

## How can I find out more about the Cancer Registry?

To find out more about the New York State Cancer Registry, please call 518-474-2255 or email [nyscr@health.ny.gov](mailto:nyscr@health.ny.gov). Cancer statistics are available on the New York State Department of Health website at [health.ny.gov/statistics/cancer/registry](http://health.ny.gov/statistics/cancer/registry)

## Other Resources

If you would like information on cancer support groups, call the **American Cancer Society (ACS)** at (800) 227-2345.

**The Cancer Information Service** can answer questions about different types of cancer. They can be reached at (800) 422-6237 or [NCIinfo@nih.gov](mailto:NCIinfo@nih.gov).

**ACS Cancer Facts and Statistics**  
[cancer.org/research/cancer-facts-statistics](http://cancer.org/research/cancer-facts-statistics)

**ACS Cancer Statistics Center**  
[cancerstatisticscenter.cancer.org](http://cancerstatisticscenter.cancer.org)

**National Program of Cancer Registries**  
[cdc.gov/cancer/npcr](http://cdc.gov/cancer/npcr)

**New York State Cancer Registry**  
[health.ny.gov/statistics/cancer/registry/about.htm](http://health.ny.gov/statistics/cancer/registry/about.htm)

**North American Association of Central Cancer Registries (NAACCR)**  
[naaccr.org](http://naaccr.org)

**Surveillance, Epidemiology, and End Results Program**  
[seer.cancer.gov](http://seer.cancer.gov)

New York State Department of Health  
Bureau of Cancer Epidemiology  
150 Broadway, Suite 361  
Albany, NY 12204  
(518) 474-2255  
[nyscr@health.ny.gov](mailto:nyscr@health.ny.gov)

# New York State Cancer Registry

## Patient Information



Department  
of Health

[health.ny.gov](http://health.ny.gov)

## About the New York State Cancer Registry (NYSCR)

The New York State Cancer Registry (NYSCR) is a statewide data system located in the New York State Department of Health. The NYSCR is responsible for collecting information on all cases of cancer diagnosed or treated in New York State.

Cancer is a reportable disease in every state in the United States. Under New York State Public Health Law, doctors, dentists, hospitals, laboratories, and other health care providers must report all cases of cancer they find to the NYSCR.

The NYSCR has collected statewide data since 1976. This information can be used to look at cancer patterns and trends for all areas of the state. The data are also used for public health planning and for research to help understand the causes and effects of cancer.

## What cancers are reported to the NYSCR?

The NYSCR collects data on all malignant cancers, except basal and squamous cell cancers of the skin. Reportable cancers include both in situ cancers (very early cancers) and invasive cancers which have more potential to spread. The NYSCR also collects data on benign brain and nervous system cancers. Benign tumors are growths that do not have the potential to spread beyond the tissue where they started.

## What information is collected about patients with cancer?

The NYSCR collects data on the cancer site, stage at diagnosis, cell type, and some treatment information. When a person is diagnosed with more than one type of cancer, this information is collected for each separate cancer.

The NYSCR also collects some information such as age, gender, race, ethnicity, and address for each person diagnosed with cancer.

## How does the NYSCR protect patient privacy?

All information reported to the NYSCR is confidential, and strict procedures are in place to protect patient privacy. Only summarized information is published to guard against disclosing confidential data about persons with cancer.

State law allows limited use of confidential cancer data for research. Any research study that uses data with patient-level information must be approved by an Institutional Review Board (IRB). The IRB protects patient rights and ensures that patients understand the purpose, benefits, and potential risks of a research study. These research studies are important to help understand the causes and effects of cancer. Researchers who are approved to use the data must pledge that the information will remain protected.

## Is cancer reporting covered under HIPAA?

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) permits reporting of personal health information to public health entities. Because the NYSCR is a public health entity, HIPAA allows health care providers to send reports of cancer to the NYSCR to comply with state law. Consent from each patient reported to the NYSCR is not required under HIPAA.

## How are the data used?

Data collected by the NYSCR are used to:

- monitor the number of new cancer cases over time;
- examine disparities in cancer risk, treatment, and survival;
- examine treatment choices and other predictors of cancer outcomes;
- respond to public concerns and questions about cancer; and
- conduct research on causes of cancer.

## Are patients asked to participate in research studies?

Some research studies require additional information from cancer patients. Before sending a patient's contact information to a researcher, the NYSCR sends a letter to the patient to allow them to decline to participate or "opt out" of the study. A patient's information is sent to an approved researcher only if the patient does not opt out.