Self Instructional Manual for Tumor Registrars: Book 1, Objectives and Functions of a Tumor Registry.
National Cancer Inst. (NIH), Bethesda, Md.
DHEW-NIH-75-917
137p.

Data Collection; *Health Occupations Education; Medical Case Histories; *Medical Record Technicians; Occupational Information; Programed Instruction; *Programed Texts; Records (Forms); Study Guides

Cancer; *Tumor Registrars

The programed text is designed to provide tumor registrars with a means of learning the procedures for abstracting charts of cancer patients and for carrying out the other functions of a tumor registry. It was developed as an adjunct to on-the-job training for use without direct instructor supervision. Directions and suggestions for using the manual are provided. The content is presented in three major sections. The first deals with the definition of a tumor registry, general introduction to tumor registries, types of registries, confidentiality of patient records, and functions of registries (data collection, patient follow-up, education, and research). Descriptions of job activities and job aids of the tumor registrar are contained in the second section. The final section presents the relationship between the tumor registry and the hospital in general, other hospital departments, and outside medical organizations. The material is presented in paragraph and outline form. Objective and subjective test items are interspersed followed by answers. Important words in tumor registry vocabulary are underlined and defined. Sample medical record forms are included in the text. Also contained are a two-page glossary, a selected bibliography for learner use, and a subject index. (MS)
SELF INSTRUCTIONAL MANUAL
for
TUMOR REGISTRARS

SEER PROGRAM
Book 1 - Objectives and Functions of a Tumor Registry

Originally Prepared for the Louisiana Regional Medical Program
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The overall objective of this course of instruction is to provide a mechanism whereby tumor registrars may learn the procedures for abstracting medical charts of cancer patients and for carrying out the other functions of a tumor registry. Until development of the present program, tumor registrars were trained by traditional lecture and workshop techniques and by on-the-job training. Instruction often was provided by medical doctors who seldom had much time to devote to the training of tumor registrars. The few training programs in existence required the trainees to live at the training site from one to four weeks. In addition to the limited enrollment capabilities of such programs, few hospitals were able to provide the funds to support their tumor registry personnel while away on the training assignment.

The development of new tumor registries and tumor registry systems has been hampered, in part, by the lack of trained personnel. One of the persons intimately aware of this problem was Robert F. Ryan, M.D.; the technical consultant to the tumor registry at Charity Hospital, New Orleans. In response to the needs of the Charity Hospital registry and to the requests of others, Dr. Ryan, in 1967, initiated a proposal for the development of a self-instructional training program for tumor registrars. To assist in this effort, the services of the Human Resources Research Organization (HumRRG) were obtained. In 1968, under the joint direction of Dr. Ryan and Dr. C. Dennis Fink (HumRRG), a proposal was prepared and submitted to the Louisiana Regional Medical Program, Joseph F. Sabatier, M.D., Director. Project approval was received in 1969. Work began on the development of the program in early 1970, and continued into the fall of 1971.

Through 1971 the prime contractor for the project was the Tumor Registry of Charity Hospital, New Orleans. This registry is under the supervision of Edward T. Krementz, M.D., Chairman of the Tumor Registry Board, and Head, Section of Oncology, Tulane University Medical School. Technical support in the form of review of the early draft instructional material was provided by Miss Brent S. Robertson and Mrs. Jane Roberts, Director and Computer Liaison, respectively of the Charity Hospital (New Orleans) Tumor Registry. Miss Robertson and Mrs. Roberts provided assistance in securing the training material used in the program and in explaining the procedures for abstracting medical charts.

The technical consultant for the program was Robert F. Ryan, M.D., Professor, and Head, Section of Plastic Surgery, Tulane University Medical School. Dr. Ryan provided a technical review of all portions of the project, supervised the establishment of project facilities in the New Orleans area, and provided guidance for the design and development of the program. Mr. C.O. Renick, Jr. coordinated the gathering of background information, training materials, and general program administration.
The original instructional material for the program was developed by Human Resources Research Organization, under the technical direction of C. Dennis Fink, Ph.D., Program Director, with the assistance of Richard D. Behringer, Ph.D., and Mrs. Judith C. Klotz. HumRRRO is a nonprofit corporation established in 1969 to conduct research in the field of training and education. It is a continuation of the George Washington University Human Resources Research Office, D.C., which was established in 1951.

In addition to the support and encouragement provided by the Louisiana Regional Medical Program, technical assistance, counsel, and information were provided by persons associated with the Regional Medical Programs Service, Health Services and Mental Health Administration of the Department of Health, Education and Welfare (DHEW), and the Tumor Registry Training Program, Cancer Research Institute, University of California, San Francisco, California.

A change in program emphasis and the ultimate demise of the Regional Medical Program implied loss of financial support for further development of the training program along the lines of the original program goals.

In 1973, the Biometry Branch of the National Cancer Institute recognized the potential of this type of training program as a desirable component in the development of a Collaborative Program for Cancer Surveillance, Epidemiology, and End Results Reporting (SEER Program). Under the general direction of Dr. Max H. Myers, Head, End Results Section, National Cancer Institute, the instructional program was revised, with some changes in emphasis, to conform to the needs of the SEER program. To accomplish this task, a revision committee was appointed to review and complete the program:

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The revision committee is grateful to Mrs. Ardyce J. Asire for her contribution in proofing and coordination of the materials and to Mrs. Joyce Campbell for computer entry of the text.
LESSON BOOK #1

OBJECTIVES, FUNCTIONS, AND ACTIVITIES OF A TUMOR REGISTRY
LESSON BOOK #1: OBJECTIVES, FUNCTIONS, AND ACTIVITIES OF A TUMOR REGISTRY

- Section A- Objectives and Content of Instructional Package 1

- Section B- Objectives and Functions of a Tumor Registry
  - A General Definition of a Tumor Registry
  - A General Introduction to Tumor Registries
  - Types of Registries
  - Confidentiality of Patient Records
  - Major Functions of Registries
    - Data Collection
    - Patient Follow-Up
    - Education
    - Research

- Section C- Job Activities of a Tumor Registrar

- Section D- Relationship of Tumor Registries to Hospital Departments and Medical Organizations
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SECTION A

OBJECTIVES AND CONTENT OF INSTRUCTIONAL PACKAGE 1
Section A

OBJECTIVES AND CONTENT OF INSTRUCTIONAL PACKAGE 1

ADMINISTRATIVE INFORMATION

The general objective of this Instructional Package is to provide you with an overview of the role and activities of a tumor registry and tumor registrar.

A medical dictionary should be obtained before beginning this first Instructional Package. This will be one of your most valuable references. (See page 70 for other reference materials.)

Test items are interspersed throughout the package thus acting as an immediate check of your understanding of the material under study.

Sample forms have been included to give you some idea of the forms you will find in a patient's medical record, however these forms do vary somewhat from hospital to hospital. These samples are of a different color from the text for easy identification.

Words important in tumor registry vocabulary are underlined as they appear in the text and defined at the bottom of the page as well as in the Glossary of Terms.

It has been found in using programmed texts that learning takes place more readily if the answers are actually written in the blanks with a pen or pencil rather than "saying" or "thinking" the answers. Learning takes place even when you write in an incorrect answer if you cross it out and then write in the correct answer.
SECTION B

OBJECTIVES AND FUNCTIONS OF A TUMOR REGISTRY
A GENERAL DEFINITION OF A TUMOR REGISTRY
A GENERAL DEFINITION OF A TUMOR REGISTRY

A tumor registry, sometimes called a cancer registry, is an office where information is maintained on persons who have had some type of cancer. In addition, a registry may contain information about certain types of tumors or diseases which, although not cancerous, have a tendency to become so. The medical staff at each hospital will determine whether any non-cancerous cases are to be included in the registry.

A tumor registry collects and stores information on tumor (cancer) patients, conducts periodic follow up on these patients, and prepares reports on the data collected. The basic document on which this information is recorded is called an abstract. For each tumor patient, an abstract is prepared containing:

1. **Demographic information**, such as, age, sex, race, and place of residence.
2. Pertinent medical history, such as, the name and date of the original diagnosis and any prior treatment of the cancer.
3. The name(s), date(s) and results of procedures and techniques used to diagnose cancer, such as, biopsies, cytologies, x-rays, scoping procedures, and exploratory surgery.
4. The types of therapy used to treat the cancer patient, such as, surgery, radiation, chemotherapy, and immunotherapy.
5. Follow-up medical information on the patient after discharge from the hospital to ascertain any additional therapy the patient may have received and the quality of the patient's survival, if living. If the patient is deceased, determine the cause of death.

**abstract**—A summary, an abridgment (the word "abstract" may be either a noun or a verb)

cancer—A malignant tumor

tumor—Classically means a swelling or mass; in current usage means a new growth of tissue or cells.

demography—The study of mankind collectively; especially of geographic distribution and physical environment
If you examined the files of a tumor registry, you would find that they contain abstracts of patients who had been:

(Check correct answer.)

(✓)

a. Diagnosed and treated for cancer.

b. Treated for a non-cancerous tumor of a type that may occasionally become cancerous.

c. Neither a or b.

d. Both a and b.
d--Both. Most of the abstracts contained in a tumor (cancer) registry will concern patients who are treated for cancer, i.e., malignant tumors. However, there are types of non-cancerous (benign) tumors that are also reported to a tumor registry. Some of these may become cancerous; these may be called premalignant tumors.

malignant--Malicious, virulent

malignant tumor--An uncontrolled, invasive growth capable of metastasizing (spreading to a distant part of the body); opposite of benign

benign--Not malignant; not recurrent; favorable for recovery

A tumor registry performs a variety of services for the hospital staff including preparation of reports from the registry data. Basically, however, a tumor registry collects, stores, and disseminates ________ about cancer patients.
Information. You could have said "data" or "knowledge" or something similar. In this course of instruction you will learn how to collect information about cancer patients.

A tumor registry collects such information as:

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

*diagnosis*--The determination of the nature of a disease.

In addition, the tumor registry collects information about:

(Check correct answer.)

(✓)

- a. The health of the patient since discharge from the hospital.
- b. Therapy, if any, used to treat the patient.
- c. A continuing summary of cancer-related and other major disease conditions of the patient which may contribute to death.
- d. None of these.
- e. All of these.
All of these. Registries are concerned with the diagnosis, treatment, and subsequent well-being of the cancer patients registered in their files.

The hospital tumor registry will contain information on all outpatients and inpatients who have been diagnosed or treated for cancer at that hospital. Some patients will be treated exclusively in the outpatient clinic. Others will be admitted to the hospital for treatment. These are called inpatients. All records of patients who have been diagnosed or treated either as inpatients or outpatients are incorporated into the tumor registry. Your hospital Cancer Committee will decide what tumors are to be included in your registry.

The major exception to this statement concerns patients with skin cancer. Certain types of skin cancer are quite common, but since they are of a less serious nature than most other cancers, they may not be included in the hospital registry. In any case, these patients are often treated only in the physician’s office. It is difficult to get complete and accurate information on such patients and how they were treated. Your Committee on Cancer will decide if these cases should be included in your registry.

**outpatient**—A hospital patient who does not occupy a bed

**inpatient**—A patient who occupies a bed in the hospital

A registry contains information on cancer patients. However, a tumor registry may not contain information about certain categories of cancer patients. As examples, which of the following cancer patients probably would not be included in the tumor registry? (Check the correct answer(s)).

(✓)

- a. A cancer patient who was treated in the outpatient clinic of a hospital.
- b. A cancer patient who had a private room in a hospital.
- c. A cancer patient who was diagnosed and treated in an outside physician’s office.
A patient treated in a physician's office. A tumor registry contains records of patients treated in the hospital as outpatients (clinical patients) or as inpatients (hospitalized patients). Patients whose entire treatment was given in a physician's office would not appear in the hospital tumor registry.
A GENERAL INTRODUCTION TO TUMOR REGISTRIES
A GENERAL INTRODUCTION TO TUMOR REGISTRIES

The material you are about to read covers:

a. Types of Registries
b. Confidentiality of Patient Records
c. Major Functions of Registries

Data Collection
Patient Follow-up
Education
Research
Types of Registries
Types of Registries

Tumor registries can be classified into three general types: hospital-based registries, central registries (including population-based registries), and special-purpose registries. The types of registries may be characterized as follows:

1. **HOSPITAL-BASED REGISTRIES** collect information about all tumor (cancer) patients at a particular institution. Such a registry can provide information that can be used by the hospital administration and professional staff to assess the effectiveness of the diagnosis and treatment of cancer patients. Through continuing follow-up it may also assist in maintaining medical supervision of the patient. This is the type of registry existing in most hospitals.

2. **CENTRAL REGISTRIES** vary in scope and purpose. A central registry may be the main office of a group of hospital registries and may utilize the services of epidemiologists and statisticians as well as clinicians. It may encompass only a sample of hospitals in a county, region, or state, but cover a large number of cancer patients so that it may undertake a wide range of studies and accumulate data which may be statistically significant. In its broadest sense, a central registry may be a population-based registry collecting data on all cancer patients who are residents of a particular area. It includes residents who receive their cancer treatment outside the area, as well as patients for whom the only record of cancer is found on the death certificate or the autopsy report. Population-based registries are interested in information on trends in the occurrence of various forms of cancer, in changes in diagnostic and treatment practices and their associated "end results", and in epidemiology of cancer.

3. **SPECIAL-PURPOSE REGISTRIES** collect information on one aspect or one type of cancer. Some examples of special-purpose registries are those that collect information only on bone tumors, ovarian tumors, radiologically-treated tumors, or tumors of pediatric patients. Such registries may be useful for a special type of clinic or for medical specialty groups. For the typical hospital, however, their scope is too limited.

**end results**—"End results" refers to the evaluation of cancer therapy in terms of patient survival after treatment.
Match each of the following registry descriptions with its appropriate registry designation:

<table>
<thead>
<tr>
<th>Description</th>
<th>Type of Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Collects information about all cancer patients at a particular institution.</td>
<td>a. Special-purpose registry</td>
</tr>
<tr>
<td>2. Collects information about cancer patients in the gynecology department only.</td>
<td>b. Central registry</td>
</tr>
<tr>
<td>3. Collects information about all cancer patients who are residents of a particular state or geographic area.</td>
<td>c. Population-based registry</td>
</tr>
<tr>
<td>4. Collects information from several hospitals which are submitting data to a central office.</td>
<td>d. Hospital-based registry</td>
</tr>
</tbody>
</table>
Answer: 95

1. d
2. a
3. c
4. b
Confidentiality of Patient Records
Confidentiality of Patient Records

Each patient's medical record must be regarded as confidential information. Frequently registries have confidentiality agreements which are signed by all registry staff at the time of hiring. As a condition of employment, the employee promises not to discuss or disclose, except as authorized, information obtained on the job that would identify a patient.

Laws concerning confidentiality vary from state to state and must be taken into consideration in releasing information about an individual.

Central registries must exercise the same care that an individual registry does in preserving the confidentiality of medical records. No individual patient or hospital is ever identified in published figures, but the statistical data about groups of patients is often an important product of central registry activity.

Now that computers play such an important part in the collection of medical information, care must also be taken to assure confidentiality of all data stored on a computer. Access must be restricted to registry personnel only, and resulting reports must be handled with the greatest care to assure confidentiality. This includes attention to the destruction of computer listings discarded by the registry.

The importance of confidentiality cannot be emphasized too much. People have been known to lose their jobs because they were diagnosed as having cancer. The possibility that some cancers are caused by viruses has resulted in social ostracism for some patients and their families. Therefore, all tumor registry employees must strive to protect the confidentiality of patient information.

Q6

In your own words describe some of the ways that confidentiality of tumor (cancer) patients might be violated:

a. 

b. 

c. 

d. 

You might have said:

1. By mentioning patients by name on coffee break in the cafeteria.

2. By giving out information about the patient to an insurance company or other persons without the patient's authorization.

3. By carelessly leaving a listing of cancer patients where it could be read by unauthorized persons.

4. By tossing listings of cancer patients in the wastebasket without shredding or in someway masking the information.

5. By allowing an unauthorized person access to the computer file of the registry cancer patients.

6. By mailing post cards which convey confidential information which may be read by others.

A hospital registry contains information only on its own cancer patients, but as a member of a central registry system, it submits this information to the central registry. Care must be exercised to preserve confidentiality of patient records: (Check one.)

(✓)

a. On the hospital level.

b. On the central registry level.

c. Both of these.
Answer: 07

Both of these.
Major Functions of Registries
Major Functions of Registries

A registry, first of all, collects information (data) on patients with tumors. Then it periodically follows these patients throughout their lifetimes to determine their state of health and length of survival. The registry prepares reports based on the tumor registry data for the information (education) of the hospital staff. Finally, it provides a base for clinical research by the medical staff. These four major functions of registries will now be discussed in detail.
DATA COLLECTION
DATA COLLECTION AND ITS USES

Individual physicians and hospitals as well as community, state, and national medical organizations need a variety of information on cancer patients. Tumor registries are the basic unit for collecting this information and providing it in a usable form. Individual physicians and hospitals use this information to review their own efforts with respect to such things as:

1. How well they do at early detection of cancer cases.
2. How frequently certain treatments are used for various types of cancer and how effective these treatments are.
3. How long patients survive after incurring various types of cancer.

Physicians who treat cancer patients are constantly concerned with examining and improving cancer-patient care. The data collected by the tumor registry will include information about diagnosis and treatment of cancer as well as the survival experience of cancer patients. As information is collected on individual patients, this information can be analyzed as to the types of cancers as well as age, sex, and race of the patients having these cancers. More information in this regard will be given later.

Q8

Based on the material you have just read, it would appear that the data collected by the tumor registry will assist the physician in: (Check the correct answer(s).)

(✓)

a. Determining whether or not cancer patients are being diagnosed at an earlier stage of disease than in previous years.

b. Developing improved laboratory techniques to teach undergraduate medical students.

c. Determining how well they are doing in getting former patients to return for periodic checkups.

d. Determining if more cancer patients are surviving longer.
Activities a, c, and d could assist the physicians in finding out how well they are doing and in determining the effectiveness of their methods of diagnosis and treatment.

Three functions of a tumor registry, in addition to data collection, are:

a. 

b. 

c. 

Answer: Q9

a. Follow-up of cancer patients.

b. Training of physicians (education).

c. Research.
According to current medical opinion, former cancer patients should be examined periodically throughout their lifetimes. This keeps the patients under medical supervision so that any further spread of cancer may be identified early enough to increase the probability of effective treatment. The term "follow-up" refers to all the activities involved in keeping track of patients after discharge (obtaining information at least once a year regarding their state of health) and informing former patients and/or their physicians when the time for a periodic checkup is due.

Some types of cancer have a history of spreading or metastasizing very rapidly. Therefore, it is important to follow (in this case, re-examine) the former patient at more frequent intervals than once a year to see if the condition has recurred. Some persons claim that patient follow-up is the most important service provided by a tumor registry because it ensures continued medical supervision of the patient.

A second and very important reason for patient follow-up is based on the observation that persons who have had one type of cancer may be prone to develop other types. Periodic checkups of former cancer patients are imperative to ensure the early detection of additional malignancies as well as continued successful treatment of the patient for the first malignancy.
Patient follow-up activities also provide the information needed to examine the results of treatment. As examples: What are the chances of survival for various types of cancer? How is the survival related to the degree of spread of cancer at diagnosis? 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". In fact, as a tumor registrar you may spend more time on patient follow-up than on any other activity.

In most instances, patients treated for cancer are asked to return to the hospital or to their physician for regularly scheduled examinations. Many patients, of course, will report to their physician at scheduled intervals. However, there will always be a certain percentage of patients who, for one reason or another, do not return. The tumor registry informs the physician which patients have not returned. Attempts can then be made to contact the patient.

For a variety of reasons, a physician may not have the current address of the former patient. It then becomes the responsibility of the tumor registry to locate the patient. This will enable the physician to re-establish contact and secure information regarding the patient's state of health.
Patient follow-up information can also be used to prepare "end results" reports that describe the survival of cancer patients.

These reports describe the survival experience of various categories of cancer patients, for example, cases of treated stomach cancer. Survival rates are used to describe the percentage of people who live various lengths of time after the diagnosis of a particular type of cancer. If a series of survival rates are plotted on a graph, it is called a survival curve. A typical survival curve is presented below.

**Survival Following Treatment for Stomach Cancer**

<table>
<thead>
<tr>
<th>Percent of Patients Surviving</th>
<th>Years of Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>1</td>
</tr>
<tr>
<td>50%</td>
<td>2</td>
</tr>
<tr>
<td>20%</td>
<td>3</td>
</tr>
<tr>
<td>12%</td>
<td>4</td>
</tr>
<tr>
<td>0%</td>
<td>5</td>
</tr>
<tr>
<td>12%</td>
<td>6</td>
</tr>
<tr>
<td>20%</td>
<td>7</td>
</tr>
<tr>
<td>50%</td>
<td>8</td>
</tr>
<tr>
<td>100%</td>
<td>9</td>
</tr>
<tr>
<td>100%</td>
<td>10</td>
</tr>
</tbody>
</table>

The survival curve in the middle of this page indicates that for patients treated for stomach cancer:

1. approximately 54 percent are living one year later
2. approximately 20 percent are alive after five years
3. at the end of 10 years after treatment only about 12 percent are still alive.

Over a ten-year period cancer patients may die from causes other than cancer. Information that describes what happened to these cancer patients is a type of comprehensive information.
"Follow-up" information. This includes (along with the date of follow up (month, day, and year)):

1. Present address of patient.
2. Present state of health, or last known state of health.
3. Evidence of any recurrence of the cancer.
4. Subsequent treatment received by the patient.
5. Whether the patient is alive or dead.
6. If dead, cause of death.
7. Autopsy report information (when available).

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.
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 10 or 15 years. Also, second tumors are more apt to occur in cancer patients than in individuals who have never had a cancer.

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

a.

b.
Answer: 012

You could have listed the following reasons:

1. To assist in the early identification of the recurrence of a cancer.

2. To assist the physician in getting former cancer patients to return for scheduled treatments and/or checkups.

3. To insure periodic examinations of former cancer patients since they are prone to develop other cancers.

4. To gather various types of information so physicians can review types of treatment in terms of survival.

013

If possible, a former cancer patient should be followed until death. List four types of follow-up information that should be collected:

a. ________________________________

b. ________________________________

c. ________________________________

d. ________________________________
You could have listed such types (dated) as:

1. Present address of patient.
2. Present state of health, or last known state of health.
3. Evidence of any recurrence of the cancer.
4. Subsequent treatment received by the patient.
5. Whether the patient is alive or dead.
6. If dead, cause of death.
7. Autopsy (necropsy) report information (when available).

**autopsy**—The postmortem examination of a body

**necropsy**—A postmortem examination; autopsy

---

Which of the following statements about patient follow-up are TRUE and which are FALSE? (Circle T or F.)

a. A former patient should be followed at regular intervals.

b. A cancer patient is "cured" if the cancer has not reappeared within three years after treatment.

c. After a patient has been followed for five years, it is still advisable to obtain information about the patient on a regular basis.
Answer: 014

a. True. The patient will be followed by the physician at least once a year. For cancers which spread very rapidly, the physician may wish to examine the patient at more frequent intervals.

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 10 or 15 years.

c. True. To obtain information on survival rates, it is necessary to follow former patients until death.
EDUCATIONAL BENEFITS OF A TUMOR REGISTRY
EDUCATIONAL BENEFITS OF A TUMOR REGISTRY

On a yearly basis, sometimes more often, a tumor registry prepares one or more reports containing information such as:

1. Numbers and types of cancer patients diagnosed and treated during the past year.
2. Percentage of patients with spread of the cancer to different regions of the body.
3. Number of patients for whom follow-up was obtained.
4. Types of treatments used with patients with different types of tumors.
5. Latest survival rates for various types of cancer.

Such information allows the hospital staff and physicians to review their cancer program, and especially to analyze their successes and failures. This is a type of continuing education that allows physicians to find out what treatment is most successful and what problems need special attention.

In numerous hospitals there will be newly graduated medical students who are interns and resident physicians. This is postgraduate training during which the new MD acquires new skills and obtains additional expertise in medical skills. In some hospitals, there will be undergraduate students who are just beginning to study medicine. The information obtained from a tumor registry can be used to assist in the instruction of interns, residents, and undergraduate medical students. For instance, this information can help them learn about the natural history of cancer as well as its treatment.

natural history of disease--the course of a disease if not interrupted by treatment

Tumor registry information can be used to help interns, residents, and medical students learn about the natural history of cancer. In addition, registry information, in the form of annual reports, can assist the hospital staff in learning more about its cancer load and the treatment of various types of cancer patients. These are but two examples of the benefits that can be provided by a tumor registry.
You have now learned three of the four functions of a tumor registry. Briefly describe those three functions in your own words.

a.

b.

c.
a. To provide for the collection of data which can be used to study the diagnosis and treatment of cancer patients.

b. To provide follow-up information which describes what happens to patients after they have been treated for various types of cancers by various programs of treatment. Follow-up aids both the physician and the patient because it provides a contact with the patient that might otherwise be lost and often is the means of bringing the patient back under medical supervision.

c. To provide educational benefits to the hospital staff, and to interns, residents, and medical students.
RESEARCH BENEFITS OF A TUMOR REGISTRY
RESEARCH BENEFITS OF A TUMOR REGISTRY

A tumor registry is actually a working index of biostatistical data which is continually available for clinical research by the medical staff. At numerous hospitals there will be members of the medical staff who are conducting some type of research on the diagnosis and treatment of cancer. They may ask the registry to provide information to assist them in their research. For example, someone may be investigating the types of treatment employed with a particular type of cancer. The registry might be asked to prepare a listing of patients diagnosed as having a particular type of cancer or the registry might be asked to describe how each patient was treated, how long the patient survived, and the present or last-recorded state of health of the patient.

There are a few hospital, state, and regional tumor registries that provide information to state and national health agencies for the epidemiological study of cancer. Epidemiological studies investigate the various conditions (environmental, social, etc.) that seem related to the frequency and distribution of various types of disease within a community. A considerable portion of these studies is conducted by or for the National Cancer Institute, part of the National Institutes of Health, which, in turn, is part of the United States Department of Health, Education, and Welfare.

biostatistical—Biostatistical data include any type of numerical information about living organisms

epidemiology—The study of the occurrence and distribution of disease

Tumor registry information is used in four general ways:
To provide diagnosis and treatment data, to provide patient outcome or follow-up information, to provide continuing education for physicians, and for clinical research by physicians.
A tumor registry also can provide information that can be used to study some of the conditions associated with the occurrence of various types of cancer. This would be a type of study.
Answer: Q18

Epidemiological. Epidemiology is the "field of science dealing with the relationships of the various factors which determine the frequencies and distributions of an infectious process, a disease (e.g., cancer), or a physiological state (a condition of the body) in a human community.

Physiology. The science that treats of the functions of living organisms and their parts.
SECTION C

JOB ACTIVITIES OF A TUMOR REGISTRAR
JOB ACTIVITIES OF A TUMOR REGISTRAR

1. Selection of Records for Incorporation into Registry Files

One of the most important activities of a hospital-based tumor registry is to provide the means for obtaining an accurate account of the cancer experience in that hospital. Therefore, procedures must be established for obtaining a complete roster of its patients with cancer. All inpatient and outpatient records should be reviewed and those cases with cancer tagged and/or set aside for additional processing. Furthermore, various procedures can be adopted for alerting the tumor registrar to specific cancer patients undergoing treatment at the hospital who should be incorporated into the tumor registry. For example, reports from the pathology, radiology, and other departments can be sent routinely to the tumor registrar.

Patients' records dealing with diagnoses of interest to the registry may be selected by the medical records personnel for further processing by the tumor registrar. However, experience has shown that a fair number of records, which should be incorporated into the tumor registry, are, in fact, missed. If possible, the tumor registry should screen all records as they come to the medical record department. This increases the likelihood that those records which should be incorporated into the registry are selected.

In some hospitals, tumor registry personnel screen the medical records as well as the reports emanating from such departments as pathology, cytology, and radiology. They also attend tumor conferences. By these means, registry personnel obtain information regarding those cases that should eventually show up as candidates for incorporation into the registry.

Pathology—The scientific study of the nature of disease, its causes, processes, development, and consequences, more specifically, the microscopic examination of tissue

Radiology—The science of radiant energy and radiant substances, especially that branch of medical science which deals with radiant energy in the diagnosis and treatment of disease

Cytology—The microscopic examination of cells obtained by aspirations, washing, scrapings, and smears (such as Pap smear)

Tumor conferences—a meeting of physicians trained in various disciplines who review the diagnosis of and propose therapy for a patient with some type of tumor
The selection of records is most efficiently performed by the tumor registrar because of her unique knowledge of the tumors included in the registry. A pathologist or other knowledgeable member of the hospital medical staff should advise the registrar on problems of abstracting and coding.

2. Preparation of Abstracts

As you probably already know, when a person is admitted to a hospital a medical record is established for that person. 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. For patients with cancer, the information in their medical charts eventually is summarized and reported on a special form called a tumor registry abstract. A tumor registry abstract is a summary of information in a medical record or chart that is relevant to the diagnosis and treatment of cancer. These abstracts are filed in the tumor registry. One of the major jobs of the tumor registrar is preparing these abstracts.

In some hospitals the inpatient and outpatient charts are filed separately. If this is the situation, both inpatient and outpatient records must be reviewed. Watch for new cancer diagnoses to augment, as well as follow-up information to update, the registry files.
Medical record or medical chart.

After a patient is discharged from the hospital, the medical record is sent to the hospital's medical record department. The tumor registrar obtains pertinent records from the medical record department in order to abstract those cases which belong in the tumor registry file and also periodically examines such records for follow-up purposes.

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, and indexing them for future reference.

You have learned that a tumor registry contains information about cancer patients and that this information is obtained from medical records or charts. The special form used to record the summary of this information is called the _____________________________. 
Q20

Tumor registry abstract.

Q21

Name three types of information you would expect to find on a tumor registry abstract (in addition to such items as name, address, and age of the patient).

a. ____________________________________________

b. ____________________________________________

c. ____________________________________________
You might have listed such things as:

1. Medical history related to cancer.
2. Description of the diagnosis.
4. Patient follow-up information—health of the patient after discharge, survival, etc.
The file of cancer registry abstracts is the most important element in all cancer registry programs. These documents enable the medical staff to review the overall cancer program in the institution. It is a concise summary of the significant facts from hospital medical charts on the history, diagnosis, and treatment of every patient's cancer. To prepare a tumor registry abstract accurately, you must possess a reasonable medical vocabulary relating to the diagnosis and treatment of the various types of cancer. You must be skillful at abstracting from the medical record the information indicating the final diagnosis and the type of treatment given. In addition, you must know how to apply rules for determining the extent of spread of the disease at the time of diagnosis. This is called staging in some hospitals and extent of disease in some programs. Both of these concepts will be discussed in detail in Lesson Book 5.

Typically, the medical records are completely abstracted by a tumor registrar with a medical consultant assisting in the interpretation of the material when needed. In some cases, it may be necessary to contact the patient's attending physician for clarification of information contained in the record. At large hospitals, one or more full-time tumor registrars are responsible for preparing the tumor registry abstracts.

**Stage of Disease**—Grouping cases with similar prognoses into broad extent of disease categories, e.g., localized, regional, and distant spread.

**Extent of Disease**—Detailed description of how far the disease has spread from the primary site.
For hospitals associated with a central registry or a population-based registry, the hospital tumor registry abstract furnishes the basic information for the registry system. Small hospitals (150 beds or less) participating in such a program may rely on a member of the central registry to visit the hospital periodically and abstract records set aside for incorporation into the registry. Assuming that such arrangements can be made, it is quite appropriate to use these "circuit riders" to do the abstracting.

It often happens that the medical record does not contain all of the information needed for a complete abstract. In such a case, the abstractor must see that the attending physician is contacted for additional information. This contact is most appropriately made by the physician who is supervising the tumor registry activity at the local hospital. However, in practice, it is generally made by the tumor registrar in the physician's name. Numerous hospitals have found that a tumor registry can be instrumental in educating physicians to the need for preparing more complete and legible records.

3. Coding of Tumor Registry Abstracts

The various services that can be provided by a tumor registry include the tabulation, summarization, and analysis of cancer registry data. The use of automatic data-processing equipment can, in institutions having large caseloads, expedite and facilitate these activities. However, before registry data can be processed automatically, the information on the registry abstracts must be translated into code. Coding methodology will be discussed in detail in a later book.

In those institutions where automatic data processing is done, the abstracting and coding processes often are performed by the same person. This is the procedure typically employed at those registries not associated with a central registry. The major advantage of this procedure is that the abstractor-coder eventually learns the kinds of information that must be recorded, in order to distinguish among the coding categories.

\textit{code}--Numerical values for data
As mentioned earlier, for some central registry systems, "circuit riders" are used to abstract medical records. When this procedure is followed, the same team may code the material it abstracts. It is possible to establish—at either community, regional, or statewide level—abstracting teams that periodically visit each hospital and abstract those cases selected for incorporation into the registry system. The use of "circuit riders" not only provides uniformity in abstracting but also allows the gathering of data for hospitals too small to justify a full-time tumor registrar.

In most central registry systems, whose participating hospitals have tumor registries, the abstract is prepared by the hospital tumor registrar and transmitted to the central registry for coding and processing. This has the advantage of a group of highly expert coders at the central registry doing the coding of the abstracted material. Coding is probably more consistent when performed at the central registry. With this procedure, however, care must be taken to prepare a complete and accurate abstract. This procedure is successful to the degree that an adequate abstract, containing all the information needed during the coding process, can be provided.

4. Patient Follow-Up

A tumor registry also collects information on the progress of cancer patients after they leave the hospital. Information is collected on the health of the patient during subsequent years. Also, information is collected about the therapy the patient might have received after leaving the hospital. This information may be included in subsequent patient follow-up. Thus, the information contained in a tumor registry is collected from two primary sources: medical records and follow-up reports. Usually this follow-up information is obtained from the patient’s physician, from records of subsequent patient visits to the hospital, from contact with the patient or relatives of the patient, or from another hospital registry. Patient follow-up techniques will be discussed in more detail later in this book.

NOTE: You should be cautioned that a tumor registrar does not contact a former patient or relatives of a patient unless specifically authorized to do so by the patient’s physician. For patients who have no private physician, a physician associated with the tumor registry will authorize the contact, should it be necessary.
Information about the diagnosis and treatment of a patient while in a hospital is obtained from the:

a) ____________ ____________

Information obtained from either the records of subsequent visits to the hospital or from contacts with the patient's private physician or by direct contact with the patient is called: b) ____________ ____________
Follow-up information describes such things as 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, when the patient died.

Which of the following statement(s) is not an example of follow-up information?

(✓) (Check the correct answer(s).)

a. The patient died two years after discharge.

b. The patient was treated initially by surgery and radiation.

c. The patient’s condition was first diagnosed during a routine physical examination.

d. All of these.
Answer: 023

b and c. Statement b describes treatment that had to be performed at least in part (the surgery) while the patient was hospitalized.

Statement g describes a procedure that probably occurred before the patient was admitted to the hospital.

Statement a is a typical follow-up information item.
One of the major objectives of a tumor registry system is assurance that patients with cancer receive continuing medical supervision. It is extremely important, therefore, that a means be provided for periodically assessing the condition of the patient so that additional treatment can be provided, if needed. Search your hospital for other methods of follow up. It is quite possible that x-ray, hematology, and pathology reports as well as outpatient schedules can be routed through the tumor registry prior to being filed in the medical record. This may save your registry and the medical record department many hours of work.

Patient follow-up can be a very time-consuming activity, especially after the registry has been in existence for some period of time. At either six-month or yearly intervals, the tumor registrar obtains the latest information on the status of the patient. This means that one-sixth (1/6) or one-twelfth (1/12) of the total active cases in the registry are followed each month. The hospital records for the appropriate patients are obtained from the Medical Record Department and examined for new information. If the patient has not visited the hospital or the physician within the last 6 or 12 months, the physician is contacted with a request for information about the status of the patient. When the physician returns the current information to the registry, it is recorded in the tumor registry file. This information is, in turn, forwarded to the central registry if the hospital registry is associated with one.
Each month the tumor registrar determines which of the former patients should be followed that month, and then proceeds through various methods to obtain information about the status of each patient. Often the patient's medical chart will contain recent "check-up" information that provides all of the desired follow-up data. Other times the registrar may contact the patient's physician, using a special form letter, which the physician fills out and returns to the registry. If the doctor does not reply promptly, a second, and perhaps different, form letter may be sent out. When doctors have lost contact with patients, their consent will usually be given to the registrar to try various means of locating patients.

In most hospitals the tumor registry has permission to contact former patients for whom there is no current follow-up information. This may be done by phone or form letter. If patients mention any problems or doctors have indicated that they would like patients to come in for a check-up, the registrar may suggest that each patient make a clinic appointment or contact their private physicians. This personal involvement in service to cancer patients can be a rewarding part of the job of a tumor registrar.

In large hospital registries, patient follow-up is a major activity, and requires extra personnel to help with the job. At small hospitals, the registrar will perform all jobs but may spend the most time on patient follow-up.
For each patient in the registry, follow-up information should be collected at least on a yearly basis until the date of death of the patient. Normally, follow-up is initiated a year from date of last follow-up. Patients to be followed each month can be determined by maintaining a follow-up control file in which the names of all living patients are arranged according to the month of the last follow-up. In large community and state registries, this file may be computer-maintained in the central registry. Each month, the hospital registry is sent a list of the people for whom it should obtain information during that month.

Follow-up may involve a good deal of detective work when physicians have lost contact with patients. To reiterate, always check the hospital and clinic records first to see if the patient has been seen. When this fails to locate the patient, some of the more common sources the registrar can use to trace missing patients are:

1. A relative or friend of the patient (if authorized)
2. Other hospitals (cancer registries)
3. The telephone directory (sometimes, a "street-guide" directory is also available from the telephone company—usually for a fee)
4. City and county directories
5. The post office
6. Professional and other directories
7. Hospital social worker
8. Employer (often listed on the admission sheet)
9. Labor unions, religious groups, veterans organizations, visiting nurse associations, or any organization which might give a lead
10. Both local and state health departments or vital statistics offices for information on deaths of cancer patients in your registry
11. Obituary columns in local newspapers.

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

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:

- a. Contact the patient or relative listed as next of kin
- b. Check the medical record for subsequent visits or information subsequent to the last follow-up (the last information posted in the registry files)
- c. Contact the patient's private physician
Answer: 024

a. 3--But only when hospital policy and patient's private physician permit, the registrar to contact the patient or relatives of the patient.

b. 1

c. 2
5. **Maintenance of the Tumor Registry**

There are generally four basic components to a registry system:

A. **Accession Register** - Cases are entered in the accession register as they are abstracted using a consecutive numbering system. This can be used for auditing the registry files to check against possible loss from those files. As a minimum the register contains 1) a registry number listed sequentially by year, 2) the patient’s name, 3) the diagnosis, and 4) the patient’s hospital number.

B. **Master Patient Index File** - This is an alphabetical card file on all cases (alive and dead) which serves as a master reference to registered tumor 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. It may contain such information as the patient’s name, the hospital chart number, diagnosis (primary site and type), admission and/or discharge date, birth date, social security number (when available), and name of spouse. If the registry is computerized, an alphabetical print-out may be used as this file.
C. PRIMARY SITE INDEX FILE. This is a file of all registered tumor cases arranged according to primary site. (The classification of primary sites will be discussed later in this course.) It can be composed of either cards, abstracts, or computer printouts. It is usually arranged by site and year of diagnosis. It can be in alphabetical or chronological order within each primary site. This facilitates selection of cases for special reports and studies. It makes possible curbsy study 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.

D. 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 only living cases. It alerts the tumor registrar to cases due for follow-up. It is sometimes called a "reminder" or "tickler" file.

Cards are filed according to the date that the patient is due to be followed (month of expected next contact). 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. Each month you can see at a glance who is 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 phone number, and names and addresses of relatives or other informants.

An automated or computerized registry may develop modifications of all of the above which will utilize the capability of data processing equipment for the more efficient handling of tumor registry data.

primary site—The organ or tissue of the body where the cancer originates.
List below the usual files maintained by a hospital registry:

1. _______________________
2. _______________________
3. _______________________
4. _______________________
Answer: 025

1. Accession register or yearly listing of all patients.
2. Patient index file or master file.
3. Primary site index.
4. Follow-up control file.
6. **Preparation of Reports**

One of the major functions of a hospital tumor registry is the preparation of semi-annual or annual reports for the hospital staff. These reports summarize the cancer experience of that particular hospital. Suggestions for preparing annual reports will be presented later in this course. If a registry is associated with a central registry, the central registry can assist by producing reports of the tumor experience for each participating hospital. These hospital staff reports or similar ones may also be submitted to the American College of Surgeons to fulfill one of the requirements for approval of the hospital cancer program.

Hospital tumor registries must be able to provide quickly a wide variety of data upon request. At large hospitals, tumor registry personnel should have the capability of preparing year-end summary reports as well as reports that can be used for teaching purposes. At a small hospital, a tumor registrar should be able to prepare a few basic reports. If the hospital registry is associated with a central registry, the registrar should be able to take requests from local physicians and obtain answers quickly from the central data processing facility. It can be presumed that physicians at a local hospital will want information regarding their own patients. They may also want information regarding what is going on within their own hospital and immediate community as compared with statewide and/or national conditions.
Similarly, a central registry must to prepare reports for a variety of users summarizing the experience of its members and the statistical implications of its pooled data. The information requirements of all important users must be considered when planning a tumor registry system. However, care must be taken to ensure that a central registry does not cater to statewide and national users to the detriment of local and community hospital requirements. Above all, to be patient-oriented, a central registry facility must be capable of and oriented to answering those questions which originate at the local hospitals.
A hospital-based registry provides data and reports for its medical staff. A central (population-based) registry provides information for: (Check one.)

(✓)

- a. Regional, state and national users
- b. Individual participating hospitals
- c. Both
Answer: 026.

Both.
JOB AIDS FOR THE TUMOR REGISTRAR
It is not possible for the tumor registrar to memorize all of the information required to abstract and code a medical chart. In fact, for many types of jobs, it has been found that the job can be taught much more readily and performed much more accurately once a well-developed set of job aids has been prepared. 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 tumor registrar must also use a variety of other reference materials some of which were developed for general use by a number of medical specialties and some 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 alert you to the various types of aids and reference materials that can be used by the tumor registrar. 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 the understanding of medical terminology

A second group of job aid material includes handbooks, manuals, and various lists and glossaries of terms, such as:

1. Anatomic overlays
2. Names of cancer chemotherapeutic agents
3. Diagnostic procedures and surgical procedures related to cancer
4. Manures of tumor nomenclature and coding
5. Current Physician's Desk Reference (PDR)

A third group of job aids are journals and publications by such groups as:

1. American College of Surgeons (Tumor Registry Manual)
2. American Cancer Society
3. National Cancer Institute

Other job aids for abstracting or coding purposes are:

1. SNOP: Systematized Nomenclature of Pathology
2. MTNAC: Manual of Tumor Nomenclature and Coding
3. ICDA: International Classification of Diseases Adapted for use in the United States
4. HICDA: Hospital Adaptation of the ICDA
5. Clinical Staging Systems for Cancer:
   a. American Joint Committee on Cancer Staging and End Results Reporting (AJC)
   b. International Union Against Cancer (UICC)

chemotherapeutic—of or pertaining to the treatment of disease with chemicals

donomenclature—A system of names
A tumor registrar must keep appraiser of new developments in the diagnosis and treatment of cancer. For example, as new biotherapeutic agents are developed, you will have to learn to recognize their names or at least know how to look up the terms to determine to what type of treatment they refer. Familiarity with the PDR will be helpful in this respect. In addition, 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 which should be contained within a tumor registry and to which you may turn for additional information regarding 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 what is known as patient follow-up. As you might expect, one of the more difficult aspects of patient follow-up is locating a lost patient. Therefore, city and suburban telephone directories are a very important type of job tool. These directories should be obtained for as many cities within the area of service as can be acquired. This is done by contacting your local telephone office.
SECTION D

RELATIONSHIP OF TUMOR REGISTRIES TO HOSPITAL DEPARTMENTS AND MEDICAL ORGANIZATIONS.
RELATIONSHIP BETWEEN A TUMOR REGISTRY AND THE HOSPITAL IN GENERAL
THE RELATIONSHIP BETWEEN A TUMOR REGISTRY AND THE HOSPITAL IN GENERAL

The purpose of the next three instructional segments is to give you a general understanding of how a tumor registry relates to other hospital departments and to various non-hospital agencies. This material will provide you with additional orientation to the job of a tumor registrar.

For organizational and supervisory purposes a tumor registry must be attached to a hospital department. A tumor registry always has a director or a chief who is a member of the professional staff of the hospital. The director may be a medical oncologist, a pathologist, a surgeon, a radiologist, or other medical specialist. The director will usually be a member of the Committee on Cancer (which is discussed later). In addition to the director, consultants from other departments of the hospital who are concerned with the diagnosis and treatment of cancer may be assigned to help the tumor registrar abstract or code difficult cases.

After a patient is discharged from a hospital, the medical chart is sent to the medical records department where it is processed and filed for future reference. In a typical tumor registry, as new records are processed in the medical records department, they are screened by the tumor registrar or a member of the records department staff. This person identifies the records that deal with cancer patients and sets them aside for processing by the tumor registry. The tumor registrar abstracts the records, and they are then filed again in the medical records department. These records may be flagged to indicate that the patient is in the cancer registry files in order that readmissions of this patient will be referred to the tumor registry.
Sometimes a tumor registrar may have difficulty abstracting a chart. When this occurs, the record is set aside for review by a consultant who can be from:

(✓)

- a. The pathology department.
- b. The surgery department.
- c. Either.
- d. Neither.
c--Either department. Large hospitals may have consultants from both pathology and surgery, as well as from other departments, such as radiology, medical oncology, and nuclear medicine.

nuclear medicine--The use of radioactive isotopes in the diagnosis and treatment of cancer

A registry is headed by a member of the hospital staff. This director will often be from the department of:

a. __________________________

b. __________________________, or

c. __________________________

Answer: 027
Pathology, surgery, or radiology. 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.

**Oncology**—the sum of knowledge concerning tumors; the study of tumors

---

A cancer registry receives which of the following cases from the medical records department:

- a. The new cancer cases which must be abstracted and become part of the registry files.
- b. The cancer cases already in the registry files which have returned for follow-up care.
- c. Both.
- d. Neither.
c--Both. All cancer admissions, new admissions and readmissions, should be referred to the tumor registry.
RELATIONSHIP BETWEEN
A TUMOR REGISTRY AND OTHER HOSPITAL DEPARTMENTS
THE RELATIONSHIP BETWEEN A TUMOR REGISTRY AND OTHER HOSPITAL DEPARTMENTS

There may be frequent interaction between a tumor registrar and persons from other hospital departments. Specifically, the registrar may have frequent dealing with persons from the departments of surgery, pathology, radiology, and nuclear medicine. Much of the information that eventually appears on a tumor registry abstract originates in one of these four departments. In addition, the tumor registry must maintain a close working relationship with the medical record department. This is the department responsible for assembling the patient record, checking it for completeness, and routing it to the tumor registry.

Surgery Department

The department of surgery is one of the hospital departments most involved with the diagnosis and treatment of cancer. This is because numerous diagnostic techniques are surgical in nature. Furthermore, many cancers are treated by surgery or by some combination of treatments which include surgery.

When surgery is performed, a detailed description of the surgical procedure and outcome is prepared 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 information. It should state the exact location of the cancer in the body, the size of the area affected by the cancer, and the extent to which the cancer has spread throughout the body. Samples of the report of surgery (or description of operation) follow on the next two pages.
Report of Surgery

Operative Findings

(The Operative Record may also be known as the Report of Surgery or the Surgical Report.)

(Continued on next page)
DESCRIPTION OF OPERATION

PREOPERATIVE DIAGNOSIS (Written and signed before surgery.)

Operation Performed

Operative Risk Poor, Fair, Good

Anesthesia Started

Operation Started

Operation Ended

Postoperative Diagnosis

Specimens Removed

Drains

Surgeon

First Assistant

Dictated by
Pathology Department

All tissue removed by biopsy or surgical excision is sent to the pathology department where it is examined in detail. In addition, samples of fluids (i.e., sputum, pleural, ascitic) are sent to the pathology department for detection of possible malignant cells. A pathology report is prepared to describe the findings of these examinations. This is an extremely valuable report to the tumor registrar. It usually contains the most detailed, accurate description of the primary site of the cancer and the type of cancer (type in terms of cells and/or tissue involved). The pathology department also performs autopsies, and the findings are reported in detail in the patient's chart.

The pathology department contains such laboratories as a histology lab (for the microscopic examination of tissue), a cytology lab (for the microscopic examination of cells), and a hematology lab (for performing various blood tests). (The hematology lab may be a part of the clinical laboratory.) Each of these laboratories uses a special form to describe test findings. Often these forms are color coded. As a tumor registrar you will be able to recognize these forms and to recognize when they contain significant information that should be recorded on a tumor registry abstract. Samples of these reports follow.

Pathology reports may be used as a source for locating the cancer cases. The names of patients which are obtained from the pathology department can be compared with the list of patients who have been identified by the medical records department. This procedure helps assure that all cancer patients are entered into the registry. Autopsy reports are also found in the pathology department. They may be used for verification of the primary site and extent of disease as well as for determination of other possible primary sites.

hematology — the science of blood, its nature, functions, and diseases

histology — the microscopic examination of tissue obtained by biopsy (excision of a tissue sample), surgery, or autopsy

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.
## Pathology Request

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<th>Physician (With Signature)</th>
<th>Address of Hospital Location</th>
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### Date Record Pathology

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### History/Treatment

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### Pre-Operative Diagnosis

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### Post-Operative Diagnosis

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| PATHOLOGIC FINDINGS | |
|---------------------| |

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### Hematology Report

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<tr>
<td>Monocytes</td>
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<tr>
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<tr>
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### Comment:

- **Hemoglobin Electrophoresis**
- **Direct Coombs'**
- **Screen Fragility (.5% saline)**
- **Prothrombin Time**
- **Partial Thromboplastin Time**
- **Plasma Recalcification Time**
- **Serum Pro Time**
- **Screen Fragility (.5% saline)**

### Other Values:

- **Hemolysis begins**
- **Control begins**
- **Hematology begins**
- **Control begins**
- **Prothrombin Time**
- **Partial Thromboplastin Time**
- **Plasma Recalcification Time**
- **Serum Pro Time**
- **Screen Fragility (.5% saline)**
- **Osmotic Fragility**
- **Hemolysis begins**
- **Control begins**
- **Complete**
- **Complete**
- **Complete**
- **Complete**
- **Complete**

**CONSULTATIVE HEMATOLOGY**

**DEPARTMENT OF PATHOLOGY**
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**Notes:**
- CBC:
- STAT:
- TODAY:
- OTHER:

**Date:** 12/30/14

**Order by:** MD

**Specimen:**
- 101 COMPLETE BLOOD COUNT
- 103 DIFFERENTIAL
- 302 PART. THROMBOPLASTIN (SEC)
- 111 SEDIMENTATION RATE (mm/hr)
- 116 RETIC COUNT (%)
- 128 L. E. PREP
- 125 RBC INDICES

**Control Values:**
- Control Factor: 100
- Control Factor: 100
- Control Factor: 100
- Control Factor: 100
- Control Factor: 100
- Control Factor: 100
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**Specimen Preparation:**
- Aniso:
- Polychromatophilic:
- Micro:
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**Drawn by:** TECH

**Date:** 12/30/14

**Time:** 5:19:36 PM

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99
LABORATORY OF EXFOLIATIVE CYTOLOGY

CYTOLOGIC EVALUATION
(To be filled out by cytology)

The present material was prepared from

and contains

DO NOT WRITE IN THIS SPACE
DO NOT FOLD THIS FORM
TO BE FILLED OUT BY CYTOLOGY

<table>
<thead>
<tr>
<th>Specimens are accepted only Monday through Friday from 9:00 A.M. to 4:00 P.M. unless special arrangements have been made.</th>
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<tbody>
<tr>
<td>TO BE FILLED OUT BY CLINICAL PHYSICIAN: SPECIMENS WILL NOT BE EXAMINED UNLESS THIS PORTION IS FILLED OUT COMPLETELY</td>
</tr>
<tr>
<td>Sex: ☐ Female ☐ Male Race: ☐ White ☐ Non-White Marital Status: ☐ Single ☐ Married ☐ Widowed Age: ☐ Div or Sep. ☐ Special Research Study</td>
</tr>
<tr>
<td>Cigarette Smoking: ☐ Does NOT smoke ☐ Less than 20 per day ☐ 20-40 cig. per day ☐ More than 40 per day Clinical Findings: ☐ ? Cancer ☐ Cancer Date: ☐ Mass on X-Ray ☐ Tbc Findings: ☐ Not done ☐ Done Other: ☐ Other:</td>
</tr>
<tr>
<td>X-Ray Diagnosis: ☐ ? Cancer ☐ Cancer ☐ Tbc ☐ Sarcoid ☐ Other: Previous Radiation Therapy: ☐ No ☐ Yes Previous Cytology?: ☐ No ☐ Yes Date: ☐ (year) If yes, suggestive No ☐ of cancer?: ☐ Yes</td>
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<tr>
<td>Type of Irradiation: ☐ Other: Previous Biopsy?: ☐ No ☐ Yes</td>
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<tr>
<td>Type of Specimen: ☐ First sputum ☐ Repeat sputum ☐ Sputum after bronchoscopy ☐ Bronchial washing ☐ Direct bronchial specimen Left ☐ Right Urine ☐ Buccal Mucosa for Sex Chromatin Determination Prostate Breast. Right ☐ Left ☐ Nasopharynx Larynx Esophagus Gastric Bowel Pericardial fluid</td>
</tr>
<tr>
<td>Remarks: IF YOU WISH TO HAVE A COPY OF THIS REPORT PLEASE TYPE (OR PRINT) YOUR NAME. (A copy of this report will automatically go to the patient's record.)</td>
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<tr>
<td>Submit all sputum specimens via Rm. W618, Billings Hospital. All other specimens to Rm. 210, Chicago Lying-In Hospital, Research Pavilion</td>
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<tr>
<td>SEE REVERSE SIDE FOR TECHNIQUES OF SMEAR PREPARATION</td>
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Radiology Department

A radiology department uses x-ray equipment for diagnostic purposes and therapeutic purposes. "Beam" radiation is administered from an external source which may be either x-ray or cobalt.

The radiology department is concerned with the use of x-rays and other forms of radiation for both diagnosis and treatment of disease. There are various types of cancer that can be diagnosed and treated by some form of x-ray or radiation. Therefore, as a tumor registrar, you must learn to recognize reports from the radiology department and to discern when they contain significant information relative to the diagnosis and treatment of cancer which must be summarized on the abstract. Samples of radiology reports follow on the next several pages.

These reports are often overlooked, especially when the radiology service is maintained as a separate enterprise outside the hospital. Care must especially be taken in searching the radiology records if such is the case.
## Radiology Request

### Revenue Centers
- 133 Diagnostic Centers
- 135 Isotopes
- 136 Therapy

### Requested By
- M.D.

### Referring Service

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<th>STRETCHER</th>
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### Clinical Diagnosis and Pertinent Clinical Data (History)

### Radiology Technical Data

#### Contrast Media and Amounts, Medications

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RADIATION THERAPY
REQUEST FOR CONSULTATION

CLINICAL REPORT AND DIAGNOSIS:

REQUEST FOR CONCERNING
Opinion Only □
Treatment □

HISTOPATHOLOGY:
What has the patient been told about the diagnosis?

PREVIOUS RADIATION THERAPY: Yes □ No □ Date: ................................

INSTITUTION:

ADDRESS: ...........................................................................................................M.D.

REPLY TO CONSULTATION

DATE: ....................................................................................................................

.............................................................................................................................M.D.

(over)
RADIATION THERAPY SUMMARY

PATIENT'S NAME

REF DOCTOR

DIAGNOSIS

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REMARKS

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TOTALS

105
REPORT OF ELECTROENCEPHALOGRAM

Surname    First name    Middle name    Date of test

Referred by

Reference Diagnosis

Right, Handed □    Left Handed □    Age

Interpretation of Electroencephalographic Tracings.

M.D.
Department of Nuclear Medicine

Some of the larger hospitals have what is known as the department of nuclear medicine. In others its functions are included in the radiology department. This department is concerned with the use of radioactive material for diagnosis and treatment. Tests performed by this department will appear on a special form and may contain information of importance to the tumor registrar. These tests are called scans. Radioactive isotope therapy includes the application or internal use of such materials as radium, radioactive iodine (I131), radioactive phosphorus (P32), and radioactive gold (Au198).

In contrast to the radiology department, a nuclear medicine department is concerned with the use of radioactive materials (radioactive isotopes). Samples of reports follow.
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Date of Report
Signed
FORM 55c

RADIOACTIVE IODINE TRACER STUDY

DATE DOSE ADMINISTERED

AMOUNT

FOUR (4) HOUR

THYROID UPTAKE

BODY BACKGROUND

ADJUSTED STANDARD

PERCENTAGE UPTAKE 4 HOURS

(TYPICAL RANGE 7 TO 23%)

TWENTY-FOUR (24) HOUR

THYROID UPTAKE

BODY BACKGROUND

ADJUSTED STANDARD

PERCENTAGE UPTAKE 24 HOURS

(TYPICAL RANGE 12 TO 35%)

*STANDARD MINUS BACKGROUND

109
### Isotopes - Radiotherapy

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**NUCLEAR MEDICINE CONSULTATION**

**CLINICAL REPORT AND PROVISIONAL DIAGNOSIS:**

(For all thyroid studies list ALL current medications and dates of previous x-ray contrast examinations)

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Medical Record Department

Every hospital has a medical record department which is responsible for assembling various medical reports for each patient, checking them for completeness, combining them in a single patient file, and indexing them for future reference.

Patient records of interest to the tumor registry are routed to the registrar from the medical record department. In some hospitals the tumor registry may actually be located in the medical record department. In a small hospital a member of the medical record staff may maintain the tumor registry on a part-time basis.

Committee on Cancer

At those hospitals actively involved in the treatment of cancer patients, especially institutions seeking approval of their cancer program by the American College of Surgeons, there will be a committee called the hospital Committee on Cancer.

The purpose of this committee is to oversee the cancer program at that hospital. More specifically, this committee is established to:

1. Furnish leadership in cancer care.
2. Oversee operation of the cancer registry.
3. See that an annual report of cancer case load and patient follow-up is prepared.
4. Establish a schedule for frequent tumor conferences (conferences at which the diagnosis and treatment of specific cancer patients is discussed).

This committee is composed of physicians who are actively interested in the diagnosis and treatment of cancer—surgeons, pathologists, radiologists, medical oncologists, and others. The director of and consultants to the tumor registry usually are members of this committee. Problems related to the tumor registry can be taken before this committee for solution.
Many hospitals schedule frequent meetings called tumor conferences that are held for the purpose of discussing ways to diagnose and treat various types of cancer patients, especially difficult cases. These conferences are extremely valuable in that they provide a kind of continuing education for the hospital staff and a form of training for interns, residents, and medical students. Alternative treatments for particular cases may be formulated. Previous patients may be presented for re-evaluation.

Usually, the tumor registrar attends tumor conferences. This is a useful activity since it enables the registrar to learn about new diagnostic and treatment techniques. Also, it may be the first opportunity for the registrar to learn about patients who will eventually be incorporated into the registry. The tumor registrar frequently acts as secretary of the tumor conferences and may actively participate by having data available regarding number of cases, treatment, and "end results" on the types of cases being presented. In some hospitals the tumor registrar takes an active part in the selection of cases to be presented to the tumor conference.

A tumor registry exists for the purpose of providing various types of services. By attending tumor conferences, the registrar will obtain a better understanding of the kinds of information needed by the physician who must diagnose and treat cancer. In addition, a rapport develops between the tumor registrar and the members of the medical staff: The tumor registrar comes to know the staff members who can help with difficult abstracting, coding problems, and patient follow-up. The medical staff, in turn, becomes aware of information available in the registry and is more likely to use it.
A tumor registrar should be familiar with reports from various departments within a hospital that are involved in the diagnosis and treatment of cancer. Of particular importance are the diagnostic laboratories in the pathology department. Name three labs which probably would be in the pathology department.

a. ____________________________
b. ____________________________
c. ____________________________
It may contain a histology lab, cytology lab, and hematolgy lab.

Q31

A histology lab makes microscopic examinations of tissues; a cytology lab makes microscopic examinations of cells. A report of a blood test would come from the:

( )

a. Histology lab.

b. Cytology lab.

c. Either one.

d. Neither one.
d—Neither one. Blood tests are made by the hematology lab which is often a part of the clinical laboratory which is supervised by the pathology department.

**clinical laboratory**—That lab doing routine tests used by the physicians responsible for direct patient care (It includes blood counts, blood chemistry, urinalysis, and bacteriological examinations of sputum, etc. This lab is in contrast to a research lab used for special studies.)

---

Q32

A report of an x-ray taken to aid in the diagnosis of a patient would most likely be prepared by the:

(✓)

☑ a. Department of nuclear medicine.

☑ b. Radiology department.

☑ c. Neither.
Answer: Q32

b. Radiology department.

d. Pathology department would generate the following reports: (Check YES or NO.)

- Operative
- Cytology
- Diagnostic X-ray
- Hematology
- Histology
- Isotope scan
- Autopsy

YES ☐ NO ☐
YES

b, d, e, g—Cytology, hematology, histology, and autopsy.

NO

a, c, f—The radiology and nuclear medicine departments would keep their own records (X-ray reports and films). The operative report would be dictated by the surgeon and is always a part of the medical record. Logs are kept in many departments which aid in case finding as will be discussed later.

034

Tissue removed during surgery is sent to the (a) ____________ department where it is given a careful (b) ______________ examination.
a. Pathology department (actually, histology lab);

b. Microscopic or histological examination. This is the most definitive way of diagnosing a malignant neoplasm. Prior to the microscopic examination, the pathologist will make a careful gross (non-microscopic) examination which is also described on the pathology report.

neoplasm—A new growth

A hospital Committee on Cancer oversees the cancer program of a hospital. A tumor conference or tumor board provides a means for group discussion of a difficult case of cancer.

a. Where would the registrar learn the most about new cancer treatment techniques?

(✓)

(1) Cancer committee meetings.
(2) Tumor conferences.

b. Where would the tumor registry director discuss a problem associated with the operation of the registry?

(✓)

(1) Cancer committee meetings.
(2) Tumor conferences.
a-(2)--Tumor conferences. Here members of the staff especially interested in cancer often discuss new treatment techniques.

b-(1)--Cancer Committee meetings. This group can handle administrative problems associated with registry operation.
RELATIONSHIP BETWEEN
A TUMOR REGISTRY AND OUTSIDE-THE-HOSPITAL MEDICAL ORGANIZATIONS
THE RELATIONSHIP BETWEEN A TUMOR REGISTRY AND OUTSIDE ORGANIZATIONS

There are many ways in which a tumor registry may provide information to or receive information from agencies outside the hospital. These relationships will be determined, at least in part, by the staff of the hospital. The registry director will provide the tumor registrar with detailed guidance regarding the types of information that can be sent to agencies and persons outside the hospital.

There are two basic types of data which may be requested:

a) Individual patient information and b) Grouped data.

Central Tumor Registries

A tumor registry may be part of a community, regional, or state registry system. Such systems are valuable in that they pool or combine information on the occurrence of cancer. They also permit the study of trends in therapy and survival and the comparisons between regions. By establishing a registry system, it is possible to devise work-sharing techniques. For example, the abstracting of records may be done at the local registry and the preparing of reports done at the community, regional, or state level.
Outside Agencies

There are various government and private agencies that are interested in tumor registries.

1. The National Cancer Institute of the National Institutes of Health has established a program called the "Surveillance, Epidemiology and End Results Reporting" program. The SEER program provides information on trends in the incidence of the various forms of cancer in the United States, variation in the occurrence of cancer among different population groups and in different geographic areas, and changes in diagnostic and treatment practices and the associated "end results" among typical cancer patients. Data are obtained from a selected number of population-based cancer registries that provide uniform information on a continuing basis and participate in ad hoc studies designed to identify and assess etiologic and prognostic factors.

2. The American College of Surgeons is concerned with all aspects of cancer control. Through its Commission on Cancer it actively promotes the establishment of hospital-based programs for improved quality of care for patients with cancer. As of 1956, a cancer registry became a mandatory requirement for approval of a hospital cancer program. The Commission on Cancer surveys registries which are functioning components of institution-wide cancer programs. Its Cancer Registry Manual presents in detail a basic guide for hospital personnel in the implementation and subsequent operation of a hospital-based cancer registry. The address of the American College of Surgeons is 55 E. Erie St., Chicago, IL 60611.

ad hoc--For the particular end or case at hand without consideration of wider application
3. The American Cancer Society, Inc., is a national voluntary organization dedicated to cancer research and both public and professional education and service. It is composed of 57 divisions in all 50 states plus six metropolitan areas and the District of Columbia. There are over 3,000 units organized to cover the counties in the United States. Below each unit are thousands of branches that have become permanent organizations for reaching people at the grass-roots level with ACS program activities. Through its state and local organization, the ACS has given active support to tumor registries. Consult your telephone directory for the address of the nearest ACS local office.

4. The National Tumor Registrars Association is an organization dedicated to the education and professionalization of tumor registrars. Thus, the need to up-grade and standardize the quality of cancer statistical data may be realized. To ensure the qualifications of registry personnel, the NTRA plans to certify those registrars who qualify by experience, education, and appropriate written tests with the title "Certified Tumor Registrar." Membership and certification by the NTRA is voluntary.
APPENDIX

GLOSSARY OF TERMS
GLOSSARY OF TERMS

abstract--A summary, an abridgment (the word "abstract" may be either a noun or a verb)

ad hoc--For the particular end or case at hand without consideration of wider application

autopsy--The postmortem examination of a body

benign--Not malignant; not recurrent; favorable for recovery

biostatistical--Biostatistical data include any type of numerical information about living organisms

cancer--A malignant tumor

chemotherapeutic--Of or pertaining to the treatment of disease with chemicals

clinical laboratory--That lab doing routine tests used by the physicians responsible for direct patient care. It includes blood counts, blood chemistry, urinalysis, and bacteriological examinations of sputum, etc. This lab is in contrast to a research lab used for special studies

code--Numerical values for data

cytology--The microscopic examination of cells obtained by aspirations, washings, scrapings, and smears (such as Pap smear)
demography--The study of mankind collectively; especially of geographic distribution and physical environment
diagnosis--The determination of the nature of a disease

dend results--"End results" refers to the evaluation of cancer therapy in terms of patient survival after treatment

epidemiology--The study of the occurrence and distribution of disease

extent of disease--Detailed description of how far the disease has spread from the primary site of a cancer

hematology--The science of blood, its nature, functions, and diseases

histology--The microscopic examination of tissue obtained by biopsy (excision of a tissue sample), surgery, or autopsy

inpatient--A patient who occupies a bed in the hospital

malignant--Malicious, virulent
malignant tumor—An uncontrolled, invasive growth capable of metastasizing (spreading to a distant part of the body), opposite of benign

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, and indexing them for future reference

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

natural history of disease—the course of a disease if not interrupted by treatment

necropsy—A postmortem examination; autopsy

neoplasm—A new growth

nomenclature—A system of names

nuclear medicine—The use of radioactive isotopes in the diagnosis and treatment of cancer

oncology—the sum of knowledge concerning tumors; the study of tumors

outpatient—A hospital patient who does not occupy a bed

pathology—The scientific study of the nature of disease, its causes, processes, development, and consequences, more specifically, the microscopic examination of tissue

physiology—The science that treats of the functions of living organisms and of their parts

primary site—The organ or tissue of the body where a cancer originates

radiology—The science dealing with x-rays or emissions from radioactive substances

stage of disease—Grouping cases with similar prognosis into broad extent of disease categories, e.g., localized, regional, and distant spread

tumor—Classically means a swelling or mass; in current usage means a new growth of tissue or cells

tumor conference—a meeting of physicians trained in various disciplines who review the diagnosis of and propose therapy for a patient with some type of tumor
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