

Research at the Bureau of Cancer Epidemiology

The Bureau of Cancer Epidemiology participates in population-based research studies. These studies examine cancer risk, outcomes, and health disparities. The Bureau houses the New York State Cancer Registry (NYSCR). NYSCR collects information on all cancers diagnosed or treated in New York State. These data provide information on cancer trends. NYSCR data can also identify differences in cancer risk, treatment, and survival. External researchers can apply to use NYSCR data for research by emailing bcerdu@health.ny.gov. This includes studies that involve patient contact.

What Are Population-Based Patient Contact Studies?

Population-based research seeks to understand causes of disease and disease outcomes. Research may look at different exposures in a population. This can include physical, social, and environmental factors. Studying these factors can help researchers find contributors to disease. NYSCR may contact eligible cancer patients to tell them about a research study. The research may examine cancer risk, disparities, or health outcomes. NYSCR research also seeks to promote health equity in the state.

What patient information does the NYSCR receive?

NYSCR receives data on the tumor site, stage, cell type, and some treatment information. When someone is diagnosed with more than one cancer, NYSCR receives information on each tumor. NYSCR also receives certain sociodemographic information including age, gender, ethnicity, race, and residence. NYSCR only receives information related to a patient's cancer diagnosis and first course of treatment.

How does the NYSCR protect privacy?

All information reported to NYSCR is confidential. Strict procedures are in place to protect patient privacy.

More information on the policies regarding data sharing can be accessed here:

- [NYSCR Data Release and Policy Manual \(PDF\)](#)

More information on the New York State Cancer Registry:

- [New York State Cancer Registry and Cancer Statistics](#)
- [About the New York State Cancer Registry](#)

Learn More About NYSCR's Patient Contact Studies

Some research studies require additional information from cancer patients. This is important to help understand the causes and effects of cancer. NYSCR sends a letter to eligible patients to allow them to decline to participate in the study. If a patient does not decline, then their contact information is sent to the approved researcher. The researcher will then contact the patient about the research study. For some studies, NYSCR researchers contact the patient directly about participating in a study. NYSCR researchers are active collaborators on studies involving patient contact and participate in all aspects of the research, including as co-authors on publications.