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The HOSPITAL CANCER REGISTRY

Definition, Purpose, Value, Operation, and Cost

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B. Aubrey Schneider, Sc.D.*
(1912-1960)

The effectiveness of cancer control is best measured by the end results (survival rates) attained. However, such results can be brought to light only through careful compilation of adequate clinical records covering the diagnosis, treatment and follow-up of patients with the disease....

... The cancer registry program throughout the United States is becoming an increasingly effective force in stimulating progress in cancer control; and ... its impact is greatest in the place where it is needed most; namely, in the small general hospital.

—B. Aubrey Schneider, Sc.D.: *Progress in Cancer Control through Cancer Registries.* Ca 8: 207-210, 1958

*Dr. Schneider was Assistant Director of the Statistical Research Section of the American Cancer Society from September 1946 until his death on September 22, 1960. He was a pioneer in the development of the cancer registry concept in this country and made many contributions in registry record-keeping procedures. Much of the material in this publication was developed as a result of his effort and experience.—ED

The Tumor Registry—A Definition

John S. Spratt, Jr., M.D., F.A.C.S.

A tumor registry is a collection of diagnostic, therapeutic and survival data on patients with neoplastic diseases. It is supplementary to the usual diagnostic files of a hospital and is necessary because of the chronicity and complex ramifications of cancer as a disease. The end product of good cancer therapy is added years of life, lived comfortably and productively. Because the history of a cancer, both before and after treatment, may spread over many years, it is necessary that the cancer patient be kept under physician surveillance for a longer period of time than with other diseases. The tumor registry is an aid to see that this is done. The accumulation of biostatistical data from a tumor registry can serve a variety of useful purposes and these are summarized in Table 1.

Quality Control

The first purpose of a registry listed in Table 1 is *quality control* in the diagnosis and treatment of cancer. The first component of quality control relates to the sites and stages of cancers when first seen. The consistent discovery and treatment of cancer in advanced stages may well imply that the patient-population under consideration either does not have access to, or is not utilizing the existing cancer diagnostic facilities for earlier diagnosis.

Registries are used most extensively in studying the efficacy of treatment. The first consideration is the treatment rate or the percentage of patients receiving definitive therapy of different types. The treatment rate is an index of the temerity or aggressiveness of cancer therapy within a particular institution and must always be considered in conjunction with the treatment mortality rates. Optimally, the treatment rate should be as high as possible, commensurate with a low treatment mortality rate. A low treatment rate and a high treatment mortality rate would indicate extremely poor and inexperienced cancer therapy. Between these two extremes exists a broad spectrum of practices that varies widely with the philosophy, training and experience of various hospital staffs. The optimum rates are the ones associated with the best end results for *all* cancer patients and not just the "treated" or "determinant" cases.

Another economically important consideration in the assessment of the quality of treatment is, of course, morbidity, as expressed by the total period of time a patient is incapacitated by treatment. For example, are two months of hospitalization required due to delay in recovery or rehabilitation, when two weeks should be adequate?

The last, and most widely used, quality control in the treatment of cancer is the end results. Conventionally, the five-year survival rate has been the index for comparison. Some cancers, *but not all,* have shown their lethality by the end of the fifth post-treatment year. The wider usage of the life table

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Table 1

PURPOSE OF A TUMOR REGISTRY

1. Quality Control in Diagnosis and Treatment

Report on sites and stages.
Treatment:
1. Rates
2. Mortality
3. Morbidity

End results.

2. Follow-Up

Detection of treatable disease:
1. Local recurrences
2. Regional metastases
3. Isolated remote metastases
4. New neoplasms

Palliation of untreatable cancers.
Accumulation of time-mortality data for the assay of end results.

3. Education

Feedback of quality control data to hospital staff with comparisons to other institutions.
Resident and undergraduate student training in natural history and treatment of cancer.

4. Research

Case location
Clinical-pathological-mortality correlations
Epidemiology
Other

method for calculating cumulative survival rates insures a more complete use of the available data.

There are a number of statistical methods for ascertaining whether significant differences in end results associated with various forms of treatment, sites and stages exist. The end results should also be compared in different periods of time to ascertain whether there is continued improvement or regression in the quality and effectiveness of treatment. When the end results from two different populations are compared, subtle variations in population characteristics require careful statistical scrutiny to eliminate the elements of bias that would exclude comparableness. Sometimes, these subtle differences can be studied only by carefully planned and randomized prospective studies which insure the similarity of the populations receiving alternate therapies. A good and permanent registry is essential to the completion of such studies.

Follow-up

The second major purpose of a tumor registry is to insure that systematic follow-up is carried out. Follow-up is an expensive and time consuming undertaking, both for the patient and the physician. Consequently, it has to be looked at objectively to make certain that the patient derives the maximum possible benefits from his participation, and that the physician's time is not consumed by unnecessary patient visits. Consequently, the follow-up schedule must conform to the natural history of each type of neoplasm. In this way, there is early detection of local recurrence, regional metastases, isolated remote metastases, and non-simultaneous additional primary cancers which may be treated effectively. Through the follow-up, the physician should also become aware when the uncured patient gets into difficulty from the progression of his cancer and will require some of the various forms of humane palliation available. The follow-up system is essential to the continued accumulation of time-mortality data for the assay of end results.

Education

Feedback to a hospital staff of information derived from a registry insures the continuing education of the hospital staff in the diagnosis of cancer; in the appreciation of cancer as a major medical problem, and in the quality of care within their institution. In resident medical education, the registry can be an important tool for teaching the significance of a chronic disease as a biological continuum, spreading over many years of life. There is a tendency in our general hospitals, predominantly oriented toward acute care, to fail to create an educational environment whereby the student and resident become aware of the chronicity of some

human diseases. Residents in surgery and radiotherapy, in particular, are sometimes so preoccupied with the immediacy of an operative procedure or therapeutic plan that they fail to look into the past history of the patients, to find out why the patient was so long in coming for treatment, or into the future of the disease process. The trainee should realize that the uncured patient may spend several years dying from a painful and debilitating disease which may exhaust his financial resources, and ostracize him from both friend and family—finally, he dies a rather lonely death. The trainee should also appreciate that the cured patient may develop late complications as a by-product of primary treatment.

Research

Lastly, the registry is a working index of biostatistical data, continually available for clinical research by the medical staff. The registry facilitates the location of cases, the determination of clinical pathological and mortality correlations, and if sufficiently complete, can be used for epidemiological studies. The other clinical research uses of the registry are limited only by the range of imagination and insight of an individual investigator.

The elements necessary for the operation of an efficient tumor registry are listed in Table 2. First, the nomenclature and staging have to be simple, and the entire body of data recorded in the registry should have a numerical coding system adaptable to automatic data processing. Only when this is done is it easy to calculate the reports necessary for quality control and to feed them back to the hospital staff. Such a system also facilitates information-recall for various other purposes which the staff may require. Both the patient and the physician have to understand the need for the registry and be willing to cooperate in its function. Every patient with a neoplastic disease needs to be indoctrinated in the chronicity of his problem and the importance of maintaining contact with his physician and, through his physician, with the tumor registry. Also, the complete cooperation of the State Bureau of Vital Statistics is essential for the accumulation of accurate mortality data.

Table 2

ELEMENTS NECESSARY FOR EFFICIENT OPERATION OF A TUMOR REGISTRY

1. Simplicity in nomenclature with numerical coding of all basic data.
2. A plan for insuring that numerical coding makes data adaptable to:
   - The easy calculation of the reports necessary for quality control.
   - Information recall.
3. Indoctrination of patient and physician to cooperative participation.
4. Systematic follow-up:
   - Numerous systems assuring periodic contact.
   - Schedule for contacts should conform to natural histories of different cancers.
5. Cooperation of State Bureau of Vital Statistics.

Summary

A tumor registry is a working index of cancer cases used to study the natural history of neoplastic diseases in man. The data from a registry are used to prove that cancer is prevented, cured or palliated by various therapeutic practices. The registry, to have valid time-mortality data, and to insure that the cancer patient is re-examined at proper intervals, must have a link to the patient through a clinic system or through the offices of physicians. Many registries, for want of a purpose, become static repositories of unused data. The function of registries should be scrutinized to determine if the effort involved in maintaining the registry leads to better understanding of cancer as a disease, and to better care and treatment of cancer patients in the hospital undertaking the operation of a registry.

The Purpose and Value of a Hospital Cancer Registry

Abraham Ringel, M.A.

Purpose

There is a considerable variation in the quality of cancer care in the United States today. The Cancer Registry Program of the American College of Surgeons, and the support that is given to it by the American Cancer Society, reflect an attempt to raise it to its highest possible level. Both organizations believe that one of the basic elements of sound cancer control is an effective mechanism for measuring the quality of cancer diagnosis and treatment in an institution, i.e., a Hospital Cancer Registry, as described in the College's *Manual for Cancer Programs.* In furthering a Cancer Registry Program, it is important to recognize the purposes and problems connected with it, and to differentiate the points of view that obscure its primary objective.

In general, there are three types of cancer registries in the United States. The first type may be described as Special Purpose Registries. These are limited in scope and are focused on one form or aspect of cancer: bone tumor registries, oral registries, pediatric tumor registries, tissue and slide registries, are examples. They serve a very useful purpose, but their primary function is education and reference.

The second type of registry, the Epidemiological Registry, obtains information about the prevalence and incidence of various sites and types of cancer, as well as other research information which can only be obtained from a large volume of data. There is no need for a great number of such registries—a selected number, strategically located in the United States where the volume of cancer is significantly large, is adequate for most purposes. Furthermore, the cost of operating and maintaining an Epidemiological Registry, assuming qualified personnel are available, is usually more than most hospitals and communities can afford.

The foregoing types of registries are either limited in nature or have special purposes extraneous to the primary objective of the American College of Surgeon's Hospital Cancer Registry Program. The College recommends the third type of registry—the Hospital Evaluatory Cancer Registry, and the American Cancer Society participates in the support of this program. This type of registry measures the quantity and quality of medical care provided for cancer patients at a given institution. It has been described as the "mirror" which can reflect to the hospital staff how well it is diagnosing and treating cancer in its hospital. As such, a Cancer Registry is a medical program which must be developed in response to physician interest and function under medical supervision and guidance. Its

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results should be used by the hospital medical staff in evaluating procedures and in promoting possible improvements. A registry, conceived and organized without physicians' interest, guidance and control, will result in a useless expenditure of time and money. On the other hand, a program established under proper auspices, with physician interest and participation, will be an effective tool for measuring the progress of cancer control in the hospital, and will provide a major stimulus to that control.

The American College of Surgeons has indicated that the minimum content of a Hospital Evaluatory Cancer Registry is: (1) the name and address of every hospital patient, private and public, inpatient or outpatient, who enters the hospital for diagnosis and/or treatment of cancer; (2) adequate identifying and diagnostic information; (3) a basic abstract of the clinical record; and (4) an annual follow-up note for as long as the patient remains alive. From this base, the content can be elaborated as far as those conducting the registry desire. For such a registry to be effective, 100 per cent of the hospital's cancer experience, including cases diagnosed without histopathological proof, must be recorded.

Information obtained from a registry of this kind is primarily for the consideration of the professional staff of a hospital. Data show how the staff is doing in the diagnosis and treatment of cancer and are not for pure statistical compilation. For this reason, minimum standards of statistical accuracy and clarity must be maintained. When fully evaluated by a responsible medical staff, this information can form a basis of support for whatever action might be necessary to improve the end results in a given procedure.

In order to encourage the evaluation of the data in the individual hospital registries, the American College of Surgeons has made it a requirement for approval that an annual Report of Survival and End Results be presented to the medical staff. The medical staff may then compare its statistics with published data of the National Cancer Institute, and with such publications as the Cancer Prognosis Manual of Dr. Arthur G. James of the Ohio State University Medical Center, and at local and state medical society meetings.

Value

The value of a hospital cancer registry varies in direct proportion to its proper organization and use.

In initiating and promoting the individual hospital cancer registry program, the American College of Surgeons recognized this fact and has outlined both the necessary organizational structure and the informational reports that could be derived from a properly organized and active registry. Thus, in listing its "Minimum Standards for Approval of Cancer Programs" in general hospitals, the College notes two pre-conditions that must be met before a hospital cancer registry can function properly and meet its requirements for approval:

1. "Hospitals must be accredited by the Joint Commission on Accreditation of Hospitals . . . .
2. "There shall be a committee on cancer of the medical staff, consisting of physicians directly concerned with the conduct of the cancer program."

In amplification of the second precondition, the College states that "this committee should be a standing committee of the professional staff. Members named by the medical staff should be confirmed by the governing board of the hospital, and should include representatives from the departments of surgery, internal medicine, radiology, and pathology. In some hospitals it may also serve as the tumor board."

An individual hospital cancer registry is worthless without the approval and involvement of the medical staff. This becomes apparent when we examine the structure of a registry, the type and sources of the information to be collected, and the uses that can be made of this information. A hospital cancer registry is "the repository of records containing pertinent information on diagnosis, treatment, follow-up, and end results of all patients, private and nonprivate, with a diagnosis of cancer who have been admitted as inpatients or to the outpatient department of the hospital." The summarization of this information for the registry can only be obtained from the completed hospital medical chart, together with supplementary information from the departments of radiology and pathology, and follow-up information from attending physicians.

The College also notes that "if this registry is to achieve its purposes, its staff is required to record data on every patient admitted with the diagnosis of cancer. The data properly recorded in the registry should make possible a systematic follow-up of patients for an annual report to the medical staff, including an analysis of survival and end results, as well as for special studies. Such a report is essential to the assessment of the care received by patients with cancer."

The components of an annual report to the medical staff may consist of the following information:

1. The total number of cancer cases seen in the hospital during the year.
2. The number of patients presenting primary lesions versus those showing recurrences.
3. The proportion of the total case load for whom the original diagnosis was made at the institution as compared with those first diagnosed elsewhere.
4. The level of diagnosis (i.e., the proportion of microscopically confirmed cases at the institution as compared with other institutions).
5. Indication of improvement (or lack of same) in the level of diagnosis over the years.
6. The proportion of cases in which the disease is localized or advanced at the time of diagnosis, and whether this situation is changing with time.
7. The proportion of cases receiving definitive versus palliative therapy.
8. The results of diagnosis and therapy in terms of survival rates.

The information that can be made available to the medical staff in the hospital can be derived only if the records are carefully kept and follow-up scrupulously maintained, and the accumulated data properly and adequately analyzed. Obviously, this information can be of great value to the physicians, and to local community agencies. It provides the former with a measure of the quantity and quality of medical care given cancer patients, and to the latter, it furnishes a guide for their public and professional education programs, and other cancer control activities. In addition, this information can be a stimulus for intensive research of specific diagnostic procedures and therapeutic programs. One immediate effect of the registry is that of greatly improving the keeping of hospital records as they relate to cancer, because of greater interest among the attending physicians, residents, and interns, and the necessity for providing basic information for the most effective analysis of registry information.

Without the interest and guidance of the medical staff, the registrar will have difficulties and unresolved problems. One may encounter such things as "possible cancer" in the sign-out diagnoses, and there will have to be some "ground rules" for handling such

cases. How is the registrar going to resolve any difficulties or inadequacies that may be found with respect to the hospital charts or record-keeping procedures if there is no committee on a par with the record committee with which to discuss such problems? How is the registrar going to fit the physical setup and the work of the registry smoothly into existing hospital facilities and procedures with a minimum of disruption without someone in authority working out agreements on the necessary arrangements? How is one to establish or maintain a successful follow-up program if there is no general agreement as to participation and cooperation among the staff? Who will bring such matters as follow-up to the attention of the staff for discussion and agreement if there is no committee or chairman to carry out such responsibilities? What sort of information would the registrar dig out of the registry for a report to the staff if there is no guidance from a responsible chairman or committee? And, even if the registrar were able to prepare such a report, who would present it to the staff?

It is for these and similar reasons that the College lists the following duties of the Committee on Cancer:

1. "To furnish leadership in the cancer control activities of the hospital, including the appointment of a director of the cancer clinical program.
2. "To confer with the administrator relative to equipment, space, facilities, and other administrative matters.
3. "To oversee the operation of the cancer registry, with particular attention directed to the follow-up program, to the development of special studies, and to survival and end results reports.
4. "To advise and assist in the solution of problems involving relationships between the cancer program and the medical staff, or the administrative departments of the hospital.
5. "To maintain liaison with:
   (a) "Other committees of the staff, especially the tissue committee.
   (b) "Cancer control activities of the community, such as state and local elements of the American Cancer Society and local and state departments of health.
   (c) "The Department of Professional Services of the American College of Surgeons and the Committee on Cancer of the College.
6. "To prepare the rules and regulations needed for the operations of the program and for incorporation into the bylaws of the staff; and to maintain adequate minutes of their committee meetings."

It cannot be emphasized sufficiently that the key for the successful organization and operation of an individual hospital cancer registry is the active interest, cooperation, and participation of the medical staff. Such participation can truly make the cancer registry a "mirror" which reflects to the staff what is good and what is bad with respect to the diagnosis and treatment of cancer in the institution. A registry without such physician interest, guidance, and control is a useless expenditure of time and money.

References

1. American College of Surgeons: Manual for Cancer Programs. Chicago, 1961.

2. James, Arthur G.: Cancer Prognosis Manual. New York: American Cancer Society, Inc., 1961.

Bibliography

Haenszel, W., and Hon. N. B.: Statistical approaches to the study of cancer with particular reference to case registers. J. Chron. Dis. 4: 589-599, 1956.

Schneider, A.: The key to an effective hospital cancer registry program. CA Bull. Cancer Prog. 10: 173-174, 1960.

Schneider, A.: Progress in cancer control through cancer registries. Ca Bull. Cancer Prog. 8: 207-210, 1958.

U.S. Dept. of Health, Education, and Welfare: Your Hospital Cancer Registry. Washington: U.S. Govt. Print. Off., 1961.

The Operation of a Hospital Cancer Registry

Abraham Ringel, M.A.

Introduction

A hospital cancer registry should contain the records of all patients with cancer diagnosed by any means, including those without microscopic confirmation. Patients diagnosed as having "possible" or "probable" cancer, and treated *as if* they have cancer (e.g., those diagnosed by clinical means only) should be included in the registry for evaluation and comparison with patients diagnosed more definitively. On the other hand, patients diagnosed before the start of the registry should not be included, unless all patients diagnosed in these years are also included for valid comparisons between the years.

The registry is the active file of pertinent information on the diagnosis, treatment, follow-up and end results of all cancer patients. What are the sources of this information? What kinds of files and records are to be kept? What information on the diagnosis, treatment, follow-up and end results are to be collected? Finally, how may the information be summarized for presentation to the hospital medical staff?

Sources of Information

The completed hospital medical charts comprise the primary source of information for a hospital cancer registry. In some hospitals, the medical records librarian routinely sends the hospital charts of all discharged cancer patients to the registry secretary before they are filed. Elsewhere, the registry secretary receives carbon copies of the discharge sheets of cancer patients, or a list of their medical chart numbers, which enables her to obtain the medical charts.

A notation or anonymous stamp, such as a star, is often affixed to the outside cover of the medical chart to alert the medical records librarian to the chart of a cancer patient who returns as either an inpatient or an outpatient. To ensure complete coverage, lists and/or reports of diagnoses made in the pathology laboratory and in the radiology department should be made available to the registry secretary. In hospitals where outpatient charts are kept apart from the inpatient charts, the daily roster of visits should be available to the secretary. This insures the registration of new patients, and the recording of follow-up information on patients previously registered.

Registry Files and the Accession Register

The registry consists of: (1) a Site File, containing clinical abstracts of all registered cancer patients, with follow-up notes for the lifetime of the patients; (2) a Patient Index File; and (3) a Follow-up Control File. Many hospitals employ a "three-in-one" file of abstracts in strict alphabetical order (the Master Patient Index File), employing tabs to classify them by site and time of follow-up. The registry should also have an Accession Register, which is a list of the cancer patients initially admitted as inpatients or outpatients to the hospital. This is a very useful tool in the preparation of administrative and analytical reports.

The Cancer Registry Abstract

The file of cancer registry abstracts is the most important element in all

cancer registry programs. These documents enable the medical staff to evaluate the over-all cancer problem in the institution. It is a concise summary of significant facts from hospital medical charts on the history, diagnosis, and treatment of every patient's cancer. It should not be a duplicate of details concerning symptoms, diagnostic techniques and particulars of therapeutic procedures.

The abstract contains the minimum information necessary for a registry.[1,2] Additional information may be included at the discretion of the Committee on Cancer and the medical staff. If the medical chart is complete and the Committee on Cancer provides the necessary guidance for the interpretation of the medical information, a competent secretary can be trained in a few weeks to do the abstracting.

A separate cancer registry abstract form is prepared for *each* primary anatomic site of cancer. (See pages 16 and 17.) Thus, a patient with two or more primary cancer sites should have separate abstracts for each primary cancer. The only general exception to this rule is cancer of the skin.

On June 16, 1964, the Executive Committee of the American College of Surgeons Committee on Cancer ruled "that elimination of basal cell and squamous cell carcinomas of the skin from the registry does not impair the standing of the registry in the approval program of this College. Whether to include these cases may be left to the judgment of the administration and the staff of the individual institution." On the other hand, most hospitals which register skin cancers, prepare separate abstract forms for *each type of cancer, without regard to sites,* i.e., one for all basal cell, and another for all epidermoid carcinomas. Thus, an early and important decision to be made by the hospital's Committee on Cancer is whether or not to register cancers of the skin to best serve the needs of the medical staff.

How To Prepare the Cancer Registry Abstract

As noted above, the primary source of information for the registry is the completed hospital medical chart. From this, the abstract form should be filled out as follows:

Name: Enter the family name first, followed by the first and second given names. When the patient is a married female, it is desirable to enter her given name rather than her husband's name for more precise identification, i.e., "(Mrs.) Jones, Mary," rather than "(Mrs.) Jones, Walter."

Name of Spouse: Enter the name and address of the spouse, or close family or other *contact* if the patient is unmarried or is separated from the spouse.

Date of Admission: Enter the date of *first admission* (inpatient or outpatient) to the registering hospital for the cancer for which the abstract is being prepared.

Date of Discharge: Enter the date of discharge from the registering hospital after the first admission.

Age or Birth Date: Enter the age at admission to the registering hospital or the date of birth. In most instances, the age of the patient at admission to the hospital and the age of the patient at *initial diagnosis* of the cancer, will be the same. However, when the age at initial diagnosis differs from the age at admission, it should be noted (in red ink or circled) to remind the secretary to use the more significant *age at initial diagnosis* in tabulations and analyses by age. This distinction should be understood by everyone using the registry data. (See page 11 for the definition of the date of initial diagnosis.)

Race: Record whether the patient is White, Negro or Other, using the definitions of the United States Census Bureau. The White race includes Puer-

to Ricans, other West Indians, Mexicans, and Central and South Americans; and "Other" includes all "American Indians" and those identified as "Asiatics," such as East Indians, Chinese, Japanese, Korean, and so forth. Persons of mixed parentage are classified according to the race of the nonwhite parent; and mixtures of nonwhites are generally classified according to the race of the father. In areas where there is special interest in selected population groups, such as Latin Americans or Asiatics, appropriate entries may be made.

Marital Status: Indicate whether the patient is Single, Married, Widowed, Divorced or Separated.

Hospital Status: Check the appropriate boxes for Private or Nonprivate, Inpatient or Outpatient for the patient's hospital status at initial admission.

Registry No.: There are two common and acceptable methods of numbering *patients* in the registry. One method is to number each new patient with the next consecutive number indefinitely, beginning with the number 1; another is to start each new calendar year of registration with number 1 and precede this with the last two digits of the *year of accession:* for example, 63-1 to 63-260, 64-1 to 64-275, and so forth. The only advantage of this latter method is that the number of cancer cases *accessioned* in the year is more readily apparent. However, it must be remembered that all of these cases were *not* necessarily *diagnosed* during that same year. It must be emphasized that *a cancer patient is identified by only one assigned registry number* no matter how many primary cancers he may have.

Hospital and Hospital No.: In the spaces provided, enter the name of the hospital and the hospital medical chart number for this patient at the time of initial admission to the hospital.

Final Diagnosis: Enter only the *primary anatomic site* of origin of the cancer. Metastatic sites need not be recorded. When the primary site of origin of the malignancy is unknown, it should be recorded as "Primary Unknown," even though the metastatic site is known. In case of doubt, the registry secretary should consult with the Cancer Committee.

Basis of Diagnosis: Indicate the *one or more methods* used to make the diagnosis of cancer. Thus, if the cancer was initially diagnosed by clinical means and subsequently verified microscopically, both methods should be noted. The term "Histology" includes microscopic diagnoses based on specimen from biopsy, frozen section, surgery, or D. & C.; also included, are positive hematological findings relative to leukemia, bone marrow specimen, and diagnoses based upon paraffin block specimens from concentrated spinal, pleural, or peritoneal fluid. Diagnoses based on *"X-ray"* findings are self-evident. The term *"Clinical"* refers to cases diagnosed by exploratory surgery without microscopic examination, by endoscopy without positive histology, and by other clinical methods, such as palpation. *"Other"* bases of diagnosis should be specified.

Exfoliative Cytology: Note the type and whether the findings are negative or positive. Exfoliative cytology is defined as diagnoses based on microscopic examination of cells as contrasted with tissue. Included in this definition are smears from sputum, bronchial washings, prostatic secretions, breast secretions, gastric, spinal, peritoneal, or pleural fluid, and urinary sediment, and, of course, cervical and vaginal smears.

Histological Diagnosis: The diagnosis of cancer is noted essentially in terms of anatomical site and histological type. Although some doctors routinely use histological terms in phras-

ing the diagnosis, even in the absence of microscopic evidence, this section of the abstract form should contain *only* the *summary statement on the Pathology Report,* and be left blank in the absence of such a report.

Date of Diagnosis: This refers to the date of the *very first* diagnosis of *this* cancer by *any* recognized medical practitioner, even when the diagnosis was *not* proven microscopically, or was confirmed much later by histology. In other words, the date of the *very first diagnosis* should be entered here *regardless of the method of diagnosis or where it was made.* The question is often asked how a secretary can determine whether a patient was diagnosed as having cancer in the absence of microscopic confirmation. It is the contention of many physicians, however, that a *clinical* diagnosis of cancer has been made if the patient is being *treated as if he had cancer.* If subsequent histology disproves the clinical diagnosis, the case is to be removed from the registry.

Stage of Disease: One of the major reasons for obtaining information concerning stage of the disease is that it is often the most important factor influencing the doctor's choice of therapy. Thus, it would be most logical to obtain the doctor's appraisal of the extent of the disease before treatment is begun. Such information is usually not stated explicitly and would require abstracting of records by a physician. However, it is feasible to collect information concerning the stage of the disease at initiation of first treatment as appraised at a later time. Normally, the patient's medical record, when completed after the first discharge, contains statements and laboratory reports from which the stage of the disease at initiation of treatment can be derived. The stage of the disease as reported on the abstract form would, therefore, be an evaluation of the stage of the disease at initiation of the first cancer-directed therapy as appraised at the end of the first course of treatment, or after the first hospital discharge. If the patient is untreated, an evaluation of the stage of the disease at diagnosis should be recorded. The stage of the disease to be recorded is not defined as clinical staging; it is, rather, an estimate of the stage of the disease based on *all* of the evidence available at the time of the first therapy, including, in addition to the strictly clinical impression, any evidence derived from X-ray, surgery, pathology, and so forth. It could be thought of as a "corrected" clinical impression.[3] If the stage of the disease is not explicitly stated in the medical chart, the cancer registry secretary should consult her Cancer Committee. The following brief definitions may be useful guides for staging malignancies:

1. *Localized* is the designation of a cancer that is *confined to the site of origin,* regardless of tumor size.
2. *Regional Involvement* denotes a cancer which has passed the bounds of the site of origin, but whose further spread is thought to be *limited to neighboring organs or tissues,* or to regional lymph nodes.
3. *Remote Metastases* is defined as *involvement* of organs or tissues *beyond those immediately draining or neighboring* the site of origin of the malignancy.[4]

History: Enter the date of the initial diagnosis, and the date and type of treatment in this section of the abstract if the case has been diagnosed and/or treated prior to admission to the registering hospital. For these cases it must be remembered that the date of *initial* diagnosis is the *date of the prior diagnosis* and *not* the date of diagnosis at this hospital. (See preceding column, paragraph 2.) This information is generally available from the history statement in the medical chart.

Treatment: This section of the can-

cer registry abstract form should contain information on therapeutic procedures that were provided *only* during the *very first* hospital admission of this patient for *this cancer* only. Treatment that was provided during *subsequent* hospital admissions to the registering hospital, as well as in other hospitals, should be noted on the back under "follow-up information." However, when the *initial* plan of treatment extends beyond the date of discharge from the hospital, such as radiation therapy, this should also be included in this section of the abstract.

The End Results Program of the National Cancer Institute defines treatment as "any and all procedures or therapies, administered during or after the first clinical diagnosis of cancer, which usually *modify, control, remove, or destroy proliferating cancer tissue,* whether primary or metastatic—regardless of response in a particular patient. Treatment does *not* include *procedures or therapies which are purely diagnostic, symptomatic, or supportive.* Any therapy which is not considered cancer-directed or which does not fall within the definition above is to be classified as 'no treatment'."[3] (See pages 18 and 19 for the more common therapies and procedures.) Thus, it is suggested that only cancer-directed therapy (as defined above) should be checked in the boxes provided. The registry secretary should be encouraged to consult with the Cancer Committee concerning the therapies and procedures to be *recorded* on the abstract. However, it must be re-emphasized that the registry abstract should not be a duplicate of the *clinical details* in the medical chart.

Purpose: Indicate the one or more objectives of the therapy and procedures provided the patient.

Condition and Follow-up: The completion of the final section on the front of the cancer registry abstract form is self-evident. Information concerning the cancer status of the patient at discharge, whether alive or dead, and if dead, the date of death and cause of death should be noted. If the cancer status of the patient cannot be determined from the medical chart, the registry secretary should consult with the Cancer Committee or record it as "Unknown." Finally, information concerning the hospital or physician responsible for follow-up should be noted.

Follow-up Information: This should be summarized on the back of the cancer registry abstract form. It is suggested that the first line be completed at the time the front of the cancer registry abstract form is first completed in order to note the survival time. Thus, the "date" to be entered would be the date of discharge of the patient from the hospital. "Survival time in months" is to be computed from the *date of diagnosis* to the date of discharge. "Source of contact" would be the hospital chart in this instance, and the condition of the patient would be the same as that noted on the front of the abstract form. Thereafter, summary follow-up information relating to this cancer, based on visits to the outpatient department, admissions to the hospital, letters to the referring physician, or other sources, should be noted. In general, it is *not* necessary to post follow-up information at intervals of less than six months to a year, *unless there is significant information* about the patient's cancer. If the patient has undergone a long-range plan of therapy, it is recommended that the beginning date and the ending date of such therapy be entered, that the survival time be computed through the date when last seen, and a summary statement of the treatment be noted. The abstract is *not* to be used as a running summary or clinical record of what has been done for the patient at each visit.

Finally, information concerning the

cause of death, and whether or not an autopsy was performed, should be entered at the bottom of the form. Obviously, the last date of follow-up is the date of death, and the final survival time should be computed from the date of diagnosis to the date of death.

Filing Cancer Registry Abstracts

The abstracts of all patients, living and dead, are usually filed by anatomic site of cancer in alphabetical order, thus automatically creating a useful anatomic index. When the number of registered cases warrant it, two such files may be set up—one for the active cases, and one for the dead cases. The abstracts may be filed according to the major site groupings of the *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death.* (See page 20.) As noted above, registries employing the "three-in-one" file employ tabs to classify the abstracts by anatomic sites.

The Patient Index File

The Patient Index File is a permanent alphabetical index file, and may consist of individual 3″ x 5″ cards for every registered cancer patient, living and dead. (See page 21, top.) It is the master control file and enables the secretary to avoid duplicate accessions in the registry. It should contain such identifying information as:

a. the patient's full name and address
b. the hospital medical chart number
c. the patient's assigned cancer registry number
d. the patient's date of birth, sex, and race
e. the cancer diagnosis (primary site)
f. the date of initial diagnosis
g. the name and address of the referring physician
h. the (eventual) cause and date of death

If a previously registered patient returns to the hospital with another primary cancer, this cancer should also be noted on his Patient Index Card.

The Follow-up Control File

Regular clinical follow-up examination of the cancer patient, to determine the presence or absence of disease and the need for further therapy, is essential in the proper management of the disease. Consequently, a primary function of cancer registries is to help assure and promote periodic follow-up examinations, by maintaining a Follow-up Control File of reminder cards to be made out at the time of registration. The Follow-up Control Card should contain the following information (see page 21, bottom):

a. the name and address of the patient
b. the assigned cancer registry number
c. the site of cancer
d. the date of diagnosis
e. the date when the patient was last seen
f. the name of the attending physician.

These cards should be filed in alphabetical order by month of follow-up, to alert the registrar to review the patient's medical chart at regular intervals (at least once a year), and post follow-up information on the abstract form, or communicate with the attending physician or others for follow-up information.

Follow-up information in many instances is obtained from readmission or outpatient records ("automatic" follow-up). The cancer registry secretary should not ask for follow-up information from the attending physician unless the follow-up period (usually a year) has passed since the last contact with the patient. If the patient is no longer under the care of a physician, the registry secretary should obtain his permission to contact the patient or

patient's family. If the patient has moved, the postmaster may have a forwarding address. The death registration files of state or local bureaus of vital statistics will often be able to provide information about a deceased patient, and may give the name of the physician who signed the death certificate. Information about the patient may also be obtained from relatives, the visiting nurses association, the city directory, other hospitals, and other social service agencies. (See pages 22 to 25 for sample follow-up letters.)

When follow-up reveals that the patient has died, the cause and date of death should be entered on the Patient's Index Card as well as on the cancer registry abstract, and notification should be sent to the medical records librarian for entry in the hospital chart. The Follow-up Control Card should then be destroyed. The Follow-up Control Cards remaining at the end of a follow-up period represent patients for whom no new information has been received, i.e., those lost to follow-up.

The Accession Register

The Accession Register may be a yearly listing of all patients, their diagnosis, and their assigned cancer registry numbers from the date of the establishment of the registry. Patients with multiple primary cancers will have only one registry number. Such patients may be identified with a distinctive notation, such as an asterisk, or with a notation of the other site(s).

An alternate type of Accession Register is designed to list registered patients *by year of initial diagnosis* of the primary lesion, by major anatomic sites or site groups. (See pages 26 and 20.) These lists enable the cancer registry secretary to prepare summary reports of patients by anatomic sites, and by race, sex, method of diagnosis, stage and other categories (age at diagnosis, type of initial treatment, and survival time) for the information of the medical staff and the hospital administrator. (See page 27.) They may also be used to prepare reports of survival and end results by selected sites and site groups. (See below.) However, it must be remembered that the information relating to "Date Last Contact" and "Cancer Status This Contact" must be entered *in pencil at each follow-up* until the death of the patient so that it can be erased when the follow-up information is up-dated. Survival time should be computed and recorded only after the death of the patient. When using this Accession Register, the secretary must keep track of the assigned cancer registry numbers on a separate pad or notebook.

Report of Survival and End Results

The cancer registry abstract with current information will provide the basic data for the preparation of Reports of Survival and End Results to the medical staff. (See page 28.) This is one of the requirements for approval by the American College of Surgeons.

It is suggested that initially the hospital prepare a one-year report for cases diagnosed during a recent year. Thus, if a report is to be filled out for the cancer cases diagnosed in 1962, it would be necessary to obtain the cancer registry abstracts for all cases diagnosed during that year and followed for one year through 1963—the living as well as those who died within the year of diagnosis. The vertical columns on the report form can be filled in according to the groups of patients to be reported upon, such as patients for whom there is microscopic confirmation, patients divided by sex, race, site groups or individual sites of cancer, stage of disease, age groups, and so forth. The cancer registry abstracts should then be divided into three groups: (1) those patients for whom follow-up information is not available

(not followed) for the full period covered by this report; (2) patients living for the full period covered by this report; and (3) patients who have died within the period covered by this report. Within each major group, the abstracts should then be subdivided into three additional subgroups—patients having evidence of cancer, no evidence of cancer, and patients for whom this information is not available. The number of abstracts in each of the three subgroups should be entered on the form and totaled. The per cent of patients followed during the period E, and the per cent of patients who survived during the full period covered by this report, F, can then be computed according to the formula on the report form.

In subsequent years, when the medical staff desires a report of patients for a two-year or three-year period, or longer, the registrar can obtain the abstracts of those patients who might have survived two, three, or more years. Thus, if a three-year survival report is to be prepared in 1964, the abstracts of patients diagnosed in 1959, and 1960, and followed through 1962 and 1963, respectively, should be removed from the files. Following the same procedure as that outlined above, that is, sorting the abstracts for each year into three groups, and within these groups into three subgroups, it will then be possible to obtain the totals of the various categories, and to compute the follow-up and survival information for the cases diagnosed in 1959 and 1960. The two three-year reports can then be compared, and could be added together to obtain a cumulative three-year follow-up and survival report.

The preparation of summary reports and reports of survival and end results by specific sites or site groups is a relatively simple matter for those registries using the alternate type of Accession Register. (See pages 26-28.) For example, it is possible to prepare a five-year report of survival for breast cases diagnosed in 1958 and followed through 1963, by tabulating all of the necessary information from the Accession Register List of breast cases diagnosed in 1958. Similar reports may be prepared for any period of time by site groups, specific sites, or other variables. (See pages 29-31.)

A properly trained cancer registry secretary should have little difficulty in maintaining and operating a registry, provided she has the continuing assistance and guidance of a physician supervisor and the cooperation of the medical staff.

References

1. American College of Surgeons: Handbook for Cancer Registry Secretaries. Chicago, 1962.

2. American College of Surgeons: Manual for Cancer Programs. Chicago, 1961.

3. Manual of the Uniform Punch Card of the End Results Program, CCNSC, National Cancer Institute, U.S. Public Health Service, Department of Health, Education, and Welfare, Washington, D.C., January 1, 1959. (Unpublished.)

4. California Tumor Registry: A Guide for the Tumor Registry Secretary in Recording Stage. Berkeley: State of California Department of Public Health, 1964.

5. Karnofsky, D. A.: Cancer chemotherapeutic agents. Ca 11: 58-66, 1961.

Cancer Registry Abstract Form

PATIENT

NAME

STREET ADDRESS | CITY | STATE | REGISTRY NO.

NAME OF SPOUSE | DATE OF ADMISSION | DATE OF DISCHARGE | HOSPITAL

AGE OR BIRTH DATE | RACE | SEX | MARITAL STATUS | PRIVATE ☐ NONPRIVATE ☐ | OUTPATIENT ☐ INPATIENT ☐ | HOSPITAL NO.

DIAGNOSIS

FINAL DIAGNOSIS (SPECIFY PRIMARY SITE OF CANCER)

Basis of Diagnosis

AUTOPSY ☐ HISTOLOGY ☐ X-RAY ☐ CLINICAL ☐ OTHER (SPECIFY) ☐

Histological Diagnosis (PATHOLOGY REPORT) GRADE

DATE OF DIAGNOSIS | EXFOLIATIVE CYTOLOGY

Stage of Disease LOCALIZED ☐ REGIONAL INVOLVEMENT ☐ REMOTE METASTASIS ☐ NOT APPLICABLE ☐ UNSPECIFIED ☐

HISTORY

Was case positively diagnosed as cancer before this admission? NO ☐ YES ☐ IF SO, DATE:

Has patient been previously treated for this cancer? NO ☐ YES ☐ RECURRENCE ☐
If "Yes" specify date, type of treatment, and doctor or hospital NO EVIDENCE OF DISEASE ☐

DATE | TREATMENT

TREATMENT

Type SURGERY ☐ RADIATION ☐ CHEMOTHERAPY ☐ HORMONES ☐ NONE ☐ UNKNOWN ☐
PATIENT REFUSES TREATMENT ☐ OTHER (SPECIFY) ☐

Purpose CURATIVE ☐ PALLIATIVE ☐ DIAGNOSIS ONLY ☐ UNKNOWN ☐

Date and Type of Treatment

CONDITION

Condition at Discharge ALIVE ☐ DEAD ☐

If Dead, Date of Death AUTOPSY: YES ☐ NO ☐ NOT STATED ☐
Cause of Death

If Alive NO CLINICAL EVIDENCE OF CANCER ☐ NOT FREE OF CANCER ☐ UNKNOWN ☐

FOLLOW-UP

Name and address of Hospital or Physician responsible for follow-up

Name of person submitting this report **Date**

Name of Institution to be inserted when form is used in a Central Cancer Registry.

FOLLOW-UP INFORMATION

DATE	SURVIVAL TIME MONTHS	SOURCE OF CONTACT	ALIVE	NO EVIDENCE OF CANCER	EVIDENCE OF CANCER	LOCAL RECURRENCE	METASTASIS	STATUS UNKNOWN	DEAD	SUBSEQUENT TREATMENT OR REMARKS

CAUSE OF DEATH — AUTOPSY YES ☐ NO ☐ NOT STATED ☐

SOURCE OF INFORMATION — DATE OF DEATH

Front of the Cancer Registry Abstract Form is shown on page 16. Above is reverse side of the form.

TREATMENT DIRECTED AT CANCER OR METASTASES

Treatment is *restricted* to any and *all procedures or therapies*, administered during or after the first clinical diagnosis of cancer, which usually *modify, control, remove*, or *destroy cancer tissue* whether primary or metastatic, regardless of response in a particular patient, and regardless whether curative or palliative. Treatment *does not* include procedures or therapies which are purely *diagnostic, symptomatic*, or *supportive*.[3,5]

SURGICAL ATTACK ON CANCER (Examples)

Most operations ending in "*ectomy*," including regional lymphadenectomies (cervical, axillary, groin, para-aortic, and pelvic lymph node and radical neck dissections). See Hormones and Supportive below.
Cautery
Cryotherapy
Electrocoagulation
Fulguration (for bladder and skin cancers)
Local excision (with *complete removal* of cancer tissue or excisional biopsy)
Transurethral resection (TUR) *with removal of cancer tissue*

CHEMOTHERAPY (Examples)

Polyfunctional Alkylating Agents
- (HN2 Mustargen)
- Chlorambucil (Leukeran)
- Cyclophosphamide (Endoxan, Cytoxan)
- Triethylene Melamine (TEM)
- (TSPA, ThioTEPA)
- (Busulfan, Myleran)

Antimetabolites
- (Amethopterin, Methotrexate)
- (Aminopterin)
- 6-Mercaptopurine (6-MP, Purinethol)
- 6-Thioguanine (6-TG)
- 5-Fluorouracil (5-FU)

Miscellaneous Drugs
- Actinomycin D
- Demecolcin
- o,p,'DDD
- Potassium arsenite (Fowler's solution)
- Urethane

RADIATION TO CANCER TISSUE (Examples)

Betatron
Cobalt Bomb
Linear Accelerator
Neutron Beam
X-Ray

Internal use of *radioactive isotopes* whether given *orally, intracavitarily*, or by *intravenous injection*.

All implants, moulds, seeds, needles, applicators of radioactive material – such as *radium, radon, radioactive gold*, etc.

HORMONES (Examples)

Adrenal Cortical Compounds
- Cortisone acetate
- Hydrocortisone acetate
- Prednisone (Meticorten)

Adrenocorticotropic Hormone
- (ACTH)

Androgen
- Testosterone propionate
- Fluoxymesterone (Halotestin)

Estrogen
- Diethylstilbestrol
- Ethinyl estradiol (Estinyl)

Progesterone
- Hydroxyprogesterone caproate (Delalutin)

Other Therapy for Hormonal Effect, including ablative operations and when the endocrine gland is not the primary site or sites of metastases (examples)
- Adrenalectomy, Hypophysectomy } Most sites
- Oophorectomy for cancer of the breast
- Orchidectomy for cancer of the prostate
- X-Ray "sterilization" (to the gonads)

PROCEDURES NOT USUALLY TO BE CONSIDERED AS CANCER-DIRECTED THERAPY

DIAGNOSTIC OR EXPLORATORY PROCEDURES

All Diagnostic and Exploratory Surgery (Examples)
- Laparotomy
- Thoracotomy

Biopsies, if only part of the tumor is removed
Blood smears
D and C for Uterine Cancer (Dilatation and Curettage)
Diagnostic X-ray
Exfoliative Cytology
Procedures ending in "oscopy" such as
- Bronchoscopy
- Cystoscopy (only)
- Gastroscopy
- Laryngoscopy
- Sigmoidoscopy

Ventriculography
Removal of lymph node

SUPPORTIVE AND SYMPTOMATIC PROCEDURES

Definitions: **Supportive:** Procedures designed to sustain strength of patient.
Symptomatic: Procedures designed to alleviate symptoms, but not to cure.

Blood Transfusion (for any reason)
Catheterization
Nerve section for pain
Paracentesis - Thoracentesis (Removal of Fluid)
Pain Relief Drugs
Plastic Surgery

Surgery which only short-circuits the neoplasm without removing tumor tissue, for example:
- Some Anastomoses
- Cecostomy
- Colostomy
- Uretero-sigmoid transplants

Other operations ending in "otomy" or "ostomy", for example:
- Cordotomy (Chordotomy)
- Craniotomy
- Gastrostomy
- Ileostomy
- Leucotomy (Leukotomy)
- Nephrostomy
- Phlebotomy (for Polycythemia Vera)
- Splenectomy (sometimes)
- Ureterostomy
- Vasectomy (only for tumors of Bladder, Prostate, Testis)
- Ventriculostomy

FILING CANCER REGISTRY ABSTRACTS

It is suggested that registries with few cases in each site category, file their abstracts according to major sites and site groups.

Below are the major sites and site groups and their site classification numbers according to the International Statistical Classification of Diseases, Injuries and Causes of Death (Volume 1, World Health Organization, 1955 Revision):

Buccal cavity and pharynx	(140-148)
Stomach	(151)
Large Intestine, except rectum	(153)
Rectum	(154)
All other digestive organs	(150,152,155-159)
Lung	(162)
All other respiratory system	(160,161,163-165)
Breast	(170)
Cervix uteri	(171)
Corpus uteri	(172)
All other female genital organs	(173-176)
Prostate	(177)
All other male genital organs	(178,179)
Kidney and bladder	(180,181)
Skin (except melanoma)	(191)
All other sites	(190,192-198)
Unspecified sites and generalized carcinomas	(199)
Leukemia and aleukemia	(204)
All other lymphatic and hematopoietic tissues	(200-203,205)

PATIENT INDEX CARD

NAME _____ HOSP. NO. _____

ADDRESS _____ REG. NO. _____

_____ RACE _____

BIRTH DATE _____ SEX _____

DIAGNOSIS _____

DATE OF DIAGNOSIS _____

REFERRED BY _____

CAUSE OF DEATH
AND DATE _____

FOLLOW-UP CONTROL CARD

NAME: REG. NO. _____

ADDRESS:

SITE: DATE DIAGNOSED:

DATE OF LAST FOLLOW-UP	DOCTOR	TYPE OF FOLLOW-UP	REMARKS

HOSPITAL LETTERHEAD
(Name of Patient)
(Hospital patient number)
(Diagnosis of patient)

Re:
Pt. #:
Dx:
Date of Admission:

Date_____

Dear Doctor_____:

An annual follow-up of registered cancer cases seen in (*name of hospital*) since (*year*) is conducted by the Cancer Registry of this hospital. This is a basic part of our cancer program to meet the requirements of the American College of Surgeons.

Please record below the latest information you have on the patient listed. If you have seen the patient within the past year, we ask only that you record the last information in your office records.

Sincerely,

Chairman, Committee on Cancer

---

1. **ALIVE:**

   DATE YOU LAST HEARD FROM THE PATIENT_____

   DID YOU EXAMINE THE PATIENT FOR THE ABOVE NEOPLASM?_____

   STATUS OF THE PATIENT AT THAT TIME: (CHECK ONE)

   FREE OF THE NEOPLASM ☐ NOT FREE OF THE NEOPLASM ☐

2. **DEAD:** DATE OF DEATH_____ PLACE OF DEATH_____

3. **MOVED AWAY:** DATE_____ NEW ADDRESS_____

4. **REFERRED TO ANOTHER PHYSICIAN:** NAME AND ADDRESS_____

_____

IF YOU ARE UNABLE TO COMPLETE NUMBERS 1 OR 2, MAY WE HAVE YOUR SIGNATURE TO THE AUTHORIZATION BELOW:

Since I am unable to secure a follow-up report for the current year regarding the present status of the above-named patient, you are hereby authorized by me to use any ethical means to obtain this information for your records.

Signature_____

HOSPITAL LETTERHEAD

Date_____

Name
Out-of-State Health Office
Street Address
City, State

Dear Sir:

We have recently learned of the death of the patient listed below. In order that our follow-up may be complete, would you kindly send us a copy of the death certificate, or fill in date of death and cause of death, below.

We appreciate your cooperation in making our Tumor Registry of value.

Sincerely yours,

Chairman, Committee on Cancer

NAME _____ DIAGNOSIS_____

LAST KNOWN ADDRESS_____

DATE OF LATEST INFORMATION_____

DATE OF BIRTH_____ RACE_____ SEX_____

MARITAL STATUS_____ SPOUSE'S NAME _____

MOTHER'S MAIDEN NAME _____ FATHER'S NAME _____

PATIENT'S OCCUPATION_____

CAUSE OF DEATH_____

DATE OF DEATH_____

HOSPITAL LETTERHEAD

Date_____

Name of Patient
Street Address
City, State

Dear_____:

We are writing to find out how you have been feeling since you were last seen in this hospital.

Would you be kind enough to give us a brief report of your condition in the space below and return this letter to us in the enclosed envelope.

Thank you very much for your cooperation.

Sincerely yours,

_____, M.D.

Enclosure

---

1. DATE_____

2. HAVE YOU RECOVERED FROM THE CONDITION FOR WHICH YOU WERE IN THIS HOSPITAL?

YES ☐ NO ☐

3. HAVE YOU HAD ANY FURTHER TREATMENT FOR THIS CONDITION?

YES ☐ NO ☐

IF YES, BY WHOM AND WHERE?

NAME OF PHYSICIAN_____

PHYSICIAN'S ADDRESS_____

CITY_____ STATE_____

4. NEW ADDRESS, IF YOU HAVE MOVED_____

_____

HOSPITAL LETTERHEAD

Date _____

Name of Relative or Other Informant
Street Address
City, State

Dear _____:

The (*name of hospital*) is doing a special study of a number of our former patients. We are interested in the present condition of (*name of patient*) and have been unable to contact (him).

Would you be kind enough to fill out the requested information in the form below and return this letter to us. We are especially interested in the whereabouts of (*name of patient*) so that we may keep in touch with (him) for purposes of our study.

We are enclosing a stamped, self-addressed envelope for your convenience.

Thank you for your cooperation.

Sincerely yours,

_____, M.D.

Enclosure

PRESENT WHEREABOUTS OF: (NAME OF PATIENT)

STREET ADDRESS _____

CITY _____ STATE _____

PRESENT CONDITION:

APPARENTLY WELL ☐ NOT WELL ☐

PRIMARY SITE(S): ISC NO(S).

CASES DIAGNOSED FROM 19 TO 19

REGISTRY CASE NUMBER	HOSPITAL CASE NUMBER	PATIENT'S NAME	RACE	SEX	AGE AT DX.	DATE OF DIAGNOSIS	HISTOLOGICAL DIAGNOSIS OR OTHER BASIS OF DIAGNOSIS	STAGE	TYPE OF INITIAL THERAPY[1]	DATE LAST CONTACT OR DEATH	CANCER STATUS THIS CONTACT[2]	SURVIVAL TIME MOS.
TOTALS												

1. THERAPY THAT AFFECTED THE CANCER: S-SURGERY. R-RADIATION. C-CHEMOTHERAPY. H-HORMONES
2. W-WITH CANCER. WO-WITHOUT CANCER. U-CANCER STATUS UNKNOWN. DOC-DEATH FROM OTHER CAUSES (ADD CANCER STATUS)

HOSPITAL:

CITY:

CANCER REGISTRY SUMMARY

YEAR:

SITE OF CANCER	MALE CASES					FEMALE CASES					MALE AND FEMALE CASES				
	NUMBER WHITE	NUMBER NON-WHITE	NUMBER RACE UNSPEC.	TOTAL MALE NO.	TOTAL MALE %	NUMBER WHITE	NUMBER NON-WHITE	NUMBER RACE UNSPEC.	TOTAL FEMALE NO.	TOTAL FEMALE %	NUMBER WHITE	NUMBER NON-WHITE	NUMBER RACE UNSPEC.	TOTAL MALE & FEM. NO.	TOTAL MALE & FEM. %
MOUTH AND PHARYNX															
DIGESTIVE SYSTEM															
RESPIRATORY SYSTEM															
BREAST															
FEMALE GENITAL ORGANS	---	---	---	---	---										
MALE GENITAL ORGANS															
URINARY ORGANS						---	---	---	---	---					
SKIN (EXCEPT MELANOMA)															
OTHER & UNSPECIFIED SITES															
LEUKEMIA & LYMPHOMA															
TOTAL					100.0					100.0					100.0

SITE OF CANCER	METHOD OF DIAGNOSIS										STAGE AT DIAGNOSIS									
	MICROSCOPIC CONFIRMATION		X-RAY ONLY		CLINICAL AND OTHER		UNSPECIFIED		TOTAL		LOCALIZED		REGIONAL INVOLVEMENT		DISTANT METASTASES		STAGE UNSPECIFIED		TOTAL	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
MOUTH AND PHARYNX										100.0										100.0
DIGESTIVE SYSTEM										100.0										100.0
RESPIRATORY SYSTEM										100.0										100.0
BREAST										100.0										100.0
FEMALE GENITAL ORGANS										100.0										100.0
MALE GENITAL ORGANS										100.0										100.0
URINARY ORGANS										100.0										100.0
SKIN (EXCEPT MELANOMA)										100.0										100.0
OTHER & UNSPECIFIED SITES										100.0										100.0
LEUKEMIA & LYMPHOMA										100.0										100.0
TOTAL										100.0	---	---	---	---	---	---	---	---	---	---
										100.0										100.0

REPORT OF CANCER SURVIVAL AND END RESULTS

FOR CASES DIAGNOSED AND/OR TREATED AT THE _____ HOSPITAL

PRIMARY SITE OF CASES INCLUDED IN THIS REPORT _____

CASES DIAGNOSED AND/OR TREATED DURING THE YEAR(S) _____

SURVIVAL AND END RESULTS THROUGH THE YEAR(S) _____

_____ YEAR SURVIVAL AND END RESULTS		1. TOTAL NO. OF CASES	2.	3.	4.	5.	6.	7.
A. CASES DIAGNOSED AND/OR TREATED DURING THE YEAR(S) _____								
B. PATIENTS NOT FOLLOWED FOR FULL PERIOD COVERED BY THIS REPORT	B1. WITHOUT CANCER AT LAST FOLLOW-UP OR EXAMINATION							
	B2. WITH CANCER AT LAST FOLLOW-UP OR EXAMINATION							
	B3. CONDITION UNKNOWN AT LAST FOLLOW-UP OR EXAMINATION							
	B4. SUM OF PATIENTS NOT FOLLOWED FOR FULL PERIOD OF THIS REPORT							
C. PATIENTS LIVING FOR FULL PERIOD COVERED BY THIS REPORT	C1. CLINICALLY FREE OF CANCER							
	C2. NOT FREE OF CANCER							
	C3. STATUS WITH REGARD TO CANCER UNKNOWN							
	C4. SUM OF PATIENTS LIVING FOR FULL PERIOD OF THIS REPORT							
D. PATIENTS DEAD WITHIN PERIOD COVERED BY THIS REPORT	D1. a. DEATH FROM OTHER CAUSES, CANCER PRESENT							
	b. DEATH FROM OTHER CAUSES, CANCER NOT PRESENT							
	D2. DEATH DUE TO CANCER							
	D3. PRESENCE OF CANCER NOT DETERMINED AT DEATH							
	D4. SUM OF PATIENTS DEAD WITHIN PERIOD OF THIS REPORT							
E. PER CENT OF PATIENTS FOLLOWED FOR FULL PERIOD COVERED, $\frac{C4 + D4}{A}$								
F. PER CENT OF PATIENTS SURVIVING FULL PERIOD COVERED BY THIS REPORT, $\frac{C4}{A - B4}$								

_____ YEAR REPORT OF CANCER SURVIVAL AND END RESULTS

_____ Hospital

BY MAJOR SITE GROUPS

CASES DIAGNOSED IN 19____ REPORT THROUGH 19____		ALL SITES	MOUTH AND PHARYNX	DIGESTIVE SYSTEM	RESPIRATORY SYSTEM	FEMALE GEN. ORGANS	MALE GEN. ORGANS	URINARY ORGANS	SKIN	OTHER & UNSPEC. SITES	LEUKEMIA AND LYMPHOMA
A. TOTAL NUMBER EXPOSED TO RISK											
B. PATIENTS NOT FOLLOWED FOR FULL PERIOD COVERED BY THIS REPORT	B1. WITHOUT CANCER										
	B2. WITH CANCER										
	B3. CONDITION UNKNOWN										
	B4. TOTAL										
C. PATIENTS LIVING FOR FULL PERIOD COVERED BY THIS REPORT	C1. WITHOUT CANCER										
	C2. WITH CANCER										
	C3. CONDITION UNKNOWN										
	C4. TOTAL										
D. PATIENTS DEAD WITHIN PERIOD COVERED BY THIS REPORT	D1. a. DUE TO OTHER CAUSES, CANCER PRESENT										
	b. DUE TO OTHER CAUSES, CANCER NOT PRESENT										
	D2. DUE TO CANCER										
	D3. CANCER PRESENCE UNDETERMINED										
	D4. TOTAL										
E. PER CENT OF PATIENTS FOLLOWED FOR FULL PERIOD COVERED $\frac{C4 + D4}{A}$											
F. PER CENT OF PATIENTS SURVIVING FULL PERIOD COVERED BY THIS REPORT $\frac{C4}{A - B4}$											

_____YEAR REPORT OF CANCER SURVIVAL AND END RESULTS

_____Hospital

BY SELECTED SITES

CASES DIAGNOSED IN 19_____ REPORT THROUGH 19_____		STOMACH	LG. INTES. EXCEPT RECTUM	RECTUM	LUNG	BREAST	CERVIX	PROSTATE	KIDNEY & BLADDER	SKIN	LEUKEMIA & ALEUKEMIA
A. TOTAL NUMBER EXPOSED TO RISK											
B. PATIENTS NOT FOLLOWED FOR FULL PERIOD COVERED BY THIS REPORT	B1. WITHOUT CANCER										
	B2. WITH CANCER										
	B3. CONDITION UNKNOWN										
	B4. TOTAL										
C. PATIENTS LIVING FOR FULL PERIOD COVERED BY THIS REPORT	C1. WITHOUT CANCER										
	C2. WITH CANCER										
	C3. CONDITION UNKNOWN										
	C4. TOTAL										
D. PATIENTS DEAD WITHIN PERIOD COVERED BY THIS REPORT	D1. a. DUE TO OTHER CAUSES, CANCER PRESENT										
	b. DUE TO OTHER CAUSES, CANCER NOT PRESENT										
	D2. DUE TO CANCER										
	D3. CANCER PRESENCE UNDETERMINED										
	D4. TOTAL										
E. PER CENT OF PATIENTS FOLLOWED FOR FULL PERIOD COVERED $\frac{C4 + D4}{A}$											
F. PER CENT OF PATIENTS SURVIVING FULL PERIOD COVERED BY THIS REPORT $\frac{C4}{A - B4}$											

_____ YEAR REPORT OF CANCER SURVIVAL AND END RESULTS OF _____ PATIENTS

_____ Hospital

BY SEX, STAGE, INITIAL THERAPY AND AGE AT DIAGNOSIS

CASES DIAGNOSED IN 19____ REPORT THROUGH 19____		TOTAL NO.	MALE	FEMALE	LOCALIZED	REG. METASTASES	SURGERY ONLY	SURGERY & RADIATION	45 YRS & UND. (AT DX)	46 - 60 YRS. (AT DX)	61 - 75 YRS. (AT DX)	76 YRS. & OVER (AT DX)
A. TOTAL NUMBER EXPOSED TO RISK												
B. PATIENTS NOT FOLLOWED FOR FULL PERIOD COVERED BY THIS REPORT.	B1. WITHOUT CANCER											
	B2. WITH CANCER											
	B3. CONDITION UNKNOWN											
	B4. TOTAL											
C. PATIENTS LIVING FOR FULL PERIOD COVERED BY THIS REPORT	C1. WITHOUT CANCER											
	C2. WITH CANCER											
	C3. CONDITION UNKNOWN											
	C4. TOTAL											
D. PATIENTS DEAD WITHIN PERIOD COVERED BY THIS REPORT	D1. a. DUE TO OTHER CAUSES, CANCER PRESENT											
	b. DUE TO OTHER CAUSES, CANCER NOT PRESENT											
	D2. DUE TO CANCER											
	D3. CANCER PRESENCE UNDETERMINED											
	D4. TOTAL											
E. PER CENT OF PATIENTS FOLLOWED FOR FULL PERIOD COVERED $\frac{C4 + D4}{A}$												
F. PER CENT OF PATIENTS SURVIVING FULL PERIOD COVERED BY THIS REPORT $\frac{C4}{A - B4}$												

Financial Aspects of a Hospital Cancer Registry

Abraham Ringel, M.A.

The expenses involved in organizing and routinely operating a cancer registry in a small-to-moderate-sized general hospital (under 400 beds), as outlined in the American College of Surgeons' *Manual For Cancer Programs*, is a subject of considerable importance for hospital administrators and members of the medical staff, and one on which there is a paucity of information. This article is an attempt to resolve some of their questions concerning the purely administrative costs and requirements of a registry. It will *not* deal with the voluntary supervisory and guidance responsibilities of the hospital's Committee on Cancer in the operation of a registry, or the professional requirements and cost of comprehensive analysis of registry data and special studies. The duties of the Committee on Cancer have been outlined in the College's *Manual*, and the cost of analysis of registry data and special studies will vary according to the different interests and needs of the medical staff.

The major expense in the routine operation of a hospital cancer registry is for a secretary. Ideally, a cancer registry secretary should have training and knowledge comparable to that of a medical secretary, with some aptitude for elementary statistical tabulations. However, in the absence of such a person, a successful hospital cancer registry may be operated by an alert general secretary with no more than a high school education, provided she receives adequate training and has the close and continuing supervision and guidance of the hospital's Committee on Cancer. In general, the pay scale for a medically knowledgeable cancer registry secretary is comparable to that of a medical secretary. The higher salary for such a person, as compared with that of a general secretary, will be more than compensated for in greater efficiency in transcribing, completely and accurately, the pertinent data from the medical records.

The personnel time required to operate a hospital cancer registry is not only dependent upon the knowledge and ability of the secretary, but also the following variables: (1) the size of the hospital and the volume of the cancer load; (2) the amount of detail recorded on the cancer registry abstract; (3) the organization of the medical records department, and the availability of all medical charts (inpatient and outpatient) to the cancer registry secretary; (4) the completeness and legibility of the medical record charts; (5) the availability of information from the pathology laboratory and the department of radiology; and (6) the response for follow-up information.

In general, it is estimated that a cancer registry secretary will require a maximum of one hour to register a new cancer patient, and an average of one-half hour per case, to obtain and record follow-up information. This is predicated on the assumptions that the conditions noted in variables three to six inclusive mentioned above are favorable. On the other hand, if the registry secretary must hunt for medical charts and/or for necessary information lacking in the charts, and if she has to send several letters before obtaining adequate follow-up information, more time will have to be allowed. The accompanying table gives estimates of the optimum and maximum number of actual *work* hours of secretarial help required *per week* to carry

out the routine work involved in maintaining a hospital cancer registry for 15 years, per 100 new cancer patients annually.

It should be noted that these time estimates will permit the secretary to prepare routine tabulations and reports of the registry data, at least annually. However, she will probably not have time to answer inquiries and requests for information, or to code the data for data processing equipment if required. Provision must also be made for work-breaks, sickness, and vacation time. As noted above, the time of physicians and other researchers to prepare analytical and special study reports evaluating the management of cancer in the hospital—the fundamental reason for the registry—will not be dealt with here, since this will vary according to the professional resources, interests and needs of the medical staff.

The American College of Surgeons has made no specific requirements with respect to the forms to be used in a hospital cancer registry. However, they have suggested the following:

1. An abstract or summary of the hospital medical chart of each primary site of cancer in every cancer patient. (See pages 16 and 17.)
2. A patient index card to identify every patient in the registry. (See page 21.)
3. A follow-up control card to alert the secretary to obtain up-to-date information concerning the patient's cancer. (See page 22.)
4. An accession register, usually kept in a three-ring binder, in which the cancer cases are recorded by year of registration or diagnosis. (See page 26.)

A generous estimate of the cost of reproducing, by photo-offset, the abstract form is $15 a thousand, and $10 a thousand for each of the other three forms, or a total of $45. In greater quantities this cost will be much lower. On the other hand, the purchase of forms, and special cabinets to house them, from commercial sources will be considerably higher.

Since the cancer registry secretary must work in close consultation with the Committee on Cancer, it is important that her supervision be their responsibility. Also, it is desirable that the cancer registry be located in a separate room (or corner) so that the secretary may work with a minimum of distraction. The area reserved for the registry should be large enough to contain a desk and chair, typewriter, four-

Estimates of the Optimum and Maximum Number of Hours Per Week of Secretarial Help Required for the Routine Operation of a Hospital Cancer Registry for 15 Years[1] Per 100 New Cancer *Patients Annually*[2]

	Optimum	Maximum
1st Year	1.9	1.9
2nd Year	2.5	3.0
3rd Year	2.9	3.9
4th Year	3.3	4.7
5th Year	3.7	5.4
6th Year	4.0	6.1
7th Year	4.3	6.6
8th Year	4.6	7.2
9th Year	4.8	7.7
10th Year	5.0	8.1
11th Year	5.3	8.6
12th Year	5.4	8.9
13th Year	5.6	9.3
14th Year	5.8	9.6
15th Year	5.9	9.9

NOTE: A hospital may compute its personnel requirements by multiplying either column by one hundredth of its bed capacity. For example, a 250 bed hospital will require an average of 4.8 hours of secretarial help per week during the first year ($1.9 \times 2.5 = 4.8$), and 9.3 hours per week during the fifth year ($3.7 \times 2.5 = 9.3$).

[1]*Based on survival experience, reported in the California Tumor Registry Monograph "Cancer Registration and Survival in California."*

[2]*There is a great deal of variation in the relationship between the number of beds and new cancer patients. In California, the case/bed ratio ranged from 0.73 in county hospitals to 1.61 in private hospitals. These estimates are based on a one-to-one relationship of new patients annually and the average daily total bed capacity.*

drawer file cabinet(s) to house cancer registry abstract forms, two-drawer cabinet(s) for the patient index and the follow-up control files, and a telephone. The hospital should also provide basic reference books such as the *Manual for Tumor Nomenclature* and a medical as well as an ordinary dictionary, a sturdy three-ring binder for the accession register, stationery and postage, and miscellaneous other secretarial supplies.

Other than the initial equipment and overhead costs, more than 95 per cent of the costs of the routine operation of a registry in the average general hospital is for secretarial help. This expense, assuming the efficient organization of the medical records department and the co-operation of the medical staff, is not burdensome and can be absorbed by most hospitals.

References

1. *California Tumor Registry: Cancer Registration and Survival in California. Berkeley: State of California Department of Public Health, 1963.*

2. *American College of Surgeons: Manual for Cancer Programs. Chicago, 1961.*

Automatic Data Processing of Cancer Registry Information

Abraham Ringel, M.A.

The use of automatic data processing machines to expedite and facilitate the tabulation, follow-up, and analysis of cancer registry data is not new. The rental or purchase of these machines is costly, and the necessary personnel to operate them require special training, and are difficult to recruit. Therefore, their use in the average general hospital is justified only after registries have accessioned several thousand cancer cases, (and are adding new cases at a minimum rate of about 300 annually), and the equipment and personnel can be used in conjunction with other medical or administrative record-keeping procedures.

The information entered on the cancer registry abstract form suggested by the American College of Surgeons (see pages 16 and 17) may be translated into a numerical code for a punch card system such as that shown on pages 37-41.) Shown on page 42 is a sample code sheet on which the coded information may be entered. This form may be duplicated to 8½ by 11 inches in size and filed in *alphabetical* order in a standard file cabinet drawer. On the other hand, some registries code the initial identifying and diagnostic and treatment information through the patient's first discharge from the hospital (column 52) on the front of a 5- by 9-inch card, and the follow-up information on the reverse side to facilitate handling and filing. It will be noted that the information through column 52 identifies and describes the patient, and the initial diagnosis and treatment of the primary cancer through the patient's first discharge from the hospital. Columns 53 through 69 should reflect the very last date of follow-up of the patient and all of the *cumulated* information concerning survival time (columns 56-58), *different types* of subsequent treatment following initial therapy (column 61), and, if desired, the total number of hospital admissions (column 66) and hospital days (columns 67-69) for this primary cancer.

In general, once coded, the first 52 columns need never be changed except if the primary site, histological diagnosis, or other items have to be corrected. All cases, new and old, should always be coded completely through the end of the code sheet. The date of last contact (follow-up) of new cases should be the date of discharge from the hospital, and the information that follows should reflect this date. Thereafter, the last date of contact of the patient, together with all of the subsequent follow-up information, are to be coded at least annually until the patient's death. The unassigned columns in the 80-column punch-card may be used for codification of more specific information concerning the various sites of cancer for special studies, e.g., smoking history to study lung cancer, eating habits to study cancer of the stomach, etc.

After the abstracted information has been coded, a punch-card should be made and filed in *numerical* order. After new follow-up information has been entered on the abstract form and coded, the code sheet should be matched with the punch-card for the case, and both sent to the key-punch machine operator. The operator can then duplicate the ini-

tial information (columns 1 through 52) and punch in the up-dated follow-up information. The old punch card should then be destroyed, and the code sheet and new punch card should be filed. After the patient dies, the last follow-up information is to be coded and entered on a punch-card, and the code sheet may be destroyed.

A deck of punch cards which reflect the collected up-dated information in the cancer registry together with a sorter-counter may be used to expedite counts by site, sex, stage of the disease at diagnosis, types of treatment, identify patients who need to be followed, etc. With a tabulator the cards may be used to print out annual accession books by site and year of diagnosis, to identify and print out part of the follow-up form letters to go to physicians, to help in preparing survival and end results statistics, and in other ways. Some registries also use duplicate decks of the punch-cards as their patient index and follow-up control files.

Needless to say, a method of processing cancer registry information with the aid of machines is not the only answer for the proper analysis and use of the wealth of information accumulated in the hospital cancer registry. Unless the information so processed is properly communicated to the entire medical staff and is used to further improve care of cancer patients, the cancer registry is not worth the time, effort, and resources expended on it.

GENERAL HOSPITAL CANCER REGISTRY CODE

COLUMN — ITEM AND CODE

NOTE: Every column must have a *numerical* code number or X (*only one*) except columns 6-30 (if the name does not fill all of the columns provided.

1 - 5 **REGISTRY CASE NUMBER**

The registry number is the *patient's permanent identification number*. Assign a registry number to *each new cancer patient* in consecutive order starting with the last two digits of the year in which the patient is first accessioned, e.g., 63-001 to 63-329; 64-001 to 64-346; 65-001, etc. In coding the separate abstracts for patients with two or more primary cancers, each abstract should be identified with the same registry number assigned at the time the first primary cancer was registered.

6 -30 **NAME OF PATIENT**

Enter last name, first name, middle initial. (e.g., Jones, Mary C.) If only the husband's name is given for a married woman, insert Mrs. after middle initial. (e.g., Jones, George A., Mrs.)

31 **NUMBER OF PRIMARY CANCER SITES FOR THIS PATIENT (Separate Code Sheet and Punch Card For Each Primary Site)**

0 - One primary cancer site only
If an additional primary site is reported, code thus:
1 - First primary cancer site
2 - Second primary cancer site
3 - Third, etc.

NOTE: When a second primary site is reported for the same patient it is necessary to re-code the code sheet and re-punch this column on the punch-card indicating the first primary site. The 0 originally coded and punched to indicate only one primary must be changed to 1 to indicate that this is the first primary cancer site of a patient with more than one primary. Skin lesions of different types as coded according to the Manual for Tumor Nomenclature are to be considered as separate primaries, e.g., basal cell carcinomas of the skin of the face and trunk, squamous cell carcinoma of the forehead, baso-squamous cell carcinoma of the skin of the nose.

32 **RESIDENCE OF THE PATIENT**

1 - Your city
2 - Elsewhere in your county
3 - Adjacent county
4 - Elsewhere in your state
5 - Out of state
X - Unknown

COLUMN	ITEM AND CODE

33-34 **AGE AT TIME OF INITIAL DIAGNOSIS**

Record age of patient at time of initial diagnosis of this primary cancer. If originally diagnosed anywhere else, code age according to the date of initial diagnosis elsewhere. Record age directly.

XX - Age unknown

35 **SEX AND RACE**

0 - White male
1 - White female
2 - Negro male
3 - Negro female
4 - Other male
5 - Other female
6 - Male, race unknown
7 - Female, race unknown
8 - White, sex unknown
9 - Negro, sex unknown

36 **MARITAL STATUS**

1 - Single
2 - Married
3 - Divorced, or Separated
4 - Widow, or Widower
X - Unknown

37 **TYPE OF ADMISSION**

1 - Private or Semi-Private
2 - Clinic or Service
X - Unknown

38-41 **PRIMARY SITE**

Use code from "International Statistical Classification of Diseases, Injuries, and Causes of Death." If no fourth digit is included in the International Site Code record X in column 41.

42-44 **HISTOLOGICAL DIAGNOSIS**

Use code from "Manual of Tumor Nomenclature and Coding."

XXX - No histological diagnosis

45 **BASIS OF DIAGNOSIS**

1 - Autopsy
2 - Microscopic Confirmation
3 - Exfoliative Cytology (Pap smear, Sputum, etc.)
4 - X-ray
5 - Clinical
6 - Other (Blood smear, Bone marrow)
X - Unknown

NOTE: If two or more types of diagnoses are indicated, give priority to the type with the *lowest* code number. (e.g., if both Microscopic Confirmation and X-ray are indicated, code #2.)

COLUMN	ITEM AND CODE

46 - 48 **DATE OF INITIAL DIAGNOSIS**

Code year directly in Column 46-47. (e.g., 1962 = 62)
Code month directly in Column 48.

1 - January
2 - February
3 - March
4 - April
5 - May
6 - June
7 - July
8 - August
9 - September
0 - October
X - November
Y - December

XXX - Date of Initial Diagnosis Unknown

NOTE: If month of original diagnosis is unknown, code 7 in column 48. If the season is given, code as follows: Winter - 2; Spring - 5; Summer - 8; Fall - X.

49 **WHERE DIAGNOSED INITIALLY BY ANY MEANS**

1 - At this hospital
2 - At another hospital
3 - In a doctors office
X - Unknown

50 **STAGE AT INITIAL DIAGNOSIS**

1 - Localized - No metastases (including carcinoma in situ)
2 - Regional metastatic involvement, or extension
3 - Remote or diffuse metastases
X - Unknown, Unspecified or Not Applicable

51 **TYPE OF INITIAL TREATMENT DIRECTED TO THIS CANCER**

0 - None, treatment refused, or treatment not completed
1 - Surgery
2 - Radiation
4 - Chemotherapy, and/or Hormonal therapy
9 - Palliative and Supportive treatment. (Surgery without removing tumor tissue, e.g., Colostomy, Anastomeses, etc; Vasectomy for tumors of bladder, prostate, testis; Blood Transfusion; Catheterization; removal of fluid; pain relief drugs, etc.)
X - Unknown or not available.

NOTE: If two or more types of treatment are indicated, code sum of appropriate code numbers. Do not add 9 to any other number. (e.g., Surgery and radiation = 3, surgery and chemotherapy = 5, radiation and hormones = 6, etc.) *Biopsies and other diagnostic procedures are not to be considered as therapy.*

52 **STATUS OF PATIENT WITH RESPECT TO THIS CANCER AT DISCHARGE FROM HOSPITAL**

0 - Dead
1 - Alive - Free of this cancer
2 - Alive - Not free of this cancer
3 - Alive - Unknown as to presence of this cancer
X - Unknown - Whether living or dead

COLUMN	ITEM AND CODE

53 - 55 **DATE OF LAST CONTACT WITH PATIENT**

Same code as Columns 46 - 48

56 - 58 **SURVIVAL TIME FROM DATE OF INITIAL DIAGNOSIS (Cols. 46 - 48)**

Code survival time in months directly, (e.g.) 31 months = 031, etc. (14 days or less = 0 months; 15 days to 44 days = 1 month; etc.)

59 **SOURCE OF FOLLOW-UP**

1 - Hospital Admission
2 - Attending Physician
3 - Outpatient Visits (clinic, X-ray therapy, etc.)
4 - Visiting Nurse
5 - Vital Statistics Death List - State Bureau of Vital Statistics
6 - Autopsy
7 - Personal Contact, Letters, Phone calls, etc.
8 - Other sources
X - Unknown

60 **PRESENT STATUS OF PATIENT WITH RESPECT TO THIS CANCER**

0 - Dead - No evidence of this cancer
1 - Dead - With this cancer
2 - Dead - Status of this cancer unknown
3 - Dead - Local recurrence of this cancer
4 - Dead - Metastases from this cancer
5 - Alive - No evidence of this cancer
6 - Alive - With this cancer
7 - Alive - Status of this cancer unknown
8 - Alive - Local recurrence of this cancer
9 - Alive - Metastases from this cancer

61 **ALL TREATMENT FOLLOWING INITIAL TREATMENT RELATING TO THIS CANCER ONLY (cumulated)**

0 - None or check-up only
1 - Surgery
2 - Radiation
4 - Chemotherapy and/or Hormonal therapy
9 - Palliative and supportive treatment (see column 51)
X - Unknown or Not Available

NOTE: If two or more types of treatment are indicated, code the *sum* of the appropriate code numbers. Do not add 9 to any number. *Biopsies and other diagnostic procedures are not to be considered as therapy.*

COLUMN	ITEM AND CODE

62 - 65 **CAUSE OF DEATH**

0000 - Patient Living

Use code from "International Statistical Classification of Diseases, Injuries, and Causes of Death." If no fourth digit is included in the International Statistical Classification, code X in column 65. Note that the code for cause of death *specified* by the physician as "unknown" is 795.5. Code XXXX if information as to cause of death cannot be obtained.

66 **CUMULATED TOTAL NUMBER OF HOSPITAL ADMISSIONS FOR THIS CANCER ONLY**

Determine the total number of times this patient was ever admitted to *any hospital for this cancer*, and code directly.

0 - None
1 - One admission
2 - Two admissions
3 - Etc.
9 - Nine or more admissions
X - Unknown, or not available

67 - 69 **CUMULATED TOTAL NUMBER OF HOSPITAL DAYS FOR THIS CANCER ONLY**

Determine the total number of days this patient ever spent in *all hospitals because of this cancer*, and code directly. For example:

000 - None
001 - One day
050 - Fifty days
129 - One hundred twenty-nine days
999 - Nine hundred ninety-nine or more days
XXX - Unknown, or not available

70 - 80 **AVAILABLE FOR SPECIAL STUDIES**

GENERAL HOSPITAL
Cancer Registry Code Sheet

REGISTRY CASE NO.
(COL. 1–5)

COLUMN	
6–30	NAME OF PATIENT

COLUMN	ITEM	CODE
31	NO. OF PRIMARIES	
32	RESIDENCE OF PATIENT	
33–34	AGE AT INITIAL DIAGNOSIS	
35	SEX AND RACE	
36	MARITAL STATUS	
37	TYPE OF ADMISSION	
38–41	PRIMARY SITE	

COLUMN	ITEM	CODE
42–44	HISTOLOGICAL DIAGNOSIS	
45	BASIS OF DIAGNOSIS	
46–48	DATE OF INITIAL DIAGNOSIS	
49	WHERE FIRST DIAGNOSED	
50	STAGE AT INITIAL DIAGNOSIS	
51	TYPE OF INITIAL TREATMENT	
52	CONDITION AT DISCHARGE	

FOLLOW-UP DATA

DATE LAST SEEN			SURVIVAL TIME			SOURCE OF FOLLOW-UP	PRESENT STATUS	SUBSEQUENT TREATMENT	LIVING OR CAUSE OF DEATH				TOTAL ADMISSIONS	TOTAL HOSPITAL DAYS							
53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74