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Manuals

Book 1

Objectives and Functions of Cancer Registries Hospital and Central

SEER Program
Self Instructional Manual for Cancer Registrars

THIRD EDITION

1

NATIONAL INSTITUTES OF HEALTH

NATIONAL CANCER INSTITUTE

SEER PROGRAM

SELF INSTRUCTIONAL MANUAL FOR CANCER REGISTRARS
Book 1: Objectives and Functions of Cancer Registries
Hospital and Central (Population-Based)

Third Edition

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A special desire of the SEER Program is to present objectives and functions of all types of cancer registries from the small hospital registry to the large population-based registry in a clear and concise manner understandable to all. This is only possible with the help of many people in the registry field.

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FOREWORD

Before we begin the study of cancer registries, we should consider the purpose of collecting cancer patient data. How will the data be collected and who will use the data. To direct our efforts in cancer control and prevention, we need a broad base of information about cancer patients, such as how the disease is diagnosed and treated, and the outcome. The systematic collection, recording, and analysis of these data provide a fund of information that may be used to identify subjects for clinical and epidemiological research. The value of cancer patient data is enhanced when numbers of cases can be grouped to reveal patterns that may not be obvious from a small number of cases.

The hospital cancer registry serves a variety of ancillary functions for the institution's oncology program. The multidisciplinary[1] nature of registry data provides a unique overview of the cancer experience of the institution. The registrar in a CoC[2] approved cancer program must be a member of the cancer committee and must participate in quality assurance, patient care evaluation, cancer conferences, and special research studies.

In a teaching hospital, the cancer registry is a source of educational and research material for medical students, interns, residents, oncology nurses, health information management students, and other health care professionals. In a broader sense, cancer registry data are used at the community, state, and national levels to establish the need for, to develop, and to monitor health education programs.

Large-scale collection of cancer patient data can be accomplished in different ways:

CANCER SURVEYS

In the United States, cancer surveys were completed in 1937 and 1947. These surveys encompassed ten large metropolitan areas. In 1969-71, the Third National Cancer Survey covered seven metropolitan areas and two entire states. The purpose of these studies was to provide representative incidence data for the United States by age, sex, race, anatomic site, and histology. Following the Third National Survey, the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute continued the project as an ongoing program and expanded the areas covered.

MORTALITY STATISTICS

A count of deaths by cause is maintained by city, county, and state jurisdictions and forwarded to the National Vital Statistics System, a part of the National Center for Health Statistics. These compilations are used extensively, together with morbidity data, in the analysis of cancer frequency and trends that occur over time among the different population groups.

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[1] Multidisciplinary: pertaining to the many skills required to manage the cancer patient, particularly those of the surgeon, radiation therapist, and medical oncologist.

[2] COC: Commission on Cancer

INCIDENCE REPORTING

Incidence is the rate at which a certain event occurs. In our study of cancer, incidence is the number of new cases diagnosed during a certain period in a defined geographic area. The reporting of incidence rates requires:

1. the definition of a specific area whose population is known.
2. the complete reporting of all cases resident in that area at the time of diagnosis.

Hospital registries are not generally in a position to report incidence rates.

CANCER REGISTRIES

A cancer registry collects information on all cancer patients diagnosed and/or treated at an institution or within a geographic area. Most hospital-based registries report their data to a central registry, which may or may not be population-based. Some registries are limited to collecting information on a particular cancer site or another subgroup of cancer cases.

Cancer registries can be classified into three general types:

1. Hospital-based registries.
2. Central registries (including population-based registries).
3. Special-purpose registries.

Hospital-Based Registries

A hospital-based registry collects information about cancer patients diagnosed and/or treated in an institution. The registry data can be used by hospital administration to assess needs and by the professional staff to assess both the effectiveness of the diagnosis and treatment and the need for patient services. Continuing annual follow-up provides end results[1] or outcome data and may encourage follow-up care.

Central Registries

Central registries vary in scope and purpose. A central registry collects information from hospitals in a county, region, or state. The large number of cancer cases in the database makes the analyses statistically significant and allows the central registry to do a wide range of studies.

The term "central registry" can be loosely applied to any group of hospital registries that submit their data to a central database and could share the services of epidemiologists, statisticians, and clinicians.

Population-Based Incidence Registries

Population-based incidence registries collect data on all cancer patients who are residents of a particular area. The database includes cases of residents who received their cancer treatment outside the area and those cases for which the death certificate or the autopsy report is the only available information. Population-based registries are interested in:

1. incidence data for certain types of cancer or certain sites.
2. changes in diagnostic and treatment practices and their associated outcomes.
3. the epidemiology of cancer.

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[1] End results: the evaluation of cancer therapy as it affects patient survival after treatment.

In order to ensure complete coverage of the defined area, population-based registries survey non-hospital sources such as pathology laboratories, radiation therapy facilities, ambulatory care facilities, freestanding surgery facilities, physicians' offices, and death certificates. Over ninety percent of the cancer patient data comes from hospital records of cancer patients, but this percentage is changing as more patients are diagnosed and treated in ambulatory facilities, such as physicians' offices and free-standing surgery facilities.

Special-Purpose Registries

Special-purpose registries collect information on one aspect or one type of cancer, such as those that collect information only on bone tumors, ovarian tumors, radiologically treated tumors, or tumors occurring in pediatric patients. Such registries are useful for a special type of clinic or for medical specialty groups. Some special-purpose registries collect information on non-cancerous conditions such as birth defects, stroke, AIDS, or trauma. Others monitor specific procedures or medical devices such as ocular implants, heart and liver transplants, and silicone prosthetic implants. The type and purpose of these special-purpose registries are continually being expanded. The general guidelines that direct the establishment and structure of cancer registries can be applied to all types of registries.

SECTION A

OBJECTIVES AND CONTENT OF BOOK 1

ADMINISTRATIVE INFORMATION

Book 1 is an overview of the functions of the registry and the role of the registrar.

Obtain a medical dictionary before you begin this instructional manual, it will be one of your most valuable references.

Test items are interspersed throughout the manual and can be used to check your understanding of the material.

Sample forms have been included that are similar to the forms you will find in a patient's medical record. Forms vary from hospital to hospital.

Key words are defined in footnotes and in the Glossary of Terms.

You can learn more readily and improve your retention by writing the answers in the blanks rather than "saying" or "thinking" the answers. Don't turn the page to look at the answer. Try to answer the question by writing in the correct response; then look at the answer. Learning takes place even when you write an incorrect answer, cross it out, and then write in the correct answer.

The text and tests are designed for you to learn and retain the material. Fill in the blanks! Make the programmed text work for you!

SECTION B

OBJECTIVES AND FUNCTIONS OF A CANCER REGISTRY

OBJECTIVES OF A CANCER REGISTRY

A cancer registry systematically collects, stores, summarizes, and distributes information about cancer patients (cases) who are treated in a particular institution or live in a particular geographic area. These data describe the patient (case) and the disease. Data collected include patient demographic information, cancer identification, diagnostic procedures, cancer-directed treatment, and survival. These data can be analyzed and the information distributed for the benefit of cancer patients, individually and collectively, and for the education of the medical professional and the community.

Specific objectives, such as meeting CoC requirements or legislative mandates may differ, but the general objectives will be the same for all types of cancer registries.

FUNCTIONS OF A CANCER REGISTRY

The cancer registry collects information about the cancer patient and the disease process in a standardized manner. It conducts periodic follow-up, usually on an annual basis, to monitor the patients' progress, and summarizes and analyzes data for annual and special reports.

The cancer registry functions are:

1. Case finding (case ascertainment): Identifying reportable cases. Reportable cases are those with in situ or invasive malignancies that are diagnosed or treated within the registry's area of coverage and those borderline or benign cases added to the reportable list.
2. Abstracting: Using the medical record as well as other sources to identify and document information about the patient and the patient's disease in a standard manner on a paper or computerized form.
3. Follow-up: For the patient's lifetime, the registry continues to monitor the patient's health status at periodic (usually annual) intervals.
4. Quality control: Procedures that ensure the accuracy and completeness of registry data.
5. Reporting: Analyzing data and distributing information using the registry database.
6. Organizing and participating in cancer program activities, including educational efforts and screening programs.

The registry must maintain strict confidentiality of the patient data. (See Section M.)

Hospital-Based Registry

A cancer program must meet the needs of the facility's administrative and medical staff. The hospital cancer registry collects data on cases as required by the facility's cancer committee or medical staff and on cases required by the state registry. If the hospital has an approved cancer program, the cancer registry must also fulfill the requirements of the CoC.

Central Registry

Central registries vary in scope from special purpose registries, such as a childhood cancer registry, to population-based registries, which collect data on all cancer patients who are residents of a defined area. If a central registry contributes data to the SEER Program, it must also collect and submit data required by SEER.

Although the objectives are different from the objectives of a hospital registry, a central registry must base its requirements on the needs of the hospitals as well as its own needs. It provides reports and training for the participating hospital registries. The central registry also helps the hospital prepare for a CoC approval survey.

SECTION B QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 The cancer registry files may contain case abstracts of patients who have been diagnosed and/or treated for:

A. Cancer.

B. Non-cancerous tumor.

C. Neither A nor B.

D. Both A and B.

Q2 A cancer registry provides a variety of services for the hospital staff, including abstracting and distributing _____ about cancer patients.

Q3 The cancer registry may collect information about:

A. The health of the patient since discharge from the hospital.

B. Therapy, if any, used to treat the disease.

C. Continued monitoring of the patient's cancer status and health status.

D. All of the above.

E. None of the above.

Q4 The information about each patient is extracted from his/her _____ _____ and summarized on an _____ form.

SECTION B TEST ANSWERS

Q1 The cancer registry files may contain case abstracts of patients who had been diagnosed and/or treated for:

Answer:

D Both A and B. Most abstracts in the cancer registry files are cases of patients who are treated for cancer (malignant tumors). Some benign[1] tumors may be collected by a cancer registry. Some of these benign tumors are pre-malignant; in other words, they have the potential to become cancerous. Others may have no malignant potential, but are life threatening because they originate in certain organs (for example, brain or liver tumors).

Q2 A cancer registry provides a variety of services for the hospital staff, including abstracting and distributing **information** about cancer patients.

You could have said "data," "knowledge," or something similar. In this course of instruction, you will learn how to collect information about cancer patients. A cancer registry collects such information as:

1. A description of the patient's diagnosis.[2]
2. A description of the procedures used to diagnose the patient.
3. A summary of the cancer-related history of the patient.

Q3 In addition, the cancer registry may collect information about:

Answer:

D. All of the above. Registries are concerned with the methods of diagnosis, the course of treatment, and the subsequent well being (outcome) of the cancer patient.

Q4 The information on each patient is extracted from his/her **medical record** and summarized on an **abstract** form.

SECTION C

CASE FINDING (CASE ASCERTAINMENT)

One of the most important functions of a hospital-based cancer registry is to provide an accurate account of

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[1] Benign: Not malignant; does metastasize; favorable for recovery.

[2] Diagnosis: The determination of the nature of a disease.

the cancer experience in that hospital by identifying and collecting information on all cancer patients. Policies and procedures must be established to identify all cases that meet the criteria for inclusion in the hospital registry database.

REPORTABLE LIST

Before case finding can be carried out, a list must be developed of all diagnoses to be included in or excluded from the registry database. This "reportable list" will vary depending upon the type of registry and the requirements of those people and agencies that use the registry data, such as the registry's accrediting agency, the state registry, and the hospital cancer committee. Reportable lists may range from a simple list of invasive and in situ tumors to a complex list that includes benign and borderline tumors.

Hospital-Based Cancer Registry

The reportable list for a hospital cancer registry would include:

1. cases required by CoC (if the hospital cancer program is accredited by CoC).
2. cases required by the state cancer registry.
3. cases required by the hospital cancer committee.

Reportable Cases

The database in a hospital cancer registry will include all patients who have been diagnosed and/or treated for cancer at the hospital since the registry's reference date.[1] The case is reportable whether the diagnosis and/or treatment were done in an inpatient unit or an outpatient[2] clinic.

Clinically diagnosed cases must be included in the registry. A clinically diagnosed case is one in which the diagnosis has not been microscopically confirmed (presence of disease has not been confirmed by biopsy, cytology, or by any microscopic analysis of tissue). Clinical diagnosis is documentation by a recognized medical practitioner that a patient has cancer.

Cases with a behavior code of 2 or 3 in the International Classification of Diseases for Oncology, Second Edition (ICD-O-2) must be included in the database. The ICD-O-2 is published by the World Health Organization and is the accepted reference for determining malignancy.

ICD-O-2 Behavior Codes

Code	Definition
0	Benign
1	Uncertain whether benign or malignant
2	Carcinoma in situ
3	Malignant, primary site
6	Malignant, metastatic site
9	Malignant, uncertain whether primary or metastatic site

Benign (behavior code 0) or borderline (behavior code 1) cases would be included if required by the state

[1] Reference date: The date on which complete reporting begins. All patients diagnosed and/or treated for cancer on or after this date must be included in the registry.

[2] Outpatient: A patient occupies a bed in the hospital less than 24 hours.

registry or by the facility's cancer committee or medical staff. Some examples are benign brain tumors, benign head and neck tumors, and pre-leukemic blood disorders.

Exceptions

The CoC excludes the following histologies/sites from the required list although the ICD-O-2 behavior code is 2 or 3:

1. Intraepithelial neoplasia (all sites)
2. Carcinoma in situ of the cervix (cervix only)
3. Localized basal cell and squamous cell carcinoma of non-genital skin sites (C44.0-C44.9 only)

Basal and Squamous Cell Carcinoma of the Skin

Basal and squamous cell carcinomas of the non-genital skin sites occur frequently. Most cancer registries do not collect them because basal and squamous cell carcinomas of the non-genital skin sites have a better prognosis than most other invasive cancers. The patients are often treated only in the physician's office, which makes it difficult to get complete and accurate information.

The CoC requires that basal and squamous cell carcinoma of non-genital skin sites be included when, at initial diagnosis, it has invaded regional tissue or lymph nodes, or metastasized.

COC and SEER Reportable Requirements for CIN and Intraepithelial Neoplasia

	CoC	**SEER**
CIN (Cervix)	No	No
VIN (Vulva)	No	Yes
VAIN (Vagina)	No	Yes
PIN (Prostate)	No	No

SAMPLE REPORT

REPORTABLE LIST FOR A HOSPITAL-BASED CANCER REGISTRY

I. As a CoC accredited program; XXX Hospital will collect cases as required by CoC in the Registry Operations and Data Standards (ROADS) manual.

A. All patients diagnosed and/or treated at XXX Hospital who meet the following criteria:
   1. Timing: Patients diagnosed and/or treated on or after the registry's reference date (January 1, 199-)
   2. Diagnosis: Diagnosis of a malignancy with a behavior code of 2 or 3 in the *International Classification of Diseases for Oncology* (ICD-O-2)

B. Exceptions: The following malignant conditions are not required by CoC although the ICD-O-2 behavior codes are 2 and 3
   1. Intraepithelial neoplasia (all sites)
   2. Carcinoma in situ of cervix (cervix only)
   3. Localized basal or squamous cell carcinoma of non-genital skin sites (C44.0-C44.9)

II. Cases required by the State of XX (not included in I)
A. Patients with a documented history of cancer
B. Cerebral meningioma

III. Cases required by the hospital cancer committee (not included in I or II)
A. Hydatidform mole (trophoblastic tumor) (M_ _ _ _)

Central Cancer Registry

The reportable list for a central cancer registry would include:

1. All cases within their demographic area with an ICD-O-2 behavior code of 2 or 3.
2. Those cases required by the National Program of Cancer Registries (NPCR) (for registries that report to NPCR).
3. Cases required by SEER (for registries that report to SEER).
4. Cases required by the state legislature (for registries that submit cases to their state).

Reportable Cases

The central registry may be a special-purpose registry or a population-based registry. Special-purpose registries collect information on specific tumors or patients (such as a brain tumor registry or a pediatric registry). Population-based registries collect information on all residents of a certain geographic area who develop cancer (such as a state registry or a regional registry).

The objectives of a central registry are different from those of a hospital registry, but the majority of cases in the central registry database are collected and reported by participating hospitals. It is of mutual benefit for the central registry to consider the needs of the participating hospitals when formulating the central registry's reporting requirements.

Central registries provide several services to the participating hospital registries:

1. Registrar training
2. Quality control of data
3. Data reports
4. Assistance to the hospital preparing for a CoC approval survey.

SECTION C TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 A cancer registry is required to collect information on certain cancer patients. Which of the following cases would a hospital cancer registry probably collect?

A. A cancer patient treated in the hospital outpatient clinic

B. A cancer patient who had a private room in the hospital

C. A cancer patient treated only in the hospital radiation therapy department

D. All of these cases

Q2 Every registry must have a _____ _____ of all cases to be included in the registry.

Q3 Your registry would include all cases of tumors with *an International Classification of Diseases for Oncology* (ICD-O-2) behavior code of 2 or 3, that is, _____ and _____ tumors.

Q4 The *International Classification of Diseases for Oncology* (*ICD-O*-2) serves as an excellent reference list because its _____ code identifies the presence or absence of malignancy.

Q5 What other tumors may be collected by the registry?

_____

Q6 The hospital cancer registry contains information on all patients who have been _____ and/or _____ for cancer at the hospital facility, whether as an ____- patient or an ____- patient.

Q7 Are clinically diagnosed cases included in the registry?

Yes

No

SECTION C TEST ANSWERS

Q1 A registry is required to collect information on certain cancer patients. Which of the following cases would a hospital cancer registry probably collect?

Answer:

D. All of these cases

A cancer registry contains information abstracted from records of patients treated in the hospital as outpatients or inpatients. (For example, if a patient is diagnosed and has a limited excision in a physician's office, then is admitted to the reporting hospital for a wide excision, the hospital cancer registry would be required to include the case.) Note: A 1996 CoC requirement (to be implemented in the year 2000) states that patients diagnosed and treated only in a staff physician's office (class of case 6) must be included in the hospital registry.

Q2 Every registry must have a **reportable list** of all cases to be included in the registry.

Q3 Your registry would include all cases of malignant tumors with an *International Classification of Diseases for Oncology* (ICD-O-2) behavior code of 2 or 3, that is, **in situ** and **invasive** tumors.

Q4 The *International Classification of Diseases for Oncology* (ICD-O-2) serves as an excellent reference list because its **behavior** code identifies the presence or absence of malignancy.

Q5 What other tumors may be collected by the registry?

Answer

The registry might include patients with **benign** tumors and/or **borderline** tumors, which, although not cancerous, have a tendency to become so. These tumors would carry a behavior code of 0 for benign or 1 for borderline tumors.

Q6 The hospital cancer registry contains information on all patients who have been **diagnosed** and/or **treated** for cancer at the hospital facility, whether as an **in**patient or an **out**patient

Q7 Are clinically diagnosed cases included in the registry?

Answer:

Yes. Clinically diagnosed cases (cases not microscopically confirmed) must be included in the registry.

SOURCES USED TO IDENTIFY NEW PATIENTS (CASE ASCERTAINMENT)

Total case ascertainment is the identification and inclusion of all reportable cases and the avoidance of over-reporting. Over-reporting happens when:

1. Non-residents are entered into the system.
2. Conditions such as dysplasia[1] are reported as malignancies.
3. Disease progression, recurrence, or transformation is reported as a new primary.
4. A case is reported from more than one source.

It is important that both central and hospital registries are aware of the case ascertainment sources available within the hospital because hospital cancer registries report many of the cases in the central registry database.

Case Finding (Case Ascertainment) In the Central Registry

Case finding for a population-based registry is identifying every resident within the registry's coverage area with a reportable diagnosis. It may be difficult to identify cases diagnosed and treated in physicians' offices or other facilities outside of the hospital.

Hospitals Outside the Reporting Area

Residents of the defined population area are sometimes diagnosed and treated in facilities located outside of the reporting area, for example, in nearby communities across state lines and even distant cancer centers. Central population-based registries must assess the frequency of these occurrences and establish procedures for capturing these cases.

Free-Standing Facilities

Free-standing facilities, such as pathology laboratories, outpatient surgery clinics, radiation oncology centers (ROCs), and private medical oncology groups must be routinely surveyed for new cases.

Physicians' Offices

Increasing numbers of cancer patients are being diagnosed and treated only in physicians' offices. A mechanism for finding these cases must be established.

Nursing Homes/Convalescent Facilities/Rehabilitation Hospitals

Many elderly patients are residents of nursing homes at the time of diagnosis. Patients may also be short-term residents of convalescent or rehabilitation facilities. However, these facilities are usually sources of follow-up information rather than case finding.

Death Certificates

Death certificates with a mention of cancer identify missed cases and assess the completeness of reporting in a hospital or in the reporting area. A disproportionate number of cases reported by death certificate only would indicate problems of under-reporting. Registrars are encouraged to tap into existing databases of all case finding sources described in the Computers and the Cancer Registry Section. Copies of death certificates or computerized death certificates are generally made available to central registries by local or state departments of vital statistics.

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[1] Dysplasia: An abnormal tissue development that does not meet the criteria for malignancy, for example, dysplasia of cervical epithelium.

Record Keeping

A central registry should create a facility information sheet for each reporting facility that would include the following:

1. The name and address of the facility.
2. The case finding sources in the facility.
3. The contact person: name, title, e-mail address, telephone number, and *FAX* number.
4. Where and how the reports are filed.
5. Any information that would be helpful to a new or untrained employee.

A sample hospital information sheet is shown on the next page.

SAMPLE REPORT

FACILITY INFORMATION SHEET FOR CANCER REGISTRIES

Facility Name _____ Facility No. _____

Street Address _____ City _____ County _____

State _____ Zip _____ No. of beds _____ Reference (begin) date _____

Cancer Registrar _____ Telephone _____

Scheduled days _____ No. days notice required _____

HEALTH INFORMATION MANAGEMENT (HIM) DEPARTMENT

Health Information Manager _____

Filing system [ ] Unit number [ ] Serial [ ] Serial-unit [ ] Other _____

Outpatient Dept. Records filed [ ] separately [ ] with inpatient records

Coding System [ ] ICD-9-CM [ ] SNOMED # _____ [ ] ICD-8 [ ] _____

DX Indexing System [ ] PAS [ ] Screening Log [ ] Other_____

Pull list prepared by _____ Records pulled/filed by _____

Pathology Department

[ ] Inpatient Pathology-person to notify of pending visit_____
[ ] How are reports filed? _____
[ ] Outpatient Pathology Records filed [ ] With inpatient [ ] Separately
[ ] Bone Marrow Reports filed [ ] In pathology dept. [ ] In hematology dept.
[ ] Autopsy reports

Radiation Therapy (Oncology) Department

[ ] No [ ] Yes If yes, person to contact _____
How are reports/records filed?_____

Whom to notify of pending visit? _____

How often visited?_____

Other contact information: _____

Case Finding (Case Ascertainment) In the Hospital

Over-reporting occurs in hospitals for many of the same reasons that it occurs in central registries. Over-reporting may also occur when a case is reported from more than one source within the hospital.

Procedures should be adopted to identify cancer patients undergoing treatment at the hospital. For example, copies of reports or logs from the pathology,[1] radiotherapy,[2] hematology,[3] chemotherapy infusion unit, and other departments may be sent routinely to the cancer registrar. Admission, discharge, and same-day surgery listings may be reviewed in the HIM department.

It is important to systematically search all the major case finding sources within the hospital such as:

1. Pathology reports
2. Medical record
   A. Inpatient
   B. Outpatient
3. Disease (diagnostic) index
4. Radiation oncology
5. Medical oncology

Pathology Reports

Pathology reports are usually the best source for identifying reportable cases. Types of pathology report:

1. Histology (analysis of tissue from a biopsy or a surgical resection)
2. Cytology (analysis of cells such as: Pap smear, pleural and peritoneal fluid, bronchial washings, node aspiration)
3. Bone marrow
4. Autopsy reports

Copies of all pathology reports or a computer-generated list of all pathologic diagnoses should be sent to the registry at regular intervals. The reports or list must include inpatient and outpatient procedures as well as consultations (reviewed slides submitted from outside sources). The cancer registrar should review all pathology reports because she/he is familiar with the reportable terminology. If someone else selects cases to send to the registry, malignancies that do not include the word carcinoma or cancer may be missed (such as Waldenstrom's macroglobulinemia).

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[1] Pathology: The scientific study of the nature of disease, its causes, processes, development, and consequences; more specifically, the microscopic examination of tissue.

[2] Radiotherapy: The medical specialty that uses radiant energy and radiant substances in the treatment of disease.

[3] Hematology: The medical specialty that pertains to the anatomy, physiology, pathology, symptomatology, and therapeutics related to the blood and blood-forming tissues.

If pathology reports are not sent to the registry at regular intervals, the registrar must review the reports on-line (if the pathology department has computerized reports) or go to the department to review the pathology files. Pathology reports are usually filed in numeric order. Any missing or incomplete reports should be investigated. The following forms are examples of how the registry can monitor missing or incomplete pathology reports.

Example

CANCER REGISTRY
PATHOLOGY CASE FINDING FORM

NAME OF HOSPITAL _____

PATHOLOGIST _____

Date of Case finding	Starting with Path Number	Ending with Path Number	Date Ending	No. of Missing Path Reports
2-15-99	S 99-00001	S 99-00622	1-31-99	3
3-19-99	S 99-00623	S 99-01425	2-28-99	1
4-16-99	S 99-01426	S 99-02089	3-31-99	4

Example

CANCER REGISTRY
MISSING PATHOLOGY REPORTS FORM

NAME OF HOSPITAL _____

Date of Case finding	Path Report Nos. Missing	Date Rechecked	Cancer Yes/No
2-15-99	S 99-00482	3-19-99	N
2-15-99	S 99-00526	3-19-99	N
2-15-99	S 99-00601	4-15-99	
3-19-99	S 99-01223		

Health Information Management (HIM) (formerly Medical Record Department)

A medical record is created whenever a patient is admitted to the hospital as an inpatient or an outpatient. When the patient is discharged, the medical record is sent to the Health Information Management department[1] (HIM) for processing. The HIM Department stores and maintains the patients' medical records and the disease index. When the patient leaves the hospital, the HIM department:

1. assembles the medical record.
2. combines the individual parts of the medical record into a unit record (single patient file).
3. checks the medical record for completeness and records deficiencies
4. codes and indexes the medical records for reimbursement and future reference (disease index).
5. files the medical record.

The cancer registrar or a member of the HIM staff screens new inpatient and outpatient medical records to identify those that deal with cancer patients. The cancer registrar should review all medical records because he/she is familiar with the reportable terminology. When cases are identified, the registry staff immediately abstracts the information (concurrent abstracting) or prepares a suspense file. A suspense system is a computerized or manual file of reportable cases that have not been entered into the database. The suspense system permits information from multiple sources to be merged when case finding methods overlap.

The disease (diagnostic) index maintained by the HIM department should be reviewed on a regular basis. Diseases are coded and indexed using the *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM)*. The list may be on-line or a printout will be available from the HIM department. The list identifies patients with selected diagnostic code numbers, i.e., reportable diagnoses. Codes of particular interest to the cancer registry are:

1. Malignant neoplasms (140.0 - 199.1)
2. Malignant neoplasm of lymphatic and hematopoietic tissue (200-208.9)
3. Carcinoma in situ (230 - 234)
4. Gamma heavy chain disease/Franklin's disease (273.2)
5. Waldenstrom's macroglobulinemia (273.3)
6. HIV-related malignancies (042)
7. Personal history of malignant neoplasm (V10.0-V10.9)
8. Radiotherapy encounter (V58.0)
9. Maintenance chemotherapy (V58.1)

[1] Health Information Management department: The department of the hospital responsible for assembling the various medical reports for each patient, combining them in a single file, ensuring completeness, and coding and indexing them for future reference.

The disease (diagnostic) index is particularly helpful in identifying clinically diagnosed cases. The list should be used as a quality management tool to assure complete case finding. Cases that are often diagnosed clinically include:

1. Liver and intrahepatic bile ducts (155.0-155.2)
2. Pancreas (157.0-157.9)
3. Lung and bronchus (162.2-162.9)
4. Brain (191.0-191.9)
5. Unknown site (199.0-199.1)

In the future, the HIM departments will be using ICD-10th Revision codes. *The International Classification of Diseases for Oncology,* Second Edition (ICD-O-2*),* which is used for cancer registry coding, has already made the transition to ICD-10.

Radiation Oncology and Medical Oncology Departments

Cancer patients make up a large part of the caseload of the radiation oncology and medical oncology departments. Patients may have been initially diagnosed at the reporting hospital, or they may have been referred to the department from outside physicians or hospitals. Since patients are often treated on an outpatient basis, if outpatient records are not coded or filed with inpatient records at the facility, they might not be listed in the hospital disease index.

Radiation therapy includes external and internal sources of radiation. A hospital may have a separate department of nuclear medicine[1]. Reports needed by the registry include the reports of treatment using:

1. Beam radiation or linear accelerator
2. Radioactive implants—radium, radon, cesium, radioactive gold
3. Radioisotopes other than implants—I-131, P-32

It is important to have a contact person in the radiation oncology, nuclear medicine, or the radiation therapy department so that all sources are covered.

Assessing the Completeness of Reporting

It is recommended that hospital registries, as well as central registries, establish procedures for systematic audit of their case finding to assess the completeness of reporting. These procedures should be spelled out in the registry's procedure manual.[2] See Section F for specific Quality Control procedures.

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[1] Nuclear medicine: The medical specialty that studies the characteristics and uses of radioactive substances in the diagnosis and treatment of cancer and other disease.

[2] Procedure Manual: A manual which documents, in detail, the current procedures used by the registry to carry out its various operations and functions.

SECTION C TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q8 What are the major sources for case finding for the following types of cases?

A. In a hospital (for both hospital and central registries):

1. _____
2. _____
3. _____
4. _____
5. _____

B. For central registries: patients diagnosed outside a hospital:

1. _____
2. _____
3. _____
4. _____
5. _____

Q9 The principal case finding source in the health information management department is the

_____ _____.

Q10 The system currently used by the Health Information Management Department for disease coding is

A. ICD-O-2

B. ICD-9-CM

C. Both A and B

D. Neither A nor B

Q11 In reviewing the pathology reports, cases are frequently missed because they are not yet in the file. To avoid the problem of missed cases you should:

_____

Q12 Why is a check of the radiation oncology reports important for case finding?

_____

Q13 Name three kinds of radiation reports you might find.

A. _____

B. _____

C. _____

Q14 What is the value of a Facility Information Sheet for a central registry?

_____

_____

SECTION C TEST ANSWERS

Q8 What are the major sources for case finding for the following types of cases?

A. In a hospital (for both hospital and central registries):
1. Medical records (The records you will review are found by first reviewing the disease index, also known as the diagnosis index)
2. Pathology reports (including bone marrow reports, cytology reports such as pleural and peritoneal fluids and bronchial washings—there may be separate files for these reports)
3. Autopsy reports (located in the pathology department)
4. Radiation therapy reports (including external beam, radioactive implants, and radioisotopes—radioisotope therapy reports may be in nuclear medicine)
5. Outpatient records (if separate from the inpatient records)

B. For central cancer registries: patients diagnosed outside of a hospital:
1. Hospitals outside their reporting area
2. Non-hospital facilities
3. All physicians' offices
4. Nursing homes, convalescent facilities, or rehabilitation hospitals
5. Death certificates

Q9 The principal case finding source in the Health Information Management Department is the **disease index**.

Q10 The system currently used by the Health Information Management Department for disease coding is

Answer

B. ICD-9-CM

Q11 In reviewing the pathology reports, cases are frequently missed because they are not yet in the file. To avoid the problem of missed cases you should:

Answer

A. Keep a log of missing pathology numbers, and check back later.
B. Keep a record of follow-up searches to see if the pathology report is still missing.

Q12 Why is a check of the radiation oncology reports important for case finding?

Answer

The patients may have been initially diagnosed elsewhere, treated as an outpatient, and have no record except in this department.

Q13 Name three kinds of radiation reports you might find.

Answer

A. Beam radiation or linear accelerator
B. Radioactive implants
C. Radioisotopes

Q14 What is the value of a Facility Information Sheet for a central registry?

Answer

The Facility Information Sheet provides easy transition if the person who routinely does the case finding is absent or is no longer in the employ of the registry.

SECTION D

ABSTRACTING

Abstracting information is the essence of the cancer registry. The accuracy and completeness with which this function is performed determines the value of the registry. Users of cancer registry data must be confident that the abstracted information is a true representation of the patients' demographics, diagnosis, and treatment.

When a person is admitted to a hospital, a medical record is established. This medical record will contain information about the patient's medical history, diagnosis, and treatment. At some hospitals, a medical record is called a medical chart, but we will always use the term medical record. For a patient with cancer, the information in the medical record is summarized using a special form (which may be on paper or in electronic format) called a cancer registry abstract. A cancer registry abstract is a summary of information from the medical record and other sources that is relevant to the diagnosis and treatment of cancer. An abstract is completed for each reportable case. One of the major responsibilities of the cancer registrar is the preparation of these abstracts.

ABSTRACTING PROCEDURES

Assemble Source Documents

In order to prepare an abstract, it is necessary to assemble all available source documents. Ordinarily, this means obtaining the patient's completed medical record, making sure that the records for all admissions and outpatient visits are included. Outpatient records may not be filed in the medical record. For instance, the outpatient medical record for radiation and/or chemotherapy may be filed in the radiation or medical oncology clinic rather than in the HIM department medical record. The cancer registrar will be required to obtain this information.

Determine Reportability

Reportable Cases

In CoC-approved programs, the registry must report all cases required by CoC in addition to those cases required by the state and the hospital's Cancer Committee. The reference document naming these cases is called the reportable list.

A reportable case is an inpatient or outpatient who was diagnosed with cancer and/or treated for cancer at the reporting facility after the registry's reference date. A reportable diagnosis will have an ICD-O-2 behavior code of 2 or 3 with the exception of:

1. intraepithelial neoplasia
2. carcinoma in situ of the cervix
3. localized basal and squamous cell carcinoma of the non-genital skin (cases with regional[1] and distant[2] disease must be abstracted).

The reportable list may also include a few borderline malignancies[3] and benign tumors that are of interest to your state registry or hospital cancer committee. The reportable list should be reviewed and updated periodically, particularly if any non-cancer diagnoses are collected.

Not Reportable (ACoS[4] CoC)

Those cases that are not required by the CoC include:

1. A patient with a history of cancer, but who has no evidence of continuing or recurrent disease when seen at the hospital. (Note: "History only" cases may be required by the state.)
2. Patients with evidence of cancer who are treated for other (co-morbid) conditions only.
3. Patients with evidence of cancer who are admitted to the hospital for something other than the diagnosis or treatment of cancer. The patients may be admitted for side effects of cancer (neutropenia, excessive weight loss).
4. Patients with evidence of cancer who are admitted to the hospital only for placement of devices to deliver cancer-directed treatment (venous access devices) or palliative devices (stents).
5. Patients with evidence of cancer who are admitted to the hospital for consultative service only.
6. Patients with evidence of cancer who are admitted to the hospital for terminal care (hospice, skilled nursing) only.
7. Patients who are clinically diagnosed by scans or x-rays and the diagnosis is confirmed or first-course treatment is delivered by another facility.
8. Patients whose diagnosis is confirmed by slides sent to the hospital pathology department; the patient has not physically entered the hospital as an outpatient or an inpatient.

Check Medical Record for Completeness

A medical record may be missing an important piece of information. The abstractor should review the record to determine if the essential documentation is available. The medical record should contain:

1. History and physical examination (H & P) recorded at the time of admission (examinations and procedures done before admission may be found in the H & P)
2. Reports of diagnostic procedures (x-rays, scans, and lab tests)

---

[1] Regional: A cancer that has spread beyond the organ where it started, to involve adjacent tissues or lymph nodes.

[2] Distant: A cancer that has spread beyond the organ and the surrounding tissues where it started to a site in the body that is at a distance from where the cancer started.

[3] Borderline malignancies: A tumor whose behavior is uncertain whether benign or malignant; a tumor that may remain benign but has the potential to invade an organ and become malignant.

[4] ACoS: American College of Surgeons

3. Consults
4. Progress notes (vital for identification of planned treatment regimens).
5. Nurses notes
6. Discharge summary (vital for identification of planed treatment regimens).

If the patient had a surgical procedure, the medical record should also contain:
1. Operative report(s)
2. Pathology report(s)

If the hospital has active outpatient clinics, the hospital unit medical record may contain copies of outpatient procedures and/or the summary reports generated from the radiation and chemotherapy treatment units. Copies of the missing reports should be ordered from the appropriate department.

Prepare Abstract

An abstract is a concise summary of the significant facts relating to the history, diagnosis, treatment, and outcome of every cancer patient. Most registrars enter data directly into the computer using their registry software. Some registrars complete a standard paper abstract, then enter the data from a paper abstract or worksheet. Once abstracting into the computer has been completed, a paper (hard copy) abstract can be printed on demand. Offsite backup of computer files is essential.

If the registrar wishes to keep paper files, the paper abstract form or the computer-generated form is filed by primary site. Within each primary site, the abstracts are filed by year of accession and then alphabetically. If a paper file is kept, it must be updated each time information is changed on the computerized database.

The cancer registry database enables the medical staff to review the overall cancer experience in the institution.

Coding

In order to tabulate, summarize, and analyze cancer registry data, most data elements must be coded. Most registry software programs expedite coding by providing help screens and pick lists. It is important, however, to use the appropriate reference manuals to identify and select the correct code.[1] Coding site and histology information is discussed in detail in *SEER Self-Instructional Manual, Book 2, Cancer Characteristics and Selection of Cases.*

Central registries receive electronic submissions of coded data from hospital registries. Some central registries may accept paper abstracts with data names, codes, and text. If the hospital does not have a cancer registry, the central registry may receive an abstract containing only text that the central registry will code and process. This procedure is successful if the abstract is complete and accurate.

[1] Code: Alphabetic, numeric, or symbolic values for data.

ITEMS OF INFORMATION COLLECTED

Certain basic data items are considered essential for inclusion in any cancer registry. Other items collected will depend on the type of registry (hospital-based, central or population-based incidence, or special purpose registry). An individual hospital may add items that are of special interest to its cancer program. A central or population-based incidence registry may add items important to cancer control in its area. Hospitals seeking American College of Surgeons approval of their cancer program must collect the ACoS required data items.

Data items fall into two general categories:

1. Patient information items (items that describe the patient, independent of his or her disease)
2. Tumor-specific information (items which describe the specific tumor)

Examples of Patient Information

1. Patient name
2. Date of birth
3. Social Security number
4. Race/ethnicity
5. Sex
6. Medical record number

Examples of Tumor-Specific Information

1. Date of initial diagnosis
2. Place of residence at diagnosis
3. Primary site (topography)
4. Laterality
5. Cell type (morphology, histology)
6. Behavior (in situ, malignant)
7. Grade (differentiation)
8. Date of admission
9. Extent of disease/stage
10. Diagnostic confirmation
11. Dates and types of therapy
12. Surgery
13. Radiation therapy
14. Chemotherapy
15. Immunotherapy
16. Other definitive therapy
17. Follow-up information (see Section E)

The items describing the patient will usually be found on the "face sheet" or "admission record", but are sometimes found in progress notes, nurses' notes, consultation reports, or the patient's history and physical examination report. For information on items that describe the tumor, review of the patient's medical history, diagnostic workup, and therapeutic management is essential. (See Section I, Health Information Management, medical reports, for a listing of the various medical reports.)

All data items must be collected using standard data definitions and codes. For hospitals participating in a central registry, a manual of definitions and codes is provided. For comparability with CoC requirements, a data collection manual is available. The SEER Program, the CoC, and NAACCR have coordinated efforts to standardize codes and definitions for specific data items. All registries are strongly encouraged to use these standardized codes to ensure the comparability of data.

The basic references are:

Registry Operations and Data Standards (ROADS), Volume II of Standards of the Commission on Cancer. Commission on Cancer of the American College of Surgeons, Chicago, IL, 1996.*

Registry Operations and Data Standards (ROADS) Supplement, Volume II of Standards of the Commission on Cancer. Commission on Cancer of the American College of Surgeons, Chicago, IL, 1998. **

Standards for Cancer Registries, Volume IV: Standard Data Edits. Edited by J. Seiffert, S. Capron, and J. Tebbel. Sacramento, CA: North American Association of Central Cancer Registries (NAACCR), April 1996.

The SEER Program Code Manual, Third Edition. SEER Program, National Cancer institute, Bethesda, MD, 1998.**

AJCC Cancer Staging Manual, 5th edition. American Joint Committee on Cancer. J. B. Lippincott, Philadelphia, PA, 1997.**

The International Classification of Diseases for Oncology, 2nd edition. World Health Organization, Geneva, Switzerland, 1990.

* Effective with 1996 diagnoses.
** Effective with 1998 diagnoses.

THE ABSTRACTOR

Abstracting is usually done by the cancer registrar with the ad hoc assistance of a medical consultant. Occasionally it may be necessary to contact the attending physician for clarification of information or to get missing information. At large hospitals, one or more full-time cancer registrars are responsible for preparing the abstracts.

Smaller hospitals (150 beds or less) may hire "circuit riders"[1] to do the abstracting for the hospital and for the state/central registry. The use of these professional services provides uniformity in abstracting and quality data for small hospitals that cannot justify a full-time cancer registrar. In some states, central registry staff may periodically abstract cases. In larger hospitals, the cancer registrar usually abstracts the required information for the central registry.

Abstracting cancer-specific information requires particular skills on the part of the abstractor:

1. Knowledge of basic human anatomy
   A. to identify and code the primary site of the cancer
   B. to understand the potential for spread to other organs and tissues (stage)
   C. to understand the lymphatic drainage for all of the major organs of the body
2. Familiarity with microscopic anatomy (the cellular structure of tissues).
3. Familiarity with the classification of tumors by histologic type
4. Knowledge of the difference between benign, uncertain potential, and malignant tumors
5. Understanding of diagnostic procedures used to establish the diagnosis of cancer and to assess the extent of disease

[1] Circuit riders: Registrars who travel from one hospital to another abstracting medical records of cancer patients for inclusion in a central cancer registry.

6. Knowledge of staging systems, which are based on size of the tumor, depth of invasion, extension beyond the primary site, lymph node involvement, and sites of distant metastasis
7. Ability to interpret therapy reports such as surgical, radiation therapy, chemotherapy, endocrine (hormone) therapy, immunotherapy, and other new and experimental therapy administered for the definitive treatment of cancer.

JOB AIDS FOR THE CANCER REGISTRAR

It is not possible for the cancer registrar to memorize all of the information required to abstract a case. The job can be taught more readily and performed more accurately once a set of job aids has been set up. To accompany this training program, you should obtain a medical dictionary, an atlas of anatomy, and a textbook on the diagnosis and treatment of cancer.

The cancer registrar must also use a variety of reference materials. Some of these materials were developed for general use by several medical specialties and some were developed especially for the registrar. In this course of instruction, emphasis will be placed on learning how to use these job aids.

At this point in the course, we wish only to inform you about the various types of aids and reference materials that can be used by the tumor registrar. The selected bibliography at the end of this book provides more information on these publications.

The first general group includes:
1. Medical dictionaries
2. Atlases of anatomy
3. Textbooks on the diagnosis and treatment of cancer
4. Textbooks on pathology, physiology, and surgery
5. Textbooks on medical terminology
6. Textbooks on registry operations

A second group of job aid material includes handbooks, manuals, and various lists and glossaries of terms, such
1. Manuals of tumor nomenclature[1] and coding
   A. *Clinical Staging for Cancer*
   B. American Joint Committee on Cancer *AJCC Cancer Staging Manual*
   C. SEER *Extent of Disease (EOD) Coding*
   D. *International Classification of Diseases for Oncology*, Second Edition (ICD-O-2)
   E. *International Classification of Disease*, Ninth Edition, Clinical modification (ICD-9-CM)
   F. *Systematized Nomenclature of Medicine* (SNOMED)
2. Names of cancer chemotherapeutic[2] agents
   A. *SEER Program Self Instructional Manual for Tumor Registrars, Book Eight*
3. Diagnostic procedures and surgical procedures related to cancer
   A. COC *Registry Operations and Data Standards (ROADS)*
   B. *The SEER Program Code Manual*
4. Current *Physician's Desk Reference* (PDR)

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[1] Nomenclature: A system of names.

[2] Chemotherapeutic: Of or pertaining to the treatment of disease with chemicals.

A third group of job aids is journals and publications by such groups as:
1. CoC
2. American Cancer Society
3. National Cancer Institute
4. NAACCR
5. National Cancer Registrars Association

A cancer registrar must keep abreast of developments in the diagnosis and treatment of cancer. For example, as new chemotherapeutic agents are developed, you have to recognize their names or at least know how to look up the terms to determine to what type of treatment, if any, they refer. Familiarity with the *PDR* will be helpful even after you become an experienced registrar; you will encounter situations you will not be able to handle without additional information. To assist you in acquiring this information, we have developed a list of references that should be used to obtain additional information about the diagnosis and treatment of cancer. (See the Selected Bibliography for more information.)

You already have become familiar with some of the activities involved in patient follow-up. One of the more difficult aspects of patient follow-up is locating a lost patient, so city and suburban telephone directories are very helpful. Get as many directories as possible for the cities within your service area. Contact your local telephone office to order directories. Several services are available on the worldwide Web that allows the user to research telephone numbers and addresses nation-wide.

You can see that collecting information for the cancer registry requires a great deal of specialized knowledge. To assist you in acquiring this knowledge, the following Self-Instructional Manuals have been developed:

Book 2, Cancer Characteristics and Selection of Cases will lead you through the intricacies of site and histology coding.

Book 3, Tumor Registrar Vocabulary: The Composition of Medical Terms introduces you to medical terminology and helps you become proficient with the terminology found in medical records.

Book 4, Human Anatomy as Related to Tumor Formation covers human anatomy with particular emphasis on lymphatic drainage and the types of tumors that are likely to arise in the various anatomic sites.

Book 5, *Abstracting a Medical Record: Patient Identification, History, and Examinations* describes the medical record and the parts of the medical record where pertinent information is found.

Book 6, *Classification for Extent of Disease* documents the specific information needed to determine the extent to which a tumor has spread, or the stage of disease. Staging is probably the most difficult aspect of cancer registry abstracting. Note: This book is out of print and has been replaced by the *SEER Extent of Disease* 1988 (3rd Edition) and the *Summary Staging Guide* 1997.

Book 7, *Statistics and Epidemiology for Cancer Registrars*, teaches the statistics and epidemiology needed by the cancer registrar to analyze and present the data.

Book 8, Antineoplastic Drugs, will help decide how to categorize, and code drugs used for treating cancer.

SECTION D TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 Are there any malignant tumors that a registry might elect not to pick up?

_____

Q2 Within a hospital, information about a patient's medical history, diagnosis, and treatment is found in or contained in the patient's _____ _____.

Q3 You have learned that a cancer registry contains information about cancer patients and that this information is obtained from the medical record. The special form used to record the summary of this information is called the _____ _____ _____.

Q4 Before abstracting a patient's medical record, you can save time if you make sure of the following:

A. _____

B. _____

C. _____

D. _____

Q5 The abstracted information may be in the form of a _____ _____,

_____ _____ _____ or both.

Q6 List some of the demographic items collected by cancer registries.

A. _____

B. _____

C. _____

D. _____

E. _____

F. _____

Q7 List some of the data items that relate to the patient's tumor.

A. _____

B. _____

C. _____

D. _____

E. _____

Q8 Abstracting of cancer registry data requires a wide range of knowledge in the following areas:

A. _____

B. _____

C. _____

D. _____

E. _____

SECTION D TEST ANSWERS

Q1 Are there any malignant tumors that a registry might elect not to pick up?

Answer

The only exceptions are basal cell and squamous cell carcinomas of the non-genital skin. (Even these should be included if at initial diagnosis the basal or squamous cell carcinoma has invaded regional tissue or nodes, or has metastasized.)

Q2 Within a hospital, information about a patient's medical history, diagnosis, and treatment is found in or contained in the patient's **medical record**.

After a patient is discharged from the hospital, the medical record is sent to the hospital's Health Information Management (Medical Record) Department. The cancer registrar obtains pertinent records from the medical record department in order to abstract those cases that belong in the cancer registry and periodically examines such records for follow-up purposes.

Q3 You have learned that a cancer registry contains information about cancer patients and that this information is obtained from the medical record. The special form used to record the summary of this information is called the **cancer registry abstract**.

Q4 Before abstracting a patient's medical record, you can save time if you make sure of the following:

Answer

A. All the necessary source documents have been assembled—outpatient as well as inpatient records
B. Diagnosis is reportable—a malignant tumor or a non-malignant tumor on the reportable list
C. Patient is reportable—patient is diagnosed and/or treated after the reference date and, for a central registry, is a resident of the reporting area
D. Medical records are complete—x-rays, pathology reports, operative reports, discharge summary are filed in the record

Q5 The abstracted information may be in the form of a **paper abstract**, **computer-stored data**, or both.

Q6 List some of the demographic items collected by cancer registries.

Possible answers

A. Patient name
B. Date of birth
C. Social security number
D. Race/ethnicity
E. Sex
F. Medical record number

Q7 Some data items that relate to the patient's tumor include:

Possible answers

A. Primary site
B. Histologic (morphologic) type/behavior/grade
C. Stage or extent of disease
D. Diagnostic confirmation
E. Type of treatment

Q8 Abstracting of cancer registry data requires a wide range of knowledge in the following areas:

Answer

A. Gross and microscopic anatomy
B. Diagnostic procedures
C. Histologic classification of tumors
D. Staging systems
E. Treatment modalities

As a specialist in cancer data collection, the cancer registrar may also become involved in other educational and research activities within the hospital and in the community.

SECTION E

PATIENT FOLLOW-UP

The term "follow-up" refers to all the activities involved in keeping track of patients after discharge.

The purpose of follow-up is twofold:
1. Lifetime medical surveillance of the cancer patient
2. Acquisition of data needed for analysis of the length and quality of survival

A patient who has been diagnosed and/or treated for a malignant disease should be carefully monitored and examined throughout his/her lifetime. Regular check-ups allow the patient's physician to identify disease progression or recurrence early enough to increase the probability of effective treatment.

Routine patient follow-up is also valuable because people who have had one type of cancer may develop other types. Periodic examination of cancer patients is imperative to ensure the early detection of new malignancies, recurrences, or disease progression.

Follow-up activities provide the information needed to statistically evaluate the results of various methods of diagnosis and treatment. As examples: What are the chances of survival for various types of cancer? How is the survival related to the stage (extent of disease) at diagnosis? What treatment methods are most effective? Are former cancer patients able to live useful lives? These and many other questions can be answered by information collected as part of "patient follow-up".

ROLE OF THE CANCER REGISTRY

The registry plays an important role in patient follow-up. The annual follow-up letter sent to the patient's physician or to the patient may prompt the scheduling of the patient's annual examination. Some patients do not see their physicians for regular follow-up. The follow-up letter identifies those patients who have not returned. Attempts can be made by either the physician or the registrar to contact the patient.

The usual practice is to follow patients annually. However, some types of cancer have a history of spreading or metastasizing very rapidly, and for the registry may elect to follow these patients at a more frequent interval.

FOLLOW-UP PROCEDURES

Establishing Policies

Establishing follow-up procedures and policies should be the responsibility of the registrar and the hospital's cancer committee. The committee must determine how follow-up will be handled in the hospital. At a minimum, patients must be followed annually from the date of last contact.

SEER Programs

The SEER Program requires that its registries maintain a 95 percent follow-up rate.

American College of Surgeons (ACoS) Commission on Cancer (CoC) Programs

Follow-up data that must be collected are:

1. Date of last contact
2. Status of the patient
3. Status of the cancer
4. Date(s) of treatment for cancer
5. Type(s) of treatment for cancer
6. Site(s) of distant metastasis
7. Site and histology(ies) of any subsequent primary(ies)

Cancer cases are considered delinquent if no contact has been made in the past 15 months. A 90 percent successful follow-up rate of all living and deceased patients and an 80 percent successful follow-up rate for all living patients are required to comply with the CoC standards. Not included in the follow-up calculations:

1. Non analytic cases
2. Foreign residents
3. Benign or borderline malignancies
4. Intraepithelial neoplasia
5. Cancer in situ of the cervix
6. Localized basal and squamous cell carcinoma of the skin
7. Patients over 100 years of age who are delinquent or lost to follow-up

The hospital's cancer committee may require that follow-up be done more frequently for certain cancer sites, or selected groups of cases. The cancer committee decides which cases will be followed more frequently.

The cancer committee may establish a policy that allows the registrar to contact the patient or patient's relatives if the patient has not been seen by the following physician. This policy must be approved by the executive committee of the medical staff. A cancer registrar should not contact a former patient or relatives of a patient unless authorized to do so by the patient's physician, the cancer committee, or the patient.

Finding the Patient

The first step in follow-up is to check the hospital and clinic records for visits or readmissions since the last visit documented on the abstract. Reports from pathology, radiology, and oncology clinics that are sources of case finding may also be sources of follow-up information.

If there is no current information in the medical record, the registry should contact the patient's physician by telephone or form letter. This contact may remind the physician that the patient's follow-up is due. If the physician has lost track of the patient, the registry (if authorized) may attempt to contact the patient directly.

Former patients can be contacted by telephone or form letter. If the patient mentions any health problems, or if the physician said that the patient should come in for a checkup, the registrar may assist the patient by making doctor appointments or arranging for transportation. This personal service to cancer patients can be a rewarding part of the registrar's job and may involve the assistance of social workers, the American Cancer Society, a hospice, and others.

Patients may be seen in multiple medical facilities by multiple physicians during the course of their disease. Patients who are treated at more than one facility may be included in more than one registry.

Registries may be able to share information and responsibility for follow-up to avoid duplication of efforts. Before a registry shares information or follow-up responsibilities, permission should be granted by the governing body or other authorizing official of the hospital. A central registry may also provide follow-up within the bounds of confidentiality.

When the above procedures fail to locate the patient, some of the more common sources used to trace patients (not necessarily in order of importance) are:

1. A letter or phone call to a relative or friend of the patient (if authorized)
2. Other hospitals (cancer registries)
3. Telephone directories (a "street guide" directory is also available from the telephone company, usually for a fee.)
4. Internet search programs such as the white pages at http://www.switchboard.com (these programs vary in cost and reliability)
5. Post office
6. Hospital social workers
7. Employer (often listed on the admission sheet) (if authorized)
8. Local and state health departments or vital statistics offices (for death information)
9. Obituary columns in local newspapers
10. Motor vehicle department records

The cancer registrar should always verify the last date that the patient was known to be alive. A listing in a directory is not proof that the patient is still living.

If a death certificate is obtained, check the birth date, Social Security number, address, maiden name, and type of cancer to be sure you have a match with the patient in your file. Be certain that this is the same primary cancer and not a second primary malignancy that may need to be abstracted.

Death certificates often record the cancer(s) status at the time of death incorrectly. If the death certificate does not list the presence of cancer, the patient may have been free of disease or there may be an error in the information. Verify the information from the death certificate by comparing it with the disease status information in your registry. A death certificate may identify a new case that should be added to the registry.

When attempting to locate patients through non-hospital sources, the patient's identity must be protected at all times.

FOLLOW-UP DATA ITEMS

Patient-Specific Information

1. Date of last contact or death
2. Vital status (alive or dead)
3. Cause of death (central registry only)
4. Place of death (hospital, city, state) (central registry only)
5. Autopsy performed (yes, no)
6. Autopsy findings (evidence of this or another cancer)

Tumor-Specific Information

If the patient has multiple primaries, tumor-specific information is collected for each primary.

1. Disease status (free, local recurrence, residual disease, distant metastasis)
2 Date of first recurrence after disease-free interval
   A. For patients with multiple primaries, it may be difficult to identify which primary has recurred. If there is no histologic or cytologic evidence to identify the primary, consult the pathologist or another physician for advice
   B. If the physician cannot identify which primary has metastasized, code all of the primaries as having metastatic disease. Update the codes later if the source of the metastasis has been identified.
3. Site(s) of first recurrence
4. Date and type of subsequent treatment

TWO CARDINAL RULES FOR THE CANCER REGISTRAR

The confidentiality of the patient's identification and diagnosis must be maintained. Never identify a patient verbally or in writing to anyone except the patient's personal physician without proper authorization.

The registrar must have the approval of the patient's physician or the Cancer Committee to contact patients or relatives directly.

Section M of this manual discusses confidentiality issues.

SECTION E TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 After initial diagnosis and treatment, cancer patients may experience further spread or recurrence of their disease, develop other primary cancers, remain disease-free for long periods of time, or die from causes other than cancer. Information that describes what happens to these cancer patients after discharge is a type of

_____ information.

Q2 Patient follow-up information should be obtained:

A. For at least three years after patient discharge

B. For at least five years after patient discharge

C. For at least ten years after patient discharge

D. Throughout the lifetime of the patient

Q3 In your own words, describe at least two reasons why patient follow-up is considered one of the most important services that can be provided by a cancer registry.

A. _____

_____

B. _____

_____

Q4 The governing body of a hospital establishes certain follow-up procedure policies. List some of these policies.

A. _____

B. _____

C. _____

D. _____

E. _____

Q5 Which of the following statements about patient follow-up are true and which are false? Circle T or F.

A.	T	F	A former patient should be followed at regular intervals.
B.	T	F	A cancer patient is "cured" if the cancer has not reappeared within three years after treatment.
C.	T	F	After a patient has been followed for five years, it is still advisable to obtain information about the patient on a regular basis.

Q6 Follow-up information describes the patient's treatment after discharge from the hospital, any recurrence of the patient's cancer, length of time the patient has survived, state of health of the patient, and if dead, the date of death. Which of the following statements is an example of follow-up information?

A. The patient died two years after discharge with no evidence of cancer.

B. The patient's diagnosis was confirmed at surgery.

C. The patient's condition was first diagnosed during a routine physical examination.

D. All of the above.

Q7 Patient follow-up should be collected at least on an annual basis. In what order should the registrar proceed to do patient follow-up? Number the following statements in priority order-first, second, third.

_____ A. Contact the patient or relative listed as next of kin.

_____ B. Check the medical record for subsequent visits or information after the last follow-up (the last information posted in the registry files).

_____ C. Contact the patient's private physician.

SECTION E TEST ANSWERS

Q1 After initial diagnosis and treatment, cancer patients may experience further spread or recurrence of their disease, develop other primary cancers, remain di9sease-free for long periods of time, or die from causes other than cancer. Information that describes what happens to these cancer patients after discharge is a type of **follow-up** information.

Q2 Patient follow-up information should be obtained:

Answer

D. Throughout the lifetime of the patient.

At one time, a cancer patient was considered cured if the condition had not reappeared five years after treatment. It is now known that there is a possibility of recurrence even after 15 years or more. In addition, new primary cancers are more likely to occur in cancer patients than in individuals who have never had a cancer.

Q3 In your own words, describe two reasons why patient follow-up is considered one of the most important services that can be provided by a cancer registry.

Answer

Here are four reasons why patient follow-up is considered one of the most important services that can be provided by a cancer registry:

A. To assist in the early identification of the recurrence of a cancer
B. To assist the physician in getting former cancer patients to return for scheduled treatments and/or checkups
C. To ensure periodic examinations of former cancer patients, since they are prone to develop other cancers
D. To gather various types of information so physicians can review types of treatment as they affect survival.

Q4 The governing body of a hospital should establish certain follow-up procedure policies. List some of these policies

Answer

A. What diseases are to be followed
B. Whether carcinoma in situ is to be followed
C. How often follow-up is to be conducted—at 12-month intervals or more frequently for certain cancer sites
D. Whether the cancer registry has blanket permission to contact a patient or family member under certain conditions, or whether permission from the patient's physician is required
E. What assistance the registry can provide to patients who contact the registry in response to a follow-up letter or telephone call.

Q5 Which of the following statements about patient follow-up are true and which are false?

Answer

A. True. The patient should be followed by the physician at least once a year. For cancers that spread very rapidly, the physician may wish to examine the patient at intervals that are more frequent.
B. False. By an outmoded definition, a cure for cancer had occurred when the patient was free of the condition for five years. We now know that there is a possibility of recurrence even after 15 or more years.
C. True. Information on patient survival is still important since some cancers may recur after five years.

Q6 Follow-up information describes the patient's treatment after discharge from the hospital, any recurrence of the patient's cancer, length of time the patient has survived, state of health of the patient, and if dead, the date of death. Which of the following statements is an example of follow-up information?

Answer

This **IS** an example of follow-up information gathered after the patient's discharge.

A. The patient died two years after discharge with no evidence of cancer.

The following are **NOT** examples of follow-up information:

B. The patient's diagnosis was confirmed at surgery. (This statement describes treatment that was performed when the patient was hospitalized following diagnosis).
C. The patient's condition was first diagnosed during a routine physical. (This statement describes a procedure that probably occurred before the patient was admitted to the hospital).

Q7 Patient follow-up should be collected at least on an annual basis. In what order should the registrar proceed to do patient follow-up? Number the following statements in priority order—first, second, third.

Answer

B.	First	Check the medical record for subsequent visits or information after the last follow-up (the last information posted in the registry files). (Reviewing the Health Information Management Department's files for subsequent visits saves postage and time generating follow-up letters.
C.	Second	Contact the patient's private physician. (The patient's private physician is the best source of follow-up information after the patient is discharged).
A.	Third	Contact the patient or relative listed as next of kin. (Contact the patient or relatives of the patient only when hospital policy and the patient's private physician permit).

THE FOLLOW-UP CONTROL LIST OR FILE

Computerized Registry

A computer printout that can be produced in a timely manner may be used as the follow-up control list. The follow-up file must be audited periodically to ensure that all living patients, including those lost to follow-up (delinquent), remain in the system. Cases must remain on the follow-up file until current follow-up is obtained.

In most computerized registry software programs, it is possible to flag lost to follow-up cases and cases that will not be followed annually. These "non-followed" cases should continue to be included in the calculation of the overall follow-up rate.

Manual Registry

A tickler card is maintained for each living patient. This card is filed alphabetically by the month when follow-up is due, in other words, a year from the date of last follow-up information. This tickler card generally includes:

1. Patient's name, current address, and phone number
2. Name of spouse, other relative, employer, or guardian
3. Name, address, and phone number of other informant(s)
4. Date of birth
5. Social Security Number
6. Medical record number
7. Primary site(s)
8. Physicians' names and addresses (especially if not part of your medical staff)
9. Date follow-up letter was sent to physician, patient, or other follow-up sources
10. Date of response to letter
11. Date of last patient contact by respondent
12. Tumor status
13. Source of last information
14. Special notes (for example, patient does not speak English)

When current follow-up information is received, record the new information and move the follow-up (tickler) card forward one year from the last date patient was known to be alive (not the date the letter was returned). For example, if the patient was to be followed in October, but returns to the hospital in August, there is no need to follow that patient in October. Instead, under a yearly follow-up system, the patient's card is filed for follow-up the next August. If no new follow-up information is obtained, the existing follow-up date is unchanged, and follow-up efforts should be continued.

The tickler card may be discarded or filed with the abstract after the patient's death. Many registrars keep the card in the tickler file until all information has been received, such as a final hospital narrative summary and autopsy report (if done), or a copy of the death certificate.

END RESULTS

In addition to the important service to cancer patients and their physicians in fostering lifetime medical surveillance, the cancer registry produces the essential data for the study of cancer patient survival. Various data fields collected through the follow-up process allow for the calculation of survival information by primary site, stage of disease, age group, sex, race/ethnicity, and type of treatment.

The survival experience of one hospital's cancer cases can be compared with those of other hospitals and with those of large central registries. Physicians should be able to look at how well their patients are doing in terms of length of survival. Small registries and newly established registries are limited in the extent to which survival analysis can be performed.

Self Instructional Manual, Book 7, Statistics and Epidemiology for Cancer Registrars, provides the cancer registrar with guidance in analyzing patient survival.

Follow-up becomes an increasingly time-consuming activity as the size of the registry grows. Each year several new cases will be added. Also, the efforts required to locate patients will multiply as patients move in- and out-of-state, remarry, change jobs, change physicians, or change insurance. In a large registry, patient follow-up becomes a major activity, and personnel may be trained to specialize in this activity.

SECTION E TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q8 A cancer patient should be followed until death. List four types of follow-up information that should be collected.

A. _____

B. _____

C. _____

D. _____

Q9 The registry must have a mechanism for alerting the cancer registrar when follow-up is due for its patients. This is called a follow-up file or a tickler file. What information is needed to follow the patient and to match the information received with the proper patient?

A. _____

B. _____

C. _____

D. _____

E. _____

F. _____

Q10 List some of the uses of follow-up information.

A. _____

B. _____

C. _____

D. _____

E. _____

SECTION E TEST ANSWERS

Q8 A cancer patient should be followed until death. List four types of follow-up information that should be collected.

Possible answers

You could have listed such types of follow-up information as:

A. Date of last contact and current address of patient
B. Present state of health or last known state of health (disease status)
C. Evidence of any recurrence of the cancer—date and site of first recurrence
D. Date and type of subsequent treatment received by the patient
E. Vital status of the patient (alive or dead)
F. Cause of death (if not living)
G. Autopsy[1] (necropsy)[2] findings (when available)

Q9 The registry must have a mechanism for alerting the cancer registrar when follow-up is due for its patients. This is called a follow-up file or a tickler file. What information is needed to follow the patient and to match the information received with the proper patient?

Possible answers

A. Patient's name, current address, and telephone number
B. Physicians' names and addresses
C. Name of spouse or other informants' names and addresses
D. Primary site(s)
E. Date of birth
F. Social Security Number

Q10 List some of the uses of follow-up information.

A. Alert patients and physicians to the need for continuing care
B. Assist physicians in locating lost patients
C. Provide the hospital with data on how well and how long its patients survive
D. Meet the requirements of the CoC for approval of the hospital's cancer program
E. Provide information for the study of cancer that is not available elsewhere

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[1] Autopsy: The postmortem examination of a body.

[2] Necropsy: A postmortem examination; an autopsy.

SOURCES FOR OBTAINING FOLLOW-UP INFORMATION

1. The World Wide Web (Internet) has several people search programs available. These programs differ in services provided, price, and reliability.
2. Directories
   A. City telephone directories for the immediate area surrounding your hospital may provide a direct lead to a patient's new address and telephone number. Check under the spouse's name if the patient is a married female or under the parent's name if the patient is a child.
   B. Some cities have directories that list the name, address, and profession of all persons living at a particular address. The public library or chamber of commerce will have the city directory for your city.
   C. Criss-Cross Reference Directory (Reverse Directory) is a complete directory of residents and businesses in your city and suburbs arranged by street, house, and telephone numbers. Haines publishes these directories for over 50 cities in the United States. Information can be obtained on cost and how to lease or purchase these directories by writing:

      Haines and Company
      7957 Fernham
      Forestville, Maryland 20747
      Telephone: 301 736-2720

      Executive Office
      8050 Freedom Ave., NW
      North Canton, Ohio 44720
      Telephone: 216 494-9111

If your hospital does not have this directory, your public library probably has a selection of city directories. Your local chamber of commerce will more than likely have one for your city. It may be possible to obtain follow-up by writing or calling a patient's former neighbor, or apartment house manager for a forwarding address. This should be done only with the knowledge and approval of the Cancer Committee. In addition, patient confidentiality must be maintained at all times.

   D. If you do not have a ZIP Code Directory in your office, you may purchase one from your local Postal Service. The Post Office will also give you any ZIP code you need via telephone. You will find this number listed in the government listings of your local telephone directory under United States Postal Service, or you can look up the ZIP code on the Internet at http://www.usps.gov/ncsc/lookups/lookup-zip+4.html.
   E. Internet telephone directories and electronic files of telephone numbers and addresses should be used with caution because they are frequently out of date by the time they are published. Furthermore, many people have the same name, and it is often difficult to make certain the correct person is contacted.
   F. As a very last resort, if no city directories are available in your area, you can make a written request to the Library of Congress in Washington, D.C. The address is Library of Congress, Main Reading Room, Washington, DC 20540-4660. You must identify yourself, your institution, the purpose of your call, and identify the city to which your patient has moved. When requesting an address for a married female, have available the husband's first name and middle initial.

3. County welfare departments, maternal and child health bureaus, Medicare, Medicaid, crippled children's services, vocational rehabilitation, Catholic charities, or other similar organizations. For information write or call your state welfare department, social services division.
4. Address correction. You can obtain a new address for first class mail from the post office, within the proper zip code area, if a forwarding address was given. To receive this service:
   A. Establish a "Postage Due Account" with your own post office. A ten-dollar deposit is usually sufficient to set up this account. Your hospital may have already established a "Postage Due Account."
   B. On the exterior left-hand corner of the envelope, write "ADDRESS SERVICE REQUESTED" or "CHANGE SERVICE REQUESTED". When this letter is forwarded to the patient, the sender is notified of the new address. Your "Postage Due Account" is then charged 50 cents (as of February 1999) for the service. Forwarding addresses are kept for one year by the Post Service substation that serves the patient's residential area. If you do not want your letter forwarded, print "DO NOT FORWARD" under "ADDRESS CORRECTION REQUESTED" on the envelope. The post office will send you the address only. When the Post Office returns a piece of mail marked "Expired," it probably means that the Forwarding Order has expired, not the patient.
5. Certified letters, with a return receipt request, will help to determine if the patient is alive. There is no assurance that only the addressee signs the certified receipt. The Post Office charge for this service (as of February 1999) is $2.98 for a letter weighing 1 oz. or less. This includes the cost of regular 33 cents postage, a $1.40 certification fee, and $1.25 for the return receipt request. There is an additional fee of $2.75 if you request "restricted delivery" to a specific person.
6. Department of motor vehicles: Request a copy of the "Department of Motor Vehicles Request for Information" form. Photocopy it and enclose it with a cover letter stating that your purpose is to locate the person for medical follow-up. This form may be used to request information from any state although the format may be different.
7. A labor union to which a patient may belong keeps excellent retirement and death benefit records of its members. If your patient is not known in the area office, you will be directed to the appropriate regional office. Most unions will cooperate with you.
8. Most mineworkers are members of the United Mine Workers of America (UMWA), Health and Retirement Funds. Their main office: 4455 Connecticut Avenue, NW, Washington, DC. 20008. Telephone: (202) 895-3700.
9. Insurance companies and banks with which the patient is known to have business.
10. Public schools may be able to tell you to what school a student's grade transcript was forwarded when the family moved. Also, the alumni groups for college graduates and the school health administration office or infirmary may have forwarding addresses.
11. State boards of certification for certain professions, for example, physicians (MDs and osteopaths), dentists, or lawyers.

12. The Social Security Administration will forward a letter to a person you are trying to locate. Write a letter to the patient. Place it in an unsealed, stamped envelope using the patient's full name and Social Security number. Write a second letter to the Social Security Administration stating the purpose of your request to have the enclosed letter forwarded, that is for medical follow-up. Enclose a check or money order for $3.00 payable to the Social Security Administration. Mail to Social Security Administration, Department of Health and Human Services, Office of Central Records Operation, 300 North Greene Street, Baltimore, Maryland 21201. To verify the amount due for this transaction, call (410) 965-7700.
    A. Social Security will not give you information regarding the whereabouts of the person you are seeking. However, you will be informed that an attempt has been made to forward your letter. Remember that it is imperative that you have the patient's Social Security number to obtain this service.
13. Special religious groups, diocesan offices, parish priests, or church pastors.
14. The registrar of voters, department of elections in the patient's city of residence, this will be listed in your local telephone directory.
15. American embassy or legation of a particular country for Americans living abroad, or the State Department Medical Division, Foreign Service, Washington, DC 20524.
16. City or county assessor if the patient or patient's spouse is a homeowner.
17. Present or former employer of the patient or the parents of a child.
18. Credit bureaus.
19. Visiting nurses' associations in the counties of the institution or patient's residence.
20. State office where certain professions must be registered (for examples, state pharmacy board, state racing commission or real estate board).
21. Professional directories (for example, state and national medical directories). The American Medical Association publishes the American Medical Directory, a directory of physicians in the U.S., Canal Zone, Puerto Rico, Virgin Islands and certain specific islands and of U.S. doctors temporarily located in foreign countries. It also includes Doctors of Osteopathy and other non MD special affiliates who are members of the AMA. The first part is an alphabetical listing of these physicians, and the second and third parts are alphabetical listings of the state and city where the physician has his medical practice. A complete name and address for the physician is included along with other information, for example, date of birth (DOB), his/her primary and secondary medical specialties, medical school, and year of graduation. The American Hospital Association (AHA) has a publication, "Hospitals," which lists by geographic locations AHA-registered and osteopathic hospitals in the U.S. and associated areas, U.S. government hospitals outside the U.S., and accredited long-term care facilities. For each hospital is listed a complete address (state, city, county), telephone number (area code), administrators, facility classification codes, bed capacity (including inpatient, newborn, and admission data), and whether the facility has a cancer registry. Both publications should be found in your local hospital reference library.
22. U.S. Veterans Administration. It is most helpful for you to have the patient's Social Security number when requesting information from this source. See the government pages of your local telephone book.
23. Death certificate requests may be sent to state and/or local health departments. Addresses for these departments, in the United States and outlying areas, are available on the Worldwide Web at http://vitalchek.com and are listed in a publication entitled "Where to Write for Vital Records: Birth, Death, Marriage, and Divorce." HHS Pub. No: 93-1142. Order from Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402, and Telephone: 202 783-3238. Stock No.: 017-022-01196-4, Price $2.25. This document can be downloaded from the worldwide Web at http://cdc.gov/nchswww/data/w2w/2-98.pdf.

24. Each state makes its own policy and sets its own fee for disbursing vital records. Some states will send you uncertified information (a photocopy of the certificate), while others will fill in the blanks on the form letter you send. Be explicit in your request. Draft a form letter giving the following information:
    A. Full name of person whose record is being requested. In the case of a child, parents' full name, and mother's maiden name
    B. Sex and race
    C. Parents' names, including maiden name of mother
    D. Month, day, and year of birth or death
    E. Place of death (city, town, county and state, name of hospital, if known)
    F. Purpose for which information is needed
    G. Month, day, and year of the last date you knew this patient to be alive. The complete date should be written out rather than using numerical abbreviations. Many places reverse the day and month in the date (for example, 09/03/87 could mean March 9, 1987).
    H. Social Security number
    I. Be explicit in supplying identifying information to vital statistics. Give them a time frame in which to work. They may return your request stipulating the years that were searched. Make a note of this on your record, so that at a future date you will not ask them to research those same years. Remember they are doing you a favor; give them all the information you can find in your medical record. If your cancer committee allows, give them also the general anatomic site of the patient's malignancy.
25. Patient linkage services. For patients who may have expired, death information may be obtained from the following sources:
    A. **Death Records of the U. S. Citizens Who Die in Foreign Countries:** Request should include full name of person at time of death and date/place of death. Send to Passport Services Office, Correspondence Branch, U.S. Department of State, 1425 K St., NW, Washington DC 20524. The fee for a copy is $4.00. Make check payable to the Department of State. Expectations: Reports of deaths of members of the U.S. Armed Forces.
    B. **National Death Index** (NDI): Requests for information, users' manuals, and application forms may be obtained from The National Death Index, Division of Vital Statistics, National Center for Health Statistics, 6525 Belcrest Road, Room 840, Hyattsville, MD 20782. Telephone: 301 436-8951. There is a fee for this service.
    C. **Air Force:** Secretary of Defense, Washington, DC 20301
    D. **Coast Guard:** Commandant, P.S., U.S. Coast Guard, Washington, DC 20226
    E. **Death Records of U. S. Citizens on Aircraft or Vessels on the High Seas**—U.S. Department of State, Washington, DC 20524
    F. **Death Records Maintained by Foreign Countries**—Most foreign countries record births and deaths and will provide certificates of deaths occurring within their boundaries. You may obtain assistance by writing to the Office of Special Consular Services, U.S. Department of State, Washington DC 20524.

The sources listed above may be used as guidelines. When you try to locate a person, think about what you might be doing if you were that patient. The social service notes in the medical record may state the patient has moved to another city, or that the patient has a daughter or son in a particular area. Use this information to help locate that patient. Be certain when you locate your patient that you make a note of your follow-up source. You do not want to repeat your detective work again next year if it is avoidable.

Always remember to maintain the confidentiality of the patient's diagnosis when dealing with agencies and other follow-up sources.

Address the letter using the name and title of the person to whom you are writing and make sure of the spelling. Your follow-up letters will receive more attention if you have addressed your request to, for example, Ms. C.M. Carmody, Cancer Registrar, or Dr. J.D. Williams, Chief, Oncology Department. When you address a person directly, you make them feel important, and a response will be forthcoming more readily than would a request addressed to Cancer Registrar or Doctor-in-Charge of the Oncology Department.

If your hospital serves many non-English speaking people, you will need foreign language dictionaries and interpreters to write follow-up letters to patients and to speak with patients.

SECTION F

QUALITY CONTROL

Quality control means assessing for completeness, accuracy, and uniformity of data at the case finding, abstracting, coding, and data processing levels. All of the activities involved in collecting data for the cancer registry serve no useful purpose if the aggregate statistics are incorrect, incomplete, inexact or, more importantly, based on varying interpretations of rules and philosophy. Quality control should be an ongoing process, and time should be allotted for registry personnel to carry out special quality control functions.

A detailed procedure manual and a manual of codes and coding rules set the basis for quality control. These manuals should reflect current practice in the registry and document any changes that occur over the life of the registry.

The registry should always perform quality control on data before presenting reports to Grand Rounds or monthly staff meetings and on abstracts prepared by outside consultants or contractors or new registry staff abstractors.

IDENTIFY INCOMPLETE CASE FINDING AND/OR CASE INFORMATION.

Completeness can mean both that all cases are reported and that the data on individual cases are complete. For example, cases might be checked to see whether pathology and staging information is present.

Through systematic quality control you can:

1. **Identify inaccurate abstracting and/or coding.** If the data were abstracted and coded again, the result should be consistent with what was first abstracted and coded. Random errors are the most difficult to spot. Abstracting and coding errors are revealed only through quality control. Quality control also determines the validity of the data.
2. **Identify lack of uniformity in interpreting coding rules.** This is especially true for a large institution where several people are abstracting and coding. Over time, definitions can vary from one individual to another and from one hospital to another. Uniformity of data can be assured only if constant checks are maintained to control the consistency.
3. **Eliminate costly correction procedures by finding errors early.** If an error goes undetected for several years, it can be very costly to review all the records that might be in error and make the appropriate corrections.
4. **Avoid drawing erroneous conclusions from analyses based on faulty data.** Your reputation and that of your registry are in jeopardy if you publish erroneous conclusions. Avoid embarrassment by constant quality checks before and after you analyze your data.
5. Only then can you, the registrar, assure the user that the data are:
   A. **Reliable** for analysis and research.
   B. **Representative** of the cancer experience of your institution or population.

Other factors can affect the quality of the data, such as data requirements, training, budget, reporting time constraints, and data sources, to name a few. Not all factors affecting the quality of the data are under the control of the cancer registrar. However, knowing the weak points in your database can make the registry more effective because then you can direct your quality control efforts where they will do the most good.

Important also is the timeliness of the data. It should be available within a reasonable time after diagnosis, that is, when it is needed. Standard setters and their timeliness guidelines include:

CoC Hospital registries must complete case abstracting within six months from the date of diagnosis.

NPCR Hospital registries must complete case abstracting and report the case to the state registry within four months from the date of diagnosis. The state registry must complete case processing and report the case within six months from the date of diagnosis.

SEER The SEER registries report cases twice per year, on February 1 and August 1. On February 1, the central registries report all cases diagnosed before January 31 of the previous year and all cases diagnosed two years ago.

On August 1, the registries report all cases diagnosed before Aug 31 of the previous year.

For example:

Date	Required data
February 1999	Remainder of 1997 cases Cases diagnosed before Jan 31, 1998
August 1999	Cases diagnosed before August 31, 1998

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 The only way to become aware of problems that may arise in the data is through _____ _____.

Q2 Quality control of cancer registry data implies that the data will be _____, _____, and _____.

Q3 Without quality control what are some of the problems you may have?

A. _____
B. _____
C. _____
D. _____
E. _____

Q4 From the user's standpoint, cancer registry data should be _____ and _____.

SECTION F TEST ANSWERS

Q1 The only way to become aware of problems that may arise in the data is through **quality control.**

Q2 Quality control of cancer registry data implies that the data will be **complete**, **accurate**, and **uniform**.

Q3 Without quality control, some of problems you may have are:

Answer

A. Incomplete case finding and/or case information. (Either the entire case is missing or some reports are missing for a particular patient.)
B. Inaccurate abstracting and/or coding.
C. Lack of uniformity in interpreting coding rules.
D. Costly correction procedures when errors are found later.
E. Drawing erroneous conclusions from analyses based on faulty data.

Q4 From the user's standpoint, cancer registry data should be **reliable** and **representative of the cancer experience of your institution.**

QUALITY CONTROL OF CASE FINDING

The main objective of case finding is completeness of case finding to avoid under-reporting. This means locating the records of all eligible patients with reportable diagnoses. In section C, we discussed the sources of patient records for hospital-based and population-based registries. While routine procedures should be established to set tight controls on each source used for case finding, periodic audits will usually turn up missed cases.

Some ICD-9-CM code numbers in the disease index should be carefully reviewed because the disease may have been clinically diagnosed particularly primaries such as liver, pancreas, lung and bronchus, brain, and unknown primary site. These cases may have been clinically diagnosed. Patients who did not have their complete diagnostic workup at your hospital, or cases for which tissue specimens were sent to outside pathology laboratories, present special problems unless copies of outside reports are filed in the patient's medical record.

Some cases are overlooked simply because the diagnosis is outside of the ICD-9-CM neoplastic disease code range (140-239). Examples include Gamma heavy chain disease/Franklin's disease, Waldenstrom's macroglobulinemia, and a personal history of malignant neoplasm. See Section C for a more complete list.

POTENTIAL PROBLEMS WITH OVER-REPORTING

Over-reporting can also be a problem. There is a possibility of reporting a single primary multiple times. This may occur for several reasons:

1. The patient may be picked up from more than one source, that is, through a pathology report, the disease index, and the radiation therapy department. Records from all sources may not be consolidated into one record because the names are not identical, for example Betty on one report and Elizabeth on another.
2. A metastatic site may be mistakenly abstracted as a new primary.
3. Because different histologic terms are sometimes used to describe progressive stages or phases of the same disease, the progression may be abstracted as a new primary. This is particularly true for lymphatic and hematopoietic diseases, Hodgkin's disease, non-Hodgkin's lymphoma, leukemia, and multiple myeloma. Appendix B in the *ROADS* manual or *Book 4* of the *Self-Instructional Manuals for Cancer Registrars* will help you recognize which diagnoses are presumed to be second primaries and which are not.
4. A patient name change or an incorrect patient identification number (medical record number or Social Security Number) may result in over-reporting.

QUALITY CONTROL OF FOLLOW-UP

Long-term follow-up of patients is needed if data are to be used for the evaluation of treatment and the assessment of results. The success of the cancer program depends upon finding answers to questions such as: How long and how well did the patient survive following diagnosis and treatment? Did the patient have a long-term disease-free interval? Did the patient have a recurrence or residual disease? What was the cause of death and was cancer present?

The calculation of survival rates (see also Book 7, *Statistics and Epidemiology for Cancer Registries*) will be affected by having too many cases that are "lost." Cases withdrawn from the calculations before long-term follow-up or death will severely restrict the usefulness and reliability of survival rates. To find out how well you are achieving follow-up, divide your caseload into three categories:

1. Cases of patients known to be alive within the last 15 months
2. Deaths verified by death certificate, physician, obituary, or other reliable source
3. Cases lost-to-follow-up (delinquent), no contact for more than 15 months.

In its simplest form, the successful follow-up rate is the percentage of total cases that are in the first two categories. A detailed CoC follow-up rate worksheet appears on the next page. As expected, a large number of deceased cases will tend to improve the overall follow-up rate. To comply with CoC guidelines for cancer program approval, it is also the responsibility of the cancer committee to monitor separately the follow-up rate for living patients.

STANDARDS FOR CASE FINDING AND FOLLOW-UP

The SEER Program has developed standards based on its experience and quality control studies, which might be useful to you in evaluating your case finding as well as your follow-up.

Case ascertainment

Ninety-nine percent of all cases seen in hospitals should be registered each calendar year. For central registries reporting cancer incidence rates[1], case ascertainment in non-hospital sources is essential in order to avoid under-reporting cases managed outside the hospital and to reduce the number of Death Certificate Only (DCO) cases. The percent of DCO diagnoses should not exceed 1.5 percent of the total number of invasive cases registered for a given year after follow-back[2] efforts have been completed.

[1] Incidence rates: Rate of occurrence of new cases that are diagnosed during a set time period in a defined population.

[2] Follow-back: A check to verify that Death Certificate-Only cases were *not* diagnosed and/or treated prior to death.

FOLLOW-UP RATE WORKSHEET

Use the following scheme for calculating follow-up rates.

I. **Follow-up rate for all patients (living and dead)**

		Number	Percent
Total cases in the registry since reference date		(____)	_____
1. Less benign and borderline cases		(____)	_____
2. Less carcinoma in situ of the cervix cases		(____)	_____
3. Less cases of in situ and localized basal and squamous cell carcinoma of skin		(____)	_____
4. Less foreign residents (excludes Virgin Islands and Puerto Rico)		(____)	_____
5. Less non analytic cases		(____)	_____
Subtotal cases = Analytic cases	(A)	_____	100%
1. Less number dead	(-B)	_____	_____
Subtotal cases (number living)	(C)	_____	_____
1. Less number current (known to be alive in the last 15 months)	(D)	_____	_____
Total (lost to follow-up or not current)	(E)	_____*	_____*

[*should be 10% or less of Line A]

Note: Line A minus Line B equals Line C
Line D plus Line E also equals Line C
Line B plus Line D plus Line E equals Line A
Or
$A - B = C; D + E = C; B + D + E = A$
To calculate percentages, divide lines B, C, D, and E by Line A

II. Follow-up rate for living patients only

1. Enter the total number from Line C	(C)	_____	100%
2. Subtract the total number from Line D	(D)	_____	_____
3. Total lost/not current of living patients	(E)	_____	_____

Note: To calculate percentages, divide lines D and E by line C
OR: $D + E = C$

A target rate of 80% for the follow-up of only LIVING patients has been established by the CoC.

Follow-Up

Complete follow-up is essential if survival rates are to be calculated. The CoC requires:

1. a 90% follow-up rate for all patients (living and dead)
   A. At least 90 percent of all patients registered (living and dead) should have either
      1. a reported follow-up date within 15 months (if alive) or
      2. a known date of death
2. an 80% follow-up rate for living patients only
3. do not use the following cases in follow-up rate calculations:
   A. Benign and borderline histologies
   B. Patients with carcinoma in situ of the cervix
   C. In situ and localized basal and squamous cell skin cancers
   D. Foreign residents
   E. Non analytic cases

The SEER Program requires a successful follow-up rate of 95 percent. Follow-up is done in conjunction with other procedures such as death clearance. The follow-up success rate calculation is based on all patients alive as of January 1 of the year in which follow-up is to take place. Patients with carcinoma in situ of the cervix are excluded from the calculation of the follow-up rate.

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q5 The main objective of case finding is _____.

Q6 What is over-reporting? _____

Give four examples of how it can occur.

A. _____

B. _____

C. _____

D. _____

Q7 In addition to lifetime medical surveillance of the cancer patient, follow-up is needed to evaluate _____ and to calculate _____ _____.

Q8 How is the follow-up rate calculated?

_____

_____.

SECTION F TEST ANSWERS

Q5 The main objective of case finding is **completeness**. (Under-reporting is likely to occur unless all sources of case finding are controlled.)

Q6 What is over-reporting?

Answer

Over-reporting is the result of reporting the same patient more than once. It can happen when:

A. The case is abstracted from different sources and the records are never consolidated.
B. A metastatic site is reported as a new primary.
C. Progression of disease is not recognized because different histologic terms are used to describe the tumor.
D. The patient's name has changed.

Q7 In addition to lifetime medical surveillance of the cancer patient, follow-up is needed to evaluate **treatment** and to calculate **survival rates**.

Q8 How is the follow-up rate calculated?

Answer

The follow-up rate can be calculated in two ways:

1. By dividing the number known to be dead or alive within the past 15 months by the number of all registered cases after all exclusions have been subtracted.
2. By counting the number of "lost" cases, calculating the percent lost, and subtracting from 100 percent.

QUALITY CONTROL OF ABSTRACTING

A complete and accurate abstract of the patient's medical information is the basic element of a cancer registry. The data items are collected using definitions and codes that have been developed after considering the needs and objectives of potential users.

If a hospital has an approved cancer program, the registry must adhere to the data requirements of the CoC. Central registries may have additional requirements specific to their particular program that will impact requirements of hospitals in their area of coverage.

Editing of abstracts for quality control may be done at several levels in the abstracting process. This may be in the form of visual edits, computer edits, and reabstracting/recoding studies.

Visual Edits

Many data items are amenable to visual review. For instance, visually comparing the items "age" and "birth date" will often reveal discrepancies of one or ten years. Comparing "name" and "place of birth" may identify race or ethnicity. For sex-specific sites such as cervix, uterus, ovary, prostate, and testis, a visual check that the sex is correct can be done quickly and easily.

A comparison of "site" and "histology" could reveal improbabilities or inconsistencies between the type of tumor and the site of origin. Some histologies are site-specific, i.e., a particular cell type occurs in a specific organ.

Immediate visual checks can find errors while the source documents are still available.

The following list contains some data items or identifier that can be visually edited.

VISUAL EDITS OF CANCER REGISTRY ABSTRACTING

ITEM	COMPARE TO ITEM	PROBLEM OR ERROR IDENTIFIED
Age	Birth date	Incorrect age Incorrectly entered birth date
Race	Patient name	Race, ethnicity
	Place of birth	Validity of race and ethnicity codes
Sex	Patient's name	Validity of "Sex" code
	Primary site	Validity of codes for sex-specific cancers (cervix, prostate)
Past history (prior diagnosis of cancer)	Current diagnosis	Prevent over-reporting
Primary site and type	Primary site and type	Prevent over-reporting
Treated or not treated	Primary site and type	Prevent over-reporting
Histologic type Squamous cell carcinoma	Primary sites Oral and nasal cavities Pharynx and larynx Trachea, bronchus and lung Esophagus Cervix, vagina, and vulva Anus, penis	Most common sites for specific histology
Histologic type Adenocarcinoma	Primary sites Stomach Small and large intestines, rectum Pancreas, gallbladder Endometrium, endocervix Prostate	Most common sites for specific histology
Histologic type Transitional cell carcinoma	Primary sites Bladder, urethra Renal pelvis, ureters Anorectal junction (cloaca)	Most common sites for specific histology

ITEM	COMPARE TO ITEM	PROBLEM OR ERROR IDENTIFIED
Histologic type Hepatoma/liver cell carcinoma Cholangio-carcinoma	Primary sites Liver Bile ducts (intra- and extrahepatic)	Most common sites for specific histology
Histologic type Hypernephroma Renal cell carcinoma Wilms' tumor	Primary site Kidney parenchyma	Most common sites for specific histology
Histologic type Seminoma Dysgerminoma Cystadenocarcinoma Granulosa/theca cell carcinoma	Primary sites Testis Ovary	Most common sites for specific histology
Histologic type Liposarcoma Fibrosarcoma Leiomyosarcoma Rhabdomyosarcoma Mesothelial sarcoma	Primary sites Soft tissue (adipose) Soft tissue (fibrous) Muscular wall of organs (uterus, stomach, small intestine) Skeletal muscles, organ walls (rare) Pleura, peritoneum	Most common sites for specific histology
Histologic type Osteogenic sarcoma Ewing's sarcoma Chondrosarcoma	Primary sites Bone Cartilage	Most common sites for specific histology
Histologic type Malignant lymphoma Hodgkin's disease	Primary sites Lymph nodes and other aggregates of lymphoid tissue	Most common sites for specific histology

ITEM	COMPARE TO ITEM	PROBLEM OR ERROR IDENTIFIED
Histologic type Leukemia Multiple myeloma	Primary site Bone marrow	Most common sites for specific histology
Histologic type Astrocytoma Glioblastoma multiforme Medulloblastoma	Primary site Brain (nervous system)	Most common sites for specific histology
Stage	Text supporting stage of disease. Narrative description of tumor extension, nodal involvement, and distant metastasis	Validity of stage
Treatment	Compare treatment to management guidelines for that site and stage of disease	Identify errors in treatment codes
Treatment	Compare cancer-directed treatment and diagnostic procedures Disease status and treatment (disease free, but no treatment)	Identify errors in treatment codes
Dates	Chronology of dates Intervals between admission, diagnosis, and treatment Initial course of therapy and first cancer-directed treatment	Identify unexplained delays

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q9 Quality control of abstracting can be performed in at least three different ways. They are:

A. _____

B. _____

C. _____

Q10 Name three examples of item comparisons which can be made as a cross-check for consistency.

A. _____

B. _____

C. _____

SECTION F TEST ANSWERS

Q9 Quality control of abstracting can be performed in at least three different ways. They are:

Answer

A. Visual edits
B. Computer edits
C. Reabstracting/recoding studies

Q10 Name three examples of item comparisons which can be made as a cross-check for consistency.

Possible answers

You could have chosen any of the following as examples of crosschecks.

A. Age and birth date
B. Race and place of birth
C. Sex and sex-specific sites such as prostate or ovary
D. Past history and current history
E. Histologic type and primary site
F. Stage and description of tumor extension
G. Treatment recorded and treatment expected
H. Chronology of dates of admission, diagnosis, and treatment

COMPUTER EDITS

The computer is an invaluable aid in quality control, but it cannot edit for all illogical ideas, subtle inconsistencies, or incomplete records. Examples of these deficiencies include:

1. Inconsistencies or errors in demographic items like name, race, or place of birth
2. Deciding whether a patient has a new primary or a metastasis
3. Rare site-histology combinations
4. Comparing the narrative description of the extent of disease to the stage of disease coded on the abstract
5. Delays in diagnosis or treatment
6. Unexpected delays between treatment modalities
7. Expected or recommended treatment that does not appear on the abstract
8. Patient refusal of treatment
9. Therapy contraindicated due to other conditions
10. Treatment to be given elsewhere

Although hands-on editing is still needed, computer edits identify the majority of abstracting and coding discrepancies. Edits are extremely efficient at detecting impossible combinations of codes and in comparing fields. Editing data as they are entered into the computer (for instance, single field edits) has the advantage of immediate feedback while the source documents are still readily available for review.

Computer edit checks fall into the following three categories:

1. Intra-field (single field) edits—invalid codes that have not been assigned to a particular field, for example, a code 7 when the field includes only codes 1-4 and 9
2. Inter-field edits—codes that are inconsistent between fields, for example, a female prostate case, a date of last contact that is earlier than the date of diagnosis
3. Inter-record edits—codes that appear on multiple records for the same patient (the patient has more than one primary), such as vital status

The North American Association of Central Cancer Registries (NAACCR) has published standardized computer edits in *Standards for Cancer Registries, Volume IV: Standard Data Edits*. (See Bibliography)

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q11 What are some of the limitations of computer edits?

A. _____

B. _____

C. _____

Q12 Certain categories of edit checks are most useful when performed by the computer. Name them and give an example of each.

A. **Type of edit check:** _____ edits

Example_____

B. Type of edit check: _____ edits

Example_____

C. Type of edit check: _____ edits

Example_____

SECTION F TEST ANSWERS

Q11 What are some of the limitations of computer edits?

Answer

The computer cannot always edit for:

A. Illogical information
B. Subtle inconsistencies
C. Incomplete records

Q12 Certain categories of edit checks are most useful when performed by computer. Name them and give an example of each.

Possible answers

A. Type of edit check: **Intra-field** edits Example: **A code 7 when the field includes only codes 1-4 and 9**.
B. Type of edit check: **Inter-field** edits Example: **A follow-up date earlier than the date of diagnosis.**
C. Type of edit check: **Inter-record edits**: Example: **When a patient has more than one reported cancer, multiple record comparisons**.

REABSTRACTING, RECODING

In addition to detecting errors and omissions, dual and independent abstracting by a second person is useful in uncovering differences in interpretation of rules and data item definitions. Discussion of any differences is an excellent tool for training new abstractors and introducing changes in policy or in definitions of data items.

Reabstracting every case is impractical. The usual procedure is to reabstract ten percent of the abstracts chosen by random sample[1]. The technique of sampling will be discussed later in this section.

Coding the various data items must be done according to established rules and definitions. Coding must be consistent over time and from one individual to another. Differences in interpretation can easily creep in unless abstracts are carefully monitored. There are several reasons for coding errors:

1. Misinterpretation of coding rules
2. Changes in codes or coding rules
3. Incomplete information
4. Data entry error

In addition to actual coding errors, the excessive use of catchall or nonspecific categories should be carefully monitored. Examples of catchall or nonspecific categories are:

1. Not recorded, unknown, unspecified, not stated
2. Nonspecific topography codes (.9) for sub-sites, such as stomach, NOS or colon, NOS
3. Use of primary site (C80.9) - unknown primary
4. Nonspecific morphology codes, such as carcinoma, NOS; leukemia, NOS; and melanoma, NOS
5. Nonspecific surgery codes (surgery, NOS, mastectomy, NOS)

Repeated coding errors call for additional training and discussion. Nonspecific codes may be used because physician documentation is inadequate. Problems such as this should be brought to the attention of the cancer committee. Nonspecific codes may be used because the abstractor did not try to obtain missing reports and the chart had incomplete information.

The use of standardized coding schemes is encouraged. Using standardized codes and code definitions makes it possible to compare your data with others. Hospital registries that participate in the CoC approvals program must collect and code data using the *Registry Operations and Data Standards (ROADS)*. SEER registries must collect and code data using the SEER *Program Code Manual.* The *International Classification of Diseases for Oncology* (ICD-O-2) is used by SEER and other national and international programs for coding site and histology.

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[1] Random sample: A method of statistical selection in which every individual in the population has an equal and independent chance of being chosen for the sample.

As the demand for more information becomes evident, other changes in data requirements may become necessary. Changes or revisions in codes and definitions, interpretation, inclusions, and exclusions that occur over time should be carefully documented with the date these changes were implemented. Sometimes conversions[1] from old data to new data are successful, but in the worst scenario, data from different periods will have to be analyzed separately.

[1] Conversion: The change of one set of codes to a different set of codes, for example, changing primary sites morphology coded by ICD-O-1 to ICD-O-2 codes

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q13 What are some of the benefits of reabstracting?

_____

_____

Q14 Why is the training of coders so important?

_____

_____

Q15 The quality of data will be improved if the use of _____ categories can be kept to a minimum.

Q16 When it is not possible for a second person to reabstract every case, the usual procedure is to select a _____ _____ of cases to quality control.

SECTION F TEST ANSWERS

Q13 What are some of the benefits of reabstracting?

Answer

Assessing the completeness of the abstract
Uncovering differences in interpretation among abstractors

Q14 Why is the training of coders so important?

Answer

Training for coders is important because codes and coding rules are subject to differences in interpretation. (No matter how carefully rules are written, there is always the possibility of misinterpreting the written word. A common understanding of all the rules and conventions is essential.)

Q15 The quality of data will be improved if the use of **catchall** categories can be kept to a minimum. (You could have said nonspecific, unspecified, unknown, or not recorded.)

Q16 When it is not possible for a second person to reabstract every case, the usual procedure is to select a **random sample** of cases to quality control.

QUALITY CONTROL STUDIES

In large institutions and those facilities participating in a central registry program, periodic audits may be necessary to uncover missed cases, incomplete and inaccurate abstracting and coding, and insufficient follow-up. These studies usually will be performed on cases registered over a selected interval of time. Depending on the size of the registry, this period may be as much as a year or as small as a random sample of several months.

In selecting the months to be sampled for a case finding study, certain precautions should be taken. For instance, January should not be included in a sample of fewer than six months because proportionally more January records are likely to contain diagnoses from the previous year. To ensure that the sample reviewed is not clustered into any one part of the year, half of the months sampled should be in the first six months and half in the last six months.

For reabstracting and/or recoding studies, an interval of time (usually a year) is selected for review. A random sample is taken of cases first seen during that calendar year. A ten-percent sample is usually adequate. If the error rate is high, a larger sample may be indicated.

The decision may be made to review a sample of all sites or selected sites. The decision to review selected sites is based on previous quality control studies that identified specific issues such as cases that are likely to be missed or difficult to abstract and code. Specific sites may be targeted when there have been changes in coding rules.

Studies conducted by central registries have the additional purpose of determining consistency and accuracy rates among their participating registries. However, it is not always feasible to audit every facility in the system. It may be necessary to randomly sample the facilities included in the study.

Evaluation of the findings is an important phase of these studies. Are the errors major or minor? A major error is one that would compromise the reliability of the cancer registry data for analysis and research. Are the errors consistent or random? What adjustments should be made in collecting these data? The registrar may be able to make the necessary corrections or they may require action by the cancer committee.

COMPLETING THE QUALITY CONTROL PROCESS

The primary reason for undertaking a quality control study is to identify problems or inconsistencies in a registry. However, there must be action taken to correct the problems and prevent them from recurring. It is very important to provide feedback to the abstractors and coders so they understand the problem and can take corrective actions. Feedback can be given in several ways.

1. Discuss individual errors privately. Patterns of errors can be discussed in group sessions with the registry staff. The group sessions would focus on inconsistencies among abstractors.
2. Schedule training sessions if the quality control study indicates a need for more education in a particular subject area. Training can be done in the registry as an in-service session or in a seminar/workshop format for a larger audience.
3. Review any documentation that may be unclear or confusing. Rewrite coding or rule definitions that were misinterpreted or misunderstood.

4. Take any necessary steps to improve case finding or follow-up procedures that caused problems. Steps to improve these procedures may include obtaining cooperation from other hospital departments and offices to assure case finding and follow-up completeness.
5. Create a working plan based on the issues raised by the quality control study. Focus on problem areas, working on the most serious problems first. It may take awhile for the data to show that corrective action has been taken, even if changes are made immediately to definitions and procedures.
6. Regular sessions with the registry's medical consultant are important. Schedule weekly or semi-monthly meetings to discuss problem cases and to review general questions about the abstracting and coding processes.

When changes have been made to correct problems, the registry must be sure that the changes were effective. An additional quality control study should be done as soon as sufficient data has been collected using the new procedures or definitions. Another quality control study should be performed one, two years after the new procedures or definitions were implemented to assure that the procedures, or definitions that were changed continue to be effective. This closes the quality control "loop" of identifying an issue, studying the issue, making corrections to processes, and re-evaluating the issue after changes have been implemented.

SECTION F TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q17 After a quality control study has been completed and the findings have been reviewed, what would the next steps be?

A. _____

B. _____

C. _____

D. _____

E. _____

Q18 A quality control study cannot review all cases for a given period so the study may be limited to the following areas:

A. _____

B. _____

SECTION F TEST ANSWERS

Q17 After a quality control study has been completed and the findings have been reviewed, what would the next steps be?

Answer

A. Discuss errors with the registry staff.
B. Provide staff with additional training.
C. Rewrite problem definitions for clarification.
D. Focus on problem areas.
E. Schedule regular sessions with the medical consultant.

Q18 A quality control study cannot review all cases for a given period so the study may be limited to the following areas:

Possible answers

A. A specific site or sites
B. Problem sites that are difficult to abstract
C. Problem cases that are difficult to code
D. Problem sites where cases are likely to be missed
E. Sites where coding rules have changed recently

SECTION G

CANCER REGISTRY FILES

There are generally five basic files maintained by a hospital cancer registry system: accession register, patient index file, suspense file, abstract file, and follow-up control file.

ACCESSION REGISTER

Cases are added to the accession register as they are abstracted using a consecutive numbering system. The register is an annual, sequential listing of all reportable cancers entered into the registry. The accession register can be used for auditing registry files to check timeliness of abstracting, completeness of case finding, and other aspects of registry procedures. The accession register can be computerized or manual. A computerized register must be available for printing on demand. As a minimum, the register contains:

1. Accession number (unique registry number)
2. Sequence number
3. Patient's name
4. Primary site
5. Date of diagnosis
6. Patient's medical record number or a unique patient identifier

If the registry serves multiple institutions, the accession register must contain an institution identifier.

PATIENT INDEX FILE/MASTER PATIENT FILE

The patient index file may be computerized or manual. If computerized, the patient index file must be available for printing on demand.

The manual patient-index file is an alphabetical card file of all cases (alive and dead) which serves as a master reference to registered cancer cases. Multiple neoplasms for the same patient should be indexed on the same master patient-index card. The file card must contain enough identifying information to avoid duplicate registration of cases.

The computerized patient index listing and the manual patient-index file must contain the following information:

1. Patient's name
2. Medical record number
3. Accession number
4. Primary site(s)
5. Laterality
6. Histology(ies)
7. Date(s) of diagnosis

8. Sequence number(s)
9. Date of death
10. Date of birth
11. Sex

Optional information (could be included):
1. Admission and/or discharge date
2. Social Security Number (when available)
3. Name of spouse

If the patient has multiple primaries, the patient index must include the following information for each primary:
1. Primary site
2. Laterality
3. Histologic type
4. Date of diagnosis
5. Sequence number

SUSPENSE FILE

The suspense file is a file or list of cases that have been identified by the registry but have not yet been completely abstracted. The list of cases should be sorted by date of diagnosis.

A suspense list may be computerized or manual and must contain:
1. Patient's name
2. Patient identifier (medical record number, Social Security Number)
3. Date of diagnosis
4. Primary site

If the registry serves multiple institutions, the suspense file must include an institution identifier ("Institution ID Number").

Information from multiple sources (pathology, medical records, radiation oncology, and so forth) for the same patient can be merged in the suspense file.

PRIMARY SITE/ABSTRACT FILE

If the registry maintains copies of its abstracts, the abstract file contains paper abstracts or computer-generated abstracts of all registered cancer cases arranged according to primary site. (The classification of primary sites will be discussed later.) The file is usually arranged by primary site and year of diagnosis. It can be in alphabetical or chronological order within each primary site.

In a manual registry, the abstract file facilitates selection of cases for special reports and studies. It makes possible a quick review of particular cancers by the hospital staff. It also facilitates the selection of cases for preparation of summary reports. Abstracts filed by site eliminate the need for an additional card file.

In registries approved by the CoC, storage of paper documents is not required if the registry computer system can print abstracts on demand.

FOLLOW-UP CONTROL FILE

Lifetime follow-up is an integral part of the care of the cancer patient. Every cancer patient must be followed at least annually. A follow-up control file includes information on living patients only. It alerts the cancer registrar to cases due for follow-up. It is sometimes called a "reminder" or "tickler" file as discussed in Section E.

An automated or computerized registry will utilize the capability of computers for efficient handling of follow-up procedures. A follow-up list, list of cases that are lost-to-follow-up, and a variety of follow-up letters can be generated by computerized registry software. Section K of this manual will introduce you to computers and ways in which they can be used in the operation of your cancer registry.

In a manual follow-up system, cards are filed according to the date that the patient is due to be followed (month of expected next contact). Each month you can see at a glance which are to be followed, and at any time, you can detect those patients for whom follow-up information is late or missing. The follow-up card may be used to record sources of follow-up information, such as the patient's physician(s), the patient's address and telephone number, and names and addresses of relatives or other information.

SECTION G TEST QUESTION

Circle the best answer or fill in the blank as appropriate.

Q1 List the usual files maintained by a hospital registry:

A. _____

B. _____

C. _____

D. _____

E. _____

SECTION G TEST ANSWER

Q1 List the usual files maintained by a hospital registry.

Answer

A. Accession register or yearly listing of all patients
B. Patient index file
C. Suspense file
D. Primary site/abstract index
E. Follow-up control file

SECTION H

PREPARATION OF REPORTS

The collection of cancer registry data, case finding, abstracting, coding, quality control, and follow-up, culminates in use of the data. This may mean providing follow-up information on a single patient or preparing a comprehensive summary of all of the cases in the registry according to their demographic characteristics, diagnosis, treatment, and survival. Most applications will fall somewhere in between. Most reports will involve cases of selected sites or histologies, age groups, times, or treatment modalities.

The cancer registrar should be prepared to retrieve relevant information from the files and to summarize and present the data in well-designed reports. Tables and graphs should be used to illustrate specific observations. The presentation of numerical information—counts and percentages—should be accompanied by some descriptive narrative pointing out important features of the data.

The cancer registry database contains a wealth of information for education and research. It may provide all of the information needed for a particular study, or it may be used as a springboard to a more comprehensive investigation.

SPECIAL REPORTS

Sometimes physicians will request only the raw data from which they will do their own analysis. It is the cancer registrar's responsibility to make sure that users of the data are provided with the definitions of data items, the collection rules pertinent to those data and the inclusions and exclusions inherent in the data. It is particularly important to notify data users of changes in classifications and coding of cases over the years.

Reports on cancer registry activities should be presented periodically at tumor board (cancer conference) and to the Cancer Committee. Two examples of reports are:

1. a graphic representation of the number of cases entered and followed over a period of time.
2. a cross tabulation of a single primary site compared to a selected variable, such as age, sex, histology, stage, treatment, or survival.

REQUEST LOG

To document use of cancer registry data, a log of data requests must be maintained. The log must contain:

1. Date of request
2. Topic of the report including period covered
3. Variables included in the report
4. Name of person or persons requesting the report
5. Purpose of the report, such as study, paper, oral presentation
6. Final disposition of report, for example, presented at a medical staff meeting, published in a medical staff bulletin, or presented at a county medical association meeting

ANNUAL REPORT

For hospitals seeking CoC approval of their cancer program, there are certain requirements to be met. The CoC requires that the hospital report annually on its activities. In addition, cancer registry data must be used throughout the year for special studies, cancer conferences, administrative reports, and other purposes. An annual report must be published by November 1 of the following year and must include:

1. Narrative summary
   A. A narrative summary describes the goals, achievements, and activities of the hospital's cancer program for the reporting period. It is written by a physician member of the Cancer Committee, usually the chairman.
2. Report of registry activity
   The report will cover the range of registry activities, such as:
   A. The number of cases abstracted during the year.
   B. Follow-up activity and status, including number of cases followed follow-up percentage for living patients and follow-up percentage for all cases.
   C. The number and type of requests for data.
   D. A list of publications using cancer registry data.
   E. Participation of registry staff in cancer-related hospital, community, and professional association activities.
   F. Statistical summary of registry data for the calendar year including:
      1. Data distribution of primary sites.
      2. Tables and graphs highlighting the most frequent sites.
      3. Comparison of data using national, state, or regional data, if available.
      4. Narrative statement that links the data to the management of cancer in the hospital.
3. Detailed statistical analysis of at least one major cancer site (one of the five sites most frequently seen at the reporting institution). Patient-care improvement studies can be used if appropriate.
   A. The analysis must include survival data calculated by the life-table or actuarial method (observed rate).
   B. The analysis should include other descriptive statistics in appropriate graphic, tabular, or narrative form.
   C. Overall narrative analysis or critique of the data by a physician member of the cancer committee.
   D. The statistical analysis should be done using AJCC stage.

The contents of the annual report can be individualized depending on the size of the hospital, the reference date of the registry, and the interests of the staff. Copies of the report should be distributed to the hospital's medical and administrative staffs.

Preparation of Tabular Material

Use tables to present numerical information clearly and to make it easy to analyze and to compare the data. They may be short, compact tables included in the body of the report or long multi-page tables displayed in an appendix. Tables should be a part of the presentation and should illustrate something that is relevant to the discussion. Tables that are not discussed in the form in which they appear should be placed in the appendix. *Book 7, Statistics and Epidemiology for Cancer Registrars* of the Self-Instructional Manual series, provides guidelines for the construction of tables and graphs.

Use of Graphic Material

Graphs will generate interest in your report and are often the best means of demonstrating certain findings. They are particularly effective in showing trends and making comparisons that might not be as easily understood if presented in a table format. As with tables, graphs should be an integral part of the presentation. Remember that not all types of graphs are suited to all situations. For example, a single pie chart for lung cases by stage of disease is fine, but using two pie charts to compare the ratio of males to females would not provide an easily understood visual representation. The creation and use of the different types of graphs—bar graphs, pie charts, line graphs, picture graphs, and geographic maps—are included in Book 7.

The registrar should also be aware that the use of graphics without a narrative discussion or descriptive text could detract from the effectiveness of the report.

Writing the Narrative

The preparation of reports requires good writing skills. There are many good references on styles of report writing which are beyond the scope of this manual. A well-written report should be:

1. Clear — Convey the exact meaning as simply as possible.
2. Complete — Account for all inclusions and exclusions, such as non analytic cases, in situ stage, not-recorded, and not applicable categories.
3. Substantive — Only make significant statements that are supported by the data.
4. Correct — Observe rules of good grammar, punctuation, and spelling. Check accuracy of numbers and statements based on numbers.
5. Consistent — Organize material so that subheadings, abbreviations, punctuation, and changes in type style are consistent throughout the report.
6. Concise — Eliminate superfluous words and phrases except to introduce variety to the text. Some examples of superfluous words and phrases are:

REPLACE SUPERFLUOUS	WITH
In the event that	If
At this time	Now
Prior to	Before
In order that	So
In view of the fact that	Because
A number of	Several
A considerable number of	Many
In a considerable number of cases	Often
In most cases	Usually
Is characterized by	Shows

Other principles of effective writing to bear in mind:

1. Write short sentences.
2. Use active rather than passive words or phrases.
3. Use your dictionary and thesaurus liberally.
4. Proofread, revise, rewrite, and proofread again.

Deciding what to say will come after careful examination of the data. Summarizing the data in the registry will yield valuable information about the cancer experience in your hospital or region. The summaries will facilitate the identification of trends and changes such as:

1. Concentrations of patients in certain age groups.
2. Changes in site distributions over the years.
3. Variations in stage distributions between sites and over time.
4. Improvements or leveling-off of survival time following diagnosis.

With a little experience, preparation of the annual report can be an exciting undertaking and one which will be the rewarding result of all the work it takes to gather the data for the registry.

Layout of the Report

Appearance is a major factor in an effective report. The visual impact of your report format will go a long way to invite readership. Design each page so that it attracts attention and is easy to read. Create an uncrowded appearance by use of ample margins and white space. Present the material in small units with the use of subheadings. The judicious use of tables and graphs interspersed with narrative interpretation is most attractive. Use various type sizes (10-point, 12-point, and 16-point) and type styles (plain, bold, Italics, capitalization) to add variety.

The arrangement of a long, formal report corresponds to the standard parts of a book:

1. Title Page
2. Table of Contents
3. List of Tables and Figures
4. Body (narrative)
5. Appendix (long tables)

Reports are a Group Effort

The registrar should not work alone in analyzing and presenting data but should seek the professional assistance of physicians, medical illustrators, statisticians, epidemiologists, health education specialists, and even the public relations and graphic design staff in the institution. However, the cancer registrar and the cancer committee should be responsible for the final editing of the data and its interpretation.

SECTION H TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 What is the purpose of a cancer registry? How can this purpose be achieved?

A. _____

B. _____

Q2 To document the use of registry data, a _____ of requests must be maintained. It must include the following information:

A. _____

B. _____

C. _____

D. _____

E. _____

F. _____

Q3 Hospitals seeking American College of Surgeons (ACoS) Commission on Cancer (CoC) approval of their cancer programs must prepare an _____ _____ that contains information about the activities of their _____ _____and_____ _____.

Q4 The annual report must include:

A. _____

B. _____

C. _____

D. _____

Q5 Name two reasons for using tables in reports.

A. _____

B. _____

Q6 Name two reasons for using graphs in your reports.

A. _____

B. _____

Q7 What are six essential elements of a well-written narrative?

A. _____

B. _____

C. _____

D. _____

E. _____

F. _____

Q8 What is the usual format for a long, formal report?

A. _____

B. _____

C. _____

D. _____

E. _____

SECTION H TEST ANSWERS

Q1 What is the purpose of a cancer registry? How can this purpose be achieved?

Answer:

A. The basic purpose of a cancer registry is to **provide data for education and research**.

B. This purpose can only be achieved by **using the data in reports**. Data must be provided to physicians or authorized users as needed or requested.

Q2 To document the use of registry data, a **log** of requests should be maintained. It must include the following information:

A. date of the request
B. topic of the report, including period covered
C. variables included in the report
D. person or persons requesting the report
E. purpose of the report, such as study, paper, oral presentation
F. final disposition of report, (for example, presented at a medical staff meeting, published in a medical staff bulletin, or presented at a county medical association meeting)

Q3 Hospitals seeking American College of Surgeons (ACoS) Commission on Cancer (CoC) approval of their cancer programs must prepare an **annual report** that contains information about the activities of their **cancer program** and **cancer registry**.

Q4 The annual report must include:

Answer

A. A narrative summary that includes goals, achievements, and activities of the hospital's cancer program.
B. A report of registry activity, such as number of cases abstracted and followed during the year, number of type of requests for data, copies of publications using cancer registry data, and participation of registry staff in cancer-related hospital, community, and professional association activities.
C. A statistical summary of registry data for the calendar year.
D. A detailed statistical analysis of one or more major sites of cancer, including survival data.

Q5 Name two reasons for using tables in reports.

Answer

A. It is easier to analyze data that is organized in tables.
B. It is easier to compare data when it is displayed in tables.

Q6 Name two reasons for using graphs in your reports.

Answer

A. Graphs create interest in your report.
B. Graphs are often the best way to represent certain findings.

Q7 What are six essential elements of a well-written narrative?

Answer

The narrative should be:

A. Clear: Convey the exact meaning as simply as possible.
B. Complete Explain all inclusions and exclusions.
C. Substantive Only make significant statements that are supported by the data.
D. Correct Observe rules of good grammar, punctuation, and spelling. Check accuracy of numbers.
E. Consistent Organize material so that subheadings, abbreviations, punctuation, variations in type style are consistent.
F. Concise Eliminate superfluous words and phrases.

Q8 What is the usual format for a long, formal report?

Answer

A. Title page
B. Table of Contents
C. List of Tables and Figures
D. Body
E. Appendix

SECTION I

RELATIONSHIP OF CANCER REGISTRIES TO MEDICAL FACILITIES, OTHER DEPARTMENTS AND MEDICAL ORGANIZATIONS

The purpose of this segment is to give you a general understanding of how a cancer registry relates to the facility administration, to other departments, and to institutional committees. This section will also provide you with additional orientation to the job of a cancer registrar.

RELATIONSHIP TO THE FACILITY AND OTHER DEPARTMENTS

There may be frequent interaction between a cancer registrar and persons from other departments such the departments of surgery, pathology, radiology, and nuclear medicine. Much of the information that eventually appears on a cancer registry abstract originates in one of these four departments. In addition, the cancer registry must maintain a close working relationship with the HIM department. This department is responsible for

1. assembling the patient record.
2. analyzing the medical record for completeness.
3. coding diagnoses and procedures to create a disease index.
4. routing the medical record to the cancer registry.
5. storing the medical record on a permanent basis.

ADMINISTRATIVE ORGANIZATION

The administration of a medical facility usually consists of three components:

1. Governing body of the hospital
2. Administrator/Chief Executive Officer
3. Medical staff organization
   A. Chief of Staff/President of Medical Staff Executive committee
   B. Clinical departments: pathology, radiology, physical medicine, nuclear medicine, special care units
   C. Medical staff committees: cancer committee, utilization review, medical education, credentials, bylaws, quality assurance

CANCER REGISTRY ORGANIZATION

Administration

A cancer registry in a large hospital is usually an autonomous department with a certified cancer registrar (CTR) serving as its director or chief. A cancer registry in a small hospital may be located within other administrative units, for example, pathology, radiation therapy, surgery, or the HIM department. The registry's medical director/consultant is a member of the professional staff of the hospital, and is usually a medical oncologist, a surgeon, a pathologist, or other medical specialist.

Cancer Committee

The CoC requires that the cancer committee:

1. Be a standing committee of the medical facility.
2. Provide leadership for all oncology-related activities.
3. Have a multidisciplinary[1] composition.
4. Be responsible for the cancer registry.
5. Supervise the cancer registry and ensure accurate and timely abstracting, staging, and follow-up.
6. Monitor quality management and improvement through completion of patient care studies that focus on quality, access to care, and outcomes.
7. Publish an annual report by November 1 of the year following the collection of the data.

The CoC recommends that the cancer committee:

1. Develop and evaluate annual goals and objectives for the clinical, educational, and programmatic activities related to cancer care.
2. Promote a coordinated multidisciplinary approach to patient management.
3. Ensure that educational and consultative cancer conferences are available to the medical staff and allied health professionals.
4. Ensure that educational and consultative cancer conferences cover all major sites and related issues.
5. Ensure an active supportive care system for patients, families, and staff.
6. Promote clinical research.
7. Perform quality control of registry data.
8. Encourage data usage and regular reporting.
9. Ensure that the content of the annual report meets requirements.

Medical Consultant

The medical consultant is responsible for the direct supervision of the cancer registry. The medical consultant will usually be a member of the cancer committee. Consultants from other departments of the hospital may be assigned to advise the cancer registrar on abstracting or coding difficult cases.

1. Pathologists
2. Surgeons
3. Medical oncologists
4. Radiologists
5. Medical specialists

[1] Multidisciplinary: Including representatives from all appropriate disciplines.

Cancer Conference (Tumor Board)

The CoC requires that cancer conference

1. provide consultative services to cancer patients.
2. are multidisciplinary in attendance and participation.
3. present enough cases to equal ten percent of the annual analytic caseload.
4. present all major sites each year.
5. convene at least as frequently as is appropriate for the facility's category of approval.
6. ensure that didactic conferences are limited to 25 percent of the total conferences presented.

The CoC recommends that cancer conference meet the following goals:

1. Physicians from other disciplines (who do not treat cancer patients) attend and participate in cancer conferences.
2. The cases presented represent the case mix seen by the facility.
3. The documentation of the conference include the meeting date, disciplines represented, the number in attendance, sites discussed. It should also identify the conference as prospective or retrospective.
4. The majority of conferences are patient-oriented and consultative.

Departmental cancer conferences can be counted as cancer conferences, but they must be designated in advance as cancer conferences, and must have multidisciplinary attendance.

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The cancer registrar's involvement in the cancer conference includes presentation of data and identification of cases for discussion

HEALTH INFORMATION MANAGEMENT (MEDICAL RECORD) DEPARTMENT

As described in Section C, after a patient is discharged from the hospital, the medical record is sent to the health information management department (HIM). The HIM is responsible for assembling various medical reports for each patient, checking the record for completeness, combining it into a single patient file, and coding and indexing the records for future reference as follows:

1. Assemble medical reports from time of admission to discharge in a specific order, such as:
   A. Admission record (face sheet)
   B. Discharge summary
   C. History and physical
   D. Diagnostic procedures
   E. Operative (surgical) reports
   F. Pathology reports
   G. Medical laboratory reports
   H. Radiation therapy reports
   I. Progress reports
   J. Nurses' notes
   K. Consults
2. Analyze the reports for completeness

3 Code for reimbursement
   A. Choose various parameters from computer software program to group or index diagnosis-related groups
   B. Diagnostic index, assign codes for each diagnosis, using ICD-9-CM
   C. Operations index
   D. Physicians' index
   E. Master patient index
4. File the medical records, usually using a numerical, terminal digit system

DEPARTMENT OF SURGERY: ORGANIZATION

The department of surgery is one of the hospital departments most involved with the diagnosis and treatment of cancer because numerous diagnostic techniques are surgical in nature. In addition, many cancers are treated by surgery or a combination of treatments that includes surgery.

Specialties

Many of these specialists have a subspecialty in cancer surgery, for example, gynecologic oncology.

1. General surgery
2. Head and Neck
3. Gynecology
4. Genitourinary
5. Orthopedic
6. Pediatric
7. Plastic/reconstructive
8. Neurosurgery
9. Thoracic

Procedures

1. Diagnostic (See *Book 5, Abstracting a Medical Record: Patient Identification, History, and Examinations*)
2. Definitive surgical procedures, excisions, resections of involved organ(s), tissues, lymph nodes (See section L)
3. Supportive/palliative
4. Reconstructive

The Operative/Surgical Report

When surgery is performed, a detailed description of the surgical procedure and outcome is dictated by the surgeon and inserted into the medical record. A report of surgery or operative report is important for the registrar as an indication of what procedure was done, as well as a source of important diagnostic and staging information. It should state the exact location of the cancer in the body, the size of the tumor, and the extent to which the cancer has spread throughout the body. The operative report includes:

1. Specimen description
2. Pre-operative diagnosis
3. Name of operation
4. Post-operative diagnosis
5. Operative findings

Samples of the surgery report (or description of operation) follow. Additional reports can be seen in See *Book 5, Abstracting a Medical Record: Patient Identification, History, and Examinations*.

SAMPLE OPERATIVE REPORT # 1
PAGE 1

PATIENT:	Mary Kidd
DATE OF OPERATION:	7/28/98
PREOPERATIVE DIAGNOSIS:	Infiltrating ductal cancer of the left breast
POSTOPERATIVE DIAGNOSIS:	Infiltrating ductal cancer of the left breast
OPERATION:	Left breast lumpectomy and axillary dissection

INDICATIONS: The patient is a 67-year-old female who had left breast cancer diagnosed by serial biopsies, infiltrating ductal with a 1.5 cm lesion noted on mammogram.

PROCEDURE: The patient was brought to the operating room, intubated and was sterilely prepped and draped in the usual sterile fashion. Incision was made to include prior biopsy site. The incision was carried down and careful dissection was done around the needle level placed for localization. Careful dissection was done down to 7 cm into the needle. Once dissection had been carried off a careful hemostasis was achieved and the mass was removed in the base 10 cm down. All noted gross tumor was removed. A separate incision was made in the axilla after subcutaneous sutures were placed in the breast tissue to close the breast, followed by subcuticular closure of the breast. Once the incision had been made in the axilla, the incision was carried down to the axillary contents, which were removed. The axillary vein was identified and the thoracodorsal and long thoracic nerve were incised. The lymph nodes were removed and sent as a wedge specimen to pathology. The wound was closed initially with Vicryl #3-0 subcutaneous sutures followed by subcuticular closure of the skin. The wounds were dressed and a fresh dressing was placed on the left breast. The patient was then extubated and sent to the recovery room in stable condition.

SAMPLE OPERATIVE REPORT # 2 PAGE 1

PATIENT:	Mavis Gates
DATE OF OPERATION:	7/2/98
PREOPERATIVE DIAGNOSIS:	Obstructive right colon cancer with diffuse liver metastases
POSTOPERATIVE DIAGNOSIS:	Obstructive right colon cancer with diffuse liver metastases
OPERATION:	Right colon resection with end-small bowel to side-colon anastomosis (CPT 44160)
ESTIMATED BLOOD LOSS:	300 cc
BLOOD REPLACEMENT:	None
IV FLUIDS ADMINISTERED	Albumin, 1,000 cc
OPERATIVE TIME:	Approximately four and one half-hours

INDICATIONS FOR PROCEDURE: Ms Gates is a 77 year-old female who was admitted on an emergency basis three days earlier. She had a CAT scan that showed diffuse liver metastases. More importantly, she came in with symptoms of partial obstruction and on colonoscopy was found to have a partially obstructing cecal carcinoma. She was brought to the operating room after being able to be partially cleaned out.

PROCEDURE: The patient was placed supine on the operating room table. Next, the abdomen was prepped and draped in the usual sterile manner. A skin incision was made and taken around the umbilicus. The fascia was divided using electrocautery. The Thompson retractor was used to gain full surgical exposure. As mentioned, she had liver metastases noted. There was a large mass in the cecum obstructing the terminal ileum, and more importantly, there was extensive retroperitoneal extension almost to the point of the head of the pancreas and the duodenum. It took us several hours to dissect the right colon off the prerenal space because of the extensive tumor mass. There certainly was partial obstruction but we were able to clean her out, and though her small bowel was dilated, it was not ischemic and it was not full of material. The terminal ileum was divided with the GIA stapler and the midtransverse colon was divided using the GI stapler. The right branch of the middle colic artery and vein were ligated and divided, as well as the right colic and mesocolic branches. We were finally able to get a good resection after spending some time in the retroperitoneum and getting it off the ureter, the duodenum, and the head of the pancreas.

The stapled end of the transverse colon was oversewn and an end-small bowel to side-transverse colon anastomosis was done using standard two-layer technique with #3.0 silk on the outside and a running #3.0 Maxon inner layer. The patient tolerated the procedure well. The mesenteric defect was closed with absorbable sutures. The fascia was closed with Prolene suture, the skin was stapled. The patient tolerated the procedure well and was taken to the recovery room.

SAMPLE OPERATIVE REPORT # 3 PAGE 1

PATIENT:	Audrey Hind
DATE OF OPERATION:	7/133/98
PREOPERATIVE DIAGNOSIS:	Bilateral thyroid nodules
POSTOPERATIVE DIAGNOSIS:	Bilateral thyroid nodules
OPERATION:	Total thyroidectomy
ANESTHESIA:	General endotracheal
ESTIMATED BLOOD LOSS:	Estimated blood loss was minimal
IV FLUIDS:	Crystalloid, 1100 cc
SPECIMEN:	Thyroid gland
COMPLICATIONS:	None
DRAINS:	None

OPERATIVE FINDINGS: A large multinodular thyroid bilaterally. No evidence of lymphadenopathy. Both recurrent laryngeal nerves identified and preserved as well as the superior laryngeal nerves. Parathyroids were visualized and preserved.

INDICATIONS: The patient is a 29 year old female with a history of thyroiditis, thyroid nodule and cyst getting larger who presents for evaluation for thyroidectomy.

PROCEDURE: The patient was brought to the operating room and general anesthesia was achieved. The patient was prepped and draped in the usual sterile fashion. A collar incision was made with a #15 scalpel blade and dissected down with Bovie electrocautery down to the platysma muscles. Flaps were raised onto the platysma over the deep cervical fascia up to the thyroid cartilage proximally and down to the sternal notch and clavicles inferiorly. The strap muscles were opened in the midline vertically in the avascular plane using Bovie electrocautery. Strap muscles were dissected apart with Bovie electrocautery and Metzenbaum scissors, and vessels were tied between two clamps. The sternothyroid muscles were retracted medially beginning on the right side. We dissected down staying close to the clamp, finding a large multinodular gland. The middle thyroid vein was first identified and ligated and transected. We then moved the dissection superiorly up, freeing up the superior pole, identifying the superior pole vessels, ligating and transecting them as well. The superior laryngeal nerve was identified and preserved. The clamp was then retracted towards the midline, superior laryngeal nerve was identified and preserved. Fatty tissue on the posterior part of the surface, which appeared to be parathyroid was dissected off and preserved. Dissection within the area of the middle thyroid vein inferior to the cricopharyngenus muscle and the cricothyroid membrane and the tracheoesophageal groove was identified. What appeared to be a nonrecurrent laryngeal nerve on the right side was dissected into the cricopharyngeal muscle and was preserved throughout the entire course. The inferior pole vessels were then taken, being careful to stay away from the inferior parathyroid gland and recurrent laryngeal nerve. We were able to mobilize the whole gland. Buried ligaments were taken off the trachea using Bovie electrocautery and dissected towards the left of midline. Attention was then taken to the left gland that was approached in a similar fashion.

Sample operative report # 3 page 2

Staying close on the gland we transected the middle thyroid vein, went up superiorly to identify the nerve, ligated and transected the superior thyroid vessels. The laryngeal nerve was identified and what appeared to be parathyroid was dissected off the posterior portion of the gland, dissecting down and identifying the recurrent laryngeal nerve throughout its entire course, taking inferior vessels. Again a large nodular gland was retracted and pulled up inferiorly. All vessels on both sides and tissue that was suspicious was ligated with silk ties and transected. The buried ligaments were again taken off the trachea. All vessels were identified, as well as all parathyroid. The specimen was removed and labeled. There was no evidence of any parathyroid in the specimen and the specimen was sent for pathology. The wound was well irrigated. There was no evidence of any active bleeding. Small subcutaneous areas were once again tied with #4.0 silk ties. The strap muscles were reapproximated with a Vicryl suture. The platysma was approximated with interrupted Vicryl sutures and the skin was closed with clips. Dry sterile dressing was applied. The patient tolerated the procedure well and was extubated. During extubation, the vocal cords were observed to move bilaterally with fiberoptic bronchoscopy by the anesthesia department and were both visualized to move equally. The patient tolerated the procedure well and was brought to the recovery room in stable condition.

SAMPLE OPERATIVE REPORT # 4 PAGE 1

PATIENT:	George Whitfield
DATE OF OPERATION:	10/29/98
PREOPERATIVE DIAGNOSIS:	Carcinoma of prostate
POSTOPERATIVE DIAGNOSIS:	Carcinoma of prostate
OPERATION:	Ultrasound-guided transperineal prostate implant
ANESTHESIA:	Spinal

HISTORY: The patient is a 55 year-old gentleman who is known to have CA of the prostate and was earlier given external beam radiotherapy and comes in for the implants.

PROCEDURE: The patient was brought to the operating room and was given spinal anesthesia. He was put in the dorsal lithotomy position, prepped and draped in a sterile fashion and an ultrasound probe was introduced into the rectum and water was added to the balloon. The prostate gland was scanned from the base to the apex. The perineal template was added to the probe and two stabilizing needles were inserted into the prostate gland. The first needle was introduced and inserted into the prostate via the transperineal approach using the template coordinate as a guide. The pattern of needles and seed placement was determined from a computerized treatment plan based upon recent volume study. The position of each needle tip and its depth of insertion into the prostate were monitored using ultrasound and fluoroscopy. The plan called for a total of 89 palladium 103 seeds to be inserted. When this was accomplished, the implant area was visualized using fluoroscopy and six additional seeds were added to the apical region of the prostate. After this, the probe was removed. The penis was sprayed with Betadine and a cystoscopy was performed. No loose seeds were seen in the bladder. The prostatic urethra did show some signs of needle entry, but no seeds were seen in the prostatic urethra either. The Foley catheter was then put into the bladder and the patient was transferred to the recovery room in good condition. He was scheduled to have the x-rays and CT of the pelvis in the department of oncology the next day along with the removal of the Foley catheter.

PATHOLOGY DEPARTMENT ORGANIZATION

The pathology department performs the microscopic[1] examination of tissues and cells. Reports from this department usual contain the most detailed, accurate description of the primary site and the histologic type.

Types of Microscopic Examinations

1. Histology[2] (tissue, bone marrow) biopsy, surgical excision/resection
2. Cytology[3] (cells) such as Pap smear, sputum, pleural and ascitic fluids
3. Hematology (blood)
4. Autopsy

Each of these microscopic examinations is reported on a special form to describe test findings. Often these forms are color coded. A cancer registrar will be able to recognize them and to know when they contain information that should be recorded on a cancer registry abstract.

Pathology Report

A pathology report contains:

1. Clinical diagnosis/pre-operative diagnosis
2. Specimen description
3. Gross findings
4. Microscopic findings
5, Final diagnosis

Pathology reports may be used as a source for locating cancer cases. The names of patients that are obtained from the pathology department can be compared with the list of patients who have been identified by the health information management department to ensure that all cancer patients are entered into the registry.

Examples of pathology reports follow. Additional reports can be seen in See *Book 5, Abstracting a Medical Record: Patient Identification, History, and Examinations*.

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[1] Microscopic: of or pertaining to a microscope, which is an optical instrument that uses a combination of lenses to produce magnified images of objects too small to be seen by the unaided eye.

[2] Histology: The microscopic examination and study of tissue obtained by biopsy (excision of a tissue sample), surgery, or autopsy.

[3] Cytology: The microscopic examination of cells obtained by aspirations, washings, scrapings, and smears (such as a Pap smear).

SAMPLE SURGICAL PATHOLOGY REPORT # 1
PAGE 1

PATIENT: Mavis Gates
SPECIMEN NUMBER: 98-0592
SEX: F
DATE RECEIVED: 7/2/98

CLINICAL DIAGNOSIS AND HISTORY: None given

GROSS DESCRIPTION
The specimen is labeled as obstructed right colon with retroperitoneal extension. The specimen is received fresh and consists of a grossly identified segment of colon with ileum, pericolonic fat, and attached mesentery. Grossly, the appendix is not identified. The colon measures 14.5 cm in length and 5.5 cm in diameter. The distal part of the colon is dilated and a mass can be palpated in that area measuring 8.0 cm X 4.5 cm. The ileum measures 13.5 cm in length and 2.0 cm in diameter. The external surface of the colon and ileum is pinkish tan, smooth, with a small area of irregularity corresponding to the area with the mass. The pericolonic fat in the cecal area shows multiple masses measuring 2.0 cm X 1.0 cm to 4.5 cm X 3.5 cm, respectively. Opening the bowel reveals a small amount of brownish fluid. 10 cm from the distal margin there is an exophytic mass measuring 5.0 cm X 4.5 cm in maximum dimension. The center of this mass is excavated and hemorrhagic. The borders are raised. The colonic mucosal surface also shows a tiny nodule approximately 1 cm from the large mass, measuring 0.2 cm. The remaining mucosal surface of colon and ileum is unremarkable. The specimen will be fixed, and sections will be given after fixing the specimen.

Upon sectioning, grossly the mass appears to be involving the entire thickness of the colon wall and invading pericolonic fat. One mass in pericolonic fat grossly appears in contiguity with mass on mucosal surface. Section from this area is submitted in cassette G. Other two masses on pericolonic fat grossly appear to be enlarged mesenteric lymph nodes.

Cassettes:
A.&B. Colonic margin
C. Ileal margin
D. Mass with deepest invasion
E. Mass with normal mucosa
F. Mass
G. Mucosal mass in contiguity with pericolonic mass
H. Random section
I. Small nodule on mucosal surface
J. Smaller mesenteric mass
K. Larger mesenteric mass
L.-O. One bisected lymph node in each cassette
P.-R. Multiple unbisected lymph nodes
Multiple selections/18 cassettes. Representative sections submitted.

Sample pathology report # 1 page 2

FINAL DIAGNOSIS: Obstructed right colon with retroperitoneal extension

TUMOR TYPE:	Adenocarcinoma
TUMOR GRADE:	Moderately differentiated
INVASION DEPTH:	Through serosa, with involvement of adjacent segments of colon and mesentery
MARGINS:	Proximal and distal margins of resection are free of tumor
VASCULAR INVASION:	Present
REGIONAL LYMPH NODES:	Nine definitive lymph nodes are identified, eight are positive for tumor (8/9). In addition, nine nodules are identified within the pericolonic tissue as suspected lymph nodes by gross examination. None of these shows residual lymphoid tissue, but all are positive for tumor (9/9).
ADDITIONAL PATHOLOGIC FINDINGS:	Mesenteric masses and the grossly described mucosal nodule are all positive for tumor.
DISTANT METASTASES:	Other sites are not evaluated with this material.

SAMPLE SURGICAL PATHOLOGY REPORT # 2
PAGE 1

PATIENT: George Whitfield
SEX: M
DATE: 6/02/98

TISSUE SOURCE:
Part 1: BX Prostate right
Part 2: BX Prostate left

FINAL DIAGNOSIS
#1: Right prostate, needle biopsy, showing two our of four cores with foci of infiltrating prostatic adenocarcinoma, Gleason combined score 6 (3+3).

#2: Left prostate showing fibromuscular stroma with hyperplastic glands with foci of PIN 2-3.

RADIOLOGY DEPARTMENT ORGANIZATION

The radiology department uses x-rays and other forms of radiation for the diagnosis and treatment of disease. In some institutions, the diagnosis and the treatment may be done in separate departments. For example, a patient may be diagnosed in radiology and treated in radiation oncology. Various types of cancer can be diagnosed and treated by x-ray or radiation. Cancer registrars must be able to identify the radiology reports that contain information about cancer diagnosis or treatment.

These reports are often overlooked, especially when the radiation oncology service is a freestanding clinic. Special care must be taken to obtain and process the radiology records from freestanding clinics.

Diagnostic Radiology/Nuclear Medicine

Most cancers are diagnosed by the radiology and/or nuclear medicine departments. Information about these departments and the reports they generate is found in *Book 5, Abstracting a Medical Record: Patient Identification, History, and Examinations*. For samples of diagnostic radiology reports, see Book 5.

Therapeutic Radiology

Therapeutic radiology is the delivery of ionizing radiation[1] from either an external or an internal source.

Radiation equipment used in cancer therapy is of higher voltage than that used in the diagnostic process. The orthovoltage x-ray machine, typically 250 kV (kilovolts), is a relatively low energy machine used only for treatment of superficial lesions. A cobalt unit, which houses a quantity of radioactive cobalt (Co-60), and the linear accelerator (linac) producing high level x-rays are in the multi-million volt range.

Many cancer patients are treated with radiation therapy as the primary treatment modality or with radiation in combination with other types of therapy. The cancer registrar must maintain a working relationship with the radiology department in order to complete case finding and obtain all treatment information.

External source—teletherapy

1. Orthovoltage x-ray machine
2. Cobalt unit
3. Linear accelerator
4. Neutron beam generator
5. Betatron
6. Gamma knife

Internal source (Nuclear Medicine)—Brachytherapy

1. Radioactive implants (interstitial)
2. Radioactive isotopes (oral, intracavitary, or by intravenous injection)

The following pages are examples of radiation oncology reports.

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[1] Ionizing radiation: High-energy radiation used to destroy cancer cells.

SAMPLE TELETHERAPY REPORT
DEPARTMENT OF RADIATION ONCOLOGY PAGE 1

PATIENT: Audrey Hind
SEX: F
DATE: 8/24/1998
DIAGNOSIS: Squamous cell carcinoma, NOS
GRADE: Not determined
SITE: Lower lobe of lung
AJCC STAGE: cT3N2M0 Stage Group IIIA

FUTURE MANAGEMENT
Post-radiation surgery is not planned
Post radiation chemotherapy is not planned

ADJUVANT THERAPY None
EXTERNAL IRRADIATION: Treatment period from 11/20/98 to 01/08/99
Volume: Rt. Lung/mediastinum (Protocol 98-04)
Site(s): Primary, adjacent tissues, regional nodes
Intent: Cure.

TOTAL TUMOR DOSE (CENTIGRAYS)	# TREATMENTS	DURATION (DAYS)
Maximum: 6500 Minimum: 6000	30	60

RESPONSE TO TREATMENT
Normal Tissue: As expected
Tumor Regression: Not evaluable

PHYSICIAL FACTOR SOURCE FIELD	ENERGY	TECH DIST	ARRANGEMENT	MODS*
1 Linac, x-rays	6 MV SAD	100 CM.	Opposed pair	1
2 Linac, x rays	6 MVSAD	100 CM.	Opposed pair	3
3. Linac, x rays	18 MVSAD	100 CM.	Intersecting	2

(*)Modifiers: 1 = No modifiers, 2 = Wedge filter, 3 = Compensating

PORT NO.	DETAILS/DESCRIPTION	LENGTH	WIDTH(CM X CM)	PF
1 AP/PA	Rt. Lung/Mediastinum	25.5	17.0	1
2 AP	Rt. Lung/Mediastinum	25.5	17.0	2
3 RPO/LAO	Rt. Lung/Mediastinum	24.0	17.0	3
4 RAO	Rt. Lung/Mediastinum	20.0	20.0	3

James Oliver, MD

SAMPLE ISOTOPE ABLATION REPORT
DEPARTMENT OF NUCLEAR MEDICINE PAGE 1

NAME: Greg Fong
BIRTHDATE: 5/24/50

5/25/98

ADMINISTRATION OF I-131 FOR ABLATION OF RESIDUAL THYROID TISSUE:
47.59 mci I-131 orally and 1.07 mci Tc-99m pertechnetate intravenously.

COMPARISON: None

HISTORY: 45-year old Asian male has papillary thyroid cancer with intraglandular metastases. He is status post near total thyroidectomy that was done on 2/28/98. He is here for ablation of residual thyroid tissue noted in the thyroid bed on recent scan.

As requested by the patient's physician, 47.59 mci of I-131 was administered for ablation of residual thyroid tissue in the neck. Prior to treatment, radiation safety issues, risks, and complications of therapy, and alternate methods of therapy were discussed with the patient. Informed consent was then obtained.

A 7-day post therapy study was obtained with anterior and posterior whole body images and spot images of the neck and lower abdomen. These again demonstrate a single focus of increased uptake of radionuclide in the neck that corresponds with the focus of increased uptake that was seen on the diagnostic study prior to therapy. Otherwise, normal biodistribution of radionuclide in the salivary glands, stomach, bowel, and bladder is seen in the post-therapy images.

IMPRESSION:

1. Administration of 47.59 mci I-131 for ablation of residual thyroid tissue in the neck.

2. 7-day post therapy scan demonstrates a single focus of increased uptake in the neck that corresponds with the focus of increased uptake in the neck that was seen on the pre-therapy cancer study. No evidence of iodine avid metastases outside of the thyroid bed is demonstrated.

SAMPLE NUCLIDE ABLATION REPORT
DEPARTMENT OF NUCLEAR MEDICINE PAGE 1

NAME: Audrey Hind
DATE: 8/24/98

NM Therapy: Thyroid ablation
PROCEDURE: The patient has undergone thyroidectomy for a thyroid carcinoma. Her metastatic survey scan shows residual thyroid tissue in the thyroid bed bilaterally. An ablation dose of radioiodine-131 was decided upon.

Accordingly, the patient received 152.2 mci of Radioiodine 131 on 8/24/98.

IMPRESSION:
Thyroid carcinoma post thyroidectomy. Residual thyroid bed activity. Ablation therapy with 152.2 mci of radioiodine-131 on 8/24/98.

SAMPLE RADIATION SUMMARY REPORT
DEPARTMENT OF RADIATION ONCOLOGY PAGE 1

NAME: David Jacoby
DATE: 9/1/98

Mr. Jacoby is a 75 year-old gentleman who was seen at the request of Dr. Kenworth. Besides some other co-morbidities, he was diagnosed with small cell carcinoma, Stage IIIB, located at the right lower lobe with mediastinal adenopathy. He underwent a course of radiation concomitantly with chemotherapy and only required a brief interruption because of leukopenia and he has an appointment to come for re-evaluation in two weeks.

CLOSE SERIES **TREATMENT DATES: 7/6/98 through 8/10/98**
Equipment: 10 MV linear accelerator
Portal with field size: Fields #1 and 2: AP PA lung. 13X14.5 cm. Custom blocks.
Tumor Dose: 3600 cGy
Number of Fractions: 20
Elapsed Days: 35

CLOSE SERIES **TREATMENT DATES: 7/6/98 through 8/10/98**
Equipment: 10 MV linear accelerator
Portal with field size: Fields #3 and 4: LAO and RPO cone down to lung. 9X12 cm. Custom blocks.
Tumor Dose: 1440 cGy
Number of Fractions: 8
Elapsed Days: 13

Total received by the pulmonary lesion was 5040 cGy. The spinal cord was removed from the fields after 3874 cGy.

SAMPLE BRACHYTHERAPY NOTE
DEPARTMENT OF RADIATION ONCOLOGY PAGE 1

NAME: Elaine Tang
DATE: 7//20/98

IDENTIFICATION: The patient is a 57-year old female with Stage IVA, T2 N2 poorly differentiated squamous cell carcinoma of the distal vagina. She also presented with bilateral inguinal lymphadenopathy. She completed external beam radiation therapy along with concomitant chemotherapy at this hospital. She received 4500 cGy to the pelvis using AP/PA fields. She received 4950 cGy to the inguinal regions as measured at D3.

The patient did have some difficulty during external beam radiation therapy with leukopenia and skin desquamation as well as fevers. On 9/14/98, the patient had a MRI for template planning which showed thickening of the vagina, left greater than right but without enhancement on T2 images. There was no adenopathy and no parametrial extension of disease. On T1 images, there was noted to be a high intensity cystic mass adherent to the uterus, which appeared stable in appearance when, compared to prior CT scans.

PROCEDURE: On the morning of September 18, 1998, the patient was admitted to the Pre-Surgical Area. She was given 5,000 units of subcutaneous heparin. An epidural catheter was placed. The patient was then taken to the Operating Room. TED hose stockings and intermittent compression stockings were placed on the patient's legs. The patient was sedated and then placed in the dorsal lithotomy position. On examination, she was noted to have a small 1 x 2 cm firm somewhat rough area on the anterior vaginal wall. The cervix was somewhat firm to palpation. Rectovaginal examination was benign. There did not appear to be parametrial extent of disease. The patient was then cleaned, prepped, and draped in the usual sterile fashion.

A weighted speculum was placed into the vagina. A right angle retractor was used to visualize the cervix and vagina. There were noted to be small 1 cm x 2 cm plaque-like areas on the anterior and lateral walls of the vagina. There were no discrete masses seen in the vagina. The cervix appeared normal. Gold seeds were placed into the cervix at approximately the 10 and 3 o'clock positions. A tenaculum was used to secure the anterior lip of the cervix. The uterus was then sounded to approximately 6 cm. The keel of the tandem was set at 5.5 cm and the tandem was inserted into the uterus through the cervical os. A Foley catheter was then placed into the urethra and the balloon inflated with Hypaque. A vaginal obturator was then placed over the tandem and into the vagina. The template was then placed over the obturator and placed flush against the patient's perineal skin. Twenty cm stainless steel needles were inserted to a depth of approximately 11 cm into the perineum. Fifteen needles were inserted. Eight of the needles were surrounding the vaginal obturator, four needles were to the left of the vaginal obturator and one needle to the right of the vaginal obturator. Two needles were placed anterior to the obturator. The template was then secured to the perineum using four sutures one at each corner of the template. A rectal marker was then placed. AP and lateral as well as slightly oblique films were taken in the operating room to verify positioning of the tandem and needles and to assist in treatment planning. One gram of ceftizoxime was given to the patient in the Operating Room. The patient was awakened from anesthesia and taken to the postoperative area in stable condition.

Page 2
Sample brachytherapy note continued

BRACHYTHERAPY PLANNING: Using the films taken in the Operating Room, a plan was designed which delivered 3,000 cGy minimum tumor dose in 50 hours. The dose rate was 60 cGy/hour. The patient was then attached to the microselectron pulse dose rate machine. Her treatment was started at approximately 3 p.m. on 9/18/98. The patient's radiation therapy was completed on 9/20/98 at 5:53 p.m. The patient received 50 pulses during this treatment period

During the hospital stay, the patient was given heparin, 5000 units subcutaneously q. 8 h as well as ceftizoxime, 1 gram IV q. 12 h.

The patient tolerated the procedure well and had good pain control with the epidural morphine.

When the 50 hours of treatment were completed, the patient was given 5 mg of Valium IV. The sutures securing the template to the perineum were cut and removed. The template was then pulled from the perineum. Pressure was applied to the perineum. The patient had minimal bleeding. She was able to void on her own after the fourth catheter was pulled. She was discharged home on 9/21/98 in good condition. Post-removal survey of the room following removal of the template showed no radiation reading above background.

CUMULATIVE DOSES: The patient received a minimum tumor dose of 3000 cGy. This, combined with the 4500 cGy external beam, brings the minimum tumor dose to 7500 cGy. The patient's maximum bladder dose during this insertion was 2400 cGy. This, combined with the 4500 external beam, brings the total maximal bladder dose to 6900 cGy. The patient's maximum rectal dose during this insertion was 2200 cGy. This combined with her 4500 cGy external beam radiation therapy brings her maximum rectal dose to 6700 cGy.

COMPLICATIONS: None

FOLLOW-UP: The patient was discharged with Tylenol with codeine #3 p.r.n. pain. She was also given, Keflex, 500 mg. p.o. q.i.d. for seven days. The patient is to return to see Dr. Tumm in approximately three weeks. The patient was instructed to call or visit the Emergency Room should she develop fevers, abdominal pain, increased vaginal bleeding, or increased hematuria or hematochezia.

SECTION I TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 A physician consultant will review difficult medical records and assist the cancer registrar with coding questions. The physician consultant may be a member of:

A. The pathology department

B. The surgery department

C. The medical oncology department.

D. Any of the above

Q2 The hospital cancer registry is often a part of one of the following hospital departments:

A. _____

B. _____

C. _____

Q3 Circle those cases a cancer registry would receive from the Health Information Management department:

A. New cancer cases that must be abstracted and become part of the registry files

B. Cancer cases already in the registry files that have returned for follow-up care

C. Both

D. Neither

SECTION I TEST ANSWERS

Q1 A physician consultant will review difficult medical records and assist the cancer registrar with coding questions. The physician consultant may be a member of:

Answer

D. Any of the above. Large hospitals may have consultants from both pathology and surgery, as well as from other departments, such as radiology, medical oncology, and nuclear medicine.

Q2 The hospital cancer registry may be a part of one of the following hospital departments:

Answer:

Pathology, surgery, radiology, cancer center, administration, or HIM. These departments are most often involved with the diagnosis and treatment of cancer. In a large hospital, the registry might be attached to the oncology or nuclear medicine departments.

Q3 Circle those cases a cancer registry would receive from the Health Information Management department.

Answer

C Both. All cancer admissions, new admissions, and readmissions should be referred to the cancer registry.

RELATIONSHIP OF CANCER REGISTRY TO OTHER MEDICAL ORGANIZATIONS

Central Cancer Registries

A facility's cancer registry may be part of a community, regional, or state registry. Such central registry systems are valuable in that they pool or combine information on the occurrence of cancer in the area covered. They also permit the study of trends in therapy and survival, as well as comparisons between regions.

The American Cancer Society, Inc. (ACS)

The American Cancer Society is a nation wide, community-based, voluntary health organization devoted to the control and elimination of cancer through research, education, and service. With the help of over two million volunteers working in more than 3400 local units in 19 divisions throughout the United States, the ACS conducts programs directed at cancer prevention, early detection, and patient care. As part of this work, for over 40 years the ACS has maintained an active department of epidemiology and statistics. That department conducts epidemiology research and supports ongoing surveillance of cancer incidence, mortality, and survival trends, and of current patterns in cancer risk factor distributions. ACS is a sponsor of NAACCR, and throughout its history has been a strong advocate for high quality, population-based, cancer incidence registries.

The address and number of your local division appear in your telephone book. The national office is located at 1599 Clifton Road NE, Atlanta, GA, 30329. The telephone number is 404 320-3333. ACS also maintains a 24-hour line for questions at 800 ACS-2345. The Internet address is http://www.cancer.org.

The National Cancer Registrars Association, Inc. (NCRA) (formerly National Tumor Registrars Association)

The National Cancer Registrars Association (NCRA) was chartered in May 1974 as a non-profit, professional organization and currently has over 2,000 members. The NCRA purposes are:

1. to establish standards of education for cancer registrars.
2. to inform members of the latest methods of cancer diagnosis and treatment.
3. to inform members of current trends in incidence and survival.
4. to make cancer patient data readily available for clinical and epidemiological research.

Annual conferences of the NCRA offer educational sessions designed to improve registrars' knowledge and professional expertise. Educational programs are also offered through the many state and local registrar organizations.

Professional recognition for the cancer registrar is provided through an NCRA-sponsored certification examination held semi-annually. Applicants must meet specific qualifications. Individuals who pass the examination administered by the National Board for Certification of Registrars (NBCR), a sibling organization of NCRA, become Certified Tumor Registrars (CTRs). Membership in the organization and participation in the certification process are voluntary. Inquiries regarding membership in NCRA should be directed to the NCRA National Office, P.O. Box 15945-295, Lenexa, KS 66285-5945. The e-mail address is WWW.ncra-org.com. The national office telephone number is 913 438-NCRA. Questions about the certification exam should be directed to the NBCR National Office, PO Box 15945-302, Lenexa, KS 66285-5945. The telephone number is 913 599-4994 and the *FAX* number is 913 541-0156.

North American Association of Central Cancer Registries (NAACCR) (formerly American Association of Central Cancer Registries)

Established in 1985, NAACCR is a collaborative umbrella organization for cancer registries, governmental agencies, professional associations, and private groups in North America interested in enhancing the quality and use of cancer registry data. Central cancer registries in the United States and Canada are members. Sponsoring members include:

1. The American Cancer Society
2. American College of Surgeons
3. American Association of Cancer Institutes
4. American Joint Committee on Cancer
5. Association of Community Cancer Centers
6. The Centers for Disease Control and Prevention
7. The National Cancer Institute
8. The National Cancer Registrars Association
9. Statistics Canada

The address of NAACCR's Cancer Surveillance and Control Program is 2121 West White Oaks Drive, Suite C, Springfield, IL 62704. The telephone number is 217 698-0800 and the *FAX* number is 217 698-01880.

NAACCR is governed by an Executive Board. Many of the decisions of NAACCR, however, are made at the committee level. Each of the nine committees has broad responsibilities.

NAACCR has two committees that affect data collected and exchanged at the institution level. NAACCR's Uniform Data Standards Committee provides a mechanism for reviewing and recommending proposed changes in data codes, data definitions, and new data items. This process ensures that data remain comparable over time. The Information and Technology Committee has developed a format for the transfer of oncology data among users.

No action taken by NAACCR is ever binding on any member. NAACCR positions and standards are recommendations, never requirements. Membership is available to any institution, agency, firm, or group supporting the Association's aims.

Categories of membership:

1. Full: Full member organizations are central registries that are, or have the potential to become population-based registries.
2. Individual: Individual members are those persons who are not currently working in a member organization who have demonstrated career and professional commitments and interests that are consistent with or complementary to those of NAACCR.
3. Sponsoring: Sponsoring member organizations are national organizations primarily involved in cancer control, prevention, and research.
4. Sustaining: Sustaining member organizations are organizations interested in promoting the purposes of the association.

The National Cancer Institute: The SEER Program

The National Cancer Act of 1971 mandated the collection, analysis, and dissemination of all data useful in the prevention, diagnosis, and treatment of cancer. The act resulted in the establishment of the National Cancer Program under which the Surveillance, Epidemiology, and End Results (SEER) Program was developed. A continuing project of the National Cancer Institute (NCI), the SEER Program collects cancer data on a routine basis from designated population-based cancer registries in various areas of the United States. Trends in cancer incidence, mortality, and patient survival in the United States, as well as many other studies, are derived from this data bank.

The current geographic areas comprising the database of the SEER Program represent an estimated 13.9 percent of the United States population. The database contains information on more than two million in situ and invasive cancers that were diagnosed between 1973 and 1996. Approximately 120,000 new cases are accessioned yearly in 9 areas, including the states of Connecticut, Iowa, New Mexico, Utah, Hawaii, and the metropolitan areas of Detroit, San Francisco, Seattle-Puget Sound, and Atlanta. The California metropolitan areas of San Jose, Monterey, and Los Angeles were added in 1992.

Areas were selected primarily for their ability to operate and maintain a population-based cancer reporting system and for their epidemiologically significant population subgroups. With respect to selected demographic and epidemiologic factors, they provide a reasonable representative subset of the United States population.

The main goals of the SEER Program are:

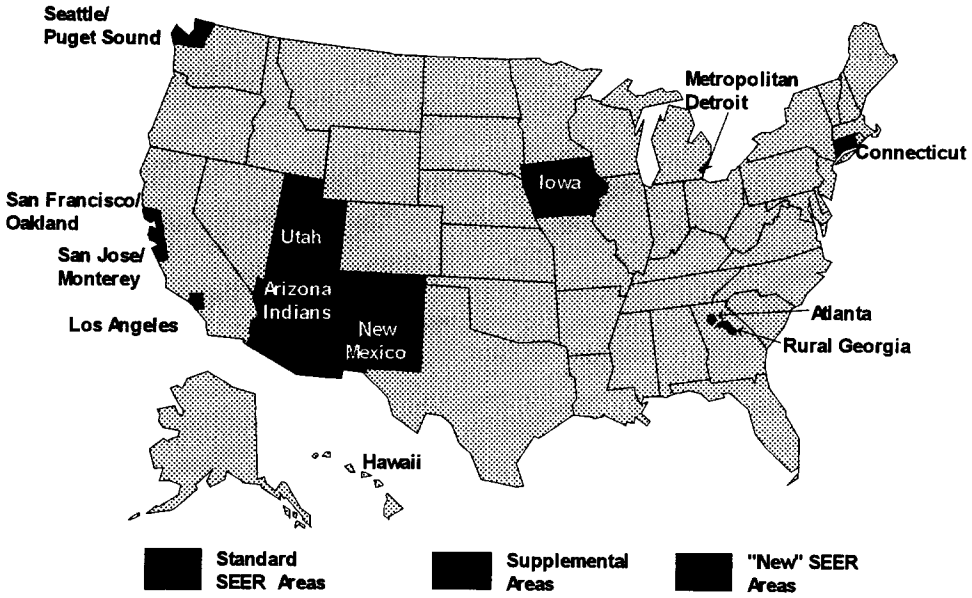
1. Assembling and reporting estimates of cancer incidence and survival in the United States on a periodic basis.
2. Monitoring annual cancer-incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups defined by geographic, demographic, and social characteristics.

The address of the SEER Program is:

Cancer Statistics Branch
Surveillance Program
Division of Cancer Prevention and Control
National Cancer Institute
Executive Plaza North, Room 343J
6130 Executive Blvd.
Rockville, MD 20852-7352
301 496-8510
FAX 301 496-9949

A map showing the SEER areas appears on the following page.

SEER Program, 1999



COMMISSION ON CANCER (COC) OF THE AMERICAN COLLEGE OF SURGEONS (ACOS)

The CoC is a multidisciplinary, voluntary organization dedicated to reducing the morbidity and mortality caused by cancer through prevention, monitoring and reporting of care, standard setting, and education.

Members on the Commission represent the major medical and oncologic disciplines:

1. Surgery
2. Gynecology
3. Medical oncology
4. Urology
5. Diagnostic and therapeutic radiology
6. Pediatrics
7. Pathology

Interdisciplinary representation includes:

1. Hospital administration
2. Oncology program administration
3. Oncology nursing
4. Nutrition
5. The National Cancer Institute and the Surveillance, Epidemiology, and End Results (SEER) Program
6. The national American Cancer Society
7. The Centers for Disease Control and Prevention
8. The National Cancer Registrars Association
9. NAACCR

All members have full voting privileges and are eligible for appointment as a standing or ad hoc committee chairperson.

The work of the Commission is conducted through the actions of an Executive Committee and five standing committees: Approvals, Cancer Liaison, Education, National Cancer Data, and Standards.

Background of the CoC

The Commission began in 1913 at the fourth annual congress of North American Surgeons when the Cancer Committee was formed to evaluate the efficacy of surgery and radiation therapy in the management of cancers of the uterine cervix and corpus.

In response to a request from the American Cancer Society, the Approvals Program was initiated in 1930 and charged with improving the quality of care of the patient with cancer. The early program focused on cancer clinics.

On a parallel track, the Education Committee was established to design educational programs for surgeons. Those educational programs were presented at the spring and fall meetings of the American College of Surgeons.

In 1947, the Cancer Liaison Committee was created to oversee a national network of surgeons, medical and radiation oncologists, pathologists, and other clinicians in all hospitals. The role of the cancer liaison network was to serve as a conduit for two-way communication with institutions involved in the programs of the Commission.

The scope of the Approvals Program was expanded to include more hospitals. In 1956, a cancer registry became a requirement for approval of a hospital cancer program. In 1950, the Committee on Cancer was renamed the Commission on Cancer and its membership expanded to include representation from other national organizations and groups involved in cancer control and surveillance. In 1966, a requirement for approved programs to conduct multidisciplinary cancer conferences was added.

In 1976, the first patient-care evaluation-study was conducted to assess the role of oral contraceptives in primary cancers of the liver. Later that year, the Approvals Program expanded its requirements to include two patient care studies each year. The registry was required to do one short-term and one long-term review of patient care on a site-specific basis. See Section J for more information on patient-care evaluation studies.

In 1989, the National Cancer Data Base (NCDB) was founded to provide a database that was clinically focused and outcome oriented. The NCDB collects data from hospital-based registries. Reporting to the NCDB is an approval requirement. The NCDB is supported by the American Cancer Society and the American College of Surgeons. The Standards Committee was established in 1995 to evaluate the clinical relevance of data items in registries, to design and maintain a system for making available patient care guidelines, and to monitor the demands for data made on institutional-based registries.

In 1996, new standards for approval were introduced along with revised standards for registry operations and data management.

Approvals Committee

The Approvals Committee oversees the Approvals Program, a voluntary accreditation activity for hospitals, ambulatory care facilities, clinics, and managed care organizations. Consultations and surveys are conducted by regionally based cancer registrars and clinicians. Commission-approved programs are categorized into the following groups:

1. NCI-designated comprehensive cancer programs
2. Teaching hospital cancer programs
3. Community hospital comprehensive cancer programs
4. Community hospital cancer programs
5. Hospital associate cancer programs
6. Integrated cancer programs
7. Freestanding cancer center programs
8. Affiliate hospital cancer programs
9. Managed care cancer programs

Some of the requirements have specific modifications for the approval category or the scope, size, and type of institution. Facilities must meet the following two requirements to be eligible to apply for certification:

1. The facility must be accredited by the Joint Commission on Accreditation of Health Care Organization or a comparable recognized authority.
2. The facility must have specific resources for state-of-the-art diagnosis and treatment of cancer.

The cornerstones of an approved program are mandatory, minimal resources that must be established and functioning in each institution:

1. A multidisciplinary cancer committee
2. Multidisciplinary cancer conferences or tumor boards
3. A quality management program
4. An institution-wide, comprehensive cancer data management system (registry)

The guidelines for ten programmatic areas are found in the CoC publication, *Cancer Program Standards* (1996). The ten areas are:

1. Institutional and programmatic resources
2. Program management and administration
3. Clinical management
4. Inpatient and outpatient care
5. Supportive and continuing care services
6. Research
7. Quality management and improvement
8. Cancer data management
9. Public education, prevention and detection
10. Professional education and staff support

There are specific standards for pediatric facilities.

Institutions are provided with a self-assessment tool to assist them in evaluating their compliance with guidelines. The *Cancer Program Standards* and the companion volume, *Registry Operations and Data Standards,* serve as models for a comprehensive cancer program.

Research and Development and Special Issues

There are two standing subcommittees of the Approvals Committee, Research and Development and Special Issues. The latter reviews survey and background materials for programs for which a less than unanimous approval decision is recommended. The subcommittee's recommendations are reviewed and acted upon by the full Committee on Approvals. The focus of the Research and Development Subcommittee is to address input from approved programs, medical groups, and database organizations. A primary goal is to position the Approvals Program to meet the needs of the changing health care field.

Cancer Liaison Committee

The Cancer Liaison Committee directs the activities of 2,200 physician liaisons in as many cancer programs. Chairmen are appointed in each state, and there are four Area Chairmen. The committee is charged with a clinical goal each year. In the past, the committee's goals have included early detection for breast cancer, colorectal screening, enhancing the participation of surgeons in clinical trials, promoting participation in the National Cancer Data Base, and smoking cessation programs for youth. Most of these activities were in support of the clinical initiatives of the American Cancer Society. In 1995, the Triad Program was introduced to bring together national, state, and local clinicians, epidemiologists, state health department leadership, and cancer registry organizations to identify cancer control issues and design and implement cancer control strategies.

Education Committee

For many years, the focus of the committee's responsibilities was the postgraduate courses and symposia of the Spring Meeting and the Clinical Congress of the American College of Surgeons. In 1981, a multidisciplinary Cancer Management Course was developed for physicians. The course includes didactic presentations and skill stations. In 1988, an international cancer management course was initiated and the Education Committee implemented the *Fundamental Tumor Registry Operations* (FTRO), a basic education program for cancer registrars.

In 1995, three subcommittees were established. The Oncology Subcommittee is charged with design and implementation of multidisciplinary programs for surgeons and non-surgeons. The International Cancer Management Subcommittee oversees international courses. Registry education is addressed by the third subcommittee, Registry Education.

National Cancer Data Committee

The National Cancer Data Committee (NCDC) and the National Cancer Database Governing Board direct the patient care evaluation studies and the National Cancer Data Base. The National Cancer Database Governing Board is a conjoint body of the American Cancer Society and the American College of Surgeons.

Subcommittees are formed to design the hypotheses and studies for specific sites. Two national studies are conducted each year. One or more papers are published on each of the studies.

National Cancer Data Base (NCDB)

The major purposes of the National Cancer Data Base are:

1. Provide a scientific resource suitable for comprehensively assessing cancer patient care and outcome on a national basis and disseminating such information to the medical community. Data to be assessed by multidisciplinary teams include surveillance of trends in stage at diagnosis, diagnostic practices, therapeutic procedures, and outcome.
2. Enhance ongoing cancer programs among CoC-approved and other cooperating hospitals by providing annual comparative reports of national, regional, and hospital outcome.

The NCDB is intended to improve the process by which cancer patient care and research advances are transferred to physicians' practices, to enhance quality assurance, and to enhance the quality of life and survival of cancer patients.

The National Cancer Data Base issues an annual call for data to institutionally based cancer registries. The data are analyzed, and each participating facility receives a report of its individual data as well as the aggregate data. An *Annual Review of Cancer* is published each year under the aegis of the Editorial Subcommittee.

In 1994, electronic reporting of the patient-care evaluation studies was introduced, allowing participating registries to submit study data along with their standard registry data submission to the National Cancer Data Base.

Standards Committee
Newly formed in 1995, the Standards Committee is charged with providing clinical oversight for data standards and designing and maintaining a mechanism to respond to requests for patient care guidelines.

Cancer Department
The Cancer Department of the American College of Surgeons serves as staff for the activities of the Commission. In addition, the department provides administrative support for the American Joint Committee on Cancer. The latter is responsible for a unified staging system for most cancers based on the tumor (T), lymph node status (N), and presence of distant metastases (M). The staging schema is identical to that of the International Union Against Cancer (UICC).

Other
Publications available from the cancer department include:
1. *Standards of the Commission on Cancer, Volume I: Cancer Program Standards*
2. *Standards of the Commission on Cancer, Volume II Registry Operations and Data Standards (ROADS)*
3. *Annual Review of Cancer*
4. *Approvals Program Directory*
5. A bibliography of patient care evaluation study articles
6. Several pamphlets about Commission programs.

The mailing address is 633 N. Saint Clair St, Chicago, IL 60611-3211 and the telephone number is 312 202-5474. Fax numbers are 312 202-5009 and 312 202-5011.

The Approvals Process
The Approvals Program is voluntary. Institutions are visited by a surveyor in response to a written request by a member of the institution's administrative or professional staff. An institution is initially eligible for approval when the clinical program has been in successful operation for at least one year, and the cancer database covers a minimum of two years with one year of successful follow-up. Institutions pay a fee for the survey.

Institutions seeking approval for the first time must be evaluated by a CoC consultant before survey.

After an institution has been surveyed, the surveyor's report about the cancer program is reviewed by three members of the Committee on Cancer and one Cancer Department staff member. Institutions receiving full four-year approval are reviewed and notified immediately. All other approval recommendations are decided by a majority vote of the full Committee on Approvals. The full committee meets twice yearly, followed by approval by the Executive Committee of the CoC and the Board of Regents of the American College of Surgeons.

A hospital may receive one of the following designated approval categories:

1. Four-year Approval. The hospital cancer program meets the established criteria.
2. Three-year Approval with Contingency. A previously approved program meets the established criteria but has one or more measurable, correctable deficiencies for which documentation of corrective action could be easily provided.
3. One-year Approval. Broad and multiple deficiencies exist in a previously approved program, but the administrative and professional staffs are motivated to correct the deficiencies within a reasonable time and have the potential to do so. These programs are offered a consultative visit and are resurveyed within 18 months.
4. Nonapproval. Multiple broad deficiencies exist in a previously approved program, and the likelihood for correction appears to be remote. If these programs wish to regain approval, they are eligible for consultation and resurvey as an initial (new) program.
5. Deferred. Unclear or insufficient information about a cancer program is submitted, and an approval decision cannot be made. Additional information is requested from the institution so that a decision can be made at the next meeting of the Committee on Approvals.
6. Consult Only. This designation is assigned to an initial (new) program that does not meet the criteria for a four-year approval. Since an initial program cannot be given a three-year approval with contingency, a one-year approval, or non-approval, a different designation is needed to identify those programs that are in the approvals process.

AMERICAN JOINT COMMITTEE ON CANCER (AJCC)

The AJCC was first organized in 1959 as the American Joint Committee for Cancer Staging and End-Results Reporting (AJCC). Their purpose was to develop a system of clinical staging for cancer that was acceptable to the American medical profession. The Committee had six founding organizations, the American College of Surgeons, the American College of Radiology, the College of American Pathologists, the American College of Physicians, the American Cancer Society, and the SEER Program of the National Cancer Institute. Each of the founding organizations has three representatives on the full committee that usually meets annually. Most of the work of the AJCC is carried out by multidisciplinary task forces that are established by the full committee to review staging systems for individual anatomic sites. These task forces report to the full committee.

The AJCC has liaison representation from several other professional organizations, including:

1. The American Academy of Pediatrics
2. The American College of Obstetricians and Gynecologists
3. The American Urological Association
4. The Association of American Cancer Institutes
5. The National Cancer Registrars Association
6. The SEER Program of the National Cancer Institute

Several organizations worked on the clinical classification of cancer, but the International Union Against Cancer's (UICC) Committee on Clinical Stage Classification and Applied Statistics (1954) was the most active. The committee was later known as the TNM Committee. The AJCC adopted the clinical staging system and added the pathologic stage of disease. The pathologic stage uses all clinical information and adds the information obtained from the examination of the surgically resected specimen. This results in a dual stage classification pTNM and cTNM, "p" referring to pathologic and "c" referring to clinical.

In 1980, the name was changed to the American Joint Committee on Cancer (AJCC), reflecting the broader scope of the committee's interests and activities as seen in its *AJCC Cancer Staging Manual*, currently in its fifth edition.

The TNM system is a classification of the anatomic extent of disease. The three variables, T, N, and M (Tumor, Lymph Node, Metastasis) are grouped into a single statement of outcome labeled the stage group or stage of disease. The TNM and stage grouping follow the natural course of cancer growth and metastasis. The size of the untreated primary cancer or tumor (T) increases progressively, and at some point in time the regional lymph nodes become involved (N) and, finally, distant metastases (M) occur.

The classification published by the AJCC is identical to that published by the Union Internationale Contre le Cancer (UICC). The UICC TNM Committee and the AJCC have agreed to publish identical staging systems to ensure worldwide consistency in staging. Support for the AJCC is provided by the National Cancer Institute, the American Cancer Society, and the CoC.

THE JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO)

The mission of the Joint Commission on Accreditation of Healthcare Organizations is to improve the quality of health care provided to the public. Growing out of the American College of Surgeons' Hospital Standardization Program begun in 1918, the Joint Commission was formed in 1951 as a professionally sponsored national accrediting body. The Joint Commission is a private, not-for-profit organization governed by members of health care professional organizations and representatives from the public.

The Joint Commission achieves its mission today by setting health care standards, evaluating and accrediting over 9,000 health care organizations nationwide, including over 80 percent of United States hospitals, and serving as a consultant and educator. Indeed, the high caliber of the Joint Commission's standards has been recognized by the federal government, by most state governments, and by payers across the country for licensure and reimbursement purposes. In addition, the Joint Commission has been called upon for educational services or consultation by organizations such as the Robert Wood Johnson Foundation, the Malcolm Baldrige National Quality Award, and the United States Agency for International Development. The Joint Commission provides these services across the United States and in countries around the world, including Saudi Arabia, Canada, and in Europe.

In anticipation of the evolution toward the new performance measurement mandate in health care in this country, the Joint Commission began designing a major research and development effort, the "Agenda for Change", in the late 1980s. The "Agenda for Change" is a set of initiatives to integrate the accreditation process with a national reference database of comparative performance information. The ultimate intent is to produce an information base that will be useful to providers, patients, purchasers, and other stakeholders.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR)

Statewide, population-based data on cancer incidence are crucial for measuring the success and efficacy of programs designed to reduce disability and death from cancer. In recognition of this, in 1992 Congress authorized the Centers for Disease Control and Prevention (CDC) to establish the National Program of Cancer Registries (NPCR). The NPCR makes grants to state health departments or their designees for the support and enhancement of population-based central cancer registries. The goal of the NPCR is to assure collection of a minimum set of accurate, uniform, and timely data on every cancer case. Central cancer registries in many states began participating in the NPCR in September 1994, and NPCR currently covers:

1. 45 states
2. District of Columbia
3. 3 U.S. territories, Puerto Rico, the Virgin Islands and Palan.

NPCR also works with other national organizations to improve the quality, completeness, and timeliness of data on cancer cases, and NPCR staff provides consultation and training to grantees around the United States. The address of the NPCR is: Mailstop K-55, DCPC, NCCDPHP, CDC, 4770 Buford Highway NE. Atlanta, Georgia 30341. Telephone 770 488-4783.

SECTION I TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 The cornerstones of a CoC-approved cancer program are:

A. _____

B. _____

C. _____

D. _____

Q2 According to the CoC, the majority of an institution's cancer conferences must be _____ - _____ and _____.

Q3 The CoC requires the cancer registry to have which of the following files. (check Y for yes or N for no)

	Y	N
A. Suspense file	[ ]	[ ]
B. Accession register	[ ]	[ ]
C. Charge master file	[ ]	[ ]
D. Doctors' alpha file	[ ]	[ ]
E. Master patient file	[ ]	[ ]
F. Abstract file	[ ]	[ ]
G. Follow-up file	[ ]	[ ]
H. Pathology report	[ ]	[ ]

Q4 The American College of Surgeons' approval requirement for the follow-up rate of the registry is _____.

Q5 Match the following organizations to their primary activity.

[ ] American Cancer Society	A. Certification of cancer registrars
[ ] American College of Surgeons	B. Approval of cancer programs
[ ] American Joint Committee on Cancer	C. Clearinghouse for data items and coding schemes
[ ] National Cancer Registrars Association	D. SEER Program
[ ] National Cancer Institute	E. Public and professional education
[ ] North American Association of Central Cancer Registries	F. Staging manual

SECTION I TEST ANSWERS

Q1 The cornerstones of a CoC-approved cancer program are:

Answer

A. Cancer Committee
B. Cancer conferences or tumor boards
C. Patient care evaluation
D. Cancer registry or cancer data system

Q2 According to the American College of Surgeons Committee on Cancer, the majority of an institution's cancer conferences must be **patient-oriented** and **consultative**.

Q3 The CoC requires the cancer registry to have which of the following files.

Answer

	Y	N
A. Suspense file	[X]	[ ]
B. Accession register	[X]	[ ]
C. Charge master file	[ ]	[X]
D. Doctors' alpha file	[ ]	[X]
E. Master patient file	[X]	[ ]
F. Abstract file	[X]	[ ]
G. Follow-up file	[X]	[ ]
H. Pathology report	[ ]	[X]

Q4 The American College of Surgeons' approval requirement for the follow-up rate of the registry is **90 percent**.

Q5 Match the following organizations to their primary activity.

Answer

American Cancer Society	(E) Public and professional education
American College of Surgeons	(B) Approval of cancer programs
American Joint Committee on Cancer	(F) Staging manual
National Cancer Registrars Association	(A) Certification of cancer registrars
National Cancer Institute	(D) SEER Program
North American Association of Central Cancer Registries	(C) Clearinghouse for data items and coding schemes

SECTION J

QUALITY MANAGEMENT AND IMPROVEMENT
COMMISSION ON CANCER

WHAT IS QUALITY MANAGEMENT AND IMPROVEMENT?

A cornerstone of a CoC-approved cancer program is a multidisciplinary, broad-based system of planning, measuring, evaluating, and improving the quality and outcome of cancer patient management. Indications of quality include, but are not limited to:

1. Absence of or reduction in clinically unnecessary diagnostic or therapeutic procedures
2. Accessible and available health services
3. An increased likelihood of desirable outcomes
4. Accurate, appropriate, and complete documentation of patient care
5. Appropriate and timely consultation
6. Appropriate and timely diagnosis
7. Appropriate and timely follow-up of tests and findings
8. Appropriate and timely referrals
9. Continuity of care
10. Diagnosis and treatment that are consistent with the patient's clinical needs and with current professional knowledge
11. Patient compliance and cooperation
12. Patient satisfaction

Quality management measures provide opportunities for cancer program leadership to monitor compliance with clinical guidelines and identify issues, develop strategies, and effect change, which will improve patient care and satisfaction.

The patient-care evaluation process was introduced in 1976 with a Commission-initiated study of the relationship of estrogen use and primary cancers of the liver. Since that time, a minimum of two annual national studies have been conducted under the aegis of the National Cancer Data Committee, a multidisciplinary committee of the CoC. The studies are primarily site-specific. Each site-specific study may be done as a short-term (The most recent complete reporting year) and/or long-term study (outcome of cases entered into the registry five or ten years earlier). In addition to site-specific studies, special studies have included quality assessment of registry data and a review of pediatric malignancies. Data from the national studies are analyzed centrally by Commission members and staff, and articles are published in various peer-reviewed journals. In addition, each participating institution receives an analysis of its data and the aggregate data from the study for purposes of comparison or benchmarking.

Shortly after the first patient-care study was completed, the Committee on Approvals implemented a requirement that all Commission-approved cancer programs must conduct two annual studies of patient care. Institutions could design studies of local interest or participate in the Commission's national studies. With the introduction of the *Cancer Program Standards* (1996), the quality management and improvement standards were expanded to address the comprehensive aspects of quality management activities.

QUALITY MANAGEMENT

The cancer committee is responsible for establishing plans for the quality management of patient care and data

Quality Management and Improvement

The cancer committee is responsible for establishing quality improvement priorities of the institution's cancer program and monitoring the effectiveness of the quality management activities. At least two patient care enhancements or improvements must be documented each year. Quality issues are issues that affect survival, quality of life, or patient satisfaction:

1. Accessibility of health care
2. Appropriateness of services
3. Continuity of care
4. Cost of services
5. Medical record documentation
6. Patient compliance
7. Patient risk minimization
8. Patient satisfaction
9. Physician performance
10. Support staff performance

The committee must identify and develop at least two quality improvement priorities, one priority must include a site-specific patient survival rate. The committee may monitor the institution's adherence to management guidelines or develop an institution specific quality improvement activity. The cancer committee is responsible for:

1. establishing a quality improvement plan
2. developing measurement criteria
   A. Treatment guidelines used to monitor quality include, but are not limited to:
      1. *Management of Cancer Pain* (for adults or infants, children and adolescents) found on the worldwide web at www.ahcpr.gov. Published by the Agency for Health Care Policy and Research, Public Health Service, US Department of Health and Human Services.
      2. *National Cancer Institute Consensus Guidelines*
      3. *Standards for Breast Conservation Treatment,* published by the American Cancer Society.
3. evaluating the results
4. implementing improvement measures
5. documenting and reporting quality management activities to appropriate caregivers and leadership groups. The documentation must show that the patient-care enhancements or improvements were successful.

Minimally, the cancer committee must review the study design. Committee review, before the study, will ensure that the target can be met. Oversight during the study assures the quality of the data accrued. The committee analyzes the results of the study, designs and implements appropriate interventions, and monitors the effectiveness of the interventions in achieving the desired result.

If the cancer committee elects to use the Commission's annual, national studies to meet the quality management requirements, they must:

1. review the study design and criteria.
2. provide quality control of the collected data.
3. evaluate the findings.
4. make appropriate recommendations.
5. design and implement interventions to effect quality improvement.
6. monitor the effectiveness of the interventions to ensure that the desired results are achieved.

There must be sufficient number of cases in the database or the analysis will not be valid.

Cancer Data Management

The cancer committee is responsible for the quality control of the registry data. A documented quality control plan must include these registry activities:

1. Case finding
2. Abstracting (accuracy and consistency)
3. Staging (accuracy and consistency)
4. Timely data collection
5. Reporting
6. Method and content of computerized data edits
   A. Software provider edits
   B. Institution-specific edits

Physicians must review a random sample of at least 10 percent of the annual analytic cases. The review process must be documented. The review must include:

1. site
2. histology
3. stage of disease
4. first course of treatment

Other Studies

Copies of patient-care evaluation studies and a bibliography of articles based on the various studies are available from CoC. Call the Cancer Department of the American College of Surgeons at 312-202-5474 or write to American College of Surgeons, 633 N. Saint Clair St., Chicago, IL 60611.

SECTION J TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 The ACoS requires approved cancer programs to complete _____ patient care enhancements or improvements per year. One quality improvement priority must include a site-specific patient _____ _____.

Q2 The types of studies that may be used to meet the patient-care evaluation requirement for a cancer program approved by the CoC include:

A. Institution-developed quality improvement activity

B. Develop criteria to evaluate the institution's compliance with management guidelines

C. Cancer program annual report

D. Both A and B

E. All of the above

SECTION J TEST ANSWERS

Q1 The ACoS requires approved cancer programs to complete **two** patient care enhancements or improvements per year. One quality improvement priority must include a site-specific patient **survival rate**. (Institutions that have less than five years of data may omit the survival data, but must compare the hospital's data with national or regional data.)

Q2 The types of studies that may be used to meet the patient-care evaluation requirement for a cancer program approved by the CoC include:

Answer

D Both A and B. A: an institution-developed quality improvement activity and B: criteria to evaluate the institution's compliance with management guidelines

The institution-developed quality improvement activity must have cancer committee involvement. Data from the patient-care evaluations may be published in the cancer program's annual report, but the annual report itself does not constitute a patient-care evaluation.

SECTION K

COMPUTERS AND THE CANCER REGISTRY

Computers have revolutionized how cancer registries operate just as they have every other information-driven industry. Computers are an integral part of every aspect of a cancer registry, from case abstracting to data storage and retrieval, and from quality control to patient follow-up and preparation of statistical reports. The use of computers in the registry has an impact on the quality of the data, the staff needed to operate the registry and the training they require, as well as the ease of use and accessibility of the data.

Computers are ideally suited for storing very large amounts of information and rapidly performing repetitive tasks that can be precisely described. Many registry tasks and functions have been automated, that is, tasks and functions that were formerly performed manually are now performed by machines. Automated cancer registry applications include:

1. Direct entry of case abstracts into the computer instead of preparing handwritten abstracts
2. File maintenance (data entry, sorting, printing)
   - A. Suspense file
   - B. Accession register
   - C. Master index file
   - D. Abstract file
   - E. Follow-up file
   - F. Special request log
3. Follow-up letter generation
4. Edits and validity checks
5. Case listings and tabulations for annual and special reports
6. Computation of survival rates
7. Requisition of medical records
8. Record linkage
   - A. Health information management department disease and operations index
   - B. Other in-house databases: pathology, radiology, surgery
9. Death clearance

Computers cannot make judgments or "think". The well-trained cancer registrar must still select, classify, analyze, and interpret the information. For example, a cancer registrar can classify and code the primary site and histologic type of a cancer, but the computer cannot. Once the cancers are classified and coded, the computer can tabulate a report of numbers of cases by primary site and histologic type very quickly. Once the tabulation is prepared, the cancer registrar can interpret the tabulation, but the computer cannot.

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 Name two jobs that computers do better than people:

A. _____

B. _____

Name one thing people do better than computers: _____

Q2 Which of the following cancer registry activities would be appropriately computerized?

A. Deciding whether a particular drug administered to a patient should be coded as part of the first course of cancer-directed therapy

B. Calculating the mean (average) survival time in months for all cases in the registry of leukemia in children under age 15

C. Addressing and printing a standard letter to the attending physician of each patient due for follow-up in June

D. Preparing an alphabetic list of all patients in the registry

E. Preparing a bar graph showing the number of breast cancer cases by age group in the registry

F. Interpreting a bar graph showing the number of breast cancer cases by age group in the registry for an in-service training session

G. Checking that only valid zip codes have been entered in the records in the registry

SECTION K TEST ANSWERS

Q1 Name two jobs that computers do better than people:

Answer

A. Store very large amounts of information
B. Rapidly perform repetitive tasks

Alternatively, you may have said something like:

C. Perform mathematical calculations rapidly
D. Process data
E. Tabulate a report

Name one thing people do better than computers:

Answer

Think, interpret, or make judgments

Q2 Which of the following cancer registry activities would be appropriately computerized?

Answer

All of the tasks listed except A and F would be appropriate for a computer to perform. Tasks A and F would not be appropriate for automation, since they require judgment and understanding.

COMPUTER PROGRAMS—SOFTWARE

Computers perform tasks they are programmed to do. A computer program[1] is essentially a set of instructions written in a language[2] the computer can understand. Examples of languages are C, Pascal, Basic, COBOL, and FORTRAN.

Programs are called software, in contrast to the computer equipment itself, which is called hardware[3]. Software instructs the computer to perform certain tasks. Some programs called operating systems[4] are fundamental to the functioning of the computer itself, and control how information is stored, retrieved, processed, and displayed. DOS (disk operating system) and Windows™ are examples of operating systems for PCs (personal computers). Other programs, known as applications in computer science, do the more specialized work, such as word processing, database management, and drawing graphs. Cancer registry software systems are examples of specialized applications.

Application programs that a hospital cancer registry will need should have at a minimum these functions:

1. Case entry
2. Database management, in other words, the ability to maintain the data in a structured, consistent format and allow for additions, updates, and deletions
3. Extensive editing, or quality checking, of data
4. Reports and statistics, including survival rates
5. Follow-up processing
6. Maintenance of other files, such as a file of physicians
7. Word processing, to allow preparation of documents and correspondence
8. Graphics, to facilitate production of graphs and charts of cancer data for publications and presentations
9. Utility programs for file handling and backup.[5]
10. Communications software to allow remote access to other computers or systems. Networks enable electronic transfer of data and files for reporting to a central registry, accessing online[6] information services, or obtaining technical support for hardware and software.
11. Network[7] software. Networks allow local access to computers or systems. Local networks allow multiple users in a single department to share files or hardware with multiple departments within a hospital or agency and multiple hospitals and agencies with each other.

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[1] Computer program: A set of coded instructions for execution by a computer; using the program instructs the computer to perform a desired sequence of operations.

[2] Language: In computer science, a system of symbols and rules used for communication with or among computers.

[3] Hardware: The physical equipment of the computer system, including the computer itself, monitor, keyboard, printer, and so forth.

[4] Operating system: In computer science, software designed to control the hardware of a specific computer allowing users and application programs to employ it easily.

[5] Backup: A procedure (program) to copy and save files and off load in case of hardware or other system failure.

[6] Online: Connected or available through a system, especially a computer or telecommunications system.

[7] Network: A system in which a number of computers and peripheral devices are linked to form an interconnected series for sharing resources.

Most programming is done by specialists, and most programs used in a registry are commercial products which the registry is licensed to use. The cancer registrar does not need to know how to write computer programs, but does need to know how to evaluate, select, and use hardware and software effectively to accomplish the registry's goals and objectives.

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q3 A computer program is essentially a set of instructions written for the computer and is called _____ in contrast to computer equipment, which is called _____ .

Q4 Programs that control how information is stored, retrieved, processed, and displayed by the computer are called _____ _____, while programs which do more specialized work, such as word processing, database management, and drawing of graphs are called _____.

Q5 DOS and Windows™ are examples of _____ _____.

Q6 Match each task on the left with the type of software application on the right you would use for the task.

Answer

_____1.	Preparing the text for the hospital's annual report	A.	Graphics program
_____2.	Preparing back-up copies of registry data for off-site storage	B.	Communications
_____3.	Sending a file of cases to the state central registry electronically over telephone lines	C.	Cancer registry application
_____4.	Preparing a pie chart showing the percentage of breast cancer cases diagnosed at each stage of disease	D.	Word processing
_____5.	Abstracting a cancer case directly into the computer	E.	Utility programs

SECTION K TEST ANSWERS

Q3 A computer program is essentially a set of instructions written for the computer and is called **software** in contrast to computer equipment, which is called **hardware**.

Q4 Programs which control how information is stored, retrieved, processed, and displayed by the computer are called **operating systems**, while programs which do more specialized work, such as word processing, database management, and drawing of graphs are called **applications**.

Q5 DOS and Windows™ are examples of **operating systems**.

Q6 Match each task on the left with the type of software application on the right you would use for the task.

Answers

1. Preparing the text for the hospital's annual report	D. Word processing
2. Preparing back-up copies of registry data for off-site storage	E. Utility programs
3. Sending a file of cases to the state central registry electronically over telephone lines	B. Communications
4. Preparing a pie chart showing the percent of breast cancer cases diagnosed at each stage of disease	A. Graphics program
5. Abstracting a cancer case directly into the computer	C. Cancer registry application

COMPUTER EQUIPMENT—HARDWARE

When considering the type of computer equipment needed for a registry, there are three basic things to keep in mind in order to make informed, intelligent decisions:

Type of RegistryFinally, the type of registry is important. Is data collection the focus of your registry, or is preparation of cancer committee reports and minutes, graphic displays, and statistical analyses? Is the registry part of the health information management department or another information collecting system, or is it a completely separate entity?

Growth

Growth may be in terms of future expansion of the hospital itself or of its oncology department. Determine, if possible, what your hospital sees as its priorities pertaining to the collection and use of cancer data.

Speed

The demands made on your time and the number, frequency, and complexity of requests for data made by your supervisors and committees will help determine the speed of the computer.

Many of the different parts of the computer are hardware. Some of these parts are external, that is, you can see and touch them, such as the monitor[1] and the keyboard. Others, such as the CPU[2], are on the inside of the case and cannot be seen.

THE COMPUTER

What You See

The monitor or CRT (cathode ray tube) is the most apparent part of the computer. Monitors come with a color display, so the most difficult decisions are how much resolution or clarity you want, and how large a viewing area you need. The largest and most expensive monitors permit you to display more information on the screen with better resolution. These are preferred if you are doing a lot of graphics or desktop publishing.

On a computer monitor, resolution is determined by pixels, a short name for picture element. A pixel is the smallest dot that can be represented on a screen. The more pixels you have per square inch, the higher the resolution, or clearer the picture is.

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[1] Monitor: The visual display unit or screen of a computer.

[2] CPU: Central processing unit, the functional "brain" of a computer that controls the interpretation and execution of instructions.

Keyboards are an important part of the computer because of the problem with repetitive motion disorders. Nearly all keyboards are manufactured with the number keypad to the far right, arrow and cursor movement keys to the near right, and function keys[1] at the top or side. The latest ergonomic[2] keyboard is shaped so that your hands are turned inward and your wrists are elevated. If you spend a great deal of time at your computer, it is well worth having this type of keyboard.

Inside The Computer

The case of the computer houses all of the parts that actually make the computer run. The CPU chip (or brain of the computer) is inside this case. In common usage, both the computer case itself and the CPU are called the Central Processing Unit. For purposes of clarity, we'll call the case that houses all these parts the housing unit, and we'll call the chip the CPU.

The housing unit holds the floppy, hard disk, and CD ROM drives, the memory, and the CPU chip. There are three types of data storage devices or drives. They hold information (or data) that you can access easily. The floppy drives[3] are the ones into which you put diskettes. There is an opening in the front of the unit where you can put a 5¼" diskette, a 3½" diskette, or a Zip disk.

Disk and CD ROMs store information in bytes[4]. Their capacity is measured in Kilobytes (or Kb). A Kilobyte equals 1,024 bytes, usually rounded out to 1,000 bytes. 1,000 Kbytes are considered one Megabyte (or Mb).

There are different sizes of disks[5]. Dual density diskettes hold less information than high-density diskettes. There are 5¼" and 3½" sizes for both dual and high-density disks. The amount of information they can hold is:

1. 5¼" Dual Density = 360 Kbytes
2. 5¼" High Density = 1,200 Kbytes (or 1.2 Mbytes)
3. 3½" Dual Density = 720 Kbytes
4. 3½" High Density = 1,440 Kbytes (or 1.44 Mbytes)
5. Zip Disk = 100 Mbytes

[1] Function keys: A set of keys, usually labeled F1, F2, F3, etc., used by themselves or with Shift, Control, and Alt keys to provide quick access to frequently used commands.

[2] Ergonomic: Designing and arranging things people use so that the people and things interact most efficiently and safely.

[3] Floppy drive: A drive in the computer used where data and/or programs are accessed from a floppy disk.

[4] Byte: Amount of space needed to store a single character (number, letter, or code).

[5] Disk: A removable, rotating, magnetic plate that is considered a secondary computer data storage medium.

The Zip disk has the largest capacity for holding information, so it is valuable for storing backup data or copying files from the hard drive. Today's standard is the 3½" high density, but 5¼" high-density diskettes are still available. Most programs are being distributed on 3½" floppy disks or CD ROMs, so the latest standard is recommended. Most computers have a CD ROM drive and many have a Zip drive.

Note: When figuring space on any data storage device such as a floppy disk or a hard disk, consider the following. If, for example, you have 10,000 Kbytes of information on your hard drive, it is actually taking up 10 Mbytes of space. It equals the same amount of space. One Gigabyte is the same as 1,000 Mbytes.

The hard drive[1] is built into the computer (it is sometimes called the fixed disk) and can't be touched by the operator. This drive is the main storage device for a single computer. Computers that are part of a network can also store information on other devices connected to the network.

It's very important to consider future growth when trying to decide how large a hard drive you should be using. Software programs have become so large that today one program could easily take up most of the space on your hard drive if it only has a capacity of 80 Mbytes. In 1993, the average hard drive held about 200 Mbytes of data. Today (1999) the average size is 8 gigabytes, and the cost of hard disk storage is dropping as technology advances. It would be wise to purchase the largest hard drive you can afford to accommodate the growth of your registry. A large hard drive may not be necessary if you are on a network where the file server[2] has a very large hard drive that will provide memory for the smaller individual workstations.

If you are acquiring a commercial cancer registry software system, the vendor will have a list of recommended specifications for size and speed of the computer and peripherals.

Some guidelines to determine how large a hard drive is needed now, and the size that may be needed in the future:

1. How many cases do you abstract per year? How much space does each case take up? (The software vendor that programs your registry reporting software should be able to tell you this.)
2. What other programs do you use to make your registry run?
   A. Word processing
   B. Spreadsheets
   C. Windows
   D. Desktop publishing
   E. How large are they (Mbytes)
   F. Will you be getting new programs that take up even more disk space than the ones you already have?
3. Will you be going to a network configuration?
4. Will your registry be combining data with another hospital's registry or a central registry?
5. Is follow-up automated?
   A. Are follow-up letters produced on your computer?
   B. Will you be downloading (receiving) data from the Internet or the hospital computer system?

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[1] Hard drive: A fixed disk drive in the computer where the data are physically stored.

[2] File server: A software program that allows all the computers on the network to communicate with each other.

Other computer components inside the housing unit that you can't see are the CPU chip and the memory chips. These two items will determine the speed at which you do your work. We suggest that you get the fastest chip and the most memory that is recommended for your automated registry.

The CPU chip is the brain of the computer. All information you process has to go through this chip, which is why it is called the Central Processing Unit.

CPU chips are given numbers that relate to their power. The latest software cannot run on any computer that has a CPU chip with a number less than 286. Between the 286 and the Pentium chip are the 386 and 486. As implied, each one is progressively more powerful and faster. Until recently, the most powerful and fastest chip on the market was the Intel Pentium, which is essentially a 586 chip. Today the Intel Pro is a step up from the Pentium, and numbers are no longer used.

Chips come with different speeds called megahertz[1]. Each chip could have several different speeds. For example, a 486-66 chip runs much slower than a 486-100. The number following the hyphen represents megahertz, or how fast the chip processes instructions. However, a 586-66 CPU, with a higher class of chip, is faster than a 486-100. Both speed (megahertz) and class of CPU determine processing speed.

Chips look like wafers with several little metal legs affixed to them on opposite sides. Those legs help them attach to a circuit board in the housing unit and transfer information to other chips on the boards.

[1] Megahertz: One million cycles per second (typically used in reference to a computer's clock rate).

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q7 What three things are important to keep in mind when selecting computer equipment for your registry?

A. _____

B. _____

C. _____

Q8 On a computer monitor, resolution is determined by the number of _____ per _____.

Q9 A key on your computer's keyboard that is pre-programmed for a specific action is a _____ _____.

Q10 The letters CPU stand for _____ _____ _____.

Q11 How many Kbytes does it take to make 12 Mbytes? _____.

Q12 How much data can the 3½ inch HD diskette hold? _____.

Q13 What is the hard drive sometimes called? _____ _____.

Q14 Name five guidelines used to determine how large a hard drive your registry needs.

A. _____

B. _____

C. _____

D. _____

E. _____

Q15 The CPU chip is considered the _____ of the computer.

SECTION K TEST ANSWERS

Q7 The three things to keep in mind when selecting computer equipment for your registry are:

Answer

A. Speed
B. Growth
C. Type of registry

Q8 On a computer monitor, resolution is determined by the number of **pixels** per **inch**.

Q9 A key on your computer's keyboard that is pre-programmed for a specific action is a **function key**.

Q10 The letters CPU stand for **Central Processing Unit**.

Q11 How many Kbytes does it take to make 12 Mbytes?

Answer

12,000 Kbytes

Q12 How much data can the 3½ inch HD diskette hold?

Answer

1.44 Mbytes.

Q13 What is the hard drive sometimes called?

Answer

The fixed disk.

Q14 Name five guidelines to determine how large a hard drive your registry needs.

Answer

You might have cited any of the following:

A. The number of cases abstracted per year and the space required for the data
B. The number and kinds of programs used to make your registry run, such as, word processing, spreadsheets, Windows, desktop publishing, and the size in Mbytes
C. The number of new programs that may be acquired and the space that they will require
D. Registry plans to change to a network configuration
E. Registry plans for combining data with another hospital's registry or central registry
F. Automated follow-up with follow-up letters produced on the registry's computer and printer

Q15 The CPU chip is considered the **brain** of the computer. (All the information you process has to go through this chip.)

COMPUTERS-HARDWARE (CONTINUED)

Memory or RAM[1] (Random Access Memory) is probably the most misunderstood part of the computer. RAM is used by the computer in the execution of instructions or tasks given by the operating system or an application program. Each memory chip represents one or more megabyte of memory. The standard for business computers is to have at least 16 Mbytes of memory or more. You learned earlier that the hard drive physically stores data; the memory also stores it, but only temporarily; that is, when you're working on a program. The computer must have enough memory to run the program.

The more memory, the faster the screen display, and the faster the programs run. This is because memory chips sit there waiting to be filled. When you start a program, it brings that part of the program you're working on into memory. If you have 8 Mbytes of RAM, and you're only using 1 megabyte with your current program, just think how many more programs you can run, or how fast you can run just the one program. As you eventually fill-up all the memory, your program(s) will begin running more slowly because it has to write part of the program to temporary space on the hard disk. This is why you want to have a lot of memory in order not to hinder your work. If you don't have enough when you first get your computer, it's easy to add more memory later.

People are often confused by memory and hard disk space. Think of it this way: A program that you have installed on your computer has been installed on the hard disk and is there permanently, or until you delete it. When you want to run that program, portions of it come up in the computer's memory (or temporary work area) until you exit the program. Therefore, you have a permanent area (hard disk) and a temporary area (memory) that work together to enable you to use your computer program.

Peripherals

Additional computer-hardware components that can help your registry run more smoothly are the printer, modem, and back-up tape drive[2]. These parts don't actually make the computer run, but they are important elements of a fully automated registry. They are usually called peripherals because they are attached to the outside of the computer.

Printers

There are so many printers on the market that it would be impossible to list them all. The three major types are: dot matrix, inkjet and laser.

If you normally print abstracts and a few lists, a dot matrix printer may be suitable for your registry. It prints by pushing dots in a certain pattern onto the paper to form a letter or symbol. Dot matrix printers require a type of paper called tractor feed or pin feed that has holes on either margin; this allows the printer to roll the paper forward to the next line or the next sheet.

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[1] RAM: Random Access Memory is the working space, or temporary storage area, for the program you are using and the document on your screen.

[2] Back-up tape drive: A secondary storage medium that holds a copy of the contents of the hard disk.

An ink jet printer costs just a little more than a dot matrix printer does. These printers produce fine quality graphics and letters. Ink jet printers use regular paper and produce letters by spraying ink onto the paper. Color ink jet printers can print documents in color.

If you print graphics along with your reports, or need extra fonts (type faces) for sending professional-looking reports, consider a laser printer. These printers are quiet and, at 300 or more dots per inch, look extremely professional. Laser printers use regular paper. Again, as with any equipment, think about your future needs when deciding on what type of printer would be best.

Most printer speeds are determined by how many pages per minute can be printed (PPM). Another measurement for laser or inkjet printers is the resolution or dots per inch (DPI). The average PPM is 15, and the average DPI is 600 for most printers. The higher the PPM or DPI, the greater the cost of the printer.

Another consideration in selecting a printer is costs for replacement ribbons, ink cartridges, or toner cartridges. Consider the registry's expected volume of printing and the cost per image printed.

Modems

Modems are becoming important adjuncts to the operation of your registry. They send information via the telephone lines. You can transmit cases through the modem, you can use electronic mail, you can *FAX* (and receive) information that you have on your computer. Modems have recently increased from a high speed of 9600 baud[1] to 56 bps (28,800 bits per second) or even higher. The numbers represent the speed at which information can pass along the telephone line. Just remember that if one modem is a 9600 baud modem and the system to which it is communicating has a 14.4 modem, the information will transmit at the lower speed. If, on the other hand, both modems are 14.4, then both will transmit at the speed of 14.4. Any fully automated registry should have a modem.

More information is at your disposal when you have a modem. The National Cancer institute, the CDC and SEER, as well as several other organizations, offer bulletin boards and Internet sites with a wealth of information that can be accessed only if you have a modem.

Modems usually come with their own basic software. There are excellent software packages available (pcAnywhere or Procomm, for example) that will allow more flexibility and additional enhancements, such as the ability to transfer files, or the ability to communicate with other types of modem software.

Back-Up Systems

You should back up your work every day and your system every week. A back-up is a copy of your computer files on electronic media that can be removed from the computer. This can be accomplished by installing a tape back-up system or by using floppy disks. You are more likely to perform regular back-ups if the process is quick and easy, because the more information you have on your hard disk, the more time would be involved. A tape drive will save you time and money. With a tape back-up system, you simply put a tape in the opening provided in the housing unit (or you can plug a portable back-up unit into your computer), and set the backup program to run at a convenient time. Backing up with floppy disks is less efficient; it may require the use of multiple diskettes. Obviously, a tape back-up system is the choice for a large registry. Backing up is the best

[1] Baud: A unit of speed equal to one bit per second.

insurance for any potential disaster. Registries have had their computers stolen, their hard drives erased, and have experienced the ravages of earthquakes, floods, and fires. A back-up is the best protection from these potential disasters. Prepare back-up copies on a regular basis, and consider safe, confidential, off-site storage of back-up files. Periodically, (perhaps 3 times per year) reinstall the back up on another computer (not the original one) just to assure yourself that the backup program is operating properly.

NETWORKS

If you have more than one computer or have more than one person working in your registry, you should consider purchasing a network so that all the computers can work together and ultimately save time and money. Networks and network software allow more than one person to work on the same program at the same time. It's a highly efficient way of keeping and working on large amounts of data.

A network consists of two or more computers cabled together so that the computers can communicate and, therefore, share data and peripherals with each other. This is facilitated by network software installed on the workstations and on a computer called the file server, which acts as the holder of the majority of files and thus needs a large hard drive. Not as large a hard drive is then needed on the workstation computers. A file server allows the separate computers or workstations to communicate.

A file server can be dedicated or non-dedicated. A dedicated file server means that no one can input data at the file server workstation. It receives and distributes information for each of the other workstations. It can work faster if it's allowed to be dedicated. All the other workstations are connected in a configuration designed specifically to work best for your registry. A non-dedicated file server is a computer that you can use to enter information into the database just like any other workstation. You give up speed, but you gain another workstation. Again, the workstations are attached in the best possible configuration for the most efficient use in your registry.

Creating a network means linking the computers with cable and installing the network software that allows the computers to communicate with each other. Much of the planning, cabling, and configuring is done by outside consultants or your facility's information management system (IMS) department. If you have a network, you will need registry software specifically designed to run in a network environment.

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q17 RAM stands for _____ _____ _____.

Q18 The difference between hard disk space that contains the programs and random access memory is that random access memory is a _____ holding place, and a hard disk is a _____ holding place for your program and data.

Q19 On a printer, output resolution is determined by the number of _____ per _____.

Q20 Elements such as the printer, the modem, and the back-up tape drive, which can be attached to the computer but don't actually make it run, are called _____.

Q21 Networks allow you to _____ programs and data so you can work more efficiently.

Q22 When would you use a dedicated file server? _____.

SECTION K TEST ANSWERS

Q17 RAM stands for **Random Access Memory**. (It temporarily stores the data you are working on.)

Q18 The difference between hard disk space that contains the programs and random access memory is that random access memory is a **temporary** holding place, and a hard disk is a **permanent** holding place for your program and data.

Q19 On a printer, output resolution is determined by the number of **dots** per **inch**.

Q20 Elements such as the printer, the modem, and the back-up tape drive, which can be attached to the computer but don't actually make it run, are called **peripherals**.

Q21 Networks allow you to **share** programs and data so you can work more efficiently.

Q22 When would you use a dedicated file server?

Answer

You would use a dedicated file server if you wish to store and distribute information, but not enter data from that location.

COMPUTERIZED EDITS

The computer is very good at editing certain kinds of data. Edits enforce relationships among data items and control what data can be entered. Carefully programmed edit checks can be an important element of quality control. The programs or routines[1] that perform these checks are known as edits, and are usually categorized in three types:

1. Single-field or item edits verify that the contents of a single field or data item are valid without reference to any other field or item. For example, an edit of the item "Sex" would verify that only valid codes are used in the field.
2. Multi-field or inter-field edits check the contents of one or more items against another. For example, a common inter-field edit checks the code for "Sex" against the code for "Primary Site" and identifies prostate cancer in a female as an error.
3. Multi-record or inter-record edits check multiple items in different records for internal consistency. Usually all records for a single patient in the database (that is, all of the patient's tumors) are compared to check for duplicate reports or inconsistent data.

Some edits are strictly pass-fail, and data must be corrected before the case passes the edits. Other edits may allow for looser criteria and provide warnings or allow review of possibly incorrect data. To increase comparability of data between registries, it is essential that edits be programmed correctly and, wherever possible, that they adhere to agreed-upon standards for the items and their relationships.

Edits should be applied to the data at the time of abstracting, if possible. If edits are applied at the time of abstracting, the source data in the medical record are still at hand and errors can be corrected immediately.

Maintaining the integrity of the data is always the responsibility of the cancer registrar. It is essential that data not be lost or changed in any unintentional or accidental way and that, when the inevitable problems do arise, the registry can recover the data in its original form. This requires that:

1. computer equipment must be installed and maintained properly.
2. electrical power supplies sprinkler systems, and fire extinguishers and other physical plant features must be carefully evaluated.
3. the registry must have plans in place to recover from a disaster such as a flood, tornado, or earthquake.
4. most importantly, adequate back-up procedures must be followed. Routine back-up copies of data files must be made and stored safely. Provisions must be made for storage at a location other than the registry itself.

Cancer registrars must take precautions to protect the confidentiality of all data stored in the registry's computers. Data access can be protected by assigning passwords to authorized users. Equipment and diskettes should be locked-up and inaccessible when not in use. If files are mailed, the use of registered mail, overnight mail, or courier should be considered. If files are sent electronically, consideration should be given to encrypting[2] the data or to sending names in a separate transmission.

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[1] Routine: A set of programming instructions designed to perform a specific, limited task.

[2] Encrypt: To scramble computerized information to prevent unauthorized access.

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q23 For each possible edit error described below, indicate whether it is the result of a single-field edit, an interfield edit, or a multi-record edit.

_____ A. A patient has two tumors in the file with sequence number coded 01.

_____ B. Valid codes for the patient's race are in the ranges 01-14, 20-22, 25-28, 30-32, and 96-99, but this patient's race is coded 85.

_____ C. The date of diagnosis of the patient's cancer is recorded as 6/13/94, and her date of birth is recorded as 8/20/94.

_____ D. The histologic type of the cancer is retinoblastoma (a tumor of the eye that occurs in infants and small children), the patient's birth date is 10/10/50, and the date of diagnosis is listed as 12/2/93.

_____ E. The histologic type of the cancer is retinoblastoma, and the primary site is coded as liver.

_____ F. The patient has two separate cancers recorded in the registry. In one of the records, the patient is listed as alive in June 1994, but in the other record, he is listed as dead in May 1994.

_____ G. The date of diagnosis is listed as February 30, 1994.

_____ H. The date cancer-directed treatment began is recorded as 9/18/93, but no treatment for the cancer is recorded.

Q24 List several things the cancer registrar must do to maintain data security and integrity in a computerized registry.

A. _____

B. _____

C. _____

D. _____

SECTION K TEST ANSWERS

Q23 For each possible edit error described below, indicate whether it is the result of a single-field edit, an interfield edit, or a multi-record edit.

multi-record	A.	A patient has two tumors in the file with sequence number coded 03.
single-field	B.	Valid codes for the patient's race are in the ranges 01-14, 20-22, 25-28, 30-32, and 96-99, but this patient's race is coded 85.
interfield	C.	The date of diagnosis of the patient's cancer is recorded as 6/13/94, and her date of birth is recorded as 8/20/94.
interfield	D.	The histologic type of the cancer is retinoblastoma (a tumor of the eye that occurs in infants and small children), the patient's birth date is 10/10/50, and the date of diagnosis is listed as 12/2/93.
interfield	E.	The histologic type of the cancer is retinoblastoma, and the primary site is coded as liver.
multi-record	F.	The patient has two separate cancers recorded in the registry. In one of the records, the patient is listed as alive in June 1994, but in the other record, he is listed as dead in May 1994.
single-field	G.	The date of diagnosis is listed as February 30, 1994.
interfield	H.	The date cancer-directed treatment began is recorded as 9/18/93, but no treatment for the cancer is recorded.

Q24 List several things the cancer registrar must do to maintain data security and integrity in a computerized registry.

Possible answers

You may have listed:

A. Preparing routine back-up copies of data files and storing back-ups off-site
B. Installing equipment correctly and maintaining equipment adequately
C. Using passwords to access data files
D. Encrypting data files that are transmitted or sent by mail
E. Locking the rooms and cabinets where equipment and diskettes are stored
F. Having a disaster-recovery plan in place

POTENTIAL FOR ELECTRONIC DATA PROCESSING

Cancer registries will be increasingly reliant on computerized processes to maintain complete data as patient care shifts outside the hospital setting and staffs are downsized. One important area to investigate is the possibility of downloading data that are already available in some other computerized database. Accessing information from the Disease and Operations Index (DOI) and from pathology reports in the registry can be a terrific time-saver in both case finding and follow-up. Programs can be developed to facilitate both the screening of reports for potentially reportable cases, and the matching of cases already in the cancer registry database. The use of electronic reporting can have a tremendous impact on the completeness, accuracy, and timeliness of case finding and follow-up.

Population-based incidence registries that perform centralized case finding may want to consider developing mechanisms for a) electronic reporting of the DOI and pathology reports by hospitals and pathology laboratories and b) electronic processing of that data at the registry. The decision to develop these mechanisms may actually be forced upon the registry as pathology laboratories, and eventually hospitals, decide to fully utilize computer systems and become paperless facilities. Hospital-based registries may also want to consider automating this aspect of their case finding.

Manual screening of the DOI and pathology reports can be a staff-intensive activity, particularly for central registries. It is also time-consuming to check each of the potentially reportable[1] cases against the registry's master patient index file to determine whether the case is already registered (that is, whether it has a match on the master patient index file). A computer program can be written to link the incoming electronic pathology or DOI data with the registry's master patient index file to identify the possible matches.

If the DOI and the pathology reports are received electronically, the registry can have computer programs developed to facilitate both the screening and the matching processes. Examples of these systems and programs have been developed by the staff at the Puget Sound area SEER registry at the Fred Hutchinson Cancer Research Center in Seattle, Washington.

The registry can reduce the staff time that is usually spent either handwriting or photocopying information from the hardcopy DOI or the pathology reports. By eliminating the clerical, and/or data entry activities, more staff time can be devoted to deciding whether the patients medical record should be pulled and reviewed by an abstractor.

Because the full text of the pathology report is available during case finding, abstractors do not need to document pathology information. In some registries, up to 40 percent of the abstracting time is spent documenting the pathology information, making that step one of the most time-consuming aspects of the abstracting process.

When the electronic pathology files are a part of the registry's master patient file, the registrar can perform control procedures on the coding of selected fields. The registrar would be able to use the pathology text without having to request the pathology report. Electronic storage of pathology reports eliminates the need to store the hard copies and reduces the potential of misfiling the reports.

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[1] Potentially reportable: A hospital discharge record with an ICD-9 (ICD-10) code on the reportable list, or a pathology report indicating a reportable disease that has yet to be checked against the registry's master patient index to determine if the case already exists in the registry.

If this reporting mechanism is region wide, medical researchers using data from a population-based incidence registry will have access to all the pathology reports for those cases in the database.

Pathology reports contain information that interests medical researchers but is not routinely collected or coded by registrars. Abstracting and coding all items from pathology reports would be cost-prohibitive. However, if all the pathology reports are electronically stored at a central location, medical researchers can easily retrieve and analyze the pathology reports of selected patients. If a patient remained in the geographic region during the disease course, collecting all pathology reports could aid medical researchers in the study of the progression of this disease.

In order to utilize electronic reporting of files from other agencies, the registry must have a computerized system that can be modified by a programmer on registry staff. Vendors of commercial registry systems may or may not be able to incorporate an electronic reporting/processing system into their existing products.

A registry supervisor and programmer should be involved in negotiating the means of electronic reporting for each reporting facility. Although cancer may be a reportable disease in the state, it may not be possible for each reporting facility to transmit the DOI and/or full pathology reports to the registry in a standard format. In fact, some pathology laboratories may need registry assistance to develop a way to download their data from their computer system to a tape or floppy disk.

The health information management departments and pathology laboratories often customize vendor-created software to meet their institution's needs. If the software has been customized, institution-specific versions of the application may be electronically linked to the registry database. The registry must have sufficient programming staff time allotted to develop programs capable of reading electronic submissions from all facilities and storing the data in a standard format.

Although software development is time-consuming and costly, electronic data transmission can result in long-term savings and increase the usefulness of the registry data.

SECTION K TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q25 Centralized registries may consider electronic linkage to the registry where electronic reporting of_____ and _____ _____ or _____ _____ is done by hospitals and pathology laboratories. In fact, it may become forced on us as facilities begin to fully utilize their computers and become _____.

Q26 Having the full text of the pathology report available at the registry at the time of case finding means:

A. _____

B. _____

C. _____

D. _____

Q27 Although the development of electronic reporting and processing systems is time-consuming and costly, it can result in _____.

SECTION K TEST ANSWERS

Q25 Centralized registries may consider electronic linkage to the registry where electronic reporting of **disease** and **operation indices** or **pathology reports** is done by hospitals and pathology laboratories. In fact, it may become forced on us as facilities begin to fully utilize their computers and become paperless.

Q26 Having the full text of the pathology report available at the registry during case finding (abstracting) means:

Answer

You might have said:

A. Registrars would no longer need to abstract pathology information.
B. By storing the electronic pathology files as part of the registry, master patient file allows the registrar to perform quality control procedures on the coding of selected fields.
C. Storage of the pathology reports electronically eliminates the need to store the hard copies of the pathology reports and the problems caused by incorrectly filed reports.
D. If electronic reporting is region wide, medical researchers utilizing data from a population-based incidence registry will have access to all the pathology reports for patients in the database.

Q27 Although the development of electronic reporting and processing systems is both time-consuming and costly, it can result in:

Answer

You might have said:

A. Long-term savings.
B. An increase in the usefulness of the registry database to medical researchers.

SECTION L

CANCER THERAPY

There are several rules for recording cancer-directed treatment. The abstractor must be familiar with the rules in order to collect treatment data that are consistent, complete, and amenable to analysis. The abstractor must examine the medical record to find out if the patient has received any therapy for this or any other cancer before being seen at the reporting hospital.

The main emphasis in studying cancer therapy is on the first course of therapy. First course of therapy is all cancer-directed treatment planned and received by the patient after his/her initial diagnosis and before disease progression or recurrence. Establishing the date of first diagnosis, the date treatment started, and determining the complete first course of therapy is essential to the analysis of survival and recurrence rates. Subsequent treatment given after completion of the planned first-course or after the disease progresses or recurs is analyzed separately.

The collection of complete treatment information can be the most time-consuming part of abstracting. The first course of therapy may consist of multiple treatment modalities and often these treatments are given in more than one setting. Treatment may have started before admission, continued during admission, and extended at an office or a freestanding facility after discharge. It is the responsibility of the abstractor to gather information on all treatments received by the patient.

CLASS OF CASE

Accurately determining the "class" of case is critical to the validity of cancer registry data. The class of case is a data item that describes the reporting facility's involvement in the patient's diagnosis and treatment. Patients with cancer may present to a reporting hospital at various points in the course of their disease and its treatment. Therefore, a case may be:

0 diagnosed at your hospital after your reference date and received all of the planned first course of therapy elsewhere
1 diagnosed at your hospital since your reference date and received all or part of the first course of therapy at your facility
2 diagnosed elsewhere and received all or part of first course of therapy at your facility
3 diagnosed elsewhere and received all of first course of therapy elsewhere
4 diagnosed and treated at your hospital before your reference date
5 diagnosed at autopsy
6 diagnosed and received all of first course treatment in a staff physician's office
8 was diagnosed only on the basis of a death certificate
9 Unknown class of case

Only the first three categories (classes 0, 1, and 2) are included in the routine analysis of registry data and are called analytic cases. When the CoC implements class of case 6, it will be an analytic class because physicians at your facility participated in the initial diagnosis and/or first course of treatment of these patients.

Cases in classes 3, 4, and 5 are non analytic. Physicians at your facility did not have the same degree of responsibility for the care of these patients. Usually these patients were admitted with recurrent disease or were not diagnosed until autopsy. This distinction is particularly important when calculating survival rates, which are discussed in detail in Book 7 of this series.

CoC does not require that the registry include the following cases, although some might be required by the central registry to which the facility reports:

1. Patients seen only in consultation to confirm a diagnosis or a treatment plan.
2. Patients with a history of cancer who currently have no evidence of the disease.
3. Patients with localized basal and squamous cell carcinoma of the skin, except for lesions of the mucous membranes.
4. Patients with precancerous conditions or benign tumors (behavior codes 0 and 1). (Selected diagnoses may be included at the discretion of the facility's cancer committee.)

DEFINITION OF TREATMENT

The SEER Program defines cancer-directed treatment as procedures that are directed toward cancer tissue, whether the primary (primary tumor or primary site) or metastases (secondary tumor or metastatic site). Therapies that remove cancerous tissue (such as surgery) or cause regression or destruction of cancerous tissue (chemotherapy, endocrine or hormone therapy, immunotherapy, and radiation therapy) are described as definitive. Definitive therapy is not always curative (intended to remove all clinical evidence of disease). Some examples of definitive treatment that is not curative are:

1. Patient has metastatic disease at diagnosis. The metastatic tumor was surgically removed, but the primary tumor was not treated. The surgery was not performed with curative intent.
2. A lung cancer patient's tumor extends into the spinal column. Radiation is used to shrink the primary tumor away from the spinal column so that the patient's pain is controlled.
3. Patient does not complete the prescribed course of treatment.
4. The tumor does not respond to treatment.

Palliative treatment (as described in example #2) is administered to make the patient more comfortable, but treatment is recorded as cancer directed when tumor (primary or metastatic) is modified, controlled, or destroyed. Radiation modified the primary tumor (decreased the size of the tumor). The term "palliative" describes why the patient was treated (intent) but does not describe treatment results (decrease in the size of the primary tumor).

Non definitive (not cancer-directed) treatments do not remove, modify, or control primary or metastatic tumor. For example, as part of the diagnostic work up, patients with suspected thyroid cancer may receive levothyroxine for a thyroid suppression test or a radioactive iodine isotope (^{123}I or ^{131}I) for radionuclide imaging studies. These small doses do not modify cancer tissue, so the procedures are not cancer-directed treatment. However, following surgical resection of a thyroid cancer, patients may receive the same agents (levothyroxine or higher doses of ^{131}I) to decrease the rate of recurrence or to cause regression or destruction of metastatic disease. Within this regime, the same agents modify cancer tissue, and are recorded as cancer-directed therapy. Although most non definitive treatments are given to establish a diagnosis or to make the patient more comfortable, the terms "diagnostic" and "palliative" do not automatically mean the treatment is non definitive. For example: although documentation describes a breast biopsy as diagnostic, the procedure is cancer-directed if it removes all gross (macroscopic) tumor, (margins may be microscopically involved).

TYPES OF TREATMENT

With experience, you will learn the type(s) of treatment commonly recommended for various cancers. The choice of treatment may vary depending on several factors:

1. Histology of the tumor
2. Extent of the disease (EOD)
3. Presence of intercurrent disease (for example, heart disease, renal disease)
4. Age and health of the patient
5. Intent of treatment (for cure or for palliation)
6. Personal preferences of the patient

Surgery, radiation therapy, chemotherapy, endocrine (hormone) therapy, and immunotherapy are common cancer-treatment types or modalities that may be used alone or combined with other treatment modalities (multimodality therapy). An example of single modality therapy:

1. A patient has a mastectomy for early stage breast cancer.

Definitive treatment for breast cancer often involves a multimodality approach, surgery, chemotherapy, radiation therapy, and hormone therapy. Examples of multimodality therapy are:

1. A patient with low stage cancer of the breast has a lumpectomy followed by radiation therapy to the breast area (multimodality therapy: surgery and radiation).
2. Patients whose breast tumors are large or have unfavorable prognostic indicators may have a surgical procedure (modified or partial mastectomy), then receive systemic adjuvant[1] chemotherapy to prevent or delay the recurrence of breast cancer. The patient then has radiation therapy to the ipsilateral chest wall and axilla and hormone/endocrine therapy (such as tamoxifen).

For each treatment modality or combination of modalities, a series of codes are assigned to describe the specific treatments in more detail. The SEER Program and the CoC have worked together to develop and implement a standard set of codes for surgery, radiation therapy, chemotherapy, endocrine therapy, immunotherapy, and other cancer-directed therapy. The codes are presented with detailed instructions in the *SEER Program Code Manual, Third Edition*, and the CoC *Registry Operations and Data Standards, 1998 Supplement*. Treatment modalities are described briefly in the following paragraphs.

Surgery: Cancer-Directed

Surgery is the oldest type of cancer therapy. Discussions of the surgical treatment of tumors appear in ancient Egyptian writings. The development of general anesthesia and antiseptic techniques in the mid-19th century established a radical surgical procedure as the traditional treatment for malignant disease and, for many patients, the only possibility for cure. The use of radical surgery has changed dramatically in recent years due to innovations in surgical technique, increased understanding of disease process for specific tumors, and the ability to control microscopic disease by other treatment methods. Today many cancers can be successfully treated with a more limited surgical resection and adjunct radiation therapy, chemotherapy, endocrine therapy, or immunotherapy.

Surgery of Primary Site

Cancer-directed surgery of the primary site is a procedure that removes the gross primary tumor (margins must be grossly free, but may be microscopically involved). The least radical procedure, removal of the primary

[1] Adjuvant: Treatment received in conjunction with other treatment.

tumor only, is often called an excisional biopsy. The excision of the primary tumor may include a partial or complete removal of the organ of origin. The names of the procedures that remove organs usually end with "-ectomy" (colectomy, gastrectomy, laryngectomy, and mastectomy). When a tumor arises in structures such as soft tissue, bone, and skin, the surgical removal is often called an excision, resection or amputation.

Cancer-directed surgical procedure codes are site-specific. For example, site-specific surgery codes for oral cancer include codes for electrocautery or cryosurgery and for laser surgery (procedures not used to treat breast cancer). Site-specific codes for the uterus include codes for the resection of adjacent organs (ovaries, fallopian tubes). Site-specific surgery codes are listed in Appendix C of the *ROADS* manual and in the *SEER Program Code Manual, Revised Edition.*

Scope of Regional Lymph Node Surgery
The information collected on regional lymph node surgery is not limited to cancer-directed surgery, as all surgical procedures that aspirate or remove regional lymph nodes are recorded. For several years, regional lymph node dissections were performed to remove regional disease and to prevent or delay a recurrence. The number of lymph node dissections performed has decreased in current years and the emphasis has been on examining nodes for diagnostic and staging purposes.

Surgery of Other Regional Site(s), Distant Site(s) or Distant Lymph Node(s)
Usually, these surgical procedures remove gross tumor from a site other than the primary. The information collected is not limited to cancer-directed surgery. If the surgeon states that a regional or distant site is removed because, clinically, it is involved with tumor, the surgical procedure is coded even if the pathology report is negative for tumor involvement.

Surgery: Non Cancer-Directed
Non cancer-directed surgery is a procedure that does not removes the gross tumor (margins are grossly involved or not evaluable). Most, but not all non cancer-directed surgery is for diagnostic or staging purposes. Physicians dictate operative reports for most surgical procedures, including those that are not cancer-directed such as endoscopy examinations, explorative surgeries, and bypass procedures. Endoscopy procedures (such as bronchoscopy, colonoscopy, cystoscopy, gastroscopy, laryngoscopy, sigmoidoscopy) permit the examination of the interior of a tube or hollow organ. A diagnostic biopsy or brushing of any abnormal-appearing tissue is often done during an endoscopy by a long biopsy forceps or a brush passed through a channel in the endoscope. Note that all of the endoscopic procedures listed above end in "-oscopy."

Exploratory surgery
Exploratory surgery may be performed if cancer of an internal organ is suspected but tissue for diagnosis cannot be obtained by other means. For certain cancers (lymphoma, ovarian cancer), surgical exploration of the abdomen and/or pelvis may be used to determine the extent of disease. However, the use of abdominal exploration (laparotomy) for staging has become less frequent with the development of sophisticated body imaging techniques, such as computer-assisted tomography (CAT scans) and magnetic resonance imaging (MRI). Less invasive surgical explorations of body cavities are done with the use of the mediastinoscope, the thorocoscope and the laparoscope. Biopsies are often done during these minimally invasive "scope" procedures, and are coded as an exploratory with biopsy.

Palliative[1] surgery

Surgery or other invasive procedures may be performed as palliative measures to relieve symptoms or to control complications of cancer. One of the more common palliative procedures is using a scope to place a "stent" or tube into hollow tube to keep the passageway open when direct tumor involvement or compression have caused a narrowing or occlusion. For example, stents may be placed in the gastrointestinal tract or the urinary tract where it is obstructed or narrowed by an unresectable cancer. For a bowel obstruction, parts of normal bowel are connected (anastomosed) to form a passage (bypass) around the cancerous tissue. Alternatively, an artificial opening ("-ostomy") may be created for feeding or elimination purposes. For example, a gastrostomy allows feeding in some patients with cancer of the esophagus or sites in the head and neck; a colostomy allows elimination in certain patients with colorectal cancer. Although most non definitive treatments are given to establish a diagnosis or to make the patient more comfortable, the terms "diagnostic" and "palliative" do not automatically mean the treatment is non definitive. For example: although documentation describes a breast biopsy as diagnostic, the procedure is cancer-directed if it removes all gross (macroscopic) tumor (margins may be microscopically involved). A detailed description of non cancer-directed procedures and examples of the operative reports are included in Book 5 under Manipulative and Operative Procedures.

[1] Palliative surgery: Performed to relieve symptoms or control complications of cancer or cancer-directed treatment.

SECTION L TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 When classifying treatment for your hospital according to the class of case rules, in which of the following examples would the case be analytic?

A. Patient was first diagnosed and treatment planned at your facility, but patient chose treatment in a distant city in order to be close to family during recovery.

B. Patient was first diagnosed and treated elsewhere and admitted to your facility for additional treatment after developing metastatic disease.

C. Patient's first course of therapy was initiated at your facility and continued at another facility following discharge.

D. Patient's first course of therapy was initiated before admission to your facility, continued at your facility, and extended at the doctor's office following discharge from your facility.

Q2 For analytic purposes, cancer cases are grouped by _____ ___ _____.

Q3 The oldest type of cancer-directed therapy is _____.

Q4 Which of the following are cancer-directed therapy?

A. Resection of a tumor mass

B. Colostomy

C. Partial removal of the primary organ

D. Diagnostic biopsy (incisional)

E. Cystectomy

F. Excision of a metastatic site

G. Bronchoscopy

H. Gastrostomy

Q5 Exploration of the abdomen and/or pelvis to determine the extent of disease (staging laparotomy) has been supplanted by sophisticated non-invasive machine imaging such as the _____ _____ and _____.

SECTION L TEST ANSWERS

Q1 When classifying treatment for your hospital according to the class of case rules, in which of the following examples would the case be analytic?

Answer

Only in examples A, C, and D would all the treatment given be analytic.

A. Patient was first diagnosed and treatment planned at your facility, but patient chose treatment in a distant city in order to be close to family during recovery.

C. Patient's first course of therapy was initiated at your facility and continued at another facility following discharge.

D. Patient's first course of therapy was initiated before admission to your facility, continued at your facility, and extended at the doctor's office following discharge from your facility.

Example B is non analytic.

B. Patient was first diagnosed and treated elsewhere and admitted to your facility for additional treatment after developing metastatic disease.

First course of treatment was done elsewhere. The treatment initiated at your hospital after metastasis developed was not in the original plan and, therefore, is not considered first course of treatment.

Q2 For analytic purposes, cancer cases are grouped by **class of case**.

Q3 The oldest type of cancer-directed therapy is **surgery**.

Q4 Which of the following are considered cancer-directed therapy?

Answer

A. Resection of a tumor mass

C. Partial removal of the primary organ

E. Cystectomy

F. Excision of a metastatic site

All of the treatments above remove cancer tissue.

Non-cancer-directed treatments:

B. Colostomy
D. Diagnostic biopsy (incisional)
G. Bronchoscopy
H. Gastrostomy

Those procedures described in B, G, and H do not remove tumor tissue. D, diagnostic biopsy (incisional), does not remove the gross tumor. An incisional biopsy removes only enough cancer tissue to confirm the diagnosis, leaving gross tumor in the patient's body.

Q5 Exploration of the abdomen and/or pelvis to determine the extent of disease (staging laparotomy) has been supplanted by sophisticated non-invasive machine imaging such as the **CAT Scan** and **MRI**.

Radiation

The two approaches to radiation therapy in common clinical use are teletherapy and brachytherapy. Teletherapy (beam radiation) involves administration of radiation from a source such as an orthovoltage or supervoltage radiotherapy machine; the source of the radiation is external (and at a distance) from the patient. Radiation sources for teletherapy include orthovoltage x-ray machines, cobalt units, linear accelerators, neutron beam generators, betatrons, and the gamma knife. The choice among sources of external radiation depends largely on the availability of therapy machines, the biological characteristics and location of the tissue target, and specific radiotherapy requirements (such as dosage fractionation). Orthovoltage has had limited use in cancer therapy since the development of higher voltage machines such as cobalt (supervoltage) and the linear accelerator (megavoltage).

In brachytherapy, the radiation source is close to or internal to the target tissue. Examples of brachytherapy include radioactive implants and internal administration of radioisotopes. Implants may be in the form of radioactive needles, seeds, or special applicators. They may be inserted directly into the target tissue (interstitial implants) or placed within a natural body cavity (intracavitary applications). Radioactive cesium (^{137}Cs), iridium(^{192}Ir), gold (^{198}Au), and iodine (^{125}I) are frequently used for brachytherapy.

Another radiation therapy application is the systemic administration of radioactive isotopes. An isotope is one of two or more nuclides that are chemically identical yet differ in mass number, since their nuclei contain different numbers of neutrons. A radioactive isotope has an unstable composition and decomposes spontaneously by emission of energy; the energy then interacts with surrounding tissue to produce its therapeutic effect. This radiotherapy approach often takes advantage of the biological characteristics of the target tissue. For example, because thyroid tissue absorbs iodine at a greater rate than other body tissues, the radioisotope ^{131}I concentrates in thyroid tissue and can be given systemically to treat metastatic thyroid cancer. Similarly, because phosphorus accumulates in bone, the isotope ^{32}P can be administered as therapy for hematological conditions such a polycythemia vera (overproduction of red blood cells by the bone marrow). Radioisotopes injected for diagnostic or imaging studies (for example, radioisotope scans) usually emit smaller amounts of energy and/or are used at much lower doses than those injected for cancer-directed therapy.

The radiation therapy report for external radiotherapy will document the areas of the body treated, whether at the primary site of the tumor and adjacent lymph nodes, or at sites of tumor spread or metastasis. In certain situations (such as Hodgkin's disease), radiotherapy may be administered for prophylactic reasons to lymph node areas that do not appear to be involved with disease. When the bone marrow is involved, radiation may be given, in lower doses, to larger areas of the body. Examples are:

1. Hemi-body radiotherapy for palliation of multiple myeloma.
2. Whole body radiotherapy in preparation for bone marrow transplantation.

Radiotherapy reports will indicate the total radiation dose in rads (radiation absorbed dose) or Gray (1 Gray equals 10 rads), the number of fractions (individual treatments), and the treatment schedule (the number of fractions, radiation dose per fraction, and treatment duration in days or weeks). While the reporting of these details of radiotherapy is not required by the American College of Surgeons or by most hospital-based and central registries, a special purpose registry designed specifically for the study of radiotherapy treated tumors will require this additional information.

SECTION L TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q6 The two approaches to the administration of radiation therapy are _____ and _____.

Q7 Indicate with a B or T whether the following treatment approaches are teletherapy or brachytherapy:

___ Gamma knife

___ Radioactive isotope

___ Interstitial implant

___ Linear accelerator

Q8 In addition to the area(s) of the body treated, radiation therapy reports will include detailed information on the _____, _____, and _____ _____.

Q9 What is a rad? _____

What is a Gray? _____

Q10 What is a fraction? _____

SECTION L TEST ANSWERS

Q6 The two approaches to the administration of radiation therapy are **teletherapy** and **brachytherapy**.

Q7 Indicate with a B or T whether the following treatment approaches are teletherapy or brachytherapy.

Answer

- **T** Gamma knife
- **B** Radioactive isotope
- **B** Interstitial implant
- **T** Linear accelerator

Q8 In addition to the area(s) of the body treated, radiation therapy reports will include detailed information on the **dosage**, **fractions**, and the **treatment schedule**.

Q9 What is a rad?

Answer

A rad is a **radiation absorbed dose**.

What is a Gray?

Answer

One Gray **equals ten rads**.

Q10 What is a fraction?

Answer

A fraction is **the number of individual treatments**.

Chemotherapy And Combination Drug Therapy

Chemotherapeutic agents are drugs or chemicals that are administered to destroy cancer cells or slow their growth. Most cancer registries record only the chemotherapeutic agent and do not include the dose, method of administration, or treatment schedule.

In general, chemotherapeutic agents are classified into groups according to their action on tumor cells. Common classes of drugs and examples are:

1. **Alkylating agents** cause structural changes in DNA strands, which interfere with cell function and replication. Examples include nitrogen mustard (Mustargen), phenylalanine mustard (Melphalan), cyclophosphamide (Cytoxan), and chlorambucil (Leukeran).
2. **Antimetabolites** replace natural metabolites and alter enzymes, which are important in cell function and replication. Examples include methotrexate (MTX), 5-fluorouracil (5-FU), and 6-mercaptopurine (6-MP).
3. **Vinca alkaloids** derived from the periwinkle plant (Vinca rosea) interfere with the formation of mitotic spindles necessary for normal cell division. Examples include vinblastine (Velban) and vincristine (Oncovin).
4. **Antitumor antibiotics** were identified as natural products of microorganisms, which demonstrated antitumor activity. Examples include actinomycin D, mitomycin C, doxorubicin (hydroxydaunomycin, Adriamycin), and daunorubicin.
5. **Miscellaneous agents** do not fall into distinct categories, often because their mechanisms of action are complex or incompletely understood. Examples include hydroxyurea and procarbazine.

In current oncology practice, chemotherapeutic drugs are most often given in combinations rather than as single agents. Clinical studies have found that carefully selected combinations of drugs can increase tumor response rates, prevent or delay the development of drug resistance, and modulate side effects of therapy compared to the individual agents. The combinations usually take advantage of different mechanisms of drug action to maximize the toxic effects on cancer cells and minimize the same effects on normal cells.

Combination chemotherapy involves specific doses and schedules of administration of the component drugs. The program for administration of the agents is termed a regimen, and each administration of the program is called a cycle of chemotherapy. For example, breast cancer patients often receive combination therapy with cyclophosphamide, methotrexate, and 5-fluorouracil (the CMF regimen). This regimen describes administration of its three component drugs at different times during a 28-day treatment course, or cycle. Combination regimens occasionally include hormonal agents or immunotherapeutic agents together with chemotherapeutic agents.

As you become familiar with the names of many chemotherapeutic drugs, you will notice that specific combinations are given acronyms. An acronym is usually formed from the first letter of the names of the agents used. For example:

1. MOPP - nitrogen **m**ustard, vincristine (**O**ncovin), **p**rocarbazine, **p**rednisone
2. CHOP - **c**yclophosphamide, doxorubicin (**h**ydroxydaunomycin, Adriamycin), vincristine (**O**ncovin), **p**rednisone
3. VBP - **v**inblastine (Velban), **b**leomycin, Cis**P**latin

Chemotherapeutic drugs and combination regimens are covered in detail in *Book 8,SEER Self Instructional Manuals Antineoplastic Drugs*, Third Edition.

SECTION L TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q11 Chemotherapy agents are administered to destroy or slow the growth of cancer cells, but their mechanisms of action tumor cells vary. Match the agent to its mechanism of action:

A. Cause structural changes in DNA strands, interfering with cell function and replication.	1. **Vinca Alkaloids** (Vinblastine/Velban, Vincristine/Oncovin)
B. Natural products of microorganisms which demonstrate anti-tumor activity	2. **Antitumor Antibiotics** (Actinomycin-D, Mitomycin C, Doxorubicin/Adriamycin, Daunorubicin)
C. Interfere with the formation of mitotic spindles necessary for normal cell division	3. **Antimetabolites** (Methotrexate/MTX, 5-Fluorouracil/5-FU, 6-metcaptopurine/6-MP)
D. Alter enzymes, which are important in cell function and replication	4. **Alkylating agent** (Cytoxan, Leukeran Melphalan, Mustargen

Q12 Chemotherapy may be given as a _____ agent or in a _____ of drugs.

Q13 Breast cancer patients often receive a combination of cyclophosphamide, methotrexate, and 5-fluorouracil, that is, the CMF _____.

SECTION L TEST ANSWERS

Q11 Chemotherapy agents are administered to destroy or slow the growth of cancer cells, but their mechanisms of action on tumor cells vary. Name the type of agent described below and give an example of each agent.

Answer

A. Cause structural changes in DNA strands, interfering with cell function and replication.	4. **Alkylating agent** (Cytoxan, Leukeran, Melphalan Mustargen)
B. Natural products of microorganisms which demonstrate anti-tumor activity	2. **Antitumor Antibiotics** (Actinomycin-D, Mitomycin C, Doxorubicin/Adriamycin Daunorubicin)
C. Interfere with the formation of mitotic spindles necessary for normal cell division.	1. **Vinca Alkaloids** (Vinblastine/Velban, Vincristine/Oncovin)
D. Alter enzymes, which are important in cell function and replication	**3. Antimetabolites** (Methotrexate/MTX, 5-5-Fluorouracil/5-FU, 6-metcaptopurine/6-MP)

Q12 Chemotherapy may be given as a **single** agent or in a **combination** of drugs.

Q13 Breast cancer patients often receive a combination of cyclophosphamide, methotrexate, and 5-fluorouracil, that is, the CMF **regimen**.

Endocrine (Hormone/Steroid) Therapy

Cancer-directed treatment, which has an effect on cancer tissue by changing the patient's hormone balance is classified as endocrine[1] therapy. Endocrine glands in the body secrete substances (hormones) which act on other organs or at other sites to regulate body mechanisms such as growth, metabolism, and reproduction. Endocrine glands include the pituitary, thyroid, parathyroid, adrenal, pineal, and thymus glands. A complete discussion of the endocrine system and the hormones each gland produces is found in *Book 4, Human Anatomy as Related to Tumor Formation*.

Endocrine therapy can be administered in many ways:

1. Hormones (estrogen, progesterone, testosterone)
2. Agents which interfere with the release or synthesis of hormones by the endocrine glands
3. Antihormones
4. Corticosteroids (for example, prednisone)
5. Withdrawal of hormones

In general, hormone-responsive cancers are those that arise from tissue requiring hormones for normal development, chiefly breast and prostate. All of these classes of endocrine therapy are discussed in detail in Book 8, Antineoplastic Drugs.

To a lesser extent, endocrine surgery and radiation can be used to remove or suppress hormone-producing tissues. The resulting decrease in naturally produced hormone may have a therapeutic effect on a hormone-dependent cancer of another site. Examples of surgical procedures for endocrine therapy of breast and prostate include:

1. Removal of the testes (orchiectomy) in men with prostate cancer to decrease testosterone levels.
2. Removal of the ovaries (oophorectomy) in women with breast cancer to decrease estrogen levels.

The use of endocrine surgery to manage cancer has decreased as a result of the development of a broad spectrum of antihormones and other hormonal agents. For example, procedures to remove endocrine glands with complex functions, such as the adrenal glands (adrenalectomy) and the pituitary gland (hypophysectomy) are seldom used in current clinical practice.

Immunotherapy

Biologic therapy or immunotherapy produces its anti-cancer effects by enhancing the patient's natural defense mechanisms against the disease. This category covers all chemical or biological agents that alter the immune system or change the host response (defense mechanism) to the cancer. The drugs, chemicals, or biologic agents are often referred to as biological response modifiers.

Agents and substances used in biologic therapy, or immunotherapy, may be classified according to the way in which they modify the host defense mechanism: active or passive. Many of these approaches are investigational.

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[1] Endocrine: Secreting internally, applied to organs and structures whose function is to secrete into the blood or lymph system a substance (hormone) that has a specific effect on another organ or part of the body.

Non-specific stimuli to the immune system with agents such as BCG (Bacillus Calmette-Guerin), B-Parvum, the interferons, and levamisole are examples of active immunotherapy.

Specific attempts to develop antibodies to tumor antigens (monoclonal antibodies) and/or to stimulate lymphoid cells (cytotoxic T lymphocytes) to destroy cells are called passive immunotherapy.

Immunotherapy is discussed in detail in *Book 8, Antineoplastic Drugs*.

Other Cancer-Directed Therapy

Some kinds of therapy cannot be assigned appropriately to the treatment categories described above. These include newly developed methods of treatment, which differ greatly from proven treatment approaches. Examples include the use of hyperbaric oxygen as an adjunct to traditional treatment, hyperthermia, and arterial embolization (blockage) for renal cell (kidney) cancer.

Alternative medical approaches and unproven therapies such as laetrile and krebiozen are not generally given in hospitals in this country. However, occasionally a patient's medical record might indicate that he/she received these drugs or therapies before admission to your hospital.

The text and tables in the self-instruction manual, Book 8, Third Edition, will assist you in identifying and classifying antineoplastic drugs. The treatment of cancer is a dynamic field and will continue to hold your interest as you learn about new diagnostic and treatment methods. Attending cancer conferences and educational meetings will help you to keep up with current developments.

SECTION L TEST QUESTIONS

Q15 Hormone-responsive cancers are those that arise from tissue requiring hormones for normal development, chiefly _____ and _____ cancers.

Q16 Examples of surgical procedures for endocrine therapy are _____ in women and _____ in men.

Q17 _____ produces its anti-cancer effects by enhancing the patient's natural defense mechanisms against the disease.

Q18 Immunotherapeutic drugs, chemicals, or agents used are sometimes called _____ _____ _____.

Q19 All cancer-directed treatment will fall into one or more categories: surgery, radiation therapy, chemotherapy, endocrine therapy, or immunotherapy. True _____ False _____

SECTION L TEST ANSWERS

Q15 Hormone-responsive cancers are those that arise from tissue requiring hormones for normal development, chiefly **breast** and **prostate** cancers.

Q16 Examples of surgical procedures for endocrine therapy are **oophorectomy** in women and **orchiectomy** in men.

Q17 **Immunotherapy**, produces its anti-cancer effects by enhancing the patient's natural defense mechanisms against the disease.

Q18 Immunotherapeutic drugs, chemicals, or agents used are sometimes called **biological response modifiers**.

Q19 All cancer-directed treatment will fall into one or more categories: surgery, radiation therapy, chemotherapy, endocrine therapy, or immunotherapy.

Answer

False. There are some cancer-directed therapies, mostly experimental and unproven, that cannot appropriately be classified into one of these major categories.

SECTION M

CONFIDENTIALITY AND SECURITY
NAACCR Cancer Surveillance and Control Program
Edited by Jennifer E. Seiffert, MLIS, CTR

Confidentiality is of paramount concern to all cancer registries. There may be no greater threat to the operation and maintenance of a cancer registry than an actual or perceived breach of confidentiality. In fact, an actual or perceived breach of confidentiality in one registry threatens all registries.

This section reviews the elements of a comprehensive confidentiality policy that relate to research uses, reporting, and release of cancer data.

Confidentiality policies and procedures are required in all phases of cancer registry operations in order to:
1. Protect the privacy of the individual patient
2. Protect the privacy of the facilities and health care professionals reporting the cases
3. Provide public assurance that the data will not be abused
4. Abide by any confidentiality-protecting legislation or administrative rules that may apply

Although the cancer reporting laws and regulations under which a central registry operates, or the administrative rules under which a hospital registry operates, may define only patient-specific data as confidential, registries should also treat any information that specifically identifies a health care professional or an institution as confidential. Information that characterizes the caseload of a specific institution or health care professional should also be considered proprietary and confidential.

THE REGISTRY'S RESPONSIBILITIES IN MAINTAINING CONFIDENTIALITY

It is the responsibility of every registry to protect its data from unauthorized access and release. The cancer registry must maintain the same standards of confidentiality as customarily apply to the doctor-patient relationship, as well as to medical records in general. This obligation extends indefinitely, even after the death of the patient.

The costs of inappropriate release of confidential data are many. Inappropriate release of data could damage an individual whose diagnosis of cancer was made public. Support and cooperation of facilities submitting data to a central registry could be severely compromised. Personnel responsible for inappropriate release should be administratively disciplined or fired.

If data are maintained both on paper and in electronic form, data security policies and procedures must address both types of data.

REGISTRY STAFF MEMBERS

1. The registry staff should sign, as part of their employment agreement, a declaration that they will not release confidential information to unauthorized persons. This declaration should remain in effect after cessation of employment. The director should maintain a list of staff members indicating the nature and extent of their access to registry data.
2. The training of all central registry staff must include a comprehensive session concerning the confidentiality of data.
3. Failure to observe the confidentiality policies should result in firm disciplinary action or even dismissal. Some circumstances may warrant legal action against staff members who fail to comply with the confidentiality policies of the registry. Depending on the jurisdiction, there may also be criminal and liability penalties for failure to maintain required confidentiality.

NON-REGISTRY STAFF

Non-registry staff, especially medical investigators, may request access to confidential registry data. Such requests must be in writing. All non-registry staff who request access to these records must, at a minimum, agree to adhere to the same confidentiality safeguards practiced by registry staff.

DATA SECURITY

The following components will generally be required to assure data security:

1. The director of the registry must be responsible for data security.
2. Suitable locks and/or alarm systems must be installed to control access to the registry, and a list of persons authorized to enter the registry should be maintained by the director.
3. Registry staff must be responsible for the confidentiality of all data encountered during the collection of cancer data.
4. Confidential data must not be transmitted by any means (mail, telephone, electronic) without explicit authority from the director or a staff member to whom such authority has been delegated.
5. Registries should consider use of registered mail, overnight mail, or courier services for confidential data and should consider separating names from other data for transmission and use of encryption.
6. Precautions must be taken for both physical and electronic security of confidential data sent on magnetic or electronic media.
7. Use of the computer for confidential data must be controlled by electronic and, if possible, physical measures to enhance the security of the data.
8. Use of anonymous data sets for reporting purposes.
9. Measures must be taken to ensure the physical security of confidential data stored on paper, microfilm, or microfiche.
10. A policy must be developed for safe disposal of confidential waste.

RELEASE OF REGISTRY DATA

Release of cancer registry data for clinical purposes, for research, and for health care planning is central to the utility of the registry, and the registry should develop procedures for data release that ensure maintenance of confidentiality

1. For the purpose of complete case ascertainment, a state cancer registry may exchange confidential data with other state cancer registries if reciprocal case sharing agreements, which include confidentiality provisions, are implemented.
2. The cancer registry may permit release of confidential data to treating hospitals in their own or other states for the purpose of patient follow-up.

3. Confidential information about data subjects or data suppliers must not be released for purposes other than those specified by the registry, unless all parties concerned provide written consent for such release and agree in writing to adhere to all confidentiality policies.
4. Data should not normally be provided to individuals about themselves, except where required by law.
5. Confidential information must not, under any circumstances, be published or made available to the public.
6. Inquiries from the news media must be referred to the director or another member of the staff who has been delegated the authority to respond.
7. Measures must be taken to eliminate the possibility that individuals might be identifiable from tables containing cells with very few entries, for example, a table of ZIP codes listing rare diseases.
8. Registries should provide a document describing their procedures and criteria for release of registry data to researchers who request access to data.

INAPPROPRIATE USES OF CONFIDENTIAL INFORMATION:

Confidential cancer registry data must never be made available for uses such as the following:

1. Businesses that are trying to market a product to cancer patients
2. Health care institutions that are trying to recruit new patients
3. Insurance companies that are trying to determine the medical status of a patient
4. Neighbors or friends who are curious about a person's health

DATA FOR SUMMARY STATISTICS

Reports of summary statistics do not generally raise concerns of confidentiality. However, in the case of central registries, confidential information may be conveyed inadvertently through summary statistics. The registry should institute a policy to suppress the publication of summary statistics in some instances, especially when data are being presented for geographic areas with small populations. For example, some registries suppress the reporting of statistical data when there are fewer than 10 cases reported in a single cell of a table, if the cell of the table represents a combination of variables, such as sub-state or sub-provincial geographic area, race, age, and sex, that could inadvertently identify individuals. However, for straightforward breakdowns by age, sex, and large geographic areas such as state or province, cells with 0, 1, or a few cases need not normally be suppressed.

DATA FOR RESEARCH

The registry should develop a set of guidelines to govern the accessibility of registry data to independent scientific investigators. The following criteria may be useful for developing such guidelines:

1. Requests for data to be used for research must be in writing and include a suitably detailed outline of the proposed research and a justification of any need for confidential data.
2. The written research plan should be reviewed by appropriate registry staff. Requests for data must meet the registry guidelines on confidentiality. The registry should determine that the research needs cannot be adequately addressed with non-confidential information.
3. The proposed research should be approved by an appropriate Institutional (Human Subjects) Review Board or ethics committee, if necessary.
4. The researcher should sign a written agreement to adhere to all confidentiality policies. Written agreements should include provisions for use of the information and for its return or destruction at the end of the study.

5. The researcher should demonstrate adequate resources to conduct the research, including funding, staff, and technical expertise, and should demonstrate a history of having successfully conducted scientific research in the past.
6. The scientific objectives of the study should be peer reviewed to ensure scientific validity.
7. The registry must ensure that confidential information is not under any circumstances published or displayed in reports that summarize the research results. The registry must retain the right to review any reports before their dissemination to ensure that confidentiality has been respected.

PATIENT CONTACT FOR PARTICIPATION IN EPIDEMIOLOGIC STUDIES

Cancer registries sometimes serve to identify cancer patients as potential subjects for epidemiologic studies. In these instances, the investigators must meet all the criteria outlined above. Philosophies differ as to whether physician permission is needed before patient contact. Many patient advocacy groups maintain that only a patient has the right to decide study participation and his/her physician does not have the right to make that choice on the patient's behalf. In many epidemiologic studies, the physician informed that the patient will be asked to participate in a study. The physician is asked whether there are any contraindications to patient contact (patient too ill, or patient unaware of the diagnosis). The physician is not asked for permission to contact the patient. Many investigators feel that this procedure protects the physician from any risk of adverse action on the part of the patient. Other investigators still insist on physician permission before contacting the patient. Further, local Institutional (Human Subjects) Review Boards may also insist on physician permission as a condition of study approval.

OTHER RESOURCES CONCERNING CONFIDENTIALITY

Although this document provides guidelines for developing a comprehensive confidentiality policy, registries are encouraged to consult the following references for more information. In addition, examples of confidentiality policies may be obtained from established central cancer registries.

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FEDERAL LEGISLATION

Agencies contracting with or receiving grants from the U.S. federal government should be aware of two pieces of federal legislation, namely:

1. The Privacy Act of 1974 (as amended)
2. The Freedom of Information Act (as amended) 1986

SECTION N

DIAGNOSIS-RELATED GROUPS

DIAGNOSIS-RELATED GROUPS (DRGS) AND THE PROSPECTIVE PAYMENT SYSTEM (PPS)

Diagnosis-Related Groups (DRGs) were established by amendment to the Social Security Act in 1983 to set reimbursement rates for Medicare patients. Medicare is a nationwide federally funded health insurance program for the aged, certain disabled persons, and certain individuals who need kidney transplantation or dialysis. This health insurance program consists of two parts. Part A, Medicare hospitalization insurance, helps pay for inpatient hospital services, skilled nursing facility services, home health services, and hospice care. Part B, supplementary medicine insurance, helps pay for the services of independent practitioners and outpatient hospital services, laboratory services, and other medical and related services. Today, other third party payers[1] are using DRGs in addition to the Health Care Financing Administration (HCFA), which oversees the Medicare Program but DRGs are not required by all insurance carriers.

What Is A DRG?

A diagnosis-related group (DRG) is one of approximately 500 classifications of diagnoses in which patients demonstrate similar resource consumption and length-of-stay patterns.

Beginning with fiscal 1991, the procedures and diagnoses discussed in steps one through four below, group a case to a DRG before it is assigned to a major diagnostic category (MDC). Other procedures and diagnoses are assigned to an MDC before a specific DRG is identified.

The following questions must be answered before arriving at a specific DRG.

1. Was a liver transplant, bone marrow transplant, lung transplant, or tracheostomy performed?
2. If yes, the case will group to DRGs 480-483, 495. If no, did the patient have two or more significant trauma diagnoses?
3. If yes, the case will group to DRGs 484-487. If no, did the patient have a human immunodeficiency virus (HIV) infection?
4. If yes, the case will group to DRGs 488-490. If no, what is the patient's principal diagnosis? The principal diagnosis will be assigned to an MDC. Most MDCs are associated with an organ or system of the body (for example, MDC 4 relates to diseases and disorders of the respiratory system).
5. Was an operating room (OR) procedure performed? Most MDCs contain a surgical and a medical subcategory.
6. Finally, what type of surgical procedure or principal diagnosis did the patient have? Each division of an MDC is broken down further into DRGs. Other factors, such as age, secondary diagnoses, some non-surgical procedure(s), and discharge status, also may affect the final DRG assignment.

[1] Third party payer: An insurance company, an agency, or group that pays for medical services for its members or subscribers.

DRG Prospective Payment System

Under the original Medicare system, hospitals were reimbursed on a retrospective cost basis. At the end of the fiscal year, the hospital would be told what per diem rate it would receive based on various factors. Although hospitals could forecast what these per diem rates might be, they really did not know in advance. Because of the escalation in health care costs, HCFA proposed a Prospective Payment System (PPS), which in 1983 became a component of the Social Security Amendments. The hospitals now know how much Medicare would pay for a DRG before the patient was admitted. Built into this payment are a mean average length of stay, average ancillary utilization cost, and other factors. Depending on the current legislation, the averages may be national, hospital-specific, regional, urban, rural, or a blend, for example, 75 percent national, 25 percent regional.

The DRG payment system is based on averages. That is, payment is determined by the resource needs of the average Medicare patient for a given set of diseases or disorders. These needs include the length of stay and the number and intensity of services provided. Therefore, the more efficiently a provider delivers care, the greater its operating margin (profit) will be.

Keys To A Financially Successful DRG Program

1. Decrease length of stay
2. Decrease service utilization (tests/procedures)
3. Increase early discharges
4. Increase pre-admission testing

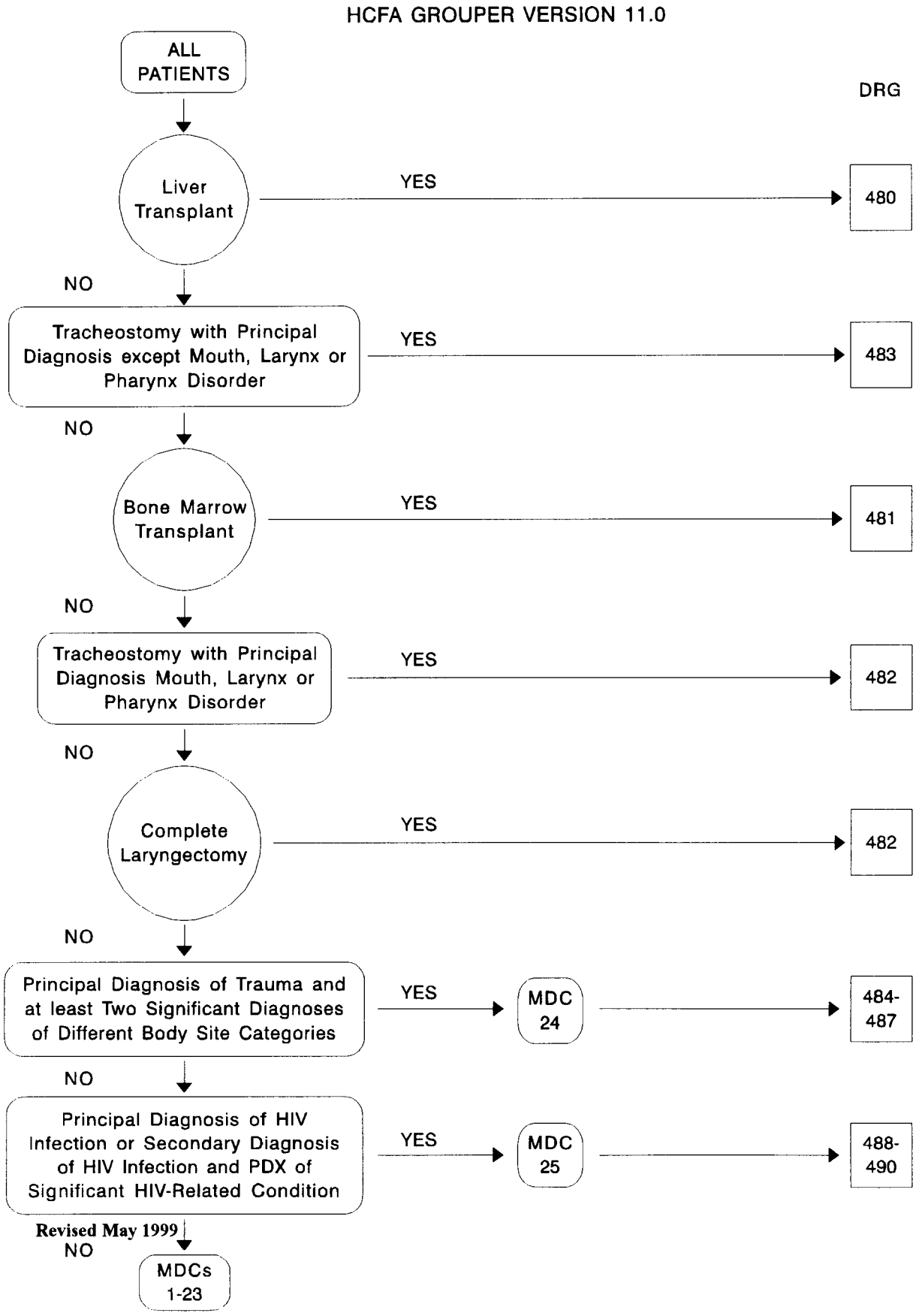
In order to support the DRG assignment, the medical record must be comprehensive, complete, well documented, legible, and completed in a timely manner.

Since the payments vary widely, the accuracy of the DRG assignment is very important. The key to ensuring appropriate hospital reimbursement is excellent medical chart documentation and accurate disease coding. Once a PPS patient is discharged the principal diagnosis, secondary diagnoses, principal procedure, and secondary procedures (if any) are:

1. determined by chart and Attestation Statement review
2. coded using the most current version of the *International Classification of Diseases*.
3. entered into the computer.

The principal diagnosis is sequenced first. The principal diagnosis is the condition for which the patient was admitted to the hospital for care. The principal diagnosis may differ from the admitting diagnosis.

Computer software called a "grouper" determines the DRG by asking a series of questions as demonstrated in the diagram on the next page.


HCFA GROUPER VERSION 11.0
ALL PATIENTS
DRG
Liver Transplant
YES
480
NO
Tracheostomy with Principal Diagnosis except Mouth, Larynx or Pharynx Disorder
YES
483
NO
Bone Marrow Transplant
YES
481
NO
Tracheostomy with Principal Diagnosis Mouth, Larynx or Pharynx Disorder
YES
482
NO
Complete Laryngectomy
YES
482
NO
Principal Diagnosis of Trauma and at least Two Significant Diagnoses of Different Body Site Categories
YES
MDC 24
484-487
NO
Principal Diagnosis of HIV Infection or Secondary Diagnosis of HIV Infection and PDX of Significant HIV-Related Condition
YES
MDC 25
488-490
NO
MDCs 1-23

Major Diagnostic Category

There are about 25 MDCs, and each category contains a varying number of the approximately 500 DRGs. The number of MDCs and DRGs varies slightly from year to year. The DRG numbers are not consistent from one category to another; they may take into account such factors as age, complications and comorbid conditions (CCs), malignancy, secondary diagnoses, specific diagnostic and surgical procedures, and (in MDC17 only) whether radiotherapy (DRG 409) or chemotherapy (DRG 410, 492) was given.

Twelve of the MDC categories include codes for neoplasms. These vary in specificity. For example, there is only one code for Respiratory Neoplasms (DRG 82), but for Myeloproliferative Disorders and Poorly Differentiated Neoplasms (MDC17), there is a range of numbers (DRG 400-414, 473, 492).

As described earlier, certain high-cost procedures (MDCs 24 and 25) are assigned directly to a DRG: liver, bone marrow and lung transplants, tracheostomy, multiple significant trauma, and HIV infection. Diseases and disorders falling into MDCs (1-23) are assigned to the major diagnostic category first.

Not all of the 25 categories have neoplasm-related groups, for instance, eye (MDC2), pregnancy and childbirth (MDC14), mental diseases and disorders (MDC19), and burns (MDC22).

Major Diagnostic Categories for Neoplasms

MDC1	Nervous System (DRG 10, 11)
MDC3	Ear, Nose, and Throat (DRG 64)
MDC4	Respiratory System (DRG 82)
MDC6	Digestive System (DRG 172, 173)
MDC7	Hepatobiliary System and Pancreas (DRG 199, 203)
MDC8	Musculoskeletal System and Connective Tissue (DRG 239)
MDC9	Skin, Subcutaneous Tissue, and Breast (DRG 257-260, 274-275)
MDC11	Kidney and Urinary Tract (DRG 303, 318-319)
MDC12	Male Reproductive (DRG 338, 344, 346-347)
MDC13	Female Reproductive (DRG 354-355, 357, 363, 366-367)
MDC17	Myeloproliferative, Poorly Differentiated Malignancy, and Other Neoplasms (DRG 400-414, 473, 492)
MDC23	Factors Influencing Health Status (DRG 465)

The following is a sampling of DRGs related to neoplasms, which demonstrate how ancillary factors influence the assignment of a DRG number:

DRG	DRG Description
10	Nervous System Neoplasm with CC
82	Respiratory Neoplasms
173	Digestive Malignancy without CC
199	Hepatobiliary Diagnostic Procedure for Malignancy
239	Pathological Fractures and Musculoskeletal and Connective Tissue Malignancy
257	Total Mastectomy for Malignancy with CC
303	Kidney, Ureter, and Major Bladder Procedures for Neoplasm
363	D and C, Conization, and Radioimplant for Malignancy

400 Lymphoma and Leukemia with Major OR Procedures
403 Lymphoma and Nonacute Leukemia with CC
405 Acute Leukemia without Major OR Procedure, Age 0-17
409 Radiotherapy
410 Chemotherapy without Acute Leukemia as Secondary Diagnosis
465 After Care with History of Malignancy as Secondary Diagnosis
492 Chemotherapy with Acute Leukemia as Secondary Diagnosis
495 Lung Transplant

A Drg Decision Tree For Breast Cancer
The following example shows how reimbursement segments based on DRGs are calculated.

Assume that a DRG with a relative weight 1.0000 translates into a $3000 reimbursement.

The patient was admitted for evaluation of possible bone metastases, having had a breast primary three years ago. Tests were done that proved bone metastases. The patient received chemotherapy on the third day of her hospital stay. She was discharged on the fifth day.

An experienced DRG coder entered the responses listed in the column titled "correct." An inexperienced DRG coder saw the chemotherapy and assumed it was an admission for chemotherapy (responses in the column titled "incorrect"). Using the codes entered by the inexperienced coder, the Grouper analysis for DRG assignment results in a $1442.40 loss for the hospital.

	CORRECT	INCORRECT
Length of Stay (LOS)	5 days	5 days
Principal Diagnosis	History of breast cancer	Bone metastasis
	Bone metastasis	Admitted for chemotherapy
Principal Procedure	Chemotherapy	Chemotherapy
	Bone scan	Bone scan
DRG assignment	239	410
DRG AV LOS	7.5 days	2.4 days
DRG WGT	$3,000 X Wgt	$3,000 X Wgt
Reimbursement ($3,000 X wgt)	$2865.00	$1422.60

Note the DRG weight in the preceding example. Each DRG is set at a predetermined fixed amount and forms the basis for payment. The weight is fixed, not the dollar amount. That varies from hospital to hospital based on a complex formula.

Also, note in this example the average length of stay (Av. LOS). The hospital's costs exceeded the reimbursement just on the length of stay alone for DRG 410. The hospital cannot bill the patient, so it has to absorb the loss. For DRG 239, the hospital's costs most likely were less than the reimbursement because the patient stayed a shorter time than the average for that DRG. In this case, the hospital achieves savings, all else being equal, because of the shorter stay.

All else being equal is important to stipulate because there are many factors that can make a difference in the final amount reimbursed to the hospital. For example, the hospital may receive more reimbursement for an unusually long and/or costly admission. In the PPS, these cases are designated as day or cost outliers if they exceed the trim points.[1]

[1] Trim points: High and low day cut-offs assigned to each DRG. (High- and low- cost trim points, usually 3 standard deviations)

SECTION N TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q1 Why were DRGs established?

A. _____

B. _____

Q2 What is a DRG? _____

Q3 Under Medicare, hospitals were originally reimbursed on a retrospective basis, but because of the escalation of health care costs, HCFA proposed the _____ _____ _____.

Q4 Payment is based on the needs of the _____ _____ _____ for a given set of diseases or disorders.

Q5 Why is the accurate DRG assignment so important?

Q6 Name two factors that are most important for ensuring appropriate hospital reimbursement.

A. _____

B. _____

Q7 Computer _____ called a grouper determines the DRG by asking a series of questions such as _____ of stay, the number and intensity of the _____ provided, and the _____ _____.

Q8 There are about 25 _____s and each category contains a varying number of approximately 500 _____s.

Q9 The DRG numbers vary from one category to another. Name four factors by which they may vary:

A. _____

B. _____

C. _____

D. _____

Q10 Certain high cost procedures are assigned directly to a DRG, for example, liver, bone marrow, and lung _____, _____, and ____ infections.

Q11 The DRG has a fixed _____ which forms the basis for payment.

Q12 If the hospital exceeds the average length of stay allowed for a particular diagnosis, the hospital must _____ ____ _____; if less than the average length of stay, the hospital _____ _____.

SECTION N TEST ANSWERS

Q1 Why were DRGs established?

Answer

DRGs were established for setting reimbursement rates for Medicare patients. Today many third party payers also use DRGs.

Q2 What is a DRG?

Answer

A DRG is one of about 500 classifications of diagnosis in which patients demonstrate similar resource consumption and length-of-stay patterns.

Q3 Under Medicare, hospitals were originally reimbursed on a retrospective basis, but because of the escalation of health care costs, HCFA proposed the **Prospective Payment System** (PPS).

Q4 Payment is based on the needs of the **average Medicare patient** for a given set of diseases or disorders.

Q5 Why is the accurate DRG assignment so important?

Answer

Accurate DRG assignment is important because payments vary widely and only if the DRG assignment is correct will the hospital receive appropriate reimbursement.

Q6 Name two factors that are most important for ensuring appropriate hospital reimbursement.

Answer

A. Excellent medical chart documentation
B. Accurate disease coding

Q7 Computer **software** called a grouper determines the DRG by asking a series of questions such as **length** of stay, the number and intensity of the **service** provided, and the **principal diagnosis**.

Q8 There are about 25 **MDCs** (Major Diagnostic Categories), and each category contains a varying number of approximately 500 **DRGs** (Diagnosis Related Groups).

Q9 The DRG numbers vary from one category to another. Name four factors by which they may vary:

Answer:

You might have named any of the following:
A. Age
B. Complications and co-morbid conditions
C. Malignancy
D. Secondary diagnoses
E. Specific diagnostic and surgical procedures
F. Whether radiotherapy or chemotherapy was given

Q10 Certain high cost procedures are assigned directly to a DRG, for example, liver, bone marrow, and lung **transplants**, **tracheostomy**, and **HIV** infections.

Q11 The DRG has a fixed **weight** which forms the basis for payment.

Q12 If the hospital exceeds the average length of stay allowed for a particular diagnosis, the hospital must **absorb the loss**; if less than the average length of stay, the hospital **achieves savings**.

ROLE OF THE CANCER REGISTRAR WITH RESPECT TO DRGS

The cancer registrar can be invaluable to the hospital if she/he has a thorough understanding of DRGs and PPS. Reports that include primary and secondary sites, stage, length of stay, the DRG, and the average length of stay associated with the DRG can be prepared for the cancer committee and administration. Aggregating the data by primary site, then by DRG, often results in identifying potential cost savings when hospital and DRG averages are compared. Perhaps one group of physicians has a different practice pattern than another. If the quality of care is identical, perhaps the cancer committee could discuss a change in practice to reduce the length of stay. There are many approaches the registrar can take to provide valuable PPS data on cancer patients. Remember, the cancer registrar is more knowledgeable about cancer, how it is diagnosed, how it spreads, and how it is treated, than any other non-physician.

For example, cancer registrars are the people who can most accurately:

1. identify a diagnosis of malignant brain tumor.
2. pick up important histologic components of a diagnosis such as an acute leukemia or a specific type of leukemia.
3. identify a comorbid condition such as malignant pleural effusion.

By using their expertise in this manner, cancer registrars can identify potential cost savings for hospitals. If these diagnoses were missed, the hospital would have lost money. A person with cancer registrar expertise is more knowledgeable about tumor extensions beyond the primary and nodal involvement. Certified Tumor Registrars can perform a service for the Health Information Management Department by reviewing medical records and commenting on ways to improve DRG coding.

Because of the PPS, many diagnostic and therapeutic procedures are done on an outpatient basis or in a physician's office. Records of these procedures may not appear routinely in the hospital medical record. To accurately assess the diagnostic workup, the extent of the disease, and the complete course of therapy, the registrar must search beyond the hospital inpatient record and obtain copies of outpatient records and laboratory reports. The cancer committee should assist the cancer registry in developing mechanisms for obtaining these records to ensure complete cancer registry abstracts. The quality and usefulness of cancer registry data depend on their completeness.

In addition, because of PPS, a registrar may observe a decline in newly diagnosed cancer patients for certain sites, when in fact an increase would have been expected. Why? Because definitive diagnostics and treatment were performed in a 23-hour-hold unit or in an outpatient setting and the cases were not picked up during case finding. Another good possibility might be that the specialist in that type of cancer might have left the hospital; consequently, these referrals will have ceased.

The impact of PPS and DRGs is everywhere. Third party payers other than Medicare require PPS for all inpatients in some states. Therefore, it is important for the registrar to understand how these systems work. Learn the systems and apply them appropriately to the cancer registry data. Report your findings frequently to administrative and medical staff.

Peer Review Organization

Since the purpose of PPS is to reduce the cost of health care without compromising the quality of the care, Congress legislated the creation of a monitoring system to evaluate outcome. As with any system attempting to classify individuals, there are difficulties. Hospitals could discharge patients and readmit them the next day to collect two or more DRG payments when only one was appropriate and ethical. By choosing the principal diagnosis with the highest DRG weight assignment when it violates the definition of principal diagnosis, a greater reimbursement is paid to the hospital. The latter, referred to as DRG creep, is obvious fraud.

To ensure the level of quality and to discourage abuses such as DRG creep, Peer Review Organizations (PRO) were established on a state, regional, and national level. Once PPS hospitals bill Medicare via their fiscal intermediaries (FI), the FI reports the cases to the local PRO. On a monthly basis, the PRO sends the hospital a list of accounts which it will review. The hospital is responsible for making the charts available to the PRO along with other information as requested. When possible, the PRO reviews on site. The DRG validator checks the ICD-9-CM coding for accurate and correct sequencing, and a nurse reviewer checks on the quality issues and determines that an acute level of care was required. The nurse reviewer refers any potential problems to the physician reviewer. If the physician reviewer decides that problems do exist, a potential initial denial is issued to the responsible MD and the hospital for questionable cases. The physician must respond in writing within 7 days of the notice or the PRO decision for denial will become final. If coding or hospital administrative quality problems are found, the hospital is issued the notice and must respond in the same time frame.

If the PRO upholds its decision after reviewing the responsible physician's rebuttal, the physician or the hospital has the right to request a second physician review through reconsideration. This request must be made within 30 days of the denial. Usually any problems are resolved at reconsideration. However, there are more opportunities and higher levels for appeal. For more information on the PRO policies and procedures, ask your administrator for a copy of your hospital's PRO contract.

Not all cases are reviewed. Certain subsets are selected for 100 percent review such as readmissions within 30 days, transfers, and selected procedures. However, if a hospital exceeds the PRO's maximum error rates over a 3 month period, the hospital may undergo intensified review for the next quarter. For example, instead of a 3 percent random selection of all cases, 50 percent may be required. The time and labor needed by hospitals to meet PRO requirements can be extensive and costly.

The regional PROs monitor the local or state PRO, and the SUPER PRO monitors the entire PRO program.

SECTION N TEST QUESTIONS

Circle the best answer or fill in the blank as appropriate.

Q13 Why is the cancer registrar in a position to assist the hospital in using the PPS to the best advantage?

_____

_____

Q14 A thorough knowledge of PPS and DRG will enable the cancer registrar to prepare reports for the cancer committee and administration that may identify _____ _____ _____ _____.

Q15 To ensure the quality of DRG information and to discourage DRG creep, the _____ _____ _____ were established at state, regional, and national levels.

SECTION N TEST ANSWERS

Q13 Why is the cancer registrar in a position to assist the hospital in using the PPS to the best advantage?

Answer

The registrar is more knowledgeable about how cancer is diagnosed and treated than any other non-physician in the facility.

Q14 A thorough knowledge of PPS and DRG will enable the cancer registrar to prepare reports for the cancer committee and administration that may identify **potential cost savings**.

Q15 To ensure the quality of DRG information and to discourage DRG creep, the **Peer Review Organizations** were established at state, regional, and national levels.

DRG DEFINITIONS

Attestation statement A form signed by the physician certifying the accuracy of all diagnoses and procedures before charges are submitted for payment.

Case mix complexity The resource intensity demands that patients place on a hospital.

Clinical laboratory A laboratory performing routine tests used by the physicians responsible for direct patient care. (The clinical laboratory performs blood counts, blood chemistry, urinalysis, and bacteriological examinations of sputum and other exudates. This laboratory is different from a research laboratory that is used for special studies.)

Comorbidity A pre-existing condition that will, because of its presence with a specific principal diagnosis, cause an increase in length of stay by at least one day in approximately 75 percent of the cases.

Complication A condition which arises during the hospital stay that prolongs the length of stay by at least one day in approximately 75 percent of the cases.

Cost outlier Those cases that do not exceed the length of stay criteria but where charges (adjusted to cost) exceed a fixed multiple of the applicable DRG prospective payment, or exceed such other fixed dollar amount, whichever is greater.

Day outlier Those cases where the length of stay exceeds the average length of stay for discharges in the DRG by a fixed number of days or a standard deviation, whichever is less. Day outliers occur automatically at a specified point in time for each DRG.

Diagnosis-related groups (DRGs) A patient classification scheme in which patient types are defined by patient's diagnoses or procedures, and in some, but not all, cases by the patient's age or discharge status. Patients within a DRG demonstrate similar resource consumption and LOS patterns.

DRG creep Inflating diagnoses to obtain a higher payment rate.

Grouper A computer software program that assigns DRGs based on diagnosis and procedure codes.

LOS Mean (average) length of stay.

Major diagnostic category An MDC is one of approximately 25 subdivisions to which all of the codes of ICD-9-CM have been assigned. MDCs are based on organ system wherever possible.

Operating room (OR) procedure A procedure that falls into a defined group of procedures that normally require the use of an operating room.

Peer grouping Classifying hospitals into groups based on size, teaching status, profit/nonprofit status, location, service mix, physician mix, and patient mix.

Principal diagnosis That condition which is determined to be the reason for admission to the hospital.

Principal procedure A procedure that was performed for definitive treatment rather than one performed for diagnostic or exploratory purposes to take care of a complication. The principal procedure is that procedure most related to the principal diagnosis.

Prospective reimbursement (payment) A payment method in which hospital rates are set in advance, before services are rendered, and are based upon the relative weight (RW) attached to expected classes and volume of patients.

Relative weight (RW) An index number that reflects the relative resource consumption associated with each DRG. The higher the relative weight, the greater the payment to the hospital.

Resource intensity The amount of services (personnel, supplies, tests) used. See also service utilization.

Service utilization The number and complexity of tests and procedures performed.

Third party payer An insurance company, an agency, or group that pays for medical services for its members or subscribers.

Trim points High and low day cut-off assigned to each DRG. (High- and low- cost trim points, usually 3 standard deviations.) Cases within the trim points will be billed the DRG rate per case.

GLOSSARY OF TERMS

Abstract A summary, an abridgment. (The word "abstract" may be either a noun or verb.)

ACoS American College of Surgeons

Ad hoc For the particular end or case at hand without consideration of a wider application

Adjuvant Treatment received in conjunction with other treatment

Analytic Cases initially diagnosed at your hospital and/or receiving all or part of the first course of therapy at your institution; The basis for data analysis.

Application A computer program designed for a specific task or use

Automate To convert to automatic operation

Autopsy The postmortem examination of a body

Backup A procedure (computer program) to copy and save files in case of hardware or other system failure

Back-up tape drive A secondary storage medium to copy the contents of the hard disk

Basal cell carcinoma A slow-growing, locally invasive, but rarely metastasizing, neoplasm derived from basal cells of the epidermis or hair follicles

Baud In electronic communication, a unit of speed equal to one bit per second

Benign Not malignant; not metastatic; favorable for recovery

Biostatistical Refers to numerical information about living organisms

Borderline malignancy A tumor whose behavior is between benign and malignant, which may remain benign but has the potential to invade an organ and become malignant

Byte Amount of electronic space needed to store a single character (number, letter, or code)

Cancer A malignant tumor

Cancer program category In the CoC Approvals process, a hospital's classification as determined by its available services, staff qualifications, residency program, oncology fellowships, research, and cancer conference activity

Chemotherapeutic Of or pertaining to the treatment of disease with chemicals

Circuit riders Registrars who travel from one hospital to another abstracting medical records of cancer patients for inclusion in a central cancer registry

CoC Commission on Cancer

Code Numerical or symbolic values for data, or a slang term for a computer program

Computer program Computer program: A set of coded instructions for execution by a computer; using the program instructs the computer to perform a desired sequence of operations.

Conversion The change of one set of codes to a different set of codes, for example, changing primary sites or morphology coded by ICD-O-1 to ICD-O-2 codes

CPU central processing unit The functional "brain" of a computer that controls the interpretation and execution of instructions

Cytology The microscopic examination of cells obtained by aspirations, washings, scrapings, and smears (such as a Pap smear)

Demographics A description of the characteristics of a person or group

Demography The study of mankind collectively; especially of geographic distribution and physical environment

Diagnosis The determination of the nature of a disease

Disease (diagnostic) index A listing of all diagnoses for patients admitted to the hospital, usually prepared by the health information (medical record) department on a monthly or semi-annual basis.

Disk A removable, rotating, magnetic plate that is considered a secondary computer data storage medium

Distant A cancer that has spread beyond the organ of origin and surrounding tissues to a site in the body at a distance from where the cancer started

Dysplasia An abnormal tissue development that does not met the criteria for malignancy, for example, dysplasia of cervical epithelium.

Encrypt In computer science, to scramble computerized information so as to prevent unauthorized access

Endocrine Secreting internally, applied to organs and structures whose function is to secrete into the blood or lymph system a substance (hormone) that has a specific effect on another organ or part of the body

End results The evaluation of cancer therapy as it affects patient survival after treatment

Epidemiology The study of the occurrence and distribution of disease

Ergonomic Designing and arranging things people use so that the people and things interact most efficiently and safely.

Extent of disease Detailed description of how far the disease has spread from the primary site of a cancer

File server A software program that allows all the computers on the network to communicate with each other

Floppy drive A drive in the computer where data and/or programs are accessed from a floppy disk

Follow-back A check of a patient's medical history to verify that Death Certificate Only cases were not diagnosed and/or treated before death

Follow-up Refers to all activities involved in monitoring cancer patients after discharge

Function keys A set of keys, usually labeled F^1, F^2, F^3, etc., used by themselves or with Shift, Control, and Alt keys to provide quick access to frequently used commands

Hard drive A fixed disk drive in the computer where the data are physically stored

Hardware The physical equipment of the computer system, including the computer itself, monitor, keyboard, printer, and so forth

Health information management (medical record) department The department of the hospital responsible for assembling the various medical reports for each patient, combining them in a single patient file, ensuring completeness, and coding and indexing them for future reference

Hematology The medical specialty that pertains to the anatomy, physiology, pathology, symptomatology, and therapeutics of blood and blood-forming tissue

Histology The microscopic examination and study of tissue obtained by biopsy (excision of a tissue sample), surgery, or autopsy

Incidence rates Rate of occurrence of new cases diagnosed during a set time period in a defined population

Inpatient A patient who occupies a bed in the hospital for at least 24 hours.

In situ Confined to the site of origin without invasion of the basement membrane of the tissue involved

Ionizing radiation High energy radiation used to destroy cancer cells

Language In computer science, a system of symbols and rules used for communication with or among computers

Malignant tumor An uncontrolled, invasive growth capable of metastasizing (spreading) to a regional or distant part of the body; opposite of benign

Megahertz One million cycles per second (typically used in reference to a computer's clock rate)

Metastasis The spread of a cancer to an adjacent (regional) or distant part of the body

Microscopic Of or pertaining to a microscope, which is an optical instrument that uses a combination of lenses to produce magnified images of objects too small to be seen by the unaided eye

Monitor The visual display unit or screen of a computer

Morphology The cellular structure; the histologic type of a tissue

Multidisciplinary Including representatives from all appropriate disciplines.

Nanosecond One billionth of a second.

Natural history of disease The course of a disease if uninterrupted by treatment

Necropsy A postmortem examination; an autopsy

Network A system in which several computers and peripheral devices are linked together to form an interconnected series for sharing resources

New primary A subsequent cancer unrelated to any previous cancer

Nomenclature A system of names

Nuclear medicine The medical specialty that studies the characteristics and uses of radioactive substances in the diagnosis and treatment of cancer and other diseases

Oncology The sum of knowledge concerning tumors; the study of tumors

Online Connected or available through a system, especially a computer or telecommunications system

Operating system In computer science, software designed to control the hardware of a specific computer allowing users and application programs to employ it easily

Outpatient A hospital patient who does not occupy a bed in the hospital for 24 consecutive hours.

Pathology The scientific study of the nature of disease, its causes, processes, development, and consequences; more specifically, the microscopic examination of tissue

Patient index file An alphabetic card file or a computerized listing of living and dead patients that includes the dates of diagnoses and all primary sites together, sometimes called a Master Patient Index or MPI

Peripheral An auxiliary device, such as a printer, modem, or storage system that works in conjunction with a computer

Physiology The science of the functions of the living organisms and their parts, and of the physical and chemical factors and processes involved

Potentially reportable A hospital discharge record with an ICD-9 (ICD-10) code on the reportable list, or a pathology report indicating a reportable disease that has yet to be checked against the registry's master patient index to determine if the case already exists in the registry.

Primary site The organ or tissue of the body where the cancer originates

Procedures manual A manual which documents, in detail, the current procedures used by the registry to carry out its various operations and functions

Radiotherapy The medical specialty that uses radiant energy and radiant substances in the treatment of disease.

RAM Random access memory is the working space, or temporary storage area, for the program in use and the document on screen.

Random sample A method of statistical selection in which every individual in the population has an equal and independent chance of being chosen for the sample

Reference date The date on which complete reporting begins. All patients diagnosed and/or treated for cancer on or after this date must be included in the registry.

Regional A cancer that has spread beyond the organ where it started, to involve adjacent tissues or lymph nodes

Reportable cancers All diagnoses (benign tumors, borderline tumors, cancers) that are included in the registry

Routine In computer science, a set of programming instructions designed to perform a specific, limited task

Sequence number An assigned number that describes the chronology of diagnoses for all primary malignant and in situ cancers over the lifetime of a patient

Squamous cell carcinoma A malignant neoplasm that is derived from stratified squamous epithelium

Stage of disease Grouping of cases into broad categories that have prognostic significance, such as localized, regional, and distant.

Surgicel A hemostatic agent used to control bleeding

Topography The site of origin, the primary site

Tumor Classically, a swelling or mass; in current usage it means a new growth of tissue or cells

Tumor conference A meeting of physicians and health care professionals who are trained in various disciplines. The physicians review the diagnosis or proposed therapy for cancer patients.

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