

Tracking cancer by the numbers

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The Georgia Cancer Registry puts a wealth of data at the fingertips of Rollins researchers. Pictured l-r: Tim Lash, Joe Lipscomb, Michael Goodman, Kevin Ward, and Penelope Howards.

Is a woman's ability to have children compromised after cancer treatment, and should she be counseled to freeze her eggs? Is robotic prostate surgery less likely to result in impotence? Are women with breast cancer who are on Medicaid getting the recommended treatment? Help in answering these and other important questions can be found

within an immense database: the Georgia Cancer Registry.

Housed in the Rollins Department of Epidemiology, the Georgia Cancer Registry collects information on each new diagnosis of [cancer](#) within the state and contributes these data to two national databases—the National Cancer Institute's Surveillance, Epidemiology, & End Results Program and the Centers for Disease Control and Prevention's National Program of Cancer Registries.

"The major mission of the registry, or any surveillance system for that matter, is to do descriptive epidemiology," says Kevin Ward, who oversees the registry as director of the Georgia Center for Cancer Statistics. "It allows us to follow cancer trends over time and identify cancer patterns in various populations within Georgia.

"But the real value of the registry is how it's used for research," Ward continues. "I'm not sure everyone realizes what an incredibly rich resource we have here."

In fact, having the registry here helped Winship Cancer Institute of Emory University earn and retain its distinction as an NCI-designated cancer center. "The registry is an invaluable resource for Winship and our investigators," says Walter J. Curran Jr., Winship's executive director. "But it goes far beyond that. Investigators from around the country turn to it. The Georgia registry is uniquely diverse and aligned with experienced faculty researchers at Rollins. This alignment creates a powerful tool in the fight against cancer."

The diversity to which Walter Curran refers reflects the demographics of Georgia, with its large, diverse population—both urban and rural as well as poor, middle-class, and wealthy. The Georgia registry is one of the few with a large African American cohort as well, making it an invaluable resource when studying racial disparities in cancer incidence,

care, and outcomes.

Beyond surveillance, the registry offers researchers a pool from which to draw participants for studies. "When researchers recruit subjects from a cancer center or hospital, they just get a sample that reflects that particular center's population," says Ward. "The registry, however, mirrors the general population, so researchers are able to generalize their findings."

The Georgia registry can also be linked to other data sources, such as Medicare and Medicaid. Such links allow researchers to look at things such as cost of care, quality of care, and outcomes other than mortality.

"Because of the registry, we know the frequency of each type of cancer, whether it is going up or down, who is most affected, and how quickly and accurately cancers are diagnosed and treated," says Rollins Dean James Curran. "It gives us clues as to the causes of cancer and also to the causes of bad outcomes of cancer. The registry does all of this for every citizen of the state, and that's a very valuable resource to the doctors who care for people, to the researchers who study cancer, and to the patients themselves.

Fertility fallout

When Penelope Howards wanted to look at how cancer treatments impact fertility, she turned to the registry. Through it, she was able to identify every woman in Georgia who had been diagnosed with cancer during her prime reproductive years—between ages 20 to 35. Each of the women who allowed the cancer registry to release her name was invited to complete an interview.

A large number of the nearly 1,300 women who agreed to participate were childless at the time of diagnosis, and many of those who did

already have a child said they would like to have more.

Though Howards, associate professor of epidemiology at Rollins, is still analyzing the data, early results hint that cancer survivors are, in fact, less likely to have children after treatment than women of the same age who did not have cancer. That may seem obvious—the trauma and expense of going through cancer treatments could well discourage having children. But Howards is also testing participants' post-treatment ovarian reserves to see if they remain able to have children if they want to.

She also identified a hole in pre-treatment care. Only half of the women who were childless at cancer diagnosis remember being counseled about how their treatment could affect their fertility. And they weren't told about options that could preserve their ability to start a family.

"We've been able to freeze sperm before [cancer treatment](#) to use in the future for quite a while now," says Howards. "The ability to freeze [eggs](#) and embryos is more recent. If women are not even having this conversation with their doctors, they won't know they have these options."

Since Howards looked at all types of cancers and all types of treatments, she hopes eventually to be able to discern differences in the way they impact fertility. "A woman who is facing cancer might have a choice of different treatment regimens, where one is preferred but will definitely affect her fertility and another that is potentially less effective but would leave her more likely to be able to have children later," she says. "We hope this study will illuminate those types of choices."

Informing treatment choices

The landmark Prostate Cancer Outcomes Study (PCOS) of the mid-1990s combined registry data from six regions, including Georgia,

to determine how prostate cancer treatments impacted quality of life. Quite negatively, it turns out. Fifteen years out, most men suffered [impotence](#), whether they had surgery or chemotherapy, and about one fifth had bladder or bowel trouble.

Treatments, however, have progressed markedly since the PCOS study. Men can now choose from options such as robotic surgery and new types of radiation. And many men choose active surveillance—forgoing radical treatment for the time being, while tumor progression is closely followed. Michael Goodman, an associate professor in epidemiology at Rollins, is using registry data to see how these newer treatments impact quality of life.

"The unique thing about prostate cancer is that there is no standard of care," says Goodman. "With [breast cancer](#) or colon cancer, it's basically a cookbook—use this treatment for this cancer at this stage. With prostate cancer, it's between you and your doctor, so the results of this study will likely help thousands of men make an informed decision."

Goodman is particularly interested in following patients who choose "active surveillance," which is a relatively new option. "In some cases the treatment is undeniably worse than the disease," he says. "That can make active surveillance a viable option, but we don't know much about it. How widely practiced is it? How is it handled in small hospitals where most cases are treated? It's important to answer questions like these."

Links to quality of care

Joe Lipscomb wanted to determine if cancer patients were receiving the recommended quality of care. Lipscomb, a Georgia Cancer Coalition Distinguished Cancer Scholar in Rollins, linked the registry with data from Medicare, Medicaid, the State Health Benefit Plan (SHBP), and Kaiser Permanente to look at treatment patterns for breast and colorectal

cancer patients over a four-year period.

He found some differences in care by insurer. For example, 92% of patients with stage III colon cancer who were covered by SHBP or Kaiser Permanent got the recommended chemotherapy treatment, but only 75% and 77% of those covered by Medicaid and Medicare, respectively, did. He also found that across all plans, only 82% of women with a certain type of breast cancer were getting the recommended treatment.

His study did not look at why some cancer patients got standard of care and some did not, but he expects epidemiology students will do just that for their master's theses. Race, ethnicity, age, and location could be factors.

"The cancer registry was originally created for cancer surveillance—in particular, to track trends in disease incidence, stage at diagnosis, and deaths," says Lipscomb. "But we are seeing it can be used for so much more."

Recording recurrence

All cancer registries record only population-wide primary cancer occurrences. That design was fine when a cancer occurrence was almost always a death sentence.

Tim Lash, [epidemiology](#) professor, thinks it's not so fine anymore. "Today, when more people are surviving their cancer and perhaps even being cured, it's no longer acceptable to focus only on mortality," he says.

He and his colleagues want to augment the Georgia Cancer Registry so it will be a first-of-its-kind registry to track recurrence. "I don't want to

overstate where we are in the process—it's a goal at this point," says Lash. "But if you're an epidemiologist trying to study the course of cancers, what groups are more at risk for recurrence, or what factors predict good outcomes, you're out of luck. All of that could be studied if we had population-wide information on recurrence."

Lash contends that Georgia is the perfect place for one. The state's population of 10 million is large enough to make data meaningful. Georgia has a long-established, high-quality cancer registry and an NCI-designated cancer center. Says Lash, "The fact that the registry and Winship are both here at Emory creates a powerful synergy for launching this addition to the registry."

Provided by Emory University

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