Overview of Evaluating Surveillance Systems
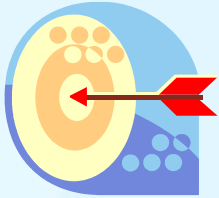
Presenter's Name

Presenter's Title

Title of Event

Date of Event

Learning Objective

Using a sample evaluation report of a noncommunicable disease (NCD) surveillance system, identify how the components were described and evaluated.

Lesson Overview

- Why evaluate surveillance systems
- CDC Evaluation Framework
- Example of an evaluation of a surveillance system

IMPORTANCE OF EVALUATING SURVEILLANCE SYSTEMS

# **Why is it Important to Evaluate?**

- Produce recommendations in order to improve:
    - Efficiency
    - Quality
    - Effectiveness
    - Usefulness
    - Cost

When is an Evaluation Effective?

- An evaluation is effective when…

    - It is useful, feasible, advisable and precise.

    - The information can be used in decision-making and allocation of resources.

    - It contributes information in order to generate lines of research.

    - It meets the performance standards.

Who is Interested in Evaluation Results?

- Users
- Staff members
- Policy makers
- General public
- Communications media
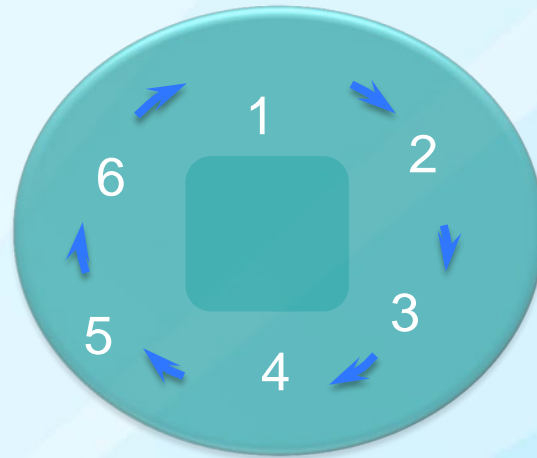
CDC EVALUATION FRAMEWORK

CDC Framework for Program Evaluation

STEPS

- Engage stakeholders
- Describe the surveillance system
- Focus the evaluation design
- Gather credible evidence
- Justify conclusions
- Ensure use and share lessons learned

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

Kamil Barbour, PhD

Epidemic Intelligence Officer 2010

Arthritis Epilepsy and Quality of Life Branch

Division of Adult and Community Health, NCCDPHP

October 26th, 2010

National Center for Chronic Disease Prevention and Health Promotion
Division of Adult and Community Heath,. Arthritis Epilepsy and Quality of Life Branch

Department of Health and Human Services

Centers for Disease Control and Prevention

Objectives

- Stakeholders
- System description
- Evaluation design
- Credible evidence
- Conclusions
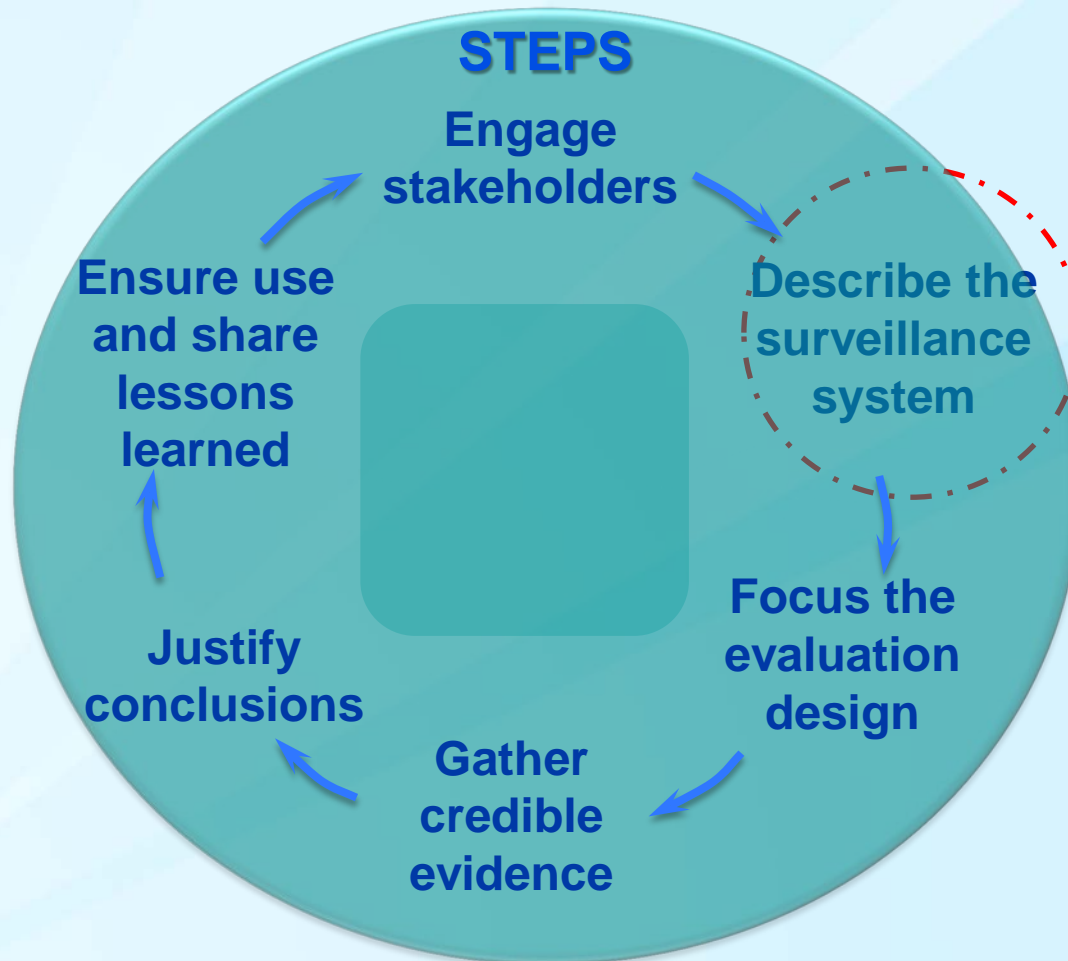- Recommendations
- Lessons learned

Step 1 – Engage Stakeholders

- **Stakeholders are** *people and/or organizations* that are:
  - Interested in the **program**,
  - Interested in the **results** of the evaluation, and/or
  - Have a **stake** in what will be done with the results of the evaluation.

Stakeholders

- CDC Arthritis Program

- National organizations

- State and local health departments

- Public health policymakers

- Healthcare professionals

- The public

Step 2 – Describe the Surveillance System

STEPS

Engage stakeholders

Describe the surveillance system

Ensure use and share lessons learned

Focus the evaluation design

Justify conclusions

Gather credible evidence

Describe Surveillance System to Be Evaluated

1. Importance in public health
2. Purpose and operation
3. Resources used

Describe Surveillance System: Step 1

1. Importance in public health
    a) Indices of frequency
    b) Indices of severity
    c) Disparities or inequities associated with the health-related event
    d) Costs associated with the health-related event
    e) Preventability
    f) Potential future clinical course in the absence of intervention
    g) Public interest

System Description : Public Health Importance of Arthritis

- An estimated 49.9 million (22.2%) cases of doctor-diagnosed among adults.[1] Conservative estimate.

- Approximately 21.1 million have arthritis-attributable activity limitations (AAAL).
    - 9.1% of adults overall
    - 42.4% of arthritis cases

- $128 billion (1.2% of GDP).[2]

[1]Cheng Y, Hootman J, Murphy LB LGHC. Centers for Disease Control and Prevention. Prevalence of doctor-diagnosed arthritis and arthritis-attributable activity limitation-United States,2007-2009. Morb Mort Weekly Rep 2010; 59(39):1261-1265

[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 -States, 2003 MMWR, vol 56, pg 4-7, 2007

Public Health Importance of Arthritis

- Demographic, anthropomorphic , medical, and lifestyle differences in arthritis prevalence[1]

  - Higher in women (24.3%) vs. men (18.2%)

  - Higher among older population

  - Higher among whites (23.0%) vs. Blacks (21.7%) and Hispanics (20.5%)

  - Obesity is associated with arthritis

[1]Cheng Y, Hootman J, Murphy LB LGHC. Centers for Disease Control and Prevention. Prevalence of doctor-diagnosed arthritis and arthritis-attributable activity limitation-United States,2007-2009. Morb Mort Weekly Rep 2010; 59(39):1261-1265

Describe Surveillance System: Step 2

2. Purpose and operation
   a) Purpose and objectives of system
   b) Planned uses of data from system
   c) Health-related event under surveillance, including case definition
   d) Legal authority for data collection
   e) The organization(s) where system resides
   f) Level of integration with other systems, if appropriate
   g) Flow chart of system
   h) Components of system

Describe Surveillance System: Step 2, Part H

h)   Components of system

1.   Population under surveillance

2.   Period of time of data collection

3.   Data collection

4.   Reporting sources of data

5.   Data management

6.   Data analysis and dissemination

7.   Patient privacy, data confidentiality, and system security

8.   Records management program

Purpose of Arthritis Surveillance System Using Data from NHIS

- Estimate magnitude of arthritis burden

- Interpret data

- Make recommendations

Operation of NHIS

- NHIS surveillance system
  - Annual
  - Household interview
  - Conducted by National Center for Health Statistics (NCHS)
- NHIS design
  - Stratified, multi-stage
  - Probability design
  - Oversampling of minorities

Operation of Arthritis Surveillance within NHIS

- 6 core questions
  - Arthritis prevalence
  - AAAL

- 5 optional questions
  - Joint Pain
  - Arthritis Attributable Work Limitations (AAWL)
  - Arthritis Management
    – Losing weight
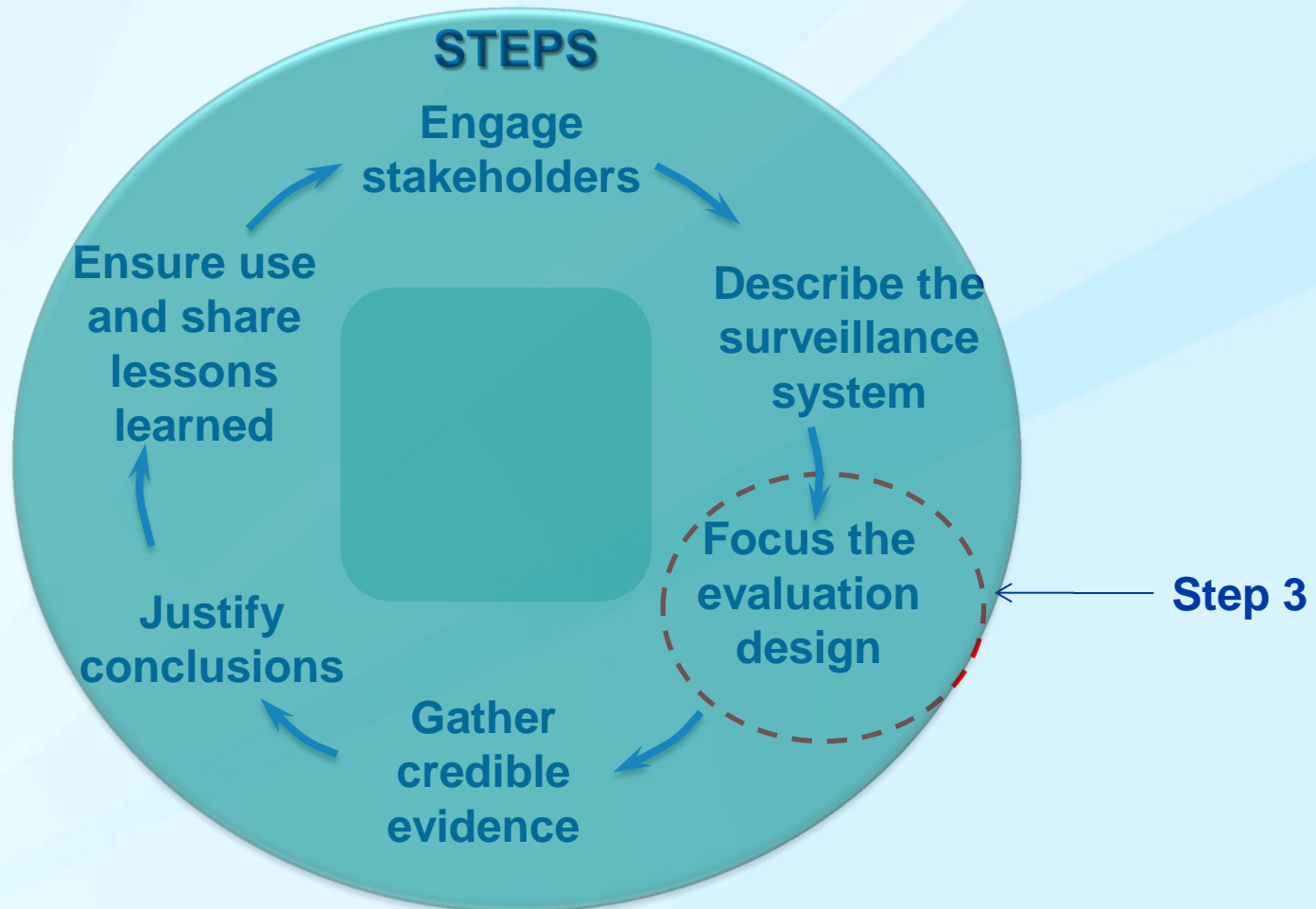   – Exercise
    – Educational course

Describe Surveillance System: Step 3

3. Resources used

    a) Funding sources

    b) Personnel requirements

    c) Other resources

Resources for Arthritis Surveillance within NHIS

- Core arthritis questions
  - No cost

- Optional arthritis questions
  - $600,000
  - Split evenly among CDC and NIH

Step 3 – Focus the Evaluation Design

STEPS

Engage stakeholders

Describe the surveillance system

Focus the evaluation design

Gather credible evidence

Justify conclusions

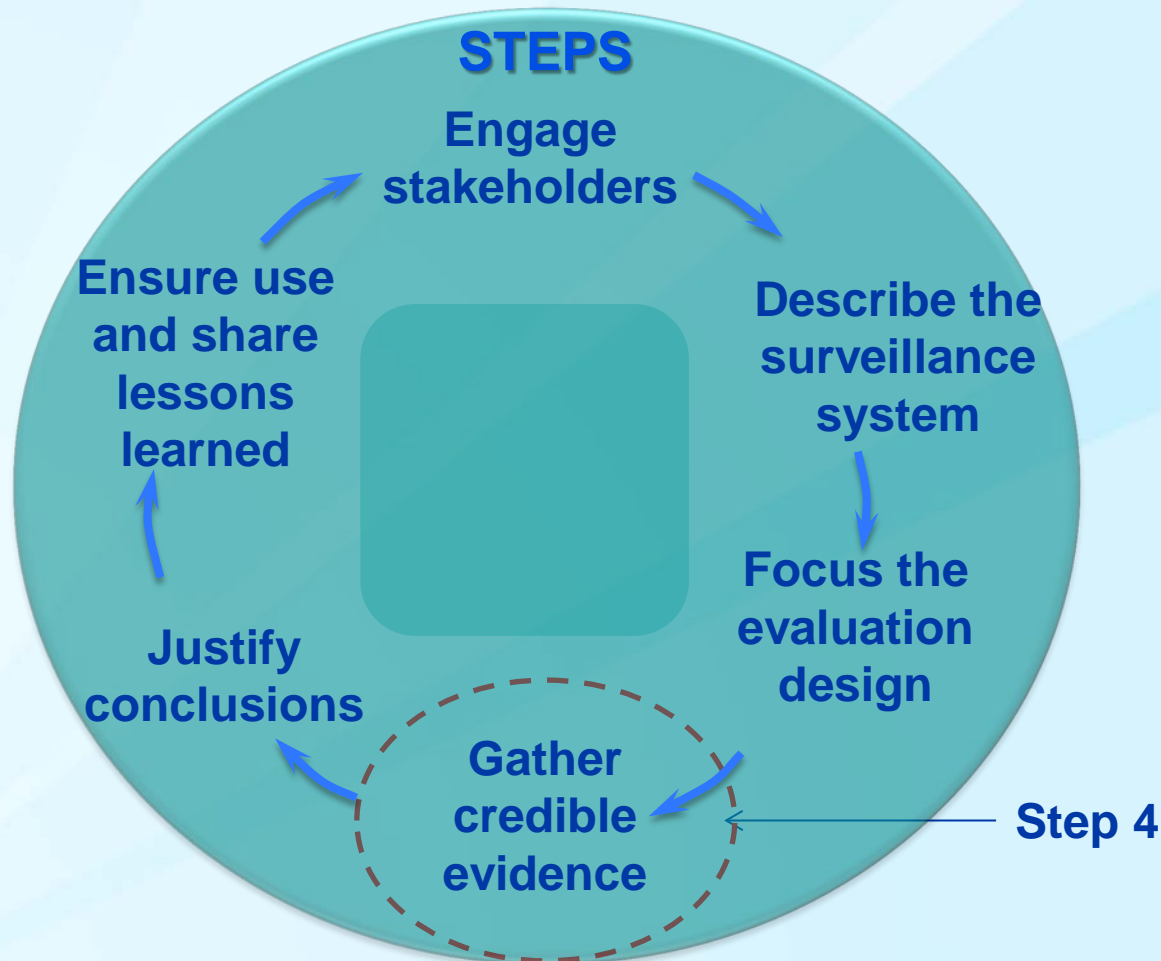Ensure use and share lessons learned

Step 3

Step 3 – Focus the Evaluation

1. Determine the specific purpose of the evaluation

2. Identify stakeholders who will receive findings and recommendations

3. Consider how information will be used

4. Specify questions to be answered by evaluation

5. Determine standards to assessing performance of system

Evaluation Design

- Comprehensive review of CDC Arthritis Program

- Information obtained
  - Discussing with key informants
  - Reviewing data sources and results

- Evaluation will focus on single case definition
  - "Have you ever been told by a doctor or other health care professional that you have some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia"?

Step 4 – Gather Credible Evidence

STEPS

Engage stakeholders

Describe the surveillance system

Focus the evaluation design

Gather credible evidence

Step 4

Justify conclusions

Ensure use and share lessons learned

Gather Credible Evidence Phases

1. Indicate the level of usefulness

2. Describe each system attribute

When is a Surveillance System Useful?

- Detects the events under surveillance

- Presents estimates on magnitude of event

- Detects trends, changes in occurrence

- Contributes to the prevention and control of the monitored events

- Promotes research

- Identifies measures of performance

System Attributes

- Simplicity

- Flexibility

- Data quality

- Acceptability

- Sensitivity

- Predictive value positive

- Representativeness

- Timeliness

- Stability

How Can You Evaluate Simplicity?

- Type and quantity of data to identify occurrence of the event

- Data collection methods

- Methods for handling data

- Methods of analyzing and disseminating data

- Integration with other surveillance systems and information

- Steps to process the report of the event

- Flow of the data: average time between steps and transfer of data

- Who analyzes data and how

How Can You Evaluate Flexibility?

- Response of the system to new demands

- Analysis of design and flow of system

- Capacity to respond to information needs

Credible Evidence: Usefulness, Simplicity and Flexibility

- Usefulness: Arthritis case definition has been validated

- Simplicity: Standardized questions and survey methodology

- Flexibility: NHIS flexible for changes in case definition of arthritis if needed . From 1996 to 2001 case definition included chronic joint symptoms. Case definition changed in 2001 to current version after conducting two validation studies.

How Can You Evaluate Data Quality?

- Identify percentage of responses that have "do not know" or are blank

- Compare registered data with the real values

- Determine fulfillment of standards

Data Quality: Validation Study #1

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

- 389 Subjects from a Massachusetts clinic aged 45-64 years (N=179) and aged ≥65 years (N=210)

- Telephone interview followed by clinic interview

- Rheumatologist diagnosed arthritis was gold standard

- 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

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.

Data Quality: Validation Study #2

- 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

- Specificity and sensitivity similar. Combining case definitions led to low specificity (58.1%)

- Reliability very high for doctor-diagnosed (κ=0.88) compared to chronic joint symptoms (κ=0.44)

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.

How Can You Evaluate Acceptability

- Obtain percentage of:
    - Subject participation
    - Complete forms
    - Questions rejected

How Can You Evaluate Sensitivity

- Estimate the proportion of the total number of cases in the population under surveillance being detected by the system

- Measuring sensitivity requires:

  - Collection of or access to data to determine the true frequency of the condition in the population under surveillance

  - Validation of the data collected by the system

How Can You Evaluate Predictive Value Positive?

- Confirm number of cases reported by the system

- Identify number of false positives

- Identify effects of the PVP on use of resources in public health

How Can You Evaluate Representativeness?

- Compare the presence of the characteristic in the **population** with the presence of the characteristic in **sample population**

- Can be examined through special studies in a case sample

Acceptability and Representativeness

- Acceptability is high

- Estimated response rate for NHIS 90%

- Question Refusal Rate low (0.04%)

- Representative of the adult civilian non-institutionalized population in the U.S.

National Health Interview Survey Response Rate. Response Rate Link.

Ref Type: Electronic Citation

How Can You Evaluate Timeliness?

- Examine the speed between steps in a public health surveillance system

    - For chronic diseases: evaluate the elapsed time from diagnosis rather than date of symptom onset

- Assess the availability of information for immediate control efforts or long-term program planning
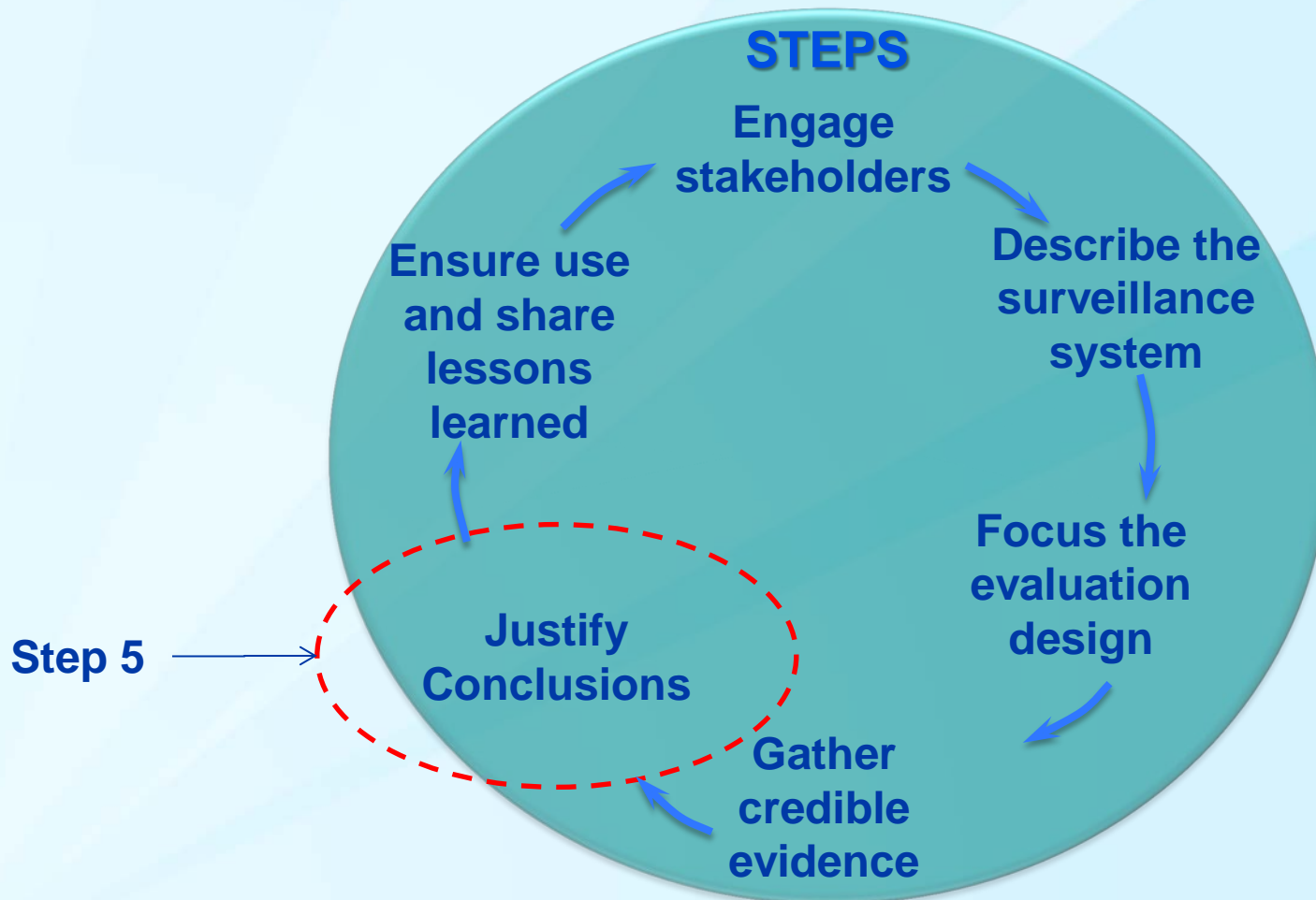
How Can You Evaluate Stability?

- Measure:

  - Frequency of system outages

  - Downtime for servicing during periods of need

  - Frequency of personnel deficiencies from staff turnover

  - Downtime of data providers

  - Budget constraints

Timeliness and Stability

- Data is made available in a timely manner an estimated 6 months after survey completion.

- If requested NHIS data can be made available after 3 months.

- NHIS has been established since 1957.

- Arthritis case definition has not changed since 2001.

Step 5 – Justify Conclusions

STEPS

Engage stakeholders

Describe the surveillance system

Focus the evaluation design

Gather credible evidence

Justify Conclusions

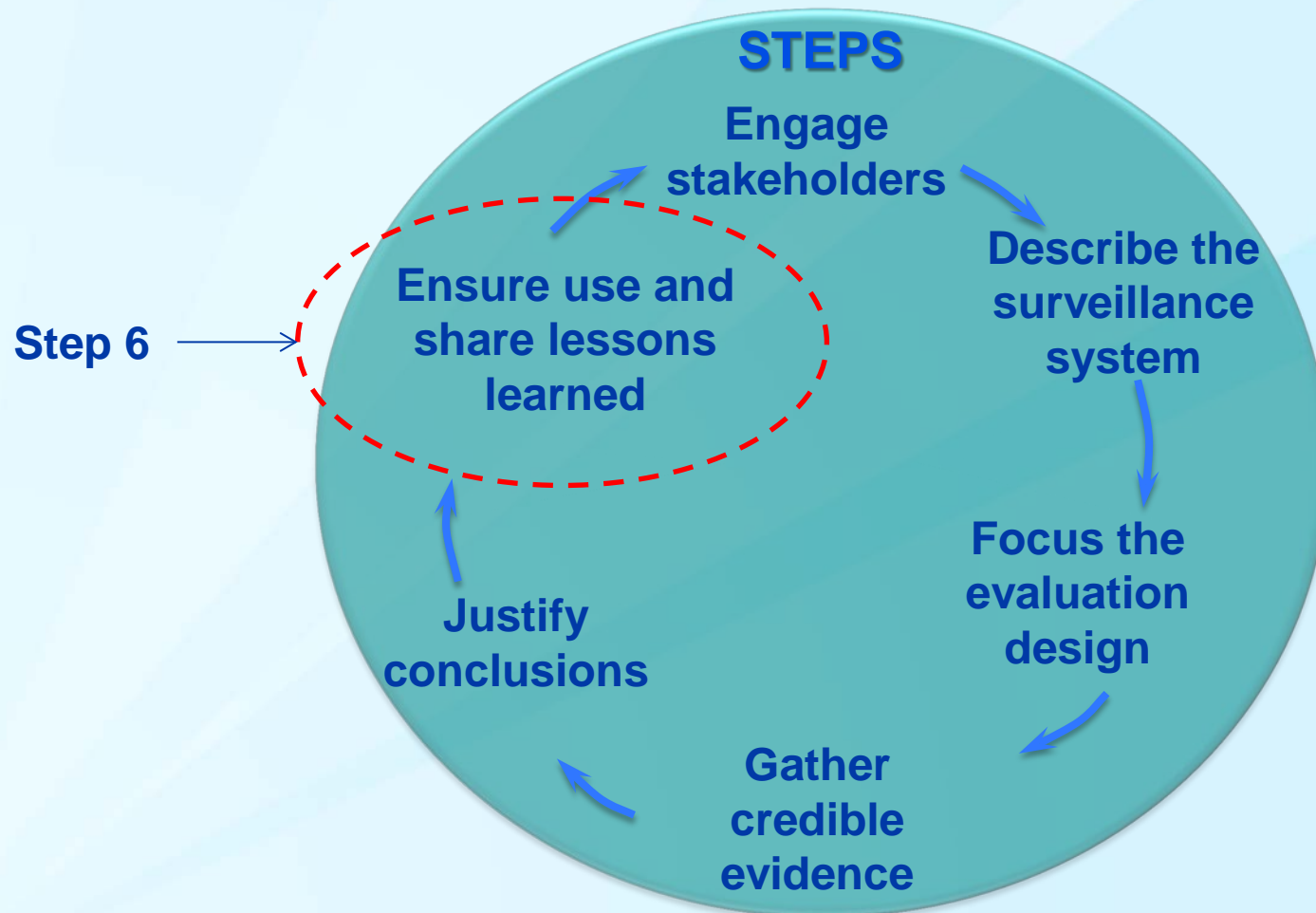Ensure use and share lessons learned

Step 5

Justify Conclusions

- State whether or not the surveillance system is addressing an important health problem.

- Explain if the surveillance system is meeting its objectives.

- Recommendations should address the continuation and/or modification of the surveillance system.

Conclusions and Recommendations

- Current case definition for arthritis should remain in NHIS

- Case definition has been validated in two studies

- Specificity and reliability is high

- Make optional questions mandatory and annual

Step 6 – Ensure Use and Share Lessons Learned

STEPS

- Engage stakeholders
- Describe the surveillance system
- Focus the evaluation design
- Gather credible evidence
- Justify conclusions
- Ensure use and share lessons learned

Step 6 →

Ensure Use and Share Lessons Learned Questions

- How can you ensure use of the evaluation?
- How can you communicate findings and recommendations from the evaluation?

Lessons Learned

- Prior case definition has low specificity and reliability

- CDC arthritis program recommended lowering burden of false positive arthritis diagnoses at the expense of more false negative.

- Arthritis has a high prevalence in the population therefore a specific case definition would capture a high percentage of true positives.

- More accurate annual arthritis prevalence can be estimated

Skill Assessment

1. You will work in small groups to complete the skill assessment.

2. You will read background information about a surveillance system.

3. Using the Field Guidelines for the Evaluation of a Surveillance System, you will answer the questions in your Participant Guide.

4. Spend no more than 30 minutes on the assessment.

5. Be prepared to share your work with the class.

Centers for Disease Control and Prevention (CDC). Overview of Evaluating Surveillance Systems. Atlanta, Georgia: Centers for Disease Control and Prevention (CDC); 2013.

For more information please contact Centers for Disease Control and Prevention
1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
Visit: www.cdc.gov | Contact CDC at: 1-800-CDC-INFO or www.cdc.gov/info

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.