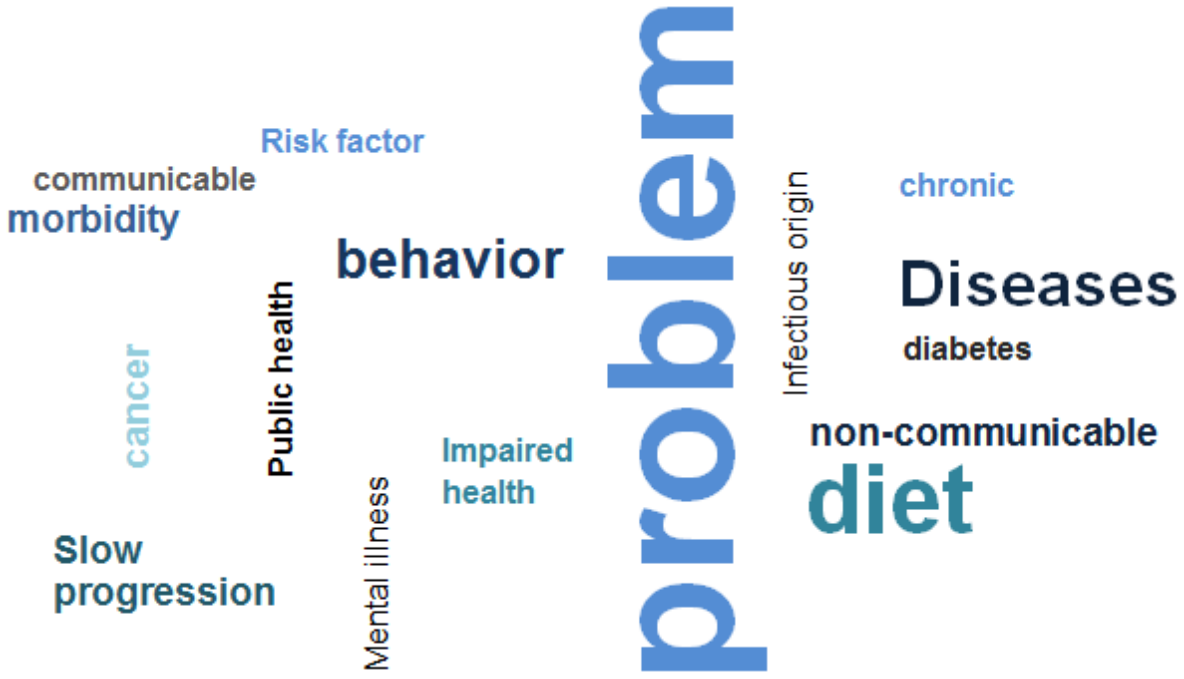
PARTICIPANT GUIDE



NCD Surveillance in Public Health

Created: 2013

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NCD Surveillance in Public Health

LEARNING OBJECTIVES

- Identify whether a non-communicable disease (NCD) surveillance system is active or passive;
- Draw a diagram of the flow of data through an NCD surveillance system; and
- Identify possible sources of selection bias and information bias for an NCD surveillance system.

ESTIMATED COMPLETION TIME

- 4 hours *(2 hours, 30 minutes interactive presentation; 1 hour, 30 minutes Skill Assessment)*

PREREQUISITES

- Prioritizing Public Health Problems

REFERENCES AND RESOURCES

- WHO/WPRO. A Guide to Establishing Event-Based Surveillance. http://www.wpro.who.int/emerging_diseases/documents/eventbasedsurv/en/
- WHO. Ionizing Radiation: IPHECA. http://www.who.int/ionizing_radiation/research/chernobyl/en/
- WHO GTSS http://www.cdc.gov/tobacco/global/gtss/index.htm (data tool link towards the bottom of the page)
- Nsakashalo-Senkwe M, Siziya S, Goma FM, Songolo P, Mukonka V, Babaniyi O. Combined prevalence of impaired glucose levels or diabetes and its correlates in Lusaka urban district, Zambia: a population based survey. Int Arch Med. 2011 Jan 12;4(1):2.
- Padrão P, Damasceno A, Silva-Matos C, Laszczyńska O, Prista A, Gouveia L, Lunet N. Alcohol consumption in Mozambique: regular consumption, weekly pattern and binge drinking. Drug Alcohol Depend. 2011 May 1;115(1-2):87-93.
- Principles and Practice of Public Health Surveillance Lisa M. Lee, Steven M. Teutsch, Stephen B. Thacker, Michael E. St. Louis (2010)
- Teutsch, S.M.; and Churchill RE. (Eds). Principles and Practice of Public Health Surveillance. 2nd ed. New York, NY: Oxford University Press. (2000)
- Choi, B.C.; McQueen, D.V.; Puska, P.; Douglas, K.A.; Ackland, M.; Campostrini, S; and Torres R.E. (2008). Enhancing global capacity in the

surveillance, prevention, and control of chronic diseases: seven themes to consider and build upon. In Journal of Epidemiology & Community Health, 62(5):391-397.

- Chowdhury. P.; Balluz, L.; Town, M.; Chowdhury, F.M.; Bartolis, W.; Garvin, W.; Akcin, H; Greenlund, K.J.; and Giles, W. (2010). Surveillance of certain health behaviors and conditions among states and selected local areas – Behavioral Risk Factor Surveillance System, United States, 2007. In Morbidity and Mortality Weekly Report Surveillance Summaries, (Feb) 5;59(1):1-220.
- Ehrlich, J.R.; Schwartz, N.J.; Ng, C.K.; Kauffman, E.C.; and Scherr, D.S. (2009). The impact of multiple malignancies on patients with bladder carcinoma: a population-based study using the SEER database. In Advance Urology, 406965.
- Kazaura, M.R.; Kombe, D.; Yuma, S.; Mtiro, H.; and Mlawa, G. (2007). Health seeking behavior among cancer patients attending Ocean Road Cancer Institute, Tanzania. In East African Journal of Public Health, 4(1):19-22.
- INDEPTH. (2010) Available from: http://www.indepth-network.org/ [Accessed on June 10, 2010]. DSS network.
- McQueen, D.V.; and Puska, P. (2003). Global Behavioral Risk Factor Surveillance. New York: Kluwer Academic/Plenum Publishers.
- Mokdad, A.H. (2009). The Behavioral Risk Factors Surveillance System: past, present, and future. In Annual Reviews of Public Health, 30:43-54.
- Ngom, P.; Binka, F.N.; Phillips, J.F.; Pence, B.; and Macleod, B. (2001) Demographic surveillance and health equity in sub-Saharan Africa. In Health Policy and Planning; 16(4): 337-344.
- Ng, N.; Hakimi, M.; Van Minh, H.; Juvekar, S.; Razzaque, A.; Ashraf, A.; Ahmed S.M., Kanungsukkasem, J.; Soonthornthada, K.; and Huu Bich, T. (2009). Prevalence of physical inactivity in nine rural INDEPTH Health and Demographic Surveillance Systems in five Asian countries. In Global Health Action, 2: 10.3402.

MODULE CONTENT

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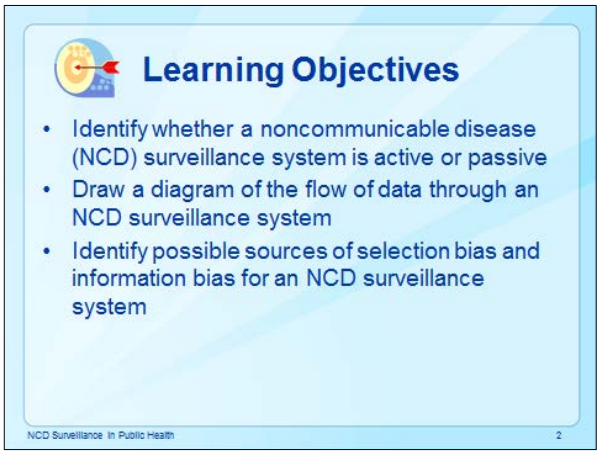

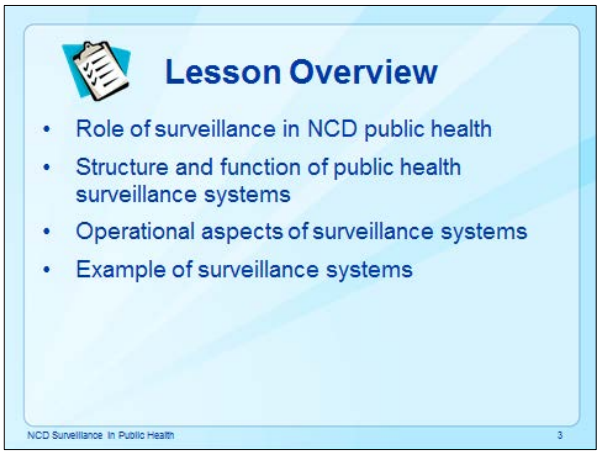

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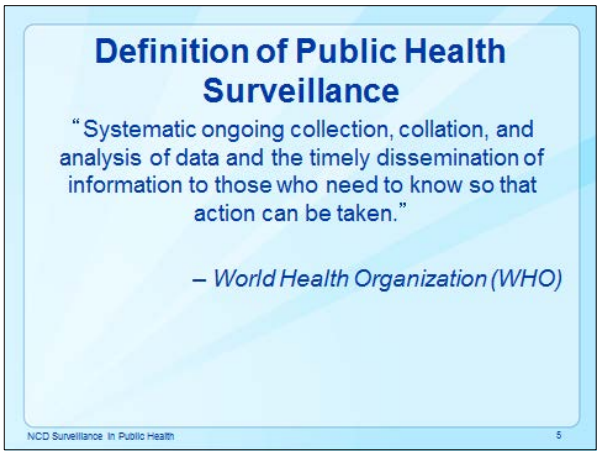
Definition of Public Health Surveillance
"Systematic ongoing collection, collation, and analysis of data and the timely dissemination of information to those who need to know so that action can be taken."
– World Health Organization (WHO)
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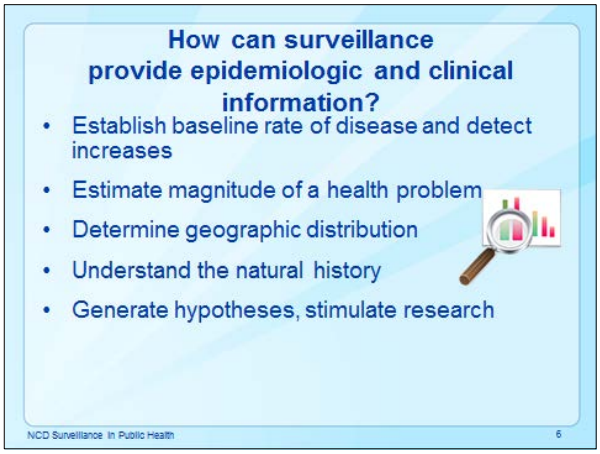
How can surveillance provide epidemiologic and clinical information?
• Establish baseline rate of disease and detect increases
• Estimate magnitude of a health problem
• Determine geographic distribution
• Understand the natural history
• Generate hypotheses, stimulate research
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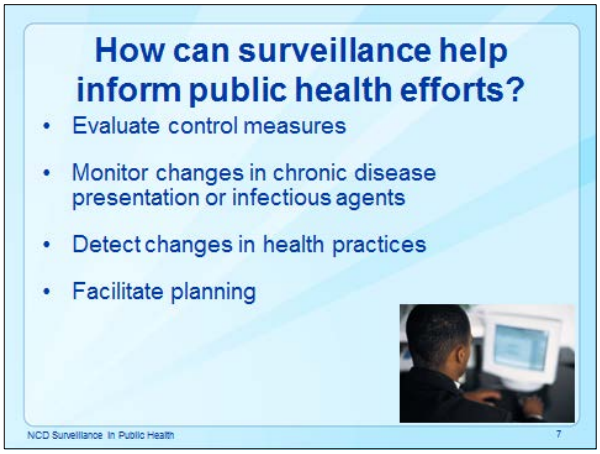
How can surveillance help inform public health efforts?
• Evaluate control measures
• Monitor changes in chronic disease presentation or infectious agents
• Detect changes in health practices
• Facilitate planning
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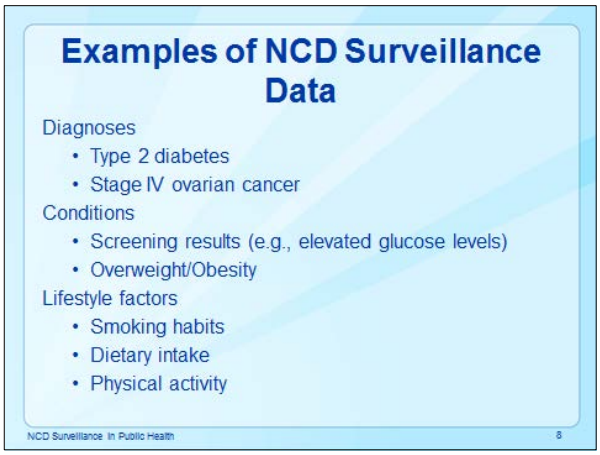
Examples of NCD Surveillance Data
Diagnoses
• Type 2 diabetes
• Stage IV ovarian cancer
Conditions
• Screening results (e.g., elevated glucose levels)
• Overweight/Obesity
Lifestyle factors
• Smoking habits
• Dietary intake
• Physical activity
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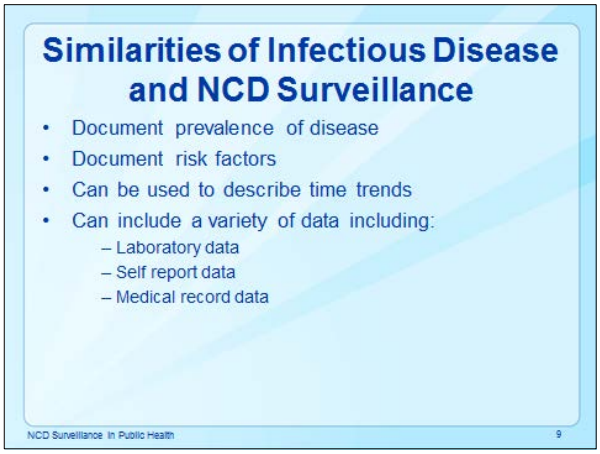
Similarities of Infectious Disease and NCD Surveillance
• Document prevalence of disease
• Document risk factors
• Can be used to describe time trends
• Can include a variety of data including:
– Laboratory data
– Self report data
– Medical record data
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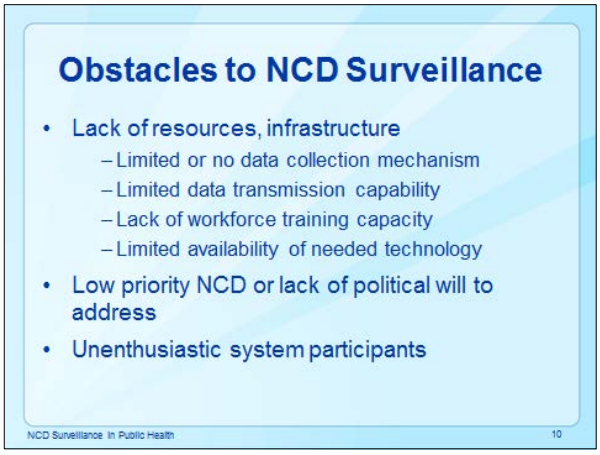
Obstacles to NCD Surveillance
• Lack of resources, infrastructure
– Limited or no data collection mechanism
– Limited data transmission capability
– Lack of workforce training capacity
– Limited availability of needed technology
• Low priority NCD or lack of political will to address
• Unenthusiastic system participants
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Components of Surveillance: Population
• National surveillance
• Specific to high-risk groups
– Occupation
– Health status (e.g., pregnancy clinics)
– Geographic area
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Components of Surveillance: Data Collection
• Health departments and/or organizations
– Collect the data
– Use forms for paper-based, fax, or emailed reports
– Mine data from electronic records
• Laboratory
– Testing
– Diagnosis
Clinic 3
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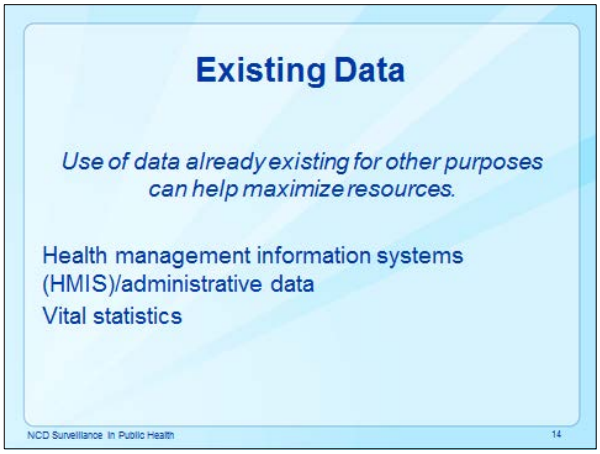
Existing Data
Use of data already existing for other purposes can help maximize resources.
Health management information systems (HMIS)/administrative data
Vital statistics
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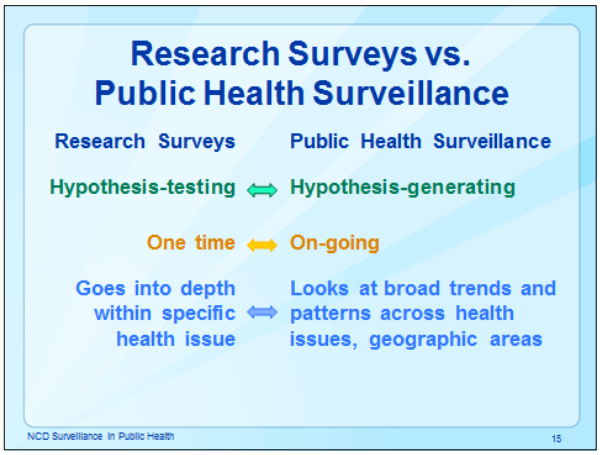
Research Surveys vs.
Public Health Surveillance
Research Surveys
Public Health Surveillance
Hypothesis-testing
Hypothesis-generating
One time
On-going
Goes into depth within specific health issue
Looks at broad trends and patterns across health issues, geographic areas
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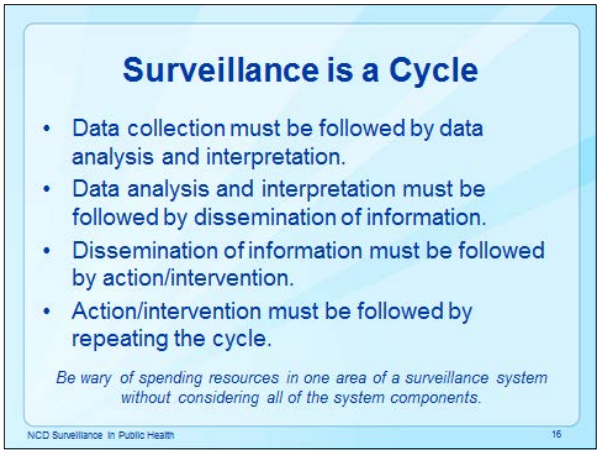
Surveillance is a Cycle
• Data collection must be followed by data analysis and interpretation.
• Data analysis and interpretation must be followed by dissemination of information.
• Dissemination of information must be followed by action/intervention.
• Action/intervention must be followed by repeating the cycle.
Be wary of spending resources in one area of a surveillance system without considering all of the system components.
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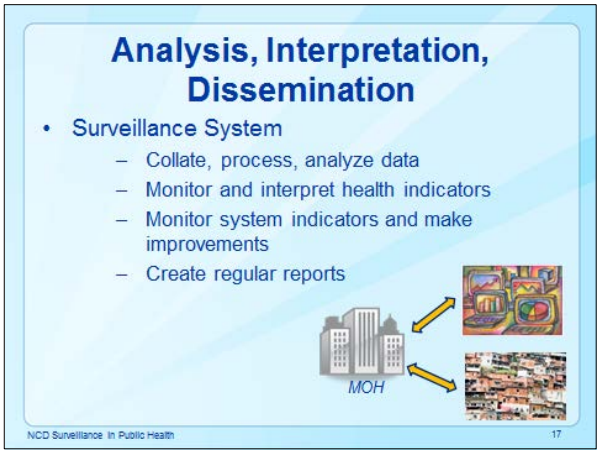
Analysis, Interpretation, Dissemination
• Surveillance System
– Collate, process, analyze data
– Monitor and interpret health indicators
– Monitor system indicators and make improvements
– Create regular reports
MOH
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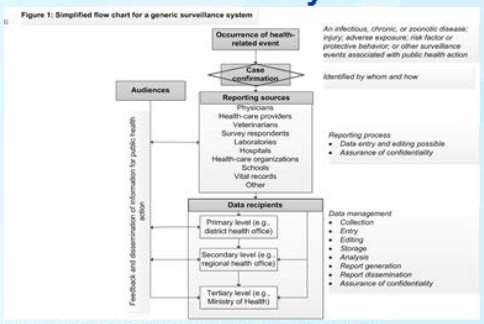
Surveillance System



Adapted from CDC's Updated Guidelines for Evaluating Public Health Systems (CDC, 2011).

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Surveillance System Stakeholders

- Participants in the system
- Users of the system
- Users of the results
- Public health practitioners
- Healthcare providers
- Community representatives
- Local, state, and national governments
- Nonprofit organizations
- Public

Engage stakeholders to ensure the system provides useful information.

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OPERATIONAL ASPECTS OF SURVEILLANCE SYSTEMS

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Priority Data Sources for NCD Surveillance

- Vital registries
- Disease registries
- Ongoing periodic health surveys
- Administrative data
- Sentinel surveillance

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Types of Surveillance

Types of surveillance data collection
- Passive
- Active

Types of surveillance systems
- Population-based
- Sentinel

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Passive Surveillance Defined

"Passive" initial report for public health authorities

Most common type of data collection
- Healthcare providers and laboratories submit standard forms
- Can rely on data collected for other reasons

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Passive Surveillance in Use

Advantages	Disadvantages	Examples
• Inexpensive for the health office • Relative low effort approach	• Barriers to electronic reporting • Delay in reporting • Missing data • Minimal data on risk factors	• Lab reporting (e.g., cancer, lead, pollutants) • Discharge records • Administrative data

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Active Surveillance Defined

Action required by local public health authority to collect data

- Phone calls
- In-person visits

Requires more resources than passive surveillance

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Active Surveillance in Use

Advantages	Disadvantages	Examples
• More targeted/ detailed/ specific data • May facilitate timely collection of data	• May be more expensive than passive • Need for dedicated personnel	• Annual surveys on lifestyle and behavioral risk factors

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Population-Based Surveillance

- System accepts data from all providers and/or laboratories in a country
- Sometimes involves a legal mandate for providers and laboratories to report ("reportable" or "notifiable")
- Reporting forms are standardized by health district or nationally
- Reporting accomplished through local collection, passed through district/province level to the national level

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Sentinel Surveillance

- Surveillance on a selected subset of potential sources
- Collection of data from a limited number of sites
  - Can be passive, active, or a combination
- Sites can be chosen to be representative of a population of interest
  - Clinics
  - Hospitals
  - Laboratories
  - Individual providers

- Representative sample of cases is highly recommended

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Sentinel Surveillance in Use

- Useful if there is no existing surveillance system or if one has been disrupted
- Can be expensive
- Difficult to ensure that selected sites are representative of a larger population
- More information on risk factors can be collected
- Example:
  - Demographic Surveillance System

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Dissemination of Information

- To which groups of people should surveillance results be distributed?
- Decision-makers (policy makers as well as heads of surveillance, epidemiology, or public health offices)
- Participating providers/reporters, colleagues
- The population under surveillance (the community)

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Methods of Dissemination

- Decision makers
  - Reports, staff meetings, conferences
- Participating providers
  - Weekly, monthly, or yearly bulletins or summaries
- General population or public
  - Press releases, websites, posters, radio announcements, community meetings


Supplement

Unhealthy Air Quality — United States, 2006–2009

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Accuracy of Surveillance

- Bias: A systematic error in the collection or use of data
  - May lead to an over- or under- estimate of a problem
  - May lead to false conclusions
  - Incorrect conclusions may lead to misdirected public health interventions
- Types of bias
  - Selection
  - Information

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Selection Bias

- Degree to which surveillance data do not represent the population or geographic areas
- Method of accessing the population affects the information gathered
  - Point of medical care vs. lack of resources or availability to access care
  - Physicians or organizations which are easily recruited vs. those that are *representative*

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Information Bias

Degree to which the data obtained do not accurately reflect the true values or measures

- Missing fields, especially those important to the topic
  - Example: "Smoking" field is blank, especially among smokers who may not want to admit to smoking
- Question or field is open to interpretation
  - Example: "Diagnosis" could be from the initial doctor, the hospital discharge records, the underlying cause of disease, or listed as cause of death

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EXAMPLES OF NCD SURVEILLANCE SYSTEMS

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Global Tobacco Surveillance System (GTSS)
• Purpose is to enhance the capacity of countries to design, implement, and evaluate their national comprehensive tobacco action plan and to monitor the key articles of the WHO Framework Convention on Tobacco Control
• Countries choose to administer survey components
• Data collected through four surveys
• Aimed at youth, schoolteachers/administrators, students in the medical field, and adults
• Each collects data about tobacco knowledge, attitude, use, and/or intention to quit in the target population.
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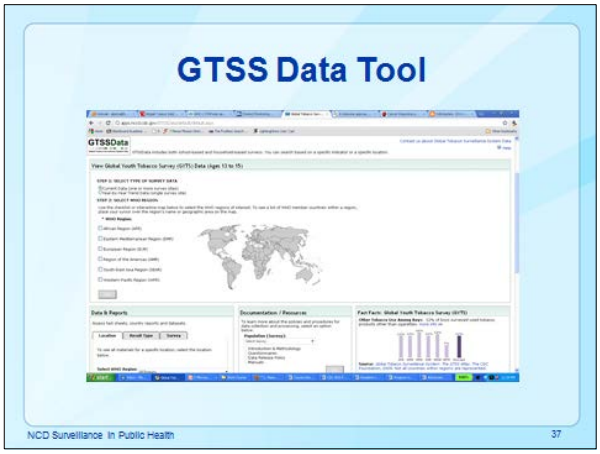
GTSS Data Tool
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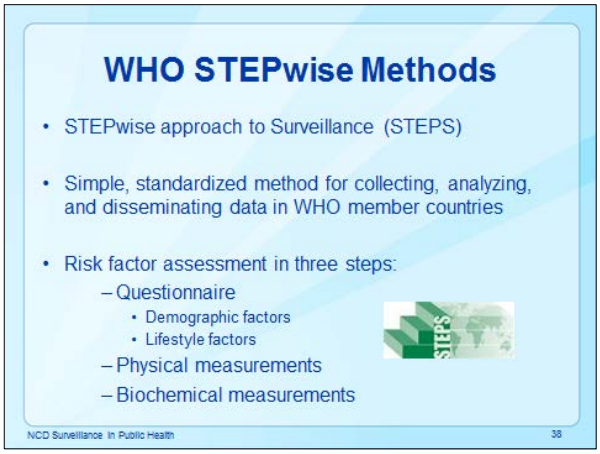
WHO STEPwise Methods
• STEPwise approach to Surveillance (STEPS)
• Simple, standardized method for collecting, analyzing, and disseminating data in WHO member countries
• Risk factor assessment in three steps:
– Questionnaire
• Demographic factors
• Lifestyle factors
– Physical measurements
– Biochemical measurements
STEPS
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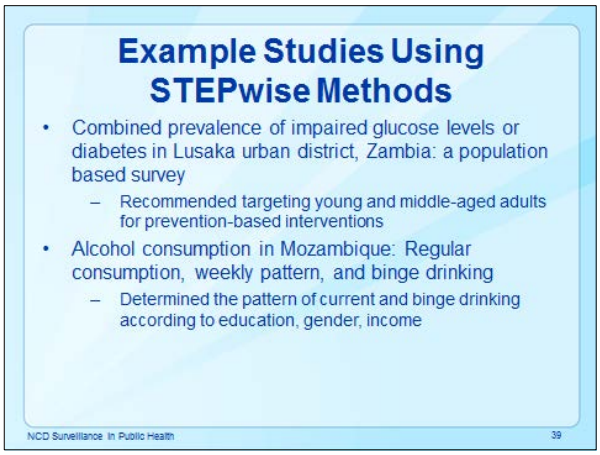
Example Studies Using STEPwise Methods
• Combined prevalence of impaired glucose levels or diabetes in Lusaka urban district, Zambia: a population based survey
– Recommended targeting young and middle-aged adults for prevention-based interventions
• Alcohol consumption in Mozambique: Regular consumption, weekly pattern, and binge drinking
– Determined the pattern of current and binge drinking according to education, gender, income
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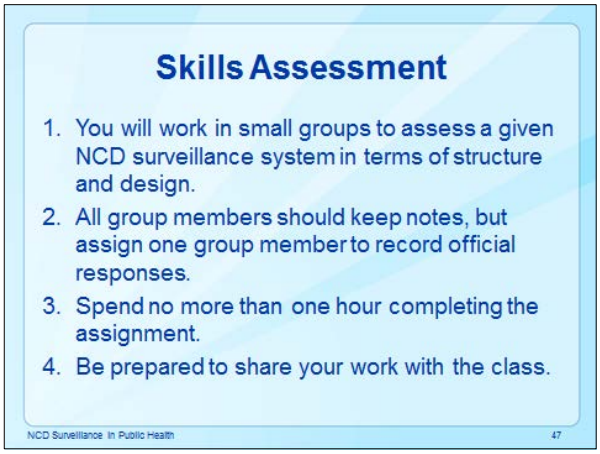
Skills Assessment
1. You will work in small groups to assess a given NCD surveillance system in terms of structure and design.
2. All group members should keep notes, but assign one group member to record official responses.
3. Spend no more than one hour completing the assignment.
4. Be prepared to share your work with the class.
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Activity

Instructions:

1. Read the information below about an NCD surveillance system.
2. Work with your group to the answer the questions that follow.
3. Be prepared to share your responses with the rest of the class.

System description

The National Cancer Surveillance System (NCSS) is a population-based cancer registry that serves to capture specific cancer diagnoses. Participating hospitals and providers were selected to represent the nation's population in terms of geographic distribution and urban/rural setting, and have agreed to voluntarily participate in the registry. Providers are provided no compensation for their participation.

Data collection

Local health departments collect data from participating physicians and hospitals. Reporting can take place through any one of three methods:

- mail-in of a standard form
- fax-in of a standard form
- telephone surveillance office and verbally provide the required information

Each participating provider or hospital is asked to report cases monthly, including when there are zero cases diagnosed. Data collected include age, address, occupation, marital status, weight, height, smoking status and history, previous cancer history, diagnosis, site and stage of cancer diagnosed.

Local health departments note that many providers do not report on a monthly basis. Sometimes a provider appears to "save up" cases and will mail in forms every few months on an irregular basis. Although local surveillance officers spend most of their time handling infectious disease outbreaks, one local officer has noted that she doesn't have the capacity to make copies of reporting forms when they run out, and doesn't know if the hospital in her jurisdiction does either. Additionally, the postage for regular reporting can add up, and the postal system is hard to rely on, especially during seasons when water and mud make roads between localities difficult to travel.

When their schedule allows, local surveillance officers follow up on incomplete forms or with providers who have consistently not reported.

Data collation, analysis, and interpretation

Local health offices accept forms from participating providers, and are required to enter the data into a database at their local office, and then submit forms to the district-level health offices, as well as the database (when possible). While all local health offices have computers, only 23% of local health offices nationally have computers systems that are 5 years old or less. District surveillance officers have noted that they often receive hard copies of NCSS surveillance forms hand-delivered when local health officers travel to district offices for meetings.

District surveillance offices are required to enter all data into an electronic database and perform basic analyses showing percent of cases that are male and female, percent of cases in standard age groups, and number of cases diagnosed thus far this year compared to the number diagnosed by the same time the previous year and 3 years ago (which marked the beginning of the NCSS). While all surveillance officers have computers, not all of them have training on manipulating databases or creating tables and graphs. District officers are required to send a semi-annual report, accompanied by the database, to the national level. The report is sent by fax and email, and the database is sent by email only.

At the national level, data are collated from all districts. National level analysts have access to the original data forms upon request: they may ask the district office to send copies, or call the district surveillance officer to ask for clarifications. Data are analyzed by available “person” and “place” characteristics, and an annual surveillance summary is created highlighting any changes in trends during the current year compared to the previous three years for which data are available.

Information dissemination

The yearly surveillance summary is published in the national epidemiology bulletin. Additionally, a “lay-person friendly” version of trends and basic risk factors gleaned from the data are posted on the Ministry of Health website. For the most recent annual surveillance summary, a press release highlighting the main findings was issued.

Up until now no public health action has been taken on the basis of the surveillance data, but national level surveillance officers plan to use the evidence gathered thus far to highlight the importance of specific types of cancers in the country as a whole in order to advocate for funding to strengthen the surveillance network. They hope that a strong NCSS network would be a good conduit for disseminating prevention information to the population at risk.

1. **Is this surveillance system active, passive, or a combination?**

2. **Draw a diagram representing the flow of data from the source, to the point where data are analyzed, to the point of dissemination of information and results.**

3. **List at least one possible source of selection bias and one possible source of information bias in this system.**