Surveillance Systems: Source of Data for Surveillance

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Data Sources

- Notifiable diseases
- Laboratory specimens
- Vital records
- Sentinel surveillance
- Registries
- Surveys
- Administrative data systems
- Other data sources

Brief History of Reporting. Notifiable diseases.

- Reporting of notifiable diseases began in 1878. Congress authorized USPHS to collect morbidity (cholera, smallpox, plague, yellow fever)
- Congress authorized forms in 1902
- By 1928, all states were participating (weekly)
- Compulsory notification for selected infectious diseases began in other countries in late 1800’s
- Determination of diseases for reporting: CSTE/CDC
- In 1996 national reporting for quarantinable (same)
- Other discussed annually (In 1996, 52 infectious)
- Each state has its own list; it varies from state to state
Brief History of Reporting. Notifiable d. (cont.)

- In recent years, notifiable-disease reporting mechanisms have been used to collect information on noninfectious conditions
- Occupational related (lead p., pesticide, lung diseases).
- Other noninfectious (spinal cord i., Alzheimer's d.)
- National reporting of vaccine conditions:
  - 1988 health-care providers and manufacturers report suspected adverse effects following specific vaccinations to FDA
  - Vaccine adverse effects reporting system (VAERS): 1990
  - 23 countries report to WHO's collaborating center (International Drug monitoring)

Notifiable diseases

- Data collection, transmission, and dissemination
- Purpose: to direct local, state, and/or national control and prevention programs
- Information: generally by health-care providers (local/state)
  - By telephone if indicated, weekly by telephone or mail, some conditions-risk factors- to CDC, absenteeism (schools, industry)
- Surveillance may be:
  - Passive: report initiated by the health-care provider
  - Active: report initiated by the health department
  - Sentinel: selected individuals report

Notifiable diseases (cont.)

- Current status: National Notifiable Diseases Surveillance System (NNDSS)
- CSTE/CDC collaboration
- List revised at annual CSTE meeting
- Voluntary reporting by states to CDC
- Reporting mandated at state level
- Reportable diseases vary by state
National Notifiable Disease Surveillance

- Reporting mandated by state law/regulation
- Health care providers, laboratories report to local HD (county)
- County HD submits reports to State
- State reports voluntarily to CDC
- Reports transmitted to CDC primarily through National Electronic Telecommunications System for Surveillance (NETSS)
- Began in 1985
- By 1990, all states report by NETSS

Morbidity and Mortality Weekly Report

- Publish by CDC
- Reports national case counts for most notifiable diseases the week after reported to CDC
- Available by printed or electronic report
- Most state health dep: weekly/monthly reports
- Surveillance for zoonotic diseases; also monitoring animal hosts (encephalitis, rabies, Rocky m., Lyme disease.)
- Laboratories: (emerging d., some states requirements)

National Notifiable Disease Surveillance (cont.)

- Strengths and limitations:
  - Under reporting
  - Well characterize problem, completeness 6-90% for many, more complete for serious consequences (rabies, plague) or rare diseases (diphtheria, tetanus).
  - Factors contributing to incomplete reporting:
    - Lack of medical consultation, avoid social stigma, lack of awareness of reporting requirements, lack of interest, incomplete etiologic definition, inadequate knowledge of case definitions, variation of expertise in different areas, changing in procedures, variation in laboratory procedures.
  - Ways to improve reporting:
    - Increase usefulness of data for local decision making, case or outbreak investigations, media coverage, case def., training.
National Notifiable Disease Surveillance (cont.)

In spite of limitations SS based on reporting of notifiable conditions are a mainstay of PHS:
- Information is available quickly & from all jurisdictions
- Can detect outbreaks or other changes in timely manner so that control can be initiated
- Can detect changes in patterns of disease by demographic characteristics or risk groups (HIV)
- Evaluation of information led changes in strategies for disease control and prevention (i.e. changes in measles and hepatitis B vaccination)
- Data are important for developing health education
- Reports of adverse drug reactions (vaccination)
- Reporting mechanisms important for preliminary assessment (HIV, Toxic-shock s., Legionnaire's d.)

Vital statistics

Brief History:
- Systematic registration of vital events as plague (origins in parish registers of 15th century in Western Europe)
- Bills of mortality begun in 1532 (London, plague mort.)
- John Graunt: use numerical methods to study mort.
- 1989 model birth certificate: prenatal risk factors
- In 19th century: civil registers superseded parish
- William Farr in Great Britain, 1830s: use of standard procedures for collecting, coding, reporting vital events
- He developed nomenclature and statistical classification
- Farr and D'Espine's work: form the basis of the international disease classification system used today.

Importance to surveillance:
- Information is collected at birth and at death.
- 80 countries report statistics to WHO (ICD-9)
- Often they are only health-related data.

Uses:
- monitor trends, progress
- difference between pop. groups, geography, occupation
- generate hypotheses

Usefulness:
- depends on health event,
- on procedures used to collect, code and summarize;
- on quality of report
Vital statistics

- Birth and death certification
  - Responsibility for registration is vested in states
  - They are encouraged to adopt standard certificates
  - Usually filed with a registrar within 24 hrs.
  - Birth: physician or attendant certifies date, time & place
  - Death: funeral director responsible, assures medical info. was provided: cause, interval between onset and death, other conditions, manner of death, autopsy.
- Coding, classification, & calculation rates
  - ICD9, calculation of national death rates, age-standardized rates, for international comparison use world standard pop., final national mortality & natality.

Examples of Surveillance based on VS

- Weekly reports: 121-City SS (US) for deaths, 1952, part of influenza surveillance, published in MMWR
- Monthly or quarterly reports: final mortality available every 2 months, Monthly Vital Statistics Report (MVSR) published by NCHS every 4 months; Mortality SS: time-series regression models published monthly MVSR, monitors trends: heart disease, homicide, lung cancer, HIV.
- Infant mortality and adverse reproductive outcomes
- Occupational mortality

Sentinel Surveillance

- Monitoring key health events in general or special populations, to obtain timely information not available from other sources needed for PH or medical action.
- Sites: hospitals, clinics, counties.
- Providers: primary care practitioners: some infectious, dementia, gastric ulcers, multiple sclerosis, pesticide poisoning, drug abuse, requests for mammography, cervical smears, HIV tests.
- International effort: Eurosentinel, GB, Netherlands, Belgium, France, US, Canada.
Registries

- Popular for monitoring PH impact of chronic d.
- Information from multiple sources is linked
- Information collected systematically from:
  - Hospital discharge, treat. records, pathology reports, death certificates.
  - Information is consolidates for each individual (no duplication)
  - Case series used for descriptive analyses and assessment of treatment eff.
  - Population Based can be used to determine incidence rates
- Types of Registries
  - Case series and hospital-based registries (Ca, rare conditions, trauma)
  - Population-based registries: for health planning, etiologic hypotheses.
  - Exposure registries: exposure to physical, chemical, biologic; (ATSDR)
  - Outcome registries: Cancer registries (42). Oldest pop-based: Connecticut Tumor R., SEER: estimate Ca-related incidence, identify unusual changes
  - Birth-defects registries: Birth defects monitoring program (BDMP).

Surveys

- Are not surveillance but can support it.
- Collect specific data from selected pops.
- Provide useful information for assessing prevalence of health conditions & pot. risks.
- Monitor changes in prevalence over time

Health Interview Surveys:
  - National Health Inf. Survey (NHIS), 1957, self reported illness, chronic conditions, injuries, impairments. Representative sample of households
  - Behavioral Risk factor SS (BFRSS), collaboration between CDC’s National Center for Chronic Disease Prevention & Health Promotion (NCCHPHP) and state health departments. Telephone survey.
  - Youth Risk Behavior Survey (YRBS): from NCCHPHP; types behavior

Provider-based surveys
  - National Center for Health Statistics (NHCS) surveys
  - National Hospital Discharge Survey: sample of short stay
  - National Ambulatory Medical Care Survey (NAMCS) sample physician
  - National Disease and Therapeutic Index (NDT): Provides ongoing data on conditions seen in ambulatory-care settings

Other surveys:
  - National Survey of Family Growth (NSFG)
  - National data on demographic & social factors assoc. with childbearing, adoption, and maternal and child health, household interviews
  - National Health and Nutrition Examination Survey (NHANES)
  - Prevalence chronic conds., anthropomorphic measures & nutrition
  - Serological surveys (prevalence data such HIV and HBV)