



NEW JERSEY STATE CANCER REGISTRY

ABSTRACT INSTRUCTION MANUAL FOR PHYSICIANS, AMBULATORY CARE CENTERS & RADIATION TREATMENT FACILITIES 2019

CANCER EPIDEMIOLOGY SERVICES

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**Fighting cancer with quality data
and innovative research**

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INTRODUCTION TO THE NEW JERSEY STATE CANCER REGISTRY

The New Jersey State Cancer Registry (NJSCR) is a population-based incidence registry and includes all cancer cases diagnosed in New Jersey residents since October 1, 1978. The NJSCR serves the entire state of New Jersey, which includes a population of approximately 8.9 million people.

The purpose of the NJSCR is to track cancer incidence in an effort to advance scientific research, public and professional education programs, planning, implementation and evaluation of cancer control and prevention activities. The NJSCR has been recognized for its high-quality data, and we continue to strive to improve the quality and enhance the usefulness of the data.

The NJSCR was established by legislation (NJSA 26:2-104 et. seq.) in 1977 in response to concern that New Jersey was suffering from the highest cancer mortality rates in the country. New Jersey regulations require that all health care facilities, physicians, dentists, clinical laboratories and other health care providers report all newly-diagnosed cancer cases to the NJSCR within six months of diagnosis.

The information collected by the NJSCR includes patient demographic characteristics, medical information on each cancer and treatment information. The vital status of each patient is followed annually until death. The cause of death is also incorporated into the data when the information is available.

The NJSCR participates in the National Program of Cancer Registries (NPCR), established by the Centers for Disease Control and Prevention (CDC) in 1992 by the Federal Cancer Registries Amendment Act (Public Law 102-515). NPCR promotes statewide, population-based registries to collect uniform data elements in a standardized format. The NJSCR is also a member of the North American Association of Central Cancer Registries (NAACCR) which is a professional society established in 1987. NAACCR is interested in the ongoing development of cancer registries and the establishment of registry standards.

USE OF REGISTRY DATA

Data collected by the NJSCR are analyzed by epidemiologists at the NJSCR Cancer Surveillance Research Program (CSRP) along with researchers from universities, the NJ Department of Health, the National Cancer Institute (NCI) and the CDC and are used to:

- Identify factors related to cancer causes and prevention.
- Monitor trends and patterns of cancer incidence, survival and treatment.
- Serve as a resource in conducting epidemiologic studies in New Jersey.

- Assist public health officials, hospital administrators and physicians to plan services, prioritize health resource allocations and develop and measure prevention and intervention strategies.
- Share and compare cancer data with other state cancer registries and public health agencies.
- Develop assessments of cancer incidence in occupational and community settings.

Patient and provider information and any data that could be used to identify an individual is never released without the written consent of the patient. Deidentified, aggregate data is publicly available at <https://nj.gov/health/ces/cancer-researchers/cancer-data/>. For more information on how cancer data in New Jersey is used, or to view our reports and publications, please visit <https://nj.gov/health/ces/cancer-researchers/>.

CONFIDENTIALITY

State and Federal laws require the strictest confidentiality of all identifying information, including that of the patient and the provider. The New Jersey Cancer Registry Statute N.J.S.A. 26:2-107 states that reports of individual patients made to the NJSCR are held in the strictest confidence. Reports made pursuant to this act are used only by the Department of Health and Senior Services and such other agencies as designated by the Commissioner of Health. N.J.S.A.26:2-108 states that no individual or organization providing information to the Department of Health in accordance with this act shall be held liable for divulging confidential information. Please note: reporting information about cases of cancer in accordance with the NJSCR authorizing statute and regulations is permitted by the Health Insurance Portability and Accountability Act. The privacy rule contains a specific provision authorizing covered entities to disclose protected health information as required by law. Public Health reporting under the authority of the State law is specifically exempted from the Privacy Rule Regulations 45CFR154.512(6)(l)(i). A copy of the Cancer Reporting Statute, Regulations and listing of Reportable Diseases and Conditions Reportable List can be referenced at the end of this manual.

HOW TO REPORT TO THE NJSCR

Physicians, labs, ambulatory centers, and radiation treatment facilities are responsible for reporting cases of cancer and other reportable conditions. A report must be submitted for each cancer patient diagnosed, and/or treated in the facility (including physician practices, labs, ambulatory centers and radiation treatment centers). Physicians must report all patients, regardless of prior hospitalizations, including those with pathology diagnosis from independent labs. A separate report must be submitted for each primary malignancy or reportable condition.

Beginning in 2018, N.J.A.C. 8:57A-1.6 requires all physicians and other health care providers to report to NJSCR in **standard electronic format**. Acceptable formats include either a registry abstract following the North American Association of Central Cancer Registries (NAACCR) standard record layout (www.naaccr.org) or using HL7 Clinical Data Architecture (CDA) through the Meaningful Use (MU) program. Fax, mail or email are not acceptable reporting formats.

Meaningful Use Reporting

Reporting through MU is the preferred method for physician practices and outpatient facilities utilizing Certified EHR Technology (CEHRT). Visit <https://nj.gov/health/meaningfuluse/cancer.shtml> for more information and to register for MU reporting in New Jersey.

NAACCR Standard Record Layout Reporting

The NJSCR can provide non-hospital facilities and physician practices with no-cost, secure, web-based software, developed by the Centers for Disease Control and Prevention (CDC). NJSCR staff will provide technical and training support. Reporting in this manner requires manual entry of demographic, tumor and treatment information into the web-based reporting form. The data are transmitted securely to the NJSCR. For more information on reporting in NAACCR standard record layout or to request software, please visit <https://www.nj.gov/health/ces/reporting-entities/non-hospital/>.

WHEN TO REPORT TO NJSCR

N.J.A.C.8:57A-1.4 requires reporting of all patients with malignancy or other reportable condition to the NJSCR within 6 months of the date of first contact for the reportable diagnosis.

REPORTABLE CASES

Every New Jersey health care facility, physician, dentist, other health care provider and clinical laboratory shall report to the NJSCR all cases having the following diagnoses:

- ✓ All *in situ* or invasive neoplasms with a behavior code of “/2” or “/3” in the International Classification of Diseases for Oncology (ICD-O) Manual.
- ✓ All solid benign and malignant tumors of the brain and central nervous system, including meninges and intracranial endocrine structures, that have the following behavior codes in the ICD-O:
 - “/0” benign disease;
 - “/1” disease of uncertain malignant potential;
 - “/2” *in situ* disease; or
 - “/3” invasive disease.

- ✓ The following diagnoses are NOT to be reported to the NJSCR:
 - Basal cell or squamous cell carcinomas of the skin **except when diagnosed in the lip, anus, labia, clitoris, vagina, vulva, prepuce, penis, or scrotum**; or
 - Carcinoma in situ of the cervix and/or squamous intraepithelial neoplasia III (CIN III).
- ✓ If the following ambiguous terms are used to describe a reportable condition, it must be reported: **apparent(ly), appears, appears to, comparable with, malignant appearing, consistent with, most likely, probable, suspected, suspicious, presumed, favor(s), typical of.**
- ✓ Patients with a **clinical diagnosis of cancer**, which was based on clinical judgment, must be reported.
- ✓ If more than one primary disease occurrence cancer is diagnosed in a patient, **a separate report must be submitted for each primary** malignancy, or reportable disease or condition.
- ✓ Certain other benign (O) and borderline conditions (+) are reportable. Refer to the listing of Reportable Diseases and Conditions at <https://www.nj.gov/health/ces/reporting-entities/njsr/>.
- ✓ **Consult-only cases are reportable.** A consult may be done to confirm a diagnosis or treatment plan.
- ✓ New Jersey residents and non-residents must be reported including residents of foreign countries. If patient was diagnosed in a foreign country, please indicate this on the report, along with the name of the country, if known.
- ✓ Only patients with active disease or undergoing treatment should be reported.

DEMOGRAPHIC INFORMATION

Please provide the following patient information. Accurate demographic information will enable the registry to create new case reports and/or match your submission to previous, concurrent or future reports.

Patient's Name

Record the patient's last name, first name and middle name. Document any known aliases or maiden names.

Date of Birth

Record the exact date of the patient's birth in month, day, and year.

Social Security Number (SSN)

Record the nine-digit Social Security number. Medicare claim numbers with a suffix "A" may also be entered in these fields. Do not record spouse's Social Security number or those ending with B or D.

A Note About Social Security Number

Reporting each patient's SSN to the NJSCR is important. It is used to link reports from multiple sources for the same patient as well as to differentiate between patients with the same or similar names and dates of birth. Please make every attempt to document and submit the patient's SSN. This information is kept strictly confidential by NJSCR.

Patient's Address at Diagnosis

Record the number and street address of the patient's residence when the cancer was first diagnosed and treated. If the patient has multiple cancers, the address may be different for each primary. Use actual street address and avoid PO box in address. If the patient's residence is a long-term care facility, please record the name and address of the facility. If the address was a foreign country, please include this. Also record the current address elsewhere on the report if it differs from the address at diagnosis.

City, State, ZIP Code

Record the city, state, and zip code of the patient's residence at the time when the cancer was first diagnosed and treated.

Race and Ethnicity

Record the race of the patient. Every attempt should be made to record the correct race; record multiple races for patients who identify as multiracial. Indicate if the patient is of Spanish/Hispanic origin. People of Spanish/Hispanic origin may be of any race.

Marital Status at Diagnosis

Record the patient's marital status at the time when the tumor was first diagnosed.

Sex

Record the patient's sex at birth: male, female, other (non-binary)

TUMOR INFORMATION

The following information identifies the type and location of cancer with which the patient was diagnosed. Please provide complete and accurate information on the type and location of cancer for each patient's record.

Primary Site/Laterality of This Cancer

The primary site is the anatomical location of tumor origin; the metastatic site is the area of the body where the tumor has spread to. **Be careful not to record the metastatic site.** Review all reports in the patient's medical record and record the most accurate statement for primary site and laterality. **Laterality** refers to the side of the body in which the cancer originated for sites with paired organs (e.g. left lung, right kidney). It applies to the primary site only.

Histologic Type of This Cancer

Record histologic type including the grade or degree of differentiation as stated in the FINAL pathologic diagnosis. If a diagnosis indicates two different grades or degrees of differentiation (such as "well and poorly differentiated"), record the higher grade.

Date This Cancer Was First Diagnosed

Record the first date a diagnosis of cancer was made. Please include the month, day, and year. If the date of diagnosis is unknown, attempt to estimate the year of diagnosis.

Initial Visit for This Cancer

Record the month, day, and year that this patient was first seen in your office for this cancer.

Date of Last Contact

Please record the last date of contact with this patient (i.e., office visit, lab report or another physician's report). If the patient is deceased, please record date of death.

TNM Stage

The TNM Classification is based on the evaluation of the primary tumor (T), regional lymph nodes (N), and distant metastasis (M). Stage Group (Stage 0-4). For information regarding the use of TNM staging refer to AJCC Cancer Staging Manual, visit <https://cancerstaging.org>.

Staging Prognostic factors

Record prognostics factors that can alter staging and influence treatment or prognosis, such as pretreatment tumor markers or other special studies that may alter staging or treatment.

Tumor Size

Record the largest dimension or diameter of the primary tumor in millimeters. For melanoma of the skin, please record the depth and thickness also.

TREATMENT INFORMATION

Did This Patient Receive Any Treatment for This Cancer?

Please indicate whether the patient has received or is currently receiving any treatment for this cancer. If treatment was or is currently being received, please ***specify the type and date treatment was initiated***. If treatment was performed elsewhere, please indicate the where the treatment was performed.

Surgery

Record the date and type of cancer-directed surgery performed. An excisional biopsy is cancer-directed surgery. Review the operative and pathology report and record surgical procedures performed, including any lymph node surgeries. ***If reporting melanoma excision or re-excision record whether margins are negative and if the negative margins are greater than 1 cm.***

Radiation

Record the date, type, amount, and duration of radiation administered to the primary or metastatic site. Radiation treatment includes include external beam radiation, x-ray, cobalt, linear accelerator, stereotactic radiotherapy, brachytherapy, Gamma Knife, radioactive implants, and radioisotopes.

Chemotherapy

Record the date, type, and duration of chemotherapy administered to the patient. Record the generic or trade names of the drugs used for chemotherapy. Record combination therapy abbreviations.

Hormone/Other Therapy

Record the date, type and duration of therapy administered to the patient.

- Hormone therapy such as antihormones, endocrine surgery, and endocrine radiation therapy.
- Immunotherapy such as biological response modifier therapy, bone marrow transplant, and stem cell transplant.
- Other cancer-directed therapy that is not defined under Surgery, Radiation, or Chemotherapy, such as bone marrow transplants.
- Clinical trials.
- Unproven therapy.

Referred to:

If you have referred this patient to another physician for treatment of this cancer, please provide the name of the hospital and/or physician. Please include physician's address telephone and fax number.

**For further information concerning cancer reporting and our publications, please
contact the following:**

New Jersey State Cancer Registry
Cancer Epidemiology Services
NJ Department of Health
PO Box 369
Trenton, NJ 08625-0369
Phone (609) 633-0500
Fax (609) 633-7509
Ops.NJSCR@doh.nj.gov

RESOURCES

Please visit our website to obtain additional reference material, up-to-date cancer statistics and to obtain additional information about our surveillance activities:

<http://www.nj.gov/health/ces/>

For information about electronic cancer reporting through Web Plus click the link below.

<http://www.nj.gov/health/ces/reporting-entities/non-hospital/>

For information about Meaningful use cancer click the link below.

<http://www.nj.gov/health/meaningfuluse/cancer.shtml>

NJSCR List of Reportable Diseases and Conditions

<https://www.nj.gov/health/ces/documents/NJSCR2019reportablelist.pdf>

The AJCC Cancer Staging Manual

<https://cancerstaging.org>

International Classification of Diseases in Oncology

<http://codes.iarc.fr/>