**Chapter 7**

**Secondary Data Sources**

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**Real-World Case 7.1**

Hundreds of hospitals, clinics, and health departments automatically report certain symptoms and diagnoses to the government each day. This practice of biosurveillance helps officials track the spread of flu, detect outbreaks, and watch for odd symptoms that might signal a brand new disease or bioterrorism. Although information is reported daily, doctors rarely know what their colleagues nearby are diagnosing. Instead they often call the health department to ask if anyone has heard of any outbreak of certain cases. Work is being done to create a mechanism to track diseases before they become outbreaks (CNS News 2011).

Researchers are now working on technology that will link local biosurveillance to electronic health records, and even mobile applications. Providing data on the amount of disease or infection that is spreading locally can improve diagnosis and treatment methods.

Federal health officials are working to create an easy-to-use web tool that will allow doctors and consumers to search for local surveillance information. Websites and mobile applications such HealthMap, CDC Influenza, and Flu Near You are tools used to track cases in specific areas (Arbiter Online 2015).

Arbiter Online. 2015. Phone Apps Track Influenza. https://arbiteronline.com/2015/01/23/phone-apps-track-influenza/.

# Real-World Case Discussion Questions

# What tools are utilized to assist in tracking outbreaks? Disease registries are used by tracking icd codes. They use secondary data. Cancer registries track incidents of cancer which too can track clusters or areas that are at high risk. Epi Info viral hemorrhagic fever (VHF) application,  helped the cdc track virus out breaks specifically ebolla. GIS is a sophisticated mapping technology that allows specialists to enter data, enabling them to track the spread of diseases and predict where the disease is most likely to proliferate based upon a number of pre-determined factors. Also Foodborne Outbreak Online Database (FOOD Tool) is helpful in tracking foodborne illness.

2. Investigate HealthMap, CDC Influenza, and Flu Near You (links below). How do these help health departments track disease outbreaks?

* <http://www.healthmap.org/en/> This map is helpful in what is close to certain populations and where cluster of outbreaks may happen. It will identify if there are secondary issues caused from the initial breakouts.
* <http://www.cdc.gov/flu/weekly/fluactivitysurv.htm> This site can identify when there is a flu outbreak, where it is and what populations should take notice. In addition, it can help track effectiveness of vaccine and how quickly it spreads
* <https://flunearyou.org/> This website can be an educator of the flu virus. It can help arm people with the tools they need to survive an outbreak and the risks they be facing.

3. Why is tracking diseases so important? Tracking a disease can help prevent future outbreaks by containing it in certain areas. It is helpful in tracking where it began which many times, is the way to stop it. It can be helpful to track how it is changing and what might be the expectation as it mutates.

**Real-World Case 7.2**

Registries are an important and integral component of our healthcare system. Registries allow entities to collect data on real-world patient outcomes, create a feedback mechanism for health care providers, and facilitate changes in care based on the feedback received (Wheatley 2014).

A collaborative effort between Kaiser Permanente Institute for Health Policy, AcademyHealth, and The Pew Charitable Trust joined forces to highlight the benefits of registries and their impact on healthcare policy. Six clinical data registries were profiled: Kasier Permanente’s Total Joint Replacement Registry (TJRR), Australian Orthopaedic Association (AOA) National Joint Replacement Registry (NJRR), Transcatheter Valve Therapy (TVT), National Surgical Quality Improvement Program (NSQIP), Get with the Guidelines-Stroke (GWTG-Stroke), and the Cystic Fibrosis Patient Registry (Wheatley 2014). The information generated allows stakeholders to make informed healthcare decisions.

As more and more registries are developed, such issues as de-identification, genetic testing, and standardization need to be addressed. The Surveillance, Prevention, and Management of Diabetes Mellitus DataLink (SUPREME-DM) holds nearly 1.1 million diabetic de-identfied patient records (Hall 2012). Additionally, the National Institute of Health has an online Genetic Testing Registry which allows users to search for genetic tests using the name of the test, the provider of the test or a condition or gene that could be detected via the test (Bowman 2012).

Source: Bowman, D. 2012. NIH’s Genetic Testing Registry Up and Running. http://www.fiercehealthit.com/story/nihs-genetic-testing-registry-and-running/2012-03-05.

# Real-World Case Discussion Questions

1. Research the joint venture covered in the Real-World Case 7.2 and identify the impact that registries have had on patient care. Students can access information on the joint venture at: <http://www.academyhealth.org/Programs/ProgramsDetail.cfm?ItemNumber=13797&navItemNumber=13805>. This site didn’t work

OK

2. Investigate the National Institute of Health’s online Genetic Testing Registry at <http://www.ncbi.nlm.nih.gov/gtr/>. What did you find interesting? What value does a registry like this provide? This site makes it easy to look at various genetic issues people may be facing and how they are treated and the advances that are happening with certain genetic disorders. In addition, it speaks about the various testings available and shows where the laboratories are. Sadly, there doesn’t seem to be enough world wide which may explain the cost associated with the testing and treatment.

3. Investigate the research performed with the Surveillance, Prevention, and Management of Diabetes Mellitus DataLink registry data found at <http://www.supreme-dm.org/Publications.html>. What has the research shown? Diabetes is growing and Asia and the Pacific. It can have a genetic component. It shows that the highest concentration of diabetes is with the age group of 22-44.

# Application Exercises

*Instructions:* Answer the following questions.

* 1. Check your state’s department of health website. Determine whether your state has a state-wide cancer or immunization registry. If so, determine the source of the data included in the registries. Then, find out what diseases are on the notifiable or reportable list for your state. This web site provides [reports](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/reports/index.htm) on incidence and mortality rates as well as information on [risk factors, prevention and early detection](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/prevent/index.htm) of various cancers.
* For professionals, such as [hospitals](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/hospitals/index.htm) and [physicians](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/physicians/index.htm), this web site includes educational materials and downloadable forms for submitting data to the Maine Cancer Registry.
* If you would like to find information about types of cancer and their treatments, we recommend you visit the [links](http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/links/index.htm) provided within this web site.

• Bladder cancer • Breast cancer (female only) • Cervical cancer • Colorectal cancer • Lung cancer (including bronchus) • Melanoma • Prostate cancer • Tobacco-related cancer (excluding lung cancer)

2. Visit a cancer registry as assigned by your instructor. Review the annual report. Describe the types of information included in the report and how the information is used within the facility. Then find out whether the facility uses a vendor or a facility-specific information system for the registry. Find out why the particular system was chosen and its advantages and disadvantages. Determine what data security methods are used for the system. What measures are taken to ensure confidentiality of the data?

3. Visit the credentialing office of a local hospital. Discuss how it queries the National Practitioner Data Bank for credentialing and re-credentialing purposes.

4. Using the Internet, access <https://clinicaltrials.gov/> and find a clinical trial in your city or state. Document the following information: title, condition under study, and location of the trial. Summarize the recruitment status, eligibility criteria, and phase of the clinical trial. [**Prophylaxis to Reduce Postoperative Atrial Fibrillation in Cardiac Surgery**](https://clinicaltrials.gov/ct2/show/NCT00953212?term=maine&rank=3)

Conditions:Atrial Fibrillation;   Atrial FlutterInterventions:Drug: beta blockers;   Drug: amiodarone;   Drug: ascorbic acid Recruitment is completed

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| --- |
| Study Type: | Interventional |
| Study Design: | Allocation: Randomized Endpoint Classification: Efficacy Study Intervention Model: Factorial Assignment Masking: Double Blind (Investigator, Outcomes Assessor) Primary Purpose: Prevention  https://clinicaltrials.gov/ct2/html/images/frame/triangle.gif**Eligibility**   |  | | --- | | Ages Eligible for Study: | 18 Years and older   (Adult, Senior) | | Genders Eligible for Study: | Both | | Accepts Healthy Volunteers: | No | |
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5. Access the HCUP website at <http://www.ahrq.gov/research/data/hcup/index.html> and find out if your state participates in the HCUP program. If so, determine who the state contact is for the HCUP program.

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| **Maine** |
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6. Using MEDLINE at <https://www.nlm.nih.gov/medlineplus/>, find an article on a disease registry. Summarize the article.

[**https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet**](https://www.cancer.gov/about-cancer/causes-prevention/risk/substances/cancer-clusters-fact-sheet)

**A cluster is a greater number of people expected to have cancer in a given area. This may help identify a cancer causing material in a specific area. Most though, are found not to be a true cancer cluster.**

**Concerned individuals can contact their state CDC to report suspected clusters. NCI researchers may help with the investigation.**

**Information is gathered, investigated by interviews and reports. If it is found to be concerning a deeper investigation is done. Third step is to involve an epidemiologist.**

**Review Quiz**

*Instructions:* For each item, complete the statement correctly or choose the most appropriate answer.

1. Which of the following has a certification program for state population-based registries?

a. Centers for Disease Control and Prevention

b. American College of Surgeons

c. North American Association of Central Cancer Registries

d. National Trauma Registries Association

2. Which of the following is an external user of data?

a. Public health department

b. Medical staff

c. Hospital administrator

d. Director of the clinical laboratory

3. Review of disease indexes, pathology reports, and radiation therapy reports is part of which function in the cancer registry?

a. Case definition

b. Case-finding

c. Follow-up

d. Reporting

4. What is the information identifying the patient (such as name, health record number, address, and telephone number) called?

a. Accession data

b. Indicator data

c. Reference data

d. Demographic data

5. Cancer registries receive approval as part of the facility cancer program from which of the following agencies?

a. American Cancer Society

b. National Cancer Registrar’s Association

c. National Cancer Institute

d. American College of Surgeons

6. Which national database includes data on all discharged patients regardless of payer?

a. Healthcare Cost and Utilization Project

b. Medicare Provider Analysis and Review file

c. Unified Medical Language System

d. Uniform Hospital Discharge Data Set

7. Which type of registry is used to collect information on an infant born with spina bifida?

a. Operation

b. Newborn

c. Birth defect

d. Trauma

8. What agency is responsible for developing the clinical trials database?

a. National Library of Medicine

b. Agency for Healthcare Research and Quality

c. Healthcare Cost and Utilization Project

d. MEDLINE

9. Which law requires the reporting of deaths and severe complications due to devices?

a. Medical Implantation and Transplantation Act of 1986

b. Medical Devices Reporting Act of 1972

c. Food and Drug Modernization Act of 1997

d. Safe Medical Devices Act of 1990

10. Which of the following is a database from the National Health Care Survey that uses the patient health record as a data source?

a. National Health Provider Inventory

b. National Ambulatory Medical Care Survey

c. National Employer Health Insurance Survey

d. National Infectious Disease Inventory

11. Which of the following contains a list maintained in diagnosis code number order of patients discharged from a facility during a particular time period?

a. Physician index

b. Master patient index

c. Disease index

d. Operation index

12. Which of the following contains a list maintained in procedure code number order of patients discharged from a facility during a particular time period?

a. Physician index

b. Master patient index

c. Disease index

d. Operation index

13. Which of the following is a collection of secondary data related to patients with a specific diagnosis, condition, or procedures?

a. Disease index

b. Disease registry

c. Master patient index

d. Trauma registry

14. Case finding is a method used to \_\_\_.

a. Identify patients who have been seen or treated in a facility for a particular disease or condition for inclusion in a registry

b. Define which cases are to be included in a registry

c. Identify trends and changes in the incidence of disease

d. Identify facility-based trends

15. In a cancer registry, the accession number \_\_\_.

a. Identifies all the cases of cancer treated in a given year

b. Is the number assigned to each case as it is entered into a cancer registry

c. Identifies the pathologic diagnosis of an individual cancer

d. Is the number assigned for the diagnosis of a cancer patient entered into the cancer registry

16. A population-based registry \_\_\_.

a. Includes information from more than one facility in a particular geopolitical area, such as a state or region

b. Includes only cases for a particular facility such as a hospital or clinic

c. Represents a computerized system that was developed for a particular facility

d. Provides data for comparisons in survival rates and quality of life for patients with different treatments and at different stages of cancer

17. Which of the following is made up of claims data from Medicare claims submitted by acute care hospitals and skilled nursing facilities?

a. NPDB

b. MEDPAR

c. HIPDB

d. UHDDS

18. The Medicare Provider Analysis and Review file is made up of \_\_\_.

a. Medical malpractice payments and sanctions taken against providers

b. Data collected from a sample of office-based physicians

c. Medicare claims from acute care hospitals and skilled nursing facilities

d. Data collected on births and deaths

19. Vital statistics include data on \_\_\_.

a. Research projects in which new treatments and tests are investigated to determine whether they are safe and effective

b. Births, deaths, fetal deaths, marriages, and divorces

c. Medicare claims

d. Outcomes

20. Which database must a healthcare facility query as part of the credentialing process when a physician initially applies for medical staff privileges?

a. UHDDS

b. MEDPAR

c. HEDIS

d. NPDB

21. Integration of biomedical concepts from many sources is performed by which of the following?

a. Healthcare Cost and Utilization Project

b. Medical Literature, Analysis, and Retrieval System Online

c. Agency for Healthcare Research and Quality

d. Unified Medical Language System

22. Protocols are used in which of the following?

a. National Health Care Survey

b. Health services research databases

c. Vital statistics

d. Clinical trials

23. The medical staff has asked to include benign cancers in the cancer registry. What is this process is known as?

a. Stage of the neoplasm

b. Case definition

c. Accession number

d. Casefinding

24. To identify the patients who had a craniotomy in the past year, what should be queried?

a. Operation index

b. Registry

c. Disease index

d. Physician index

25. Which is an example of aggregate data?

a. Average length of stay

b. Patient had a colonoscopy

c. Mary Smith had a blood transfusion

d. Patient was diagnosed with a peptic ulcer