THE DEVELOPMENT OF A REGIONAL COMPUTERIZED CANCER REGISTRY

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The Brockton Hospital, a 308 bed not-for-profit community hospital, has developed a regional computerized cancer registry. The purpose of the registry is to provide quality and standardized data for analysis of cancer treatment and diagnoses. The system ensures that cancer patients receive annual physicals while providing follow-up data on the current status of the patient's disease and subsequent treatment.

This paper will present the problems and methodologies that were involved in the development and utilization of the computerized registry. The presentation will be as viewed by the physician chairperson of the regional Professional Advisory Committee (PAC), the Regional Cancer Registry Manager, and the Information Resources Administrator.

BACKGROUND

A manual Cancer Registry, started in 1970 at the Brockton Hospital, provided annual cancer patient follow-up and yearly statistics on the hospital cancer case load. In 1973, the Brockton Hospital Cancer Management Program was given a three (3) year (maximum) accreditation by the American College of Surgeons.

After five (5) years, the cumulative number of cancer patients made it difficult to manually provide detailed analysis for monitoring treatment and distribution of cancer. The system was not able to keep up with the patient volume and physician demands for statistics. It was at this point that four area hospitals began discussing the possibility of a combined Registry that would allow interhospital comparison of treatment and type of cancer.

The Ad Hoc Regional Cancer Committee, which included physicians, administrators and Medical Records Directors from all four hospitals, decided that each hospital would employ their own registrar. Standardized data would be collected from each hospital and processed by the Brockton Hospital computer. Individual hospital reports, as well as combined registry reports, would then be returned to each hospital. All pertinent reports would carry the name of the hospital at which the patient was initially diagnosed. Thus, each hospital would retain its identity and the responsibility of its own registry. The Brockton Hospital would retain all propriety software and system design rights.

The following three (3) narratives describe how an eighteen (18) hospital computerized regional registry was designed and implemented.

CHAIRPERSON, ADVISORY COMMITTEE

As a physician, initially naive in the workings of a computer, it seemed that it would be a simple task to convert the manual card system to the computer. It appeared that the project merely entailed assigning numbers to descriptions, then, a functioning system would result. However, having been directly involved for two years, this physician can now appreciate all the thought and planning required for a successful conversion.

One thing a computer cannot do is work on assumptions. This became clear as numerous items had to be defined before the computer programming could start. Ideas that physicians had acquired by training and experience had to be spelled out in minute detail. It can be said that the two year implementation was not really a computer delay, but a process of defining and reaching agreements on the system.

Nearly three months were spent simply agreeing on the type of data the Committee wanted the computer to retrieve. Since the computer could give us as much information as we put in, the initial impulse was to try to enter as much information as possible. The argument was that some day we might want to retrieve it. This impulse was resisted as our awareness of system design grew more sophisticated.

Staging the extent of cancer took nearly eight months as various methods of staging were reviewed by physicians in specialty groups. Eventually it was decided to use the American College of Surgeons Joint Committee on Staging Guidelines. Numbers were assigned to the AJC descriptions. Where no descriptions were available, a four stage system (local, regional, involved nodes, metastasis) was defined. We made certain that subspecialty groups from each of the hospitals were involved in formulation of stagings for each site so that there would be minimal physician controversy after the computer program was completed.

A pathology system was agreed upon in a similar fashion.

Interpretation of survival statistics, terminology and quality control was closely monitored by the Committee's physicians. It was found that the computer could assist in insuring quality of data, but the Registrar would have to visually check many items. For example, the computer could ascertain that a code was out of range, but a wrong code within an acceptable range had to be recognized by the Registrar. The final review of output was a reasonableness check by the site physician specialist and Registrar.
The Cancer Registrar would then review all final output for reasonableness.

Many times sample data with known output would be fed into the computer in order to monitor the computer accuracy. It was also necessary to study various published reports on survival data exclusion and statistical presentations.

As the various computer reports were prepared, it became clear that a potential problem area was special one-time reports. Many times a report would generate questions that in turn would necessitate more detailed reports. In order not to overwhelm Data Systems with special one-time report requests, it was decided that the Committee would review all requests. In this manner, it would be possible to determine whether the additional information could be prepared more economically on a manual basis, or whether systems and programming costs were justified. Having the committee review all requests also insured confidentiality of data as only qualified individuals would have access to reports.

All members of the Committee who worked on the project developed an understanding and respect for each other's specialty and expertise. The physician's awareness of statistical analysis was also greatly enhanced.

CANCER REGISTRAR

A changeover to computerization evoked certain reservations for the Registrar. Dealing in data based on human factors, the Registrar's first reaction was that it could not be done. The infinite details surrounding each abstract and follow-up could never be translated into numerical codes. Even if that were possible, what meaningful product would or could result? The day-to-day concern about confidentiality, integrity of information, control of follow-up and the gathering and storage of data could not be shared by a machine. These protective instincts emerged as the registrar envisioned the masterfile, accession register, abstracts and follow-up cards being replaced by unintelligible computer reports. The manual system is a proven one, why change? Armed with a need to maintain some of the existing documents (masterfile, follow-up cards, accession register) and with a long list of those "exceptional" examples of information impossible to translate into computer jargon, the Cancer Registrar and Data Systems Director began their meetings.

The results were quite revealing. It was agreed that the follow-up card should be maintained. Although a complete alphabetical listing of patients would be updated monthly for the registry, the master file with its ability to supply a quick reference of patient record numbers would be preserved. The computer Accession Register would indicate the year accessioned and a tally of patients living, dead, due for follow-up or lost to follow-up. The only need for a manual accession record was to keep track of the last accession number assigned.

Next, the manual abstract was studied. The objective was to maintain the quality of the data already collected or improve upon it. To do this we had to define the group of possible answers for each item to be collected. The Cancer Committee, actively involved from the outset, devoted over a year to the planning, developing and refining of these criteria. Even when the coding manual was supposedly finalized, changes were necessary when translation of abstracted information was begun.

An important feature is standardization of data collection. Under the manual system bits and pieces of unclear or unconfirmable data could be noted on the abstract. If these were questioned later, the chart could be pulled and reviewed. In a computerized registry the Registrar is compelled to seek an answer at initial input registration. Almost every field of information collected has an "unspecified" or "not submitted" code. This could become a catch-all category and result in the exclusion of many cases from analysis. To avoid this, a network of referral resources from the Registrar to the Cancer Committee physician members was established. This has proven to be a valuable learning tool for the Registrar by allowing guidance and confirmation of data choices by a physician in each area of specialization.

Standardization means that the eighteen area hospitals can reference their data in a common language. Their survival data can be compared uniformly because it was gathered uniformly. With the adoption of this computerized registry program by hospitals outside of southeastern Massachusetts, we can now compare information with that facility.

The computer has become a useful tool to the registry with the Data Systems personnel becoming one of many partners in its successes and its concerns. The reservations of converting from a manual to a computerized Registry have been supplanted by a desire to find more ways to utilize the computer.

INFORMATION RESOURCES ADMINISTRATOR

The Data Systems Department was introduced to the idea of a Regionalized Computer Registry when Administration asked if the present computer resources could be used. It was decided that the hospital's present computer system could be used to do the extensive statistical analysis required of the proposed combined registry.

The first step in implementation was to review the manual system. The review showed that the present system was very well organized and could be used to determine the accuracy of the manual computer output. In general, computerization would not result in the Cancer Committee receiving less information than under the current manual system.

Data Systems presented to the Cancer Committee reports which were similar in format to that of the manual system. Flow charts were developed to show the logic and data that would go into the computer output and it became clear that many separate manual reports could be incorporated into one computer report. Under the proposed system all reports for different cancer sites would be presented in standardized formats.

A sub-committee (composed of two physicians of the Cancer Committee, the Medical Records Director,
Cancer Registrar and Data Systems Director) was formed to tentatively approve the computer report formats. Finally, a slide presentation was prepared to obtain the Regional Cancer Committee’s approval.

Core information, as recommended by the American College of Surgeons, along with additional data necessary to provide the output requirements, comprised the final data set which was also approved by the Regional Cancer Committee.

The development of input coding was a composite of generally accepted codes and definitions as well as innovative ideas of the sub-committee. As sample patients were coded, it became apparent that coding definitions had to be added or modified to insure standardization of input data. We decided that numeric codes are the most effective method for editing and standardization of input. However, it was determined that the output reports should also contain the alphanumeric description to provide readability.

After the output, the input data and all coding were approved, it was time to design an input format to collect the data from the medical record. A draft input form was designed to collect "real" data that eventually would be the initial input into the new registry. The data would first be used to test the functioning of the computer's data output. The initial use of the input form revealed transcription problems and that coding was not available to cover all input possibilities. The sub-committee, meeting weekly, revised the input form and coding many times.

It was decided that initially only the Brockton Hospital Cancer Registry would provide data for the system. In this manner the changes and problems that go along with a computer project would not be a burden to the other participating hospitals.

Only after the Regional Cancer Committee approved the output, input forms and coding manual, was the project ready for computer programming. In looking at the initial computer output, it was decided that the computer should be used to provide more extensive editing of the input data.

Finally, data was fed into the system and the computer edits were used to assist the Registrar and insure the input of quality standardized data.

Once the computer system was deemed operational by the Regional Cancer Committee, the Brockton Hospital's Cancer Registrar developed an instructional manual and proceeded to train the other four hospital registrars in the use of the new system. (Today all major hospitals in southeastern Massachusetts participate in the regional registry).

It was at this point that the Committee asked for survival statistics to begin monitoring the effectiveness of their diagnoses and treatments. The development of the survival reports presented both interpretation and communication problems as Data Systems and the Committee’s physicians did not initially recognize the uniqueness of cancer survival formulas. A literature search revealed the actuarial or life-table method could be used to obtain the cumulative observed survival rates. Using this methodology, it is possible to use survival information accumulated up to the closing date of any study to describe the manner in which a patient group was depleted during the total period of observation.

The committee wanted to compare the Registry's survival experience with regional and national statistics. Contact was made with the National Cancer Institute, the Connecticut Tumor Registry and a consultant from an area Medical School. The result was the introduction of the cumulative relative survival rate. All survival reports express both observed and relative survival rates.

The initial system design and programming costs of this project were absorbed by Brockton Hospital. The present charge to participating hospitals includes the physician advisor, computer operations, all statistic reports, microfiche, follow-up letters and eight (8) hours per month of programmer time for system enhancements. The cost also includes the Regional Registry manager's responsibility for the continual coordination and education of each hospital's registrar. The cost of each hospital to hire and locate their own Registrar is separate from the above costs.

SUMMARY

The previous narratives have shown how three different disciplines approached the implementation of a Computerized Regional Cancer Registry. Most important is the effort and dedication that all three parties provided. In effect, the implementation was a solid team effort between the Cancer Committee, Cancer Registry and Data Systems Department.

The entire project took two (2) years from initial discussions to final statistical reports. Each step was thoroughly developed and all areas tested before the next step was taken.

Recently the Brockton Hospital Cancer Management Program, including the Computerized Registry, was re-examined by the American College of Surgeons and a three year accreditation awarded.

FOOTNOTES