

ACTIVITY WORKBOOK



Evaluating an NCD-Related Surveillance System

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Evaluating an NCD-Related Surveillance System. Atlanta, GA: Centers for Disease Control and Prevention (CDC), 2013.

Activity

Skill Assessment #1 (Estimated time: 20 minutes)

Background:

For this exercise, you will work individually to identify stakeholders to involve in a surveillance system evaluation in *your* country.

Instructions:

1. Use the information about the NCD-related surveillance system you brought to class and list the stakeholders to engage in the space below. Consider the following:
 - who is funding the evaluation system
 - who will use the information derived from the evaluation system
 - whether the political/organizational environment will support changes to the surveillance system evaluation.(Note: You can add to the list of stakeholders when you return to your job.)

2. If you are in a classroom setting, find a colleague and review each other's work, providing feedback, as appropriate.

Ensure your facilitator or mentor has reviewed your work.

c. What items would you include in your description of the **resources** used to operate the surveillance system?

2. If you are in a classroom setting, find a colleague and review each other's work, providing feedback, as appropriate.

Ensure your facilitator or mentor has reviewed your work.

Activity

Skill Assessment #3 (Estimated Time: 30 Minutes)**Background:**

For this exercise, you will work individually to plan for evaluating a surveillance system in *your* country.

Instructions:

1. Use the information about the NCD-related surveillance system you brought to class and describe how you will **focus the evaluation design**. Record your response in the space below. You may include information such as:
 - purpose of the evaluation,
 - intended users of the evaluation,
 - what will be done with the information generated from the evaluation,
 - the questions that will be answered by the evaluation, and
 - the standards for assessing the performance of the system.

Surveillance Evaluation Design:

2. If you are in a classroom setting, find a colleague and review each other's work, providing feedback, as appropriate.

Ensure your facilitator or mentor has reviewed your work.

Attribute	Method or Measures
Simplicity	
Flexibility	
Data quality	
Acceptability	
Sensitivity	
Predictive value positive	

Representativeness	
Timeliness	
Stability	

3. If you are in a classroom setting, find a colleague and review each other’s work, providing feedback, as appropriate.

Ensure your facilitator or mentor has reviewed your work.

Activity

Skill Assessment #5 (Estimated time: 90 minutes)**Background:**

For this exercise, you will work individually or in pairs to assess the attributes of a sample evaluation: *Evaluation of National Surveillance of Arthritis in the U.S.: The National Health Interview Survey (NHIS)*, by Kamil Barbour, PhD, MPH:

Instructions:

1. Read Figure 1 which contains the first part of the evaluation report: stakeholders, system description, and evaluation design.
2. Read Figure 2 which contains information about credible evidence. Similar to the Practice Exercises, you will read about the methods and measures used and the key results. You will fill in the **Conclusions** and **Recommendations** sections for each attribute.
3. Let your facilitator know when you have completed the exercise and be prepared to share your responses with the class.

Figure 1:

Evaluation of National Surveillance of Arthritis in the U.S.: The National Health Interview Survey (NHIS)

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?"

Figure 2: Credible Evidence

Complete the **Conclusions** and **Recommendations** sections below:

Usefulness

Methods and measures used:

- Review of CDC's MMWRs and other publications that estimate arthritis prevalence.
- Interview of arthritis stakeholders (i.e., Arthritis Foundation, state and local health departments, and the public).

Key results: The NHIS case definition for arthritis accurately and precisely assesses the national prevalence of self-reported doctor diagnosed arthritis, which is published regularly.

Conclusions:

Recommendations:

Simplicity

Methods and measures used:

- Review of survey methodology, questionnaire, and data collection infrastructure.
- Interview of arthritis stakeholders (i.e., CDC arthritis epidemiologists who are involved with the data analysis).

Key results: This surveillance system uses an existing data collection infrastructure with standardized questions and standardized survey methodology.

Conclusions:

Recommendations:**Flexibility**

Methods and measures used: Review of NHIS arthritis case definition over time.

Key Results:

- From 1996 to 2001, the case definition included self-report of chronic joint symptoms in the last 30 days and self-report of doctor-diagnosed arthritis.
- Due to variability in state estimates of arthritis prevalence the validity and reliability of the chronic joint symptoms, part of the case definition was examined and this part of the question was removed in 2001.

Conclusions:**Recommendations:****Data Quality - Validation Study 1:****Measures and methods used:**

- Jeffrey Sachs and colleagues conducted a validation study in Massachusetts among 389 clinic patients of which 179 were aged 45-64 years and 210 were 65 years or older¹.
- A questionnaire was administered to subjects an estimated 4 weeks before the clinic visit. It contained the current NHIS case definition of arthritis (based on self-reported doctor-diagnosed arthritis) and a separate question on whether they had chronic joint symptoms in the past 30 days. (Rheumatologist diagnosed arthritis was the gold standard.)

¹ 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.

- Compared validity of self-reported doctor-diagnosed arthritis to self-reported chronic joint symptoms.

Key results:

- Aged 45-64: Self-report of doctor diagnosed arthritis was more specific than chronic joint (79% vs. 67%).
- Aged ≥ 65 : Similar specificity and sensitivity.
- Specificity higher for older group.

Conclusions:**Recommendations:****Data Quality - Validation Study 2:****Measures and methods used:**

- Compared validity and reliability of self-reported doctor-diagnosed arthritis to self-reported chronic joint symptoms.
- A convenience sample of 487 participants from Georgia aged ≥ 50 years. Telephone survey followed by medical examination.
- Rheumatologist diagnosed arthritis was gold standard.

Key results:

- Specificity and sensitivity similar. Combining case definitions led to low specificity (58.1%).
- Reliability very high for doctor-diagnosed ($\kappa=0.88$) compared to chronic joint symptoms ($\kappa=0.44$).

Conclusions:

Recommendations:**Acceptability**

Measures and methods used: Review of NHIS sampling documentation.

Key Results:

- The estimated response rate is 90% of all eligible households in the sample.
- The question refusal rate is low, only 0.04% of respondents refused to answer the case-fining question.

Conclusions:

Recommendations:

Sensitivity

Measures and methods used:

- A rheumatologist's determination based on physical examination and clinical history of a patient was considered the gold standard to confirm the case definition for both studies.
- The gold standard was used to calculate the sensitivity and specificity for the different self-report case definitions of arthritis.

Key results:

- Aged 45-64: Self-report of doctor diagnosed arthritis was more specific than chronic joint definition (79% vs. 67%).
- Aged ≥ 65 : Similar specificity and sensitivity.

Conclusions:

Recommendations:**Predictive Positive Value****Measures and methods used:**

- Jeffrey Sachs and colleagues conducted a validation study in Massachusetts among 389 clinic patients of which 179 were aged 45-64 years and 210 were 65 years or older.
- Rheumatologist diagnosed arthritis was the gold standard.
- Calculated the positive predictive value of self-reported doctor-diagnosed arthritis and self-reported chronic joint symptoms.

Key Results:

- Self-report of doctor diagnosed arthritis:
 - Aged 45-64: 74.9% PPV
 - Aged ≥65: 91.0% PPV
- Self-report of chronic joint symptoms:
 - Aged 45-64: 70.8% PPV
 - Aged ≥65: 94.8% PPV

Conclusions:**Recommendations:****Representativeness**

Measures and methods used: Review of NHIS sampling documentation.

Key results:

- The estimated response rate is 90% of all eligible households in the sample.
- The question refusal rate is low, only 0.04% of respondents refused to answer the case-fining question.

- This sample is weighted to represent the adult civilian non-institutionalized population in the U.S.

Conclusions:**Recommendations:****Timeliness**

Measures and methods used: Annual review of when data is available for use.

Key Results:

- Data can be made available 6 months after survey completion.
- If requested from NHIS, can be made available after 3 months.

Conclusions:**Recommendations:****Stability**

Measures and methods used: NHIS system.

Key Results:

- NHIS surveillance system is stable.
- NHIS was established in 1957 and has been repeated annually since and the arthritis case definition question has not changed since 2001.

Conclusions:

Recommendations:

Activity

Skill Assessment #6 (Estimated time: 30 minutes)**Background:**

For this exercise, you will work individually or in pairs and use the sample evaluation: *Evaluation of National Surveillance of Arthritis in the U.S.: The National Health Interview Survey (NHIS)*:

Instructions:

1. Read the following conclusions and recommendations from the sample arthritis evaluation report and answer the question that follows:

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.

- a. Describe how the conclusions and recommendations are supported by the findings (from Skill Assessment #5).

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

c. Refer back to Skill Assessment #5 and make note of the stakeholders. Describe how you would ensure the stakeholders use the findings from the surveillance system evaluation. How can you ensure the intended users take the appropriate actions that you are recommending?

2. If you are in a classroom setting, find a colleague and review each other's work, providing feedback, as appropriate.

Ensure your facilitator or mentor has reviewed your work.

Activity

Skill Assessment #7**Background:**

You will complete this skill assessment after the training. You will use the work you completed in skill assessments 1, 2, 3, and 4 and the **Field Guidelines for Evaluating a Surveillance System**.

Instructions:

1. Evaluate the surveillance system for which you have prepared during the training class.
2. Create an evaluation report, based on your findings.
3. Develop a PowerPoint presentation.
4. Present the report and presentation to your mentor for feedback.