Chapter 8
Indexes, Registers, and Health Data Collection

EXERCISE 8-1 Indexes
1. The purpose of a disease index is to organize patient cases according to ICD-9-CM disease codes so that data and records can be retrieved for study.
2. Patient name
3. Procedure index
4. ICD-9-CM and CPT/HCPCS procedure/service codes
5. Advantages and disadvantages to automated and manual MPI systems include:
   a. Manual MPI is relatively inexpensive to purchase as compared with automated MPI, which requires initial purchase of computer equipment and software (as well as software upgrades)
   b. Automated MPI allows for rapid retrieval of patient information, although a manual MPI allows for access when computer systems are unavailable (e.g., power outage)
   c. Manual MPI limits information that can be entered on each card, while automated MPI can be set up to the facility’s specifications for data retrieval
   d. Automated MPI usually allows for retrieval of patient information according to phonetic filing system (e.g., Soundex), while manual MPI cards can be lost if the patient’s information was typed or recorded incorrectly
   e. Manual MPI requires retrieval of information within the health information department, while automated MPI can be accessed by authorized personnel outside of the health information department
   f. Automated MPI captures patient information upon admission and allows for computer interfacing
6. Admission/discharge/transfer system
7. Computer interface
8. It is important to manage duplicate MPI records when two facilities merge to prevent duplicate patient medical record numbers and patient entries.

EXERCISE 8-2 Registers
1. Centers for Disease Control; National Center for Health Statistics
2. Case report form
3. A register is a collection of information. A registry is a structured system for collecting and maintaining information about a defined population so that analyses and reviews can be performed.
4. The uses of information collected in registries include:
   a. Estimating the magnitude of a problem
   b. Determining the incidence of disease
   c. Examining trends of disease over time
d. Assessing service delivery and identifying groups at high risk

e. Documenting types of patients served by a health provider

f. Conducting research

g. Serving as a source of potential donors

h. Serving as a source of potential participants in clinical trials

5. Registers and registries are secondary sources of patient information. They provide facilities, providers, and public health officials with information needed to assess and monitor the health of a given population.

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

7. National Center for Health Statistics

8.

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<thead>
<tr>
<th>Register/Registry</th>
<th>Sponsor</th>
<th>Description</th>
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| Adoption Information Registry                           | State agencies                 | • Helps adoptees obtain available nonidentifying information about birth parents  
|                                                         |                                | • Enables the reunion of registered adoptees with birth parents and biological siblings  
|                                                         |                                | • Provides a place for birth parents to file medical information updates that may be shared with registered adoptees |
| Alzheimer Registry                                      | State agencies                 | • Collects data to evaluate prevalence of Alzheimer’s disease and related disorders  
|                                                         |                                | • Provides non-identifying information and data for policy planning purposes and to support research |
| Birth Defects Registry                                  | State agencies                 | • Maintains statewide surveillance for collecting information on birth defect incidence  
|                                                         |                                | • Monitors annual trends in birth defect occurrence and mortality  
|                                                         |                                | • Conducts research studies to identify genetic and environmental risk factors for birth defects  
|                                                         |                                | • Promotes educational activities for the prevention of birth defects |
| Birth Defects Registry or Congenital Anomaly Register (CAR) or Congenital or Congenital Malformations Registry (CMR) | Health care facilities and state agencies | • Repository for case reports on children diagnosed before age two who have suspected or confirmed congenital anomalies, which are structural, functional, or biochemical abnormalities determined genetically or induced during gestation and not due to birthing events  
|                                                         |                                | • Facilities and state agencies identify ICD codes to use for case reporting  
<p>|                                                         |                                | <strong>NOTE:</strong> Minor anomalies may be excluded from reporting (e.g., inguinal hernias, skin tags, and so on). |
| Cancer Registry                                         | Health care facilities, groups of health care facilities (that | • Collects information about all cancers diagnosed (except basal and squamous cell carcinoma of the skin and carcinoma in situ of the cervix, unless required by the |</p>
<table>
<thead>
<tr>
<th>Registry Type</th>
<th>Organization/Regulatory Bodies</th>
<th>Purpose/Effect</th>
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<tbody>
<tr>
<td>Cardiac Registry</td>
<td>Health care facilities</td>
<td>Captures cardiac surgery information as a research tool for assessing cardiac patient outcomes and pinpointing how patient care can improve</td>
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<tr>
<td>Immunization Registries</td>
<td>Federal and state agencies, such as the National Committee on Health and Vital Statistics (NCHVS), the statutory public advisory body to the Secretary of HHS</td>
<td>Computerized systems that consolidate vaccination histories as provided by individual health care providers</td>
</tr>
<tr>
<td>Implant Registries (or Medical Devices Registries)</td>
<td>Various organizations depending on type of implant (e.g., National Breast Implant Registry, National Joint Registry, and so on)</td>
<td>Understand successful implants and assess failures through retrieval analysis. Improve patient care through improvement of implants. Monitor device performance in vivo (inside the body) to permit early corrective therapy. <strong>NOTE:</strong> Medical implant devices have a minimum life span of three months, penetrate and have a physiologic interaction with living tissue, and can be retrieved.</td>
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<tr>
<td>Inpatient Discharge Data Base</td>
<td>State and federal agencies</td>
<td>Contains hospital inpatient discharge data. Collected to study patterns and trends in the availability, use, and charges for inpatient services. Consists of core data elements, as defined by state and federal agencies (e.g., Uniform Hospital Discharge Data Set, UHDDS)</td>
</tr>
<tr>
<td>Insulin-Dependent Diabetes Mellitus Registries</td>
<td>National Institutes of Health (NIH)</td>
<td>Determine incidence of IDDM in defined populations. Identify persons for subsequent enrollment in case-control studies and other research projects</td>
</tr>
<tr>
<td>Metropolitan Atlanta Congenital Defects Program</td>
<td>Centers for Disease Control and Prevention (CDC)</td>
<td>Monitors occurrence of serious malformations in Atlanta metropolitan area. Tracks changes in trends and unusual patterns that may suggest avoidable risk factors. Maintain a case registry for epidemiologic and genetic studies</td>
</tr>
<tr>
<td>Registry Name</td>
<td>Sponsor/Manager</td>
<td>Description</td>
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<tr>
<td>National Exposure Registry</td>
<td>CDC Agency for Toxic Substances and Disease Registries (ATSDR)</td>
<td>• Identifies, enrolls, and monitors persons who may have been exposed to a hazardous environmental substance</td>
</tr>
</tbody>
</table>
| National Registry of Cardiopulmonary Resuscitation (NRCPR) | Sponsored by American Hospital Association, and managed by Tri-Analytics, Inc. | • Collects and analyzes in-hospital resuscitation data  
• Allows health care facilities to evaluate equipment, resources, and training, and improve practices |
| National Registry of Myocardial Infarction (NRMI) | Sponsored by Genentech, Inc.                                                    | • Examines trends in treatment, length of hospital stay, mortality, and variations among specific patient populations |
| Organ (or Tissue) Donor Registry                 | Organizations (e.g., The Living Bank), State agencies                           | • Computerized database that documents an individual's plan to be an organ donor  
**NOTE:** Donors should inform family and friends of organ donor plans because enrollment cards and signing the reverse of driver licenses are not legally-binding documents. |
| Rare Disease Registries (e.g., Li-Fraumeni Syndrome International Registry, Bloom’s Syndrome Registry, and so on) | National Organization for Rare Disorders                                         | • Collects clinical and genetic data  
• Provide referrals to genetic counseling and other services  
• Conduct ongoing research |
| Surveillance, Epidemiology, and End Results (SEER) Program | National Cancer Institute (NCI)                                                | • Collects cancer data on a routine basis from designated population-based cancer registries in nine areas of the United States |
| National Trauma Data Bank                        | American College of Surgeons (ACoS)                                             | • Improves quality of patient care  
• Provides established information system for evaluation of injury care and preparedness  
• Develops injury scoring and outcome measures  
• Provides data for clinical benchmarking, process improvement, and patient safety |
| United States Eye Injury Registry (USEIR)         | Helen Keller Eye Research Foundation                                            | • Provides prospective, population-based, epidemiologic data to improve the prevention and control of eye injuries |
| Vital Records (births, deaths, fetal deaths, divorces, and marriages) | Health care facilities, and county and state agencies | • Record of births, deaths, fetal deaths, induced abortions, teen pregnancies, teen suicides  
• Files certificates for births, deaths, divorces, and marriages  
• Collects mortality (death), fetal death (e.g., weight of 350 grams or more or, if weight is unknown, of 20 completed weeks gestation or more), natality (birth) data, and prepares reports  
• Distributes certificates to eligible persons (e.g., in NYS, birth certificates are distributed to person named on birth certificate; parent of person named on birth certificate—requesting parent’s |
EXERCISE 8-3 Case Abstracting

1. Case abstracting is an automated or manual process performed by health information department staff to collect patient information to determine prospective payment system status, to generate indexes, and to report data to quality improvement organizations and state and federal agencies.

2. Case abstracting allows for collection of data to generate reports and statistics for case mix analysis.

3. The advantages of an automated system include:
   a. Calculation of PPS reimbursement
   b. Rapid input of case abstract data
   c. Storage of case abstracts
   d. Output of case abstract statistics (e.g., data entry errors)
   e. Generation of reports and statistics for case mix analysis
   f. Generation of special reports according to user-defined criteria
   g. Submission of mandatory reporting data to state and federal agencies

2. The disadvantages of an automated system include:
   a. Cost of initial software/hardware purchase
   b. Cost of annual licenses
   c. Maintenance requirements for software (e.g., software updates)
   d. Training can be costly and complicated
   e. Site license limits data entry capability (e.g., if just one site license, only one staff member can enter data)

3. The advantages of a manual system include:
   a. Less costly
   b. No “downtime” (as associated with computer system)
   c. Training is fast and straightforward
   d. Multiple staff members can abstract at the same time

4. The disadvantages of a manual system include:
   a. Use of a paper-based form, which is time-consuming to complete
   b. Forms must be batched and mailed to vendor
   c. Report generation is completed by vendor, according to its schedule
   d. May require additional costs to generate special reports according to user-defined criteria

5. Batched case abstracts contain groups of paper-based abstract forms (e.g., 50) that are sent to a vendor for processing (e.g., keyboard, scanning, and so on).

6. A data set is a standard method for collecting and reporting individual data elements.

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<thead>
<tr>
<th>Data Set</th>
<th>Health Care Setting</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>Data Elements for Emergency Department Systems (DEEDS)</td>
<td>Providers responsible for maintaining record systems in 24-hour, hospital-based emergency departments (EDs) throughout the United States (participation is voluntary)</td>
<td>Develops uniform data element specifications for describing single emergency department (ED) patient encounters • Maintained by Centers for Disease Control and Prevention (CDC)</td>
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<tr>
<td>Essential Medical Data Set (EMDS) (pronounced E-MEDS)</td>
<td>Health care facilities that provide emergency services (participation is voluntary)</td>
<td>• Facilitates exchange of critical past medical history information among health care providers • Improves management of</td>
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</table>
| **Health Plan Employer Data and Information Set (HEDIS®)** | Managed care organizations (MCOs) (participation is voluntary) | • Standardized performance measures used to compare performance of managed health care plans  
• Maintained by National Committee for Quality Assurance (NCQA) |
| --- | --- | --- |
| **Minimum Data Set (MDS)** | Long-term care facilities (LTCFs) (participation is mandatory for LTCFs that participate in Medicare and Medicaid) | • Core set of screening elements for comprehensive assessment of LTCF residents; used to create resident assessment protocols (RAPs)  
• Resident Assessment and Validation and Entry (RAVEN) data entry system is used  
• Standardizes communication about resident problems and conditions  
• Facilitates quality monitoring and improvement  
• Maintained by CMS |
| **National Cancer Data Base (NCDB)** | Acute care facility (hospital) cancer registries (participation is required for cancer registries accredited by the American College of Surgeon's Commission on Cancer, ACoS COC) | • Nationwide oncology (study of cancer) outcomes database  
• Assesses patterns of care and outcomes relative to national norms  
• Maintained by American College of Surgeons ACoS) |
| **Outcome and Assessment Information Set (OASIS)** | Home health agencies (HHAs) (participation is mandatory for HHAs that participate in Medicare and Medicaid) | • Core set of comprehensive assessment for adult home care patients  
• Home Assessment and Validation and Entry (HAVEN) data entry software is used  
• Measures patient outcomes for outcome-based quality improvement (OBQI)  
• Patient assessment and care planning, and internal HHA performance improvement |
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<tr>
<th>Dataset Name</th>
<th>Description</th>
<th>Details</th>
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</table>
| The Joint Commission ORYX® Initiative | The Joint Commission accredited health care facilities (participation is required of facilities accredited by The Joint Commission) | - Program developed by The Joint Commission that integrates outcomes and other performance measurement data into the accreditation process  
  - Requires accredited facilities to track and submit clinical performance measures as part of the accreditation process  
  - Two measurement sets include core performance measures (specific indicators related to disease or process of care; e.g., acute myocardial infarction, or AMI) and non-core measures (general indicators; e.g., mortality rate for AMI patients)  
  - Maintained by The Joint Commission |
| Uniform Ambulatory Care Data Set (UACDS) | Ambulatory care facilities (ACFs) (participation is mandatory for ACFs that participate in Medicare and Medicaid) | Standard data set for ambulatory health records  
  - Goal is to improve data comparison for ambulatory and outpatient care settings  
  - Maintained by CMS |
| Uniform Clinical Data Set (UCDS) | Quality Improvement Organizations (QIOs) (participation is mandatory for hospitals that participate in Medicare and Medicaid) | HCFA (now called CMS) initiative that involves collection of approximately 1,800 data elements that describe patient demographic characteristics, clinical history, clinical findings, and therapeutic intervention  
  - Data is obtained from medical records of Medicare beneficiaries  
  - Maintained by CMS |
| Uniform Hospital Discharge Data Set (UHDDS) | Acute care facilities (hospitals) (participation is mandatory for hospitals that participate in Medicare and Medicaid) | Sponsored by National Center for Health Statistics (NCHS)  
  - Standard for collecting data for the Medicare and Medicaid programs  
  - Maintained by CMS |

7. The Medical Information Bureau is a clearinghouse of medical and avocation information about people who apply for insurance. The National Practitioner Data Bank contains information about practitioners who engage in unprofessional behavior, and it restricts the ability of incompetent practitioners from moving to another state without disclosure or discovery of previous medical malpractice payment and adverse action history.
EXERCISE 8-4 Health Data Collection
Short Answer
1. Descriptive statistics summarize a set of data using charts, graphs, and tables.

2. General data quality characteristics include data integrity, data reliability, and data validity. Data has integrity if it is accurate, complete, consistent, up-to-date, and the same no matter where the data is recorded. Data is reliable if it is consistent throughout all systems in which it is stored, processed, and retrieved. Data is valid if it conforms to an expected range of values.

3. Four areas of data quality management defined by AHIMA include data application (purpose for which the data are collected), data collection (processes by which data elements are accumulated), data warehousing (processes and systems used to archive data and data journals), and data analysis (process of translating data into information utilized for an application).

4. Continuous quality improvement (CQI) plays a role in data quality for the organization because it is “an approach to quality management that builds upon traditional quality assurance methods by emphasizing the organization and systems: focuses on ‘process’ rather than the individual; recognizes both internal and external ‘customers’; promotes the need for objective data to analyze and improve processes.” (Graham)

5. Ensuring data quality requires the following: data accessibility (ease with which data can be obtained), data accuracy (data that are error free and correct), data comprehensiveness (all required data elements are present in the patient record), data consistency (reliability of data regardless of the way in which data are stored, displayed, or processed), data definition (data elements should have defined meanings and values so all present and future users understand the data), data granularity (each attribute and value of data is defined at the correct level of detail), data precision (yields accurate data collection by defining expected data values), data relevancy (data that is valuable for the performance of a process or activity), and data timeliness (or data currency) (data must be collected and available to the user within a reasonable amount of time and up-to-date).

6. All hospitals compile statistics regarding admission (e.g., daily census count), discharge (e.g., death rate), and length of stay of patients (e.g., average length of stay), which are used to analyze and monitor operations.