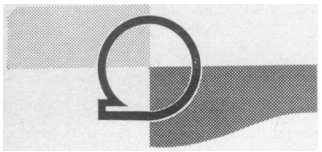

Central Registry of Cancer Cases in Connecticut

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IN 1935 the Connecticut General Assembly passed a bill providing for the formation of a State tumor study committee. As a result, the division of cancer research was established; the central cancer registry was established within this division in 1941.

During the period 1936–40 the activities of the division were confined to providing mortality statistics, educating the public and professionals, and establishing tumor clinics. In 1941 a team of physician, statistician, and specially trained clerks visited each hospital to prepare abstracts of all case histories of cancer patients admitted to these hospitals after January 1, 1935. The hospital retained the original abstract, establishing the local registry, and a copy was sent to the central cancer registry.

The central cancer registry is now called the Connecticut Tumor Registry, and all hospitals in Connecticut provide it with abstracted case histories of all newly diagnosed cancer patients and with lifelong followup records of surviving cancer patients. The public health statistics section of the State department of health supplies the registry with a copy of all death certificates on which cancer has been mentioned.

The registry now has on file records for approximately 175,000 persons with malignant and benign tumors, of whom approximately 45,000 are under active followup. More than 8,500 new cases and another 1,000 new second primary cases are currently added to this roster yearly.

The Connecticut Tumor Registry is the oldest cancer registry in the United States based upon a defined population group. The registry provides information for evaluating progress being made against cancer and the effectiveness of treatment provided for it. Connecticut statistics are often projected to the national scope. The tumor registry has achieved worldwide recognition for contributions in cancer epidemiology and in evaluation of end results.

The central registry depends on four semi-independent operations—the tumor record system, the followup system, the death certificate system, and the allocation system.

Tumor Record System

The tumor record, which is the basic reporting form, originates in the hospital tumor registry. The hospital tumor registry secretary, who abstracts each patient's history and fills out

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the tumor record, receives information from the medical records department, pathology laboratory, X-ray department, and outpatient clinic. The completed tumor record is sent to the tumor registry, and a copy of it is kept in the hospital's permanent files.

At the registry the tumor records are received by the quality control unit and inspected for accuracy and completeness. Any incomplete records are noted and questioned when a member of the unit next visits the reporting hospital. All newly received records are stamped with the date of receipt and alphabetized by patient name. Each hospital's records are kept together as a group.

These records are next given to the visual index clerk who determines if a previous report exists for the newly reported patient. If there is already a record in the registry, the new record is assigned the original number and combined with the original report. Such combinations of records are then processed by a coding supervisor who recodes the entire case to reflect the new information.

If there is no previous report on the patient a serial number is assigned, the case is listed in the daily receipts book by the visual index clerk, and the tumor record is given to a coding clerk. If more information is needed from the hospital before the case can be coded, the coder puts in a hospital inquiry slip. A death certificate search may also be requested at this time. If the report concerns a nonresident or a nonreportable condition, the tumor record is removed from the registry and sent for nonreportable indexing.

Coded case reports go to data processing where analysis, index, followup, and allocation cards are punched and subjected to mechanical quality control. The index card is used to print visual index strips and case labels. The case labels are put on the folders, and the records are filed in serial number order according to primary site of the tumor. An index book is printed and receipt lists are made; one copy of each list is kept on file in the registry and one copy is sent to the hospital which reported the cases.

Analysis cards are filed until quality control on the IBM 1401 computer is performed. Every 2 years, the analysis cards are converted mechanically to the uniform punchcard code of the End Results Evaluation Section, National Cancer Institute, Public Health Service. The original analysis cards and the converted punchcards are filed in the registry for future statistical analyses and a duplicate deck of the converted punchcards is sent to the End Results Evaluation Section.

Followup System

Followup by the reporting hospital for each patient 1 year after diagnosis and on a yearly basis thereafter as long as the patient lives is requested. However, no followup is requested for patients with superficial (noninvasive) basal cell or epidermoid skin lesions, and patients with certain nonmalignant tumors which are reported for special interest are followed for only 5 years if there is no evidence of disease on the fifth anniversary of diagnosis.

The tumor followup system uses the followup card created for each patient during the initial processing of a tumor record. The followup process originates in the data processing section where, at the beginning of each month, the followup request forms are printed from the updated followup punchcards and mailed to the hospital responsible for following these patients. This can be any hospital in the patient's history depending on the circumstances of the individual case.

At the hospital the followup forms are completed by the hospital tumor registry secretary or medical record librarian who checks any readmission or physician's reports for current information on the clinical status of the cancer, additional treatment, a recurrence since the last report, any change in diagnosis, and the vital status of the patient.

After completion by the hospital the followup forms are returned to the tumor registry. They are stamped with the date of receipt and separated into three groups—routine alive, alive with changes, and dead.

The "routine alive" are those newly dated followup forms with no changes in identifying information. These are sent directly to data processing for change card punching. Followup change cards consist of registry serial number, code number of the hospital responsible for followup, and the new date of contact. These

cards are prepared from the followup form and are filed for the succeeding month's updating at which time the new date will be entered on the patient's full followup card.

The "alive with changes" are followup forms indicating changes in identifying information such as patient's or physician's name or new tumor information. These forms are used to correct and update the followup cards, visual index strips, case labels, index book, daily receipt book, and index or analysis card as necessary.

Based on the "dead followups," which indicate the patient has died since the last contact, the visual index strips are marked with the death date. The forms are then sent to data processing for change card punching.

After the data processing has been completed followup forms are filed in the appropriate case folders.

Death Certificate System

The public health statistics section routinely forwards to the tumor registry copies of all death certificates on which cancer is mentioned. These certificates are stamped in and alphabetized monthly, then given to the visual index clerk who searches for case reports concerning these same patients. If a death certificate is matched to a case report already on file in the registry, the visual index strip is marked with the date of death and the registry serial number and number of the reporting hospital are put on the certificate.

Copies of matched death certificates are sent to the hospitals for their records. Originals are filed with the case records.

Information from death certificates for which no case match can be determined is coded and an index card is punched. Visual index strips are prepared for future use in case matching and the unmatched death certificates are temporarily filed.

If after 1 year an unmatched death certificate has not been paired with a hospital reported case, it is rechecked for variations in name spelling or aliases. When it has been determined definitely that no tumor record is in the registry, the death certificate is assigned a serial number, put in analytic code, and sent to data processing. An analysis and index card are punched and verified, quality control is performed, and an index listing is made. The original index card, which was created when the unmatched death certificate first entered the registry, is replaced by a reproduced version of the newly numbered and coded index card.

Unmatched deaths which occurred in a reporting hospital are selected and requests for tumor records are sent. The three possible replies to these requests are that the case match may have been missed because the patient's name was spelled or given incorrectly, a tumor record is being sent by the hospital, or the person did not, in fact, have cancer. In all three events, the death certificate is removed from the unmatched death certificates. In the third instance it becomes a nonreportable case, but is coded in a special nonanalytic code, allowing a record to be kept of deaths erroneously reported as due to cancer.

For unmatched deaths which occurred at home, out of State, or in convalescent homes a request for additional information concerning diagnosis and treatment is sent to the physician who certified the death. This procedure was first used in 1962. Where adequate information is obtained, either a tumor record is made or the unmatched death certificate is removed from the registry.

The cooperation of physicians who certified unmatched deaths has been remarkable. In many cases they refer the registry to out-of-State medical institutions which supply information concerning diagnosis, treatment, and survival. Often the certifying physician is able to supply the necessary data or inform the registry of another physician who can help further the inquiry.

In 1962 almost 500 requests for additional information were sent to private physicians. When all sources were exhausted enough additional information was obtained on 268 persons to form tumor records. Of these, 126 had diagnosis dates ranging from 1938 to 1961; 142 were diagnosed in 1962. Forty unmatched death certificates were classified as nonmalignant or nonresident cases and removed from the registry, and only 191 cases were left as unmatched death certificates either because the physician had died or had seen the patient only in the capacity of medical examiner.

Allocation System

The central registry has a fixed budget for distribution to the reporting hospitals. Each record can be assigned up to six points on the basis of the quantity and quality of the data reported. These points are totaled each year and are the basis for the proportion of the total budget distributed to each hospital.

Two points are given for each malignant tumor and each reportable benign tumor described on separate tumor records. The quality of the information and the completeness of followup determine whether or not additional points are awarded. For example, one point is given for a positive microscopic examination obtained either by tissue specimen or exfoliative cytology at the reporting hospital, and another point is given for a pathological report regardless of where the microscopic specimen was obtained. Information pertaining to the patient's status 6 months or more after the date of diagnosis is worth another two points.

Allocation points are kept in a separate punchcard file which is destroyed after a yearly allocation is completed.

Quality Control System

The tumor registry also has a system of quality control directed at the coded tumor record and subsequent punchcards. Several methods are used to obtain accurate coding and punching.

Lectures. As needs arise, both a cancer surgeon and a pathologist are called in to speak to coders, thereby furthering the coders' education and clearing up difficult areas of medical interpretation.

Coding conferences. Since the Connecticut tumor code is complex and exacting, problems of interpretation arise periodically. As necessary, conferences involving the entire coding staff and the research statistician in charge are held to discuss trouble areas. Any question needing a medical opinion is brought to a physician.

Personal instruction. All coding supervisors and the research statistician are available to instruct coding clerks. A physician is also available to give a medical opinion on more difficult problems. A coder may be put through a brief retraining period whenever mechanical quality control or supervisor's observation indicate it is necessary.

Record coding review. A small sample of tumor records coded during a given month are recoded by a coding supervisor. The original coder and recoder then compare their records and discuss and resolve any differences in coding or interpretation.

Punchcard consistency checks. Using electronic data processing equipment such as a collator, the index and analysis punchcards for the same case are compared on fields where the codes should be identical. In addition, using an IBM 1401 computer 74 card columns of the analysis card are checked for impossible punches and various fields on the card are compared for internal consistency. The computer program that converts the analysis card to the uniform punchcard to be sent to the National Cancer Institute also has built-in consistency checks which are performed before conversion takes place.

Hospital record abstracting review. A method to insure that records submitted by the hospital tumor registries to the central registry will be of high quality is to be inaugurated. A sample of hospital cases will be reabstracted by coding supervisors and the two records compared. In this way areas in which differences in abstracting occur will be identified and corrected.

Use of Registry Data

The central cancer registry is primarily a research tool. Since all cancer cases diagnosed in the State are registered, incidence data are available by sex, age, residence, and other demographic variables. Such data are essential for planning cancer control programs and for formulating hypotheses concerning the etiology of the disease. The ongoing nature of the registry provides information on trends in cancer incidence, a means for measuring the success of specific control programs; on trends in stage of disease at diagnosis, a measure for evaluating educational and casefinding programs; and on trends in method of diagnosis, an index of diagnostic accuracy and a measure of progress in the use of accepted diagnostic techniques.

The patient followup system makes possible the calculation of survival rates. Questions concerning survival experience and how it varies

among specific categories of diagnosed cases can be answered.

Data collected from individual hospitals and clinics contain much valuable survival information, but have limited usefulness because they are not applicable to any specific population group and are usually limited in number and scope. Such data furnish an uncertain basis for generalizations concerning characteristics and survival experiences of cancer patients because the extent to which a particular series is representative of all cases of cancer in the population is unknown, and the limited number of patients generally available in a hospital series precludes the cross-classification of cases with respect to more than a few factors. In contrast, data obtained from a communitywide registry are applicable to a population of known size and composition; when the study population is sufficiently large, the volume of material available within a number of years is large enough to permit detailed and comprehensive analysis.

The registry has proved to be a valuable resource in conducting special studies. For example, when findings based on routinely collected data warrant further investigation, additional information has been obtained by reviewing hospital records for a sample of registry cases.

Exploitation of the data results in periodic reports and monographs dealing with cancer incidence and survival. In addition, registry data have been used by numerous investigators for intensive study of selected samples of cases.

NOTE: A bibliography of monographs and of special studies developed from tumor registry data is available from the chronic disease control section, Connecticut State Department of Health, 79 Elm St., Hartford, Conn. 06115. Also available from the department are flow charts of the course of tumor records, tumor followup records, and death certificates.

Support for Researchers in Mental Health

A Mental Health Research Development Program for the recruitment, training, and employment of scientists for full-time mental health research positions is being offered by the National Institute of Mental Health, Public Health Service. Funds will be provided for special training costs and, in some circumstances, for research costs of selected behavioral scientists.

Two types of awards will be given. Research scientist development awards will support promising young scientists seeking to expand their knowledge and skills in mental health research, and research scientist awards will support research conducted by investigators with considerable experience. Awards will be granted for 5-year periods. Research scientist development awards may be renewed for one 5-year period.

Scientists working in any of the following areas of basic or applied research are eligible for awards: personality and human development, social factors in mental health, physiological and biochemical substrates in relation to behavior, and the etiology, diagnosis, treatment, or prevention of mental disorders and illness.

Awards will be granted to scientists qualified to develop or extend research programs at the institutions where they are employed. Eligible institutions include medical school departments of psychiatry, psychiatric hospitals or hospitals with psychiatric services, community mental health centers, biomedical research institutes with mental health programs, and behavioral science institutes or departments with research programs for the study of problems relevant to mental health.

Applications must be made by the department of the institution responsible for the research program. Deadlines for accepting applications each year will be the first of September, January, and May. For additional information and application forms, write the Research Fellowships Section, Behavioral Sciences Training Branch, National Institute of Mental Health, 5454 Wisconsin Avenue, Chevy Chase, Md. 20203.