

# **New York State Cancer Registry Data Release and Policy Manual**

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## II. Background

The New York State Cancer Registry is a program of the New York State Department of Health (NYSDOH). Cancer is a reportable disease in every state in the United States. In New York State (NYS), [Public Health Law Section 2401](#) requires that all physicians, dentists, laboratories, and other health care providers notify the Department of Health of every case of cancer or other malignant disease. Through the Cancer Registry, the Department of Health collects, processes and reports information about New Yorkers diagnosed with cancer.

Cancer Registry data are routinely used by programs within the Department of Health, county and local health departments, patient advocacy groups, public interest groups, researchers, and the public. The data are used for public health planning and evaluation as well as for research. Because the Registry has collected statewide data since 1976, Registry data can be used to monitor cancer incidence patterns and trends for all areas of NYS. The NYS Cancer Registry publishes updated information annually on cancer incidence by characteristics including age, sex, race, ethnicity, and geographic region.

The NYS Cancer Registry also plays an important role in research to identify the causes of cancer. Researchers often request linkages of cohort data with Cancer Registry data, to identify or confirm cancer diagnoses and to examine associations between exposures available for their cohort and cancer incidence or mortality. Researchers may also use the data collected by the Cancer Registry to identify cancer patients who could be interviewed about possible exposures they had before they were diagnosed with cancer. These can be compared to interviews among people without cancer to determine if cancer patients had different exposures. Registry data are also linked to other data sources such as hospital discharge files to evaluate health services.

New York participates in the Centers for Disease Control and Prevention's (CDC) [National Program of Cancer Registries \(NPCR\)](#) and in the [Surveillance, Epidemiology, and End Results \(SEER\) program](#) of the National Cancer Institute (NCI). The NYS Cancer Registry also participates in the [North American Association of Central Cancer Registries \(NAACCR\)](#) certification process. The NYS Cancer Registry has received gold-level certification consistently since 1998, which reflects measures of data quality including overall completeness, the percent of cases with information on key data items, the prevalence of unresolved duplicates, and the percent of cases reported from death certificates only.

This document provides information on the procedures for the release of Cancer Registry data for research and other purposes. All research studies using identifiable or potentially identifiable patient information must be reviewed and approved by an Institutional Review Board (IRB) before study initiation.

## III. Confidentiality of Data

All information reported to the NYS Cancer Registry is confidential, and strict procedures are in place to protect patient privacy. For example, access to the Registry offices is restricted and all employees are trained in handling confidential information. State law limits use of confidential data for research. All research studies involving data with patient identifiers must be reviewed by an IRB, which protects patient privacy and ensures informed consent. Statistics for areas smaller than the county level are only released when there are enough cases in the area to guard against revealing confidential information about individuals. Researchers who propose a study using identifiable or potentially identifiable patient data must follow all procedures for ensuring the confidentiality of the data. Additional information on these

procedures is provided below in Section IV on Requests for Data for a Research Project.

## **IV. Requests for Non-Confidential Aggregate, Tabular, or Statistical Data**

The NYS Cancer Registry publishes cancer statistics, including incidence and mortality data for the most recent available five-year time period and detailed data for certain geographic regions, on the [website](#). For data not already available on this website, researchers can access the [New York State Public Access Cancer Epidemiology Data \(NYSPACED\)](#) and use these data with SEER\*Stat, a program available at no cost from NCI's [Surveillance, Epidemiology and End Results](#) (SEER) program web page. The NYSPACED data files contain carefully selected data items and are a resource for researchers who are interested in the patterns of cancer incidence by county in NYS or by neighborhood in New York City (NYC). The NYSPACED data sets balance the need to protect patient confidentiality with the needs of researchers and planners. As a SEER Registry, NYS Cancer Registry data are also included in SEER public use data, which can be accessed through the SEER program web page and used with SEER\*Stat software.

Researchers should contact the NYS Cancer Registry at [nyscr@health.ny.gov](mailto:nyscr@health.ny.gov) if they need aggregate, non-confidential data that are not available in the NYSPACED or SEER data sets or in the dashboards on the [NYS Cancer Registry website](#). See below for additional information on data availability, the timeline and fees for data requests, and guidelines for citing the data source for NYS Cancer Registry data.

### **A. Data Availability**

The NYS Cancer Registry will release aggregate, de-identified data when requested for research or planning purposes, without review by an IRB. Small cell counts may be suppressed or combined with another category to maintain patient confidentiality. Geographic areas smaller than county will only be released when there is enough data to not compromise patient confidentiality. This determination will be made by the NYS Cancer Registry. Researchers requesting data not available on the NYS Cancer Registry website should provide information on the data variables requested, information on any geographic areas of interest, and the planned use of the data.

### **B. Timeline and Fees for Data Requests**

Requests for aggregate, tabular, or statistical data will usually be completed within 4 weeks of the request date. Detailed requests or frequent requests for data will result in a charge for Cancer Registry services. Additional information on fees can be obtained by sending information on the data needed to [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov).

### **C. Guidelines for Citing Data Source**

Publications, presentations, and reports using data from the NYS Cancer Registry should acknowledge or cite the Cancer Registry data source. The suggested citations for aggregate data available on the [New York State Cancer Registry website](#) and the [NYSPACED data set](#) are noted

at the bottom of each web page. Aggregate data provided by the Cancer Registry through a data request should be cited using the following format: "Cancer <incidence or mortality> data were provided by the New York State Cancer Registry, New York State Department of Health, <date>."

## V. Requests for Data for a Research Project

Researchers interested in using de-identified or identifiable case-level data from the NYS Cancer Registry for a research project should contact the Cancer Registry by email at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov) to schedule a time for an initial discussion of the project's feasibility and timeline. Researchers should discuss their proposed project with Cancer Registry staff prior to completing any of the steps detailed below, to avoid unnecessary work and to ensure that the proper steps are followed for each proposed project. If the proposed study appears to be feasible, the researcher should request a letter of support for inclusion in funding agency applications. A letter of support does not guarantee that an application will be approved by the NYSCR Internal Peer Review Committee or that cases will be available for patient contact studies. Please note that proposals to use NYS Cancer Registry data in a funding application require approvals from the NYSDOH; **researchers should contact the Cancer Registry at least six weeks before their institution's internal due date** to allow sufficient time for budget preparation and NYSDOH approvals.

### A. Initial Form Submission: Request to Use New York State Cancer Registry Data in a Proposed Research Project

After contacting the Cancer Registry but before obtaining funding, researchers should complete and submit the NYSCR [Research Project Request form](#), which can be obtained by emailing the Registry at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov). This form helps the Registry to track information on research proposals including the project's Principal Investigator and the details of the project. This form should also be used to request a letter of support from the Scientific Director of the NYS Cancer Registry. If requesting a letter of support, please submit the form **at least four weeks before the letter is needed**. See the sections below for information on the approval process for requests to use Cancer Registry data, by type of data requested, and guidelines for requesting and using the data.

### B. Requests for De-Identified Case-Level Data

Identifiable data include: data that contain direct identifiers (e.g., names, dates of birth, addresses, telephone numbers); or record-level data that do not contain any personal identifiers but that contain a unique patient ID that would allow the investigator to identify the individual; or, record-level data that contain a large number of variables that in combination or through linkage to publicly available data could lead to the identification of individuals; or tabulated data for small geographic areas that also include sociodemographic information that could lead to the identification of individuals. Data that do not meet any of these criteria are considered de-identified case-level data.

Requests for de-identified case-level data should include information on the variables needed and the planned use of the data. Requests that are determined to involve no identifiable information will be reviewed by the NYSCR Internal Peer Review Committee. Researchers must attest that they will not attempt to learn the identity of any person whose cancer data is included in the data

file, and that if the identity of any person is discovered inadvertently, they will not use the information on the patient's identity and will report the incident to the NYS Cancer Registry as soon as possible but no later than two business days after the incident occurs. Researchers should refer to sections H through L below for additional information on requesting and using Cancer Registry data. For requests that involve any identifiable information, please see section C below on requests for identifiable case-level data without patient contact.

### C. Requests for Identifiable Case-Level Data Without Patient Contact

Requests for data meeting any of the criteria for identifiable data listed in section B above are considered identifiable case-level data. NYS does allow disclosure of identifiable cancer information for government-sponsored surveillance or research activities and for some other research. Disclosure of confidential, identifiable cancer information for research is subject to the following conditions: 1) NYSDOH determines that substantial knowledge may be gained by such disclosure, leading toward the reduction of morbidity and mortality; and 2) NYSDOH determines that the confidentiality of patient identity will be maintained.

Requests for identifiable case-level data that meet all of the following criteria will be reviewed by the NYSCR Internal Peer Review Committee: 1) The Principal Investigator is from an academic or other type of research institution; 2) the study has been peer-reviewed; 3) the study has received local or central IRB approval; and 4) data provided by the NYS Cancer Registry will not lead to either patient contact or to a request for patient medical records. Studies that do not meet all of these criteria may require additional NYSDOH consideration including review by the NYSDOH IRB. Researchers should refer to sections G through L below for additional information on the NYSDOH IRB approval process and the procedures for requesting and using Cancer Registry data. For requests that include patient contact, see section F below on requests for identifiable case-level data with patient contact.

### D. Requests for Data Linkages Without Patient Contact

Data linkage is a process to determine whether a record in one file matches one or more records in another file. Both data files must have common variables such as name, date of birth, sex, maiden name, social security number, and address. The NYS Cancer Registry uses the NCI's Match\*Pro software to perform data linkages. Below is additional information about the process for requesting data linkages with NYS Cancer Registry data.

#### *i. Virtual Pooled Registry Cancer Linkage System*

The [Virtual Pooled Registry Cancer Linkage System \(VPR-CLS\)](#) allows researchers to conduct a minimal-risk data linkage of their research cohort with multiple US-based cancer registries after obtaining IRB approval from their institutional IRB and a centralized VPR-CLS IRB. This minimizes the need for researchers to obtain a separate IRB approval from each state with which they wish to conduct a linkage. Researchers interested in conducting a VPR-CLS linkage with multiple registries including the NYS Cancer Registry should follow the application process on the North American Association of Central Cancer Registries (NAACCR) [VPR-CLS website](#).

#### *ii. Data Linkages With the NYS Cancer Registry Only*

The NYS Cancer Registry conducts record linkages for epidemiological studies that have

been approved by the NYSCR Internal Peer Review Committee. There is a fee for linkage that is based on the size of the cohort and the staff time required. Registry records that can be matched include all individuals with reported cancer diagnosed since January 1, 1976. Cases diagnosed in recent years can be matched once the data for that year are considered provisionally complete, which occurs approximately two years after the end of the calendar year in which the cancer was diagnosed. This time lag in data availability is necessary to allow reporting facilities sufficient time to record and report the case and to allow the NYS Cancer Registry sufficient time to validate and consolidate cancer reports, including reports of cancers first identified on death certificates. Researchers who are interested in conducting a data linkage of their research cohort with the NYS Cancer Registry only, instead of with multiple cancer registries through the VPR-CLS, should contact the Registry by email at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov).

### iii. *Data Linkages With Additional New York State Department of Health Data Sets*

Researchers interested in linking NYS Cancer Registry data with other NYSDOH data sets, such as the [Statewide Planning and Research Cooperative System \(SPARCS\)](#) inpatient and outpatient data or Vital Records data, should follow the request procedures for each data set of interest. The NYS Cancer Registry can conduct linkages with these data sets only after all required approvals have been obtained from the owner of each data set. For studies that involve linking NYS Cancer Registry data to another NYSDOH registry or database, the study must go through additional NYSDOH approvals as determined by the respective programs.

## E. Requests for Cancer Data With Mortality Information

The NYS Cancer Registry routinely links cancer data with vital records data to obtain vital status and the cause and date of death for deceased cancer patients. Aggregate data on cancer mortality rates for the most recent available five-year time period are published on the [NYS Cancer Registry website](#). The mortality data come from two separate registration districts – NYC and NYS exclusive of NYC – and are provided by the Vital Records Office of the NYC Department of Health and Mental Hygiene and the Vital Records Office of the NYSDOH.

To obtain case-level cancer data containing mortality information (other than vital status) for use in a research study, researchers must obtain approvals from the [Vital Records Office of the New York City Department of Health and Mental Hygiene](#) for NYC data, and from the [Vital Records Office of the NYSDOH](#) for data for areas of NYS outside of NYC. Exact date and cause of death are only released to researchers who have obtained proper approvals.

Publications, presentations, and reports using mortality data from the Vital Records Office of the NYC Department of Health and Mental Hygiene and/or the NYSDOH should acknowledge or cite the source of these data, in addition to citing the Cancer Registry data as noted in section L below. The suggested citation for mortality data received from a Vital Records Office is: “Cancer mortality data were provided by the Vital Records Office of the New York City Department of Health and Mental Hygiene and the Vital Records Office of the New York State Department of Health, <date>.”

## F. Requests for Identifiable Case-Level Data With Patient Contact

The NYS Cancer Registry periodically receives proposals for research involving patient contact, where the goal is to obtain additional information about individuals diagnosed with cancer in NYS. This research has the potential to improve the health of individuals with cancer and/or further our knowledge about factors that contribute to cancer incidence. This process will include physician notification for recent diagnoses with an option for the physician to decline contact of their patient regarding the study, followed by patient notification with an option to decline further contact about the study. If the patient does not decline or does not respond to the letter, their name, contact information, and minimal diagnostic information will be securely shared with the study's primary investigator. This will allow the researcher to contact the patient to request their participation and to obtain consent. If a letter is returned because of an incorrect address, NYS Cancer Registry staff will search for an updated address and will send a new letter if another address is available. If no other address is available and the patient cannot be reached, the patient will be excluded from the study and their information will not be shared with the study's primary investigator. This will ensure that all patients have the opportunity to decline further contact before their information is shared with the study researchers. The NYS Cancer Registry also participates in studies where the Registry directly enrolls eligible study participants.

Researchers who are interested in conducting a research study involving patient contact should contact the NYS Cancer Registry by email at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov) to discuss the project requirements and timeline. Researchers should note clearly in the email that it is a patient contact study and they should allow sufficient time for this discussion before drafting their application for funding, to ensure the Cancer Registry will have the data and personnel needed to conduct the study. After discussing the study details with the Cancer Registry, researchers should **allow at least six weeks before their institution's internal due date** for budget and NYSDOH approvals.

After obtaining funding, the study protocol and materials must be reviewed by the NYS Cancer Registry, NYSDOH, and the NYSDOH IRB prior to the initiation of any patient/proxy contact. In addition, researchers must follow all NYSDOH procedures in conducting their study, including the following procedures:

1. All written materials must include contact information for people who can answer questions about the research and participant rights.
2. Patient/proxy consent to participate must be obtained.
3. If a patient or their proxy asks to be removed from current and future research studies, this information must be sent within one week to the NYS Cancer Registry, so that the patient's record can be flagged and the patient added to a "Do Not Contact" list.
4. Researchers must immediately report any complaints about the study or the release of patient information to the NYSDOH site PI, who will report the complaint to the Scientific Director of the NYS Cancer Registry and to the Administrator of the NYSDOH IRB as needed.
5. If changes are made to any recruitment materials or processes after NYSDOH departmental and IRB approval, an IRB amendment must be submitted and approved before the changed materials may be used.

Researchers should refer to sections G through L below for additional information on the NYSDOH IRB approval process and the procedures for requesting and using Cancer Registry data.



## G. Institutional Review Board (IRB) Approval Process

Research studies using confidential, case-level NYS Cancer Registry data and meeting any of the following criteria must be reviewed by the NYSDOH IRB:

- The study involves patient contact or a review of medical records as a result of information obtained from the Cancer Registry. This includes linkage studies involving patient contact where the cancer diagnosis is identified using Cancer Registry data.
- The study is sponsored or conducted by pharmaceutical or other industry.

Researchers should contact the NYS Cancer Registry to begin the IRB submission process as soon as possible after a study is funded, to help to minimize delays in beginning the research. The NYSDOH IRB requires that the study also be approved by the Principal Investigator's institutional IRB. For multi-institutional research projects, the NYSDOH IRB requires that the study be approved by a single centralized IRB, in accordance with the revised Common Rule. For these studies the NYSDOH IRB will conduct an administrative review.

## H. Completing the Research Project Request Form

Prior to requesting Registry data for an approved research project, researchers should complete and submit the Research Project Request Form. This form can be obtained by emailing the Registry at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov). For research studies, this form should be submitted after receiving funding and IRB approval, but before requesting any data. This form helps the Registry to track ongoing research projects, data provided for each project, and the status of each project.

### **Suggested Contents of Research Proposal:**

- 1) Title of the Project
- 2) Name of the funding agency and the funding period
  - a) If unfunded, please document.
- 3) Grant/contract number, if applicable
- 4) IRB Status/Documentation
  - a) Provide Consent Documents for Review
- 5) Description of the study
  - a) Include years of diagnosis requested
  - b) Include primary cancer sites or other tumor characteristics
- 6) Background and Objectives
- 7) Methodology
  - a) Research Design
    1. Eligibility Criteria
  - b) Data Analysis Plan
    1. Including comparison group as applicable
    2. Description of how the registry's data will be used
    3. List of Requested Data Items (with NAACCR or registry-specific identifiers)
      - a. Including justification for need of sensitive or potentially identifying data items.
- 8) Project Timeline
- 9) Description of physical and policy safeguards to protect data
- 10) Description of data destruction protocol/plan
- 11) Study personnel: description of the study team's staffing and expertise to complete project

## I. Data Use Agreement

Before receiving case-level Registry data, the Principal Investigator for a research study will be required to read and sign a Research Data Use Agreement. This contract describes limitations on the use of the data, as well as restrictions on the dissemination of findings, use of personal identifiers, and contact with patients identified through data provided by the NYS Cancer Registry.

All staff working with confidential data, or with possible access to confidential information from the data, are required to have current IRB training certification and to sign a Confidentiality Pledge. The most recent versions of the Data Use Agreement and Confidentiality Pledge should be obtained by emailing the NYS Cancer Registry at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov).

## J. Timeline and Fees for Data Requests

The NYS Cancer Registry reserves the right to charge fees for the time and resources involved in processing data requests. The Registry will notify the researcher prior to fulfilling the request if fees will be assessed. In general, there will be no charge for data requests for cancer incidence information that can be completed in less than two hours. Detailed requests will usually result in a fee for NYS Cancer Registry services.

Research projects involving patient contact using NYS Cancer Registry data will require a budget for Cancer Registry services as part of the funding application. Researchers should contact the NYS Cancer Registry **at least six weeks before their institution's internal due date** to allow sufficient time for budget preparation and NYSDOH approvals.

The timeline for the Registry's filling of data requests depends on the complexity of the request, the number of other requests received, and the availability of staff to complete the request. Researchers should discuss the expected timeframe with the NYS Cancer Registry during initial conversations about the project, data requirements, and timeline.

## K. Data Use and Data Destruction Guidelines

Researchers must agree to maintain the confidentiality of identifiable data received from the NYS Cancer Registry. Identifiable data include any information that would permit directly or indirectly, the identification of any individual. When applying to use the data, researchers should indicate how the data will be stored as well as how and when they will dispose of the data after the study is completed. In addition, researchers must attest that: 1) no data will be published or released in any form where a particular individual or establishment is directly or indirectly identifiable; 2) identifiable data obtained from the NYS Cancer Registry will be used only for the proposed study; 3) identifiable information obtained from the NYS Cancer Registry will not be released to anyone or any institution without prior written approval by the NYSDOH; and 4) any publication or report produced using the data will acknowledge the source of the data. In the event of a breach of confidentiality, researchers must notify the Scientific Director of the NYS Cancer Registry as soon as possible but no later than two business days after learning of the breach. For more information, see the [NYSCR Security Guidelines](#).

## L. Guidelines for Citing Data Source

Any person or organization reporting results or analyses using NYS Cancer Registry data should include a statement acknowledging the data source in the presentation, report, or publication. A

suggested citation for Registry data is: “Data source: New York State Cancer Registry, New York State Department of Health, <date>.” Other data obtained from the NYSDOH or NYC Department of Health and Mental Hygiene should also be appropriately acknowledged in any presentation, report, or publication that includes the data.

#### M. Amendments to Applications

An amended application is required in cases where the requestor is making changes to a previously approved application. Changes that require an amendment include:

- Changes in Project Director
- Change of requesting organization
- Change in location of data storage or use
- Change to the project research scope or addition of new research scope
- Change in type of requested data files, changes in years of requested data files, or if you are requesting additional data elements
- Any other major change in the application

Please contact the NYSCR with any questions regarding project amendments. To request an amendment to an approved application, complete the NYSCR Amendment Form, which can be obtained by emailing [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov). Send the completed application to [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov).

#### N. Annual Reviews

The data use is subject to annual review by the registry. The PI will need to submit an annual review report by emailing the Registry at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov). A reminder for annual review will be sent at least 30 days before it is due.

#### O. Questions or Requests for Additional Information

For any questions or additional information regarding requests for NYS Cancer Registry data for a research project, please contact the Registry by email at [BCERDU@health.ny.gov](mailto:BCERDU@health.ny.gov).

## VI. Concerns Regarding Unusual Patterns of Cancer

The NYSDOH responds to concerns about cancer in communities. The following website describes the approach taken and what to expect when contacting the NYSDOH with concerns about cancer: [Concerned About Cancer in Your Community?](#)

To speak with someone from the Department of Health about cancer concerns, please send an email to [canmap@health.ny.gov](mailto:canmap@health.ny.gov). Please include a brief description of your concern, your name, and a daytime telephone number where you can be contacted.

## **Appendix- NYSCR Security Guidelines**

## NYSCR Data Security Guidelines

The New York State Department of Health (NYSDOH) places a high priority on protecting the data contained within the New York State Cancer Registry (NYSCR) data system.

This document identifies the NYSCR security guidelines that must be adhered to by the recipient(s) of NYSCR data and is applicable to cloud, on-premises, and hybrid environments. NYSDOH reserves the right to request information to confirm compliance with the attested security provisions, and to make updates or changes to these provisions at any time.

Data recipients shall attest annually to continued compliance with NYSCR Security Guidelines and that the data provisioned is still required for the approved project or use case. Data recipients that fail to maintain compliance or attest may have their permission to NYSCR data rescinded consistent with NYS regulations.

Security Provision
1. NYS DOH requires organizations and individuals requesting NYSCR data at a minimum adhere to <a href="#">NYS Encryption Standard (NYS-S14-007)</a> .
2. NYSCR data must be encrypted in transit using Transport Layer Security 1.2 or later. NYSCR data shall remain encrypted at rest using federally approved AES-128 or higher encryption.
3. If a stand-alone system is used, it will have an encrypted hard drive, have no access to or from the Internet, exist in a secure location (such as a locked office), be accessible only to authorized individuals, use strong password protection, and be locked after a maximum inactivity period of 15 minutes per <a href="#">NYS Account Management/Access Control (NYS-S14-013)</a> .
4. The storage system (cloud or on-premises) will be able to generate an immutable log of unique IDs that access the data, from what location if available, and the dates and times. Logging must comply with <a href="#">Microsoft Word - NYS-S14-005 Security Logging</a> . This audit log will be presented to the Department, within a reasonable time, upon request.
5. Remote connections will occur over a VPN when possible and comply with the <a href="#">NYS Encryption Standard (NYS-S14-007)</a> .
6. If using a local workstation to access the data, it will be connected to the network from a secure location, be accessible only to authorized individuals, use strong password protection, and be locked after a maximum inactivity period of 15 minutes per <a href="#">NYS Account Management/Access Control (NYS-S14-013)</a> .
7. NYSCR data shall not be stored on removable media (i.e., CDs, thumb drives, or other external storage devices), unless approved by the Internal Peer Review Committee. If approved, the device will be encrypted using a FIPS approved algorithm. Refer to <a href="#">NYS Encryption Standard (NYS-S14-007)</a> . Compliance with <a href="#">NYS Bring Your Own Device (BYOD) (NYS-S14-012)</a> is required.
8. Using a cloud hosted or third-party software for geocoding is prohibited unless approved by the NYSCR.

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| 9. Access to approved minimum necessary NYSCR data will be permitted only upon approval of the user's signed individual affidavit. The NYSCR data should be used solely for the purpose(s) stated in the application.   |
| 10. NYSCR data shall not be used, accessed, stored, or disclosed unless approved by the NYSCR, as applicable. Organizations that are unable to meet one or more of these provisions may submit a separate written request for approval of an exception in the form of an appendix to this affidavit; any request for exception(s) to these Security Guidelines must include information on compensating controls. |
| 11. Upon expiration or rescission of approval, all NYSCR data must be destroyed by an approved process following <a href="#">NYS Sanitization Secure Disposal Standard (NYS-013-003)</a> . Acceptable methods for non-recoverable destruction of stored data are physical destruction or forensic wiping.   |

## Security Guidelines Glossary

Term	Definition
NYS-S14-007 - Encryption Standard	This standard defines requirements for encryption that is used to enhance security and protect the State's electronic data ("data") by transforming readable information ("plaintext") into unintelligible information ("ciphertext").
NYS-S14-013 - Account Management Access Control Standard	This standard establishes the rules and processes for creating, maintaining and controlling the access of a digital identity to NYS applications and resources for means of protecting NYS systems and information.
NYS-S14-005 - Security Logging	This standard defines requirements for security log generation, management, storage, disposal, access, and use. Security logs are generated by many sources, including security software, such as antivirus software, firewalls, and intrusion detection and prevention systems; operating systems on servers, workstations, and networking equipment; databases and applications
NYS-S14-012 - Bring Your Own Device	This standard normalizes the management and administration of personal devices accessing state resources.
NYS-S13-003 - Sanitization Secure Disposal Standard	Information systems capture, process, and store information using a wide variety of media, including paper. This information is not only located on the intended storage media but also on devices used to create, process, or transmit this information. These media may require special disposition in order to mitigate the risk of unauthorized disclosure of information and to ensure its confidentiality.
NYSCR	The New York State Cancer Registry.
NYSCR Internal Peer Review Committee	The Internal Peer Review Committee (IPRC) is responsible for reviewing NYSCR identifiable data requests. It supersedes the Data Protection Review Board.  The IPRC is responsible for ensuring the usability, security, and availability of data for all identifiable data requests seeking to use NYSCR data. The Committee follows applicable federal and state laws when determining whether NYSCR data containing identifiable data elements may be shared.
NYS ITS	New York State Office of Information Technology Services (ITS) was created in 2012 to transform IT services in an effort to make New York State government work smarter for its citizens and enable the state to be accessible for businesses through the use of technology.  ITS provides statewide IT strategic direction, directs IT policy and delivers centralized IT products and services that support the mission of the State.