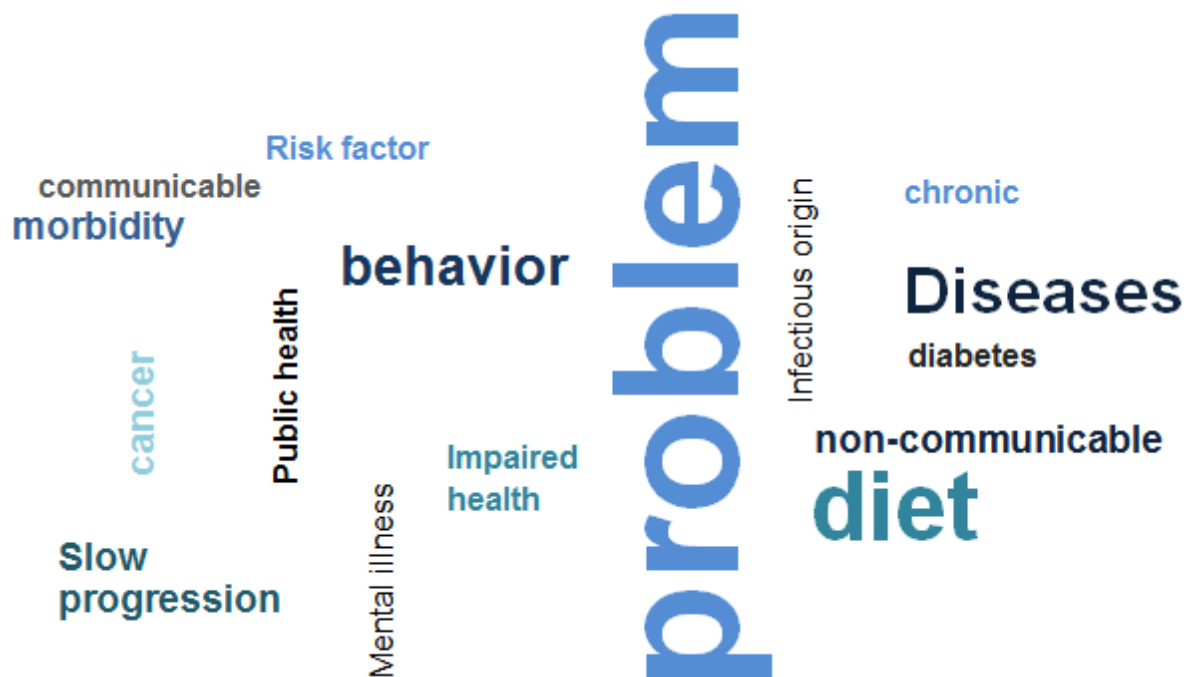


FACILITATOR GUIDE



Data Sources for NCD Surveillance

Created: 2013



Data Sources for NCD Surveillance. Atlanta, GA: Centers for Disease Control and Prevention (CDC), 2013.

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Data Sources for NCD Surveillance

LEARNING OBJECTIVES

At the end of the training, you will be able to:

- Identify the strengths and limitations of surveillance data sources
- Select and explain the source of data to use.

ESTIMATED COMPLETION TIME

- 2 ½ hours (90 minutes interactive presentation; 60 minutes skill assessment)

TRAINING TECHNIQUES

- Content and examples will be presented using lecture and group discussion. Skill assessment will be in small groups.

PREREQUISITES

- Introduction to NCD Epidemiology, NCD Burden of Disease, NCD Surveillance in Public Health

MATERIALS AND EQUIPMENT

Facilitator:

- PowerPoint file for presentation

Participant:

- Participant Guide

REFERENCES AND RESOURCES

- Disease Control Project Ch 53. 53. Public Health Surveillance: A Tool for Targeting and Monitoring Intervention. Available at: <http://www.dcp2.org/pubs/DCP/53/Section/7952>
- The Jordan Times 22 July 2010. *End Stage Renal Disease registry launched*
- Injury Episodes and Circumstances: National Health Interview Survey, 1997–2007. NHIS September 2009. http://www.cdc.gov/nchs/data/series/sr_10/sr10_241.pdf
- BA Virnig and M McBean. Administrative Data for Public Health Surveillance and Planning. Annual Review of Public Health May 2001 Vol. 22: 213-230.
- MMR Resource tool. Verbal Autopsy. 2007. http://www.maternal-mortality-measurement.org/MMResource_Tool_VerbalAutopsy.html
- MMR Resource tool. Demographic Surveillance Systems. 2007.

- F Baodem, A Hodgson, Binka F. Demographic surveillance sites and emerging challenges in international health. Bulletin of the World Health Organization, March 2006; 84(3):161-256.
- Cancer Registration: Principles and Methods. IARC Scientific Publication No. 95 Edited by O.M. Jensen, D.M. Parkin, R. MacLennan, C.S. Muir and R.G. Skeet <http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/sp95-chap14.pdf>

PREPARATION CHECKLIST

The following are action items to be completed by the facilitator prior to training:

- ___ Review slides
- ___ Add country death certificate image to slide 9, if available
- ___ Add country-specific information to slide 12, if available
- ___ Add slides for data sources used in the country

FONT GLOSSARY

The following fonts are used in this guide:

Font Type	Font Meaning
Plain	Script
Bold	Instructions
<i>Italics</i>	<i>Answers</i>

ICON GLOSSARY

The following icons are used in this guide:



Image Type	Image Meaning
	<i>Write responses during facilitator-led discussions or debriefs.</i>
Flip Chart Icon	
	Question for facilitator to ask participants.
Question Icon	

Image Type	Image Meaning
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Tip Icon

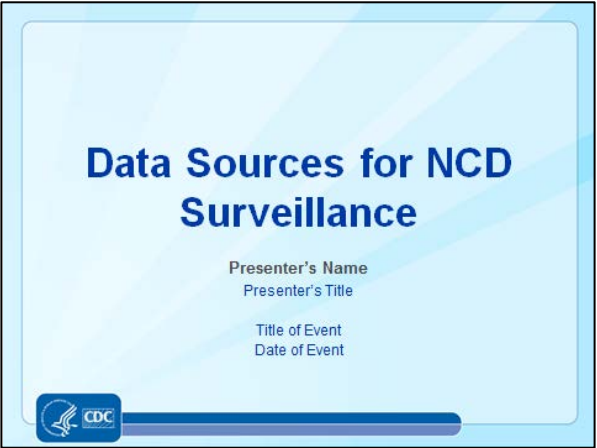
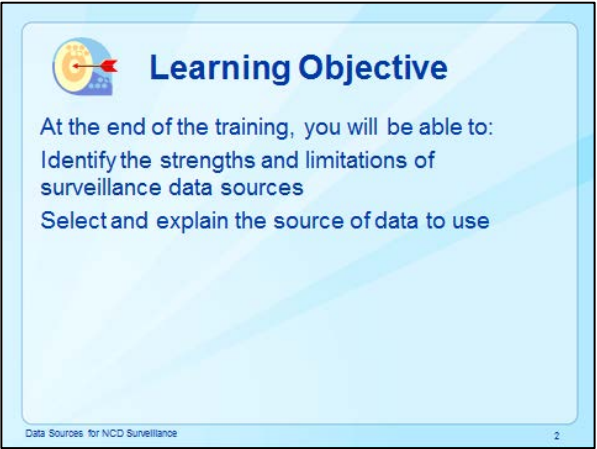
Supplemental information discussion.



. top Icon

Do not start the assignment until your facilitator tells you to begin.

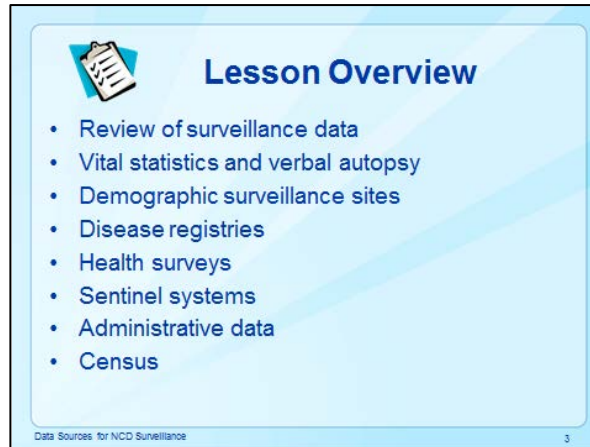
Module Content

Duration/Slide Number	What To Do/What To Say
<p>1 minute</p> <p>Slide 1</p>	 <ul style="list-style-type: none"> • Introduce yourself to participants if you are a new facilitator. • Tell participants that this lesson will take approximately 2 ½ hours to complete. • Explain that this lesson will cover the major types of data sources that are used for NCD (non-communicable disease) surveillance data collection activities. • Explain that after learning the lesson content they will complete a skill assessment with a small group.
<p>1 minute</p> <p>Slide 2</p>	 <ul style="list-style-type: none"> • Read the learning objective.

Duration/Slide Number	What To Do/What To Say
-----------------------	------------------------

1 minute

Slide 3



- Explain that this slide provides a brief overview of topics that will be covered during the lesson.
- Read the slide.

1 minute

Slide 4



- Explain that we will take just a moment to refresh everyone's memory about surveillance data.

Duration/Slide Number	What To Do/What To Say
-----------------------	------------------------

5 minutes

Slide 5

NCD Surveillance Data

- End stage renal disease
- Cancer *in situ*
- Stroke
- Anemia
- Hearing loss
- Hypertension
- Disease and Conditions
- Physical activity
- Obesity
- Nutritional intake
- Air quality
- Age-appropriate cancer screening
- Risk Factors

Data Sources for NCD Surveillance

5



Question

- **Ask:** From what you can remember, what are the main categories of NCD surveillance data?
- **Click to show the main categories (disease and conditions, and risk factors). Participants may have additional suggestions (such as “demographic data” or “clinical data”).**





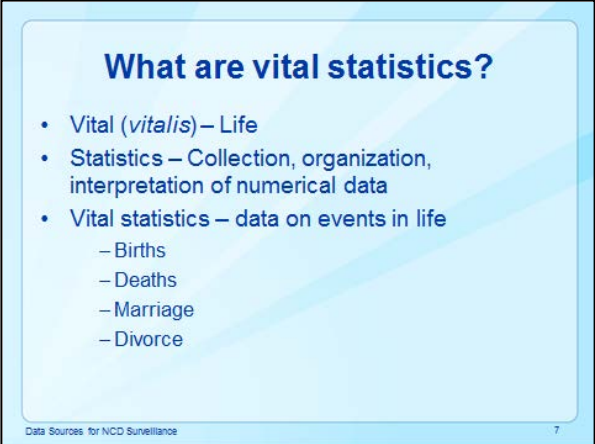
Question


- **Ask:** What are risk factors?
- **Explain that risk factors are factors that influence health and can include behaviors.**



Question

- **Ask:** What are some examples of diseases and conditions that we conduct surveillance for? What are some examples of risk factors that we conduct surveillance for?
- **Click to show suggested answers. Many additional answers are possible; acknowledge correct answers.**
- **Explain that the rest of the lesson will cover some major sources of these types of data.**

Duration/Slide Number	What To Do/What To Say
<p>1 minute</p> <p>Slide 6</p>	 <p>Slide 6 displays the title "VITAL STATISTICS" in blue text on a light blue background with diagonal stripes. At the bottom left, it says "Data Sources for NCD Surveillance" and at the bottom right, it has the number "6".</p>
<p> Question</p>	<ul style="list-style-type: none"> • Explain that the first source of data that will be presented is vital statistics. • Ask: What does “vital” mean? What are vital statistics?
<p>2 minutes</p> <p>Slide 7</p>	 <p>Slide 7 displays the title "What are vital statistics?" in blue text. Below the title is a bulleted list: <ul style="list-style-type: none"> • Vital (<i>vitalis</i>) – Life • Statistics – Collection, organization, interpretation of numerical data • Vital statistics – data on events in life <ul style="list-style-type: none"> – Births – Deaths – Marriage – Divorce At the bottom left, it says "Data Sources for NCD Surveillance" and at the bottom right, it has the number "7". </p>
	<ul style="list-style-type: none"> • Explain that the term “vital” comes from the Latin term “vitalis” meaning “of life”, and define the concepts of vital statistics. • Say: A complete vital registration system is one in which all births and deaths in the population served are legally registered, and the cause of death is medically certified. Vital registration is part of the civil registration system, which also includes records of marriage and divorce.

Duration/Slide Number	What To Do/What To Say
<p>2 minutes</p> <p>Slide 8</p>	<div data-bbox="553 287 1144 730"> <h3>Uses of Vital Statistics</h3> <ul style="list-style-type: none"> • Identify differences in health status within subgroups in the population <ul style="list-style-type: none"> – Age – Sex – Race – Others • Assess differences by geographic area • Monitor deaths considered preventable • Generate hypotheses regarding possible causes or correlates of disease <p><small>Data Sources for NCD Surveillance 8</small></p> </div> <ul style="list-style-type: none"> • Read the uses of vital statistics listed on the slide.
<p>3 minutes</p> <p>Slide 9</p>	<div data-bbox="553 823 1144 1266"> <h3>Death Certificates</h3> <p>Forms completed at time of death and signed (certified) by a physician.</p>  <ul style="list-style-type: none"> • Identifying information • Demographic information • Place of death • Date and time of death • Factors contributing to death • Cause of death <p><small>Data Sources for NCD Surveillance 9</small></p> </div> <ul style="list-style-type: none"> • Explain that one way we collect these vital statistics is through death certification. Death certificates are forms completed for every individual in a population at the time of death. • Explain that many data items can be included on the standard death certificate for a country, and the exact data that are included will vary by country. The general categories of information are listed on the slide. • Say: Decedent identifying information could be name, social security or other identification number, father's name and mother's name; factors contributing to death may include items such as tobacco use, pregnancy, injury; demographic information may include age at death, sex, residence, education, race, or occupation. Data on the death event is also recorded (place, date, contributing



Tip

**Duration/Slide
Number**

What To Do/What To Say



Question

3 minutes

Slide 10

factors). The official cause of death is also recorded. The cause of death listed is used to track diseases among the population.

- **Note:** Move to the next slide for more explanation about how the cause of death is classified.
- **Ask:** What is mortality data used for? (Answers are on the next slide.)

**Appropriate Use of
Mortality Data**

Disease or conditions that are:

- Fatal
- Easily ascertained at the time of death
- Known to have a short clinical course
- Known to have well-established risk factors

Example:

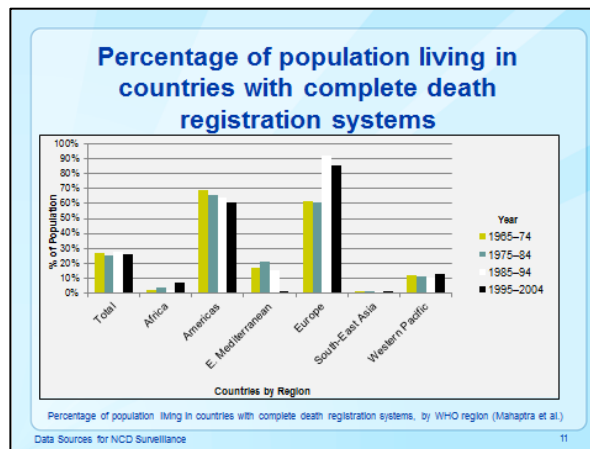
- Cancers meet criteria above
- Obesity does not (leads to other conditions, coexists with other more proximate causes)

Data Sources for NCD Surveillance 10

- **Explain** that the use of mortality data as an estimate of the occurrence of a disease or condition in a population is most appropriate for conditions that are usually fatal, those that can be ascertained easily at the time of death, and those for which risk factors are well established.

2 minutes

Slide 11



- **Say:** The data shown in this slide are taken from a series of Lancet publications on the state of the world's civil

Duration/Slide Number	What To Do/What To Say
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registration systems. Approximately 25% of the world's population live in areas which claim complete (defined as more than 90%) registration of deaths. There has been little improvement worldwide over the past four decades. Europe, North America, and the Western Pacific have well developed civil registration systems, whereas Africa and Asia, and to a lesser extent Latin America, do not.

3 minutes

Slide 12

Completeness of Death Registration

High-Income Countries	Low to Middle-Income Countries
<ul style="list-style-type: none"> • Certification of deaths is virtually complete • Data may not be complete 	<ul style="list-style-type: none"> • Most countries have under-registration of deaths • Cause of death data may be missing or invalid

Data Sources for NCD Surveillance 12



Tip



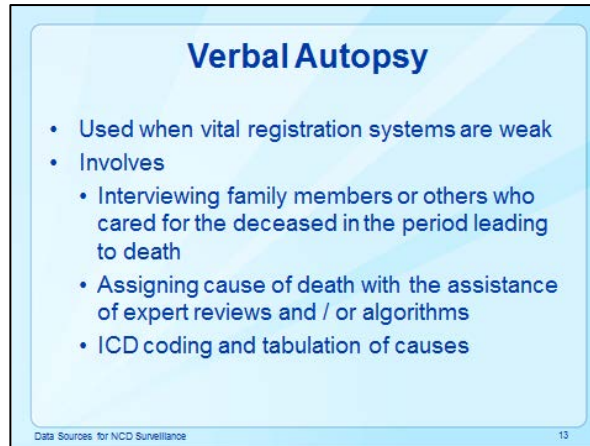
Question

- **Note:** *If available, replace content on this slide with country-specific information on the death registration process.*
- **Ask:** How complete is death and other vital statistics registration in [your country]? Have you used these data before?
- **Explain that registration and medical certification of deaths is virtually complete in most developed countries, although completeness of the data, particularly cause of death and race, continues to be a problem.**
- **Say:** In developing countries, there tends to be marked under-registration of deaths. While some areas have very good vital registration, overall a low percentage of deaths are registered. Among registered deaths, cause-of-death data are available for about one in three deaths, but this often just subdivides deaths as due to accident, violence or disease without additional details. Thus, civil registration is not yet a reliable source for causes of death in many countries - at least for causes which do not change rapidly.

Duration/Slide Number	What To Do/What To Say
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3 minutes

Slide 13



Question

- **Ask:** What is verbal autopsy?
- **Click to reveal information.**
- **Read the slide.**
- **Explain that, because many countries have a weak vital registration system, if they have one at all, verbal autopsy is an accepted source of information about the causes of death in a population. Although there are significant limitations on the validity of the data, verbal autopsy may be the only way of estimating causes of death in some populations.**

1 minute

Slide 14



- **Tell the participants that next we will discuss demographic surveillance sites as a source of health information.**

Duration/Slide Number	What To Do/What To Say
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2 minutes

Slide 15

What are DSSs?

- Used to identify risks and changes in rates of birth, death and migration over time in a specific population
- Often formed around a particular intervention study
- Become a platform for further studies

Data Sources for NCD Surveillance 15

- **Explain that demographic surveillance is the process of identifying risk factors and the corresponding changes in rates of birth, deaths, and migration in a population over time. Surveillance systems are often created around specific intervention studies and later convert into standing DSS sites that can form a platform for further studies. There are over 30 DSS sites in Africa, Asia, and the Americas. At most sites, core demographic data are supplemented with social and economic factors involved in population and changes in health.**

3 minutes

Slide 16

Uses of DSS

<p>Advantages</p> <ul style="list-style-type: none"> • Often more complete enumeration of vital events than available from vital registration • Provide comparable data over time for analysis of trends • Researchers associated with the DSS are on-site for data analysis 	<p>Disadvantages</p> <ul style="list-style-type: none"> • Data may not be generalizable to regional or national populations • Expensive to establish • Difficult to keep staff long-term, especially in rural areas
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Data Sources for NCD Surveillance 16

- **Read the slide.**

Duration/Slide Number	What To Do/What To Say
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1 minute

Slide 17



- Tell the participants that next we will cover disease-specific registries.

3 minutes

Slide 18



Question

- **Ask:** What are disease registries?
- **CLICK** to show the answer.
- Explain that registries systematically collect data about patients or individuals with a specific disease, condition, or exposure. Data can be collected from healthcare providers, but in some cases it may be more useful to utilize specialty referral centers or pathology laboratories. Disease registries are most commonly seen for cancers, which are relatively rare in the population, but also are very likely to be noticed by a healthcare professional.
- Tell the participants that data are often reported directly to a central registry office, rather than being

**Duration/Slide
Number**
What To Do/What To Say

reported to a local or district level first, although structure will differ for each system.

3 minutes

Slide 19

Using Disease Registries

Advantages <ul style="list-style-type: none"> • Captures morbidity data • Can be linked to the other data sources • Can detect clusters of disease • Can be representative of the population 	Disadvantages <ul style="list-style-type: none"> • Cannot accurately represent occurrence of very common conditions • Hospital-based registries tend to lack diagnostic data • Pathology / laboratory based registries tend to lack demographic data
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Data Sources for NCD Surveillance 19

- **Read the advantages and the practical disadvantages of disease registries.**
- **Explain that linking to vital registration data (where available) can be used to monitor mortality rates among registered cases. This can be valuable for understanding how survival is changing over time.**

3 minutes

Slide 20

Challenges to Disease Registries

- Country may lack diagnostic and treatment facilities
 - Records may be based solely on clinical data
- Diagnostic and treatment facilities may be located in large urban areas
 - In rural countries, registered cases may not represent all cases that occur.
- Census data unavailable or inaccurate due to population mobility or time lapsed since census
- Lack of resources for personnel training and follow-up of cases

Data Sources for NCD Surveillance 20

- **Explain that registries are a useful, focused tool but can pose challenges in the implementation.**
- **Read the slide.**

Duration/Slide Number	What To Do/What To Say
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- Tell the participants that for epidemiologic purposes, registries may be useful for estimating burden of disease. However, having a registry that is actually representative of all cases, and also having accurate denominator data (census) to calculate burden of disease measures, can be challenging. Challenges aside, it may be valuable to have a disease registry if resources, interest, and motivation for intervention exists; some data on NCDs is better than none at all.

1 minute

Slide 21



- Tell the participants that the next source of health data that will be discussed is health surveys.
- **Ask:** What are health surveys?
- **Ask:** Can you give us an example of what you are currently doing with health surveys?



Question

Duration/Slide Number	What To Do/What To Say
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3 minutes

Slide 22

What are health surveys?

Format

- Active surveillance
- Standardized questionnaire that can be administered at regular intervals (e.g. yearly)
- Sample of the population

Purpose

- Understand health problems and known and potential risk factors
- Compare the distribution of health problems between localities, districts, or countries over time (if survey is repeated)
- Plan public health programs

Data Sources for NCD Surveillance 22

- **Explain that unlike vital registries or disease registries, which are largely passive systems, health surveys are active surveillance – health officials contact members of the population to administer a standardized questionnaire or survey. This may take place at regular intervals, such as annually. The data collected from the survey represent a cross-section of the population under surveillance.**
- **Explain that health surveys may be administered within a district, within an entire nation, or globally. Health surveys are used by international, national, and sub-national health officials to accomplish the purposes explained on the slide.**

4 minutes

Slide 23

Advantages and Disadvantages of Health Surveys

<p>Advantages</p> <ul style="list-style-type: none"> • In-depth information, including data on risk factors • Identify areas of need and where to target public health programs and interventions • Assess the effectiveness of public health programs and interventions 	<p>Disadvantages</p> <ul style="list-style-type: none"> • Costly • Self-reported data on demographics, risk factors, lifestyle, diagnoses
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Data Sources for NCD Surveillance 23

**Question**

- **Ask:** What are the advantages and disadvantages of health surveys?

Duration/Slide Number	What To Do/What To Say
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- **Click to show the lists.**
- **Say:** Health surveys are a way to collect information on risk factors or conditions that do not routinely come to the attention of medical providers. However, gathering this information is more costly than passive and secondary data collection methods.

3 minutes

Slide 24

Example (1): WHO STEPS

- Procedure for conducting chronic disease risk factor surveillance within a country, including guidelines and supporting materials
- Covers step by step procedures
 - Planning and setting up STEPS
 - Training
 - Data collection
 - Data entry
 - Data analysis and reporting

Data Sources for NCD Surveillance 24



Question

- **Tell the participants that the WHO STEPS, or the STEPwise approach to surveillance, was also covered in the NCD Surveillance in Public Health lesson.**
- **Ask:** Can anyone remind us of what the STEPS is?
- **Answer:** *STEPS is a procedure for using surveys as well as physical and clinical measurements to conduct chronic disease risk factor surveillance. It has a graduated approach to data collection.*
- **Read the slide.**

2 minutes

Slide 25


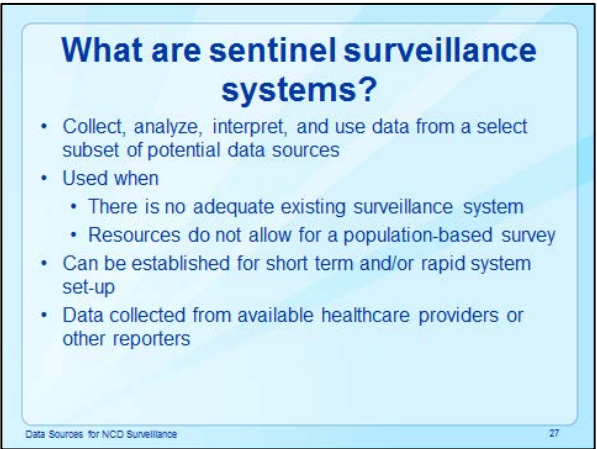
Example (2): Global Adult Tobacco Surveys (GATS)

- Developed to provide a global standard protocol for consistent monitoring of adult tobacco use
- Nationally representative household survey of all non-institutionalized men and women aged 15 years and older
- Sample question on tobacco prevalence:

Q2b. Past Smoking Status
 In the past, have you smoked tobacco on a daily basis, less than daily, or not at all?
 INTERVIEWER: IF RESPONDENT HAS DONE BOTH "DAILY" AND "LESS THAN DAILY" IN THE PAST, CHECK "DAILY"

DAILY	1
LESS THAN DAILY	2
NOT AT ALL	3
DON'T KNOW	7

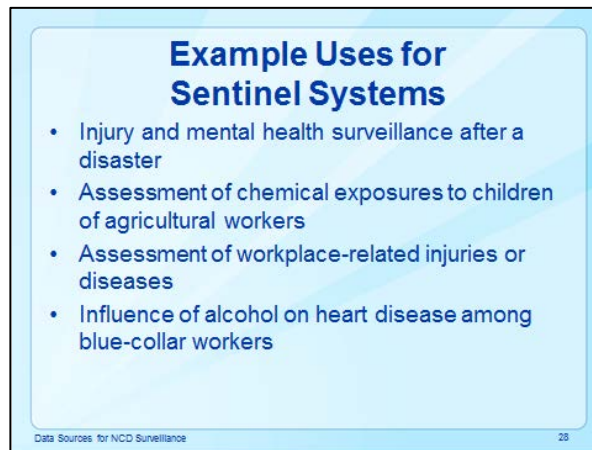
Global Adult Tobacco Survey Collaborative Group. Tobacco Questions for Surveys: A Subset of Key Questions from the Global Adult Tobacco Survey (GATS), 2nd Edition. Atlanta, GA: Centers for Disease Control and Prevention, 2011. Data Sources for NCD Surveillance 25

Duration/Slide Number	What To Do/What To Say
<p>2 minutes</p> <p>Slide 26</p>	<ul style="list-style-type: none"> • Read the slide. • Say: GATS partners created the <i>Tobacco Questions for Surveys</i> booklet that includes a subset of key survey questions from the GATS for other surveys to include. Surveys can select indicators and corresponding questions from this list to include based on their particular focus or priority, or incorporate the complete set if appropriate. 
<p>Question</p> <p>3 minutes</p> <p>Slide 27</p>	<ul style="list-style-type: none"> • Tell the participants that the next topic is sentinel systems. Sentinel systems are not as widely used for surveillance networks for NCDs as they are for infectious diseases; however, they still have a role in collecting data in the appropriate circumstances. • Ask: What are sentinel systems? When are they used?  <ul style="list-style-type: none"> • Read the slide. • Explain that, depending on the situation, participating

Duration/Slide Number	What To Do/What To Say
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4 minutes

Slide 28



Example Uses for Sentinel Systems



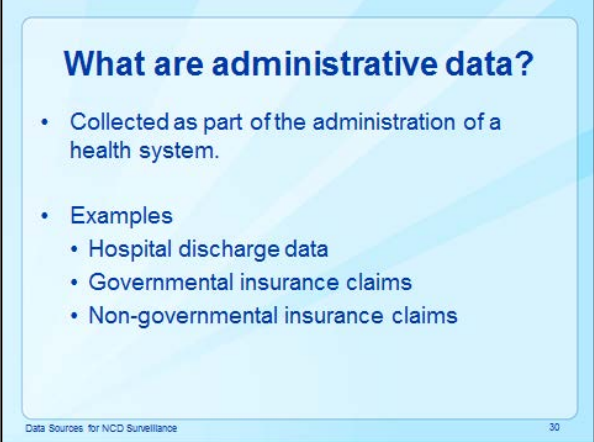
- Injury and mental health surveillance after a disaster
- Assessment of chemical exposures to children of agricultural workers
- Assessment of workplace-related injuries or diseases
- Influence of alcohol on heart disease among blue-collar workers

Data Sources for NCD Surveillance 28



Question

- **Say:** Sentinel systems are often used for infectious diseases. For example, the standard for influenza surveillance is to conduct sentinel surveillance for pneumonia and influenza-like-illness at a representative subset of hospitals, clinics, and laboratories.
- **Ask:** Can you think of examples of sentinel systems for NCDs that are, or could be, used in your country?
- **Click to show suggested answers.**
- **Explain that this slide lists some potential uses of surveillance systems in context.**
- **Read the slide.**
- **Explain that resources may not always allow a sentinel system to be established to meet data needs, but if the resources and personnel capabilities allow, sentinel systems can be useful in providing descriptive data on a health problem that allows decision makers to implement prevention measures or policy changes.**

Duration/Slide Number	What To Do/What To Say
<p>1 minute</p> <p>Slide 29</p> <p> Question</p>	<div data-bbox="548 285 1143 730">  </div> <ul style="list-style-type: none"> • Explain that administrative data is collected in every country. If it can be accessed, it can be an inexpensive method of secondary data collection. • Ask: What are administrative data?
<p>3 minutes</p> <p>Slide 30</p>	<div data-bbox="548 1003 1143 1446">  </div> <ul style="list-style-type: none"> • Explain that administrative data are not collected for surveillance purposes, but instead are collected as part of the administration – primarily billing – of a health system. • Read the administrative data sources that are given on the slide.

**Duration/Slide
Number**

What To Do/What To Say

4 minutes

Slide 31

Using Administrative Data

<p>Advantages</p> <ul style="list-style-type: none"> • High population coverage, • Typical data included are useful to surveillance, • Inexpensive to obtain, and • Possible linkage to other sources. 	<p>Disadvantages</p> <ul style="list-style-type: none"> • Information on diagnosed conditions as recorded, and • Records reflect only services billed by the organization.
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Data Sources for NCD Surveillance 31

- **Explain that identifying information in the data record can be used to link administrative medical data on an individual to data found in other sources, such as cancer registries, vital statistics, or data from population-based health surveys.**
- **Explain that there are several disadvantages to administrative data as well.**
 - **Incorrect diagnoses are possible, especially for conditions that are typically under-diagnosed.**
 - **Administrative records reflect services billed by the organization (e.g., the hospital or insurance company). Any services received outside that organization, for example, if medication or therapeutic services were purchased elsewhere, will not be reflected.**
 - **Additionally, the records contain no clinical information, unless it is required to process payment. Thus, items of interest such as blood pressure or cholesterol level, for example, may have been obtained from the patient, but lab results may not appear in the administrative data; only diagnosis and procedure codes will show up.**

Duration/Slide Number	What To Do/What To Say
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2 minutes

Slide 32



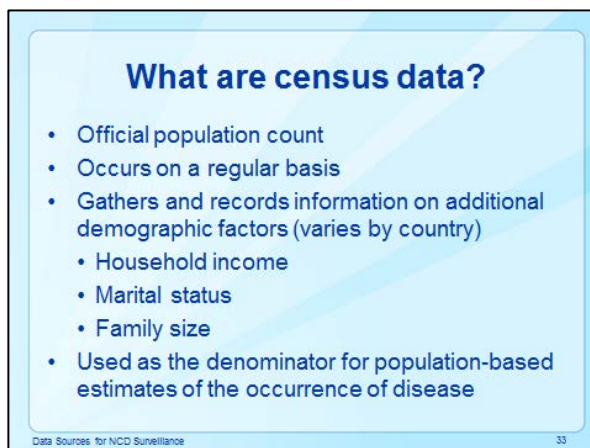
- **Remind the participants of the sources of data covered thus far: vital statistics, demographic surveillance sites, disease registries, health surveys, sentinel systems, and administrative data.**
- **Tell the participants that the last topic to be covered is census data.**
- **Ask:** What are census data?



Question

3 minutes

Slide 33



- **Say:** Censuses are counts of an entire population, and are implemented by governments on a regular basis – often every 10 years. They are used for planning and population growth monitoring in urban and rural areas, and are also used to track how basic demographics of a country's population are changing.
- **Explain that information gathered in a census includes**

Duration/Slide Number	What To Do/What To Say
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data relevant to households and individuals within the household, such as household income, marital status, family size, ages of family members, and race/ethnicity.

- Tell the participants that while the census is used for surveillance, if census information is available it can be used to create population estimates of the incidence and prevalence of diseases and risk factors collected from other sources. Information from health surveillance activities is used in the numerator (the “cases”), and census information is used in the denominator (population at risk).

2 minutes

Slide 34


Using Census Data

Advantages <ul style="list-style-type: none"> • Information gathering is attempted for every member of the population • Possibility of asking a health related question (short / long forms) 	Disadvantages <ul style="list-style-type: none"> • May not reach remote communities • Technology and capacity to compile data may be limited • Census counts are unreliable several years after the census
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List of census data sites by country (http://www.census.gov/aboutus/stat_int.html)


Data Sources for NCD Surveillance 34

- **CLICK** to show each advantage and disadvantage (one at a time).
- Read the bullets as they appear.
- Explain that in some countries a health-related question can be added to census questionnaires or surveys. For example, in countries without a good household survey program, the census may be the only possible source for estimating disability prevalence and for gaining an approximate estimate of types of disability in the country. Countries may have a short form that is used for the majority of the population, and a long form with a few additional questions that is administered to a sampled subset of the population.
- Also explain the disadvantages of census data. As with other data gathering efforts, some communities may be hard to reach, and the technology and capacity to

Duration/Slide Number	What To Do/What To Say
	<p>compile and summarize the data may be lacking. This is a particularly large effort for the census, since the quantity of data gathered is quite large.</p> <ul style="list-style-type: none"> • Tell participants that this slide shows a URL that links to census bureaus and websites of countries across the globe.
<p>10 minutes</p> <p>Slide 35- 41</p>	 <ul style="list-style-type: none"> • Tell participants that they will now participate in the Review Game. • Note: Adjust number of questions depending on number of tables and teams. If participants are already at small tables, you may keep them together as a team. Otherwise, divide the class into teams of four or five participants. • After participants are in their teams, ask each team to (quickly) give you a team name. Record team names on a flip chart. • Tell participants to discuss answers in their teams before providing them out loud. Correct answers will receive two points. You may give one point for partially correct answers. • Begin by clicking on the following slides, one question at a time. • To reveal the answers, click on the slide after the question appears (and participants answer the question).

Duration/Slide Number	What To Do/What To Say
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- Record points on flip chart.
- (Optional) Provide a prize to winning team.



Review: Answers 1-3

1. Which surveillance data source focuses on defined diseases or conditions? *Registries*
2. Which data source can also serve as a platform for further studies? *Demographic surveillance sites*
3. Name a source of surveillance data that is active. *Health surveys are active; sentinel systems and registries may be active depending on their design.*


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Review: Answers 4-6

4. Name two sources of surveillance data that use existing data (not collected for surveillance purposes). *Administrative data; census data; autopsy data.*
5. Name advantages and disadvantages of using vital statistics data for surveillance. (Many are possible!) *Adv: Demographic and death outcome data are available for a complete population. Dis: No morbidity data or further detail.*
6. Name advantages and disadvantages of using administrative data. *Adv: Inexpensive to obtain, can be linked to other sources. Dis: Only data on services billed are available.*

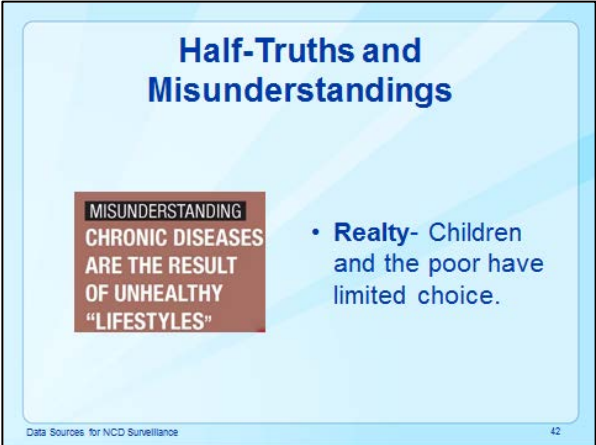
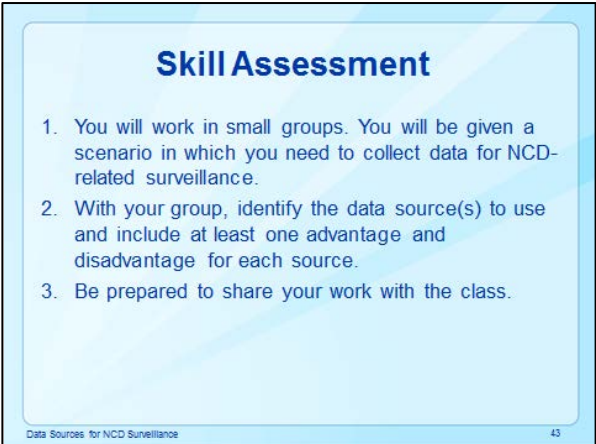
Data Sources for NCD Surveillance 39



Review: Answers 7-8

7. What kind of information can be obtained from census data? *Demographics and mortality (cause of death)*
8. Give a definition of a sentinel surveillance system. *A system that collects data from a representative sub-set of the potential data sources.*

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Duration/Slide Number	What To Do/What To Say
<p>2 minutes</p> <p>Slide 42</p>	 <ul style="list-style-type: none"> • Read the misunderstanding that appears on the slide: Misunderstanding: Chronic diseases are a result of unhealthy “lifestyles”. • Click the <u>next arrow</u> to make the animation appear. • Explain the “Reality”: Individual responsibility can have full effect only where individuals have equitable access to a healthy life, and are supported to make healthy choices. Vulnerable populations such as children and the poor may have limited choice about their lifestyle. Childhood overweight and obesity is a rising global problem. About 22 million children under five years old are overweight. Reports of type 2 diabetes in children and adolescents – previously unheard of – have begun to mount worldwide.
<p>60 minutes (45 minutes assessment; 15 minutes review)</p> <p>Slides 43</p>	 <ul style="list-style-type: none"> • Direct participants to the appropriate Slide in the

Duration/Slide Number	What To Do/What To Say
	<p>participant guide.</p> <ul style="list-style-type: none"> • Ensure participants understand that they should read the background in the Participant Guide (p14), and answer the subsequent questions working in small groups. • Facilitate division of participants into the small work groups. • Visit each group as they are working. • After 45 minutes, call the larger group together. Assign each group to share a set of advantages and disadvantages. Ask the class to provide additional advantages and disadvantages, as needed. Encourage discussion as appropriate.

Skill Assessment (From the Participant Guide)

Activity

1. You will work in small groups. You will be given a scenario in which you need to collect data for NCD-related surveillance.
2. With your group, identify the data source(s) to use and include at least one advantage and one disadvantage for each source.
3. Be prepared to share your work with the class.



Stop

Do not start the assignment until your facilitator tells you to begin.

Scenario

You are a national health surveillance officer. The Minister of Health is working to find room in the budget for NCD interventions. He/she has managed to set aside a small annual budget for the next two fiscal years (Year A and Year B), and during Year C an international NGO will match any funds that the country can put toward this intervention. The NGO has a particular interest in funding projects aimed at prevention of heart disease, and may be willing to expand funds and the scope of the intervention if the Year C effort is successful.

The task comes to you to assemble surveillance data to inform which sub-populations in the country should be targeted for intervention.

Answer the following questions:

These answers are intended to be used as a guideline. Specific answers may vary.

1. Using the table below, list at least one advantage and one disadvantage of using each data source for surveillance in this situation.

Data source	Advantages	Disadvantages
Vital statistics	<p><i>Economical – already collected for other purposes</i></p> <p><i>Already collected – could assemble data from previous years, as well as A and B</i></p> <p><i>Severe heart disease events could be fatal and would be captured by the system</i></p> <p><i>Captures demographic data</i></p>	<p><i>Country-specific: may not be available</i></p> <p><i>Captures deaths only (no morbidity)</i></p> <p><i>Does not capture risk factor data</i></p>
Disease registries	<p><i>Captures detailed information on the clinical condition and measures as well as demographic data</i></p> <p><i>Can be established such that it is representative of the population</i></p>	<p><i>There are a variety of conditions that could be classified as “heart disease”, and it could be cumbersome to register all such cases</i></p> <p><i>Surveillance infrastructure would have to be established</i></p>
Health surveys	<p><i>Can capture detailed information on lifestyle and risk factors</i></p> <p><i>Standardized resources for implementation exist from WHO and the US CDC</i></p> <p><i>Data could be collected on other conditions as well</i></p>	<p><i>Resources for organizing, implementing, compiling, and analyzing the data can be costly</i></p> <p><i>Data on diagnoses would be self-reported from the individual and clinical measurements would not be available (unless a more costly physical and/or biochemical component is added)</i></p>
Sentinel systems	<p><i>Useful when there is no existing system</i></p> <p><i>Collects high quality data</i></p> <p><i>Can be established rapidly</i></p>	<p><i>More costly than secondary data collection options</i></p> <p><i>Network of participating healthcare providers must be established</i></p>
Administrative data	<p><i>Using existing data is cost-effective</i></p> <p><i>Data are likely to be in electronic format</i></p>	<p><i>Clinically relevant measurements are not available</i></p> <p><i>Risk factor data are not available</i></p>

- Based on your assessment above, what source of data would you recommend using for this surveillance project? Justify your answer in terms of appropriateness of data, cost, and feasibility in your country.

Suggested answer and teaching notes:

Be sure that participants consider each potential data source within the context of collecting information on heart disease. Because it is not clear in the scenario how far the funding will go, accept most answers related to cost as long as they are rationally justified. Justification for feasibility will vary depending on country and health district. Suggested rationale may include:

- *Sentinel Surveillance: For a relatively short-term project with no pre-existing data collection mechanism, sentinel surveillance that includes a network involving tertiary care centers as well as clinics that may diagnose more minor/less acute conditions could be established. With provider “buy-in”, the system could be coupled with an existing notifiable disease surveillance system, if one exists. Up-front costs would include development of the data collection tool, materials and supplies costs to ensure that forms, fax machines, etc., are available to the network. Encourage participants to think about how to involve the surveillance network and encourage continued participation, (e.g., printing a quarterly brochure/report of the findings thus far). However, some may see this option as too costly.*
- *Administrative data: This would provide an easily accessible and affordable method of collecting data on the most severe (hospitalized) diagnosis. Justification for this method also includes the fact that morbidity data (not just mortality) is collected, and that may be enough information to assess sub-populations (e.g., gender, age groups, geographic areas) that are at high risk of severe outcomes.*
- *Vital statistics: If available in-country, vital statistics provide a precise and population-wide estimate of heart-disease related causes of death. Participants could argue that high risk populations identified are at highest risk, since the condition caused their death. Others may argue that it is more important to know people who are at risk of less severe events, so that effective interventions can be implemented.*
- *Health Surveys: This would be a great way to collect the needed data, especially if a biochemical and physical component such as is outlined in WHO STEPS were included. However, the cost is likely to be prohibitive.*
- *Disease Registry: A disease registry is not likely to be a practical solution for collecting heart disease health information.*