

What is the New Jersey State Cancer Registry?

The New Jersey State Cancer Registry (NJSCR) is a population-based public health cancer registry that was established in 1978 under N.J.S.A. 26:2-105 to record cases of cancer and other specified tumorous or precancerous diseases that occur in New Jersey. These data are then used to monitor incidence and mortality trends and conduct activities to apply appropriate cancer prevention and control measures to reduce the cancer burden in New Jersey.

Who is required to report cancer to the New Jersey State Cancer Registry?

State law requires that hospitals, physicians, ambulatory care facilities, radiation treatment facilities, private laboratories, and other providers report all newly diagnosed cancer cases in the State of New Jersey electronically to the NJSCR within six months of first contact, regardless of residency status (see N.J.A.C. 8:57A-1.4). However, the NJSCR prioritizes its data collection to cancers that have been reported among New Jersey residents, including residents diagnosed in other states such as Pennsylvania and New York due to reciprocal interstate data exchange agreements.

How are Brain Tumors reported?

Reportable cancer cases and other specified tumorous or precancerous diseases are defined as all primary invasive and *in situ* neoplasms, with a few exceptions (see **Figure 1**). Benign and borderline intracranial and Central Nervous System (CNS) tumors, including meninges and intracranial endocrine structures, are also reportable to the NJSCR as of January 1, 2004. Cervical cancer *in situ* diagnosed after 1995, certain carcinomas of the skin, and benign and borderline tumors of the cranial bones are **not** reportable to NJSCR. A brief list of primary brain and CNS sites are provided in **Table 1**.

Figure 1. How cancers are classified at the New Jersey State Cancer Registry (NJSCR)

Every cancer that is reported to the NJSCR is classified based on (1) primary* physical topography, (2) morphology, and (3) behavior as defined by the International Classification of Disease for Oncology, 3rd Edition ICD-O-3.

Individuals can be diagnosed with more than one primary cancer in their lifetimes. All primaries are reportable to the NJSCR and counted as an incident case.

- (1) Primary site topography code 4 characters
 - C__ site. _ subsite
- (2) Morphology or Histology code 4 characters
 - ____ tumor/cell type
- (3) Behavior code 1 character that follows the morphology code after a “ / ”
 - /_
 - /0- benign
 - /1 borderline
 - /2 in situ
 - /3 malignant
 - /6 metastasis secondary malignancy

**Primary brain and CNS cancers are separate and distinct from brain and CNS cancers that are a result of metastatic progression of a different physical/anatomical site. For example, breast cancer that has metastasized to the brain. Brain metastases are not reportable to the NJSCR.*

Cases are reported to the NJSCR through a number of mechanisms including but not limited to abstracted data from medical records at hospitals and other health care facilities, pathology

laboratory reports, and clinical and claims data submitted directly from electronic health records. In order to ensure that all cancer cases have been reported to the NJSCR, auditing is conducted, and we cross-check the cancer surveillance system to other data sources with known cancer diagnosis information such as hospital admission and discharge documents, disease lists at hospitals, surgery schedules or logs, hematology reports, and autopsy reports, to name a few. In addition to these requirements, health care facilities and providers must report all clinical diagnoses especially if the diagnosis is done without a biopsy; all cases where the patient reported a “history of” active cancer; and any consult or 2nd opinion to confirm a diagnosis or treatment plan. The NJSCR also monitors deaths due to cancer through linkages with the New Jersey Office of Vital Statistics and Registry and the National Death Index. These methods ensure 100% capture of reportable cancers throughout the State.

Because some diagnoses are not as clear or definitive as others, there are several terms that cancer registrars are trained to look for. If these “ambiguous” terms are present, cancer registrars are instructed to report the cancer:

- Apparently
- Appears
- Compatible/Compatible with
- Consistent with
- Favors
- Malignant appearing
- Most likely
- Presumed
- Probable
- Suspected
- Suspicious for
- Typical of

Primary Site Name	Primary Site Topography Codes
Brain	C71.0 – C71.9
Cerebrum	C71.0
Frontal lobe	C71.1
Temporal lobe	C71.2
Parietal lobe	C71.3
Occipital lobe	C71.4
Ventricle	C71.5
Cerebellum	C71.6
Brain stem	C71.7
Overlapping lesion of the brain	C71.8
Brain NOS	C71.9
Meninges	C70.0 - C70.9
Cerebral meninges	C70.0
Spinal meninges	C70.1
Meninges NOS	C70.9
Spinal cord	C72.0
Cauda equina	C72.1
Cranial nerves	C72.2 - C72.5
Olfactory nerve	C72.2
Optic nerve	C72.3
Acoustic nerve	C72.4
Cranial nerve NOS	C72.5
Other CNS	C72.8, C72.9
Pituitary gland	C75.1
Craniopharyngeal duct	C75.2
Pineal gland	C75.3

For non-malignant benign and borderline Brain/CNS tumors:

- The terms tumor, mass, tumor mass, lesion, and neoplasm are not used to indicate a definitive diagnosis of a benign or borderline brain or CNS tumor. Therefore, cancer registrars are instructed to only report these cases if there is a physician’s statement that the tumor is a non-malignant tumor/neoplasm.
- Benign (ICD-O-3 behavior code “/0”) and borderline (ICD-O-3 behavior code “/1”) primary intracranial and CNS tumors are reportable to the NJSCR if they were diagnosed from January 1, 2004 or later.

For a complete list of reportable conditions, go to <https://www.nj.gov/health/ces/reporting-entities/njscr/> and download the “NJSCR Reportable List updated 2021” in MS Word or PDF format. Based on this list, there are 109 known types of benign, borderline, and malignant brain and CNS conditions that are reportable to the NJSCR.

What information is included in the NJSCR?

NJSCR requires the meticulous documentation of cancer diagnoses to ensure that cancer statistics are as reliable as possible and reflect the true burden of disease. In fact, the meticulous nature of data collection and coding go beyond the classification of primary site and is applied to

other registry data including demographics, extent of disease and disease severity such as tumor size and stage, treatment protocols, and outcomes such as survival. In all, the cancer registry maintains more than 400 data items in its database. This, combined with the reporting limitations set forth in the state laws, makes it impossible to collect data directly from patients. Our surveillance system relies heavily on the detail that is provided by cancer providers who use information from medical records and other cancer reports.

The reporting law allows the NJSCR to provide cancer summaries upon request (see <https://www.state.nj.us/health/ces/> “Forms for Patients”). If the NJSCR does not have a record of your cancer, please contact your physician, oncologist, or other cancer care provider to encourage them to report information to the NJSCR as required by law.

Where can I find more data about my type of cancer?

Cancer-Rates.info/NJ, New Jersey's official source for cancer statistics, provides cancer incidence and mortality data for New Jersey displayed in maps, tables, and graphs.

www.cancer-rates.info/nj

More information can be found at:

NJSCR Data Briefs (Brain data brief coming soon!)

<https://www.state.nj.us/health/ces/briefs.shtml>

NJSCR Reports

<https://www.state.nj.us/health/ces/reports.shtml>

National Cancer Institute (NCI)

<https://statecancerprofiles.cancer.gov/>

<https://seer.cancer.gov/statistics-network/>

Centers for Disease Control and Prevention (CDC)

<https://www.cdc.gov/cancer/uscs/dataviz/index.htm>

Central Brain Tumor Registry of the United States (CBTRUS)

<https://cbtrus.org/>

American Cancer Society (ACS)

<https://www.cancer.org/cancer/brain-spinal-cord-tumors-adults.html>

