E001059

REPORT OF SURVEY OF REGIONAL MEDICAL PROGRAMS

REGISTRY PROGRAMS AND TRAINING NEEDS[1]

Introduction

The survey reported here was undertaken to meet two objectives. The first was to identify tumor registry programs being carried out under the auspices of Regional Medical Programs as well as their purposes and characteristics. The second objective was to assess the need for training by RMP registries, including such aspects as content, mode, duration, and location of training.

Methods

A questionnaire (see Appendix A) was developed and mailed to the 71 regional and area coordinators of Regional Medical Programs identified in the Regional Medical Programs Service Communication issue of June 11, 1970 (Volume 4, No. 28 S). A second mailing of the questionnaire was sent to those not responding within two months to the first mailing.

Responses were received from 65 (91.5%) of the 71 regions or areas. Four area coordinators responding indicated that their registry activities were carried out within the framework of a Regional Program and that the response from the regional coordinator would provide the required information. Thus the following findings and discussion relate to the 61 remaining questionnaires returned to us.

Findings

Number of RMP Supported Registries

Twenty-seven regions or areas (Table 1) indicated that they support tumor registry programs. Of these, 24 are currently funded and data is currently being entered into 23 of these systems.

Types of Registries

Twenty-three of the 27 registries within RMP programs are central registries, while 1 is a single hospital registry program. Three of the 27 programs regard themselves as specialized in function. Of the latter, one (New Jersey) assists primarily in the organization and maintenance of individual hospital registries, a second (Missouri) will include only breast and colon cancer cases, the third (California-Area I) will include only cases seen by radiation therapy departments.

Except for basal and/or squamous cell cancer of the skin, all but
two of the registries (one which did not answer the question and
the Missouri registry referred to above as including only breast
and colon cancer) include all sites of cancer in the tumor registry
system. Of 26 registries responding, half (13) indicated that they
register some benign tumors. Twenty-six (96%) of the registry sys-
tems (all except New Jersey) include regular follow-up of all cases
in the registry.

Of the 27 registries reporting, 11 (Table 2) identified themselves
as population based. In this list there is some overlap in that
the Intermountain Registry includes several of the other registries
identified, i.e. Idaho, Nevada, Wyoming. However the Intermountain
Registry also includes Utah which is not listed elsewhere. These
.overlapping programs are treated independently within this report
since it is not unusual for active smaller programs to be components
of larger programs. An excellent example of this would be the End
Results Program of the National Cancer Institute which brings together
data provided by active registry programs including the Connecticut
Tumor Registry, the California Tumor Registry, as well as a number of
individual hospital registries.

Registry Size

Table 3 gives the frequency distribution of the approximate number
of new cases entered into each registry each year for the 22 regis-
tries which provided this information.

Only 2 registries add less than 1,000 cases per year while 10 regis-
tries accession more than 3,000 cases. The 3 largest systems each
enter between 9,000 and 10,000 cases per year.

Purposes of Registry Programs

A check list of 6 purposes of registries was included on the questionnaire.
Responses to the questionnaire indicated that all registry programs were
established to serve at least 3 of the purposes included on the list. All
27 of the RMP supported registries are for the purpose of helping to assure
continued medical supervision of the cancer patient through follow-up and
also to assist in the continued cancer education of the medical community.
Twenty-five (93%) of the registry systems are to assist in planning activi-
ties, i.e. to assess the magnitude of the cancer problem in the hospitals
and/or community represented by the registry. Twenty (74%) plan to con-
tribute to the evaluation of increased frequency of early diagnosis and
improved cancer management following the advent of RMP. Research on the
natural history of cancer as well as on the epidemiology of cancer is to
be carried out by 17 (63%) of the registry programs. Four registries
identified goals other than those described above. Three of these are
in the area of therapy evaluation and the other directs attention to
studying the relationship between environment and cancer.

Training Needs

Of the 25 registries responding to this section on training needs, 18 (72%) stated that they would be interested in sending registry personnel to San Francisco for training in our Tumor Registry Training Program. Sixteen registries (67%) out of 24 responding indicated that they would be interested in sponsoring a 3-5 day workshop in their own region.

Training Content

For the registries interested in training for their personnel, we requested information on desired training content by job category of persons to be trained. We defined the following job classifications: central registry supervisor, data collectors, data analyzers, and individual hospital registry secretaries. Data collectors are persons such as abstractors and coders. Data analyzers are registry personnel who function as statisticians or computer programmers.

Training content was divided into two major areas. The first relates to registry operations and the second deals with knowledge of the medical aspects of cancer. The training areas related to registry operations are: central registry management, single hospital registry management, abstracting and staging, follow-up, data coding and processing, survival analysis, and preparation of reports. Training areas on the medical aspects of cancer include: human anatomy, pathology, epidemiology, methods of diagnosis, treatment rationale, and cancer of specific sites and systems.

Table 4 gives the number of registries interested in sending personnel within a given job classification to San Francisco for training. Thus 17 of the 20 registries desiring training require this training for central registry supervisors. Fifteen desire training for data collectors, 12 for data analyzers and 13 for individual hospital secretaries. It should be emphasized that these figures represent numbers of registries rather than individual trainees.

The desired training content by personnel category is given in Table 5 and is summarized below:

Central Registry Supervisors

a) Registry Operations

Seventeen regions with central registries indicated a need for training for their supervisors. The 2 most frequently requested training areas were central registry management and preparation of reports. Such training was desired by 15 regions. Twelve regions desired training in follow-up techniques and survival analysis. Next most frequently

requested was training in abstracting and staging and single hospital registry management.

b) **Medical Aspects of Cancer**

There was considerable uniformity in the response to each of the training areas listed. Between 8 and 12 registries desired training in each of the subjects listed.

Data Collectors

a) **Registry Operations**

Of 15 registries expressing a need for training of data collectors (coders or abstractors), 14 desired instruction in abstracting and staging. In order of decreasing frequency the other training content requested were follow-up, preparation of reports, data coding and processing, central registry management, single registry management, and survival analysis.

b) **Medical Aspects of Cancer**

Other than epidemiology which was requested by only 1 registry, all of the other topics were almost uniformly in demand in that from 9 to 12 regions indicated a need for their inclusion.

Data Analyzers

a) **Registry Operations**

Twelve registries indicated the need for training of data analyzers (programmers or statisticians). Eight of these desired training in data coding and processing followed, in declining frequency, by preparation of reports and survival analysis, follow-up, central registry management, and abstracting and coding.

b) **Medical Aspects of Cancer**

Five of the 12 registries responding desired inclusion of epidemiology in the training of their data analyzers. Next most in demand were lectures on pathology and treatment rationale followed by human anatomy, cancer of specific sites and systems, and methods of diagnosis.

Individual Hospital Registry Secretary

a) **Registry Operations**

Thirteen registries indicated the need for the training of

individual hospital registry secretaries. Ten of these 13
desired training in each of the areas of single hospital
registry management, abstracting and staging, and follow-
up. Seven requested training in preparation of reports,
5 in survival analysis, 2 in data coding and processing
and 1 in central registry management.

b) Medical Aspects of Cancer

Other than epidemiology for which there were no requests,
each of the other medical topics were in uniform demand
with either 8 or 9 registries desiring training in these
areas.

Length of Training

The questionnaire included a section for Regions to check the period
for which their personnel would be available for training in San Francisco.
Two-weeks of training was the most frequently checked period for each of
the 4 personnel categories. Overall this was followed in turn by one-
month, one-week, and two-months of training, respectively.

Mode of Training

In developing self-instructional programs in registry methodology the
respondents indicated a clear preference for a programmed instruction
text, followed, in turn, by a packaged video-tape and film strip pro-
gram, and finally by a correspondence course.

Discussion

The present survey shows that there are 26 central registry programs
and 1 single hospital registry program supported by Regional Medical
Programs indicating the considerable extent to which RMP is involved
in the cancer registry field. Of the activities referred to, 23 of
the systems are actually operational at the present time in the sense
that data are entering into these programs. The size of the registry
systems is also quite impressive in that all but 2 of the reported
systems enter at least 1,000 cases per year and the 3 largest systems
enter between 9,000 and 10,000 cases per year.

All of the reported registry systems are intended to serve a variety
of purposes. The most common purposes to be served are the assurance
of continued medical supervision through follow-up and assistance in
the continued cancer education of the medical community. Large pro-
portions are also intended to help in planning and for evaluation of

early diagnosis and improved cancer management. More than 60% of the registry programs are intended to be active in research on the natural history of cancer and on the epidemiology of cancer. The magnitude of the registry activities supported by RMP as well as the important purposes to be served by these registries indicate a need for facilities for training of registry personnel. This is recognized by the RMP areas themselves in that 72% of the programs with registries were interested in sending personnel to San Francisco for training within our program. Sixty-seven percent of the registries responding expressed an interest in sponsoring training workshops to be conducted by our staff within their own RMP areas.

In response to questions concerning desired content of training for their personnel, it was demonstrated that the needs vary considerably according to the role to be carried out within a registry program. Those in a supervisory position place more emphasis on training in management procedures than those performing jobs as data collectors, analyzers or individual hospital registry secretaries. Even with different areas of emphasis by job category, there was nevertheless within each job classification considerable demand for a broad spectrum of training content. Thus it was well recognized that in addition to a knowledge of basic registry operations, there is an important need for the personnel of a tumor registry program to have a strong understanding of the subject matter of cancer including topics such as anatomy, pathology, epidemiology, methods of diagnosis, and treatment rationale in addition to knowledge of cancer of individual sites and systems.

It has been the philosophy of the training program at San Francisco that the quality of the data recorded within a registry system primarily reflects the competence of the personnel and their understanding of cancer. In a field such as cancer in which definitions and classification systems are not yet standarized, the demands on registry personnel in terms of an understanding of the subject of cancer are particularly heavy. The registry system itself may become the key to making progress in the required standardization of terms. For example there is much emphasis currently on standardizing rules for staging of cancer. If a particular stage category is to include those patients with a similar prognosis, knowledge of the required grouping of cases can emerge only through registry systems set up to study problems of this kind. A further corollary of this is that in order to do such a study, it is necessary to assure that the registry is geared to the recording of the necessary information and that the quality of the information recorded is high.

Of equal importance with the need to know the technical operational aspects of a registry program, it is extremely important that registry personnel be aware of functions that a registry program can serve as well as those uses for which a registry program may be inappropriate.

For example, most registry programs would be on extremely tenuous grounds if they felt that through their activities they could provide definitive information regarding therapy evaluation. Without controlled clinical trials this is not possible.

On the other hand there are important contributions of registry programs which are sometimes not apparent. For example as a result of research activities on the natural history of various forms of cancer carried out by tumor registries, it has been noted that there has been an improvement in the quality of medical record keeping in hospitals participating in such studies.

It is also of importance that registry personnel and those guiding registry policy, should recognize that with the changing concepts in the field of cancer, procedures within registry programs must be adaptable to changes reflecting our improved understanding of these diseases as well as improved technology in data storage and retrieval methods.

Tumor registries have in the past been criticized as not being of adequate service to the individual physician. How best to serve the physician and to encourage his interest and participation in registry work is an area yet to be pursued more actively. Perhaps through regular reports presented in an interesting and brief form there may be some additional impact. Perhaps through presenting the physician with a list of each of his cancer patients with their latest follow-up status, there might be some improvement in the relationship between the registry and the physician. This issue is of extreme importance since each of the registry programs identified in the present survey have indicated their hope that the registry would contribute to the continued cancer education of the medical community. What must be recognized, however, is that a cancer registry activity must not be confused with the cancer program. The cancer registry activity is only part of a cancer program and its activities should be guided by the purposes of that entire program. Therefore the burden of defining the registry program falls primarily on those defining the cancer program itself. Hopefully this guidance to the registry will also include indications of ways in which it may be most useful in serving the medical community.

Since all of the registry programs surveyed plan to assure continued medical supervision of the cancer patient through follow-up, it is important that attention be paid to various approaches to follow-up as well as possibilites in varying follow-up schedule, perhaps according to type of cancer involved. With the progress that is occurring in the medical management of cancer patients, it is furthermore important that the concept of follow-up of cancer patients should provide for assessment of the patient's status in order to gain some insight into the quality as well as quantity of survival.

More than 60% of the registries indicated their intention to carry
out research on the natural history of cancer and also on the epi-
demiology of cancer. In view of the fact that approximately 40%
of the registries reporting indicated that they are population
based, the potential for epidemiologic studies for these registries
may be quite good. However it is of importance to recognize that
research of this nature requires personnel with training and exper-
tise both in the subject matter of cancer and in the statistical
and epidemiologic methodology to be employed.

Implications For Tumor Registry Training Program

The extent of development of tumor registry programs under sponsor-
ship of Regional Medical Programs suggests a need for a continuing
and developing program that will help meet the need for training
resulting from these activities. The nature of the training program
must be responsive to the purposes to be served by the various registry
programs. Thus it would appear that since the preponderance of the
RMP supported registries are centralized systems that further develop-
ment of the training program to meet the needs of central registry per-
sonnel should be given due consideration.

On the other hand training needs of personnel of individual hospitals
must also be met since the backbone of any central registry program is
the quality of the source material from the individual participating
institutions.

There was recognition by the regions surveyed of the need for training.
Considerable interest was expressed by RMP supported registry programs
in sending registry personnel to San Francisco for a period of intensive
training. Increased emphasis on two-week programs of training appears
indicated from the responses to desired duration of training in
San Francisco. From the responses to the question dealing with training
content, it is now possible to better plan for the category of trainees
who will come to San Francisco as well as the desired training content.

In addition to training in San Francisco, approximately two-thirds of
the regions responding indicated their interest in sponsoring a 3 to 5
day workshop in the local area. Such workshops offer a mechanism for
providing limited training to large numbers of registry personnel. The
favorable response to such workshops suggests the value of continued
development of training material and teaching techniques to optimize
the benefit to participants in such workshops. Additional emphasis on
developing workshops that will be profitable to both inexperienced and
experienced registry personnel may be indicated. Training at two levels
was offered at the workshop held at the University of California in
Los Angeles in January of 1971. Pursuing this a step further, it may
also be useful to plan for training of administrators and physicians in
a workshop of one or two days to provide for them an overview of the

registry field, its problems, and potential.

The response to the question on self-instructional material, points up the desirability of further work to be carried out in the preparation of a programmed instruction text as well as the material for a packaged video-tape and film strip program.

Table 1.

<u>RMP-Supported Registries</u>

California-Area I

Colorado-Wyoming

Georgia

Greater Delaware Valley

Illinois

Intermountain

Iowa

Kansas

Metropolitan Washington D.C.

Missouri

Mt. States-Idaho

Mt. States-Montana

Mt. States-Nevada

Mt. States-Wyoming

New Jersey

New Mexico

North Carolina

North Dakota

Oklahoma

Puerto Rico

South Carolina

Susquehanna Valley

Tennessee Mid-South and Memphis

Texas

Virginia

Washington/Alaska-Seattle

Western New York

Table 2.

Population-Based Registries

    1.   Intermountain

    2.   Iowa

    3.   Kansas

    4.   Metropolitan Washington, D.C.

    5.   Mt. States-Idaho

    6.   Mt. States-Nevada

    7.   Mt. States-Wyoming

    8.   Puerto Rico

    9.   Susquehanna Valley

  10.   Tennessee Mid-South and Memphis

  11.   Western New York

Table 3.

Registry Size

No. of New Cases Per Year (1000's)	Number of Registries
< 1	2
1-2	5
2-3	5
3-4	4
4-5	2
5-10	4
Total	22

Table 4.

Registries Requesting Training by Personnel Category

Personnel Category	No. of Registries
Central Registry Supervisors	17
Data Collectors	15
Data Analyzers	12
Individual Hospital Registry Secretaries	13
Total Number of Registries Requesting Training	20

Table 5. Number of Registries Requesting Specific Training Content by Personnel Category

Personnel Category	Central Registry Supervisor	Data Collector (Coder, Abstractor)	Data Analyzer (Programmer, Statistician)	Individual Hospital Registry Secretary
Training Content		Number of Registries		
Registry Operations				
1. Central Registry Management	15	5	4	1
2. Single Hospital Registry Management	8	2	-	10
3. Abstracting and Staging	10	14	1	10
4. Follow-up	12	7	-	10
5. Data Coding and Processing	10	6	8	2
6. Survival Analysis	12	1	6	5
7. Preparation of Reports	15	7	6	7
Medical Aspects of Cancer				
1. Human Anatomy	10	12	3	9
2. Pathology	11	12	4	8
3. Epidemiology	8	1	5	-
4. Methods of Diagnosis	11	11	2	9
5. Treatment Rationale	12	12	4	8
6. Cancer of Specific Sites and Systems	10	0	3	8
Total Number of Requesting Registries	17	15	12	13

CANCER RESEARCH INSTITUTE
UNIVERSITY OF CALIFORNIA SAN FRANCISCO
SURVEY OF REGIONAL MEDICAL PROGRAM
TUMOR REGISTRY ACTIVITIES
AND TRAINING NEEDS

PLEASE TYPE OR PRINT

RMP Region:_____RMP Coordinator:_____

Does your Region support a Tumor Registry Program? Yes_____ No_____

If NO, PLEASE DISREGARD remaining questions and return questionnaire to us promptly.

IF A TUMOR REGISTRY PROGRAM IS SUPPORTED BY YOUR REGION, PLEASE COMPLETE THE REMAINDER
OF THE QUESTIONNAIRE.

Name of Registry Program:_____Director:_____

Address:_____

CHARACTERISTICS OF REGISTRY PROGRAM

Please fill in the blanks provided for all succeeding questions.

I. Status of Registry Program

_____ _____ a. Is your registry program currently funded by RMP?
  yes   no

_____ _____ b. Is data currently entering the registry system? If yes,
  yes   no
                    when did data collection begin?_____(mo.   yr.)

II. Type of Registry

_____ _____ a. Single hospital registry program (registry consists of
  yes   no   data from only one institution)

_____ _____ b. Central registry program (registry consists of data from
  yes   no   more than one hospital)

_____ _____ c. Other type of registry program, e.g. special purpose regis-
  yes   no   try. Describe: (if more space is needed, use reverse side)

III. Size and Scope of Registry

_____ a. Approximate number of new cases entered into your registry
                each year

_____ _____ b. Are cancers of all sites included in your registry? If no,
  yes   no   indicate which cancers are excluded:

_____ _____ c. Are you including selected benign tumors in your registry?
  yes   no

_____ _____ d. Is your registry population-based, i.e. do you record <u>all</u>
 yes   no   cancers diagnosed in a geographically defined population
group? (For example, the Connecticut Tumor Registry re-
cords all diagnoses of cancer occurring among the entire
population of the state of Connecticut.)

_____ _____ e. Does your system include regular follow-up of all cases
 yes   no   in your registry?

IV. Purposes of Registry (Check all that apply)

_____ a. To assure continued medical supervision of the cancer patient
through follow-up

_____ b. To assist the continued cancer education of your medical community

_____ c. Planning (to assess magnitude of the cancer problem in hospitals
and/or community)

_____ d. Evaluation of increased frequency of early diagnosis and improved
cancer management following the advent of RMP

_____ e. Research on the natural history of cancer

_____ f. Research on epidemiology of cancer

_____ g. Other, (specify)

TRAINING NEEDS

I. Tumor Registry training programs of various duration are held in San Francisco.
Would you be interested in sending any of your registry personnel to San Fran-
cisco for participation in a training program? (Question IV provides a check-
list of training content for various categories of registry personnel)

            Yes_____   No_____

II. In addition, a limited number of three to five day workshops may be offered out-
side of San Francisco. Would you be interested in sponsoring such a workshop
in your area?

            Yes_____   No_____

III. Consideration is being given to the development of the following self-instruc-
tional programs in registry methodology. Which do you feel might be most use-
ful in meeting your training needs. Please rank in order of preference (1st,
2nd, 3rd)

_____ a) Packaged video-tape and film strip program

_____ b) Programmed instruction text

_____ c) Correspondence course

IV. If you would be interested in training for your registry personnel, please check the desired training content and time available for training for each personnel category to receive training. For your convenience, blanks are provided for further suggestions regarding training content in section on "Other Specific Topics".

REGISTRY PERSONNEL CATEGORY

TRAINING CONTENT	Central registry supervisors		Data collectors (coders, abstractors)	Data analyzers (programmers, statisticians)	Individual hospital registry secretary	Other (specify)
REGISTRY OPERATIONS	M.D.	non-M.D.				
1. Central registry management						
2. Single hospital registry management						
3. Abstracting and staging						
4. Follow-up						
5. Preparation of reports						
6. Data coding and processing						

MEDICAL LECTURES

1. Human anatomy						
2. Pathology						
3. Methods of diagnosis						
4. Treatment rationale						
5. Cancer of specific sites and systems						

OTHER SPECIFIC TOPICS	M.D.	non-M.D.	Data collectors	Data analyzers	Hospital registry secretary	Other	
1. Epidemiology							
2. Survival analysis							
3.							
4.							

PERIOD AVAILABLE
FOR TRAINING

1. Two weeks							
2. One month							
3. Two months							

V.   Remarks

_____   _____
Date   Signature