

20050405022

REPRODUCED FROM
BEST AVAILABLE COPY

AD 711249

Technical Report 70-101

Establishment of a
Tumor Registry System for Louisiana:
Proposals on Objectives,
Capabilities, and Structure

by
C. Dennis Fink

HumRRO Division No. 1 (System Operations)

June 1970

Prepared for:
Louisiana
Regional Medical
Program

This document has been approved
for public release and sale; its
distribution is unlimited.

DDC
RECEIVED
SEP 14 1970
RECEIVED

Distribution of this
document is unlimited.

HUMAN RESEARCH ORGANIZATION

Reproduced by the
CLEARINGHOUSE
for Federal Scientific & Technical
Information Springfield Va. 22151

ACCESSION TM		
CPSTI	WHITE SECTION	<input checked="" type="checkbox"/>
BDS	SUFF SECTION	<input type="checkbox"/>
UNANNOUNCED		<input type="checkbox"/>
JUSTIFICATION		
BY		
DISTRIBUTION/AVAILABILITY CODES		
EXT.	AVAIL. CODE	SPECIAL
1		

Destroy this report when it is no longer needed.
Do not return it to the originator.

**Establishment of a
Tumor Registry System for Louisiana:
Proposals on Objectives,
Capabilities, and Structure**

by

C. Dennis Fink

Distribution of this document is unlimited.

June 1970

Prepared for:
Louisiana Regional Medical Program
HumRRO Contract No. S70-11

HumRRO Division No. 1 (System Operations)
Alexandria, Virginia
HUMAN RESOURCES RESEARCH ORGANIZATION

Technical Report 70-101

The Human Resources Research Organization (HumRRO) is a nonprofit corporation established in 1969 to conduct research in the field of training and education. It is a continuation of The George Washington University Human Resources Research Office. HumRRO's general purpose is to improve human performance, particularly in organizational settings, through behavioral and social science research, development, and consultation.

This investigation was supported by the Louisiana Regional Medical Program (LRMP). The findings in this report are not to be construed as an official LRMP position.

Published

June 1970

by

HUMAN RESOURCES RESEARCH ORGANIZATION

300 North Washington Street

Alexandria, Virginia 22314

FOREWORD

The Louisiana Regional Medical Program (LRMP) has identified the need for a state-wide tumor registry as part of its cancer program. The proper development of such a registry system depends in part on information about the needs and operations of those local tumor registries which now exist within the state. The services of the Human Resources Research Organization were secured to conduct a survey to gather this information.

The survey was conducted during March 1970. Dr. C. Dennis Fink, Senior Staff Scientist, HumRRO Division No. 1 (System Operations), was the principal investigator. Assistance and consultation services were provided by Dr. Mary A. Fink, Special Virus Cancer Program, National Cancer Institute. During the planning and report preparation phases of this study, consultation services were provided by Mr. Abraham Ringel, Division of Regional Medical Programs, Health Services and Mental Health Administration, U.S. Department of Health, Education, and Welfare.

This project was supported by the Louisiana Regional Medical Program and performed at the request of the Cancer Commission of the Louisiana State Medical Society. The Cancer Commission provided the travel and per diem funds for Dr. Mary A. Fink.

This survey is in part a continuation of an earlier HumRRO study for the LRMP, described in HumRRO Technical Report 69-101, *Staffing and Training Requirements for Tumor Registry Centers in the State of Louisiana*, by C. Dennis Fink, January 1969.

Appreciation is expressed to the many people who provided valuable assistance and information during this study. They include Dr. J.A. Sabatier, Jr., and members of his staff of the Louisiana Regional Medical Program, Dr. Robert Ryan, Department of Surgery, Tulane Medical School, and the tumor registry supervisors and secretaries, medical records librarians, and hospital staff members and administrators who were interviewed during this study.

In particular, appreciation is due for the assistance provided by the two consultants for this activity, Mr. Abraham Ringel and Dr. Mary A. Fink. Mr. Ringel, Division of Regional Medical Programs, provided valuable information and reference material on the establishment and operation of tumor registry systems, and also reviewed the questionnaire which served as an interview guide. Dr. Mary A. Fink assisted in the actual conduct of the survey and reviewed the technical report.

Meredith P. Crawford
President
Human Resources Research Organization

SUMMARY AND RECOMMENDATIONS

PURPOSE OF THE STUDY

The Louisiana Regional Medical Program (LRMP) has identified the need for a state-wide tumor registry as part of its cancer program. The purpose of this survey was to obtain suggestions regarding how this registry system should be designed and what services it might provide. The study was sponsored by the Louisiana Regional Medical Program and was performed at the request of the Cancer Commission of the Louisiana State Medical Society.

PROCEDURES

Nine hospitals and clinics were visited by the survey team during the weeks of March 13 and 20, and in-depth interviews were held with the supervisors and secretaries of the tumor registry at each institution. At a number of hospitals, interested members of the medical staff and of the administration also were interviewed.

As an aid in collecting the interview data, a comprehensive questionnaire was developed describing the various operations, services, and products of a registry. The questionnaire was mailed to the supervisor of each registry with a request that it be reviewed before the visit of the survey team. During the interview the questionnaire was used to guide the questioning sequence. Topics covered during the interviews included: (a) local interest in the establishment of a state-wide registry system; (b) services which a central registry might provide to local registries; (c) degree and manner in which local registries are utilized by the medical staff; and (d) conditions under which the local hospital would be willing to join the central registry system.

Portions of the report are also based, in part, on discussions with personnel of the Division of Regional Medical Programs (DRMP) and on examination of various documents prepared by the DRMP, the American Cancer Society, the California Tumor Registry, and the Rocky Mountain Tumor Registry.

FINDINGS

The major findings of the survey are as follows:

(1) Seven hospitals and community registries were identified as being prime candidates for incorporation into the initial state-wide registry system. Taken together these registries account for the treatment of approximately 4500 of the estimated 9500 new cases of cancer per year within the state of Louisiana.

(2) The interviewees expressed a preference for organizing the initial registry system to include most of the various medical regions existing within the state, so that comparisons could be made between regions, and so that subsequent expansion within regions would be facilitated.

(3) The interviewees were in agreement that the initial registry system should, if at all possible, contain representatives of the various types of private and public hospitals existing within the state.

(4) Tumor registries now in existence throughout the state employ somewhat different criteria for selecting those cases to be incorporated into the registry. In addition, some registries do not include out-patients. Agreement would have to be reached among the participating hospitals regarding what information to include in the registry system.

(5) Generally speaking, tumor registries are little used by the medical staff; in particular, the annual reports seem to be of little value. The need for providing useful services in establishing a tumor registry system, and of convincing the medical staff at each hospital of the advantages to be gained from utilizing the system was emphasized.

(6) A desire was expressed for training workshops for registry personnel. However, it was pointed out that most hospitals do not provide travel and per diem funds for tumor registry personnel.

(7) The problem of maintaining medical record confidentiality was emphasized. Most interviewees expressed a reluctance to provide patient and physician identification to a central registry.

(8) Considerable concern was expressed over the manner in which the registry system would be financed after the initial years of funding by the DRMP. The need was expressed for a sound long-range financing plan, along with a plan for providing financial assistance to those small hospitals which otherwise might not be able to join the registry system.

RECOMMENDATIONS

The major recommendations of the study are as follows:

(1) The Tumor Registry system established should initially be specifically oriented to providing the services that would be most highly valued by the local users—the individual physician and the Tumor Committee for each hospital. To stimulate use of the system, these potential users should be carefully identified, and their needs for information and for particular services should be ascertained. In addition, means should be employed to educate users to obtain maximum benefit from the system, and procedures should be developed for periodic study of whether the registry is being used as envisaged, and, if not, reasons for low utilization.

(2) A Planning Committee should be established, consisting of 10-12 people and including representatives of the Cancer Commission, Louisiana Regional Medical Program, and hospital and community registries that are potential participants in the initial registry system. This Planning Commission should make decisions regarding such elements as:

(a) Activities to be performed in the central registry and those to be performed in peripheral registries.

(b) The amounts and kinds of services to be provided by the central registry to serve as a basis for establishing costs, staffing, and so on.

(c) The information and reports to be provided by the central registry.

(d) Procedures for assuring confidentiality of information.

(e) Procedures for continually assessing services and reports and modifying them when appropriate.

(3) The system established should consist of three varieties of components: the central registry, community registries, and peripheral or local registries. The system should be conceived with community registries serving as the core to the system.

(4) Functions performed by the system components should be:

(a) Selection of cases by personnel of the peripheral registry. As a last resort this could be performed, all or in part, by the community registry.

(b) Abstracting of cases by personnel of the peripheral registry. For smaller hospitals the community registry could perform this activity.

-
- (c) Coding of abstracts by community registry personnel.
 - (d) Maintenance of local files by personnel of the peripheral registry. At smaller hospitals the community registry could perform this activity.
 - (e) Statistical analysis by the central registry.
 - (f) Interpretive reporting and the preparation of annual reports for participating hospitals by the central registry.
 - (g) Patient follow-up by all three units of the registry system, the exact work-sharing arrangement to be established by agreement between the local hospital, the community registry, and the central registry. Patient follow-up consists of several different activities, each of which can best be performed by a different unit of the registry system.
 - (h) Training of peripheral registry personnel by the community registry with assistance from the central registry.
 - (i) Processing of requests from and inputs to peripheral registries by the community registry.
 - (j) Provision of information for and assistance to state and region-wide educational, research, and other types of programs relating to cancer by the central registry.
 - (k) Provision of capability to store, retrieve, and process information by the central registry.

(5) Special attention should be given to two problems of concern to personnel currently involved with tumor registry—funding and confidentiality of records.

(a) Initially, funding to establish a registry system would be provided by the federal government. Such support, however, is programmed to be gradually withdrawn beginning three to five years after the system has been established. In order to ensure continuing financial support for the tumor registry system, it is essential that the system establish itself as an important and useful medical tool for local users—mainly the individual physician and cancer committee of the local hospitals. It is, therefore, especially critical that mechanisms be provided to identify needs and educate users on a continuing basis. Hopefully, by this means the value of the system would be obvious and documentable, a condition which should increase greatly the probability of obtaining nonfederal funds for the continued support of the system.

(b) Maintaining confidentiality of patient records was of great concern to those interviewed. While this could be managed by coding in such a way that only the local hospital could identify patients, such coding would make it impossible for the registry to perform certain important functions (e.g., records could not be screened for duplication, to identify patients who had been to more than one hospital, and data would thereby be inflated beyond the actual number of cases; the central registry would not be able to aid in follow-up search or screen the file in terms of death certifications). It is critical that appropriate safeguards be established to ensure confidentiality and at the same time permit the system to perform needed functions for the local users.

(6) Initial participants in the registry system should include at least one representative from each of the seven health regions of the state; this would allow the system to be extended readily into a complete, state-wide registry system.

CONTENTS

Chapter		Page
1	Introduction	3
	Background and Objectives of Survey	3
	Approach	3
	Sources of Information	4
	Survey Methods	4
	Contents of Report	5
	Regional Medical Programs and Cancer Registry Activities	5
	Functions Served Ly Tumor Registries	6
	Types of Registries	6
	Major Purposes	6
2	Establishment of a Tumor Registry System for the State of Louisiana	3
	Objectives and Characteristics of Initial State-Wide Registry System	8
	Services to Be Provided	8
	Proposed Structure of System	9
	Major Steps in the Establishment of a Tumor Registry System	10
	Capabilities Required of the Registry System	12
	Organizational Structure and Responsibilities	12
	Participating Hospitals and Their Responsibilities	12
	Central Registry and Its Responsibilities	13
	Community Registry Options	13
	Provision of Statistical Capability	14
	Recommendations Re Survey Objectives	14
3	Special Problems in Establishing a Registry System	17
	Financial Support for the Registry System	17
	Confidentiality of Tumor Registry Information	19
4	Operations, Products, and Services of a Registry System	20
	Selection of Records for Incorporation Into Tumor Registry	20
	Preparation of the Tumor Registry Abstract	21
	Coding of the Tumor Registry Abstract	22
	Maintenance of Tumor Registry Files	22
	Patient Follow-Up	22
	Follow-Up: A Major Registry Activity	22
	Possible Types of Assistance to Local Registries	23
	Preparation of Reports and Listings	24
	Miscellaneous Services Provided by a Central Registry	30
	References	33
	Appendix	
	Guidelines for Cancer Registry Activities	35

Figures		Page
1	Cancer Registry Summary	25
2	Tumor Registry Annual Statistical Report	26
3	Year Report of Cancer Survival and End Results	27
4	Tumor Registry Listing (Physician)	26

**Establishment of a
Tumor Registry System for Louisiana:
Proposals on Objectives,
Capabilities, and Structure**

Chapter 1

INTRODUCTION

BACKGROUND AND OBJECTIVES OF SURVEY

The Louisiana Regional Medical Program (LRMP) has identified the need for a state-wide tumor registry system as part of its program to make improved care for cancer available to the people of the state. This effort, sponsored by the Division of Regional Medical Programs (DRMP),¹ is part of a national program to upgrade medical care in the areas of heart disease, cancer, stroke and related diseases (Public Law 89-239).

Effective planning and development of such a registry system depends in part on obtaining information about the needs and operations of those local tumor registries which now exist within the state, and their willingness to cooperate in establishing a state-wide registry system. To gather this information, the Human Resources Research Organization was asked to conduct a survey at tumor registries within the state which are prime candidates for incorporation into the initial state-wide tumor registry system.

This survey of registries was conducted at the request of the Cancer Commission of the Louisiana State Medical Society. It is this commission which would have the responsibility for overseeing the development of the registry and therefore would use much of the information developed as a result of this survey.

The purpose of this survey was to obtain information that could be used as guidance during the design of the proposed state-wide tumor registry for Louisiana. The specified objectives of the survey were:

- (1) To identify the appropriate types of registry to be located in peripheral areas in order to effectively dovetail with a central state registry in a mutually satisfactory and complementary fashion.
- (2) To determine the most feasible type of data collection system to be used in peripheral registries.
- (3) To determine how local (peripheral) registries can best be set up to serve the needs of the local physician.

APPROACH

The survey team, during the weeks of March 13 and 20, 1970, visited nine hospitals and clinics and conducted in-depth interviews with tumor registry personnel, and with other hospital personnel as appropriate. Discussions were also held with members of and consultants to the Louisiana Regional Medical Program, and information was gathered on the operations, services, and products which typify existing registry systems involved in the cancer care programs.

Findings were then developed on the basis of the information and suggestions obtained, and these were used as a basis for suggesting concepts and procedures to serve as guidance in designing and developing a state-wide tumor registry system.

¹Health Services and Mental Health Administration, U.S. Department of Health, Education, and Welfare (HSMHA, DHEW).

Sources of Information

Persons interviewed at the nine hospitals visited during the survey included the supervisors of tumor registries, tumor registry secretaries, medical record librarians, and interested members of the hospital administration and medical staff. The institutions visited were:

Sara Mayo Hospital, New Orleans
Touro Infirmary, New Orleans
Charity Hospital, Lafayette
Baptist Hospital, Alexandria
Mother Cabrini Hospital, Alexandria
Confederate Memorial Hospital, Shreveport
St. Patrick's Hospital, Lake Charles
Obstetrics and Gynecological Clinic, Baton Rouge
Earl K. Long State Hospital, Baton Rouge

Discussions and conferences were held with the following persons in various positions of responsibility in connection with the regional medical and cancer registry programs:

Dr. J.A. Sabatier, Jr., Director, Louisiana Regional Medical Program, and members of his staff.

Dr. Robert Ryan, Department of Surgery, Tulane Medical School.

Abraham Ringel, Operations Research and Systems Analysis Branch, Division of Regional Medical Programs (HSMHA, DHEW).

Valuable information and suggestions also were obtained from the following sources:

A review of the literature and reference material on tumor registries developed by the American College of Surgeons and the American Cancer Society.

A review of material prepared by the California Tumor Registry.

A review of material prepared by the Tumor Registry System sponsored by the Inter-Mountain Regional Medical Program.

A review of material prepared by the Division of Regional Medical Programs.

Survey Methods

As an aid in collecting the in-depth interview data from staff members at the nine hospitals visited, a questionnaire was developed describing the various operations, services, and products of a registry. The persons interviewed were asked to indicate their interest in the various services and products and to express a preference for the various alternative ways in which these might be provided.

Because of the length of the questionnaire it was not feasible for any particular individual to answer all of the questions. Rather, a questionnaire was mailed to the supervisor of each registry with a request to scan the content prior to the visit of the survey team. During the interview the questionnaire was then used to guide the sequence of the discussion. Comments of the respondents were summarized and recorded by the interviewers.

The major topics covered during these interviews included:

- Local interest in the establishment of a state-wide registry system.
- Services which a central registry might provide to local registries.
- Degree and manner in which local registries are utilized by the medical staff.
- Conditions under which the local hospital would be willing to join the central registry system.

Contents of Report

This report presents a distillation of the suggestions offered by the persons interviewed during the survey, and of the conclusions reached by the survey team on the basis of the interviews. Also incorporated are suggestions based in part on discussions with DRMP personnel and on examination of documents prepared by the DRMP, the American Cancer Society, and established registry systems.

General background information on regional medical programs and tumor registry functions is presented in the remaining pages of Chapter 1. The findings and conclusions are summarized in Chapter 2, and certain aspects are discussed in greater detail in Chapters 3 and 4.

Regional Medical Programs and Cancer Registry Activities

To indicate the relationship between regional medical programs and cancer registry activities, material has been adapted or quoted from two documents, *Guidelines: Regional Medical Programs* (17) and *The Cancer Registry* (15), both prepared by the Division of Regional Medical Programs. Persons interested in the establishment of tumor registries and tumor registry systems should study these two important documents.

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." (15) The object of this Act "is to influence the present arrangements for health services in a manner that will permit the best in modern medical care for heart disease, cancer, stroke, and related diseases to be available to all." (17)

Development of Comprehensive Programs. "The cancer program of a regional medical program, as with all operational programs, should be comprehensive and cohesive. The decision to engage in cancer registry activities should be made only after the region has carefully considered the purpose and use of cancer registries within the total cancer program of the region." (15) As an example, a regional program may recognize that the more effective approach in cancer care would be to consider the *total* problem of the treatment of cancer patients within the region. This broadened view permits considering the total array of resources within the region in relation to a comprehensive program for the identification of and for the care of cancer patients. Thus, what was a concern of individual hospitals about how to identify and manage cancer patients is transformed into a project or group of related projects with much greater potential for effective and efficient utilization of the region's resources to improve patient care.

Program Evaluation Criteria. The success of a region in implementing a comprehensive program for cancer is judged by the degree to which it can be demonstrated that the regional program has implemented seven essential elements of a regional medical program. These are:

- Involvement and commitment of individuals, organizations and institutions.
- Identification of needs and opportunities.
- Assessment of regional resources.
- Definition of objectives.
- Establishment of priorities.

- Implementation of operational proposals.
- System for evaluating effectiveness of program.

Ultimately, the success of any regional medical program must be judged by the extent to which it has assisted the providers of health services in developing a system which makes available to everyone in the region improved care for heart disease, cancer, strokes, and related diseases (17).

Relation Between Registry System and Comprehensive Program for Cancer. The development of a tumor registry system for Louisiana is one aspect of the comprehensive cancer program to be developed for the state. This includes the preparation of a plan for establishing and operating a state-wide tumor registry system, clearly specifying the relevance of the objectives, products, and services of this system to the comprehensive cancer program for the state.

The decision of the Division of Regional Medical Programs to provide financial support for a proposed registry system depends in considerable measure on the relevance of the proposed system to the overall cancer program for the region. A list of questions to be considered by the DRMP when evaluating proposals for support of registry activities (Appendix) is indicative of the nature of the decisions that will need to be made during the planning of a registry system for Louisiana.

FUNCTIONS SERVED BY TUMOR REGISTRIES

Types of Registries

Tumor registries can be classified into three general types—hospital evaluation cancer registries, epidemiological registries, and special purpose registries (1). The registry at Charity Hospital, New Orleans, is a hospital evaluation registry with participation by the End Results Program; all other registries within the state are of the "evaluation" variety. The registry types may be characterized as follows:

- Hospital evaluation cancer registries collect information about all cancer patients at a particular institution. Such a registry can provide information that can be used by the hospital administration and professional staff to assess the effectiveness of their treatment of cancer patients. This is the type of registry existing at most hospitals.
- Epidemiological registries collect information about the prevalence and incidence of cancer. They assemble large volumes of data that can be used to make various types of statistical comparisons. With rare exceptions, most hospitals and communities could not afford or could not make appropriate use of such a registry.
- Special purpose registries collect information on one aspect or form of cancer. For example, there may be bone tumor registries, oral registries, and gynecological registries. Such registries may be very useful for a special type of clinic or for medical specialty groups. For the typical hospital, however, their scope is too restrictive.

The central registry established for Louisiana should be designed primarily to support hospital evaluation cancer registries. To a limited extent the central registry could serve as an epidemiological registry in that it would collect data on the incidence, type, and efficacy of cancer treatment within the various regions within the state.

Major Purposes

The four major purposes of a tumor registry, as viewed by the American Cancer Society (1), are listed below. These purposes apply equally well to a local registry or to a state-wide registry system, although they are not likely to receive equal emphasis. While

formulating plans for establishing a registry, the planning group must decide which of these purposes will be emphasized initially. The four major purposes are:

1. Quality control in diagnosis and treatment

Report on sites and stages

Treatment:

- a. Rates
- b. Mortality
- c. Morbidity

End Results

2. Follow-up

Detection of treatable disease:

- a. Local recurrences
- b. Regional metastases
- c. Isolated remote metastases
- d. 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

Chapter 2

ESTABLISHMENT OF A TUMOR REGISTRY SYSTEM FOR THE STATE OF LOUISIANA

This chapter summarizes the findings from the survey and related information-gathering activities, presented in the form of coordinated suggestions for the establishment of a state-wide tumor registry system. The two final chapters of the report deal in more detail with some aspects of the problems to be solved, and with the activities and products projected for the system.

This summary section includes: (a) a conceptualization of the objectives and characteristics of the initial stage of the state-wide system, in terms of the services to be provided and the proposed structure of the system; (b) the major steps to be taken to establish the system; (c) a summation of the *basic* capabilities the system must have; (d) a discussion of the allocation of responsibilities within the organizational structure of the system; (e) a discussion of the findings with specific reference to the three objectives of the survey.

OBJECTIVES AND CHARACTERISTICS OF INITIAL STATE-WIDE REGISTRY SYSTEM

Services to Be Provided

Service-Oriented System. Tumor registries will be useful to the extent that they provide valued information and services. Unfortunately, many individual tumor registries and some tumor registry systems are not heavily utilized and indeed may be producing information and services of doubtful value. The Louisiana registry system should be strictly service-oriented. *Its general goal should be to bring about an improvement in the early diagnosis and treatment of cancer patients, by providing information and services to individual physicians, hospital administration and committees, and local, regional and state level public health and other medical agencies and societies.*

High-Priority Services. A new registry system cannot hope to provide all of the desirable services. Rather, the objective initially should be to provide those services that have the potential for making the greatest impact on the medical community in the care of cancer patients. Services should be selected which (a) can be utilized by the largest number, (b) are high-priority services as judged by potential users, and (c) can be provided in a relatively economic fashion fairly soon after the registry system is established.

Services for Multiple Types of Users. The registry system should seek to identify all groups and individuals who could use the registry system, and then determine the information and the services that would be important to the various potential users and that could be provided without disproportionately high expense. The registry system should be aggressive both in determining how it can be of service and then in providing educational information describing how these services can best be utilized.

Analysis of Services and Information Outputs. Tumor registries have a tendency to provide "nice to have" as opposed to "need to have" services and information. Therefore each proposed service and output should be analyzed in terms of *how it is related to the*

Improved care of cancer patients. For each service and information output of the system one should be able to provide the following:

- (1) A clear and substantiated description of potential users.
- (2) Evidence of (a) a need on the part of a large percentage of one or more types of users, or (b) a high-priority requirement for a small group of users.
- (3) A clear indication of how it can be used to improve, to modify, and/or to increase understanding of the handling of cancer patients.

Proposed Structure of System

Small Number of Initial Participants. The initial registry system should be composed of a small group of hospital and community registries supported by a central registry. The system should remain small and easily manageable until it is operating smoothly. Then, additional hospital and community registries can be added. At a maximum, two years should be sufficient to establish a smoothly operating model registry system.

Decentralized Operation. With respect to the operation and the staffing of the registry system, every effort should be made to decentralize registry activities while at the same time maximizing the use of full-time tumor registry personnel. This could be done effectively by organizing the registry system so that individual hospitals are supported by community registries which in turn are supported by a central registry (this approach will be discussed more fully later in this section). In this way the registry system would be decentralized, with one or two representatives functioning at the community level. These community level people would be able to assist in or perform much of the tumor registry work at small local hospitals while the larger local hospitals could employ their own full- or part-time tumor registry persons. The goal would be to have persons employed at the community and individual hospital level working on registry activities at least one-half time; in this way they would have an opportunity to rapidly acquire and successfully maintain the skills and knowledge required to operate a tumor registry.

Types and Characteristics of Initial Participants. The initial participants in a registry system should be chosen carefully since it is these participants who must plan and implement the system. They should be representative of certain types of hospitals and tumor registries, and possess certain characteristics:

(1) **Representative of both public and private hospitals.** Every effort should be made to secure the early participation of both private and public hospitals and to provide both types with strong representation on the governing body of the registry system.

(2) **Representative of both individual hospital and community registries.** Community registries have considerable merit and their early participation in a state-wide system might lead other communities to establish their own community registries.

(3) **Be widely distributed throughout the area to be covered by the registry system.** The state of Louisiana is divided into seven medical regions; it would be well to have as many of these regions as possible represented in the model registry system. When the time came for system expansion there would be within each region hospitals and persons who were familiar with the registry system operation and its value to the medical community. Also, this distribution would allow a limited type of statistical comparison among regions.

(4) **A proven capability for operating their own registries.** A central registry system does not replace local registries. It can relieve local registries of certain portions of their work load and can perform certain broader functions but, fundamentally, the reliability and validity of the overall registry system is dependent upon the quality of work performed at the local registries.

(5) **A high interest in tumor registries, and especially in the potential offered by establishment of a state-wide system.** The fact that a hospital operates a tumor registry does not necessarily mean that the hospital staff is interested in or will actively

support a state registry, or even that they make optimum use of their own registry. Other hospitals may be interested but, for a variety of reasons, may be reluctant to join a state-wide system. It may be better to invite such hospitals to join the registry some time after it has been established and has had an opportunity to demonstrate its value.

(6) Be capable of providing partial financial support for local registries. It seems appropriate to ask each hospital and/or community to contribute financially to the operation of its own registry. However, it is contemplated that the local hospitals and community registries would not be required to incur expenses beyond those they currently incur in operating their individual registry. Participants would be reimbursed for expenses they incur in support of the central registry system. Registry financing will be discussed in detail later in this report.

(7) A willingness to cooperate and to arrive at a set of common forms and procedures. It is essential that registry participants agree on the use of a common abstract and common rules for abstracting the medical records of cancer patients. Also, they must reach some agreement regarding the types of services which the registry will provide and the manner in which these services will be provided. A spirit of cooperativeness and the willingness to engage in a bit of trial and error are essential.

(8) A willingness to participate in registry system planning sessions. The initial registry participants would have the opportunity jointly to determine those services which the registry system should provide and the operating procedures for the registry. A limited number of planning sessions would be necessary to make the required decisions and to approve of the operating procedures for the central registry.

Suggested List of Initial Registry System Participants. On the basis of discussions with administrative personnel, tumor committee members, and tumor registry secretaries at the various hospitals visited during the survey, it is recommended that the following be invited to participate in the model state-wide registry system:

Charity Hospital, New Orleans
Charity Hospital, Lafayette
Touro Infirmary, New Orleans
Baptist Hospital, Alexandria
Mother Cabrini Hospital, Alexandria
St. Patrick's Hospital, Lake Charles
East Baton Rouge Parish Tumor Registry (under development)

It has been estimated that 9500 new cases of cancer occur yearly within Louisiana. The above hospitals and community registry system collectively account for treatment of approximately 4500 of these cases. The group includes both public and private hospitals, and represents most of the state's medical regions.

MAJOR STEPS IN THE ESTABLISHMENT OF A TUMOR REGISTRY SYSTEM

The intent in this section is to record some of the commonly expressed thoughts regarding the steps which should be followed and the problems which must be surmounted before a registry system can become operational.

Selection of a Sponsor for Planning Activities. Some agency must accept the responsibility for instituting and coordinating the many planned activities that must occur during the establishment of the registry system. This agency should have an obvious association with cancer problems, be interested in the establishment of a tumor registry system, and be capable of eliciting the cooperation of the medical societies and organizations within the state. It would seem most appropriate that the responsibility for overseeing the planning of a Louisiana tumor registry system be given to the Cancer Commission of the Louisiana State Medical Society.

Formation of a Planning Committee. This committee probably should be limited to 10 to 12 persons. In addition to representatives from the Cancer Commission and the Louisiana Regional Medical Program, it would include representatives from the hospitals and community registries that are potential participants in the model registry system. A highly suitable group of participants would be the pathologists who are currently overseeing tumor registry activities at the various hospitals within the state; it should be recognized that these persons are extremely busy and special schedules or weekend conferences might have to be arranged to permit them to take part. Also, it would seem appropriate to rotate the planning sessions throughout the various potential participating hospitals, or else hold the sessions at Baton Rouge or Alexandria. To assist the planners, the Cancer Commission's tumor registry consultant and consultants from the Division of Regional Medical Programs should be invited.

Utilization of Information Sources. Information is available from a wide range of sources to provide guidance and working materials for use by those persons having the responsibility for designing a registry system. The references listed in this report provide quite detailed descriptions of the operations and potential reports and services of a registry. In addition, most cancer registry systems have prepared a variety of manuals and reports which describe the operation of their registry and the products and services which they offer. In some instances documentation exists for the various computer programs developed by these registry systems. A library of cancer registry information is being developed by Mr. Abraham Ringel of the Operations Research and Systems Analysis Branch of the DRMP; persons helping to design a registry system might wish to visit the DRMP and study the material contained within this library.

Major Decision Areas Which Must be Covered by the Planning Committee. The decision areas listed below will be topics for special discussion within this report. These areas are:

(1) The relationship between the central and the peripheral registries. Decisions must be made regarding the various activities and services which will be performed at the central and at the local level, and how these two registry levels will mutually support one another.

(2) Operational estimates for the services to be provided by the central registry. Once the services have been tentatively selected, other specialists can translate these services into staffing requirements, equipment requirements, facility requirements, plans of operations, and cost estimates. This information can then be used by the committee to re-evaluate their list of tentative services and to make appropriate additions or deletions.

(3) Information and reports to be provided by the central registry. In addition to the variety of services which the central registry might provide, it also can take on much of the statistical reporting for the participating registries. The various types of reports to be produced and especially the information to be incorporated into these reports should receive very special attention.

(4) Procedures for assuring confidentiality of information. It is mandatory that measures be taken to ensure that only authorized individuals have access to registry data. Many of the people surveyed recommended that names of patients, physicians, and hospitals be coded at the local level so that such persons and organizations could not be identified without a special code known only to the physician or hospital submitting the entry. The advantages and disadvantages of this particular procedure are discussed later.

(5) Procedures for modifying registry services and procedures. It must be assumed that the initial set of registry services and reports will not be to the complete satisfaction of all participating hospitals. Therefore, means must be provided for constantly reassessing these services and reports and modifying them when appropriate.

CAPABILITIES REQUIRED OF THE REGISTRY SYSTEM

Capability of Preparing Accurate and Complete Abstracts. The data that are the basic element in a tumor registry system come from abstracts of the medical records of cancer patients. Therefore, the prime requirement is for an organizational entity that will be responsible for the preparation of accurate and complete abstracts.

If at all possible, these abstracts should be prepared by tumor registry personnel working within the tumor registry of each participating hospital. Most larger hospitals will have a tumor registry and therefore will have personnel capable of selecting and abstracting the records of cancer patients. At smaller hospitals, personnel from the medical records department can select the appropriate records, and if need be, persons from a community or central registry can prepare the abstract. Whatever the procedure followed, the essential requirement is that (a) each participating hospital be capable of selecting those records that should be incorporated into the tumor registry system, and (b) some reliable means be provided for obtaining an accurate and complete abstract of these records.

Capability of Processing Abstracts at a Central Level. The second requirement of a registry system is to be able to process abstracts at a central level. Fundamentally, this involves having the procedures, facilities, and personnel for processing the data from the abstracts and for storing and retrieving these data. The abstracting and coding can—depending on local circumstances—be done by the participating hospital, by community registry personnel, or by the central registry. The storing, retrieving, and statistical processing of the data are best performed at the central level because of the need for statistical expertise and for employment of special automatic data processing equipment, and because it is this kind of processing that provides a comprehensive picture within a region or state and permits comparisons within and between regions.

Capability of Providing Useful Outputs and Services. A third prime requirement of a registry system is for procedures, facilities, and personnel for providing the participating hospitals with useful data, reports, and services. The registry system should be capable of relieving the participating hospitals of a certain portion of their work load and of providing these hospitals with reports and services they would not otherwise have.

Organizational Flexibility. There are a number of equally appropriate ways to organize a tumor registry system, and most of these alternatives can exist side by side within the overall system. As discussed in detail in the following section, a registry system can be composed of participating hospitals, community registries, units of a central registry working at the community level, and the central registry. There are certain work activities, services, and products that should be performed or produced by the central registry, but there are many activities that can be satisfactorily performed either by the participating hospital or by some other unit of the total system. It is especially important that each participating hospital be allowed to operate all or any portion of its own tumor registry. The only *mandatory* requirement is that each participant establish procedures for assuring that copies of all cancer patient record abstracts—however they may be prepared—are forwarded to the central registry.

ORGANIZATIONAL STRUCTURE AND RESPONSIBILITIES

Participating Hospitals and Their Responsibilities

A registry system contains only two essential organizational units—the participating hospitals and the central registry unit. Each participating hospital must contain either a tumor registry or, at a minimum, that portion thereof which is concerned with the selection of records for incorporation into the registry system.

The basic responsibility of the participating hospital is to *select* those records which should enter the registry system. (In most instances the hospital also will wish to abstract its own records, but it is at this point that selection of alternative procedures can begin.) An associated responsibility is for each hospital to take the steps necessary to insure that its medical records are complete and clear, and that they are forwarded to the records department within a reasonable time after patient discharge. Obviously the degree to which accurate and complete abstracts can be prepared is directly proportional to the quality of the records being abstracted.

Central Registry and Its Responsibilities

The first responsibility of the central registry unit is for processing the abstracts to permit retrieval of information and to produce statistical reports. In addition, the registry should be responsible for providing those services (training, consultation, abstracting assistance, etc.) that are desired by the participating hospitals. In addition to its interaction with individual hospitals, the central registry can draw on data resources on a regional or state-wide basis and thereby provide information—and interpretation—that could not be produced by an individual hospital.

Community Registry Options

Two types of "optional" units can exist within a registry system—a community registry, and a version of a community registry that is a work unit of central registry representatives located at the community level. The establishment of community registries should receive careful consideration, both by the hospitals within a given community and by the developers of the state-wide registry system. Such community units can serve as middlemen between the participating hospital and the central registry—allowing for the decentralization of the state-wide system, and providing a means for the participating hospitals in a given community to share personnel and facilities.

"Locally Owned" Community Registry. In the type of community registry that is operated and supported by the hospitals of the community, the actual arrangement between a community registry and each participating hospital can be quite flexible. For one hospital, the community registry might take on the complete operation of the registry activities. At a second hospital, community personnel might abstract the cancer patient records and forward them to the central registry. For a third hospital, the community registry might participate actively in patient follow-up activities. It would be helpful if a standard relationship existed between the several participating hospitals and the community registry, but this is not essential. What is essential is that a clear agreement exists, for each participating hospital, regarding what information it will provide to the community registry, and what portion of its registry work load will be performed by community registry personnel.

"Centrally Owned" Community Registry. It is possible also for the central registry to provide one or two representatives at the community level who would act as consultants to and assume certain portions of the work load for the community hospitals. These persons could relieve small participating hospitals of most of the work involved in the operation of an individual registry.

An important advantage to community registries is the opportunity to utilize full-time tumor registry personnel. At many hospitals the case load of cancer patients does not warrant the employment of a full-time or even a half-time tumor registry secretary. The result can be that tumor registry work is performed by someone from the medical records department and is often a responsibility "in addition to other duties." In the case of community registries or central registry representatives at the community level, people can be provided who work full-time on tumor registry activities. Therefore,

training expenses for such people can more easily be justified and there is more assurance that they will maintain their tumor registry-related skills and knowledges.

Provision of Statistical Capability

It is doubtful whether an individual participating hospital or even a community registry would have a work load that would justify having its own data processing equipment and facilities. Even a state-wide system will not require extensive ADP facilities unless it has an on-line analysis capability (a capability which as yet no registry system does have). If at all possible, the central registry should utilize the computer facilities of some state or public health agency. If need be, time could be rented from a private data processing service organization.

This is a major reason why community and hospital registries can most efficiently delegate their data storage, retrieval, and processing to a central registry. The community registry, however, should play an active role in helping the participating hospitals formulate requests to the central registry and in interpreting informational outputs and reports from the central registry.

It is not enough to collect and incorporate data into the tumor registry records. This information is of no value until it has been appropriately processed and *interpreted*. It would not be difficult to generate various types of frequency count and statistical analysis or summary reports capable of interpretation by knowledgeable statisticians. However, most physicians and other users of registry data will not have the time nor the training required to interpret data presented in technical statistical form. Rather, such data should be presented in a clear and meaningful fashion and be accompanied by a straightforward interpretation.

This means that a central registry should be staffed by at least one statistician-analyst. This specialist would be responsible for analyzing the information requirements of the users of the registry and for assuring that the reports prepared for these users are in a meaningful, readable form. A constant search should be made for ways to process and present the data in new and valuable configurations. A continuing effort should be made to discover new ways for the registry to support a comprehensive cancer program of the state.

RECOMMENDATIONS RE SURVEY OBJECTIVES

In this section, materials especially relevant to the specific objectives of the consultant survey are discussed.

Objective (1): To identify the appropriate type of tumor registry to be located in peripheral areas (outlying hospitals and medical community areas) in order to dovetail effectively with a central state tumor registry in a mutually satisfactory and complementary fashion.

Community Registries as Key Unit. The advantages and disadvantages of various organizational units and arrangements have been discussed, and the need for flexibility stressed. It is recommended, however, that the state-wide registry system be designed around the concept of community registries.

Roles of Community and Central Registry. The abstracting and coding activities now performed at individual hospitals could be performed by one or two full-time persons attached to a community registry. It is suggested that each participating hospital designate a person from the Records Department to select the records and to maintain the tumor registry files within that hospital.

The community registries would be supported by a central registry which would provide computational capabilities and would prepare all reports and listings. One or two statistician-analysts should be attached to the central registry. Also, the central registry would provide special services such as training community registry and participating hospital personnel.

Within any community the following three options should be considered and any one or more implemented as appropriate.

Option No. 1—For a large hospital (300 beds or more) with a considerable volume of cancer patients. A complete tumor registry could exist at the hospital with a tumor registry secretary performing all of the typical registry activities, with the exception of coding the abstract and preparing annual reports. The secretary would prepare the abstracts and forward them to the community registry or to the central registry where they would be coded and incorporated into the central registry system.

Option No. 2—For medium sized hospitals (150-300 beds). A person within the medical records department would be responsible for selecting appropriate cases for the tumor registry. Periodically, someone from the community registry would visit the hospital and abstract and code these records. The participating hospital would maintain its own registry files. As desired, the community registry could assist in or assume responsibility for patient follow-up.

Option No. 3—For small hospitals (150 beds and under). Community registry personnel would assume the responsibility for operating all aspects of the participating hospital's registry, to include maintenance of registry files. Someone at the hospital would be taught how to select the appropriate records.

Objective (2): To determine the most feasible type of data collection system to be used in peripheral registries.

No Special Data Collection System Required. It is feasible to use remote input/output devices which transmit data over telephone lines to a central computer. The remote I/O units are used to input data into and to obtain information from a central storage and retrieval device. Assuming the establishment of registries at the community level, it does not seem necessary to link each participating hospital in the community directly to the community registry or to the central registry. This approach would be too expensive, and at each participating hospital one or more persons would have to learn to operate the input/output devices.

Special Capability Expenses. It would be feasible to link each community registry with the central registry using data transceiver equipment, but it is doubtful whether any benefits derived would justify the costs. The abstracts from the participating hospitals would be coded at the community registry and sent by wire to the central registry where, with appropriate equipment and procedures, they could be directly inputted into the registry computer. Again, the major disadvantage to this possibility is one of costs—a key punch capability would have to be established at the community level, equipment would have to be purchased, and community registry personnel would have to learn how to use it.

Available Transmission Methods Adequate. It is not necessary that the initial registry system employ data linkage equipment and procedures. This is a capability which can be added to the system sometime in the future, if this addition seems to be warranted. For the initial system, the transmission of information between all organizational units can be done by mail, by couriers, or by telephone.

Objective (3): To determine how local (peripheral) registries can best be set up to serve the needs of the local physicians.

Service to Local Physicians. It is the judgment of the author that the establishment of community registries can best serve the needs of the physicians and medical

organizations at the community level. In addition, there is a need to identify carefully the potential users of the registry and to determine their information and service requirements. For a variety of reasons, existing registry systems do not seem to serve well the needs of local physicians and medical groups. It is therefore recommended that one of the primary responsibilities of a community registry should be to constantly re-evaluate the services and products of the registry system by discussing with potential users the value and usefulness of these items and how they might be improved.

Chapter 3

SPECIAL PROBLEMS IN ESTABLISHING A REGISTRY SYSTEM

FINANCIAL SUPPORT FOR THE REGISTRY SYSTEM

As might be expected, at most of the hospitals visited during this survey there were numerous expressions of concern over the manner in which the tumor registry system would be supported. Many new medical programs initially are funded by the federal government with the understanding that this funding gradually will be withdrawn over a period of time. Theoretically, most new medical programs, assuming that they prove to be of value, eventually should become self-supporting. The question is self-supporting by whom? By the state, the participating hospitals, some organization such as the American Cancer Society?

The initial establishment of the Louisiana registry system would be funded by the Regional Medical Program. The general plan for financing the system calls for the use of federal funds for a three-to-five year period. After that, if present plans are not altered, federal funds will be withdrawn gradually. Then operating funds will have to be obtained from the state, from charges to the patient, or from organizations such as the American Cancer Society.

The proposal for developing the initial tumor registry system for the state of Louisiana should address this funding problem from the outset. If it is to survive, the registry system eventually must be supported by the various users. Ultimately this may mean that the patients and organizations presumably benefiting from the registry may be indirectly charged. It will be important, therefore, to demonstrate that whatever services are provided by the registry are indeed of value.

Fundamentally, a tumor registry system is an information-exchange activity. The value of its products lies both in the kinds of information that are gathered and the ways in which the information can be used. During the establishment of the system, every effort should be made toward planning activities and products that will demonstrate that the system has helped to improve the quality of care provided to cancer patients.

Speaking generally, there is one demonstrable product of a registry system that is the essential reason for the system being established—the provision of summary data that, over time, contribute to the total picture of the incidence of cancer and the nature of the medical gains in treating it. This product, however, is not one that can be hurried. It seems to be the feeling of those who work in this field, such as medical researchers, that data need to be accumulated for five years or more before they reflect enough experience to provide reliable evidence as to trends—perhaps in terms of documented proof of earlier detection of certain types of cancer, or of a shorter period of time in which patients are incapacitated under certain forms of treatment.

While these long-term data patterns are developing, however, there are more immediate ways in which the registry system can be shown to be operating for the benefit of the patient. For example, follow-up programs are of major importance in the treatment of cancer, and a comprehensive and sustained program of follow-up work is an activity peculiarly well suited to the facilities of a central registry system. The value of such programs (which are discussed in more detail in Chapter 4) can be clearly demonstrated in such terms as an increase, from one year to the next, in the percentage of

patients with whom contact is maintained or restored through follow-up activities by the registry system.

With respect to demonstrating the value of the system to participating hospitals, the registry system should be designed so as to reduce, wherever possible, the work load at each participating hospital which is associated with the maintenance of its own tumor registry. By such activities as consolidating certain functions from several hospitals in a single community registry, or providing quick information retrieval from automated data storage in the central registry, effectiveness of work at the local hospital level might well be improved with less time invested by the hospital staff. It would seem likely that such a work load reduction at the hospital would be associated with salary or operational savings that could in turn be allocated, in part, to the support of the central registry system.

Several activities which should be undertaken in establishing a registry system could be expected to increase the demonstrable value of the system by ensuring that its work is pertinent to cancer care problems in the region. These activities include: (a) careful identification of potential users of the registry; (b) development of means for educating users how to obtain maximum benefit from the registry; and (c) periodic investigation of the reasons for non-utilization of the registry.

Identifying Potential Registry Users. There are many different types of physicians and medical groups who could profit from the use of a tumor registry. These individuals and groups need to be identified and their specific requirements determined. They include the attending physicians, tumor committee for each hospital, hospital administrators, educators, researchers, and community and state health agencies.

The initial registry system should concentrate on providing services to the individual physician and the tumor committee for each hospital. These two groups are most directly concerned with the management of cancer patients and are in the best position to evaluate whether a registry and registry system are of value. Considerable attention should also be given to the cancer information needs of community and state health agencies. It is these agencies which might be in the best position to evaluate whether or not the state should support all or various portions of the central registry activities.

Educating the Users of Registries. It cannot be assumed that physicians and other potential users of a registry do know of the existence of the registry or of how to use the registry products and services to best advantage. As for any other medical tool, physicians need to be taught how to use a registry. To some extent the use and value of registries currently is being taught at Tulane Medical School. In addition, however, from time to time central registry personnel should prepare and distribute to physicians and medical groups within the state instructional material on how to use some particular output or service of the central registry.

Examining Non-Utilization of Tumor Registries. At numerous places in this report there are allusions to limited utilization of tumor registries. At some hospitals tumor registries are actively used. Unfortunately, at most hospitals and within a number of state systems, only limited use is made of registries. Many reasons can be offered, but there is little evidence to indicate what the "real" reasons are or what can be done to correct this situation. In many respects, the problem seems to be a circular one in that many potential users of a registry do not fully understand how to utilize the services and products of the registry. And, it may well be that many of the products and services of a registry are of much more limited value than registry personnel would like to believe. There seems to be an obvious need for examining the manner in which cancer is diagnosed and managed, for the purpose of more accurately identifying those items of information that are useful to the attending physician and that can be provided by a tumor registry.

CONFIDENTIALITY OF TUMOR REGISTRY INFORMATION

Need for Maintaining Confidentiality. During the survey, many persons expressed concern regarding the degree to which individual hospitals, physicians, and patients could be identified from central tumor registry data. Hospitals and clinics make every effort to insure that patient medical records remain within the hospital and that the information contained within these records is not divulged to unauthorized persons and organizations. Means must be found—without compromising the objectives of the registry—to assure that information contained within a central tumor registry would enjoy the same degree of confidentiality as now exists within the medical records department and tumor registry of the individual hospital.

Use of Identity Codes. The easiest way of assuring information confidentiality is to devise procedures for coding that information which could be used to identify hospitals, physicians, and patients.

The obvious advantage of an identity coding system is that it makes it extremely difficult, if not impossible, for the central registry information to be used for unauthorized purposes. The central registry information still could be used to prepare statistical reports and make statistical comparisons. In all probability, there would be certain features of the summarized data (e.g., the cancer case load) that would identify most participating hospitals to knowledgeable users.

Unfortunately, when patient and physician identities are coded it is not possible for the central registry to provide many types of services and reports. For example, the central registry could not perform a death clearance service (a service in which names on death certificates are compared with those in the central registry to identify registry entrants) or assist in the follow-up of patients or in the locating of "lost" patients unless they know the names of the entries in the registry.

Another major disadvantage of identity coding is that the central registry can no longer prevent double entries into the registry data bank. That is, a patient might, over a period of years, be treated at two or more hospitals within the state, and each hospital would submit an abstract for this patient. The result is that the central registry data would become invalid; the incidence and prevalence of various types of cancer throughout the state would be inflated and to some extent differences among regions within the state would be distorted.

For these reasons *it is recommended strongly that all efforts be made to devise procedures and suitable safeguards so that patient identity could be incorporated into central registry information.* To this writer's knowledge, all other central tumor registries have been able to overcome this particular problem. It might be well to solicit the advice and counsel of the board of directors of a selected group of these registries.

Use of Both Names and Identity Codes. As a compromise solution it would be possible to include in the central registry both the name of a patient and the code assigned to that patient. As agreed upon by the participants, certain registry reports and printouts would use codes to identify patients, physicians, and hospitals. When the registry was performing certain types of follow-up activities or conducting a death clearance search, the names of the patients would be employed.

Chapter 4

OPERATIONS, PRODUCTS, AND SERVICES OF A REGISTRY SYSTEM

Individual registries and registry systems have been in existence for some years, and there is a considerable body of literature describing the operations of both local and central registries and the services which they can provide. In this report no attempt is made to describe these operations and services in detail, but this chapter contains brief descriptions of typical or possible operations and services so that the reader can make a preliminary judgment about the interest and potential value of each service. More detailed information can be obtained from one or more of the listed references.

In a large tumor registry a variety of activities occur, including: (a) selection of cases for incorporation into the registry; (b) abstracting of medical records; (c) coding, for data processing purposes, of medical record abstracts; (d) initiation of follow-up actions for all active cases within the registry; (e) incorporation of follow-up information into registry records; (f) preparation of reports; (g) maintenance of the registry files; (h) as required, training of new registry personnel; (i) supervision of registry personnel and operations. Certain of these activities are most appropriately performed by local tumor registry personnel, others should be performed in part or completely by the central registry, still others can be performed either by the local tumor registry or by community registry personnel. In the final analysis, who performs these activities and where they are performed depends upon the judgment of each of the participating hospitals.

SELECTION OF RECORDS FOR INCORPORATION INTO TUMOR REGISTRY

Procedures for Identifying Cancer Records. One of the important objectives of a local registry is to provide the means for obtaining an accurate history of cancer cases in a particular hospital. Therefore, procedures must be established for obtaining a complete roster of patients with cancer. All in- and out-patient records should be reviewed and those cases with cancer tagged and/or set aside for additional processing. In addition, various procedures can be adopted for alerting the tumor registry that specific cancer patients are undergoing treatment at the hospital and eventually should be accessioned into the tumor registry. For example, reports from the pathology, radiology, and other laboratories could be sent routinely to the tumor registry secretary.

Possible Use of Contact Persons to Select Records. While it is a general practice to have the personnel from the medical records department select the records that should be incorporated into the registry, it would be possible to have one or more persons associated with a community registry or the central registry who would periodically visit a local hospital and select the records to be placed in the tumor registry. This would involve screening all records received by the medical records department since the last visit by the contact person.

The main advantage of this procedure would be to relieve medical records department personnel of the added duty of identifying records of cancer patients. However, this selection process does not take much time, assuming that the medical

records department personnel are capable of recognizing those records dealing with cancer. The disadvantages associated with this procedure include: (a) The participating hospital must keep an account of those records not yet screened by the registry personnel; (b) the records would be handled twice (i.e., both the medical records department at the participating hospital and the contact person would separately review them); (c) at the time of each visit the contact person would have to be provided with work space, and in many hospitals the medical records department is already overcrowded.

Of all the operational activities of a tumor registry, that of records selection seems the one most appropriately performed by a designated tumor registry secretary or by one or more persons of the medical records department. As required, a pathologist or other knowledgeable member of the hospital staff could assist and advise in this selection process. Contact persons should be used as a last resort.

PREPARATION OF THE TUMOR REGISTRY ABSTRACT

Need for Accurate Abstracts. "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 overall cancer program in the institution. It is a concise summary of the significant facts from hospital medical chart: on the history, diagnosis, and treatment of every patient's cancer." (1) The Tumor registry abstract furnishes the information which serves as an input to the central registry system. To accurately prepare a tumor registry abstract, one should possess a reasonable medical vocabulary, especially a vocabulary relating to the diagnosis and treatment of the various types of cancer. One must be skillful at abstracting from the medical record the information indicating the final diagnosis and the type of treatment given. In addition, one must know how to apply rules for determining the stage of the disease at the time of diagnosis.

Determining Who Will Abstract the Record. At larger hospitals, it is appropriate to have a full-time tumor registry secretary or a member of the medical records department responsible for preparing the tumor registry abstract. Such a person can be appropriately trained and, because of the work load, receive constant practice at abstracting records. At the smaller hospitals, only one or two records may need abstracting per week; with this light work load, it may not be justifiable to train a member of the medical records department to abstract. Under these circumstances, it would be quite appropriate for a member of a community registry or the central registry to visit the hospital periodically and abstract records set aside for incorporation into the registry.

Abstracting Incomplete Medical Records. It often happens that the medical record does not contain all of the information needed for a complete abstract. In such a case, the abstractor must see that the attending physician is contacted for additional information. This contact is most appropriately made by some member of the medical records department at the local hospital or by the pathologist who is supervising the tumor registry activity. Assuming that such arrangements can be made, then at small hospitals (150 beds or less) it is quite appropriate to use contact persons to do the abstracting. Numerous hospitals have found that a tumor registry can be instrumental in convincing physicians of the need for preparing complete and legible records.

Possible Financial Reimbursement for Complete Abstracts. In California local hospitals prepare an abstract of the cancer patient's medical records and forward the abstract to the central registry for coding. The local hospital is reimbursed for the preparation of each abstract and the amount of this reimbursement is proportional to the completeness of the abstract. If the central registry has to return the abstract to the local hospital for additional information, the local hospital is paid a lesser amount for that abstract. This procedure provides a means for defraying some of the costs of operating a local registry, and provides an incentive for preparing quality abstracts.

CODING OF THE TUMOR REGISTRY ABSTRACT

Need for Coding Abstract. The various services that can be provided by a tumor registry include the tabulation, follow-up, and analysis of cancer registry data. The use of automatic data processing equipment can expedite and facilitate these activities. However, before registry data can be processed automatically, the information on the registry abstracts must be translated into a numerical code. The End Results Program, HSMHA and other organizations have prepared "cancer registry codes" which in many instances can be modified easily to fit local and state requirements and facilities.

Coding Alternatives. The coding activity is one that can easily be delegated to community-located or centrally-located registry personnel. Alternatives for consideration are:

(1) An abstract is forwarded to a community registry or to community-located central registry personnel. Here the abstract is coded and then forwarded to the central registry.

(2) Locally prepared abstracts are forwarded to the central registry where they are coded and processed.

(3) During periodic visits to the participating hospital or to a community registry, central registry personnel code the abstracts.

Coding is an activity best performed by community registry personnel, assuming the existence of such registries. It must be anticipated that, for a certain percentage of abstracts, some information will be missing or incomplete or ambiguous. Such abstracts must be returned to the individual hospital for clarification. This process is performed much more expeditiously by community-located personnel.

MAINTENANCE OF TUMOR REGISTRY FILES

Types of Files. The usual files maintained by a tumor registry are: (a) a site file, containing clinical abstracts of all registered cancer patients, with follow-up notes for the lifetime of the patients; (b) a patient index file, a master control file which enables a secretary to avoid duplicate accessions in the registry; and (c) a follow-up control file. Also, most registries maintain an accession register which is a yearly listing of all patients, their diagnosis, and their assigned cancer registry number from the date of the establishment of the registry. If desirable, however, with central support it would be possible to locate local registry files, especially the follow-up file, at the central registry.

File Maintenance at Small Hospitals. While, typically, a local registry is maintained by a tumor registry secretary or by medical records department personnel, for small hospitals community or central registry personnel could perform this activity if this seemed to be the only feasible way to obtain information and provide services.

File Maintenance With a Centrally Located Computer. It is possible to have a state-wide registry system tied into a central computer by remote input/output devices. With such a system, participating hospitals could readily contact their own registry files located within the central computer, and with appropriate output devices they could make hard copies of portions of their files. Consideration of such a system should await a clearer indication that the benefits to be gained could justify the cost.

PATIENT FOLLOW-UP

Follow-Up: A Major Registry Activity

One of the major objectives of a tumor registry system is to provide the means for assuring that patients with tumors receive continuing attention as long as their

malignancy exists. It is extremely important, therefore, that a means be provided for periodically assessing the condition of the patient so that additional treatment can be provided if needed.

Patient follow-up can be a very time consuming activity, especially after the registry has been in existence for some period of time. At either six-month or yearly intervals, the tumor registry secretary records on each patient's abstract the latest information about the status of the patient. This means that 1/6 or 1/12 of the total active entries of the registry are followed up each month. The records for the appropriate patients are pulled and examined for new information. If the patient has visited the hospital or the physician within the last 6 or 12 months, the physician is contacted with a request for information about the status of the patient. Status information is returned to the local registry, then entered on the patient's abstract and forwarded to the central registry.

The persons interviewed as part of this survey did not express a strong interest in central registry support for their patient follow-up activities. Most registries within Louisiana are small enough so that one person can readily handle the follow-up work load. However, where follow-up exceeds 50 patients per month, local registry personnel might choose to receive assistance from a community or central registry.

Possible Types of Assistance to Local Registries

Follow-Up Reminder Service. The patient follow-up control file for each participating hospital can be maintained by the central registry. This allows the central registry to prepare each month a list of those patients who should be recontacted for their semi-annual or annual status determination. Such lists are sent to the participating hospitals where they are processed by tumor registry personnel. In many instances, follow-up information can be obtained from readmission or out-patient records. For other patients, a follow-up letter is forwarded to the attending physician with a request to provide the latest information regarding the status of the patient.

Follow-Up Form Letters. There are a variety of form letters which can be used to obtain follow-up information. These include: (a) a letter sent by a tumor registry to a physician requesting information about a particular patient, (b) a letter sent by the physician or the tumor registry to the patient, and (c) a letter sent by the physician or the tumor registry to the patient's relatives, acquaintances, and/or employer. The central registry can be responsible for printing these forms and distributing them to participating hospitals and community registries.

Lost Patient Tracing Service. For a variety of reasons a patient can become "lost" in that he cannot be located for follow-up purposes by the hospital or the attending physician. A concerted effort should be made to locate such patients to determine their status and need for additional treatment. Also, this information is needed to generate accurate survival data. The central registry can initiate a search for these lost patients by attempting to contact, via form letters, the patient himself, his relatives, or his past or present employer. In addition, a search can be made of death certificates. Pertinent information obtained about the patient would be incorporated into central registry files and, as desired, would be forwarded to the local hospital. Procedures should be devised to assure that the patient, his relatives, acquaintances, or employer were not contacted until authorized by the attending physician.

Identification of Dual Listing. Occasionally a patient becomes "lost" because he has moved from one location within the state to another and thereby has changed hospitals and physicians. When this occurs the second hospital will submit to the central registry an abstract of a patient who already is entered in the registry. If the patient is known only by a local hospital code, then double entries may occur. This will tend to inflate the cancer incidence data produced by the central registry. In addition, a situation will exist in which two hospitals are "following-up" the same patient. When patient identities are

known to the central registry, each new case can be matched against its master file and an identification made of those patients now being treated at a different hospital. Notification can be sent to the first hospital that it is no longer responsible for providing follow-up information for that patient.

Death Clearance or Death Certificate Search. This refers to a routine search of all state death certificates. Those containing information about persons with tumors would be matched against the master file of the central registry. Information about any matches would be incorporated into the central registry data bank and would be forwarded to the appropriate local hospital and physician. In this way, records could be closed for any case that has terminated in death from any reason. Another version of this service would allow any participating hospital to submit the names of its "lost" patients for comparison against the Death Certificate file. In still another version of this service, all names appearing on death certificates for a particular period of time (one month) would be placed on tape and compared with those names in the central registry's master accessions file. Of course, all versions of this service require that the identity of patients be known to the central registry.

Preparation of Reports and Listings

One of the major objectives of a tumor registry is to prepare, on a semi-annual or annual basis, one or more reports which summarize the cancer experience of that particular hospital. Most existing registries within the state of Louisiana follow some version of the reporting procedures recommended by the American College of Surgeons (ACS) and use forms recommended by the ACS. Preparation of these reports is time consuming and sometimes is beyond the capability of local registry personnel. Once appropriate computer programs have been prepared, the preparation of reports for individual hospitals by the central registry is a relatively simple procedure. Therefore, one of the goals of a central registry should be to assume the responsibility for producing all programmed reports of tumor experiences for the participating hospitals. Some of the more important types of reports and listings which a registry can produce are described briefly below.

Annual Report of Cancer Experience. For each participating hospital the central registry can prepare a summary of the annual caseload of cancer patients. Such a report summarizes incidence of cancer by the site of cancer, and for each site provides summary information concerning male cases, female cases, method of diagnosis, and stage at diagnosis. Figure 1 presents an example of this type of summary. Figure 2 contains a second example of a tumor registry annual statistical report; this is the type of report prepared by the California Tumor Registry.

Survival and End Results Reports. According to the American College of Surgeons, one of the requirements for approval of a hospital program is that on an annual basis reports on cancer survival and end results be prepared and distributed to the hospital staff. These "... periodic reports based upon registry data will serve as a guide for the care of cancer patients within the hospital and will be useful in developing the overall hospital cancer program. These reports often are a stimulus for clinical investigations and research by pointing out the areas in which studies are especially indicated." The various types of survival and end results reports which might be prepared are illustrated in a document entitled *The Hospital Cancer Registry* (1). Reports can be prepared which summarize survival and end results by all or selected sites (stomach, rectum, lung, etc.) or by major site groups (mouth and pharynx, digestive system, etc.), or a particular type of cancer can be summarized by sex, stage, initial therapy, age, diagnosis, and so forth. Figure 3 contains an example of a survival and end result report suggested by the American Cancer Society (1).

HOSPITAL: _____ CITY: _____ YEAR: _____

CANCER REGISTRY SUMMARY

SITE OF CANCER	MALE CASES			FEMALE CASES			MALE AND FEMALE CASES		
	NUMBER WHITE	NUMBER NON-WHITE	TOTAL MALE %	NUMBER WHITE	NUMBER NON-WHITE	TOTAL FEMALE %	NUMBER WHITE	NUMBER NON-WHITE	TOTAL MALE & FEMALE %
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		LOCALIZED		REGIONAL INVOLVEMENT		DISTANT METASTASES		STAGE UNSPECIFIED	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
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														

Figure 1

CANCER REGISTRATION AND SURVIVAL IN CALIFORNIA

TUMOR REGISTRY ANNUAL STATISTICAL REPORT
NEOPLASM BY SITE, MICROSCOPIC CONFIRMATION, STAGE OF DISEASE, AND FIRST COURSE OF TREATMENT
CASES ADMITTED, 1960

SITE NUMBER ¹	SITE	TOTAL CASES ADMITTED	MICROSCOPICALLY CONFIRMED	TOTAL INITIALLY DIAGNOSED	CASES INITIALLY DIAGNOSED IN REPORTING HOSPITAL								
					Stage of Disease			Type of Treatment ²					
					Localized	Regional	Remote or Disseminated	Not Reported	Surgery	Radiation	Surgery and Radiation	Other Only	None Reported
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)
	MALIGNANT NEOPLASMS, TOTAL												
	Integumentary system, Total												
	Skin												
	Superficial mucous membranes												
	Mouth												
	Other												
	Glands of skin and superficial mucous membranes												
	etc.												

1 Standard Nomenclature of Diseases and Operations, Fourth Edition, Topographic Classification Numbers.
2 First course of tumor-directed treatment received by the patient, which is usually given within four months of admission.

Figure 2

YEAR REPORT OF CANCER SURVIVAL AND END RESULTS OF		Hospital						PATIENTS				
CASES DIAGNOSED IN 19 _____		BY SEX, STAGE, INITIAL THERAPY AND AGE AT DIAGNOSIS										
REPORT THROUGH 19 _____		TOTAL NO.	MALE	FEMALE	LOCALIZED	REG-METASTASIZED	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												
		C4 + D4		A								
F. PER CENT OF PATIENTS SURVIVING FULL PERIOD COVERED BY THIS REPORT												
		C4		A - B4								

Figure 3

TUMOR REGISTRY LISTING (PHYSICIAN)

1st Priority SITE	2nd TYPE	3rd STAGE	NAME	AGE RACE SEX	DATE OF RX DX	DATE 1ST FOLLOWUP	YR. MO	4th FOLLOWUP STATUS	PHYS CODE	HOSP CODE		
STOMACH	KRUKENBERG TUMOR	REMOTE	DOE, MARY	46MF	S	02/66	00,03	DEAD WITH	100	216		
	THIOPEA ADJUVANT TO SURG TRYPT OF GASTRIC CA ANN SURG 617.3:293 MAR 68 FACTORS INFLUENCE PROGN SURGERY ADV GASTRIC CA ANN SURG 617.3:293 MAR 68 NATURAL HISTORY OF ADVANCED GASTRIC CANCER S G O 126.5:1071 MAY 68 REGIONAL 5 YR SURVIVAL RATES LOCALIZED 42% ALL 14% NATIONAL 5 YR SURVIVAL RATES LOCALIZED 39% ALL 12%											
									Current Medical References			
									Regional and National Survival Figures			
CERVIX UTERI	SQ CELL CA IN SITU	IN SITU	DOE, ELLEN	41MF	S	02/67	02/68	01,00	ALIVE W/O	100	218	
CERVIX UTERI	SQ CELL CA	LOCALIZED	DOE, MARYANN	43MF	R	01/66	09/68	02,07	ALIVE W/O	100	217	
CERVIX UTERI	SQ CELL CA	LOCALIZED	DOE, ALICE	43MF	R	01/66	10/68	02,09	ALIVE W/O	100	219	
	RECURRENT CA OF THE CERVIX SURG GYN AND OB 126.4:799 APR 68 MASS CYTOLOGIC SCREENING AND DX OF CERVICAL CA CA 21.6:1180 JUNE 68 SARCOMA BOTRYOIDES CERVIX TREATED BY VAG HYSTERECTOMY OBST GYN 31.5:617 MAY 68 MANAGEMENT OF RECURRENT CERVICAL CARCINOMA AH J OBST GYN 101.1:53 MAY 68 REGIONAL 5 YR SURVIVAL RATES LOCALIZED 70% ALL 57% NATIONAL 5 YR SURVIVAL RATES LOCALIZED 76% ALL 58%											
CORPUS UTERI	ADENOCARCINOMA	LOCALIZED	D'EE, JENNY	50MF	S	0	09/65	10/68	03,01	ALIVE W/O	100	217
	CURRENT AND DIAGNOSIS CA ENDOMETRIUM AMER J OB GYN 100:5 MAR 68 RECURRENT ENDOMETRIAL CARCINOMA SURG CLIN N AMER 48.3:619 JUN 68 REGIONAL 5 YR SURVIVAL RATES LOCALIZED 65% ALL 61% NATIONAL 5 YR SURVIVAL RATES LOCALIZED 83% ALL 70%											

Figure 4

Diagnostic Index. Figure 4 contains an illustration of a diagnostic index printout, a special report prepared on request by the California Tumor Registry. This index "is a listing of the patient's name, sex, age, and race, and of the site and type of neoplasm, type of treatment, years of survival, and other information for every case reported by that hospital. The index groups cases by primary site and year of admission to provide a ready reference when a hospital is engaged in a study of its own cases. By referring to the diagnostic index, hospital personnel may easily identify a series of cases reported by them for a specific site and for any particular year, or years, of admission. They may quickly select cases with any combination of reportable factors. The diagnostic index serves as a screening device for selecting records for more intensive study. For example, a hospital registry could, by use of the index, identify all five year survivors with localized cancer of the cervix uteri who were surgically treated following initial diagnosis in the hospital." (6)

Five-Year Interval Summary Report of Cancer Incidence. To properly evaluate trends in the incidence and treatment of cancer, it is necessary to have both yearly summaries and data which summarize incidence, diagnostic, and treatment data over five-year intervals. Such summary reports can readily be prepared by a central registry. These reports show the trends in caseload for selected sites and the sex and age distribution of cancer cases admitted during the previous five-year period. Each hospital is provided with tables showing its own experience and with similar tables based on all cases reported to the tumor registry. Such reports can be used to analyze trends and differences on a regional basis also.

Site Survival Data by Stage. The overall purpose of a tumor registry is to contribute to the survival of cancer patients. Therefore, it is important to collect data which can be used to describe survival experience for a particular hospital and for regions. Survival data become meaningful after the registry has been in operation for three or four years. As an example, the tumor registry of the Inter-Mountain Regional Medical Program produces a printout which presents survival data for specific primary sites. The data are organized in terms of the stage of the cancer at time of initial diagnosis. Such a printout can provide an estimate of "survival probability" for a particular type of cancer which has advanced to a particular stage. In addition, the registry has developed a program for producing computer-generated points which, when connected, provide a curve depicting survival rates. These curves can be generated for a specific type of cancer.

Tumor Registry Listing (Physician). The tumor registry sponsored by the Inter-Mountain Regional Medical Program produces a listing for individual physicians which is of special merit. It provides to the physician a summary of his cancer patient caseload and can be used by him to evaluate his diagnosis and treatment of cancer. Figure 4 contains an example of this listing. "The patient registry listing program with structured priorities can produce reports for individual physicians regarding their own patients. After listing the group of patients with a specific malignancy, the computer will print a bibliography of selected current medical references chosen by the cancer committees of local medical specialty organizations. The state and national five year survival figures for that site will follow the reference. Similar reports are generated for hospitals, states, and regions." Individual personal physician patient listings are strictly confidential and available at six-month intervals only on the request of that physician. (14)

Special Reports. At the discretion of the board of directors, a state tumor registry system can prepare a wide variety of special reports. The nature of the more typically produced special reports are:

(1) A report describing the cancer mortality, morbidity, and survival rates for the state or for regions within the state. These reports can be prepared for a particular year or for a selected group of years.

(2) A brief statistical report depicting the trends in cancer mortality for the state or for selected regions for a particular time.

(3) A monograph which summarizes data for all cases contained within the registry system since its inception. The California Tumor Registry has prepared such a report (6), the purpose of which was "to present and analyze the data on the characteristics, diagnosis, treatment, and survival of the 110,229 initially diagnosed cases and to raise questions for further study."

(4) A brief report containing incidence, diagnostic, treatment, and survival information for a particular type of cancer. Such reports can be prepared by the central registry or by interested medical specialties using data provided by the registry.

MISCELLANEOUS SERVICES PROVIDED BY A CENTRAL REGISTRY

Described briefly below are some of the services provided by one or more of the central registries now in existence in the United States.

Consultation Services. The central registry can provide a variety of consultation services to local and community registries. In particular, they can provide assistance to hospitals and communities which wish to establish registries.

Training and Job Aid Material. Typically, a central registry assumes the responsibility for preparing the manuals and the job aids which are to be used by the various types of tumor registry personnel throughout the system. Many such manuals and job aids already are in existence. They describe in detail how to operate a registry and how to produce various types of registry reports.

Training Workshops. As the need arises, the central registry can conduct training workshops for community and hospital tumor registry personnel. Such workshops should be held at the community level since it is difficult to obtain funds to send local personnel away for training, and it is often inconvenient, if not impossible, for registry secretaries to be away from home for more than the working day.

Data and Special Reports to Physicians and Other Individuals and Groups Engaged in Cancer Research. Most requests received by a tumor registry are for those records or abstracts dealing with a particular type of cancer within a particular time frame. Often this information is used for research purposes or for preparing a professional paper. In most instances a central registry can provide these data more rapidly and can provide much more comprehensive information than can the local registry.

Assistance in Preparing or Conducting Public Cancer Information Programs. Community or state health agencies may wish to conduct some type of public educational campaign. The central registry can assist in preparing the information to be used during this campaign.

Assistance in Preparing and Conducting Professional (Continuing) Education Programs for Physicians. It must be assumed that physicians will not be familiar with all of the ways tumor registry data and reports can be used to improve the diagnosis and treatment of cancer patients. It should be the responsibility of the central registry to identify the various ways in which its data and reports can be utilized and then to circulate this information among its potential users.

Selection of Current Medical References. The cancer committees of local medical specialty organizations can screen the medical journals and select articles containing important information on cancer. Periodically, a list of these references can be distributed to (a) each participating hospital, and/or (b) each physician whose cancer patients have been accessioned into the registry. Also, these references can be incorporated into special Tumor Registry Listing printouts prepared for and at the request of an individual physician. This service is provided by the central registry sponsored by the Inter-Mountain Regional Medical Program (see Figure 4 for an example of this listing).

**REFERENCES
AND
APPENDIX**

REFERENCES

1. American Cancer Society. *The Hospital Cancer Registry—Definition, Purpose, Value, Operation, and Cost*, New York, 1966.
2. American College of Surgeons. *Manual for Registries and Cancer Clinical Activities*, Chicago, 1955.
3. American College of Surgeons. *Handbook for Cancer Registry Secretaries*, Memorandum of Information and Guidance No. 6, Chicago, 1962.
4. American College of Surgeons. *Manual for Cancer Programs*, Chicago, 1966.
5. California Tumor Registry. *Statistics Handbook for Hospital Tumor Registries*, Berkeley, California, 1962.
6. California Tumor Registry. *Cancer Registration and Survival in California*, Berkeley, California, 1963.
7. California Tumor Registry. *A Guide for the Tumor Registry Secretary in Recording Stage*, Berkeley, California, 1967.
8. California Tumor Registry. *California Tumor Registry Handbook*, Berkeley, California, 1968.
9. California Tumor Registry. *Classification of Extent of Disease*, Berkeley, California, 1969.
10. Cutler, Sidney J. *The Use of Tumor Registry Data*, *California Medical*, vol. 106, pp. 98-107, February 1967.
11. Cutler, S.J., and Latourette, H.B. "A National Cooperative Program for the Evaluation of End Results in Cancer," *Journal of the National Cancer Institute*, vol. 22, pp. 633-646, 1959.
12. Haenszel, W., and Hon, N.B. "Statistical Approaches to the Study of Cancer with Particular Reference to Case Registers," *Journal of Chronic Diseases*, vol. 4, no. 6, pp. 589-599, December 1956.
13. Haenszel, W., and Lourie, Jr., W.I. "Quality Control of Data in a Large-Scale Cancer Register Program," *Methods of Information in Medicine*, vol. 5, no. 2, pp. 67-74, April 1966.
14. Smart, Charles R., Moslander, Virginia, and Altman, Stanley J. *An Experiment in Computerized Tumor Registries*, Intermountain Regional Medical Program, Salt Lake City, Utah, 1968.
15. Ringel, Abraham. *The Cancer Registry*, Division of Regional Medical Programs, Health Services and Mental Health Administration, U.S. Department of Health, Education, and Welfare, Bethesda, Maryland, 1970.
16. *End Results Group 1967 Code Manual*, National Cancer Institute, National Institutes of Health, U.S. Department of Health, Education, and Welfare, Bethesda, Maryland, 1967.
17. *Guidelines: Regional Medical Programs*, Division of Regional Medical Programs, Health Services and Mental Health Administration, U.S. Department of Health, Education, and Welfare, Bethesda, Maryland, May 1968 (revised).

Appendix

GUIDELINES FOR CANCER REGISTRY ACTIVITIES (DIVISION OF REGIONAL MEDICAL PROGRAMS)

In considering the difficulties involved in organizing and operating an effective cancer registry program and the constraints imposed by limited funds, the Division of Regional Medical Programs and its reviewers will seek answers to the following questions when evaluating proposals for support of registry activities:

1. How does this new registry activity or expansion of an existing registry fit into the overall cancer program in the region?
2. Are the objectives of the registry activity clear with reference to:
 - a. patient service,
 - b. follow-up services for physicians and participating hospitals,
 - c. the number of physicians that might benefit from professional educational programs utilizing registry data,
 - d. the use of registry data in public educational programs,
 - e. the kinds of research studies anticipated,
 - f. how the registry will fulfill a regional and/or national need, and
 - g. whether the registry activity will attempt any unique services to patients, physicians, hospitals, the community (with examples of such possible services)?
3. Does the proposal include documentation or other evidence of cooperative arrangements with:
 - a. medical societies (county, state),
 - b. the administrators and staffs of participating hospitals,
 - c. other professional organizations (pathologists, radiologists, surgeons, dental society, etc.), and
 - d. paramedical groups and voluntary organizations?
4. 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?
5. 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?
6. What will be the composition of the personnel, both technical and auxiliary, available to the central registry?
7. What mechanism is to be used or developed to train personnel in participating hospitals, and to review performance with respect to the abstracts they will submit?
8. What criteria will be used to phase in additional hospitals, and at what rate will they be phased into the system?
9. What kinds of automatic data processing equipment will be used, and what is the basis for the selection of the equipment?

10. Will competence in the development of software be required, what personnel or time will be needed for this, and the cost?
11. What are the justifications for the budget data for personnel, space, furniture, equipment, supplies, travel, etc.?
12. What other sources of support will be available during funding by the Regional Medical Programs, and after the Regional Medical Program grant is terminated?

Unclassified

Security Classification

DOCUMENT CONTROL DATA - R & D		
<i>(Security classification of title, body of abstract and indexing annotation must be entered when the overall report is classified)</i>		
1. ORIGINATING ACTIVITY (Corporate author) Human Resources Research Organization (HumRRO) 300 North Washington Street Alexandria, Virginia 22314		2a. REPORT SECURITY CLASSIFICATION Unclassified
		2b. GROUP
3. REPORT TITLE ESTABLISHMENT OF A TUMOR REGISTRY SYSTEM FOR LOUISIANA: PROPOSALS ON OBJECTIVES, CAPABILITIES, AND STRUCTURES		
4. DESCRIPTIVE NOTES (Type of report and inclusive dates) Technical Report		
5. AUTHOR(S) (First name, middle initial, last name) C. Dennis Fink		
6. REPORT DATE June 1970	7a. TOTAL NO. OF PAGES 41	7b. NO. OF REFS 18
8a. CONTRACT OR GRANT NO.	8b. ORIGINATOR'S REPORT NUMBER(S) Technical Report 70-101	
b. PROJECT NO.		
c.		
d.	8d. OTHER REPORT NO. (S) (Any other numbers that may be assigned this report)	
10. DISTRIBUTION STATEMENT Distribution of this document is unlimited.		
11. SUPPLEMENTARY NOTES TUMOR REGISTRY SURVEY (Louisiana Regional Medical Program)		12. SPONSORING MILITARY ACTIVITY
13. ABSTRACT Tumor registry supervisors and secretaries, and hospital administrators at nine Louisiana hospitals and clinics were interviewed to obtain information to guide the design and development of a central tumor registry and state-wide registry system. The study was conducted by the Human Resources Research Organization (HumRRO) under the sponsorship of the Louisiana Regional Medical Program. Information was obtained on (a) local interest in the establishment of a state-wide registry system; (b) services which a central registry might provide; (c) manner in which existing local registries are utilized; and (d) conditions under which hospitals would be willing to join the central registry system. Six hospitals and one community registry were identified as candidates for incorporation into the initial registry system. It was recommended that the registry system be organized around community registries with support provided by a central registry. The need for the registry system to concentrate on high-valued services and products was emphasized.		

Unclassified

Security Classification

Unclassified

Security Classification

14. KEY WORDS	LINK A		LINK B		LINK C	
	ROLE	WT	ROLE	WT	ROLE	WT
Community Registries						
Confidentiality						
Information Requirements						
Louisiana Regional Medical Program						
Medical Records						
Survey						
Tumor Registries						
Tumor Registry Products						
Tumor Registry Services						
Tumor Registry Systems						

Unclassified

Security Classification