

New Frontiers for the Colorado Cancer Registry

“Identification of individuals with genetic predisposition for cancer is critical for reducing their cancer risk and that of their family members. Current methods for identifying at-risk individuals are limited and not widely used at present.” —Lowery et al. in *Genetics in Medicine*, November 2010.

Colorado is pushing the limits of its cancer registry. Going beyond collecting and reporting data, the state provides targeted outreach and education to at-risk patients and their providers. “We are looking for outside-the-box activities that the registry can get involved in,” said Randi Rycroft, director of the Colorado Central Cancer Registry. “We have a lot of information that can be useful to the public directly.” Rycroft and her partners at the University of Colorado’s School of Public Health are exploring different ways to use the registry data to increase awareness about genetics and family history and, ultimately, change provider and patient practices to achieve better health outcomes.

In tight budget times, making the most of existing data is resourceful, and it offers unique opportunities for many states to continue moving forward with cancer genetics work even in the absence of new funding. The Colorado Central Cancer Registry is the Department of Public Health and Environment’s statewide cancer surveillance program and is funded by the state general fund and the Centers for Disease Control and Prevention. Colorado hospitals, labs, clinics and physicians report information to the registry, which uses that data to inform Coloradans and health professionals about specific cancer risks, incidence and treatment, and cancer control activities in the state. While the registry has always been used for many purposes, Rycroft and her internal and external health department colleagues continue to explore new ways that the registry can help them improve public health in Colorado.

Closing in on a Vexing Public Health Problem

Among cancers that affect men and women, colorectal cancer is the second leading cause of death in the United States, causing more than 53,000 deaths nationally in 2007, according to the CDC.¹ Likewise, in Colorado, colorectal cancer was the second leading cause of death in 2008, with only lung cancer claiming more lives.²

Digging deeper, cancer researchers and epidemiologists discovered a problem befitting a public health intervention: most people at risk for hereditary colon cancer are not being identified nor referred to genetics providers for cancer risk assessments and counseling. Lynch Syndrome (also known as Hereditary Nonpolyposis Colorectal Cancer) is the most common inherited colon cancer susceptibility syndrome. The lifetime risk of colon cancer in people with Lynch syndrome is between 52 percent and 80 percent, far surpassing the general population’s lifetime risk of 5 to 6 percent. Given this elevated

¹ U.S. Cancer Statistics Working Group. [United States Cancer Statistics: 1999–2007 Incidence and Mortality Web-based Report](#). Atlanta (GA): Department of Health and Human Services, Centers for Disease Control and Prevention, and National Cancer Institute; 2010. Available at: <http://www.cdc.gov/uscs>.

² Colorado Cancer Coalition, citing data from the Colorado Central Cancer Registry and Health Statistics Section at CDPHE. “Mortality.” Available at <http://www.coloradocancerplan.org/index.php/introduction/mortality>.

risk, it is critical to identify these individuals and provide information that will help them follow recommended screening guidelines. Unfortunately, however, most of these individuals are not being identified and as a result, they are not aware of the potentially life-saving options available to them.

Small Investments, Big Payoffs

To address this serious problem, in 2009, Rycroft and Jan Lowery, assistant professor of epidemiology at the University of Colorado's School of Public Health and researcher at the University of Colorado Cancer Center, designed a small-scale project to increase awareness about hereditary colon cancer. With a \$30,000 grant from the Mountain States Genetics Collaborative, Rycroft, Lowery and a team of genetic counselors designed a one-year study that used the registry to identify at-risk patients, conduct targeted educational outreach to patients and physicians and provide access to a free telephone information line staffed by genetic counselors. "Our primary goal was to get information to at-risk individuals so they could make informed choices," Lowery said."

Using the registry makes sense for many reasons. It's an existing and funded source of data, and as a comprehensive database, it is inherently equitable and captures nearly all cancer cases in the state. "With the registry, you can identify who meets specific criteria on a large scale," Lowery said. "The registry captures information on virtually all cancers diagnosed in the state so any intervention implemented by the registry has the potential to reach individuals of all racial, ethnic and sociodemographic backgrounds."

With the aim of increasing awareness and provider and patient knowledge about hereditary colon cancer, the project staff sent educational materials—including a brochure with a hereditary colon cancer checklist—to physicians who had patients with colorectal cancer. The registry mailed these materials along with a request for the physician's consent to contact their at-risk patients. The majority of physicians consented, which allowed the registry to send educational materials directly to patients.

Additionally, Lowery explained that they also wanted to test provider and patient reactions to a project like this. "We wanted to raise awareness, but we also wanted to test the feasibility of using the registry to contact people directly," Lowery said. Charting new territory, Lowery and Rycroft wondered how providers and patients would react. "We were concerned that patients would view [notification from a state cancer registry] as big brother trying to get a hold of [them]," Lowery said. To test this assumption, the materials were mailed from the registry itself, rather than the University of Colorado Cancer Center or Colorado School of Public Health. If the public reacted negatively, that might portend problems for similar efforts using the registry. Alternatively, if the public accepted this method, it would suggest that the registry was a viable tool for reaching out to the public.

Lowery and Rycroft also wanted to test provider reactions. Physicians do not typically receive targeted educational materials from the cancer registry. They wondered if physicians would resent the cancer registry "telling me how to practice medicine," said Lowery. Since future use of the cancer registry for education would be guided by provider and patient reactions, Lowery and her partners tested those reactions through satisfaction surveys.

At the end of the one-year project, they had a better handle on these key questions. For one, the project identified and sent targeted information about hereditary colon cancer to 430 medical providers and 200 at-risk cases. The mail-based outreach was viewed favorably by providers and patients who responded to the survey—98 percent thought that the information was clear and useful—and it appears to have influenced their behavior in a positive way. Many patients reported engaging in further dialogue with their physician, a genetic counselor or family members about having cancer risk assessment. About one-third of respondents said that they planned to have a risk assessment as a result of receiving the materials.

Challenges and Lessons Learned

Along the way, Rycroft and Lowery encountered some challenges that will inform future efforts using the registry. Rycroft said that the process of active physician consent (which requires a physician to respond), unlike passive response (which does not require a response, but gives the physician an opportunity to opt out) limited the pool of providers and patients. “It limits the case numbers and population,” Rycroft said. Moving forward, Rycroft said that another approach such as physician notification would increase the number of providers and patients.

In addition, a long look-back period of patients diagnosed in the last five years resulted in outdated patient contact information for patients who had moved or changed doctors during that time. Because of limited resources and a short project timeframe, staff members were not able to follow up with patients; therefore, this outdated information limited the number of patients who they could reach. In future efforts, Rycroft explained that they plan to initiate contact with patients within a shorter time frame since diagnosis.

According to Lowery, the project also provided other valuable lessons about what patients and providers want from projects like these. While the majority of physicians did not think that it was necessary to obtain their consent before contacting their patients for educational outreach, the majority of patients wanted their doctors in the loop. “It’s an important link because that’s what patients want,” Lowery said. Moving forward they will continue to alert providers before they communicate with patients. Not only is it what the patients want, but it also provides an opportunity to educate the providers about the project and about hereditary colon cancer.

Rycroft, Lowery and their partners concluded that using the cancer registry for outreach and education is a viable and promising approach. “With a little funding, this is something that registries can do and it would be a direct service to patients,” Rycroft said. It worked so well that Rycroft and Lowery recently submitted a proposal to the CDC for expanded work using the cancer registry. They hope that a longer time frame and additional resources will help them expand their reach and public health impact. Rycroft maintains that she’s intrigued by such projects. “There’s a potentially huge future impact with a small amount of money.”

For more information on Colorado's public health genomics and related initiatives:

Colorado Department of Public Health and Environment:

<http://www.cdphe.state.co.us/>

Colorado Central Cancer Registry:

<http://www.cdphe.state.co.us/pp/cccr/index.html>

Colorado Comprehensive Cancer Program:

<http://www.cdphe.state.co.us/pp/ccpc/index.html>

Cancer in Colorado, 1997-2007: Incidence, Mortality and Survival

<http://www.cdphe.state.co.us/pp/cccr/1997-2007/index.html>

Colorado Cancer Plan: 2005-2010

http://www.coloradocancercoalition.org/pdfs/cancerplan2005_2010.pdf

Colorado Chronic Disease Indicators Report:

<http://www.cdphe.state.co.us/ps/chronicdisease/ColoradoChronicDiseaseIndicatorsTechnicalReport.pdf>

University of Colorado Cancer Control Program

<http://www1.uch.edu/for-healthcare-professional/cancer-center/research/research-by-program/amc-program/index.aspx>