Role of the Cancer Registrar: How Cancer Registrars Ensure Quality Data for Public Reporting

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In the last 20 years, the role of the cancer registrar has evolved dramatically. The need for trained and qualified cancer registrars will only grow as the oncology healthcare industry increasingly calls for quality data. This article defines how cancer registrars can affect quality healthcare data and patient care outcomes by providing sound and logical data abstraction.

Ensuring High-Quality Data

Cancer registrars are the key to high quality data collection. It takes educated and knowledgeable registrars to ensure captured data are accurate, precise, and specific to the cancer site. A recent study from the National Program of Cancer Registries (NPCR) shows that registries staffed with a greater number of certified tumor registrars (CTR) are found to have a higher rate of case completeness and data accuracy.[1]

Cancer registrars must recognize data discrepancies, make edits, and incorporate this data into meaningful information for healthcare professionals and researchers. These data are then used to target resources to areas or populations where they are most needed.

Cancer programs then develop or revise care plans, prevention programs, screenings, and education based on the cancer information from registries. Studies are then conducted within cancer programs using registry data to improve the overall cancer care.

Registrars must be committed to lifelong learning. Just as the technology to diagnosis and treat cancer and the databases to store the information are becoming more complex, so too are the data. The HIM professional is in a unique position to assist in quality registries. The HIM professional's knowledge in data abstraction, coding, electronic health records, medical terminology, and human anatomy help registrars abstract accurate and concise information.

Supporting Registries and Quality Healthcare

There are many organizations that support cancer registrars and registries throughout the US. These organizations ensure the professional standards of registrars and the integrity of cancer data collected nationwide.

Established 20 years ago, the North American Association of Central Cancer Registries (NAACCR) facilitates a consensus forum for the national cancer data organizations in the United States and Canada. NAACCR members develop and promote uniform data standards, educate, certify state-wide registries, publish data, and promote the use of cancer surveillance data and systems for research, public health programs, and patient care. NAACCR members include the Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR), the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) Program, the American College of Surgeons Commission on Cancer (COC), the National Cancer Registrars Association, the American Joint Committee on Cancer (AJCC), Health Canada, the Canada Association of Provential Cancer Agencies, and Statistics Canada.

NPCR was established in 1992 by the CDC. It collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment. NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Islands Jurisdiction. These data represent 96 percent of the US population.

NPCR provides funds to enhance central cancer registries. In addition it provides training materials for staff and cancer reporters, offers technical assistance for registry operations, and monitors data completeness, accuracy, and timeliness. Before

NPCR was established, 10 states lacked registries, and most states with registries lacked the resources and legislative support they needed to gather complete data. Together, NPCR and the SEER program collect data for the entire US population.[2]

Registrars from COC-approved facilities can locate regional and state benchmark comparisons from the National Cancer Data Base, a joint program of the Commission of Cancer and the American Cancer Society. The information found in this database can provide additional opportunities to improve quality patient care for cancer programs.

The annual publication United States Cancer Statistics, reports on the cancer burden in the United States based on cancer registry data. It is the official federal statistics on cancer. The publication is produced by the CDC and NCI, in collaboration with the NAACCR.

The SEER program publishes data from 15 population-based registries with a higher proportion of urban and foreign-born persons than the general US population. SEER data is available at http://seer.cancer.gov. Results can be displayed in simplified tables, bar graphs, and text to share outcomes such as treatment results and survivals. Cancer data from the CDC are available at www.cdc.gov/cancer/npcr.

Looking toward the Future

For cancer registrars, there are a number of milestones and major changes coming up in the years ahead. With 2008 diagnoses the Commission on Cancer's AJCC staging policy revision will go into effect. Candidates sitting for the CTR exam must meet additional educational requirements.

In 2010, the seventh edition of the AJCC Cancer Staging Manual will go into effect for cases diagnosed and treated starting on January 1, 2010. This edition will include a clinically relevant anatomic staging system, with inclusion of nonanatomic factors to define prognosis, and the incorporation of validated predictive factors that identify response to treatment as applicable. The edition will ensure compatibility with the data that the cancer registration community enters in the Collaborative Staging System.

The COC is undertaking a formal review of its Cancer Program Standards and is planning on revisions for 2010. The goal is to shift the current standards that define cancer program structure to standards that have a stronger focus on care processes and outcomes and that result in direct patient care impact. These changes will also involve the integration of accountability and quality improvement measures. The focus will be on improving cancer burden by better tracking of data and increased linkage of systems.

The cancer registrar is a key professional that provides systems with quality abstract information in a complete and timely manner. In turn, these systems provide reports and studies that are the basis for advances in quality of care.

Notes

1. Thoburn, K. et al. "Case Completeness and Data Accuracy in the Centers for Disease Control and Prevention's National Program of Cancer Registries." CANCER 109, no. 8 (Apr. 15, 2007): 1607–16.
2. Centers for Disease Control and Prevention. "National Program of Cancer Registries, About the Program." Available online at www.cdc.gov/cancer/npcr/about.htm.

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