Unreported VA Data May Affect SEER Research, Cancer Surveillance, and Statistics Gathering

By Liz Savage

A disagreement between the federal Department of Veterans Affairs and state and national cancer registries may lead to the underreporting of thousands of cancers, and experts fear that it could seriously affect the accuracy of cancer surveillance and research in the coming years.

The greatest effect may be felt by the thousands of researchers and public health officials who use SEER (Surveillance, Epidemiology, and End Results) data as their primary source of cancer incidence and survival information. SEER compiles cancer data from registries around the country to estimate national cancer statistics. Annual cancer statistics could be artificially deflated for years to come.

“At a time when cancer is such a problem, we just can’t have an inaccurate picture being shown,” said Electra Paskett, Ph.D., professor of cancer research at Ohio State University, who regularly uses SEER data.

All 50 states mandate that all cancers be reported to their local cancer registry. These registries form the backbone of the national cancer surveillance system, which provides data for cancer statistics and research purposes. Federal facilities, such as veterans’ hospitals, are exempt from requirements on submitting cancer patient data, but historically they have cooperated with requests from state registries.

This situation changed in August when the VA issued a directive requiring state registries to implement several data security measures before they could receive any VA cancer patient data. The issue, the VA says, is a matter of protecting patient privacy. “I think it is the responsibility of a health care system, especially one as large [as the VA], to play well in the public arena and report our data. … But we have regulations that say this is how the data has to be protected because we have a higher responsibility to protect our veterans’ personal medical information,” said William Duncan, M.D., Ph.D., chief consultant of the medical-surgical service at the VA.

According to the new directive, data provided by VA hospitals must be stored in an encrypted database, separate from non-VA patient data. The registries are not allowed to share any personal information, including a patient’s name, age, social security number, or diagnosis, without the permission of the VA. And if the registry does disclose any of the veterans’ data without permission, the VA can demand the return of the data files.

The cancer registries say that these new rules are too restrictive and that complying with all of their conditions would be difficult, if not impossible. The registries routinely share their data—with neighboring states when, for example, patients are treated in a different state from where they live, or with researchers who use SEER’s free limited-use data file, which includes patient data on the age, sex, race, year of diagnosis, and geographic region.

Also, requiring the registries to segregate VA data would be “costly and awkward,” said Christie Eheman, Ph.D., acting chief for the cancer surveillance branch at the Centers for Disease Control and Prevention. “That’s just not how a cancer registry works. … We certainly respect the VA’s intent and need to respect the privacy of patients at VA hospitals, as we do for everybody. But right now, the way the directive seems to be laid out makes it very difficult for the states to actually do that and function as a registry,” Eheman said.

Long Simmering Conflict

The disagreements over VA cancer data are not particularly new. Trying to get VA cancer data has been a problem for more than 5 years, said Holly Howe, Ph.D., executive director of the North American Association of Central Cancer Registries (NAACCR). Before this new directive, there was no nationwide standard for reporting VA cancer data. “Every state had worked out relationships with their VA hospitals—some very well, others not so well. But to the extent that they worked them out, it was mutually satisfying,” Howe said.

But the issue came to a head when, in the fall of 2005, VA officials learned that the California registry was giving out patient data to researchers. “The reason we wrote this memo was that there was significant confusion [over how to handle VA patient data] and because we had a state cancer registry that decided on their own to release VA patient information to researchers,” Duncan said. The new directive doesn’t mean that these are new rules, he said. It is just a restatement of VA privacy guidelines found in their internal handbooks, which apparently had not previously been enforced.

According to Duncan, the incident in California was the first time he had heard about VA patients’ personal medical information being released to researchers. “I am unaware of any other incident where any state cancer registry had divulged any personal protected health information about a veteran. They can release aggregate data, but they cannot contact our patients without our patients’ approval,” Duncan said.

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But this scenario seems out of sync with how many of the registries, not just California, use their data. “The data are not collected just to be collected. They are used. It’s an expensive surveillance system. We try to maximize [the uses of] it,” Howe said. Many cancer registries have routinely shared patient data with researchers, she said, but only after they got the approval from the appropriate institutional review boards. “We treat no case differently based on who reports it to us. In the NAACCR database alone, since 1995, we have almost 14 million cases. And we treat every single one of them with the utmost respect and regard for confidentiality and personal privacy,” she said. However, a VA spokesperson confirmed that officials were unaware before 2005 that VA data, like all cancer patient data, were being used for research purposes.

Several states have already signed the VA directive, but others are waiting until they get more clarification from the VA. There are many unanswered questions on how to implement the VA’s new requirements. As they wait for a response, the registries and cancer surveillance experts are hoping that a compromise with the VA can be reached.

Missing: Thousands of Cancers

The biggest concern for researchers now is how to handle the change in cancer data caused by the underreporting of cancers from VA hospitals. Currently, state registries are submitting data to compile the national statistics for 2005. No one knows yet how many cancers will be missing, and the underreporting will make interpreting the data challenging. It may look like cancer rates are falling, but telling whether they are actually decreasing or if the cancers are just being missed will be nearly impossible.

In California, the cancer registry estimates that underreporting by the VA means that as many as 4% of cancers were not reported to the state registry. “Four percent may not sound like a lot … but it’s very important because these are the kinds of subtleties that we’re looking for,” said Donald Berry, Ph.D., chairman of the department of biostatistics at the University of Texas M. D. Anderson Cancer Center in Houston. In this year’s report to the nation, published by several major cancer organizations, cancer deaths declined by just over 2% per year from 2002 to 2004, an improvement from the 1% per year decline in the late 1990s. A change of only 1% demonstrates improvements in the fight against cancer, but they could easily have been obscured by inaccurate reporting of cancer data.

To help researchers and public health officials interpret the cancer data, Brenda Edwards, Ph.D., of the National Cancer Institute’s SEER program and her colleagues are trying to figure out the best way to estimate the number of missing VA cancers so that researchers can better interpret the cancer data from SEER. “It will be very complicated,” Edwards said. They are scouring historical data from VA hospitals to get a sense of how many cancers are usually reported. They are also trying to figure out what types of cancers are the most likely to be underreported, specifically which are the most common among the veterans that use VA hospitals, who are typically older, lower-income males. They expect that prostate and lung cancer rates will be particularly affected.

Even the best estimates are still only estimates, though, and there is no way to know for sure how accurate the numbers are. “There are ways to estimate [what data are missing], but they all seem very crude,” Berry said. “This is going to create a good deal more uncertainty. But it’s different from a bias that we don’t know is there. It helps to know that there is a bias there.” Researchers will still be able to use the cancer data, but recognizing that they are not capturing the whole picture will be important.

Questions Linger

It is unclear whether the VA will compromise on its data security requirements. Representatives of the CDC and NCI have sent a list of comments and questions to the VA, hoping for clarification on many aspects of the directive. The biggest questions remaining are whether the data storage rules are negotiable and what the prohibition against rereleasing the VA data actually means. Can state registries still give their data to national organizations like SEER? Can SEER rerelease the data to researchers? If so, what information can be shared? And what about linking databases? SEER commonly links with Medicare databases and the National Death Index, both of which are essential for following up on cancer patients. Doing so requires sharing patients’ personal information. Will this practice still be allowed?

While the registries are waiting for the VA’s response, many in the cancer community have ideas for reaching a compromise. Paskett suggests that when patients are diagnosed with cancer, they should be
given a consent form, which, if they sign it, would allow registries to give their name and medical information to researchers who could contact them about participating in future studies. If people prefer not to be contacted, then their cancer data will be counted only for the cancer statistics. That approach would address the VA’s concerns about privacy and would inform patients that their medical information was being entered into a state registry—something many patients don’t currently know.

But even if a compromise can be reached, the effects on the accuracy of the state and national cancer data will last for years. The 2006 data are expected to be missing even more VA data than those for 2005. For the next few years, extra care will be needed in interpreting cancer statistics. Otherwise, as cancer rates appear to fall, “we’ll get a false sense of security in terms of how we’re doing on the battle against cancer,” Paskett said.