



## The Expanding Role of Cancer Registries

New Registry Standards Require Increased Support & Cooperation from Administration & Clinical Staff

Karen Phillips

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# THE EXPANDING Role of Cancer Registries

New registry standards require

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by Karen Phillips, B.S., C.T.R.

**H**istorically, cancer registries have operated as a cancer program requirement for state-mandated reporting and approval from the Commission on Cancer of the American College of Surgeons. However, as managers of oncology programs devise ways to decrease cost, document quality care, and compete for managed care contracts, they are taking a second look at the cancer registry.

Cancer registries have always been an expensive cancer program element. Staff, computer systems, operational support, accreditation fees, and indirect costs are usually estimated to cost a typical hospital \$100 per new cancer case. Not surprisingly, hospital-based cancer programs are reevaluating the registry's potential to ensure powerful, timely analysis of data for competitive advantage.

Three fundamental reasons justify the cancer registry's expense. First, registry data may help broaden our

knowledge of the causes of cancer. Population-based state or federal registries use baseline incidence and mortality to investigate purported cancer clusters, i.e., incidence above expected rates, and to identify environmental factors contributing to the neoplastic process. The second justification for registries stems from the fact that medical science cannot yet cure every cancer. Thus, the primary purpose of hospital-based registries is to document treatments that lengthen disease-free intervals and lifetime survivals. Third, the health care system has only recently shown an interest in identifying the most cost-effective methods for cancer control or clinical care. Registries are the only means to evaluate the long-term cost, effectiveness, and outcome of care.

#### **NEW REGISTRY STANDARDS**

When President Richard Nixon signed the National Cancer Act in 1971, there was a widespread belief in a single "magic bullet" leading to the eradication of all cancers. Unfortunately, a cure has not come so easily. Because cancer is a complex of more than 100 diseases, each with its own etiologies, optimum treatment, and prognosis, research requires analysis of huge

amounts of information. Oncology outcome assessment is particularly difficult because of the time delay between diagnosis and treatment. During this time delay, patients have an opportunity to seek care in a wide variety of settings, making complete data collection difficult.

In 1992 Congress addressed the need for more complete data, creating the National Program of Cancer Registries to enhance state registries. The program, which is administered by the Centers for Disease Control and Prevention, has helped standardize cancer reporting procedures and ensure that reporting is timely, accurate, and complete.

Standard-setting organizations agree that data in today's cancer registries are key to quality improvement studies of nearly every facet of oncology program management. Recognizing the vital role of cancer registries in managed care, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Commission on Cancer have mandated new standards.

Effective July 1, 1996, JCAHO revised the intent statement in the Improving Organization Performance chapter of the *Accreditation Manual*. Citing cancer staging as an

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*Karen Phillips, B.S., C.T.R., is a registry consultant for ELM Services, Inc., in Rockville, Md.*

## More Commission Updates

- New surgery coding scheme. Final approval: October 1997; mandated use: 1998
- Fifth Edition of the AJCC *Manual for Staging of Cancer*. Release: Early summer 1997; mandated use: 1998
- Survey guidelines for a new approval category for hospital networks. Release: 1998
- Publication of findings from a pilot project on capturing physician office cases: May/June 1997
- Basic course in cancer registry data collection: Available July 1997
- New 1997 speakers bureau presentations on "Preparing for Survey" and "Benefits of an Approved Cancer Program." Available fall 1997
- Textbook entitled *Tumor Board Case Management*: Available now from Lippincott-Raven
- Bimonthly periodical *Cancer Case Presentations: The Tumor Board*: Available now from Lippincott-Raven

example, JCAHO recommends use of patient-oriented, long-term databases (registries) for both internal and external comparisons of processes and outcomes. Similarly, documentation of improvements in processes and outcomes of cancer care is a primary focus of the updated *Cancer Program Standards* from the Commission on Cancer.

In fact, JCAHO and Commission staff are working to develop a collaborative relationship that precludes duplications in the two survey processes. The two organizations hope to achieve formal recognition, endorsement, and/or reciprocity for their approvals programs. More specific information will be forthcoming throughout spring and summer of this year.

In 1996 the Commission on Cancer revised its *Cancer Program Standards* to further ensure standardized reporting procedures. In addition, the Commission made a number of important updates to its requirements for approval. The new standards are broader and address documentation of quality and outcomes, such as survival, patient satisfaction, and resource utilization, in the face of shrinking economic resources.

One of the most controversial of the Commission's new standards involves the 1998 requirement to collect data on patients who are diagnosed and treated exclusively in the physician's office. The Commission's rationale in mandating collection of these cases stems from the move to less expensive outpatient care and the recognition that decisions in a physician's office are an integral part of the hospital's cancer program. Commitment to rigorous analysis of these outpatient cases in the Commission on Cancer's National Cancer Data Base (NCDB) is expected to

answer such questions as, "What is the most cost-effective treatment plan for localized prostatic cancer?" Without a large body of data on properly staged cases diagnosed and treated in the outpatient setting and followed for life, such questions can never be answered.

These data, which are estimated to involve less than 10 percent of the registry's caseload, will permit evaluation of a much greater spectrum of outpatient care, especially in managed care settings. Because inpatient caseloads are dropping, a net increase in registry accessions is not expected. The added burden to registrars primarily involves casefinding—a task that is routinely performed by the physician's office staff.

Another problematic Commission requirement involves physician staging. Documentation of extent of disease by the managing physician at the time of treatment planning is fundamental to good care. Although this requirement is certainly not new, it remains the most difficult to enforce.

Additional Commission on Cancer revisions include: *Point system*. The survey process requires that a program must attain a successful score in each of ten sections of requirements, including institutional and programmatic resources; program management and administration; clinical management; inpatient and outpatient care; supportive and continuing

care services; research; quality management and improvement; cancer data management; public education, prevention, and detection; and professional education and staff support.

*Supportive and continuing care*. A team approach to providing site-specific care must be documented. *Cancer conferences*. Ten percent of analytic cases must be presented; 51 percent of case presentations must be prospective, i.e., oriented to treatment planning rather than retrospective case review, and 10 percent of medical staff involved with cancer care must attend. The number of monthly conferences is dependent on the number of new cases per year.

*Research*. Teaching hospitals and large (more than 750 cases per year) community hospitals must accrue at least 2 percent of cases to research trials.

*Quality improvement*. In an environment driven by reimbursement, at least two enhancements to quality of care must be documented annually.

*Management guidelines*. National or locally developed critical paths, care plans, or point of care reminders must be used.

*Cancer registry*. Use of codes from the Registry Operations and Data Standards (ROADS) is mandated. Cases must be reported to the NCDB. Cases managed only in staff physician offices must be reported.

*Continuing education.* All professional staff members, including the registrar, must have educational opportunities to maintain their credentials.

The new standards continue to stress multidisciplinary care, but with an increased emphasis on continuity of patient management, regardless of where the patient receives care and throughout the continuum of cancer control activities, from prevention and screening through lifetime follow-up. New data elements allow computerized monitoring of requirements for approval and facilitate tracking of diagnosis, treatment, and outcome by payer.

#### **THE ROLE OF REGISTRY STAFF**

The expanded role of cancer registries and oncology data management requires increased support from administrative and clinical staff. Cancer program managers should insist that the registry take a proactive stance in reporting data that affect growth forecasts and outcomes. Encouraging the registry's shift in priorities from data input to information output is paramount.

Managers must support certification of all registrars and provide for the registrar's continuing education opportunities as computerization, clinical care, and marketing needs evolve. Finally, managers must assure adequate staff and computer resources. Such resources will facilitate timely data analysis and help to integrate the registry with the hospital's other information systems; allowing registrars to automatically download data elements to the abstract.

What should physicians and other clinical staff do to enhance registry operations? They should:

- Assist colleagues in understand-

ing the purpose and necessity for accurate staging by managing physicians.

- Respond promptly and completely to follow-up letters.
- Solicit cooperation by office staff to identify cases diagnosed and treated in the office, i.e., facilitate casefinding for the hospital registry.
- Assure that dictation of discharge summaries contains complete information on staging and treatment planning for the full first course of therapy.
- Most important, *use* the registry's data to improve patient outcomes and efficiency of care.

How can registrars increase productivity? First, each registry must adopt a proactive approach to providing unsolicited information. Recognizing that every report is an opportunity for improvement, registrars should regularly analyze referral patterns, resource utilization, unusual case mix, and data quality. They should provide regular analyses of outcomes—survival, recurrence, appropriate workup, standard treatment, time from diagnosis to treatment, complications, length of stay, payer and patient satisfaction—and compare with other published databases (benchmarking).

Second, registrars should participate in development of management guidelines, care plans, point of care reminders, and critical pathways. These activities will improve outcomes for tomorrow's patient.

Third, abstracting procedures can be streamlined by decreasing the number of data elements collected. Abstracting within two months of diagnosis, rather than the Commission on Cancer-required maximum of six months, will provide current data for comparisons and reimbursement negotiations.

Performance improvements can then be implemented promptly.

Fourth, registry staff should commit thirty minutes each day to acquiring new skills and enhancing established skills. Mastering updated software and applying new concepts in health care to oncology data management is a necessary investment of time. Registrars should be familiar with resources that provide guidelines for patient management by site and stage, giving routine feedback to clinical and administrative staff when patterns of care deviate from published recommendations.

Finally, each registry must document that it contributes more than it costs by distributing data that enhance oncology program growth and profit margin. Examples might include monitoring the effect of "drive-thru" mastectomies, radical prostatectomies for advanced disease, unplanned readmissions after routine colectomies, or decreases in caseload from one or several zip codes.

Cutting the cost of cancer care is easy if compromised quality is not an issue. However, quality care is important, and registries have the data to document high quality. Historically, oncology has been a leader in data standards and analysis. The cancer registry is likely to have the most thorough, complete, and consistent database in the hospital. It provides the only systematic method to track outcomes throughout the life of the patient. Growth and profitability of oncology programs, projected to be the number-one product line in American hospitals by the year 2000, mandate a solid foundation of efficient, quality data management, which a well-run registry can provide. ■