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THE CANCER REGISTRY

by

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INTRODUCTION

Regional Medical Programs have evidenced keen interest in establishing cancer registries. Registries have been conceived as mechanisms to improve the primary care of patients; and as a resource in the planning of cancer control programs, in continuing professional education, public education, and the furthering of cancer research. This paper is an attempt to assist Regional Medical Programs and others to more fully understand the requirements and restraints in the proper organization and operation of cancer registries.

The opinions and suggested alternatives for support of cancer registry activities are those of the author, and in no way represent official endorsement. The author wishes to express sincere appreciation to Mr. George Linden, Chief of the California Tumor Registry for his valuable advice and information reflecting the experience in California, and to Dr. Sidney J. Cutler and Mr. William I. Lourie, Jr., of the End Results Section, National Cancer Institute, for their constructive suggestions. Dr. Frank R. Mark, Chief, and Mr. Francis C. J. Ichniowski, Assistant Chief of the Operations Research and Systems Analysis Branch were most helpful with the organization of this paper, and Mrs. Grace Kelly with its preparation.

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THE HOSPITAL CANCER REGISTRY

Registries of various diseases and types have been organized and operated in hospitals and health departments for many years. The purpose of some registries, such as tissue and bone tumor registries, are chiefly educational and reference. These special purpose registries are limited to the collection and analysis of data on a single type of cancer. The epidemiological registry principally develops information from a large volume of data from many hospitals about the prevalence, incidence, and survivorship of various sites and types of cancer for research purposes. Such a registry, preferably, should cover the total population in a circumscribed geographical area. Finally, the service registry is designed primarily to evaluate and improve patient care in the local hospital and community. Epidemiological registries of course, may also provide this service to their participating hospitals.

I. Historical Perspective

The American College of Surgeons has conducted a program of periodic inspection and evaluation of cancer facilities since 1930 to better the care of cancer patients by early diagnosis, improved treatment, and informed follow-up through a coordinated cancer activities program. The medical profession and hospital governing boards have sought and accepted the desirability of such official recognition by the College. The College's Commission on Cancer, composed of fellows of the College, liaison members representing professional associations of physicians, radiologists, and pathologists, the American Cancer Society, and government agencies, acts in an advisory capacity in approving hospital cancer programs.

In order to enable hospitals to evaluate their cancer workload and the quality of medical care provided patients, the College encouraged the organization of hospital-based cancer registries. In 1956, registries were made one of the conditions for approval of a hospital's cancer program (see Appendix I for the Basic Standards for Cancer Programs). (1,2) At present, there are about 850 College approved cancer programs in the United States and Puerto Rico. About 800 of the programs are in general hospitals, with about 700 in non-federal hospitals and the remainder in federal hospitals (70 percent Veterans' Administration). The 800 hospitals have a median bed capacity of about 350 beds, and about 75 percent have bed capacities of over 200 beds. The non-federal general hospitals constitute about 12 percent of all short term general hospitals and about 30 percent are affiliated with medical schools. (3)

II. Definition of a Hospital Cancer Registry

A hospital cancer registry, sometimes called a tumor registry, has been described as a "mirror" which can reflect to the hospital staff its overall and individual performance in the diagnosis and treatment of cancer patients. To provide valid information, the registry must consist of records of all cancer patients diagnosed or treated at any of the facilities of the hospital as of a given date. Patients diagnosed elsewhere who received any therapy for their malignant condition in the hospital are to be included, as well as those initially diagnosed at the hospital or its clinics. The cancer registry should include outpatients as well as inpatients, and patients with only a clinical diagnosis as well as those with pathological confirmation of their disease. The registry record, usually referred to as the abstract form, should contain pertinent information on the diagnosis, treatment, and follow-up of each patient, on a continuing basis until death, for each primary malignancy. This information is obtained principally from the patient's hospital medical chart. It is therefore imperative that the medical chart be readily available to registry personnel within a reasonable time after the patient's discharge from the hospital, or each outpatient visit. Incidentally, since the registry is dependent on complete and accurate medical charts for its information, it may serve as an impetus to upgrade the content and quality of all medical records in the hospital.

III. Objectives of a Hospital Cancer Registry

A well organized and operating registry should:

- A. Assist physicians in the provision of continuous medical care of the cancer patients with reminders to them, or to patients with the physicians's consent, of the need for re-examination annually, or more frequently. Follow-up examinations should continue during the life-time of the patient regardless of such eventualities as change of residence, or retirement or death of the physician. This is necessary to insure medical care for many patients who might otherwise not be seen by a physician, and to help in the early diagnosis of local recurrences, metastases, or new primary lesions, and possibly to further their survival and comfort.
- B. Provide the hospital staff with annual or more frequent statistical and analytical reports which evaluate the cancer problem in the institution and community, by site and histologic type, extent of disease (stage), methods of diagnosis, treatment modalities, and survival by age, race and sex. Meaningful reports may lead to the adoption of measures to improve the management of cancer patients, and assist administrators with their scheduling and operational problems. Such reports may also assist in the development of comprehensive cancer programs. The proportion of

patients successfully followed should also be reported, since this is an index of the statistical reliability of the survival data, and a measure of the quality of patient care.

- C. Be a resource for the continuing education of physicians and paramedical personnel at regular clinical conferences, medical society meetings, seminars, and institutes.
- D. Be a resource in the development of public educational programs in the geographic area served by the registry.
- E. Be a stimulus and resource for clinical investigations and research by highlighting areas which require further study.

IV. Components of a Cancer Registry

Although the individual forms and files in cancer registries are not standardized, most registries consist of separate or combination files to facilitate the identification, follow-up, and tabulation of patient information. (4) On August 5, 1968, the Division of Regional Medical Programs brought together an ad hoc committee of representatives from the American College of Surgeons, the End Results Section of the National Cancer Institute, the American Cancer Society, several operating registries, and consultants to discuss recommendations for items of information to be collected by cancer registries. These were presented at a cancer registry workshop held in Denver, Colorado, on September 17, 1968 (see Appendix II).

In general a cancer registry consists of:

- A. a primary site file of abstracts of significant information about the history, diagnosis, treatment, and end results of each primary cancer, with follow-up notes during the lifetime of the patient. (If the patient has multiple primaries there should be separate abstracts for each.) If this file is also to serve as the master control file and follow-up control file, separate tabs should be attached to the forms to identify the primary site and to remind the registrar when the (living) patients are due for follow-up re-examinations. To serve these multiple purposes the abstracts should be filed alphabetically by patient name. If the master control file and follow-up control file are separate (see below), abstracts should be grouped by major primary sites and filed in alphabetical order. This permanent file of abstracts should contain the following minimum information:
 - 1. the name, address, registry and hospital chart numbers, and the age or date of birth, race, sex, and marital status of the patient;

2. the dates of admission and discharge from the reporting hospitals;
 3. the name and address of a relative or other contact person;
 4. diagnostic information, including the primary site of the cancer, the basis of the diagnosis, the histological diagnosis if made, the date of initial diagnosis (by any means), and the extent of disease (stage) at initial diagnosis;
 5. the history of the cancer, i.e., when and where the cancer was diagnosed and treated before this admission, the type(s) and date(s) of treatment, and a note about any other primary site(s) of cancer for which the patient may have been treated;
 6. the condition of the patient at discharge;
 7. the name and address of the hospital and/or physician responsible for follow-up; and
 8. periodic notations, at least annually, of follow-up information concerning additional therapy and the status of the patient.
- B. a patient name file of every registered cancer patient, alive or dead. This permanent master control file enables the secretary to avoid duplicate accessions in the registry. The permanent file could consist of 3"x5" cards kept in alphabetical order, and should contain the following information:
1. the patient's full name and address, and that of the spouse if married, or parents if a child;
 2. the hospital medical chart number;
 3. the patient's date of birth, race, and sex;
 4. the cancer diagnosis and primary site;
 5. the date of initial diagnosis;
 6. the name and address of the referring physician; and
 7. the (eventual) cause and date of death.
- C. a follow-up control file of living patients to remind the registrar when the patient should be followed. This file

could consist of 3"x 5" cards kept in alphabetical order by patient's name within each month of follow-up. After each follow-up the patient's card is to be re-filed according to the month of next follow-up. After the patient dies his card should be destroyed. The file cards should contain the following information:

1. the patient's full name and address;
 2. the patient's registry number;
 3. the primary site of cancer;
 4. the date of diagnosis;
 5. the dates when follow-up information about the patient was obtained; and
 6. the name of the attending physician or hospital to whom requests for follow-up information are to be sent.
- D. an accession register, or list of all cancer inpatients and outpatients initially admitted to the hospital, preferably grouped by year of initial diagnosis and major sites. This can be useful for the preparation of administrative reports to measure the cancer workload in the hospital, and for summary reports to the medical staff. [See Appendix III for a suggested cancer registry abstract form (prepared by the staff of the Arkansas State Cancer Commission), patient name and follow-up control cards, and a page from an accession register.]

V. How to Organize a Hospital Cancer Registry

A cancer registry is a self-contained but integral part of a hospital's cancer program, under the over-all jurisdiction of the hospital's Committee on Cancer.

A. The Committee on Cancer

The hospital's Committee on Cancer should be a standing Committee, appointed by the medical staff from its membership and confirmed by the governing board of the hospital. It should include representatives of the departments of surgery, internal medicine, radiology, gynecology, general practice, and pathology; and may include representatives of other medical specialities concerned with the diagnosis and treatment of cancer. It should provide the impetus and over-all direction for the organization of a cancer program, including the conduct of cancer conferences, educational activities, and the operation of the registry. The

Committee must determine the objectives and scope of the registry, and concern itself with such major questions as gathering, dissemination, and analysis of data, personnel, facilities, and other matters relating to its effective organization and operation. (See Appendix IV for Organization Plan for Cancer Programs. (5))

B. Developing Objectives

The Committee on Cancer must develop the specific objectives of the registry and obtain the agreement and cooperation of the medical staff for their implementation. In order to obtain approval of the American College of Surgeons the registry will have to meet their requirements outlined in the Basic Standards for Cancer Programs (Appendix I). Depending upon interests and needs, the Committee may also develop educational programs for the medical and para-medical staffs and the public, and encourage clinical and laboratory research, using registry data as a tool and resource.

C. Supervision of Registry Operations

The registry secretary should be under the general jurisdiction of the Committee on Cancer, and the direct daily supervision of a designated person who need not be a physician (the medical record librarian or tumor clinic secretary). If the supervisor is not a physician, then a medical consultant, usually the pathologist or radiologist, should be appointed for regular consultation with her.

D. Estimating the Cancer Caseload

An important consideration in organizing a hospital cancer registry is an estimation of the cancer caseload, preferably for at least five years. There is a rough relationship between the number of new cancer patients and hospital type (whether public and private), and hospital size. For example, in California there was an average of about 75 new cancer patients per 100 beds in county hospitals, as compared with an average of about 160 patients per 100 beds in private hospitals in 1963. (6) The average number of cancer cases per 100 beds in 1964 through 1969 inclusive, by size of hospital, in Connecticut was as follows:

| <u>Number of Beds</u> | <u>Number of Hospitals</u> | <u>Average New Cases per 100 beds</u> |
|-----------------------|----------------------------|---------------------------------------|
| <u>Total</u> | <u>28</u> | <u>139</u> |
| Under 100 beds | 3 | 114 |
| 100-199 beds | 8 | 115 |
| 200-299 beds | 6 | 133 |
| 300-399 beds | 6 | 132 |
| 400 and more beds | 5 | 159 |

Source: Derived from information provided by the Connecticut Tumor Registry.

There is also a rough relationship between the number of new cancer patients, total inpatient admissions, and size of hospital. The ratio of new cancer cases to total inpatient admissions by size of hospitals in California and Connecticut was as follows:

| <u>Number of Beds</u> | <u>California</u> | | <u>Connecticut</u> | |
|-----------------------|----------------------------|---|----------------------------|---|
| | <u>Number of Hospitals</u> | <u>New Cases as Percent of Admissions</u> | <u>Number of Hospitals</u> | <u>New Cases as Percent of Admissions</u> |
| <u>Total</u> | <u>57</u> | <u>3.0%</u> | <u>26</u> | <u>3.2%</u> |
| Under 100 beds | 8 | 2.1 | 3 | 2.4 |
| 100-199 | 12 | 2.1 | 8 | 2.5 |
| 200-299 | 14 | 3.5 | 6 | 3.0 |
| 300-399 | 5 | 4.6 | 5 | 3.6 |
| 400 and over | 18 | 3.0 | 4 | 3.8 |

Source: Communication from California Tumor Registry, and derived from information provided by the Connecticut Tumor Registry.

In the absence of more specific information these data may be used to develop crude estimates of the number of expected new cancer cases in general hospitals.

E. Cost Considerations

The cost of a registry is directly related to the size of the cancer caseload, and the programs for which it was organized (patient follow-up, professional education, program planning, research, etc.). Some of the components of the total cost of a hospital cancer registry are:

1. the time of the supervisor of the registry personnel (the physician, medical record librarian, or tumor clinic secretary);

2. the salary of a registry secretary and other clerical personnel needed to operate the registry;
3. overhead costs, including the use of a separate room(s) or part of a room, furniture, file cabinets, office equipment and supplies, telephone, electricity, postage, etc.;
4. the time of the medical consultant(s) to the registry;
5. the time of personnel in other departments in the hospital to make available the inpatient and outpatient medical charts, pathology and radiology reports, and any other information needed to complete the registry abstracts;
6. the time of public health or social service personnel to assist with patient follow-up;
7. the cost of special purpose registry forms;
8. the cost of special purpose books (medical dictionary, Manual of Tumor Nomenclature and Coding, etc.);
9. travel costs to attend training courses and workshops;
10. the cost of computer hardware or computer time, if the registry is computerized;
11. personnel to code and keypunch the data, develop software, and operate the computer;
12. the cost of preparing statistical and analytical reports, and their duplication and distribution.

A survey in Ohio in 1967 found that the cost of maintaining a hospital cancer registry ranged from an average of about \$8.50 to \$11.50 per new case; in California this cost averaged about \$10.00 per case. A survey of College approved registries in 1968 found that about two of every three able to respond had annual operating budgets of \$10,000 or less, with a median of \$6,285. (7) The average cost of accessioning a new patient was \$7.60, and of entering follow-up information, \$3.44. (For a discussion of the factors to be considered in estimating these costs see Appendix V.)

VI. Special Problems

If the registry is to be other than a sterile repository of information and achieve its objectives and full potential, the following problems must be overcome:

- A. the lack of interest, cooperation and involvement of the hospital medical staff. This usually reflects the failure of the Committee on Cancer to convey to the staff an appreciation of the purpose and value of the registry, and to see to it that the registry fulfills its service and educational potentials. The survey of College approved registries found that a majority did not provide physicians with regular reports of their management of cancer patients. Perhaps this is why most registries reported fewer than ten requests for data from physicians. (7)
- B. inadequate guidance and assistance to registry personnel in their daily tasks, Continuous guidance and assistance should be available to abstract cases (often from inadequate medical charts), to deal with uncooperative physicians, and to develop routine reports for the medical staff.
- C. inadequate quality control. It is imperative that registry personnel be checked routinely on their accuracy in abstracting and coding. The hospital Records Committee should develop and enforce criteria and regulations to ensure the availability of complete, accurate, and uniform medical charts from attending physicians within a reasonable time after discharge of the patient.
- D. inadequate utilization of registry data to audit the performance of the medical staff in their management of cancer cases, and as a resource in professional and public educational programs.
- E. the unavailability and high turnover of secretarial and technical personnel due to competitive factors. Training of secretaries is, for the most part, on-the-job or at infrequent and short-term workshops. (The University of California Medical Center in San Francisco offers up to two months of training which includes lectures in registry methodology, the medical and sociological aspects of cancer, elementary statistical methods and epidemiology, films on the diagnosis and treatment of cancer, extensive in-service training in abstracting, follow-up, indexing, and the preparation of reports, attendance at consultative tumor board meetings, and field trips. However, they can only accomodate a limited number of trainees at any one time.) With respect to the availability of statistical personnel, programmers, and systems analyst for large registries, it should be noted that these persons are also in short supply and this is not likely to improve in the foreseeable future.
- F. the desirability and need to use mechanical or electronic equipment to process and retrieve data, The use of such equipment will depend upon the volume of cases, financial resources of the hospital, and the uses to be made of the information. In

general, a hospital cancer registry with fewer than 400 new cases per year can be operated manually for at least five years. After the caseload exceeds 2,000 active (living) cases it may be more economical and efficient to use automatic data processing equipment, particularly if it can also be used in other departments of the hospital. However, it must be emphasized that the use of such equipment by itself does not improve the quality of the abstracted information, but rather increases the possibility of errors. The effective utilization of such equipment will depend upon the availability of qualified programmers and systems analysts, and will significantly increase the cost of operation of the registry.

- G. the question of continuing financing. The registry must be assured of continuing financial support if it is to provide the services for which it was organized. Costs increase not only because of competitive and inflationary factors in our economy, but also because of the increasing follow-up load even when the number of new cancer cases remain stable. Also, as physicians develop an appreciation of the use and value of the data in the registry, more staff time will be needed to provide additional services, tabulations, and analyses.

THE CENTRAL CANCER REGISTRY

The American College of Surgeons does not have an official position regarding local, state, or regional central cancer registries. However, hospitals wishing to participate in such registries are expected to "maintain or have available their own data on cancer cases so as to meet the requirement for approval by the College." (1) This is in keeping with the policy and fundamental purpose of the College's individual hospital cancer program "to provide the hospital staff members with a continuing record of what is being accomplished in cancer patient care in their hospital and to insure proper follow-up." (1)

The service and educational benefits of individual hospital cancer registries can be enhanced when they are organized into a central cancer registry system. Properly organized, a central facility can promote and expedite patient follow-up, and provide participating hospitals with separate and comparative reports of their activities. If the central registry is population-based, it can also develop information on the incidence of cancer in the area, and engage in epidemiological research and special studies.

I. Definition and Objectives of Central Cancer Registries

A central cancer registry is a coordinating facility of cooperating hospital registries in a geographic area to collect, combine, compare, and evaluate uniformly defined information on cancer patients which can:

- A. facilitate and improve patient follow-up;
- B. be a resource in the identification of community problems in cancer control, and the development of programs to cope with these needs;
- C. measure and compare the quality of diagnosis and the effectiveness of various treatment modalities in the participating hospitals, separately and as a group;
- D. stimulate inter-hospital and area-wide educational programs for physicians, nurses, and technicians;
- E. provide a resource for community-wide public educational programs;
and
- F. engage in epidemiological and cooperative clinical research efforts.

II. Types of Central Cancer Registries

Central registries vary in purpose, scope of coverage, and method of operation. Following are brief descriptions of four registries which reflect these differences:

- A. The Connecticut Tumor Registry organized more than 35 years ago, requires the reporting and annual follow-up of essentially all diagnosed cases in the state from 38 hospitals. The registry receives abstracts on about 9,000 new cases, and follow-up reports on about 50,000 active cases each year. A fee based on credit points for completeness of each abstract submitted is paid to 31 community hospitals to help defray the cost of operation of the individual hospital registries, and as an incentive for the maintenance of quality reporting. Registry staff code and process the abstracts and follow-up reports, train hospital secretaries in the operation of their registries, assist them with follow-up, and prepare follow-up letters for the hospitals for transmission to the physicians. The registry publishes information about the extent and nature of the cancer problem in the state, and makes available indices to evaluate progress in bringing the disease under control. Data is developed on the number, characteristics, and geographic distribution of cancer patients to plan public health programs, and to formulate and test hypotheses concerning the etiology of the disease. The registry also provides information on trends on the extent of disease at diagnosis, survival experience, and cancer incidence to evaluate progress made over a period of years.

- B. The California Tumor Registry was established in 1947 and has grown, on a voluntary basis, to 57 participating hospitals. Many more hospitals wish to join this system but the number of participants has been limited in order to maintain the registry's excellent record of collecting uniform data of high quality with the available staff. The Registry includes all 24 hospitals in Alameda County to make a population-based system in that County. The 57 hospitals report about 20,000 new cases (about one-third of the total cancer caseload in the State), and follow about 75,000 cancer cases each year. The registry pays \$3.10 to each hospital for each completed abstract. It is estimated that this fee covers approximately one-fourth to one-half of the hospital's total cost. The registry staff codes and processes the abstracts and follow-up reports, and prepares annual reports, diagnostic indices, and reports on the survival experience (with comparisons to the total registry), for each participating hospital. Data is also prepared to answer physicians' requests, for planning public health programs, and for special studies and publications related to cancer diagnosis, treatment, and survival.

- C. The Rocky Mountain States Cooperative Tumor Registry (organized in 1967 and supported by the Intermountain, Mountain States, and Colorado-Wyoming Regional Medical Programs) includes hospitals in Utah, Idaho, Montana, Colorado, and Wyoming. Large institutions submit abstracts of all diagnosed cancer cases to the Registry, and medical students abstract cases in small hospitals for the Registry four times a year. The Registry sends follow-up inquiries directly to the patients' physicians annually, and copies of their responses to the hospital from which the abstract originated. Twice a year the Registry sends listings of the characteristics and status of the patients at last follow-up to the hospitals and the attending physicians. Various medical specialty groups are requested to review the literature and choose references to be included in the listings to the physicians, on a voluntary basis. Each group is also given an opportunity to use the registry data to analyze the malignancies with which they are most intimately concerned, and publish the results in the Rocky Mountain Medical Journal. The articles review the diagnosis, treatment, and survival of cancer patients in the area, and suggest methods for improvement.
- D. The Iowa Central Tumor Registry founded in 1965, was organized to provide continuing cancer education for physicians who take part in the cancer programs of the 54 participating hospitals. These hospitals admit more than 75 percent of the cancer patients in Iowa, and accessioned about 11,000 cases during 1969. More than 18,000 cases of cancer are being followed by the 54 hospitals. The central registry provides the following services: (1) storage, retrieval, and analysis of the cancer data collected by participating hospitals; (2) a semi-automated follow-up system; (3) a field program which assists hospitals with the organization and evaluation of their cancer programs; and (4) financial support. The principal educational impact of the Iowa Central Tumor Registry is provided by the annual reports sent to each participating hospital in October. This report includes a tabulation of the cancer data collected during the preceding year by the hospital, their current survival results computed on the basis of all cases obtained from the hospital, and a cancer patient listing. Each participating hospital is also given a report of the combined experience of all hospitals participating in the registry to provide them with a basis for evaluating their own experience. The registry also assists physicians in cancer clinical research and in providing cancer data for use in hospital cancer educational programs. The central registry biostatistician is available to assist physicians with the interpretation of the data.

III. Advantages and Benefits

A properly organized central cancer registry has several distinct advantages over individually operated hospital registries. Among these are:

- A. improved uniformity and quality of data abstracted and coded in accordance with mutually agreed upon definitions. This can be ensured by continuous monitoring and training of secretarial and coding personnel in the participating hospitals and central facility. An added dividend is a general upgrading of the medical charts in the participating hospitals due to the requirements of the central registry for complete reporting.
- B. efficiencies that come with size. Centralization of coding, keypunching, programming, and computer usage can result in substantial savings when compared to the aggregate costs of these activities in separate hospitals.
- C. availability of technology and statistical personnel (which the participating hospitals could not afford individually) to assist physicians and hospitals with the follow-up of cancer patients, and the preparation of comprehensive and comparative analysis of the management of cancer in each of the hospitals by pooling of financial resources or centralized funding.
- D. improved public and professional educational programs, and more useful analytical reports of the cancer control problem in the community due to the larger volume and diversity of cancer cases.
- E. the more immediate benefits that can accrue to patients and physicians. Routine requests for follow-up information by a registry promotes medical care of the patient. For example, following the suggestion of their Advisory Committee, the California Tumor Registry ranked the hospitals on their follow-up efforts (using only codes to identify each hospital). The proportion of patients on whom current follow-up information was received increased 19 percentage points from 71 percent to 90 percent within a two and a half year period. In a sample survey over a six-month period, the California Tumor Registry found that a little more than 60 percent of the patients had received at least one medical examination during the last year. If it is assumed instead, that 75 percent (or three-quarters) of the patients on whom follow-up information was obtained were seen by their physicians without stimulus from the registry, an

additional one-quarter were brought under medical care as a result of the registry's intensified follow-up program. Thus, in California an additional five percent (1/4 times 19 percent) of the total file of living patients were brought under medical supervision. With about 75,000 patients currently in the active file in the California Tumor Registry, about 3,500 additional patients each year are benefitting from medical care they otherwise might not have.

Also, an evaluation and comparison of central registry data relating to the extent of disease at diagnosis in the participating hospitals may improve early case finding and treatment. In California the percent of patients diagnosed with early cancers (excluding skin) increased by six percentage points over a fifteen year period. Thus, with about 20,000 new cancer patients added to the registry each year, about 1,200 additional patients may be benefitting from earlier care.

IV. How to Organize a Central Cancer Registry

The organization of a central cancer registry is not too unlike the organization of an individual hospital registry. The proper organization of such a combined effort requires:

- A. medical leadership. A central registry is a cooperative arrangement among the medical staffs of participating hospitals. It should have the endorsement of local and state medical societies, other professional organizations, the state health department, hospital administrators, and voluntary agencies. The leadership for such a combined effort may come from physicians from one or (preferably) more hospitals, local medical societies, and the state health department.
- B. a medical advisory committee. The central registry itself requires a representative professional advisory committee to consider policy and operating questions which relate to the interests of the participating hospitals as well as the objectives of the centralized facility.
- C. a definition of objectives. The advisory committee will have to define the objectives of the combined effort in the light of the specific needs and objectives of the participating hospitals. They will have to consider whether the data in the registry will be used to evaluate questions such as, the referral patterns of the different kinds of hospitals (community, specialty, and in medical centers), the diagnostic and therapeutic resources in the participating hospitals, and other questions concerning the utilization of health care facilities in the area. The advisory

committee will also have to consider whether they can or even want to operate a registry which will assist in the follow-up of patients, engage in comparative studies and the evaluation of diagnosis and therapy, and epidemiological research, versus one with more limited objectives. In this connection it should be noted that the potential for epidemiological research is not, in itself, sufficient justification for the establishment of a central registry. While it is desirable that several states in different parts of the country develop such registries for purposes of comparison, epidemiologists have long noted that research needs do not require such registries in all states in the country. (8)

D. consideration of the scope of coverage and total caseload.

A central cancer registry can:

1. include all hospitals in the state (or region),
2. consist of a selected number of hospitals in the state,
3. consist of hospitals in a local and limited geographical area (county or city), or
4. consist of a confederation of several local central cancer registries.

Whatever the scope and caseload a central registry must be nurtured patiently and carefully over a period of years (at least five) before it can prove its effectiveness in the provision of services and useful information. This can be accomplished only if the participating hospitals are incorporated and phased into the system methodically over a period of time.

The number and bed capacities of the participating hospitals will determine the total caseload in the registry. The methods suggested on page 6 can be used to estimate the caseload in the central registry. An estimate of the increasing number of cases to be followed each successive year will also be necessary. If we assume that the number of new cases will remain constant from year to year, the total active (living) caseload to be followed, based on the survival experience of the National Cancer Institute End Results Group, will be about three times as large by the fifth year of operation of the registry, about four and a half times by the tenth year, and about five and a half times as large by the fifteenth year of operation of the registry.

E. consideration of the method of operation. A central registry can acquire data by having the participating hospitals send copies of their abstracts, or the registry can send out circuit-riding

abstractors to the hospitals, or use a combination of both methods. Of paramount importance, however, is the development of mechanisms to obtain total reporting from the hospitals with uniform interpretation of the reported information. The registry may ensure consistency of information with periodic reviews of the procedures of the participating hospitals, re-abstracting of a sample number of medical charts, and training sessions and workshops of registry personnel and medical advisors. (9) Without such quality control measures the accumulated data could be meaningless.

Another aspect of the method of operation to be considered is the question of manual operation of the registry versus operation with mechanical or electronic equipment. A registry with a large number of cases will have difficulty handling the volume of reported data, and servicing the hospitals without the assistance of automatic data processing equipment. Automation of registry files can assist hospitals with the follow-up of patients, and greatly enhance the usefulness of the data in the form of frequent reports to physicians and hospitals. It should be noted, however, that the need to accurately transform (code) and keypunch data for computer processing can be one of the most time-consuming, difficult, and expensive procedures.

F. consideration of the cost of a central registry. The objectives of the registry and their effective implementation, the number of physicians and hospitals participating in the program, and the size of the caseload bear on the cost of operation of the registry. Some of the components of the cost of a central registry are:

1. the employment of a qualified supervisor (who may be a statistician);
2. personnel needed for the routine operation of the registry (secretarial, clerical, coders, keypunch operators);
3. technical personnel (statisticians, systems analysts, programmers);
4. computer hardware or computer time;
5. overhead costs which includes the use of one or more large rooms for the supervisor, the other registry staff, and the computer; the necessary desks, chairs, ordinary and special purpose file cabinets; office equipment, such as calculators, adding machines and supplies, telephones, postage, electricity, etc.;
6. the time of the medical advisory committee;

7. special purpose registry stationery, forms, binders, etc.;
8. special purpose books and manuals;
9. travel costs for visits to participating hospitals to abstract and/or review data, to attend training workshops, professional meetings, etc.

The California Tumor Registry estimates that the current cost associated with the routine operation of their registry (including follow-up) is about \$10 per new case. This includes salaries and fringe benefits (in a relatively high labor cost area), computer and other data processing costs, field visits of registry personnel to ensure the quality of the abstracts from the hospitals, the cost of obtaining copies of death certificates, and overhead costs (rent, furniture, office equipment and supplies, telephone, electricity, postage, etc.) A new registry with a small follow-up load will cost considerably less per new case in the early years of operation. The California Tumor Registry also estimates that it costs another \$4 per new case to report to each hospital on its own experience; to answer requests for data from physicians, hospitals, and other agencies; to develop research studies; and to prepare reports and publications for distribution. It must be emphasized that these estimates do not include fees or subsidies to hospitals to cover their costs of reporting to the central registry, or the cost to the participating hospitals of maintaining their own registry.

V. Special Problems

The organization and operation of a central cancer registry presents several special problems. Among these are:

- A. the need to stimulate and maintain the interest and involvement of the physicians in the participating hospitals. This may be accomplished by the representatives of the hospitals by communicating to the registry the interests and needs of the physicians. Physicians must see the results of their efforts, and made to feel members of a team effort. Periodic reports about their specialty and the activities of the hospitals in which they practice, and the organization of a professional educational program which shows how they relate to the total effort of cancer control in the area can stimulate their involvement. Rapport between physicians in the participating hospitals and the central registry can be promoted if their reciprocal responsibilities and obligations are explicitly stated and agreed upon at the outset.

- B. the problem of effective quality control. The maintenance of quality control is most important in the operation of a central cancer registry (see section IV E on page 16 above for suggested techniques). Without such control the data and any resultant analysis is of dubious validity.
- C. the availability of qualified personnel. A central registry that has more than minimum objectives requires an epidemiologist, statisticians, systems analysts, and programmers. These persons are in great demand in health and other areas, and there is little likelihood that this situation will improve in the near future. Thus, the shortage of technical personnel may short-circuit any projected benefits envisioned by the organization of a central registry. Consideration must also be given to the availability and retention of other trained registry personnel and clerical staff since they play a vital part in the daily operations of the registry and maintaining the quality of the data.
- D. the availability of long-term financing. Proponents of a central cancer registry must keep in mind that costs will continue to rise especially because of the increasing volume, and increasing demands which will be made on the registry as its usefulness is recognized. Long-range financing arrangements must therefore be made for continuation of the facility if it is to be worth the initial efforts. Also, without assurance of long-range support there is likely to be abnormal turnover of personnel. This may require operating short-cuts to the detriment of the quality of the data, and the service and educational benefits.

REGIONAL MEDICAL PROGRAMS AND CANCER REGISTRY ACTIVITIES

I. Regional Medical Programs

Public Law 89-239, enacted on October 6, 1965, authorizes the establishment and maintenance of Regional Medical Programs to assist the nation's health resources in making available the best possible patient care for heart disease, cancer, stroke, and related diseases. Through a system of grants the law attempts to provide the means for conveying to medical institutions and the professions the latest advances in medical science for the prevention, diagnosis, treatment, and rehabilitation of patients afflicted with these diseases. The grants assist in the establishment of regional cooperative arrangements among medical schools, research institutions, hospitals, and other medical institutions and agencies to achieve these ends by research, education, and demonstrations of patient care. Since the enactment of the law representative groups have organized themselves to conduct Regional Medical Programs in 55 regions using functional as well as geographic criteria. Regions include combinations of entire states, portions of several states, single states, and portions of states around a metropolitan center. (10)

II. Grants for Cancer Registry Activities

Between June 1966 and the end of February 1970, about 180 million dollars were awarded (not spent) to the 55 Regions for all planning and operational activities. Of this amount, about 128 million dollars were awarded to 53 Regions for project grants since April 1967; about two million of which has been made available in the current program period to 18 Regions for twenty operational projects with cancer registry components, in whole or part. Additional funds have been spent by some Regions for cancer registries for purposes of program planning. Except for the Rocky Mountain Cooperative Tumor Registry (page 13) registry projects are in the beginning stages of organization and operation, hence it is too early to evaluate their progress. Additional cancer registry proposals have been submitted for funding by Regional Medical Programs and others are considering doing so.

III. Alternatives for Support and Benefits

The decision to engage in cancer registry activities should be made only after the Regional Medical Program has carefully considered the purpose and use of cancer registries in a comprehensive and cohesive cancer program. A Region may wish to develop a limited registry, whereas another may wish to develop one which can provide extensive services. The choice should only be made after a careful assessment of needs, and a realistic evaluation of available re-

sources. Regions thinking about promoting cancer registry activities, may wish to consider one or more of the following options:

- A. To make available technicians to assist hospitals in the organization and operation of their individual cancer registries. Such technicians must have training in registry operations, and have some background in the preparation of statistical tabulations and reports. To service large hospital registries technicians also require competence in the development and analysis of special studies, and the use of automatic data processing machines.
- B. To provide financial assistance to hospitals to enable them to organize and operate their registries.
- C. To provide financial assistance to one or more local (county) central registries (preferably population-based) which would receive or obtain reports on all cancer cases in the participating hospitals. Central registry personnel should be available to assist hospitals with the organization and operation of their registries, the analysis of statistical data, and the development of special studies.
- D. To provide financial assistance for a Region-wide central cancer registry (preferably population-based) which would receive or obtain reports on all cancer cases in the participating hospitals. Personnel resources should be the same as that for local central registries noted in item C above.

Some benefits of the separate alternatives are:

| Benefits(x) | Support of technician(s) | Support of individual hospital registries | Support of local central registry(s) | Support of Region-wide central registry |
|--|--------------------------|---|--------------------------------------|---|
| 1. Ready access to data by hospital staff | x | x | Where hosp. registries organized | Where hospital registries organized |
| 2. Encourage medical staff participation & involvement | x | x | More likely with hospital registry | More likely with hospital registry |

(Continued)

| Benifits (x) | Support of technician(s) | Support of individual hospital registries | Support of local central registry(s) | Support of Region-wide central registry |
|--|----------------------------------|---|--------------------------------------|---|
| 3. Training resource | x | - | x | x |
| 4. Provide additional assistance in following patients | - | - | x | x |
| 5. Develop reports, analysis, studies | Limited experience and resources | Limited experience and resources | x | x |
| 6. Development of uniform data among hospitals | x | - | x | x |
| 7. Preparation of comparative reports of hospitals | - | - | x | x |
| 8. Preparation of combined reports of hospitals | - | - | x | x |
| 9. Resource to develop area-wide cancer program | - | - | Reflects local needs | x |
| 10. Resource for professional educational programs | Limited to hospital | Limited to hospital | Reflects local needs | x |

(Continued)

| Benefits(x) | Support of technician(s) | Support of individual hospital registries | Support of local central registry(s) | Support of Region-wide central registry |
|--|--------------------------|---|--------------------------------------|---|
| 11. Resource for public educational programs | - | - | Reflects local needs | x |
| 12. Engage in epidemiological research | - | - | x | x |

It appears therefore that maximum benefits may be obtained by way of local and/or region-wide population-based central registries. In the last analysis the decision to support cancer registry activities, and the extent of such support, will depend upon their relative importance as compared to other health needs in the region, the leadership and interest of the medical community, and the availability of trained personnel and financial resources at the time of initiation of such activities, and in the future.

IV. Questions Considered for Support

As has been indicated, the proper organization of a cancer registry is no simple matter and must be approached with much thought. Following are some of the question which staff of the Division of Regional Medical Programs and reviewers consider when evaluating proposals for support of a registry:

- A. How does this new registry activity or expansion of an existing registry fit into the overall cancer program in the Region?
- B. Are the objectives clear with reference to:
 1. patient services,
 2. follow-up services for physicians and hospitals,
 3. the number of physicians that might benefit from professional educational programs utilizing registry data,
 4. whether the registry activity will attempt any unique services to patients, physicians, hospitals, the community, (with examples of such possible services),
 5. how the registry will fulfill a regional and/or national need,

6. the use of registry data in public educational programs, and possibly,
 7. the kinds of research studies anticipated?
- C. Does the proposal include documentation or other evidence of cooperative arrangements with:
1. medical societies (county, state),
 2. the administrators and staffs of participating hospitals,
 3. other professional organizations (pathologists, radiologists, surgeons, dental society, etc.), and
 4. paramedical groups and voluntary organizations?
- D. Will the medical advisory group of the proposed registry (which will consider registry policies and operating questions) be representative of the participating hospitals and professional groups?
- E. How many hospitals are to be included in the central registry, how many hospitals have cancer registries presently, what is the estimate of the cancer load in each of the participating hospitals, and the anticipated combined cancer load over a five year period?
- F. What will be the composition of the personnel, both technical and auxiliary, available to the central registry?
- G. What mechanism is to be used or developed to train personnel in participating hospitals, and to review the completeness and accuracy of the abstracts they will submit?
- H. How will additional hospitals be phased into the system, and at what rate?
- I. What kinds of automatic data processing equipment will be used, and what is the basis for the selection of the equipment?
- J. Will competence in the development of software be required, what personnel or time will be needed for this, and the cost?
- K. What are the justifications for the budget data for personnel, space, furniture, equipment, supplies, travel, etc.?
- L. What other sources of support will be available during and after funding by the Regional Medical Program?

V. Consultation

Before a Regional Medical Program submits a registry proposal to the Division of Regional Medical Programs for funding it is suggested that they try to profit from the experience of previously funded and existing registries. Technical staff is also available from the Division to assist in the development of hospital and central cancer registry projects, and the training of registry personnel. Requests for such assistance may be addressed to:

Chief, Operations Research and Systems Analysis Branch
Attention: Mr. Abraham Ringel
Division of Regional Medical Programs
Health Services and Mental Health Administration
Parklawn Building, Room 10-49
5600 Fishers Lane
Rockville, Maryland 20852
Telephone Number (301) 443-1800

Appendix I

Basic Standards for Cancer Programs (2)

A. Accreditation of hospital

1. Only those hospitals which are accredited by the Joint Commission on Accreditation of Hospitals will be considered for approval. Should a hospital forfeit its accreditation after receiving approval of its cancer program, approval will be withdrawn. The hospital cancer program will be re-evaluated upon request when accreditation is restored.

2. In the evaluation of nonhospital medical institutions with cancer programs, only those which are certified by the county or state medical society will be considered for approval.

B. Hospital committee. The clinical cancer activities program is to be under the guidance of a committee on cancer composed of representatives from the several medical specialties concerned with the diagnosis and treatment of cancer. It is suggested that representatives of the departments of surgery, radiotherapy, pathology, internal medicine, gynecology and general practice be assigned to the committee, with additional representatives as desired.

C. Clinical program. The American College of Surgeons has established the following minimal standards for hospital and other recognized institutional cancer programs. The College recognizes that local situations may call for modifications which facilitate operation of the program, and makes provision for indicated variations which do not alter the established basic principles and policies.

1. The clinical program is to be conducted under rules formulated and approved by the medical staff and confirmed by the governing body of the hospital or clinic involved.

2. Clinical cancer conferences and cancer educational activities are conducted by an appointed group which may be the same as the hospital committee on cancer. A member of the group shall be appointed as director. Auxiliary professional and secretarial personnel are to be assigned to the group according to the needs for efficient operation.

3. Nonprivate patients with cancer or suspected cancer should, as a matter of policy, be referred to the cancer clinical conference for consultation.

4. Physicians should be encouraged to present their private patients to the conferences.

There should be a clear understanding that the ultimate responsibility remains with the patient's physician.

5. Clinical conferences will be held regularly, preferably weekly. Consultative sessions should be held between regularly scheduled conferences when necessary, to avoid delay in instituting treatment. The conferences will provide consultation service only, or consultation and treatment service, according to the policy established by the medical staff and confirmed by the governing board of the hospital.

a. All members of the hospital staff, including interns and residents, and physicians in the community, should be encouraged to attend the conferences.

b. Minutes of the sessions should contain a record of the attendance, the cases considered, and other pertinent information.

6. The cancer clinical activities committee should initiate professional educational activities and encourage clinical research in cancer. It should render an annual report including an evaluation of the data contained in the cancer registry, a summary of the minutes of the clinical conferences, and recommendations leading to improvement in cancer control.

7. When therapy is part of the total program, adequate facilities and equipment shall be available for diagnosis and treatment.

8. Responsibility for local fiscal support of the cancer program rests with the individual hospital. There is no general formula to fit all institutions. Financing of the program should ultimately be a part of the hospital budget.

D. Registry. An institution-wide cancer registry shall be in operation:

1. To provide service to the patient by assuring lifetime interval follow-through examinations, regardless of eventualities such as change of residence, retirement or death of the patient's physician, as well as change of residence of the patient. A registry has the administrative capability of reminding both the physician and the patient that it is time for a re-examination. Meaningful follow-through can be accomplished only by a thorough examination by a physician. This facilitates early recognition of local recurrences and metastases and early diagnosis of a new primary cancer.

(Continued on next page)

Appendix I (Continued)

2. To provide the hospital staff with statistical reports on site, stage, method of diagnosis, treatment and results for all patients with cancer treated in that hospital. Only if the follow-through examinations are maintained at a level approximating 100 per cent, will the accrued statistical data be meaningful.

E. Reports on survival and end results

1. Reports based on data obtained from the cancer registry are to be presented at least annually to the hospital staff. The reports should include analyses of data on survival and end results for various types of cancer.

2. The periodic reports based upon register data will serve as a guide for the care of cancer patients within the hospital and will be useful in developing the over-all hospital cancer program. These reports are often a stimulus for clinical investigations and research by pointing out the areas in which studies are especially indicated.

3. The hospital will have available, at the time of survey of the cancer program, evidence that periodic reports are being submitted to the hospital staff. A copy of the report must be submitted to the field representative of the College at the time of survey, together with a description of the method of distribution and presentation to the staff members. These reports, based on statistical data from the cancer registry, will be given great weight by the Commission on Cancer in evaluating programs.

Appendix II

ITEMS OF INFORMATION FOR CANCER REGISTRIES

On August 5, 1968, the Division of Regional Medical Programs brought together an ad-hoc committee of representatives from the American College of Surgeons, the End Results Section of the National Cancer Institute, the American Cancer Society, several operating registries, and consultants to discuss recommendations for items of information to be collected by cancer registries.

The information that follows represents the general consensus of this committee and is intended as a working paper for consideration by on-going registries, organizations, and institutions planning registry programs, and by various national and regional bodies. It is not intended as a set of criteria for approval of a registry by any recognized national body.

The items listed have been grouped into two categories: Core items and Optional Items. Whereas the Core Items are generally considered desirable, they do not represent minimum requirements. One member of the ad-hoc committee suggests shifting of several items from Core to Optional and vice versa. For example, he suggests that the history of diagnosis and treatment of each prior cancer be listed as Optional, but that performance status be listed as Core. Another member feels that performance status be listed as Core. Another member feels that the list is a compendium of information that should be in the hospital record rather than a guide for developing a cancer registry abstract. Obviously, the amount of information to be abstracted routinely must be geared to the purposes of each individual registry. Additional information can be abstracted on selected series of cases on a special study basis, in order to answer specific questions.

In order to implement the collection of the information listed, a registry program will have to develop specific operational procedures, definitions, and codes. The development of basically uniform definitions and codes to facilitate pooling and comparison of data is a desirable goal. Experience in a number of well-established registry programs provides a basis for developing appropriate guidelines to promote uniformity.

Appendix II (Continued)

ITEMS OF INFORMATION FOR CANCER REGISTRIES

CORE ITEMS

- * Not required at Central Registry
- ** Not required at Local Registry

A. Identification:

1. Hospital -- name or code number
2. Patient
 - a. Name -- surname, first, middle
husband's first name
(changes in name)
 - b. Chart number(s)
 - c. Hospital registry accession number
 - ** d. Central registry accession number
 - e. Address - street, city, (county), state, ZIP code
(changes in address)
 - * f. Phone number (and changes)
 - * g. Relative(s) or other contact(s)
 - 1) Relationship
 - 2) Name, address, phone number
 - h. Race
 - i. Sex
 - j. Date of birth -- month, day, year
 - k. Age at admission for present cancer
 - l. Marital status -- single, married, widowed, divorced,
or separated

B. History:

1. Prior other cancer (except for non-melanotic skin cancer)
 - a. No, yes
 - b. If yes -
 - 1) Number of prior primaries
 - 2) Diagnosis, date, treatment, and place of treatment for each
2. Prior diagnosis of present cancer
 - a. No, yes
 - b. If yes -
 - 1) Name of hospital or physician
 - 2) Diagnosis (site and type) and date
 - 3) Method of diagnosis -- histology, hematology, cytology, x-ray, clinical only, other (specify), not reported
 - 4) Was treatment given?
 - a) No, yes, not reported
 - b) Type of treatment and date(s)

C. Diagnosis (present cancer):

- ** 1. Sequence number (excluding prior non-melanotic skin cancer)--
One primary only
First of two or more primaries
Second or later primary
Unspecified sequence number
2. Primary site -- minimum detail as per ICD (8th revision), or as per Manual of Tumor Nomenclature and Coding, 1968 revision

Appendix II (Continued)

3. Date of initial diagnosis (may be clinical) --month, year
4. Confirmation of diagnosis -- histology, hematology, cytology, x-ray, clinical only, other (specify), autopsy, not reported
5. Histopathologic diagnosis
 - a. Morphologic type -- detail as per Manual of Tumor Nomenclature and Coding, 1968 revision
 - b. Date of histopathology
6. Extent of disease --assessment of extent of disease at initial treatment based on all information available during first course of treatment
 - a. Summary classification
 - In-situ
 - Localized, i.e., has not extended beyond primary site
 - Regional
 - Regional node involvement
 - Direct extension to adjacent tissues
 - Regional nodes plus direct extension
 - Not otherwise specified
 - Distant or diffuse spread
 - b. Basis of assessment of extent of disease -- histopathology, surgical exploration, x-ray, clinical only, other (specify)

D. Treatment:

1. First course -- include all tumor-directed treatments that were part of the initial attack on the cancer. Exclude any treatment given because the first prescribed course of therapy failed.
 - a. Date of initiation of tumor-directed treatment
 - b. Identify each type of treatment given and date initiated. The major types of treatment are: surgery, beam radiation, other radiation, chemotherapy, hormone therapy, endocrine surgery, and endocrine radiation.

Appendix II (Continued)

2. Subsequent tumor-directed therapy

- a. Record as per first course
- b. For coding purposes it is sufficient to combine all subsequent treatment to identify types given

E. Follow-up:

- 1. Date of contact (or death)
- 2. Type of contact, e.g., medical examination, letter, phone call
- 3. Vital status -- alive or dead
- 4. Disease status at last contact or death (including autopsy findings)

No evidence of any cancer

In remission

Evidence of cancer

Residual (never free of this cancer)

Reappearance of this cancer

Other cancer present, but no evidence of this cancer

Cancer present, but origin not known

Unknown

5. Cause of death

- a. Per death certificate
- b. Per best available information, including autopsy findings; indicate source

6. Survival time -- years and months from date of first diagnosis

* 7. Physician (or clinic) responsible for patient follow-up

Appendix II (Continued)

OPTIONAL ITEMS*

A. Identification:

1. Location of hospital -- city or county
2. Patient
 - a. Maiden name
 - b. Social security number -- may be used in lieu of accession numbers
 - c. Employer -- name, address, phone
 - d. Insurance company
 - e. V. A. claim number
 - f. Items of epidemiologic interest, e.g., occupation, county of birth of patient and parents, menopausal status, etc.

B. History:

1. Prior skin cancers other than melanoma
Same information as for other prior cancers
2. Delay (months elapsed) -- various intervals may be computed by recording:
 - a. Date of first symptoms
 - b. Date first sought medical advice
 - c. Date of first diagnosis
 - d. Date of initiation of treatment

C. Diagnosis:

2. Detailed description of location of primary tumor
3. Multiple tumors within primary site -- information on multiple tumors should include location and histology of each

*Outline letters and numbers relate to the letters and numbers under Core Items.

Appendix II (Continued)

- a. At initial diagnosis
 - b. Over time (dates)
 5. Histopathologic diagnosis
 - a. Size of tumor in cm.
 - b. Descriptive summary (including type of specimen)
 - c. Identification of laboratory or pathologist
 - d. Slide numbers
 6. Extent of disease
 - a. A more detailed descriptive scheme may be used provided it is compatible with the summary classification.
 - b. Detailed description in text form or via a check list (including bases of assessment of spread to different parts of the body)
 7. Clinical assessment of extent of disease
 - a. Summary classification per American Joint Committee
 - b. Detailed description in text form or via a check list
- D. Treatment
1. First course
 - a. Description of each type of treatment, including extent of surgery; radiation fields and dosage; specific chemotherapeutic agents, route, and dose; and date of completion of each course.
 - b. If no tumor-directed treatment was given, state reason
 - c. If other than optimal type of treatment was given, or if treatment plan was modified, give reason
 2. Subsequent tumor -- directed therapy
Description of each type of treatment (as per 1a above)

Appendix II (Continued)

3. Supportive therapy -- description and dates of non-tumor-directed treatments, such as by-pass surgery and blood transfusion, particularly when this was the only treatment given or when it preceded the first tumor-directed treatment

E. Follow-up:

1. Date of first reappearance of disease, or statement that patient was never free of disease
2. Time elapsed (years and months) from date of initiation of treatment to first reappearance of disease
3. Performance status -- at each hospital discharge, or at each contact
 - a. Classification
 - Normal activity
 - Asymptomatic
 - Symptomatic
 - Unable to work
 - Capable of selfcare
 - Not capable of selfcare
 - Severely disabled
 - Not terminal
 - Terminal
 - Dead
 - Not reported
 - b. If disabled, is disability primarily due to other disease -- yes, no, not reported
5. Cause of death -- summary of autopsy findings
6. Survival time -- years and months from date of initiation of treatment
7. Other interested physician

Appendix III

Cancer Registry Abstract

| | | | | | | |
|---|---|---|---|--|--|---|
| PATIENT IDENTIFICATION | NAME (Last) (First) (Middle) (Spouse) | | | | | State Registry No. (leave blank) |
| | ADDRESS (No. and Street or R.F.D.) (City) (County) (State Zip) (Phone No.) | | | | | Social Security No. |
| | DATE OF BIRTH | SEX (check one) <input type="checkbox"/> Male <input type="checkbox"/> Female | RACE (check one) <input type="checkbox"/> White <input type="checkbox"/> Negro <input type="checkbox"/> Amn. Indian <input type="checkbox"/> Other, specify | MARITAL STATUS <input type="checkbox"/> Never married <input type="checkbox"/> Married | | Hospital Registry No. |
| | NAME, ADDRESS, AND RELATIONSHIP OF TWO CONTACTS | | | | | Name of Hospital and Hospital Chart No. |
| INITIAL DIAGNOSIS, DESCRIPTION OF TUMOR, AND TREATMENT | 1. _____ | | | | | Date of Admission (Month, day, and year) |
| | 2. _____ | | | | | Date of Discharge (Month, day, and year) |
| | PRIMARY SITE OF THIS TUMOR | | | | | |
| | HISTOLOGICAL DIAGNOSIS (Summary of pathology report) | | | | | |
| | BASIS OF DIAGNOSIS | | | | | |
| | <input type="checkbox"/> Autopsy | | <input type="checkbox"/> X-ray | | <input type="checkbox"/> Originally clinical or X-ray, microscopic confirmation later | |
| | <input type="checkbox"/> Histology | | <input type="checkbox"/> Clinical Only | | <input type="checkbox"/> Unknown | |
| | STAGE OF DISEASE (check one) | | | | | |
| | <input type="checkbox"/> In Situ | | <input type="checkbox"/> Localized | | <input type="checkbox"/> Regional with regional nodes plus direct extension | |
| | <input type="checkbox"/> Regional with direct extension to adjacent tissues | | <input type="checkbox"/> Regional with regional node involvement | | <input type="checkbox"/> Regional, not otherwise specified | |
| <input type="checkbox"/> Distant or diffuse spread | | <input type="checkbox"/> Not recorded | | | | |
| PLACE FIRST DIAGNOSED (Name and Address of Doctor or Hospital) | | | | | DATE FIRST DIAGNOSED (Month, day, and year) | |
| PLACE(S), TYPE(S), AND DATE(S) OF TREATMENT PRIOR TO THIS ADMISSION | | | | | | |
| TYPE(S) OF TREATMENT AT THIS ADMISSION: | | | | | | |
| <input type="checkbox"/> Surgery | | <input type="checkbox"/> Beam radiation | | Record actual treatment: | | |
| <input type="checkbox"/> Other radiation | | <input type="checkbox"/> Chemotherapy | | | | |
| <input type="checkbox"/> Hormone therapy | | <input type="checkbox"/> Endocrine surgery | | | | |
| <input type="checkbox"/> Endocrine radiation | | <input type="checkbox"/> Other-directed | | | | |
| <input type="checkbox"/> Other treatment, none of above | | <input type="checkbox"/> No treatment, specify reason | | | | |
| FOR USE IN FOLLOW-UP | NAME AND ADDRESS OF ATTENDING PHYSICIAN | | | | INTERVAL TO FOLLOW-UP (check one) | |
| | NAME AND ADDRESS OF REFERRING PHYSICIAN | | | | <input type="checkbox"/> 3 months <input type="checkbox"/> 6 months <input type="checkbox"/> 12 months | |
| Name of Person Submitting Report _____ | | | | | Date _____ | |
| Reviewed by _____ | | | | | M.D. | |

Appendix III (Continued)

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. _____

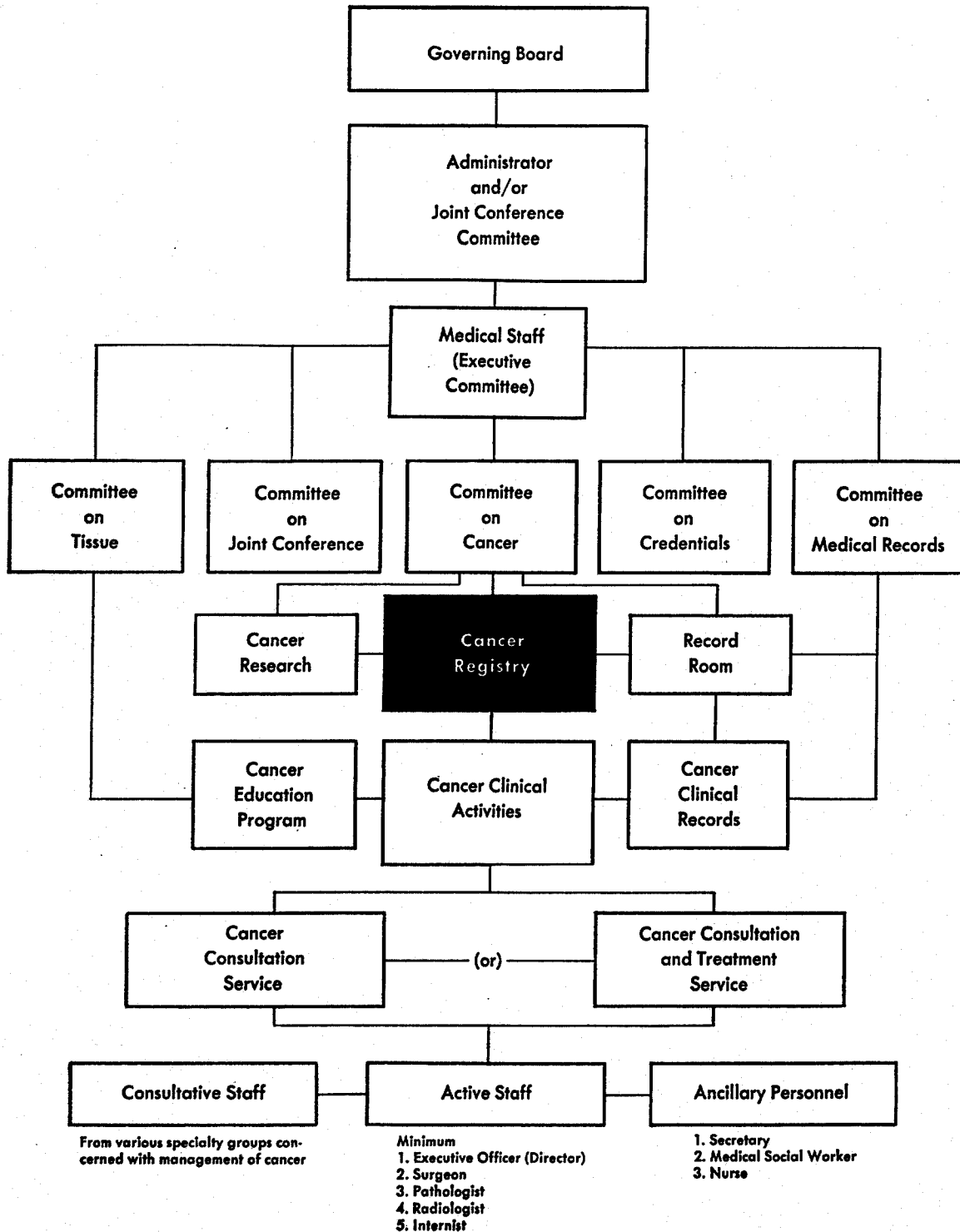
ADDRESS: _____

SITE: _____ DATE DIAGNOSED: _____

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

Appendix IV

Organizational Plan for Cancer Programs (5)



Appendix V

Cost Considerations in the Operation of a Hospital Cancer Registry

The major cost in the routine operation of a hospital cancer registry is for secretarial help. Ideally, a cancer registry secretary should have training and knowledge comparable to that of a medical secretary, with some aptitude for elementary statistical tabulations. In general, the pay scale for a medically knowledgeable registry secretary is comparable to that of a medical secretary. The higher salary for such a person, as compared to that of a general secretary, will be more than compensated for by lower turnover, greater efficiency, and accuracy in abstracting medical records. However, in the absence of such a person, an alert general secretary, with no more than a high school education can operate a registry of moderate size successfully, provided she receives adequate training, and close supervision and guidance by the medical consultant. Respondents to a survey of registries approved by the American College of Surgeons report that 64 percent of the registry personnel had either a high school or secretarial school education and that such personnel could be trained to perform adequately within twelve weeks.⁷

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 to be recorded on the abstract form; (3) the availability of medical charts (inpatient and outpatient); (4) the completeness and legibility of the medical charts; (5) the availability of information from the pathology laboratory and the department of radiology; and (6) the response from physicians and others for follow-up information. Two of every three registries reported that their secretaries worked 40 or fewer hours per week.⁷

It is estimated that a secretary will require a maximum of one hour to completely 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 assumption that variables three to six mentioned above are favorable. For example, if the secretary must hunt for missing medical charts, or for information missing from the charts, or if she has to send several letters to physicians and follow-up contacts in order to obtain adequate follow-up information, more time will have to be allowed. Estimates of the optimum and maximum number of actual work hours of secretarial help required per week to carry out the routine work of maintaining a hospital cancer registry for 15 years, per 100 new

Appendix V (Continued)

cancer patients annually, are presented in the table on the right. These estimates include the preparation of routine manual tabulations of the registry data, at least annually. However, these estimates do not include time to answer numerous inquiries and requests for information, or to code data for computer processing. Additional provision must also be made for work-breaks, sickness, and vacation time.

To this should be added the cost of the time of physicians and statistical personnel to supervise the registry and prepare analytical and special study reports to evaluate the management of cancer in the hospital -- the fundamental reason for the registry. These additional costs will vary according to the interests and needs of the medical staff.

The overhead costs of a registry must also be considered. It is desirable that the registry be located in a separate room so that the secretary may work with a minimum of distraction. Personnel will require the usual office furniture and equipment including letter file cabinet(s) to house cancer registry abstract forms, small cabinet(s) for the patient name and follow-up control files, and secretarial and clerical supplies. The hospital must also provide basic reference books and manuals, follow-up aids, a telephone, and postage. Finally, registry forms and form letters may be purchased commercially, or be prepared and reproduced by photo-offset for about \$50 per thousand.

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 Years¹ Per 100 New Cancer Patients Annually²

| | 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 ($3.7 \times 2.5 = 9.3$).

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

²There 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 0.75 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.

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