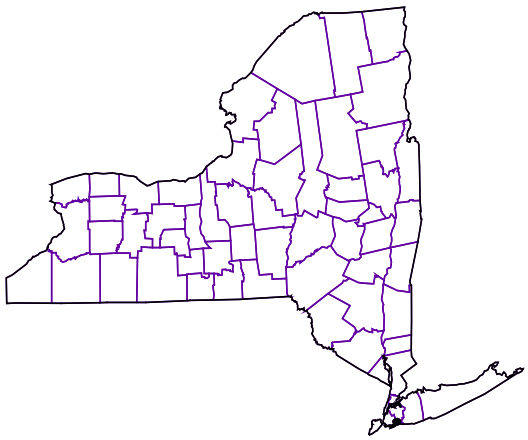
THE NEW YORK STATE DEPARTMENT OF HEALTH

New York State Cancer Registry
Provider Reporting Manual



New York State Cancer Registry 518-474-0971; fax 518-473-5951

Revised February 2026

This page was intentionally left blank.

New York State Cancer Registry Provider Reporting Manual

Table of Contents

1. Introduction

The New York State Cancer Registry (NYSCR) collects and processes information on cancer cases in New York State. In addition, the NYSCR produces reports on cancer incidence and mortality statewide and in each county, by sex and anatomic site (i.e., breast, lung, colon, prostate, etc.). Because of its comprehensive database of information on cancer cases in New York, the NYSCR serves as an important resource for citizens, healthcare professionals, and researchers.

The NYSCR is a population-based cancer incidence registry responsible for the collection of demographic, diagnostic, and treatment information on all patients diagnosed with and/or treated for cancer at hospitals, laboratories, radiation treatment centers, ambulatory surgery centers, physician practices and other health care facilities throughout New York State. Reporting of cancer cases is mandated under Public Health Law (see Appendix A).

New York State (NYS) Public Health Law, Article 24, Title 1, Section 2401 and Title 101.31 of Rules and Regulations provide the NYSCR with the legislative authority to collect confidential cancer information and to protect the confidentiality of all cancer case information received by the NYSCR. The New York State Department of Health (NYSDOH) has instituted stringent regulations to ensure maximum confidentiality of records received. Additionally, Department of Health Regulation Subparts 50-1 through 50-4 govern the storage, access and disposal of patient information and requires the development of unit-specific protocols to ensure confidentiality of personal health-related information.

When the NYSCR first started collecting data, only a minimal amount of information about the patient and tumor was collected. Over the years, the volume of cancer cases has increased, and the amount of data collected for each case has expanded. Information collected by the Registry can be divided into two major types: information pertaining to the disease process and information about the patient. Regarding the disease, the Registry collects data on the:

- anatomic site of the tumor
- stage at diagnosis
- cell type of the cancer
- type of treatment rendered

If a person is diagnosed with more than one type of cancer, this same information is collected for each unique tumor.

The Cancer Registry also collects specific socio-demographic information on each person diagnosed with cancer. This information is necessary for cancer surveillance, for targeting interventions, and for studies of cancer etiology. Some examples of this type of information are:

- age
- sex
- ethnicity
- race
- residence
- place of birth

To ensure that diagnoses are not over counted, the Registry links every incoming report to the current database, consolidating records received for the same individual and for the same tumor. To perform these linkages, the NYSCR requires health professionals to provide confidential personal identifiers of their patients, such as complete name, date of birth and, most important, Social Security Number.

2. Confidentiality

Cancer data is highly confidential, and one of the most important responsibilities of cancer registry professionals is to safeguard the confidentiality of cancer patient information. Improper disclosure of this data could result in emotional, psychological and financial harm to the patients and their families. The standard of confidentiality maintained by cancer registries is similar to that of the doctor-patient relationship and it extends indefinitely—even after the patient is deceased.

> *The identity of any person contained in a report of cancer made pursuant to the provisions of Section 2401 of the Public Health Law, or cancer data collected for other specific research studies, shall not be disclosed except to governmental or government-sponsored research projects for the purpose of scientific studies and research when the State Commissioner of Health determines that substantial knowledge may be gained by such disclosure leading toward the reduction of morbidity and mortality. The recipient shall limit the use of such information to the specific study of research purpose for which such disclosure is made, shall not further disclose such information and shall satisfy the State Commissioner of Health that the confidentiality of the patient's identity will be maintained.*

3. Data Security

The NYSCR offers the following guidelines to maintain the security of confidential patient information:

A. Obtain an individual ID and password to the Health Commerce System (HCS) for each authorized user. Do not share user IDs and passwords. Multi-factor Authentication adds another layer of security to the HCS authentication process to access HCS applications.

B. Fax: To ensure that the information is received by an authorized party only:
   1. Verify that the appropriate individual is present before transmitting confidential data.
   2. Transmit data only to a fax machine that is located within a secure area, offering limited access.
   3. Accompany each fax transmission with a cover sheet that includes a notice of confidentiality.
   4. Verify that the intended recipient received the faxed information.

C. Electronic Mail: Never use e-mail to transmit confidential patient information. If an individual wishes to send confidential data electronically, they should use the *Secure File Transfer Utility* on the Department's Health Commerce System (HCS). Please note that an HCS account enrolled with Multi-Factor Authentication is necessary to access and transmit via the *Secure File Transfer Utility*. This system allows for secure transmission of files up to 10mb. Assistance using the *Secure File Transfer Utility* is available from your Field Representative.

D. Regular Mail: All confidential patient information sent to the NYSCR must be prominently marked “confidential.” Use of registered or express mail is recommended. This allows the sender to track the package as well as confirm receipt.

4. Health Information Portability and Accountability Act (HIPAA)

HIPAA does not apply to public health agencies collecting information for the purpose of disease surveillance. Code of Federal Regulations (CFR) (45 CFR §164.512) authorize disclosure without patient consent in several circumstances, including the following:

> Disclosure is permitted to a public health authority authorized by law to access information to prevent/control disease, injury, disability, e.g., disease reporting, vital statistics reporting, public health surveillance, public health investigations, public health interventions and partner notification.

Under HIPAA, a “public health authority” refers to “an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate” (45 CFR §164.501). Such agencies are “authorized by law to collect or receive such information for the purposes of preventing or controlling disease, injury, vital events such as birth or death and the conduct of public health surveillance, public health investigations and public health interventions” (45 CFR §164.512). Central cancer registries are considered public health authorities because their duties are mandated by state laws.

Cancer reporting and surveillance are required by state law. Because New York State Department of Health is a public health authority and because cancer reporting and surveillance are required by state law, it is not necessary to complete a business associate’s agreement before providing the NYSCR with the requested personally identifiable information.

5. Reportable Diagnoses

In general, the following types of cases *must* be reported:

A. Each form of malignant cancer, EXCEPT basal cell and squamous cell carcinoma originating in skin of **non**-mucoepidermoid sites

B. Each form of in situ cancer, EXCEPT for carcinoma in situ of the cervix uteri, CIN III (cervical intraepithelial neoplasia, grade three), PIN III (prostatic intraepithelial neoplasia, grade three) and High Grade Dysplasia in the colon, rectum, or rectosigmoid.

C. Basal and squamous cell carcinoma of **mucoepidermoid sites** – labia, clitoris and clitoral hood, vulva, vagina, penis, scrotum, vermilion surface of lip, inner mucosal surface of lip and anoderm of anal canal

D. Benign, borderline/uncertain behavior and malignant PRIMARY tumors originating in any of the following sites:

- Meninges
- Brain
- Spinal cord, cranial nerves and other parts of CNS (central nervous system)
- Pituitary and pineal glands and craniopharyngeal duct

E. Each form of lymphoma, leukemia and other malignant blood conditions, i.e. chronic myeloproliferative diseases, including polycythemia vera and essential thrombocythemia, and myelodysplastic syndromes including refractory anemia

F. Serous and mucinous tumors of borderline/uncertain behavior originating in the ovaries

5.1 Reportability List for Physician/Provider Medical Practices

This guide provides a list of diagnoses reportable to the NYS Cancer Registry for the ICD-10-CM coding system. If you have any questions about determining reportability or selecting the best primary site or histology in the HCS Provider Cancer Case Reporting System, call the Cancer Registry at 518-474-0971 for assistance.

ICD-10-CM Code	Description
C00._ - C43._, C4A._, C45._ - C96._	Malignant neoplasms (excluding category C44), stated or presumed to be primary (of specified site) and certain specified histologies
Note: basal cell and squamous cell carcinoma originating in skin of non-mucoepidermoid sites are not reportable.	
C44.00, C44.09	Unspecified/other malignant neoplasm of skin of lip
C44.10_, C44.19_	Unspecified/other malignant neoplasm of skin of eyelid
C44.20_, C44.29_	Unspecified/other malignant neoplasm skin of ear and external auricular canal
C44.30_, C44.39_	Unspecified/other malignant neoplasm of skin of other/unspecified parts of face
C44.40, C44.49	Unspecified/other malignant neoplasm of skin of scalp & neck
C44.50_, C44.59_	Unspecified/other malignant neoplasm of skin of trunk
C44.60_, C44.69_	Unspecified/other malignant neoplasm of skin of upper limb, incl. shoulder
C44.70_, C44.79_	Unspecified/other malignant neoplasm of skin of lower limb, including hip
C44.80, C44.89	Unspecified/other malignant neoplasm of skin of overlapping sites of skin
C44.90, C44.99	Unspecified/other malignant neoplasm of skin of unspecified sites of skin
D00._ -D09._	In_situ neoplasms *Note: Carcinoma in situ of the cervix (CIN III - D06) and Prostatic Intraepithelial Carcinoma (PIN III-D07.5) are not reportable*
D18.02	Hemangioma of intracranial structures and any site
D18.1	Lymphangioma, any site *Note: Includes Lymphangiomas of Brain, Other parts of nervous system and endocrine glands, which are reportable*
D32._	Benign neoplasm of meninges (cerebral, spinal and unspecified)
D33._	Benign neoplasm of brain and other parts of central nervous system
D35.2 - D35.4	Benign neoplasm of pituitary gland, craniopharyngeal duct and pineal gland
D42._, D43._	Neoplasm of uncertain or unknown behavior of meninges, brain, CNS
D44.3 - D44.5	Neoplasm of uncertain or unknown behavior of pituitary gland, craniopharyngeal duct and pineal gland
D45	Polycythemia vera

D46._	Myelodysplastic syndromes
D.47.02	Systemic mastocytosis
D47.1	Chronic myeloproliferative disease
D47.3	Essential (hemorrhagic) thrombocythemia *Includes: Essential thrombocytosis*
D47.4	Osteomyelofibrosis Includes: Chronic idiopathic myelofibrosis Myelofibrosis (idiopathic) (with myeloid metaplasia) Myelosclerosis (megakaryocytic) with myeloid metaplasia) Secondary myelofibrosis in myeloproliferative disease
D47.Z_	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue, unspecified
D47.9	Neoplasm of uncertain behavior of lymphoid, hematopoietic and related tissue, unspecified
D49.6, D49.7	Neoplasm of unspecified behavior of brain, endocrine glands and other CNS
D72.11	Hypereosonophilic syndrome [HES]
N85.02	Endometrial intraepithelial neoplasia [EIN]
R85.613	High grade squamous intraepithelial lesion on cytologic smear of anus (HGSIL)
R85.614	Cytologic evidence of malignancy on smear of anus
R87.614	Cytologic evidence of malignancy on smear of cervix
R87.623	High grade squamous intraepithelial lesion on cytologic smear of vagina (HGSIL)
R87.624	Cytologic evidence of malignancy on smear of vagina
R90.0	Intracranial space-occupying lesion found on diagnostic imaging of central nervous system

6. Casefinding for Physician/Provider Medical Practices

Casefinding is a systematic method of locating all potentially eligible cases to be reported to the New York State Cancer Registry (NYSCR). Casefinding identifies both new cases and cases that may have already been identified. They are entered into a tracking mechanism and those that are reportable are subsequently submitted to the NYSCR.

6.1 Casefinding Overview

A. Identify all reportable cancer cases diagnosed and/or treated in your office.
B. Use several sources of documentation (reports or logs) to identify all cases diagnosed and/or treated at the practice.
C. The NYSCR highly recommends that practices use a log to track cases identified and reported to the NYSCR. The NYSCR can provide template logs using MS Excel and MS Word. If preferred, the practice may create their own tracking system using the following recommended fields:
    i. Date of diagnosis
    ii. Date of visit
    iii. Hospital admission indicator (yes/no)
    iv. Hospital admission date
    v. Medical record number, if applicable
    vi. Patient's last name

vii. Patient's first name
viii. Date of birth (DOB)
ix. Type of cancer/primary site (origin of tumor)
x. ICD-10-CM diagnosis code
xi. Date submitted to NYSCR
xii. Reason not submitted to NYSCR
xiii. Comments

D. Casefinding procedures and case submissions should be routinely performed at time intervals determined jointly by the NYSCR and the medical practice. Typically, this will occur on a monthly or quarterly basis.
E. Ideally, the personnel involved in casefinding and reporting should be limited in number and familiar with reportable diagnoses.

6.2 Determining Which Patients to Report and When to Report

- Patients diagnosed and/or treated in the physician office setting with a reportable cancer (see section 5.1 above) who have not been admitted to the hospital as an *inpatient* to treat the same malignancy must be reported.
  - If hospitalization status is uncertain, the case must be reported.
- The case should be reported as soon as the first course of treatment has been started.
  - If there is a decision not to treat or a decision for active surveillance, the case must be reported.
- Cases do not need to be histologically confirmed (that is, confirmed by pathological analysis). If the physician/provider states the patient has cancer and/or the physician/provider is treating the patient for the malignancy, the case is reportable.
- If a patient is diagnosed with a different type of cancer or if a malignancy has transformed to a different diagnosis (e.g., transformation of myelodysplastic syndrome to acute leukemia), report the new tumor/malignancy to the NYSCR.

6.3 ICD-10-CM Codes That Identify Reportable Cancer Cases

Use the reportability lists provided in section 5.1 above for ICD-10-CM codes and thoroughly review all available medical information to determine reportability for specific diagnoses for each patient.

6.4 Examples of Reports/Logs That May Be Used for Casefinding

The ability to generate reports or logs electronically is ideal; however, this process can also be done by manual review of various logs. Obtaining reports/logs containing data fields listed in section 6.1.C. will assist in tracking cases that were previously identified and submitted.

The following are examples of logs that can be electronically generated or manually reviewed.

- Disease index that is created based on a range of ICD-10-CM diagnosis codes, and may include date of diagnosis, date of first visit, patient name, date of birth, Social Security Number, and the ICD-10-CM code.
- Billing reports that generate lists of procedures or treatments given to a patient such as bone marrow aspiration or chemotherapy. These reports might also include ICD-10-CM diagnosis codes.
- Laboratory testing logs that document tests performed or sent out for analysis such as tissue biopsies, bone marrow aspirations/biopsies, flow cytometry, genetic testing, and tumor markers. If such a log is not maintained, then individual reports of cancer-related testing that are returned from external laboratories must be reviewed and flagged for reporting.
- Appointment reports or books from which cases may be identified
- Chemotherapy treatment logs or books, if applicable

Use multiple logs for most comprehensive case identification. Select the reports/logs available within the medical practice that will identify cases most completely (e.g., disease index) or uniquely (e.g., laboratory test logs that identify tests like JAK2 mutation).

The NYSCR staff can assist in determining suitable casefinding procedures for the medical practice. For help, call the field representative assigned to physician reporting at (518) 474-0971.

6.5 Using the Tracking Log to Monitor Casefinding and Case Submission to the NYSCR

- A tracking log, either provided by the NYSCR or created by the practice, is important for documenting cases identified and submitted to the NYSCR.
    - Cases can be entered into an MS Excel spreadsheet for tracking purposes. The advantage of this system is the ability to use search functions to look for a specific patient on the list or to sort by a particular data field.
    - MS Word tables can be used electronically or on paper to track identified patients.
    - The medical practice may develop any system desired for tracking case identification and reporting; however, it is important to put a system in place that allows documentation of reporting (for efficiency and to avoid duplication of reporting) and documentation of why specific patients were not reported (e.g., determined not to be a reportable cancer or the patient was hospitalized for the malignancy).
- The following steps describe how to use the tracking log provided by the NYSCR.
    - All cases identified through reports/patient logs described in section 6.4 are recorded on the tracking log.
    - Medical records are reviewed for reportability, using section 5.1 above for assistance.
        - If the patient is determined not to have a reportable malignant condition, the case should not be reported. Enter the reason not reported in the “Reason Not Submitted to the NYSCR.”
    - Determine if the patient has been hospitalized as an *inpatient* for treatment of the same malignancy.

        - If the patient has been hospitalized as an *inpatient,* enter “Y” or “Yes” in the Hospital Admission (Hosp Admit (Y/N)) field, document the hospital admission date, and leave the date submitted field blank. This case does not need to be reported to the NYSCR.
        - If the patient has not been hospitalized as an *inpatient,* enter “N” or “No” in the Hospital Admission (Hosp Admit (Y/N) field. This case must be reported to the NYSCR.
        - If it is uncertain if the patient has been hospitalized, the case must be reported to the NYSCR.
    - If the case is reportable, detailed information about the patient, diagnosis, and treatment is entered in the Web-based application on the New York State Department of Health’s Health Commerce System
- The fields included in the NYSCR template were selected because they will help locate the patient record as well as assist in determining reportability by the physician office.
- The log is intended as a tool for tracking patients identified and reported and will be helpful to the practice reporter(s) in the event of an audit by the NYSCR.
- If the practice decides to use an electronic tracking log, it is recommended that it be backed up on a CD, external hard drive or network drive for preservation of work.

For assistance or any questions regarding casefinding, contact the New York State Cancer Registry at (518) 474-0971 and ask for a Physician Reporting field representative.

7. The Provider Cancer Case Reporting System

The Provider Cancer Case Reporting System is located within the NYSDOH’s Health Commerce System (HCS) and is used for submitting new cancer case reports or for responding to the NYSCR’s request for information on specific cancer patients (referred to as “followback” cases). A followback case is one in which a laboratory report indicated that the physician’s patient had a malignancy, but there is no record of the patient in the Cancer Registry data base. Because laboratory reports provide very little information, the Registry is requesting that the physician submit a complete case report.

An HCS account holder must be a NYS-licensed physician or associated with a NYS-licensed physician to use this site. For information on obtaining HCS accounts for physicians and their designated staff, please call the Cancer Registry at 518-474-0971.

When signing into the “Provider Cancer Case Reporting System” application from the main HCS page, the user might encounter the following screens:

<u>No License Information Available</u>

If the HCS user encounters this page, it indicates that the account is not associated with the HCS account of a NYS-licensed physician. Contact the NYS Cancer Registry by email using the link on the page or call the Registry at 518-474-0971.

Provider selection list

When an HCS user is associated with HCS accounts of multiple physician accounts, a list of the associated physicians appears. The number of pending cases for each physician also appears. Pending cases include followback requests awaiting physician response and any new cases that were started, and saved for future editing, but not yet submitted.

Specific provider page

This page begins the reporting process for a specific physician's patient. The user has the option of beginning a new case report, continuing with a new case report that was started and then saved for future editing, or responding to a laboratory only (LAB) followback request.

Followback status tab

This page appears for followback cases only. The user decides to complete a case report or selects one of the two displayed options containing reasons for no complete case submission. If the user plans to complete a case report, they will select the button next to "Case report will be completed" and clicks the Continue button. The Patient Information tab appears; this is the first of four pages to be completed. If the user selects a reason the case report will not be submitted, they must describe their reasoning in the text box, and click the Continue button. The case report will then be removed from their list.

Patient Information tab

This tab page, the first one of three needed for the case report, is used to enter patient information. (See 8.1, below, for more information.)

Type of Cancer tab

The type of cancer the patient has must be selected before continuing to the Cancer Information tab page. (See 8.2, below, for more information)

Cancer Information tab

Information about the specific cancer is entered under this tab page. The information collected varies slightly depending on the type of cancer; therefore, the numbers, which correspond to data fields, may not be continuous. (See 8.3, below, for more information.)

Treatment tab

Information about the treatment given for the reported malignancy (or the decision not to treat) is documented in this page. (See 8.4, below, for more information.)

When ready to submit the case, the user will click on Submit Case Report at the bottom of the Treatment tab. Once submitted, the user will be returned to the specific physician page and will see the message "Thank you. Case Report successfully submitted to the New York State Cancer Registry."

Navigation Tips

- When entering a case report, the user must click the Continue button to move forward from page to page.
- To return to a previous page, use the tabs located along the top of the form below "Provider Cancer Case Reporting System", and the providers name and license number.
    - For example, to go back to the Patient Information tab from the Treatment tab, click on "Patient Information" located on the bar.
- **Do not use the web browser's 'Back' button to move back to previous pages**.

- If it is necessary to exit before finishing a case report, click the 'Save and Exit' button located at the bottom of the Patient Information, Cancer Information and Treatment tabs.
    - This patient will appear in the patient selection list with the date last saved.
- Use the tab key or cursor to move from field to field, including the month, day, and year components of date fields.

When completing case reports, the Patient Information tab, the Cancer Information tab and the Treatment Tab must be filled in as completely as possible. To save the information entered at any time prior to submission, click the 'Save and Exit' button at the bottom of the page. The case can then be completed at a later time. After the case is submitted, it can no longer be edited. The next section provides more detailed explanations of the information collected on the form.

8. Data Fields and Descriptions

The number next to each field described below corresponds to the number found next to the field on the application data entry form. When using the Cancer Information tab, some fields might not be necessary for the specific cancer being reported and do not appear on the form.

The fields designated as "Required" – marked with an asterisk (*) -must be entered before submitting the case. The system returns "Error" notes indicting problems when a user attempts to submit without completing all required items, as well as other possible inconsistencies detected.

8.1 Patient Information Tab

1. First Name – Required
   Enter the first name of the patient. Hyphens, apostrophes and spaces are acceptable; numbers and special characters are not accepted and must not start or end with a space, dash, or apostrophe. Do not leave this field blank.

2. Middle Name
   Enter the middle name or initial of the patient. Hyphens, apostrophes and spaces are acceptable; numbers and special characters are not accepted and must not start or end with a space, dash, or apostrophe.

3. Last Name – Required
   Enter the last name of the patient. Hyphens, apostrophes and spaces are acceptable; numbers and special characters are not accepted and must not start or end with a space, dash, or apostrophe. Do not leave this field blank.

4. Suffix
   Enter suffix, if applicable.

5. Name - Birth Surname
   Enter the last name (surname) of the patient at birth, regardless of gender or marital status. Leave this field blank if it is not available in the record or if it is not appropriate for the patient being reported.

6. SSN
   Enter the 9-digit Social Security Number of the patient. Enter only digits. Do not use dashes.

7. Date Of Birth (mm/dd/yyyy) – Required
   Enter the exact date of the patient's birth using the template on the form for month, day and four-digit year. When the date of birth is unknown, but an age at the time of diagnosis is available, enter an estimated year of birth. Do not leave year of birth blank.

8. Sex – Required
   Select the sex of the patient. Do not leave this field blank.

9. Marital Status
   Select the marital status of the patient at the time the specific primary tumor was first diagnosed. If unknown, select "Unknown."

10. Hispanic Origin – Required
    Indicate whether or not the patient is Hispanic by selecting one of the listed ethnicity designations. Do not leave this field blank.

11. Race – Required
    Select the patient's race from the list. White includes Mexican, Puerto Rican, Cuban, Middle Eastern, North African and all other Caucasians. Asian includes Chinese, Korean, Vietnamese, Hmong, Japanese, Filipino, Indian, Pakistani, etc. If unknown, select "Unknown." Do not leave this field blank.

12. Birth Place
    Select the country of the patient's birth. If the birth place is unknown, select "Unknown."

13. Usual Occupation
    Enter the patient's usual occupation. The usual occupation refers to the type of job the individual performed during most of his/her working life prior to the diagnosis of this cancer, even if the patient is currently retired (e.g., teacher, accountant, homemaker). Do not enter "Retired." If unknown, enter "Unknown."

14. Industry
    Enter the patient's usual type of business or industry, such as education, manufacturing, retail, etc.

15. Primary Payer - Required
    Select the primary payer/insurance carrier type at the time of initial diagnosis and/or treatment. Do not leave this field blank.

16. Tobacco Use – Required
    Select the patient's past or current smoking use of tobacco (cigarette, cigar, and/or pipe). Do not leave this field blank.

17. Address 1 – Required
    Enter the number and street name of the patient's residence at time of diagnosis. Do not leave this field blank.

18. Address 2
    Enter the name of a place or facility (e.g., nursing home, name of an apartment complex, mobile home park) at the time of diagnosis, if applicable.

19. City – Required
    Enter the city at the time of diagnosis. Do not use punctuation, special characters, or numbers. Do not leave this field blank.

20. State – Required
    Select the state of residence at the time of diagnosis. Do not leave this field blank.

21. ZIP Code – Required
    Enter the ZIP code at the time diagnosis. Do not use hyphens. Do not leave this field blank.

22. County
    Select the county of residence at the time of diagnosis from the list. If the residence was not in New York, select "Out of State" which appears last on the list. If county is unknown, leave blank.

23. Vital Status
    Select whether the patient is alive or dead.

24. Date of Death
    If the patient has expired, enter the date of death as completely as possible. If unknown, leave blank.

25. Date of Last Contact
    Enter the date the patient last had contact with your office.

8.2 Cancer Type Tab

26. Type of Cancer – Required
    Select the type of cancer reporting from the displayed list:
    - Melanoma
    - Prostate
    - Leukemia
    - Lymphoma
    - Hematopoietic – Other (includes other hematopoietic malignancies such as polycythemia vera, myeloproliferative disorders, and myelodysplasia)
    - Other types of cancer (includes all other malignancies not categorized above)

8.3 Cancer Information Tab

Note that some of the fields are not necessary for the specific cancer being reported and do not appear on the form.

27. Name of Pathology Laboratory
    Enter the name of the pathology laboratory that examined the specimen.

28. Pathology Report/Bone Marrow
    Enter pertinent information from the final diagnosis or microscopic description from the pathology report, including anatomical location of tumor or information about the cells involved. Cut and paste of electronic reports is allowed; however, only 4000 characters, or about 700 words can be submitted. If too many characters are entered for the pathology report the text will be truncated; therefore, review text before using the "Continue" button or submitting the report

29. Diagnosis Date – Required
    Enter the date the diagnosis was first made, as precisely as possible. This might be the date of a clinical diagnosis, not necessarily the date of microscopic confirmation. If unknown, enter the four digit year of diagnosis and for month and day leave blank. Do not leave the diagnosis year blank.

30. Age at Diagnosis
    Enter the age of the patient at the time of diagnosis.

31. Primary Site of Cancer – Required
    Use all pertinent information in the medical record to select, from the drop-down list, the most specific description of the location of the cancer's origin. Do not select a metastatic site. When reporting an "Other type of cancer," the list is grouped by body system organs and structures. Do not leave blank. This field is not included on the prostate and leukemia modules.

32. Laterality of Primary Tumor – Required
    Select the side of the body where the cancer originated. For unpaired organs, such as the colon, select “Not a paired site.” For paired organs (e.g., breast, kidney, arm), select the side of the body where the tumor originated. If the right and left sides of paired sites come into contact and the tumor is at the point of contact, select “midline.” Do not leave blank. This field is not included on the prostate and leukemia modules.

33. Histology – Required
    Select from the drop-down list the histological type of cancer that most specifically and accurately describes the cancer as stated as the final diagnosis. This is frequently found in the "Final Diagnosis" or "Microscopic Description" section of a pathology report. Do not leave blank.

34. Behavior – Required
    Usually found in the pathology report, the behavior describes the invasiveness of the neoplasm. Behavior should be found in the medical record, particularly the pathology report, and can fall into one of the following categories:

    Malignant – invades surrounding tissues, invasion of the lamina propria, invasive, microinvasive, metastatic site
    In situ – malignant, but still growing in place, noninvasive, noninfiltrating
    Borderline – uncertain or low malignant potential
    Benign – the tumor is growing in place without the potential for spread. Only benign tumors of the brain or central nervous system are reportable.

    The following are examples of descriptions that indicate the tumor is in situ or noninvasive:

    - Clark level 1 for melanoma (limited to epithelium)
    - Hutchinson melanotic freckle
    - Intracystic or non-infiltrating
    - Intraepidermal, NOS
    - Intraepithelial, NOS
    - No stromal involvement
    - Involvement up to but not including the basement membrane

    This field is included on the Melanoma and Other Type of Cancer modules only.

35. Gleason Pattern
For prostate cancer, select the Gleason pattern as it is described in the pathology report or medical record. The pattern is based on the two most common cell score differentiations noted by the pathologist and add up to a maximum of 10. For the example: 4+3 = 7; the selection would be "Primary pattern 4, secondary pattern 3." If no needle core biopsy or TURP was performed or the pattern is unknown, use the appropriate selections located at the bottom of the drop-down list.

36. Gleason Score
For prostate cancer, select the Gleason score as indicated in the pathology report or medical record. The score is the sum of the two Gleason patterns and can range from 2 to 10. For the example: 4+3=7; the Gleason score is 7.

37. Last Pre-diagnosis PSA value (ng/ml)
For prostate cancer, enter to the nearest tenth (##.#) in nanograms/milliliter (ng/ml) the last pre-diagnosis PSA lab value prior to the diagnostic biopsy.

38. JAK2– Required (for hematopoietic module only)
Testing for the JAK2 (Janus Kinase 2) mutation is used primarily for myeloproliferative neoplasms (polycythemia vera, essential thrombocythemia, and primary myelofibrosis). However, this is a required field and must be completed for all malignancies reported using the hematopoietic module. Select the most appropriate description of the test from the list. Do not leave this field blank.

39. Source of Diagnostic Confirmation – Required
Select the most definitive method of diagnostic confirmation (starting from the beginning of the drop-down list) used for the cancer being reported. The following describe the items that may appear in the drop-down list:

Immunophenotyping and/or genetic studies + Pos Histology: histology is positive for cancer and there are positive immunophenotyping and/or genetic tests.
Positive histology (pathology): tissue is microscopically examined and confirmed.
Positive cytology: no tissue microscopically examined; fluid cells examined.
Microscopic confirmation: microscopic confirmation all that is known; unknown if cells were from histology or cytology.
Positive lab test/marker study: based on laboratory tests/marker studies which are clinically diagnostic for cancer.
Direct visualization without microscopic confirmation: noted by provider but no sample taken for microscopic analysis
X-ray/Scans without microscopic confirmation: reported by provider from an imaging technique report only.
Clinical diagnosis (other than above): reported by provider in the medical record.

Do not leave this field blank.

40. History of Another Primary Cancer
If the patient has a history of another primary cancer, enter the type and date of diagnosis for each primary cancer. Only 250 characters can be submitted. If this is the first primary cancer, leave field blank.

41. Size of Tumor (mm)

Enter the largest dimension or diameter in millimeters (mm) of the primary tumor which is usually best described in the pathology report. This field is a three-digit field, and leading zeros are acceptable. Do not enter decimal points. Refer to the chart below for assistance.

Examples:

Record shows 0.6 mm – Enter 001 (round 0.6 mm up to 1 mm)
Record shows 6.1 mm – Enter 006
Record shows 61 mm – Enter 061
Record shows 0.61 cm = 6.1mm – Enter 006
Record shows 6.1 cm = 061 mm – Enter 061
Record shows 61 cm = 610 mm – Enter 610

Enter	Description of Tumor Size
001	1 mm or described as "less than" 1 mm
002 - 988	Enter the exact size in mm (2mm to 988 mm)
989	989 mm or larger
990	Microscopic focus or foci only, no size of focus is given
999	Unknown; size not stated; not document in patient record

This field is included on the Prostate and Other Type of Cancer modules only.

42. Breslow Tumor Thickness/Depth of Invasion – Required for Invasive Melanomas

For melanoma, enter the depth of invasion (thickness, Breslow Measurement) in tenths of millimeters (mm). This field is up to a three-digit field. Refer to the chart below for assistance.

Examples:

Malignant melanoma 0.06 mm in depth – Enter 0.1 (round > 0.0 and < or = to 0.1 to 0.1)
Malignant melanoma 0.6 mm in depth – Enter 0.6
Malignant melanoma 6.0 mm in depth – Enter 6.0
Malignant melanoma 60 mm in depth – enter 60.0
Malignant melanoma – unknown depth – enter XX.9

Enter	Description of Tumor Depth
0.1	Greater than 0.0 and less than or equal to 0.1
0.2-99.9	Enter the exact size in **tenths** of mm (0.2 – 99.9 mm)
XX.9	Unknown; size not stated; not document in patient record

43. Ulceration

Melanoma ulceration is the absence of an intact epidermis overlying the primary melanoma. Select "Ulceration present," if stated in pathology report. If there is no documentation or mention of ulceration in the pathology report, assume ulceration is not present.

44. Tumor Extension

Choose the most appropriate selection that describes the farthest contiguous growth (or extension) of the primary tumor.

This field is included on the Prostate and Melanoma modules only.

45. Regional Lymph Node Involvement

Choose the most appropriate selection to describe the regional lymph node involvement at the time of diagnosis. Do not describe metastasis to distant lymph nodes in this field.

This field is included on the Prostate and Melanoma modules only.

46. Metastases at Diagnosis
    Choose the most appropriate selection to describe the distant metastasis at diagnosis, including distant lymph nodes. If the primary cancer has not metastasized, select the drop-down choice that indicates no metastases/none.

    This field is included on the Prostate and Melanoma modules only.

47. Stage at Diagnosis
    Choose the most appropriate selection to describe how far the cancer has spread from its point of origin. This field is only present on the Other Cancers module.

48. Clinical TNM Stage of Disease
    For each (T, N, M, TNM Stage), select the clinical TNM categories that are stated in the patient's medical record, or if no TNM staging is found, leave blank. If it is unknown whether TNM is clinical (determined by palpitation or imaging) or pathologic (which is usually determined after surgical intervention), report under clinical.

49. Pathologic TNM Stage of Disease
    For each (T, N, M, TNM Stage), select the pathologic TNM categories that are stated in the patient's medical record, or if no TNM staging is found, leave blank. If it is unknown whether TNM is pathologic (which is usually determined after surgical intervention), report under clinical (field 48).

8.4 Treatment Information Tab

50. Summary Treatment Status – Required
    Select whether the patient is being managed by active surveillance / watchful waiting, received treatment, or there was a decision for no treatment. When indicating treatment was given, be sure to enter either surgery text or other treatment information. Do not leave this field blank.

51. Date Treatment First Began
    Enter the date on which cancer-directed treatment began (surgery, radiation, chemotherapy or any other systemic therapy). This includes the *date of decision* for active surveillance / watchful waiting or for no treatment.

52. Type of Biopsy
    Select the type of biopsy performed to diagnose the patient (none, biopsy of primary site, or biopsy of metastatic site).

53. Surgery of Primary Site
    Describe the type of cancer-directed surgery performed on the primary site. Include a biopsy that removes the entire tumor and/or leaves only microscopic margins (i.e., "excisional biopsies"). Only 4000 characters allowed. An error message will occur after clicking the Continue button if more than 4000 characters were entered.

54. Surgery Date
    Enter the date of the primary site surgery. Enter month and day with two digits and year as four digits, using the template on the form.

55. Reason for No Surgery
    If the patient had cancer-directed surgery, select “Surgery primary site performed.” If the patient did not have cancer-directed surgery, select the applicable reason from the drop-down list.

56. Regional Lymph Node Surgery
    Select the phrase that best describes the removal, biopsy or aspiration of regional lymph nodes (LN) at the time of the primary site surgery or during a separate surgical event.

57. # Lymph Nodes Positive
    Enter the number of positive lymph nodes. The number of positive lymph nodes must not be greater than the number of lymph nodes examined.

58. # Lymph Nodes Examined
    Enter the number of lymph nodes examined. The number of lymph nodes examined must not be less than the number of lymph nodes positive.

59. Surgery of Other Sites
    Select the best description of tissue(s) or organ(s) removal other than the primary tumor or organ of origin. This does not apply to any tissue or organ removed in continuity with the primary tumor.

60. Radiation Therapy
    If radiation therapy was given as part of first course of treatment, enter the date treatment was initiated and the type of radiation therapy given as part of the initial treatment for the reportable tumor from the drop-down list.

61. Reason for No Radiation
    If radiation was given, select "Radiation therapy given," otherwise, select the reason radiation was not given.

62. Chemotherapy
    If chemotherapy was given as part of the first course of treatment, enter the date it was initiated and the type of chemotherapy from the drop-down list, otherwise select the reason chemotherapy was not given.

63. Immunotherapy
    If immunotherapy was given as part of the first course of treatment, enter the date it was initiated and that immunotherapy was given from the drop-down list, otherwise, select the reason immunotherapy was not given.

64. Hormone Therapy
    If hormone therapy was given as part of the first course of treatment, enter the date it was initiated and that hormone therapy was given from the drop-down list, otherwise select the reason hormone therapy was not given.

65. Comments
    Use this space to provide any additional information such as hospitals or other treatment facilities/providers or other relevant comments that are not collected elsewhere. This field is limited to 4000 characters.

If you have questions related to cancer reporting, please contact the NYSCR at 518-474-0971.

Appendix A

NYS Public Health Law

Section 1. Short title.
This act shall be known and may be cited as the “Cancer Research Improvement Act of 1997".

Section 2. Section 2401 of the public health law is amended to read as follows:

Article 24. Title 1.

§ 2401. Cancer; duty to report

1. Every physician, dentist and other health care provider shall give notice immediately but not later than one hundred eighty days of every case of cancer or other malignant disease coming under his or her care, to the department, except as otherwise provided.

2. Whenever an examination of a tissue specimen in a laboratory discloses the existence of cancer or other malignant disease, the person in charge of such laboratory or the person making such examination shall immediately but not later than one hundred eighty days report the same together with all the facts in connection therewith to the department.

3. The person in charge of every cancer reporting facility shall immediately but not later than one hundred eighty days give notice of every case of cancer or malignant disease coming under the care of the institution to the department.

4. All abstracting work performed by a cancer reporting facility pursuant to the reporting provisions of this section shall be performed by a certified tumor registrar. Cancer reporting facilities may establish consortia to engage a certified tumor registrar to perform the reporting requirements of this section. A "certified tumor registrar" is an individual certified by a nationally recognized not-for-profit organization which certifies tumor registrars. The provisions of this subdivision shall not apply to any cancer reporting facility which renders services for one hundred or fewer cases of cancer and malignant disease per year as determined by the commissioner.

5. The department shall establish and update as necessary a manual designating which specific data elements shall be reported to the department pursuant to this section. The department shall make such manual available to every cancer reporting facility, physician, dentist and other health care provider required to comply with the provisions of this section.

6. The department shall establish and update as necessary a data dictionary to standardize information interpretation of data elements reported by cancer reporting facilities and other health care providers. The department shall make such dictionary available to every cancer reporting facility, physician, dentist and other health care provider required to comply with the provisions of this section.

7. The department shall, to the extent funds are made available, establish or contract for regional training programs to provide training to any cancer reporting facility, physician, dentist or other health care provider required to comply with the provisions of this section. Such regional training programs shall provide training relating to the specific data elements which must be reported pursuant to this section, the data dictionary established pursuant to this section, and any other subjects which are intended to ensure quality, timely and complete compliance with this section.

8. The department shall, meet cancer registry goals established by a nationally recognized central cancer registry organization unless any such goal is contrary to any provision of law.

9. Where a cancer reporting facility fails to comply with the provisions of this section, the department may elect to perform registry services for such facility. Such cancer reporting facility shall reimburse the department for actual expenses incurred.

10. A physician, dentist, laboratory, cancer reporting facility or other health care provider which violates any provision of this section shall be subject to a civil penalty as provided in section twelve of this chapter.

11. The notices required by this section shall be upon forms supplied by the commissioner and shall contain such information as shall be required by the commissioner.

12. For the purpose of this section, a "cancer reporting facility" means a hospital as defined in article twenty-eight of this chapter, clinic or any organization certified pursuant to article forty-four of this chapter, or other similar public or private institution.

13. The commissioner shall have the power to promulgate any such rules and regulations as shall be necessary and proper to effectuate the purposes of this section.

§ 2401-a. Reporting

Annual report. The commissioner shall, submit an annual report to the governor, the temporary president of the senate and the speaker of the assembly. The report shall include an evaluation of the cancer registry as it relates to timeliness, quality and completeness; an evaluation of the utility of the registry for scientific research; an evaluation of the access, timeliness and quality of reporting information to researchers and other similar individuals; an evaluation of the registry's data elements, including treatment, stage of disease, occupation and residence; an evaluation of the feasibility and utility of inclusion of occupational history and residence history; and an evaluation of integrating the registry with other data bases maintained by state agencies and departments, including the statewide planning and research cooperative system.

Quarterly report. The commissioner shall submit a quarterly report to the governor, the temporary president of the senate and the speaker of the assembly. The quarterly report shall include an evaluation of whether the registry is achieving cancer registry goals established by a nationally recognized central cancer registry organization, including numerical goals concerning timeliness, quality and completeness.

Skin cancer reporting. The department shall annually submit a written report to the governor and the legislature on the incidence of skin cancer in the state of New York, by type and as a percentage of the overall number of reported cases of all types of cancer, as well as the associated causes of each type of skin cancer, if such causes are readily ascertainable. Such report shall be generated based on data gathered and reviewed pursuant to this title, and shall provide information which is as current as practicable; provided, however, a retrospective of the past ten years of information collected pursuant to this title and predominant trends associated with such information, as concerns skin cancer and its associated causes, shall be a component of such report and each report submitted thereafter.

At the discretion of the commissioner, such reports may provide additional information other than the information required by this subdivision. The first report created pursuant to this subdivision shall be submitted one year after the effective date of this subdivision. The reports generated pursuant to this subdivision shall be made available to the public on the department's website.

§ 2402. Cancer; reports confidential.

The reports of cancer cases made pursuant to the provisions of this article shall not be divulged or made public so as to disclose the identity of any person to whom they relate, by any person, except in so far as may be authorized in the sanitary code.