Getting the Most from Your Cancer Registry

✦ **by Loretta Lausin, CTR**

Many community cancer centers are sitting on a treasure trove, and they may not even know it. Tucked away somewhere in their hospital or health system is a powerful tool that can assist cancer program leadership to make informed business decisions, help improve the care of cancer patients, and offer support to pay-for-performance and quality reporting initiatives. That often under-utilized tool is your cancer registry.

Traditionally, hospital registries were viewed as a place to store basic data and a tool for meeting state reporting requirements. In recent years, as quality measurement trends have developed, healthcare professionals have looked to their cancer registries to help them evaluate and improve their patient care.

On the other side of the fence, policymakers and payers are also implementing pay-for-performance policies that rely on data. Even consumers are looking for information that will help them make informed decisions about their care. Cancer registries hold the keys to these and many other initiatives. Quality measurement is just one purpose of registries, however. Faced with fierce market competition and dwindling profit margins, today's cancer program administrators rely on the wealth of information contained in their cancer registries to aid in their strategic decision making.

A wide range of organizations and individuals can and should be tapping into cancer registries to facilitate their work. These include national organizations, government agencies, and healthcare providers. For example, a number of national organizations, such as the Association of Community Cancer Centers, the American Cancer Society, and the American College of Surgeons Commission on Cancer, use registries to:

■ Explore trends in cancer care
■ Create regional, state, and national benchmarks for clinicians
■ Provide a vehicle for quality improvement.

Government agencies, including the Centers for Disease Control and Prevention and the National Cancer Institute, collect and analyze cancer incidence for specific populations or geographic areas and measure progress in cancer prevention and control. Government payers are looking to use cancer data in quality measurement and pay-for-performance initiatives.

Healthcare institutions also have a wide range of uses for cancer registry data, including:

■ Evaluating the clinical care of their cancer patients
■ Monitoring and evaluating their programs and services
■ Identifying opportunities to improve and expand their services.

This article focuses on this last audience. Specifically, we will identify and explore the opportunities for cancer programs to more fully use their cancer registries and cancer registrars.

Administrative Planning, Marketing, and Financial Decision-Making

From a cancer program administrator's perspective, the cancer registry is a gold mine. Administrators are on a continuous quest for the most up-to-date information on which to base decisions about investing in marketing, building new facilities, purchasing new equipment, and hiring new staff. Savvy administrators know that cancer registry data systems gather and store much of this information. A well-maintained cancer registry can help cancer program administrators:

■ Identify the most commonly diagnosed cancers for their geographic area and patient populations
■ Estimate anticipated revenues by disease site
■ Plan for current and future staffing needs
■ Make decisions about how to allocate resources for capital investments in the cancer service line
■ Study and perhaps improve referral patterns
■ Help recruit physicians and other specialists
■ Analyze the costs and use of ancillary services
■ Gather information that is needed to apply for and obtain grants
■ Identify areas for implementing effective fundraising campaigns
■ Develop a sound business plan for their cancer service line in the short and long term.

So, for example, using your cancer registry data to determine your revenue by disease site and the most commonly diagnosed cancers for your region, you can make decisions about hiring additional staff and/or making capital investments in particular technologies or services.

Cancer Research and Outcomes

The ultimate goal in cancer care is to identify the best possible treatments and achieve the best possible outcomes. Cancer registries are a vital contributor to research and outcomes measurement. Clinicians can use registries for case identification to conduct both retrospective and prospective studies and for potential clinical trials. The registry also contains outcome and survival data. Based on the needs of particular studies, the registry is easily modified to collect supplemental data, such as prognostic indicators, risk factors, and family history. Working closely with registrars, the cancer registry can be customized to support a wide variety of needs specific to the facility.

Community Use

Hospitals and other healthcare organizations can use cancer data for a wide range of activities benefiting the community. For example, cancer registry data may be used for planning new programs or evaluating current services such as community screening programs, public education programs, support groups, hospice programs, and survivors' day programs. The geographic location of patients by age, race, and gender distribution is useful information for social agencies. Keep in mind, however, hospitals must adhere to their established policies and procedures regarding the release of patient information in order for cancer registry data to be used for community programs or events.

Clinical Care Performance

Cancer registries can be a valuable tool for improving patient care and outcomes. Using registry data, clinicians can compare the diagnosis, stage, treatment, and survival outcomes of patients with national or regional data. Drawing comparisons with national data enables cancer care teams to identify any deviations from regional or national standard patterns of care.

Registry data can also help clinicians establish outcome benchmarks, develop best practices or clinical guidelines, and ensure adherence to treatment guidelines. As clinical guidelines are developed, cancer programs can use registry data to monitor physician compliance. (For more information about quality measures in cancer care, see sidebar on pages 26 and 27).

Improving *Your* Cancer Registry

After becoming familiar with the many ways cancer registry data can help improve business functions and support quality initiatives, the next step is to determine whether your registry is reaching its full potential and, if not, how to improve its utilization. The first step in this process is to obtain a copy of your facility's cancer registry request log.

Review your registry data request log to identify:
- Data requested
- The date of each request
- Confirmation that the data requests were fulfilled
- The intended use of the data
- The name of the person or facility requesting the data.

After this review, the next step is to perform an assessment of your cancer registry. An assessment should use the data request log to identify who is using the registry and for what purposes. For example, are data being used to:
- Justify capital investments?
- Develop community outreach activities?
- Develop marketing strategies and materials?
- Investigate future and potential reimbursement through pay-for-performance initiatives?
- Obtain CoC approval or commendation?

If data are not being used, try to understand why. Perhaps your registry staff needs to be better trained and educated in how to make use of the data in a meaningful way. Or perhaps your organization does not have an effective "vision" for your registry.

Based on your improved understanding, develop strategies to increase use of your cancer registry data. Your program may want to start with additional staff training. Highly skilled, well-trained registrars are crucial to your ability to maintain and extract meaningful information from your registry. Identify a champion within your cancer program who can work with and advance the registry. Interview key stakeholders and learn how you can strengthen their connections with the registry and entice them to take full advantage of it. Stakeholders include clinicians, administrators, researchers, and strategic planning, marketing, and development professionals.

Stakeholder interviews should include such questions as:
- How often do you utilize data from the registry?
- If you do not use registry data, why not?
- Do you have suggestions for ways we can make the data more useful?
- If you currently use registry data, what types of reports do you request?
- Do you currently maintain or use a separate database containing specific patient or treatment data in your office or from some source other than the cancer registry? If yes, why? What kind of data do you track?
- What one piece of statistical information would you like to have regarding patient treatment?
- Would you be interested in learning more about the data?

Cancer Registrars at Work in the Community Setting

◆ *Case Study 1: Measuring Trends and Identifying Opportunities for Expansion.* Northeast Ohio's Ireland Cancer Center at Southwest General Health Center has made its cancer registry a priority and, in turn, is able to draw frequently upon its resources. The cancer center's top-down commitment has reaped

Ireland Cancer Center at Southwest General Health Center in Cleveland, Ohio.

significant benefits for the facility.

"We are committed to quality cancer care and quality cancer data," said Tom Selden, chief executive officer of Southwest General Health Center. "As CEO of a hospital with a successful cancer program, certain analytics are necessary to make key business decisions. The data found in our cancer registry have been a resource to obtain vital information for cost-benefit analysis, physician recruitment, clinical care performance, and outcome measurements."

For example, when hospital executives wanted to review current trends in cancer incidence by various disease sites, cancer registrars easily generated the necessary report. After reviewing the data, hospital leadership decided in January 2006 to make a significant investment in capital equipment. Registry data analytics then tracked increased utilization and patient outcomes related to the new treatment options to document a positive return on investment.

Debbie Harwood, RN, BSN, nurse manager at the Ireland Cancer Center at Southwest, understands the critical role a cancer registry has in a quality cancer program. For this reason, the facility chose to locate the registry staff within the cancer center itself.

"This 'face time' with the CTRs helps build relationships. It assists physicians with access to data, which enables them to perform clinical outcomes analysis or benchmarking for standards in cancer care," Harwood said. Because CTRs have a credible and visible relationship with physicians, she went on to say, the cancer program is constantly measuring its outcomes against national data. Registry data are also used to measure quality of care and conduct community outreach initiatives.

◆ *Case Study 2: Evaluating Clinical Care and Identifying Opportunities for Improvement.* Another example of community utilization of cancer data comes from Metro-Health Medical Center in Cleveland, Ohio. There, registrars collaborated with physicians to perform a special study that analyzed breast cancer cases by course of treatment, stage, age, gender, race, and insurance type. Taking the statistics from this study, MetroHealth's medical oncologists wrote the abstract "Improving Breast Cancer Screening for Indigent Minorities: A County Hospital Cancer Center's Experience." The abstract was published in the *Journal of Clinical Oncology,* 2007 ASCO Annual Meeting Proceedings.

The abstract explored disparities of indigent, minority women with breast cancer who present with later stage disease, often because of lack of access to affordable screening tests. To increase the number of minority women being screened, MetroHealth hired a bilingual community breast liaison and established an advisory council of community representatives to collaborate with more than 100 neighborhood agencies. Screening locations were changed to improve accessibil-

ity, and transportation was provided. Free on-site mammograms and clinical breast exams were performed by experienced physicians, and from October 2005 to October 2006, seven community breast screenings were held. As a result, more than 2,000 women were educated and 403 women were screened, nearly 10 times the amount screened in the previous year.

In this example, the cancer registry data proved to be a vital resource in providing benchmarks to validate improved methodologies for breast cancer community outreach to minority women.

◆ *Case Study 3: Developing a Clinical Scorecard.* At Riverside Methodist Hospital in Columbus, Ohio, the physicians in the cancer program spearheaded the development of an internal quality measurement program. They were confident in the quality of care they were providing their patients, but they wanted to create a tool that would demonstrate this level of quality in a concrete way. They ended up building an initiative from the ground up that is customized to their organization. The hospital's cancer registry played a significant role.

The physicians had voiced an interest in implementing a quality project specifically around lung cancer care. Kristen Cole, director of Cancer Services at Riverside, and her staff, which includes CHAMPS Oncology Data Services registrars, spent time with the clinicians helping them decide what they wanted to measure and educating them in the registry's capabilities. From there, they determined which data elements could be captured in the registry, some of which were already being collected and some of which needed to be added. The registrars helped walk them through much of this, and created the customizations necessary to implement the project. Cole emphasized the importance of communication between the clinicians and registrars throughout the process.

The end result has been the

Members of the cancer care team at Riverside Methodist Hospital. From left to right: Kristen Cole, director; Cynthia Linton, CTR; Brian Zeno, MD, pulmonologist; Jeff Bell, MD, medical director; Kelly Damman, RN, lung health nurse.

creation of a lung cancer clinical quality scorecard. The scorecard contains seven indicators, which the team worked together to select and define. Each of the indicators has been assigned a target or goal. They were careful to develop a rationale for each indicator to clearly explain its importance and why they were choosing to measure it. The facility is currently in the process of collecting the data. Later this year, upon completion of the data collection, they will be able to compare the data with their goals and identify opportunities to enhance treatment.

The time involved in developing the scorecard has been well spent, according to Cole. "It's very important," she said. "You can't know how well you're doing until you actually take the time to look." ◗▌

The Roots of Quality Measurement

When one thinks of cancer registry data, quality measurement is likely one of the first uses that comes to mind. A handful of organizations have established themselves as standard setters in establishing quality measures for cancer care.

National Quality Forum (NQF). This private, nonprofit membership organization was created to develop and implement a national strategy for healthcare quality measurement and reporting. NQF is funded through a mix of membership dues and public and private funding from a variety of sources, including foundation, corporate, and government grants and contracts.

NQF was born out of a report issued in 1998 by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, which proposed creation of the Forum as part of an integrated national quality improvement agenda. Leaders from consumer, purchaser, provider, health plan, and health service research organizations met as the Quality Forum Planning

Committee throughout 1998 and early 1999 to define the organization's mission, structure, and financing. NQF was incorporated as a new organization in May 1999. Its mission is to improve the quality of American healthcare by setting national priorities and goals for performance improvement, endorsing national consensus standards for measuring and publicly reporting on performance, and promoting the attainment of national goals through education and outreach programs.

A few years ago, NQF initiated a quality improvement process for cancer care. The organization began by identifying seven priority areas:
1. Access to care, access to clinical trials, and cultural competence
2. Diagnosis and treatment of breast cancer
3. Diagnosis and treatment of colorectal cancer
4. Communication and coordination of care
5. Prevention and screening
6. Diagnosis and treatment of prostate cancer
7. Symptom management and end-of-life care.

The second phase of the project selected three areas—breast can-

cer treatment and diagnosis, colorectal cancer treatment and diagnosis, and symptom management and end-of-life care—around which to develop a set of national voluntary consensus standards that can be used to assess the quality of cancer care.

From this second phase, five measures for breast and colon cancers were identified:
1. Radiation therapy is administered within one year of diagnosis for women under age 70 receiving breast conserving surgery for breast cancer.
2. Combination chemotherapy is considered or administered within four months of diagnosis for women under 70 with particular breast cancer characteristics.
3. Tamoxifen or third generation aromatase inhibitor is considered or administered within one year of diagnosis for women with particular breast cancer characteristics.
4. Adjuvant chemotherapy is considered or administered within four months of diagnosis for patients under the age of 80 with a particular colon cancer diagnosis.
5. At least 12 regional lymph nodes

are removed and pathologically examined for resected colon cancer.

These NQF-endorsed measures were the outcome of work by a team of organizations that included the American College of Surgeons Commission on Cancer (CoC), the America Society of Clinical Oncology (ASCO), and the National Comprehensive Cancer Network (NCCN). Because most of the data needed to support these new NQF measures were already being captured in hospital registries, facilities were able to immediately begin monitoring these measures.

American College of Surgeons Commission on Cancer.
Established by the American College of Surgeons in 1922, the CoC:

- Develops standards to ensure quality, multidisciplinary, and comprehensive cancer care delivery in healthcare settings;
- Conducts surveys in healthcare settings to assess compliance with those standards;
- Collects standardized data from CoC-approved healthcare settings to measure cancer care quality;
- Uses data to monitor treatment patterns and outcomes and enhance cancer control and clinical surveillance activities; and
- Develops effective educational interventions to improve cancer prevention, early detection, cancer care delivery, and outcomes in healthcare settings.

The National Cancer Data Base (NCDB), a joint program of the CoC and the American Cancer Society (ACS), is a nationwide oncology outcomes database for more than 1,400 CoC-approved cancer programs in the United States and Puerto Rico. Approximately 75 percent of all newly diagnosed cases of cancer in the United States are captured at the institutional level and reported to the NCDB. The NCDB, begun in 1989, now contains approximately 20 million records from hospital cancer registries across the United States. These data are used to explore trends in cancer care, create regional and state benchmarks for participating hospitals, and serve as the basis for quality improvement. Even non-CoC hospitals collect in their registries the same data used by NCDB and can benefit from comparing their data to the NCDB Public Benchmark Reports.

As well as working with the NQF on the development of breast and colon cancer measures, the CoC has additional work underway related to these types of cancers: the Cancer Program Practice Profile Reports (CP³R) Stage III colon cancer project and the electronic Quality Improvement Packets (e-QuIP).

The Web-based CP³R offers local providers comparative information to assess adherence to and consideration of standard of care therapies for major cancers. This application seeks to implement concepts of continuous practice improvement to improve quality of patient care at the local level and permits hospitals to compare their care for these patients relative to that of other providers. The aim is to empower clinicians, administrators, and other staff to work cooperatively and collaboratively to identify problems in practice and delivery, and to implement best practices that will diminish disparities in care across CoC-approved cancer programs. The CP³R Stage III colon cancer project has demonstrated that improvements in data quality and patient care are possible when the entire multidisciplinary cancer committee supports system-level enhancements to ensure complete and precise documentation.

The Web-based e-QuIP offers individual-level case summary reports for cancers diagnosed in 2003, 2004, and 2005, as transmitted to the NCDB by each CoC-approved program cancer registry. E-QuIP provides a case-by-case review of cases reported to the NCDB and identifies cases that lend themselves to the future evaluation of concordance for various breast and colorectal cancer measures.

Centers for Medicare & Medicaid Services.
In recent years CMS has begun using its leverage as the largest payer for healthcare services to implement quality improvement projects. The CMS quality initiative was launched nationally in 2002 with the Nursing Home Quality Initiative, and expanded in 2003 with the Home Health Quality Initiative and the Hospital Quality Initiative (HQI).

In December 2006, the CMS quality initiative expanded to include physicians with the signing of the Tax Relief and Health Care Act of 2006. Among other changes, this legislation authorized the establishment of the Physician Quality Reporting Initiative (PQRI). PQRI initially included 74 reporting measures; in 2008, these measures expanded to 119. Financial incentives are attached to participation. The 2008 measures include more than a dozen that are targeted at cancer care and make use of data that are already being collected in hospital registries.

While the focus of this quality initiative is physician offices, complete hospital registries also should include this information, and as quality measurement grows at the national level, hospitals may soon find they are required to report data on cancer care, in addition to the measures they are already reporting under the HQI. ▯

The cancer registry is an important component of quality cancer care. This tool can help cancer program leadership make informed decisions about allocating your resources in terms of staffing and capital improvements. It can also help you monitor the treatment of your cancer patients and identify and implement initiatives that improve quality and outcomes. All these uses underscore the importance of understanding what the best possible treatments are for various types and stages of cancer, bringing us closer to defeating this disease. Remember, your cancer registry can and should be a vital part of your arsenal in the war on cancer. ▯

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