

Researchers can mine new health registry for wealth of data



PHOTO BY LINDA KASTLEMAN

Dr. Jeannette Bensen

North Carolinians can help make scientific history *and* advance cancer research by enrolling in the groundbreaking new UNC Health Registry funded by the University Cancer Research Fund. In doing so, they'll be part of a whole new research effort aimed at determining how best to treat and support those with cancer.

There are a lot of things that physicians still don't know about cancer, a category that encompasses a wide range of diseases with different causes and treatments. They would like to know why some patients respond to therapies better than others, why certain individuals experience debilitating side effects from treatment while others don't, why there are ethnic disparities in cancer outcomes, and how cancer treatment affects a patient's quality of life over time.

The UNC Health Registry is a far-reaching initiative that aims to answer these questions. The project will advance cancer research, prevention, treatment and care, and also seeks to reduce health disparities among North Carolinians. The study will enroll 10,000 English- and Spanish-speaking North

Carolinians who come to UNC for cancer evaluation and care.

"The Registry is a chance for researchers to learn about ways to improve treatment outcomes as well as the quality of life of cancer patients and their families," says Jeannette T. Bensen, PhD, research assistant professor of epidemiology at the UNC Gillings School of Global Public Health and Lineberger Comprehensive Cancer Center member. She is leading the project, along with an interdisciplinary group of investigators.

Bensen says she hopes that patients will understand the importance of their participation in this initiative because the questions it can answer will help change the course of cancer care.

The Registry will create an integrated record of clinical information, biological specimens and questionnaire data that includes safeguards to protect patient privacy. Additionally, those patients with a cancer diagnosis enrolled in the Registry will be followed annually and will comprise a unique part of the Registry known as the UNC Cancer Survivorship Cohort. Bensen says UNC's

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To participate in the Health Registry, patients must:

- Be 18 years or older
- Have a North Carolina address and
- Have an appointment in a UNC Hospital (e.g., the N.C. Cancer or N.C. Women's Hospital).

public health, medical and other schools have for decades contributed “excellent population-based cancer research spanning North Carolina counties, especially in the middle and eastern areas of the state. The new study will be even more comprehensive.”

The integrated nature of the project – one of very few being done on such a large scale – will link health outcomes and quality of life to sophisticated genetic analysis that can help doctors better understand how and why patients respond differently to the same treatment, how to better manage treatments to avoid side effects, how to better manage cancer after the initial round of therapy is over and how to address long-term health concerns of cancer survivors. Another unique aspect is the ability to contact patients for future studies. This will allow patients and their families to choose to be involved in exciting new studies that advance the science of cancer prevention, early detection and therapy.

“This Registry complements UNC’s rich research history by adding a hospital-based cohort that can be used to ask different questions and assemble yet another important set of information centered on a patient’s clinical care and quality of life,” Bensen adds. “UNC is one of only a few centers in the nation to establish an integrated registry and cancer survivorship cohort such as this. This resource will give researchers the potential for groundbreaking work in the field of cancer research.” ■

– *By Kim Gazella*