

Chapter 2

History of MD Anderson's Tumor Registry

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The Tumor Registry Department at The University of Texas MD Anderson Cancer Center is responsible for a database that contains demographic and disease information for all patients assigned a medical record number at MD Anderson, starting with the first patient registered on March 1, 1944. In its function as a hospital registry, the Tumor Registry database contains information about every patient seen at the institution, regardless of the patient's final diagnosis. The institution has always focused on cancer, and every patient has come to the institution because of a cancer-related issue: some with a malignancy, some with a benign or nonneoplastic condition, and some to rule out cancer. Because of this, each patient's information is of value to the hospital.

The institution, originally named the Texas State Cancer Hospital and the Division of Cancer Research in 1941 and then renamed to MD Anderson Hospital for Cancer Research of The University of Texas in 1942, had two purposes from its beginning—to conduct cancer research and to provide care for cancer patients. The registry database was initially established in September 1948 and was housed in the Department of Epidemiology. Eleanor Macdonald was appointed as Professor of Epidemiology and department head.

Miss Macdonald is known as the first cancer epidemiologist. Before coming to MD Anderson, she worked for the Massachusetts Department of Public Health, where she was the first to precisely determine incidence rates for cancer, and for the Connecticut State Health Department, where she developed the first population-based cancer registry and conducted the first vital status follow-up for cancer patients [1].

By the time Miss Macdonald arrived at MD Anderson in 1948, a total of 2,857 patients had come to the hospital. Under Miss Macdonald's leadership, a

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multifunctional department was established, and its responsibilities included abstraction of data, patient vital status follow-up, epidemiological research, and consultative services for basic and clinical researchers ([2], p. 41). In this new department, Dr. R. Lee Clark, MD Anderson's first president, established a section of information and statistics. Miss Macdonald developed a code of 200 pertinent items applicable to each patient that were designed in anticipation of requests for information for administrative, clinical, and research areas ([2], p. 107). The department also developed and maintained an IBM data processing unit to facilitate access and use of data. Information was stored on punch cards for each case and then stored in indices for "easy recall" ([2], p. 198). This processor made possible constant evaluations as well as monthly and annual assessments.

The handbook for tumor clinic secretaries that Miss Macdonald developed in 1956 at MD Anderson was an outgrowth of one used to train workers at the Connecticut State Health Department. That handbook was eventually sent to every hospital in Texas. At the request of the American College of Surgeons (ACoS), the handbook was also sent to every general hospital in the United States and Canada. The handbook was designed to enable workers without any other source of instruction to build a hospital cancer registry and follow-up service that would fulfill the requirements of the ACoS ([2], p. 315).

Miss Macdonald stepped down as head of the department in 1974. When Vincent Guinee, M.D., who had been an epidemiologist for the City of New York Health Department, became the department head in 1976, the database contained information on more than 112,000 patients. Under Dr. Guinee, the department, which changed its name to Patient Studies, continued to collect a well-defined and consistent data set on each patient and to assist researchers within the institution.

In 1979, the 66th Legislature enacted the Texas Cancer Control Act (House Bill 853), which created the Cancer Registry Program within the Texas Department of Health, making cancer a reportable disease [3]. Because of this need to have submittable data and to facilitate internal data retrievals, Dr. Guinee had the registry data moved to a mainframe NOMAD database.

Under the guidance of Dr. Guinee and at the direction of Dr. Clark, MD Anderson founded the International Cancer Patient Data Exchange System, which was funded by the International Union Against Cancer (UICC). Under this system, data from the registries at MD Anderson, Roswell Park Cancer Institute, Memorial Sloan-Kettering Cancer Center, and 11 other institutions in 10 other countries were compiled into one massive database. With this large number of patients, collaborative studies of rare cancers were carried out.

Dr. Guinee was head of the Department of Patient Studies until 1994. When he left, the database had grown to include more than 315,000 patients.

Since 1995, the department has been under the Office of the Physician-in-Chief. That year, the mainframe database was converted to 4th Dimension (4D), where it still resides. The customized in-house software makes possible the continuation of consistency in the collection of data over the span of the institution and makes possible inclusion of past histories of cancer and nonmalignant diagnoses that were originally thought to be cancer. The software also allows retention and expansion of

query tools that were initially developed on the mainframe. These query tools are essential for the extensive institutional use of the data for research and administrative purposes. As of December 31, 2011, the database contained information on more than 850,000 patients.

Registry Operations

Information is collected for all malignancies over the life of the patient, benign neoplasms seen at MD Anderson, and nonneoplastic conditions that affect the patient's cancer treatment or constitute the only diagnosis for the patient.

The MD Anderson Tumor Registry staff provide annual vital status follow-up of patients who currently have or had malignant disease, including foreign patients and patients not definitively treated at MD Anderson. This comprehensive follow-up structure provides the fundamental outcomes information necessary to conduct research on a broad spectrum of clinical research topics.

Responsibilities of the Coding Section

The Coding Section of the Tumor Registry is responsible for abstracting demographic and disease information for all patients registered at MD Anderson. The following describes the specific activities of the Coding Section.

Identification and Processing of New Patient Information

On the sixth day of each month, the Coding Section manager downloads a file of all medical records assigned to new patients during the previous month. Patients' demographic information captured during registration is also downloaded. The medical record numbers and demographic data are read into the 4D database, the transactional database used by the Tumor Registry. This read-in process includes several edits. Designated coders are responsible for resolving errors in the data and assigning codes for each patient's referral diagnosis. Certain errors are reported back to the Referral Office so the correction can be made to the institution's system. Once demographic information has been processed, it becomes part of the available Tumor Registry data and awaits abstracting of disease information by the coding staff.

New Patient Abstracting

The Coding Section of the Tumor Registry is responsible for abstracting information from the charts (either electronic or paper) of each patient who registers at MD Anderson. Abstracting is done no sooner than 4 months after a patient registers.

This allows adequate time to elapse for the charts to contain definitive staging information and final pathology reports and for the first course of therapy (defined as therapy given during the first 4 months after registration) to be completed at MD Anderson. Completion of coding of data for newly registered patients from any given month usually takes 2 months. Categories of data abstracted include additional demographic information, malignant neoplasm information (including site, histology, stage, treatment before admission to MD Anderson, treatment at MD Anderson, and sites of metastases), benign neoplasm information (including site, histology, treatment before admission to MD Anderson, and treatment at MD Anderson), and pertinent nonneoplastic conditions and follow-up information (including vital status, date of last contact/death, method of follow-up). The staff of 13 abstracters recorded information for approximately 44,000 new patients during 2011.

Once new patient abstracting is completed for a given month, the disease information becomes available for data retrievals by department staff and is also available to hospital staff from Clinic Station and the institution's data warehouse.

Reabstracting After Notification of Death

The Follow-up Section of the Tumor Registry identifies patients who have died (see Responsibilities of the Follow-up Section) and provides that information to the Coding Section. The Follow-up Section is currently verifying approximately 10,000 patient deaths per year. The Coding Section is responsible for recoding the charts of these patients. At this final death coding, any new cancers, treatments, or metastases that occurred since the last coding (usually the coding that was done 4 months after registration) are abstracted, and the vital status and death information are updated in the database.

Second Primaries

Once a month, the Pathology Department provides the Tumor Registry Department with a file of all pathology reports from the previous month. The Coding Section uses this file to identify living patients with primaries that developed after initial coding. The file of more than 8,000 pathology report codes is reduced electronically to about 300 possible new cancers. A review by the abstracting staff of each of these 300 reports results in about 100 new cancers per month being coded and added to the database.

Quality Assurance of Coded Data

Once data have been abstracted from a chart, they are "saved," at which point the computer edit program is run. Any errors detected by the edit program are corrected by the coder. The coder then gives the chart to another coder who accesses the

checking screen to verify site, histology, and stage. Through this process, the coders are able to provide visual verification of the site, histology, and stage for 100% of the charts abstracted. In more difficult cases, the manager of the Coding Section contacts physicians to ensure that the most accurate information is abstracted. In addition, feedback from data users is used to enhance data quality.

Responsibilities of the Follow-Up Section

The Follow-up Section is responsible for obtaining the vital status of every MD Anderson patient with a diagnosis of cancer on an annual basis. During 2011, last contact information was updated for almost 140,000 patients in our registry.

The records of patients who have been seen at the institution within the year are updated by computer matches with information from appointment data, resulting in an updated "alive" status. In 2011, the last contact date was updated with the appointment date for more than 85,000 patients. Passive follow-up includes matching patients with a malignant diagnosis and a "vital" status of not known dead with death certificate tapes from the Bureau of Vital Statistics (BVS) in Texas, New Mexico, and Oklahoma. Monthly death information from the BVS is compared with data for MD Anderson patients with cancer who are not known to be dead. Typically, data for more than 200,000 MD Anderson patients are compared with data for more than 15,000 new BVS-recorded deaths each month.

Active follow-up involves directly contacting the patient. The active follow-up process is separated into follow-up cycles during the given year to break the workload into manageable groups of patients. The active follow-up process includes selecting patients to be monitored in the cycle, creating computer-generated letters to be sent to patients, and making telephone calls to patients who do not reply to letters.

In the past year, more than 70,000 computer-generated letters were sent to more than 40,000 patients. A second letter is sent only if there is no response to the first letter, and a third letter is sent if neither of the first two letters is responded to. A maximum of three letters is sent, and the text of each of the three letters varies from that of the other letters. These letters have a response rate of 70–75%. Of the letter responses, 4 of 10 include a positive comment such as "thanks for your concern," "we appreciate your interest," or "thank you for caring." Patients who do not reply to the correspondence are contacted by telephone. This information is updated into the patient database, and the returned bar-coded letter is now scanned into the patient's chart.

A patient is eligible for a follow-up letter if the following criteria are met:

- Registered on or after January 1, 1962
- Not known to be dead
- Diagnosed with cancer (excluding non-melanotic skin malignancy)

From the above, the following patients are removed:

- Patients contacted within the past 12 months
- Patients with an appointment scheduled within the next 6 months

- Patients registered when younger than 18 years who are currently younger than age 18
- Patients with stop contact flags
- Patients in the Suspected Dead File (Hold File)

The follow-up letters are sent directly to the patient, not to a physician.

Death Processing

The three major sources of death information are (1) the Bureau of Vital Statistics of Texas, (2) follow-up letters and phone calls, and (3) communication from MD Anderson employees. The follow-up staff verify death information of more than 10,000 patients annually. A verified death list, averaging 900 patients, is distributed monthly to more than 40 MD Anderson departments.

Suspected Death File (Hold File)

The Follow-up Section maintains the Suspected Death File, also known as the Hold File. The Hold File is a database that lists all patients about whom death information has been received but not yet coded. The purpose of the Hold File is to avoid contacting patients who are suspected dead and to start the process of verifying their deaths. After the patient death has been verified, it can be coded and updated to the registry.

ACoS Follow-Up Results

In April 2010, the ACoS conducted an accreditation site visit at MD Anderson. The Tumor Registry's annual follow-up rates were calculated for the site visit based on the following ACoS criteria for identifying patients who are eligible for follow-up: (1) the patient has been registered since our reference date of January 1962; (2) the patient has a malignant diagnosis (not including carcinoma in situ of the cervix or basal or squamous cell skin cancer); (3) the patient is a U.S. resident; and (4) the patient is an "analytic" case (i.e., the first course of treatment was received at MD Anderson). Of the patients registered at MD Anderson between January 1962 and August 2009, a total of 148,942 analytic cases were, by ACoS definition, eligible for follow-up. The follow-up rates for this population were 92% of all patients and 97% for patients who were registered within the past 5 years.

Data Utilization Activities

The Tumor Registry database is designed to be used for clinical and epidemiologic research. The database contains demographic information about the patients and a

set of variables that are applicable to all cancers. The data allow a researcher to identify a population meeting specific criteria from which the researcher can focus on a specific topic. Because of the large volume of patients accessible from the database, researchers are able to have ample patients for retrospective case control studies, comparative studies within the institution's patient population, and survival studies comparing subsets of study populations.

The data are also used in combination with other data sets here at the institution, particularly data contained in the institution's data warehouse. The Tumor Registry data have been used to enhance financial data and operational data from our patient population that can then be used to analyze operations and projections for decisions on the institution's future operations, create financial models, carry out strategic planning, and determine market shares.

In addition to in-house use, Tumor Registry data are submitted to the Texas Cancer Registry and to the American College of Surgeons' National Cancer Database to fulfill the institution's compliance requirements.

Summary

In many ways, the functionality of the department has not changed much in the past 60-plus years. The mission of the Tumor Registry Department continues to be to collect, analyze, and disseminate high-quality data on each patient registered at MD Anderson. The abstractors continue to collect a well-defined and consistent set of data on each patient who registers at the institution. The follow-up staff continue to update the vital status of our patients. The epidemiologists continue to provide information to our researchers. In other ways, things have changed dramatically. Collection of data has moved from index cards to paper code sheets to electronic entry. Where once paper medical records, some weighing up to 20 pounds, were the only source for patient data, clinical information is now available virtually entirely in electronic form. Furthermore, the ability to link to other data sets within the institution has added tremendously to the value of the registry data.

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