Florida Cancer Data System Turns Data Into Information

Save to myBoK

by Gordon Zernich, BA

The enactment of the Cancer Registries Amendment Act in 1992 and the passage of similar state laws require healthcare facilities and state and national registries to gather information on certain diseases from patient medical records. The information is also used to identify geographic "hot spots" of cancer and for epidemiological research, business planning, and market research. For example, a registry's information about chemotherapy cases in the aggregate may be used to find out if expansion or new equipment is needed at a facility.

At a recent meeting of the South Florida Health Information Management Association, Steven Peace, CTR, quality control manager of the Florida Cancer Data System (FCDS), the third largest statewide population-based cancer registry in the country, discussed how his organization compiles and uses data.

Who Contributes What

The Florida Department of Health contracted with the Sylvester Comprehensive Cancer Center at the University of Miami School of Medicine to design and implement a cancer registry in 1978, and the University's School of Medicine has maintained it since then. FCDS has been collecting incidence data since 1981.

In Florida, cancer incidence data is provided by 205 hospitals, 250 ambulatory surgical centers, 100 radiation therapy centers, more than 100 pathology labs, and hundreds of physician offices. Approximately 93,000 unduplicated incident cases were documented in 2000.

"In a large metropolitan area, a patient may be seen in several hospitals or clinics over the course of time and each of the facilities has to send us a record of that encounter," Peace says. "Our computer matches and edits that information to form parts of the statistical abstracts we compile and publish."

Almost all healthcare facilities in the state report active, ongoing cases of malignant cancer whether or not it is considered a principal diagnosis. Psychiatric, military, and Veteran Affairs facilities are exempt from mandatory reporting.

Physician offices and certain medical specialties, including urology and dermatopathology, are the latest groups to fall under the reporting requirements. FCDS requests information from physician offices on their cancer patients, including pathology reports, chemotherapy records, and other parts of the patient's medical record, and abstracts the cases for the physicians.

How and Where Care is Delivered

The FDCS looks at where the delivery of healthcare has migrated and where cancer rates are lower than expected to see if any cases are being missed, Peace said.

"We started looking in certain specialties because we know we are missing, for example, many malignant melanoma cases throughout Florida. Florida is supposed to have an epidemic of melanoma, but it doesn't show up in our files because a patient may go in to see their dermatologist, get the lesion removed, and that's it," Peace says. "In the past these cases didn't get reported."

The FCDS has also noted an interesting trend, says Peace. "Hospitals, surgical, and radiation therapy centers see about 95 percent of the cancer patients in Florida. About 4 percent of the patients are seen in ambulatory surgical and radiation oncology centers," Peace notes. "We have found out that our colleagues in other states have a much higher percentage of cases seen outside of hospitals. That surprised us. We thought Florida's use of ambulatory care centers would be double theirs when it turned out to be more like one half of what we expected."

"Smarter" Edits

FCDS follows standards from the North American Association of Central Cancer Registries (NAACCR), which receives input from its affiliates including the National Cancer Institute, the Center for Disease Control, the Commission on Cancer, and Canadian Health Statistics from Statistics Canada, to create a standard set of reporting, collecting, coding, and correcting procedures.

"We use the standard data edit systems the major groups have put together plus we added another 100 [edits] based on things we've found in our own quality control studies," Peace says. "Abstractors make errors in these areas and we can tell the computer to find some of that stuff. We make it a little bit smarter than the NAACCR minimum standards because we know where our problem areas have been. Afterward, we set up educational programs to keep others from making those same mistakes."

Peace adds, "We try hard not to duplicate work from what health information abstractors and coders are doing. We use their codes to identify the cases but ICD-9 codes don't have all the information we need at our level of research. We use their codes to get co-morbidity and length of stay data, for example, and it makes both of our databases a little more robust and powerful as a research tool."

The costs for reporting to the FDCS and other state cancer registries are spread out over several sources. The local facilities pick up the cost of doing the initial data collection. FCDS picks up the cost of training and educating the statewide health information network, processing the data, printing all the edits, publishing reports, and entering data requests. The statutes in all 50 states puts the onus of the initial data collection on the healthcare facilities providing the care because there is a certain level of social responsibility involved in it.

Noncompliance penalties in Florida include the suspension or revocation of a facility's operating license, though according to Peace, it's pretty rare. "Usually an administrator just has to hear the consideration of such a threat and the job gets done, but it may cost more to get it done that way."

Protecting patient data continues to be a challenge-though not on FDCS' side. "We remind facilities that they need to be responsible with the information they send or receive from us. In our monthly and quarterly publications we remind healthcare providers not to send us medical records or patient information through e-mail. Some people just don't understand that e-mail is unsecured communication," says Peace.

The FCDS Web site, however, provides a secure communications line that encrypts the information sent over it, and it utilizes a firewall to maintain the system's integrity.

"The CDC paid for a good part of that," says Peace. "They helped us out advancing our technical network as part of a national program that is trying to advance healthcare information and technologies."

To access the confidential part of the FCDS data, an application needs to be reviewed by the State Department of Health Internal Review Board before approval is considered. Says Peace, "We disseminate aggregate data that does not infringe on a patient's confidentiality. If there happens to be a person in county with an unusual type cancer we use cell suppression and won't print the actual figure, so we don't allow that chance of infringing upon an individual's privacy."

***Gordon Zernich** is an orthotist/prosthetist at the Veterans Affairs Medical Center of Miami, FL. He can be reached at* zernich.g@Miami.va.gov.

Article citation:
Zernich, Gordon. "Florida Cancer Data System Turns Data Into Information." *Journal of AHIMA* 72, no.10 (2001): 74,76.

Driving the Power of Knowledge