

PARTICIPANT GUIDE



Data Sources for NCD Surveillance

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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)

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/MMMResource_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>

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Learning Objective

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

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Lesson Overview

- Review of surveillance data
- Vital statistics and verbal autopsy
- Demographic surveillance sites
- Disease registries
- Health surveys
- Sentinel systems
- Administrative data
- Census

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SURVEILLANCE DATA AND INDICATORS

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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

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VITAL STATISTICS

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What are vital statistics?

- Vital (*vitalis*) – Life
- Statistics – Collection, organization, interpretation of numerical data
- Vital statistics – data on events in life
 - Births
 - Deaths
 - Marriage
 - Divorce

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Uses of Vital Statistics

- Identify differences in health status within subgroups in the population
 - Age
 - Sex
 - Race
 - Others
- Assess differences by geographic area
- Monitor deaths considered preventable
- Generate hypotheses regarding possible causes or correlates of disease

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Death Certificates

Forms completed at time of death and signed (certified) by a physician.



- Identifying information
- Demographic information
- Place of death
- Date and time of death
- Factors contributing to death
- Cause of death

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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:

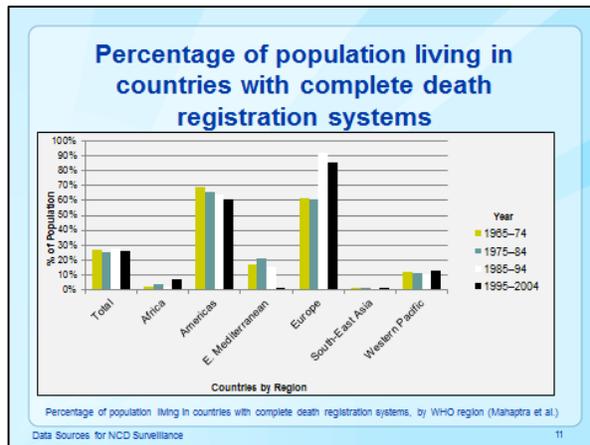
- Cancers meet criteria above
- Obesity does not (leads to other conditions, coexists with other more proximate causes)

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Completeness of Death Registration

High-Income Countries

- Certification of deaths is virtually complete
- Data may not be complete

Low to Middle-Income Countries

- Most countries have under-registration of deaths
- Cause of death data may be missing or invalid

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Verbal Autopsy

- Used when vital registration systems are weak
- Involves
 - Interviewing family members or others who cared for the deceased in the period leading to death
 - Assigning cause of death with the assistance of expert reviews and / or algorithms
 - ICD coding and tabulation of causes

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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

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Uses of DSS

<h4>Advantages</h4> <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 	<h4>Disadvantages</h4> <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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DISEASE REGISTRIES

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What are disease registries?

- Cases of defined diseases and conditions are systematically reported to a central system
- Can be based in hospitals or specialty referral centers
- Can be pathology/laboratory based
- Best for rare events, such as cancers
- Census data can be used to calculate disease rates among at-risk populations

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Using Disease Registries

Advantages	Disadvantages
<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 	<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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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

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HEALTH SURVEYS

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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

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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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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

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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.

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Notes



A slide with a light blue background. The title "What are sentinel surveillance systems?" is centered at the top in bold blue text. Below the title is a bulleted list of characteristics. At the bottom left, it says "Data Sources for NCD Surveillance" and at the bottom right, the number "27".

What are sentinel surveillance systems?

- Collect, analyze, interpret, and use data from a select subset of potential data sources
- Used when
 - There is no adequate existing surveillance system
 - Resources do not allow for a population-based survey
- Can be established for short term and/or rapid system set-up
- Data collected from available healthcare providers or other reporters

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A slide with a light blue background. The title "Example Uses for Sentinel Systems" is centered at the top in bold blue text. Below the title is a bulleted list of four example uses. At the bottom left, it says "Data Sources for NCD Surveillance" and at the bottom right, the number "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

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ADMINISTRATIVE DATA

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What are administrative data?

- Collected as part of the administration of a health system.
- Examples
 - Hospital discharge data
 - Governmental insurance claims
 - Non-governmental insurance claims

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Using Administrative Data

<h4>Advantages</h4> <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. 	<h4>Disadvantages</h4> <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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What are census data?

- Official population count
- Occurs on a regular basis
- Gathers and records information on additional demographic factors (varies by country)
 - Household income
 - Marital status
 - Family size
- Used as the denominator for population-based estimates of the occurrence of disease

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Using Census Data

Advantages	Disadvantages
<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) 	<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

List of census data sites by country (http://www.census.gov/a/b/otus/stat_int.html)

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Half-Truths and Misunderstandings

MISUNDERSTANDING
CHRONIC DISEASES ARE THE RESULT OF UNHEALTHY "LIFESTYLES"

- **Reality-** Children and the poor have limited choice.

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Skill Assessment

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 disadvantage for each source.
3. Be prepared to share your work with the class.

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