms
- Quality of training and supervision of persons who complete these surveillance forms
- Data management

Reviewing these facets of a public health surveillance system provides an indirect measure of data quality.

Read how **data quality** was assessed in the following example from the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*:

Measures and methods used: Review of survey implementation, training of country survey coordinators, data collection, data management, data analysis, and survey handbook.

Key results:

- Minimal data edit checks
- Lack of validation of smoking prevalence with comparison to a nicotine biomarker, such as serum or urinary cotinine
- No validation studies for GYTS however there is existing evidence in the literature for the validity of data from school based surveys.

Conclusions: Data quality is adequate and varies depending on the experience of the country survey coordinators, and funding.

Recommendations: Further work is needed to explore how data quality varies by country and WHO regions.

Activity

Practice Exercise #6 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **data quality** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

3. Based on what you have read, complete the conclusions and recommendations sections.

Measures and methods used:

- Review of documents, products and records- NYRBS user's manual, published report from DASH on the questionnaire psychometrics, other DASH publications.
- Interview of stakeholders- NYRBS lead in DASH

Key results:

- Data collection procedures are designed to encourage truthfulness.
- ICF Macro employs a detailed quality control protocol to ensure they are providing the highest quality data possible.
- Self-reported height and weight data are checked for biological plausibility.
- The test-retest reliability of select physical activity measures was found to be at least moderate.
- Self-report data on Body Mass Index (BMI) have demonstrated high test-retest reliability.
- A validity study comparing some national NYRBS physical activity questions to accelerometer data was conducted among middle school students in 2003, but no validity data are currently available for the dietary and physical activity behavior questions among high school students. The questions have strong content validity.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.d. Acceptability

Acceptability refers to the **willingness to use the system** by people who operate the system and people outside the sponsoring agency (e.g., persons who are asked to report data). To assess acceptability, evaluate the points of interaction between the system and its participants, including persons with the health-related event and those reporting cases.

Some factors influencing the acceptability of a particular system are:

- the public health importance of the health-related event
- acknowledgment by the system managers of the contributions made by the people who provided the data (e.g., surveillance officer, epidemiologist, data analyst, doctor, nurse)
- dissemination of aggregate data back to reporting sources and interested parties
- responsiveness of the system to suggestions or comments
- burden on time relative to available time
- ease and cost of data reporting
- federal and state statutory assurance of privacy and confidentiality
- the ability of the persons running the system to protect privacy and confidentiality
- federal and state statute requirements for data collection and case reporting
- participation from the community in which the system operates

Measures and Methods

Acceptability is a largely subjective measure but there are some quantitative measures that can be examined:

- patient or agency participation rate (if it is high, how quickly it was achieved)
- interview completion rates and question refusal rates (if the system involves interviews)
- completeness of report forms
- physician, laboratory, or hospital/facility reporting rate; and
- timeliness of data reporting

You may obtain evidence for these measures by reviewing surveillance report forms or conducting special studies or surveys.

Read the following example of how **acceptability** was assessed from the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*:

Measures and methods used: Review of survey implementation, training of country survey coordinators, data collection, key informants evaluation, data management, and survey handbook.

Key results:

- Participant Response: Proactive measures were used to enhance response rate:
    - advanced letters
    - scheduled class time during the morning of a school day
    - non-sensitive questions to minimize refusal rates
- Organization Response: GYTS data have the potential to be used by multiple stakeholders.

Conclusions:

GYTS has been conducted in about 172 countries and territories since 1999.

Recommendations:

None

Activity

Practice Exercise #7 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **acceptability** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

3. Based on what you have read, complete the conclusions and recommendations sections.

Measures and methods used:

- Review of documents, products and records - Youth Risk Behavior Surveillance System (YRBSS) summary report and slide set.
- Interview of stakeholders- NYRBS lead in DASH.

Key results:

- Average school participation rate is 78%; average student response rate is 86%; average overall response rate is 67%.
- There is low questionnaire item non-response
- Less than 2% of records are missing on each of the dietary and physical activity behavior and obesity questions.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.e. Sensitivity

A surveillance system's sensitivity can be evaluated by assessing its ability to correctly identify those who have the disease (or characteristic) of interest.

A public health surveillance system that does not have high sensitivity can still be useful in monitoring trends as long as the sensitivity remains reasonably constant over time. Questions concerning sensitivity in surveillance systems most commonly arise when changes in the occurrence of a health-related event are noted. Changes in sensitivity can be caused by some circumstances (e.g., heightened awareness of a health-related event, introduction of new diagnostic tests, and changes in the method of conducting surveillance).

Measures and Methods

The measurement of the sensitivity of a public health surveillance system is affected by the likelihood that:

- certain diseases or other health-related events are occurring in the population under surveillance
- cases of certain health-related events are under medical care, receive laboratory testing, or are otherwise coming to the attention of institutions subject to reporting requirements
- the health-related events will be diagnosed/identified, reflecting the skill of health-care providers and the sensitivity of screening and diagnostic tests (i.e., the case definition)
- the case will be reported to the system

These situations can be extended by analogy to public health surveillance systems that do not fit the traditional disease care provider model. For example, the sensitivity of a telephone based surveillance system of morbidity or risk factors is affected by

- the number of persons who have telephones, who are at home when the call is placed, and who agree to participate
- the ability of persons to understand the questions and correctly identify their status
- the willingness of respondents to report their status

The extent to which these situations are explored depends on the system and on the resources available for assessing sensitivity.

Measuring the sensitivity of the surveillance system requires:

a. collection of or access to data usually external to the system to determine the true frequency of the condition in the population under surveillance, and
b. validation of the data collected by the system.

Examples of data sources you may use to assess the sensitivity of health information or public health surveillance systems include medical records and registries.

To adequately assess the sensitivity of the public health surveillance system, calculating more than one measurement of the attribute might be necessary. For example, sensitivity could be determined for the system's data fields, for each data source or for combinations of data sources, for specific conditions under surveillance, or for each of several years. The use of a Venn diagram helps to depict measurements of sensitivity for combinations of the system's data sources. Refer to Table 1 below to see how sensitivity and predictive value positive (PVP) are calculated. For example, to calculate sensitivity, one would estimate the proportion of the total number of cases in the population under surveillance being detected by the system, represented by A/(A+C).

Table 1. Calculation of sensitivity* and predictive value positive† for a surveillance system[7]

Detected by surveillance	**Condition Present**		
	Yes	**No**	
Yes	True positive **A**	False positive B	**A+B**
No	False negative C	True negative D	C+D
	A+C	B+D	Total

[7] *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)*

*Sensitivity = A/(A+C)
†Predictive value positive (PVP) = A/(A+B)

Conducting a literature review can help determine sensitivity measurements for a public health surveillance system. Assessing the sensitivity of each data source, including combinations of data sources, can determine if eliminating or adding a current data source would affect the overall surveillance results.

In the report on *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*, the evaluator specifies that "sensitivities and PVP of GYTS tobacco use indicators cannot be calculated due to lack of a gold-standard such as cotinine measurement (which is a biomarker of nicotine use)."

D.2.f. Predictive Value Positive

Predictive value positive (PVP) is the proportion of reported cases that actually have the health-related event under surveillance (PVP is represented by A/(A+B) in Table 1 above).

Assessing sensitivity and PVP provides different perspectives regarding how well the system is operating. A low PVP means that noncases might be investigated, which can lead to unnecessary interventions; a high value can lead to fewer misdirected resources.

The PVP reflects the sensitivity and specificity of the case definition (i.e., the screening and diagnostic tests for the health-related event) and the prevalence of the health-related event in the population under surveillance. The PVP can improve with increasing specificity of the case definition. Good communication between the persons who report cases and the receiving agency can also lead to an improved PVP.

Measures and Methods

Calculating the PVP might require that records be kept of investigations prompted by information obtained from the public health surveillance system. At the level of case detection, a record of the number of case investigations completed and the proportion of reported persons who actually had the health-related event under surveillance would allow you to calculate the PVP.

Examples of data sources used to assess the PVP of health information or public health surveillance systems include medical records, registries, and death certificates.

To assess the PVP of the system adequately, calculating more than one measurement of the attribute might be necessary. For example, you can determine PVP for the system's data fields, for each data source or combinations of data sources, or for specific health-related events.

D.2.g. Representativeness

A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person.

To generalize findings from surveillance data to the population at large, the data from a public health surveillance system should accurately reflect the characteristics of the health-related event under surveillance. These characteristics generally relate to time, place, and person. An important result of evaluating the representativeness of a surveillance system is identifying population subgroups that might be systematically excluded from the reporting system through inadequate methods of monitoring them. Modifying data collection procedures can result in a more accurate projection of incidence of the health-related event in the target population.

For certain health-related events, accurately describing the event over time involves targeting appropriate points in a broad spectrum of exposure and the resultant disease or condition. In the surveillance of cardiovascular diseases, for example, it might be useful to distinguish between pre-exposure conditions (e.g., tobacco use policies and social norms), the exposure (e.g., tobacco use, diet, exercise, stress, and genetics), a pre-symptomatic phase (e.g., cholesterol and homocysteine levels), early-staged disease (e.g., abnormal stress test), late-staged disease (e.g., angina and acute myocardial infarction), and death from the disease. Measuring risk factor behaviors (e.g., tobacco use) might enable the monitoring of important aspects in the development of a disease or other health-related event.

Because surveillance data are used to identify groups at high risk and to target and evaluate interventions, being aware of the strengths and limitations of the system's data is important. Errors and bias can be

introduced into the system at any stage. For example, selection bias can result from changes in reporting practices over time or from differences in reporting practices by geographic location or by health-care providers. Differential reporting among population subgroups can result in misleading conclusions about the health-related event under surveillance.

Measures and Methods

You can assess representativeness by comparing the characteristics of reported events to all such actual events. Although the latter information is generally not known, some judgment of the representativeness of surveillance data is possible, based on knowledge of:

- population characteristics, including, age, socioeconomic status, access to health care, and geographic location
- clinical course of the disease or other health-related event (e.g., latency period, mode of transmission, and outcome [e.g., death, hospitalization, or disability])
- prevailing medical practices (e.g., sites performing diagnostic tests and physician referral patterns)
- multiple data sources (e.g., mortality rates for comparison with incidence data and laboratory reports for comparison with physician reports)

Representativeness can be examined through special studies that seek to identify a sample of all cases. For example, the representativeness of a regional injury surveillance system was examined using a systematic sample of injured persons. The study examined statistical measures of population variables (e.g., age, sex, residence, nature of injury, and hospital admission). It was concluded that the differences in the distribution of injuries in the system's database and their distribution in the sampled data should not affect the ability of the surveillance system to achieve its objectives.[8]

For many health-related events under surveillance, properly analyzing and interpreting data require calculating rates. The denominators for these rate calculations are often obtained from a separate data system maintained by another agency. Carefully consider the choice of an appropriate denominator for the rate calculation to ensure an accurate representation of

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[8] *McClure RJ, Burnside J. The Australian Capital Territory Injury Surveillance and Prevention Project. Acad Emerg Med 1995;2:529--34*

the health-related event over time and by place and person. For example, numerators and denominators must be comparable across categories (e.g., race/ethnicity, age, residence, and/or time period), and the source for the denominator should be consistent over time when measuring trends in rates. In addition, give careful consideration to selecting the standard population for the adjustment of rates.

Read the following example of how **representativeness** was assessed in the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*:

Measures and methods used: Review of survey implementation, training of country survey coordinators, data collection, data management, survey handbook

Key Results:

- Random sample
- National versus sub-national data
- Urban versus rural
- Public versus private schools
- Excludes
    - Institutionalized youth
    - Youth not enrolled in school
- Limited to enrolled students aged 13-15 years.
- Countries with sub-national data were unable to implement national sample design due to limited funding, time constraints, and political instability.

Conclusions: Prevalence of tobacco use are likely to be greater among institutionalized youth and youth not in school; therefore their exclusion from GYTS could provide an underestimate of the point estimate.

Recommendations: Further work is needed to determine whether tobacco use is greater among youth not in school.

Activity

Practice Exercise #8 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **representativeness** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

3. Based on what you have read, complete the conclusions and recommendations sections.

Measures and methods used:

- Review of documents, products and records- YRBSS surveillance summary report, Methodology of the Youth Risk Behavior Surveillance System report
- Interview of stakeholders- NYRBS lead in DASH

Key results:

- The national YRBS is representative of U.S. high school students attending regular public and private schools.
- Make-up administrations are allowed to capture information from students who were absent the day the survey was administered.
- A weight is applied to each student record based on sex, grade, and race/ethnicity and to adjust for school and student non-response.
- The NYRBS does not include non-students. Coverage is high though as only 4% of youth aged 16 to 17 years are not enrolled in a high school program or have graduated from high school.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.h. Timeliness

Timeliness is the speed between steps in a public health surveillance system. You will evaluate the timeliness of a public health surveillance system in terms of availability of information for control of a health-related event, including immediate control efforts, prevention of continued exposure, or program planning.

Tip

The need for rapidity of response in a surveillance system depends on the nature of the health-related event under surveillance and the objectives of that system.

The increasing use of electronic data collection from reporting sources (e.g., an electronic laboratory-based surveillance system) and via the Internet (a web-based system), and the increasing use of electronic data interchange by surveillance systems, might promote timeliness.

Measures and Methods

A simplified example of the steps in a public health surveillance system is shown in figure 2 on the following page.[9]

You can examine the time interval linking any two of these steps in **Figure 2**. The interval you typically consider first is the amount of time between the onset of a health-related event and the reporting of that event to the public health agency responsible for instituting control and prevention measures. Factors affecting the time involved during this interval can include the patient's recognition of symptoms, the patient's acquisition of medical care, the attending physician's diagnosis or submission of a laboratory test, the laboratory reporting test results back to the physician and/or to a public health agency, and the physician reporting the event to a public health agency.

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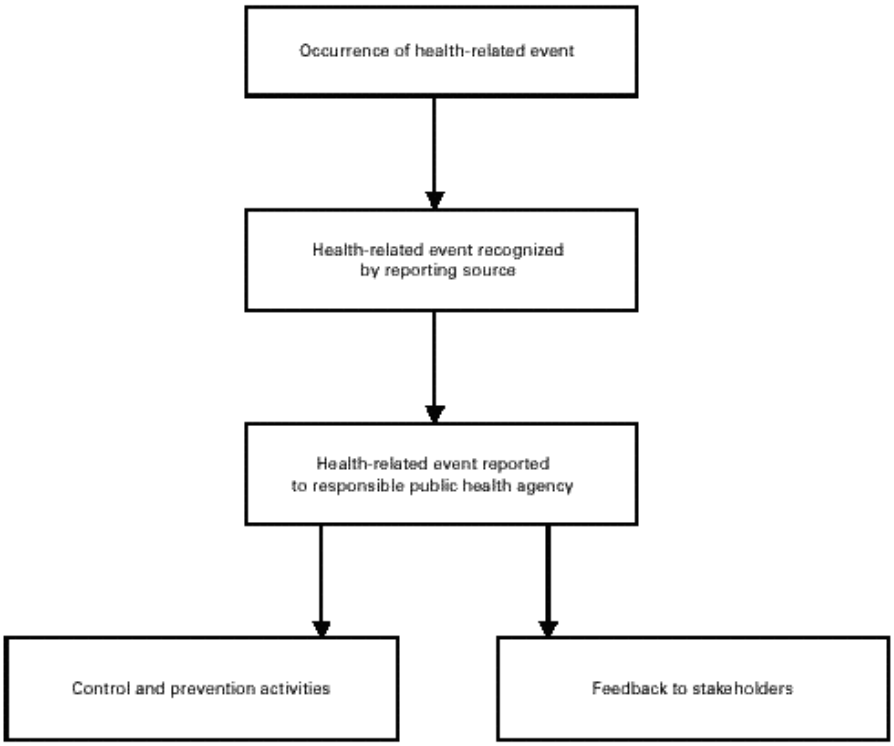
[9] *Centers for Disease Control and Prevention. Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. MMWR 2001;50(No. RR-13)*

FIGURE 2. Simplified example of steps in a surveillance system



Another aspect of timeliness is the time required for identifying trends or the effect of prevention and control measures. Factors that influence the identification process can include the severity and communicability of the health-related event, staffing of the responsible public health agency, and communication among involved health agencies and organizations. The most relevant time interval might vary with the type of health-related event under surveillance. With chronic diseases, it might be more useful to look at elapsed time from diagnosis rather than from the date of symptom onset.

Read the following example of how **timeliness** was assessed in the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*:

Measures and methods used: Review of survey implementation, training of country survey coordinators, data collection, data management, survey handbook

Key Results:

- Protocol Adaption: 1 month
- Data Collection: 6 months
- Data Processing: 1-2 months
- Data Analysis: 2-4 months
- Dissemination of Findings: 2-4 months

Conclusions: The system is presently equipped to disseminate findings within 1-2 years from the time of collection, which is adequate to achieve its objective.

Recommendations: No adjustments in timeliness is needed.

Activity

Practice Exercise #9 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **timeliness** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

3. Based on what you have read, complete the conclusions and recommendations sections.

Measures and methods used:

- Review of documents, products and records- Internal DASH documents
- Interview of stakeholders- NYBRS lead in DASH

Key results:

- Data collection is performed biennially which is appropriate given that changes in behavior patterns tend to occur slowly over time and the logistics involved in conducting the NYRBS.
- Data collection completion to dissemination takes one year with public use datasets, the online public data query system, and summary materials available at the same time as the MMWR Surveillance Summary publication.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

D.2.i. Stability

Stability refers to the:

- reliability (i.e., the ability to collect, manage, and provide data properly without failure)
- availability (i.e., the ability to be operational when it is needed) of the public health surveillance system

A lack of dedicated resources might affect the stability of a public health surveillance system. For example, workforce shortages can threaten reliability and availability. Yet, regardless of the health-related event being monitored, a stable performance is crucial to the viability of the surveillance system. Unreliable and unavailable surveillance systems can delay or prevent necessary public health action.

You can make a more formal assessment of the system's stability through modeling procedures; however, a more useful approach might involve assessing stability based on the purpose and objectives of the system.

Measures and Methods

Measures of the system's stability can include:

- the number of unscheduled outages and down times for the system's computer or cellphones that are used to collect and transmit surveillance data
- the costs involved with any repair of the system's computer, including parts, service, and amount of time required for the repair
- the percentage of time the system is operating fully
- the desired and actual amount of time required for the system to collect or receive data
- the desired and actual amount of time required for the system to manage the data, including transfer, entry, editing, storage, and back-up of data
- the desired and actual amount of time required for the system to release data.

Read the following example of how **stability** was assessed in the *Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS)*:

Measures and methods used: Review of survey implementation, training of country survey coordinators, data collection, data management, survey handbook

Key Results:

- In terms of reliability, data collection and management has been ongoing since 1999 until present day.
- GYTS is a continuous system where some countries have completed the survey through to its third or fourth round.
- Its overall stability is also contingent on the level of commitment from each country.

Conclusions: Stability is good as the system has been ongoing since 1999.

Recommendations: No improvements are needed in reliability or availability of the system.

Activity

Practice Exercise #10 (Estimated Time: 10 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of how **stability** was assessed in *Evaluation of the National Youth Risk Behavior Survey (NYRBS):*

Dietary and Physical Activity Behaviors and Obesity.

3. Based on what you have read, complete the conclusions and recommendations sections below.

Measures and methods used:

- Review of documents, products and records- Macro plan, YRBSS surveillance summary report
- Interview of stakeholders- NYRBS lead in DASH

Key results:

- Surveys have been conducted biennially since 1991.
- Macro is a reliable contractor and has been conducting the NYRBS data collection and weighting since the first administration.
- Usually 50-75% of data collectors on a given cycle return to do data collection in the subsequent year.
- The NYRBS uses a consistent methodology over time which has facilitated the testing of secular trends in health-risk behaviors.

Conclusions:

Recommendations:

4. Check your answers with those in Appendix B.

Stop

Activity

Complete Skill Assessments 4 and 5 in the Activity Workbook.

Section 7: Task E. Justify and State Conclusions, and Make Recommendations

In this section, you will learn how to justify conclusions and state conclusions, and make recommendations based on your findings.

JUSTIFY AND STATE CONCLUSIONS

Tip

To justify conclusions from the evaluation, you need to appropriately analyze, synthesize, interpret, and make judgments on the evidence you have gathered about the surveillance system's performance (Task D).

Because stakeholders must agree that the conclusions are justified before they will use evaluation findings with confidence, you need to link the gathered evidence to the relevant standards for assessing the system's performance (Task C). When writing the conclusions, state whether the surveillance system is addressing an important public health problem (Task B.1) and is meeting its objectives (Task B.2).

MAKE RECOMMENDATIONS

Your recommendations should address how the public health surveillance system should be modified or continued. Before recommending modifications to a system, consider the interdependence of the system's costs (Task B.3) and attributes (Task D.2). Strengthening one system attribute could adversely affect another attribute of a higher priority.

For example, efforts to improve sensitivity, PVP, representativeness, timeliness, and stability can increase the cost of a surveillance system, although savings in efficiency with computer technology (e.g., electronic reporting) might offset some of these costs. As sensitivity and PVP approach 100%, a surveillance system is more likely to be representative of the population with the event under surveillance. However, as sensitivity

increases, PVP might decrease. Efforts to increase sensitivity and PVP might increase the complexity of a surveillance system --- potentially decreasing its acceptability, timeliness, and flexibility.

In some instances, you might conclude that the most appropriate recommendation is to discontinue the public health surveillance system; however, you must carefully consider this type of recommendation before you issue it. The cost of renewing a system that has been discontinued could be substantially greater than the cost of maintaining and/or improving it. The stakeholders in the evaluation should consider relevant public health and other consequences of discontinuing a surveillance system.

Read the following example of conclusions and recommendations from *An Evaluation of Surveillance for Tobacco Use among Youth Worldwide: The Global Youth Tobacco Survey (GYTS).*

Recommendations for the continuation and modification of GYTS are as follows:

Conclusions and Recommendations:

Three major areas for improvement include: data quality, representativeness, and ability to evaluate sensitivity and PPV. In light of these three improvement areas, the following recommendations can be made:

1. Evaluate non-response rates, data inconsistencies and revise to link WHO MPOWER interventions.
2. Promote a national sample design as a standard recommendation but allow sub-national data with justifications.

Activity

Practice Exercise #11 (Estimated Time: 15 minutes)

Instructions:

1. Complete this exercise individually or with a colleague.

2. Refer to the following example of recommendations from the *Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity*.

Recommendations

The NYRBS is worthwhile surveillance that should be continued. A validity study of the dietary behavior and physical activity questions using 24-hour recalls and objective measures is recommended. Physical activity assessment could be improved with more detail on types of activity.

3. Answer the following questions:
   a. Describe how the evaluator linked the recommendations to the evidence gathered. (You may refer to Practice Exercises 3 -10 to review the findings.)

   b. Describe any additional recommendations that you would include in a surveillance system evaluation.

4. Check your answers with those in Appendix B.

Stop

Activity

Take out the Activity Workbook and complete Skill Assessment 6.

Section 8: Task F. Ensure Use of Evaluation Findings and Share Lessons Learned

Task F is one of the most critical steps you will perform to ensure that the time and money invested in evaluating the surveillance system was well spent. This section will discuss how to ensure the evaluation findings are used and how to choose an effective communication format for disseminating the information.

How to Ensure Use

When you focus the evaluation design (Task C), the stakeholders can comment on decisions that might affect how you gather credible evidence. When you implement the evaluation (Tasks D and E), consider how potential findings (particularly negative findings) could affect decisions made about the surveillance system. When you justify conclusions and make recommendations, schedule follow-up meetings with intended users to facilitate the transfer of evaluation conclusions into appropriate actions or decisions. This can help prevent misuse of results by ensuring that:

- evidence is applied to the questions that the evaluation focused on; and
- lessons learned are not ignored while making complex or political decisions.

Tip

Tailor strategies for communicating evaluation findings and recommendations to relevant audiences, including those who provided data used for the evaluation.

In the following section, you will learn the main steps for communicating evaluation findings:

- Determine the communications message
- Define the audience
- Select the communication channel
- Market the message

- Evaluate the effectiveness / impact

For more detailed information, you may refer to the *Data Dissemination* training module.

Determine the Communications Message

Determine the objective or purpose of your message, including actions you are recommending be taken as a result of the surveillance findings. For example, in the following conclusion of a Surveillance Summary for the Morbidity and Mortality Weekly Report, the authors indicate the need for continued monitoring of health-risk behaviors among youth and support for the Youth Risk Behavior Surveillance System (YRBSS):[10]

> The results of this report indicate a need for continued monitoring of health-risk behaviors among high school students nationally and at the state and local levels. In 2011, a total of 43 states and 21 large urban school districts collected YRBS data representative of high school students in their jurisdiction. YRBSS provides ongoing, systematic monitoring of youth risk behaviors at the national, state, and local levels. During the preceding 20 years, analysis and interpretation of YRBSS data have been instrumental in planning, implementation, and evaluation of public health and school-based policies and practices. Additional support for YRBSS will ensure data on priority risk behaviors are available to enhance and inform future efforts to protect and promote the health of youth.

Define the Audience

Identify the group (or groups) that you hope will both understand and use the evaluation findings. For each audience you identify, determine general information about them, such as gender and education level so that you can tailor your message. In the above YRBSS example, one target audience may be state and local health departments who may use the data to implement public health and school-based interventions. This group of people is most likely health professionals with college degrees who have a basic understanding of the health issues that impact their community.

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[10] *Centers for Disease Control and Prevention. Youth Risk Behavior Surveillance – United States, 2011. Surveillance Summaries. MMWR 2012; 61(SS04);1-162)*

Select the Communication Channel

There are two main types of communication channels or formats: informal and formal ones. Informal communication formats can be personal discussions, working sessions, or short communications such as memos, faxes and email. Formal communication formats can include verbal presentations, videotape presentations, conferences, public meetings, written reports, executive summaries, chart essays or poster sessions. Choose a communication format based on:

- accessibility
- reading ability
- familiarity with the surveillance system and/or the evaluation
- role in decision making
- experience using evaluation findings

Since most adults learn with some combination of an interactive and a less interactive product, you may want to present the evaluation findings and provide an executive summary or a report. Engaging people and getting them to react to your findings in a group setting can be a very useful strategy.

Market the Message

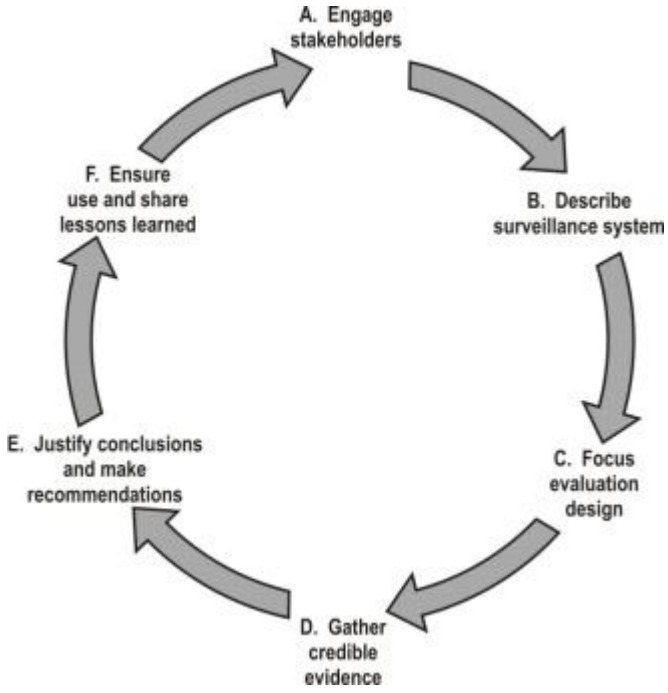
Market or package the message in a manner that is best suited for your target audience. Present information so that it captures the audience's interest and focuses attention on the issue(s). Consider using graphics to make your message more appealing and memorable.

Evaluate the effectiveness / impact of the message

Evaluate the effectiveness / impact of communicating the findings to the target audience. Determine whether the message was communicated to the right audience and whether the information had a beneficial effect on the problem or issue of interest.

Section 9: Conclusion

The purpose of evaluating public health surveillance systems is to ensure that problems of public health importance are being monitored efficiently and effectively. In this module, you have learned the six main steps for evaluating surveillance systems:



A. Engage the stakeholders in the evaluation
B. Describe the surveillance system to be evaluated
   B1. Describe the public health importance of the health-related event under surveillance
   B2. Describe the purpose and operation of the surveillance system
   B3. Describe the resources used to operate the system
C. Focus the evaluation design
D. Gather credible evidence regarding the performance of the surveillance system
   D1. Indicate level of usefulness
   D2. Describe each system attribute
E. Justify and state conclusions, and make recommendations
F. Ensure use and share lessons learned

KEY CONCEPTS

The following key concepts have been presented and are summarized below:

- It is important to engage stakeholders to ensure that the evaluation addresses appropriate questions, assesses pertinent attributes, and produces acceptable and useful findings.
- A balanced and reliable surveillance system description should be developed by consulting with a variety of people involved with the surveillance system and by checking reported descriptions against direct observation.
- When possible, a public health surveillance system should use an established case definition, and if it does not, an explanation should be provided.
- The public health surveillance system should operate in a manner that allows effective dissemination of health data in a timely manner so that decision makers at all levels can readily understand the implications of the information.
- The protection of patient privacy (recognition of a person's right not to share information about him or herself), data confidentiality (assurance of authorized data sharing), and system security (assurance of authorized system access) is essential to maintaining the credibility of any surveillance system.
- An effective evaluation design is contingent upon its specific purpose being understood by all stakeholders and the commitment of the people who need to know the findings to use the information generated from it.
- Gathered evidence must be reliable, credible, and informative for its intended use.
- A public health surveillance system is useful if it contributes to the prevention and control of adverse health-related events.
- The need for rapidity of response in a surveillance system depends on the nature of the health-related event under surveillance and the objectives of that system.
- You must examine all attributes of a surveillance system: simplicity, flexibility, data quality, acceptability, sensitivity, predictive value

positive, representativeness, timeline, stability. If there is no available data on a specific attribute, note this limitation in your evaluation report.

- To justify conclusions from the surveillance system evaluation, you must appropriately analyze, synthesize, interpret, and make judgments on the evidence you have gathered.
- Ensure you link the gathered evidence to the relevant standards for assessing the surveillance system's performance.
- Prevent misuse of evaluation results by ensuring that the evidence is applied to the evaluation questions and lessons learned are not ignored.

Stop

Activity

Locate and read the Field Guidelines for Evaluating a Surveillance System. Be prepared for a facilitator-led discussion.

Appendix

Appendix A

An Evaluation of Surveillance for Tobacco Use among Youth Worldwide:

The Global Youth Tobacco Survey (GYTS)

Eugene K.K. Lam, MD, MSPH

Stakeholders:

The stakeholders of the Global Youth Tobacco Survey (GYTS) include the World Health Organization (WHO) headquarters, its Tobacco Free Initiative (TFI) and all 6 WHO regional offices (AFRO, AMRO, EMRO, EURO, SEARO, WPRO), the U.S. Centers for Disease Control and Prevention (CDC), national entities such as local governments (Ministries of Health and Education), local schools and educators, academia and researchers, and the general public.

System Description:

Public Health Importance

Tobacco use continues to be the leading global cause of preventable death. If current trends continue, by 2030 tobacco will kill more than 8 million people worldwide each year, with 80% of these premature deaths among people living in low- and middle-income countries. Prevalence of tobacco use among youth worldwide varies across WHO regions. Overall, 12 percent of boys and 7 percent of girls aged 13-15 years currently smoke cigarettes.

Purpose & Operation

In 1998, WHO and CDC initiated the GYTS to enhance the capacity of countries to monitor tobacco use among youth; guide national tobacco prevention and control programs; and facilitate co mparison of tobacco-related data at the national, regional and global levels. The GYTS targets non-institutionalized students aged 13-15 years. Participants are selected through a 2 stage sample design. Schools are selected proportional to enrollment size and classrooms were chosen randomly within selected schools. All students in selected classes are eligible for participation. Since 1999, the GYTS has been conducted in 167 countries across all 6 WHO Regions. Over 2 million students and 11,000 schools have participated in GYTS.

Resources

GYTS is funded by the U.S. government and managed through CDC/OSH, in collaboration with WHO Headquarters in Geneva, and its 6 regional offices. Total estimated operating cost for GYTS averages approximately $1 million annually.

Surveillance Evaluation Design:

The purpose of this evaluation is to assess the performance of GYTS as a surveillance system for tobacco use.

Credible Evidence:

The GYTS is a simple survey as it only addresses tobacco indicators in select school-based students of ages 13-15 years. The system is flexible as countries are able to insert optional questions for country-specific adaptation with little additional resources.

Data quality may be adversely affected by minimal data edits and lack of a biomarker, cotinine, for validation of smoking prevalence. Non-response rates are also unknown. Acceptability is high as GYTS data have the potential to be used by multiple stakeholders. Representativeness is limited to enrolled students aged 13-15 years. Countries with sub-national data were unable to implement national sample design due to limited funding, time constraints, and political instability. Sensitivity and positive predictive value of smoking prevalence cannot be calculated due to lack of cotinine measurement. Stability is good as the system has been ongoing since 1999. The GYTS framework is generally completed within recommended 4-5 year cycle with the exception of countries that have difficulty obtaining school enrollment lists.

Recommendations:

Recommendations for the continuation and modification of GYTS are as follows:

1. Evaluate non-response rates, data inconsistencies and revise to link WHO MPOWER interventions.
2. Promote a national sample design as a standard recommendation but allow sub-national data with justifications.
3. Include validation measures (i.e. cotinine measurement) to enable calculation of its sensitivity and positive predictive value.

Lessons Learned:

1. Tobacco use is a leading cause of preventable disease and death among youth worldwide.

2. GYTS can provide valid and timely surveillance data on tobacco use indicators among adolescents worldwide.
3. Data representing all aspects of WHO MPOWER strategies are crucial for monitoring impact of policies and tobacco-related interventions.

(Adapted from) **Evaluation of the National Youth Risk Behavior Survey (NYRBS): Dietary and Physical Activity Behaviors and Obesity**

Zewditu Demissie, PhD, MPH, EIS Class of 2010

Stakeholders

NYRBS stakeholders include CDC, ICF Macro (Macro; the data collection contractor), data users from governmental and nongovernmental agencies, schools, parents, and students.

System Description

Public Health Importance: Childhood obesity rates have tripled during the past 30 years. Unhealthy dietary behaviors and physical inactivity contribute to the obesity epidemic and are associated with increased risk for some cancers, cardiovascular disease, and diabetes. Obesity prevention through improved physical activity and nutrition is one of CDC's "winnable battles.[1]"

Purpose and Objectives: The NYRBS is part of the Youth Risk Behavior Surveillance System and is designed to monitor six categories of priority health-risk behaviors that contribute to death, disease, disability, and social problems in the U.S. The objectives are to assess the distribution and co-occurrence of these behaviors among subgroups of youth and how the prevalence of these behaviors changes over time.

[1] *http://www.cdc.gov/winnablebattles*

Operation: The NYRBS is a cross-sectional survey conducted biennially since 1991 among nationally representative samples of public and private school students in grades 9-12. A 3-stage cluster sampling method with oversampling of black and Hispanic students is used. Participation is anonymous and voluntary. One class period is needed to complete the 97-item self-administered questionnaire, which includes 9 dietary behavior questions, 6 physical activity questions, and self-reported height and weight. Macro has been contracted to coordinate sample design/selection, standardized data collection, and data weighting. The Division of Adolescent and School Health (DASH) is responsible for data cleaning, analysis, and dissemination. Extensive data security measures are utilized.

Resources: CDC funds the NYRBS. The cost for each NYRBS cycle is approximately $1,500,000.

Evaluation Design

The goal of this evaluation was to determine the strengths and weaknesses of the NYRBS dietary and physical activity behavior and obesity questions. I reviewed NYRBS documentation, published manuscripts, and nutrition and physical activity guidelines, and interviewed DASH staff.

Credible Evidence

Usefulness: NYRBS data are used to describe the national prevalence of dietary behavior and physical activity behaviors among high school students. State/local

partners may use these data as a comparison tool. The data also are used to create awareness about unhealthy dietary behaviors and physical inactivity; evaluate CDC's Performance Plan; monitor the nation's progress towards meeting national public health goals/recommendations; and support policies, legislation, programs, and funding initiatives.

System Attributes: Simplicity: Considerable manpower and expertise is needed to conduct the NYRBS, however, data collection training is short and no participant follow-up is needed.

Flexibility: The NYRBS is flexible; survey modifications are considered each cycle.

Acceptability: Overall NYRBS response rates average 67% and item response rate is high. In general, less than 2% of dietary behavior and physical activity data are missing.

Data Quality, Sensitivity, Predictive Value Positive (PVP): No validity data are available for the NYRBS dietary behavior and physical activity questions; however, the questions have strong content validity. Body mass index (based on self-reported height and weight) data are reliable, have moderate sensitivity, and have high PVP. Representativeness: NYRBS data are representative of U.S. high school students. Timeliness: NYRBS data collection completion to dissemination takes one year. Stability: The system is stable using a reliable contractor and consistent methodology since 1991.

Recommendations

The NYRBS is worthwhile surveillance that should be continued. A validity study of the dietary behavior and physical activity questions using 24-hour recalls and objective

measures is recommended. Physical activity assessment could be improved with more detail on types of activity.

Lessons Learned

The NYRBS is important for monitoring how the nation's youth are meeting national recommendations for nutrition and physical activity. NYRBS data are useful for comparison to state and local data to demonstrate the success or needs for improvement at these levels.

Evaluation of National Surveillance of Arthritis in the U.S.: The National Health Interview Survey (NHIS)
Kamil Barbour, PhD, MPH. EIS 2010

Stakeholders: CDC Arthritis Program, national organizations (Arthritis Foundation, American College of Rheumatology, Healthy People 2010/2020), state and local health departments, and the public.

System Description: ***Public Health Importance:*** Arthritis is the most common cause of disability among adults. The 2007-2009 prevalence of arthritis in the U.S. is estimated to be 49.9 million (22.2%) for adults aged 18 or older.(1) An estimated 21.1 million (9.1% of adults overall and 42.4% with doctor diagnosed arthritis) have arthritis-attributable activity limitations (AAAL). Estimated 2003 costs for arthritis and other rheumatic conditions were $128 billion, 1.2% of the 2003 U.S. gross domestic product(2). ***Purpose:*** The purpose of this surveillance system is to estimate the magnitude of various measures of arthritis burden in the U.S. population and use the data to interpret and make recommendations for use in public health action to reduce arthritis burden.

Operation: NHIS is used by the CDC Arthritis Program to estimate the annual national prevalence of arthritis in the U.S. among adults aged 18 years or older. Arthritis data can

be linked to other survey burden measures (e.g., co-morbid conditions) and to estimate arthritis-attributable impacts such as AAAL, arthritis-attributable work limitation (AAWL), joint pain severity, and self-rated health. NHIS-related surveys (e.g., Medical Expenditure Panel Survey) can be used to estimate arthritis-related costs. NHIS is an annual multi-purpose, nationally sampled, in person, household interview health survey conducted by the National Center for Health Statistics (NHCS) among 35,000-40,000 households(3). There are 6 core arthritis questions that are asked annually (primarily related to prevalence, and AAAL) and 5 optional arthritis questions administered every 3 years on level of joint pain, counseling about weight loss and physical activity to help arthritis symptoms, and taking an educational course on managing arthritis, and AAWL. ***Resources:*** The core arthritis questions for NHIS are administered at no cost to the CDC arthritis program. The optional arthritis questions cost $600,000, split evenly by CDC and NIH.

Evaluation Design: This report is designed to provide a comprehensive review of the CDC Arthritis Program's national surveillance of arthritis, which is designed to assess arthritis prevalence and other measures of arthritis burden. Information for this report was gathered by 1) speaking with key informants involved with the surveillance, and 2) reviewing the data sources and results. This evaluation will focus on the single case definition question from the 6 question core module. Arthritis prevalence is assessed with a single question "Have you ever been told by a doctor or other health professional that you have some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia?

Credible Evidence: *Usefulness:* The NHIS case definition for arthritis accurately and precisely assesses the national prevalence of self-reported doctor diagnosed arthritis,

which is published regularly. ***Simplicity:*** This surveillance system uses an existing data collection infrastructure with standardized questions and standardized survey methodology. ***Flexibility***: CDC successfully lobbied for a change in the case definition in 2001. ***Data Quality*****:** A validation study(4) among subjects aged 45-64 and ≥65 years, found moderate validity (sensitivity=52.5%, specificity=79.6%, PPV=74.9% and sensitivity=68.8%, specificity=81.1%, PPV=91.0%, respectively) for the doctor-diagnosed definition of arthritis. A subsequent study(5) reported moderate validity (sensitivity=72.3% and specificity=74.3%) and high reliability (κ=0.88) for doctor-diagnosed arthritis. ***Acceptability:*** The acceptability for NHIS is very high with an estimated response rate of 90% of eligible households in the sample(6). The question refusal rate is low, only 0.04% of respondents refused to answer the case-fining question. ***Representativeness:*** Representative of the adult civilian non-institutionalized population in the U.S. ***Timeliness:*** Data are made available 6 months after survey completion. ***Stability:*** NHIS was established in 1957 and has been repeated annually since. Arthritis case definition has not changed since 2001.

Conclusions and Recommendations: The current question used in NHIS to estimate arthritis prevalence in the U.S. population should remain in the survey. The question has been validated in two studies and the specificity and reliability of the case definition is sufficient for surveillance purposes. A recommendation could be made to broaden the case definition to substantially increase sensitivity and capture a larger part of the arthritis population. Another recommendation would be to make the optional questions mandatory and administered annually, which would provide greater statistical power to

comprehend arthritis related burden, and the frequency of specific activities performed to alleviate arthritis associated symptoms.

Lessons Learned: (1) The prior case definition of arthritis that included chronic joint symptoms, while sensitive, had low specificity and reliability and therefore was excluded. (2) Including a case definition for specific types of self-reported arthritis (e.g., rheumatoid arthritis) was shown to have poor validity and reliability and would likely result in highly inaccurate estimates of arthritis burden.

References

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(2) Yelin E, Cisternas M, Foreman A, Pasta D, Murphy L, Helmick CG. National and state medical expenditures and lost earnings attributable to arthritis and other rheumatic conditions - United States, 2003 (Reprinted from MMWR, vol 56, pg 4-7, 2007). Jama-Journal of the American Medical Association 2007; 297(15):1649-1650.

(3) National Health Interview Survey. http://www.cdc.gov/nchs/data/nhis/brochure2010January.pdf . 8-15-2010. Ref Type: Electronic Citation

(4) Sacks JJ, Harrold LR, Helmick CG, Gurwitz JH, Emani S, Yood RA. Validation of a surveillance case definition for arthritis. Journal of Rheumatology 2005; 32(2):340-347.

(5) Bombard JM, Powell KE, Martin LM, Helmick CG, Wilson WH. Validity and reliability of self-reported arthritis: Georgia senior centers, 2000-2001. Am J Prev Med 2005; 28(3):251-258.

(6) National Health Interview Survey Response Rate. http://www.cdc.gov/nchs/nhis/about_nhis.htm . 8-17-2010. Ref Type: Electronic Citation

Appendix B:

Potential answers (*in italics*) to Practice Exercise #1:

a. What parameters did the evaluator use to describe the public health importance of dietary and physical activity behaviors and obesity? Fill out the table below.

Parameter	Is it included? Y or N	If yes, how is it described?
Indices of frequency	*Y*	*Obesity rates have tripled during the past 30 years.*
Indices of severity	*N*	
Disparities or inequities associated with the health-related event	*N*	
Costs associated with the health-related event	*N*	
Preventability	*N*	
Potential clinical course of action in the absence of an intervention	*Y*	*Unhealthy dietary behaviors and physical inactivity contribute to the obesity epidemic and are associated with increased risk for some cancers, cardiovascular disease, and diabetes.*
Public interest	*Y*	*Obesity prevention through improved physical activity and nutrition is one of CDC's "winnable battles."*

b. Are there other parameters you would include in the description of public health importance for dietary and physical activity behaviors and obesity?

Frequency- Could have provided some percentages of obesity among adolescents.
Cost- Could have included associated costs in annual direct medical expenditures, such as additional prescription drugs and costs from emergency room and outpatient visits.
Disparities or inequality- Could have included that childhood obesity is more prevalent among certain ethnic groups, such as African Americans and Mexicans.
Americans and Native Americans vs. other ethnic groups.

Dr. Demissie could have presented frequency, cost, and inequality information for physical activity and dietary behaviors, as well.

Potential answers (in italics) **to Practice Exercise #2**:

a. What methods did the evaluator use to describe the purpose and operation of the surveillance system? Fill out the table below.

Method	Is it included? Y or N	If yes, how is it described?
Describe purpose and objectives of the surveillance system	*Y*	*The NYRBS is designed to monitor six categories of priority health-risk behaviors that contribute to death, disease, disability, and social problems in the U.S.* *Objectives: assess the distribution and co-occurrence of these behaviors among subgroups of youth and how the prevalence of these behaviors changes over time.*
Describe planned uses of the data from the system	*Y*	*The data also are used to create awareness about unhealthy dietary behaviors and physical inactivity*
Describe health-related event under surveillance, including case definition	*Y*	*States that it is designed to monitor six categories of priority health-risk behaviors that contribute to death, disability, and social problems in the US. --- 9 dietary behavior questions, 6 physical activity questions and self-reported height and weight. This description could be expanded on.*
Cite legal authority for the data collection	*N*	
Describe where in the organization the system resides	*N*	
Describe level of integration with other systems	*Y*	*Macro has been contracted to coordinate sample design/selection, standardized data collection, and data weighting. The Division of Adolescent and School Health (DASH) is responsible for data cleaning, analysis, and dissemination*.
Draw a flow chart of the system	*N*	
Describe the components of the system (e.g., population under surveillance, what data are collected)	*Y*	*One class period is needed to complete the 97-item self-administered questionnaire, which includes 9 dietary behavior questions, 6 physical activity questions, and self-reported height and weight.*

b. Are there any other methods you would use to describe the purpose and operation of the Youth Risk Behavior Surveillance System?
Could have included the workflow of the data from data collection to final reporting.

Potential answers (in italics**)to Practice Exercise #3**:

Conclusions: *Usefulness is high because data are used to create awareness about unhealthy dietary behaviors and physical inactivity and describe national prevalence. Datasets are downloadable.*

Recommendations: *No recommendations needed at this time.*

Potential answers to Practice Exercise #4:

Conclusions: *Simplicity is moderate because data collection is labor intensive, considerable manpower and expertise is needed, and complex survey design; however, data collection training is short and no participant follow-up is needed.*

Recommendations: *Improvements in funding methods that facilitate the administration of NYRBS.*

Potential answers to Practice Exercise #5:

Conclusions: *The national YRBS has good flexibility.*

Recommendations: *None. If you are too flexibility, you lose the ability to compare over the years. Questions need to remain consistent to be able to look at trends.*

Potential answers to Practice Exercise #6:

Conclusions: *Data quality is high.*

Recommendations: *Physical activity assessment could be improved with more detail on types of activity. (Of course, you are limited to what you can include on a survey to administer during one class period. Going any longer would increase participant burden.) Conduct a validity study for dietary behaviors as well as activity.*

Potential answers to Practice Exercise #7:

Conclusions: *The national YRBS has moderate acceptability.*

Recommendations: *Possibly more outreach to schools and school districts demonstrating the importance of the data? Showcasing the uses of the data by partners and how it has produced benefits.*

Potential answers to Practice Exercise #8:

Conclusions: *NYRBS data are representative of U.S. high school students attending regular public and private schools.*

Recommendations: *None*

Potential answers to Practice Exercise #9:

Conclusions: *NYRBS data are timely*

Recommendations: *None.*

Potential answers to Practice Exercise #10:

Conclusions: *The NYRBS is stable because surveys have been conducted biennially since 1991.*

Recommendations: *Provide incentives for past data collectors to return to do data collection again.*

Potential answers to Practice Exercise #11:

a. Describe how the evaluator linked the recommendations to the evidence gathered. (You may refer to Practice Exercises 3 -10 to review the findings.)

   Worthwhile due to the usefulness of the quality data.
   Validity study was recommended since it is self-reported data.
   More detailed physical activity assessment was recommended because targeting for more specifics helps to improve recall.

b. Describe any additional recommendations that you would include in a surveillance system evaluation.
   Consider objective assessment of height and weight. Consider food frequency questionnaires to assess dietary behaviors. This is dependent on funding and results in more of a burden to respondents and more "interviewer" involvement and training.