

Data Sources for NCD Surveillance

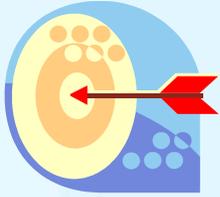
Presenter's Name

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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



Lesson Overview

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



SURVEILLANCE DATA AND INDICATORS

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

VITAL STATISTICS

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

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

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

Appropriate Use of Mortality Data

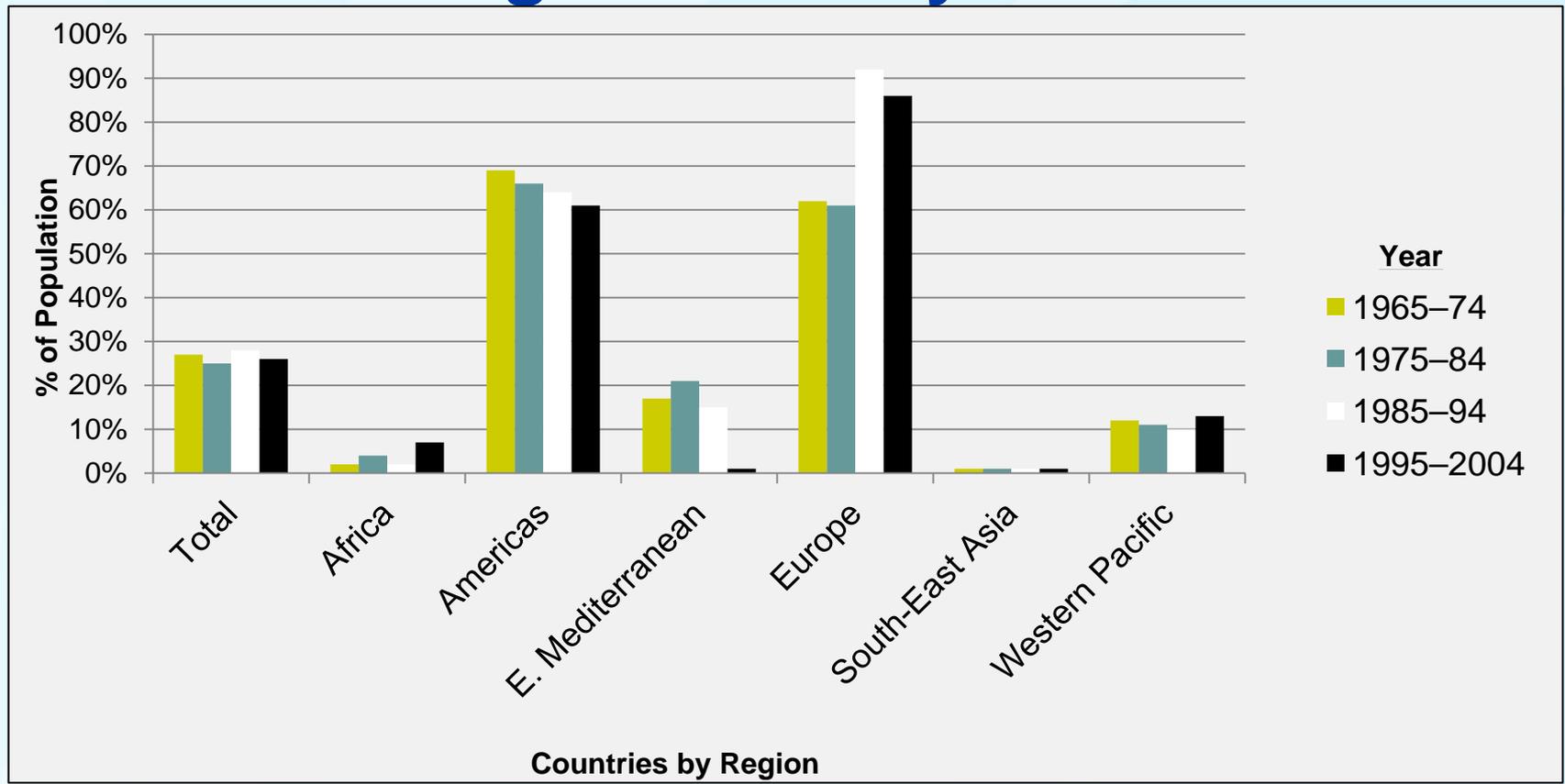
Disease or conditions that are:

- 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)

Percentage of population living in countries with complete death registration systems



Percentage of population living in countries with complete death registration systems, by WHO region (Mahaptra et al.)

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

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



DEMOGRAPHIC SURVEILLANCE SITES (DSS)

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

Uses of DSS

Advantages

- 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

Disadvantages

- Data may not be generalizable to regional or national populations
- Expensive to establish
- Difficult to keep staff long-term, especially in rural areas



DISEASE REGISTRIES

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

Using Disease Registries

Advantages

- Captures morbidity data
- Can be linked to the other data sources
- Can detect clusters of disease
- Can be representative of the population

Disadvantages

- 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

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



HEALTH SURVEYS

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

Health Surveys

Advantages

- 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

Disadvantages

- Costly
- Self-reported data on demographics, risk factors, lifestyle, diagnoses

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

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.



SENTINEL SURVEILLANCE SYSTEMS

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

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



ADMINISTRATIVE DATA

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

Using Administrative Data

Advantages

- High population coverage,
- Typical data included are useful to surveillance,
- Inexpensive to obtain, and
- Possible linkage to other sources.

Disadvantages

- Information on diagnosed conditions as recorded, and
- Records reflect only services billed by the organization.





CENSUS

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

Using Census Data

Advantages

- Information gathering is attempted for every member of the population
- Possibility of asking a health related question (short / long forms)

Disadvantages

- 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/aboutus/stat_int.html)



REVIEW

Review: Questions 1-3

1. Which surveillance data source focuses on defined diseases or conditions?
2. Which data source can also serve as a platform for further studies?
3. Name a source of surveillance data that is active.

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.*

Review: Questions 4-6

4. Name two sources of surveillance data that are use existing data (not collected for surveillance purposes).
5. Name advantages and disadvantages of using vital statistics data for surveillance. (Many are possible!)
6. Name advantages and disadvantages of using administrative data.

Review: Answers 4-6

4. Name two sources of surveillance data that are 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.*

Review: Questions 7-8

7. What kind of information can be obtained from census data?
8. Give a definition of a sentinel surveillance system.

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.*

Half-Truths and Misunderstandings

**MISUNDERSTANDING
CHRONIC DISEASES
ARE THE RESULT
OF UNHEALTHY
“LIFESTYLES”**

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

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.