# Data Governance Policy and Procedure Manual for Data Release

Statewide Planning and Research Cooperative System

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# Introduction

The Statewide Planning and Research Cooperative System (SPARCS) is a comprehensive all-payer data collection system established in 1979 as a result of cooperation between the healthcare industry and state government. The system was initially created to collect information on discharges from hospitals. SPARCS currently collects patient-level details on patient characteristics, diagnoses and treatments, services, and charges for inpatient and outpatient services (ambulatory surgery, emergency department, and outpatient services).

The enabling legislation for SPARCS is Section 2816 of the New York State Public Health Law (PHL). The regulations pertaining to SPARCS data and the SPARCS program are located in Section 400.18 of Title 10 (Health) of the Official Compilation of Codes, Rules, and Regulations of the State of New York (NYCRR).

The SPARCS Data Governance Committee (DGC) was established in September 2014 to review identifiable data requests and make approval recommendations to the New York State Commissioner of Health ("Commissioner"). The DGC is the successor to the SPARCS Data Protection Review Board (DPRB), which reviewed identifiable data requests prior to 2014. All previously approved DPRB data requests were grandfathered in under the new governance structure.

The SPARCS program is responsible for ensuring the quality, consistency, usability, security, and availability of all data requests from internal and external stakeholders seeking to use SPARCS data. The SPARCS program follows all applicable federal and state laws when determining whether SPARCS data that contain identifiable data elements may be shared and whether a disclosure of SPARCS constitutes an unwarranted invasion of personal privacy.

The SPARCS program supports open government initiatives and transparency while continuing to assure confidentiality and security of the patient data it is charged with protecting. The SPARCS program publishes a list of all projects since 2009 that have been approved to use identifiable data. This list includes the name of the project director, the organization, and the title of the project.

## SPARCS Data Access

Per regulation, SPARCS data may be used for: (1) medical or scientific research; (2) statistical or epidemiological purposes; or (3) other proper purposes as determined by the Commissioner. All entities seeking SPARCS identifiable or limited data must submit a request to the SPARCS program using the standard data request form. This manual contains detailed information about SPARCS data access, including the types of data available and the process for review and approval of data requests. In determining the purpose of a request for SPARCS data, the SPARCS program is not limited to information contained in the data request form and may request supplemental information from the applicant. The Commissioner may rescind for cause, at any time, the approval of a data request.

## SPARCS Data File Types

There are three types of SPARCS data available to researchers and others interested in using the data for authorized purposes:

1. De-identified (Public Use) data files
2. Limited data file
3. Identifiable data file

The Data Governance Committee is responsible for the review and approval of **Identifiable** data file requests. **Limited** data file requests are reviewed and processed by qualified SPARCS program staff and approved by the SPARCS Administrator. **De-identified ("Public Use")** data files are available to the public on the Department's open data platform. This section describes the contents and uses of each file type as well as procedures for accessing the data.

## De-identified (Public Use) Data Files

Public Use files do not contain personally identifiable information (PII) or protected health information (PHI). Detailed Public Use data files can be accessed easily and free of charge on Health Data New York, the Department's open data platform. There are no restrictions on the use of public use files. Many SPARCS discharge public use data files are summarized in aggregate statistical tables by calendar year, with tables grouped at the state, county, and hospital levels. A calendar year inpatient discharge record-level detail file is also published annually (2009 to current). Public Use data files are a rich resource for researchers and entities trying to understand how their research questions can be answered using SPARCS data. Prior to requesting limited or identifiable data files, applicants should review the public use data to determine if public use files can meet their research needs.

## Limited Data File

The SPARCS program applies applicable New York State standards and many of the standards set forth in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (P.L. 104-191) and implemented regulations ("the Privacy Rule") when providing data to approved requestors. SPARCS Limited data files follow the redaction policies according to many of the specifications for limited data listed at 45 CFR Section 164.514(e), but Limited data files still contain PHI and indirect identifiers that requires data requestors to sign a data use agreement. A complete list of data elements and values available in a limited data file can be found in the SPARCS Data Dictionary.

**Data Years Available**

SPARCS Inpatient and Outpatient limited data files are currently available for the following years:

- Inpatient (1982-present)

- Outpatient

    o Ambulatory Surgery (1983-present)

    o Emergency Department (2005-present)

    o Expanded Outpatient Data Collection (EODC) (2011-present)

SPARCS data is requested by calendar year for a predetermined time. An applicant can request up to three (3) years beyond the current calendar year. Review the SPARCS data request application Instructions and SPARCS Data Dictionary for additional information on the available data.

**Data Extraction Options**

Some proposed uses of SPARCS data may be achievable without sending the entire statewide data file(s) for the years requested. In those cases, the SPARCS program can extract specific subsets of the statewide data based on appropriate criteria. Extraction criteria may be proposed by the applicant or by the DGC or SPARCS Administrator during the review process. Data extractions support the SPARCS program policy of providing the minimum data necessary to complete the approved project. The following extraction criteria are currently available:

- Claim Type (IP only, ED only, or OP only)

- Patient County of Residence

- Hospital County

- Age

- Gender

- Hospital Permanent Facility Identifier (PFI)

**Mortality Indicator Requests**

The Mortality Indicator is an additional data element that can be appended to limited data if requested and approved by the SPARCS program. The Mortality Indicator connects to the limited data file via the

Claim Trans ID. This option provides researchers with indication of death to facilitate patient outcomes research. Mortality Indicators further support the SPARCS program in adhering to its minimum use necessary policy. Applicants must provide a justification explaining why mortality indicators are required for the proposed project. Mortality indicators identify whether the patient's disposition is deceased at 7|15|30|180|360 days post admission date and 7|15|30|180|360 days post discharge date. Mortality indicators are created by NYSDOH and **are available for data files from 2005 to present**.

**Requesting Limited Data File(s)**
To request a SPARCS limited data file, review the [Instructions](#), complete the [SPARCS Limited and Identifiable Data Request Form (DOH-5132)](#) and supporting documents, and send the completed request package to: [sparcs.requests@health.ny.gov.](#) The forms listed below must be submitted and deemed complete for every limited data request and are available at: [www.health.ny.gov/statistics/sparcs/forms](#).

- **SPARCS Limited and Identifiable Data Request Form (DOH-5132)**
  This form must be signed by the Project Director and a representative with the authority to legally bind the organization to the terms of the application.

- **Organizational Data Use Agreement**
  This form must be signed by a representative with the authority to legally bind the organization to the terms of the agreement.

- **Individual Data Use Agreement(s)**
  Individual Data Use Agreements (DUAs) must be signed by the Project Director and by each person that will use SPARCS data.

- **Security Guidelines**
  This form must be reviewed and signed by the requesting organization's Chief Information Security Officer or lead Information Technology administrator.

**Review Process**
Limited data file requests are reviewed by qualified SPARCS program staff and approved by the SPARCS Administrator; DGC approval and ratification by the Commissioner or Commissioner's designee are not required. SPARCS staff review the application and supporting documents for completeness and the following are verified:

- that the project adheres to approved SPARCS regulation data uses;

- the feasibility and soundness of the proposed project;

- credentials and qualifications of the applicant(s) to undertake the research;

- proposed research methodology;

- sufficiency of security and data protection protocols;

- appropriateness of publication and/or data dissemination plans; and

- appropriateness of data linkage plans, if any.

After the initial review, the SPARCS program provides the applicant with a list of questions and requested revisions, if any. This review process often requires multiple rounds of correspondence and revision. It is intended to ensure that all requests contain sufficient information for the SPARCS Administrator to make an informed decision regarding approval.

> **Note:** The timing of an organizational representative's signature of the application is at the applicant's discretion. However, if changes are required after the initial submission as described above, organizational representatives will need to sign the materials again. As a result, it is recommended that applicants obtain an organizational representative's signature as a final step in the application process after all required revisions have been

completed.

If the request is approved, the SPARCS program sends the applicant an approval letter describing the data files and years to be provided and an expiration date of the application. If applicable, an invoice for the data is sent, and upon receipt of payment the data is transferred within 30 business days using a mutually agreed-upon secure file transfer protocol (SFTP). While DGC review is not required, approval of requests for limited data files is not guaranteed. Applicants may be required to revise or amend submitted materials during the review process to bring the request into alignment with applicable laws, regulations, and SPARCS program policy.

## Identifiable Data File(s)

An identifiable SPARCS data file contains data elements which constitute PHI and PII and which could be used to directly re-identify individual patients if improperly disclosed. Due to the sensitive nature of this information, requests for access to identifiable data files are subject to the review and approval procedures described at 10 NYCRR Section 400.18, including approval by the DGC and ratification by the Commissioner or Commissioner's designee. Identifiable data file applications must be deemed complete and satisfy all applicable SPARCS program policy requirements before being presented the DGC.

### Data Years Available

SPARCS Inpatient and Outpatient identifiable data files are currently available for the following years:

- Inpatient (1982-present)
- Outpatient:
    - Ambulatory Surgery (1983-present)
    - Emergency Department (2005-present)
    - Expanded Outpatient Data Collection (EODC) (2011-present)

SPARCS data is requested by calendar year for a predetermined time. An applicant can request up to three (3) years beyond the current calendar year of the application submission year. Review the SPARCS data request application Instructions and SPARCS Data Dictionary for additional information on the available data.

### Requesting Identifiable Data Element Categories

The SPARCS Limited and Identifiable Data Request Form requires applicants to provide a justification explaining why the requested identifiable data element categories are needed for the proposed research and how the data elements will be used during the project. If approved for a category of identifiable data elements, applicants receive all elements in that category. Your justification must include the specific data elements from the category you intend to use. Some identifiable data elements may not be available for all years requested. Refer to the SPARCS Data Dictionary for information on data elements and years available. An additional charge applies per identifiable category per year requested and approved for release by the DGC. **Table 1** lists the identifiable data element categories that can be requested and the associated data elements within those categories.

**Table 1. Identifiable Data Element Categories Available for Request**

| Dates | Date of Birth | Patient Address | Patient Record Number | Policy Numbers |
|---|---|---|---|---|
| • Accident-Related Date<br>• Admission Date<br>• Discharge Date<br>• Statement from Date<br>• Statement Thru Date<br>• Procedure Date<br>• Date of Service<br>• Occurrence Date<br>• Occurrence Span from Date<br>• Occurrence Span Thru Date | • Patient Birth Date | • Patient Street Address Line 1<br>• Patient Street Address Line 2<br>• Patient Zip Code Extension<br>• Subscriber Zip Code | • Medical Record Number<br>• Mother's Medical Record Number (for newborn)<br>• Patient Control Number<br>• Previous Patient Control Number | • Subscriber Group Number<br>• Member Identification Number<br>• Service Provider Employer Identification Number<br>• Insurance Policy Number<br>• Subscriber Group Number<br>• Subscriber Group Name<br>• Subscriber Member Identification Number |

### Data Extraction Options

Some proposed uses of SPARCS data may be achievable without sending the entire statewide data file(s) for the years requested. In those cases, the SPARCS program can extract specific subsets of the statewide data based on appropriate criteria. Extraction criteria may be proposed by the applicant or by the DGC or SPARCS Administrator during the review process. Data extractions support the SPARCS program policy of providing the minimum data necessary to complete the approved project. The following extraction criteria are currently available:

- Claim Type (IP only, ED only, or OP only)
- Patient County of Residence
- Hospital County
- Age
- Gender
- Hospital Permanent Facility Identifier (PFI)

### Mortality Indicator Requests

The Mortality Indicator is an additional data element that can be appended to an identifiable data file(s) if requested and approved by the DGC. The Mortality Indicator connects to the identifiable data file via the Claim Trans ID. This option provides researchers with indication of death to facilitate patient outcomes research. Mortality Indicators further support the SPARCS program in adhering to its minimum use necessary policy. Applicants must provide a justification explaining why mortality indicators are required for the proposed project. Mortality indicators identify whether the patient's disposition is deceased at 7|15|30|180|360 days post admission date and 7|15|30|180|360 days post discharge date. There is an additional charge for appending mortality indicators to the approved data file(s). Mortality indicators are created by NYSDOH and **are available for data files from 2005 to present**.

### Linking Patient Level Data Requests

Linking SPARCS data at the individual patient level to other patient-level data sources is only possible in association with identifiable data files. To support its policy of disclosing the minimum amount of information necessary to complete an approved project, the SPARCS program offers a **cohort matching**

**service** to applicants who intend to link SPARCS data to a defined group of patients or study participants. SPARCS program staff will provide guidance on constructing a finder file to enable the cohort matching upon request. The cohort matching service reduces the need for the SPARCS program to release identifying data elements for matching purposes only.

If the research proposal includes a planned linkage between SPARCS data and one or more of following data sources, the application must describe the intended linkage and include information on the status of related data requests.

- New York City and New York State Vital Events data
- New York State Cancer Registry data
- New York State Cardiac Registry data
- New York State Sepsis Clinical data

All proposed linkages with SPARCS records must be approved by the data steward. The applicant must provide the SPARCS program with documentation of approval from each data steward before any linked data will be released. If the linkage and application are approved, the SPARCS program works with the data steward(s) to complete the linkage and provide the linked research data set to the applicant.

Applicants intending to perform a proposed data linkage on their own using SPARCS identifiable data are asked to contact the SPARCS program at sparcs.requests@health.ny.gov for consultation. The DGC determines which party should perform the linkage according to the SPARCS program's minimum use necessary policy.

**Abortion and HIV/AIDS Data Requests**

Abortion and HIV/AIDS records are redacted to the standard of the HIPAA "Safe Harbor" provision at 45 CFR Section 164.514(b) and applicable New York State Laws and Regulations, which requires masking or redaction of all direct and indirect patient identifiers. Refer to the SPARCS Data Dictionary for detailed information on specific data elements and data formats.

HIV/AIDS data is released pursuant to applicable laws and regulations, including but not limited to PHL Section 2135. Redacted elements may only be released as part of an identifiable data set for research purposes with patient consent, or to another public health entity for purposes authorized by law upon approval by the Committee. Any researcher can apply for, and if approved, receive the indirect identifiers (Safe Harbor). Abortion-related data elements may only be released for research purposes with explicit patient consent.

**IRB Review**

The use and disclosure of identifiable patient health information are governed by applicable laws and regulations, including but not limited to the Common Rule for the Protection of Human Subjects at 45 CFR Part 46. For all applications requesting access to identifiable data elements, SPARCS program policy requires (a) evidence of patient consent, or (b) an IRB-approved patient consent waiver or finding of exemption/non-research for the proposed project. Applicants must provide a copy of the patient consent instrument or research protocol for review. If the proposed research includes a linkage between identifiable SPARCS data and any other non-public data set, the patient consent instrument or research protocol must disclose the planned linkage.

**Requesting Identifiable Data File(s)**

To request a SPARCS identifiable data file, review the Instructions, complete the SPARCS Limited and Identifiable Data Request Form (DOH-5132) and supporting documents, and send the completed request package to: sparcs.requests@health.ny.gov. The following are required forms at submission and are available at: https://www.health.ny.gov/statistics/sparcs/forms/

- **SPARCS Limited and Identifiable Data Request Form (DOH-5132)**
  This form must be signed by the Project Director and a representative with the authority to legally

bind the organization to the terms of the application.

- **Organizational Data Use Agreement**
  This form must be signed by a representative with the authority to legally bind the organization to the terms of the agreement.

- **Individual Data Use Agreement(s)**
  Individual Data Use Agreements (DUAs) must be signed by the Project Director and by each person that will use SPARCS data.

- **Security Guidelines**
  This form must be reviewed and signed by the requesting organization's Chief Information Security Officer or lead Information Technology administrator.

## Identifiable Data File Requests: Review Process

Identifiable data requests are granted only upon a formal vote of approval for access by a majority of the members of the DGC. The Commissioner has the final authority over the approval, or disapproval, of all data requests. SPARCS staff review the application and supporting documents for completeness and the following are verified:

- that the project adheres to approved SPARCS regulation data uses;
- the feasibility and soundness of the project;
- credentials and qualifications of the applicant(s) to undertake the research;
- proposed research methodology;
- sufficiency of security and data protection protocols;
- appropriateness of publication and/or data dissemination plans; and
- appropriateness of data linkage plans, if any.

After the initial review, the SPARCS program provides the applicant with a list of questions and requested revisions, if any. This review process often requires multiple rounds of correspondence and revision. It is intended to ensure that all requests contain sufficient information for the SPARCS Administrator to make an informed decision regarding approval.

> **Note:** The timing of an organizational representative's signature of the application is at the applicant's discretion. However, if changes are required after the initial submission as described above, organizational representatives will need to sign the materials again. As a result, it is recommended that applicants obtain organizational representative signatures as a final step in the application process after al required revisions have been completed.

When a data request is deemed ready for consideration by the DGC, the SPARCS Program notifies the applicant that their request will be considered at the next scheduled DGC meeting. SPARCS program staff then prepare a Review and Recommendation (R&R) document (see Attachment A) summarizing the data request.

## SPARCS Data Governance Committee & Meetings

The SPARCS Data Governance Committee (DGC) was established by the New York State Department of Health (NYSDOH) pursuant to 10 NYCRR Section 400.18(d)(9). The Committee is comprised of at least three members, including at least one member not otherwise affiliated with NYSDOH. Committee members alternate between 2- and 3-year terms. All committee members are identified by the SPARCS Administrator and confirmed by the Commissioner of Health or Designee. The names and experience of current SPARCS Data Governance Committee members are made available on the SPARCS webpage on the NYSDOH public website at http://www.health.ny.gov/statistics/sparcs/.

DGC meetings are convened by the SPARCS Administrator eight (8) times per calendar year. Meetings are scheduled at the beginning of the year and run for up to 2 hours each, with the meeting dates published in advance on the SPARCS public webpage. The scheduled meeting dates are the only times during which the Committee will meet to discuss identifiable data requests. While efforts are made to ensure that Committee members are available and able to attend scheduled meetings, a quorum is not required to hold a meeting or vote on data requests. Committee members may vote on applications even if they are not able to be present at the meeting. Individuals who are not DGC members may attend to listen and speak (but not vote) at Committee meetings.

**Pre-Meeting Activities**
The complete application, supporting materials and the R&R are distributed to members of the Data Governance Committee one (1) week before the scheduled meeting date. The applicant also receives a copy of the R&R and has a final opportunity to clarify or revise information before the meeting. Members are required to review each data request and bring any outstanding questions or concerns to the meeting for discussion and group review.

**During The Meeting**
During the Data Governance Committee meeting, committee members may have additional questions or research suggestions, and will vote on whether to approve, disapprove, or request changes to the application. The Committee votes on the application and, by a majority ruling, it recommends approval or not. The applicant should be available by phone to respond to any follow up questions that are critical to the Committee vote on the application. If the applicant is unavailable the request can be deferred until the next scheduled meeting.

Committee members ensure that the applicant is qualified to conduct the research or study and has the appropriate credentials, that the requesting organization meets data security requirements, and that the proposed research is scientifically and methodologically sound. The DGC also ensures that the data is being used for a proper purpose and that the data elements requested are required to meet the project goals.

**Note:** By regulation, requests for identifiable data elements shall be considered and/or approved by the Committee only if:
   (i)    The purpose of the request is consistent with the purposes for which SPARCS data may be used;
   (ii)   The applicant is qualified to undertake the project; and
   (iii)  The applicant requires such identifiable data elements for the intended project and is able to ensure that patient privacy will be protected.

When making application determinations, both the SPARCS program and DGC evaluate the request against the minimum use necessary standard described in the HIPAA Privacy Rule at 45 CFR Sections 164.502(b) and 164.514(d). This policy ensures that protected health information is only used or disclosed when it is necessary to satisfy a particular purpose or carry out an authorized function.

**Post-Meeting Activities**
If approved by the Committee, the approved request is submitted to the Commissioner or the Commissioner's designee for ratification within 15 business days of voting. The Commissioner's decision is returned to the SPARCS Administrator within 15 business days. If the request is ratified, the SPARCS program sends the applicant a signed approval letter describing the data files, years, to be provided and application expiration date.

If the Commissioner does not ratify the Committee's decision, the application is returned to the applicant with a description of the factors that led to the denial. The applicant may apply again.

For approved applications, if applicable, an invoice for the data is also sent and, upon receipt of payment, the request is then entered in the data request queue, where the approved dataset will be created. Upon receipt of payment (if due), the data will be transferred to the applicant. Data is typically

released within 60 days of ratification.

## Data Security

Approved Limited and Identifiable data file users are required to take all necessary precautions to prevent unwarranted invasions of personal privacy resulting from any data analysis or release. Data users may not release any information that could be used, alone or in combination with other reasonably available information, to identify an individual who is the subject of the information. Data users bear full responsibility for breaches or unauthorized disclosures of personal information resulting from the use of SPARCS data.

Applications for SPARCS Limited and Identifiable data files must include a description of how the data will be securely stored and accessed, and/or transferred. Applications must also include a copy of the SPARCS Security Guidelines signed by the organization's Chief Information Security Officer or lead IT administrator.

> **Security Incident Reporting:** If the Project Director or any member of the project team becomes aware of a data security incident (e.g., inadvertent disclosure, system compromise [e.g., ransomware], or other type of breach/disclosure), they must immediately email the SPARCS program at: sparcs.requests@health.ny.gov. The email should include the SPARCS Request Number, the number of years of data involved and outline the nature of the data security incident. The email must include the title, email, and phone number for the organizational representative responsible handling the incident response.

Breaches or other infractions of the SPARCS data use agreements may result in the assessment of penalties against the Project Director, the requesting organization, or both. Penalties may include monetary fines as authorized by Public Health Law Sections 12 and 12-d, rescission of a prior approval to use SPARCS data, and/or a bar on any future use of SPARCS data by the requesting organization as whole.

## Approved Data Request Actions

### 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:

a)  changes in Project Director

b)  change of requesting organization

c)  change in location of data storage or use

d)  change to project research scope or addition of new research scope

e)  change in type of requested data files, change in years of requested data files, or if you are requesting additional data elements

f)  any other major change to the application

Please contact the SPARCS program with any questions regarding project amendments. To request an amendment to an approved application, review the Instructions, complete the SPARCS Amendment Application and supporting documents, and send the complete application package to sparcs.requests@health.ny.gov. Once received, the completed application will be reviewed according to the process for limited or identifiable applications described above.

**Note:** Requests to change the Project Director must be made by the original Project Director. The name of the new Project Director, their Curriculum Vitae (CV), and an Individual Data Use Agreement completed by the new Project Director must be included with the amendment application. If the original Project Director is no longer available, the request may be made by the Organizational Representative that co-signed the approved application.

## Administrative Actions

Certain minor actions related to approved projects (e.g. change of project contact in Section 1.D of the application, spelling or address corrections, etc.) can be approved administratively by the SPARCS Administrator or their designee. If modifications are required, send an email to sparcs.requests@health.ny.gov. All administrative actions will be announced at the next scheduled Data Governance Committee meeting.

## Data Retention and Application Expiration Data

The data retention period for approved applications is two (2) years after the final calendar year of data has been received. The approval letter will list the expiration date. The project is closed when the retention period expires, upon project completion and the return of the data, or upon withdrawal of the request. The SPARCS program will request an Affidavit of Data Destruction as the expiration date approaches.

### Extension of Data Retention Requests

In situations where more time may be required to complete the study, the data retention period may be extended for up to one (1) year. All extension requests must be submitted prior to expiration of the data retention period to sparcs.requests@health.ny.gov for SPARCS program review. If approved, an e-mail will be sent indicating the extension request is approved and listing the new expiration date.

## Data Delivery & Fees

SPARCS Limited and Identifiable data files are available on an annual or quarterly basis. The SPARCS program will release data regularly based on the following:

   a) **Initial Data File –** this data file is the first data file you will receive and will contain all approved calendar years of data up to latest complete calendar year

   b) **Annual Refresh Frequency –** if approved for annual refreshes, you would receive your next data file when the next calendar year is deemed complete

   c) **Quarterly Refresh Frequency –** if approved for quarterly refreshes, the SPARCS data release team will set up a schedule with you. The quarterly releases will include any data received during the current calendar year. This data is not deemed complete and there may be significant completeness issues from many facilities or claim types.

   **Note:** Per SPARCS submission regulations, submitters have 180 days from last discharge date to submit 100 percent of their data. A calendar year of data is not "deemed" complete until after the reconciliation process is over, typically around mid-August of the following year. For example, calendar year 2022 data will not be "deemed" complete until mid-August 2023.

If the proposed project involves a patient-level linkage between SPARCS data and another data set(s) that is not publicly available, please be aware that other data systems and/or data stewards may process and make data available on different timelines. Applicants should consult with the data steward(s) for information on the latest calendar year of data available and any lag in data availability or processing times.

The SPARCS program charges a reasonable fee to all persons and organizations receiving SPARCS

data. Data fees are based upon incurred and recurring costs for data processing, platform/data center and software. The Commissioner may discount the base fee or waive the fee upon request to the SPARCS program. The fee may be waived in the following circumstances:

    (i)        Used by a health care facility of the data it submitted to SPARCS.

    (ii)       Used by a health care facility that is licensed under Article 28 of the Public Health Law for the purpose of rate determinations or rate appeals and for health care-related research.

    (iii)     Used by a Federal, New York State, county, or local government agency for health care-related purposes.

To obtain the current price for SPARCS Identifiable and limited data sets, email sparcs.requests@health.ny.gov. Please note that additional fees may apply for data obtained from non-SPARCS sources or data stewards.

## Publication Requirements

As a condition of obtaining access to SPARCS data, all requestors are required to provide the SPARCS program with a copy of any non-proprietary report, article, manuscript, or any other derivative based upon the use or analysis of SPARCS data prior to submission for publication or publicly posting. SPARCS program staff will review submissions for small cell size adherence, alignment with approved research/use, and appropriate disclaimer. Drafts should be submitted to sparcs.requests@health.ny.gov.

For proprietary uses of SPARCS data, including the creation of dashboards or other online tools, requestors may be required to provide documentation or a demonstration of functionality prior to consideration by the SPARCS Data Governance Committee.

All publications utilizing SPARCS data must include the following disclaimer: "This publication was produced from raw data purchased from or provided by the New York State Department of Health (NYSDOH). However, the conclusions derived, calculations, and views expressed herein are those of the author(s) and do not reflect the conclusions or views of NYSDOH. NYSDOH, its employees, officers, and agents make no representation, warranty or guarantee as to the accuracy, completeness, currency, or suitability of the information provided here."

## Contact Information

The SPARCS program is located within the Office of Quality and Patient Safety (OQPS). Contact information is below.

    SPARCS Governance
New York State Department of Health, Office of Quality and Patient Safety (OQPS)
Empire State Plaza, Corning Tower, Room 1998
Albany, New York 12237

Phone: (518) 402-5835
E-mail: sparcs.requests@health.ny.gov (General Inquiries & Data Requests)
Website: http://www.health.ny.gov/statistics/sparcs/

## Change Log

The SPARCS program has made every effort to provide accurate and complete information in this manual. Any typographical error is unintentional on our part, and we urge users of this manual to bring them to our attention for correction. Edits, deletions, modifications, or changes to areas of this manual will be maintained in a change log and updated versions of the manual will be released.

| Version | Date | Updates |
|---|---|---|
| 1.0 | September 2014 | Initial publication |
| 2.0 | August 2019 | Reflect current process for mortality indicators and vital records data requests |
| 3.0 | April 2022 | Request process |

# Glossary of Terms

| Term | Description |
|---|---|
| **Breach** | An unauthorized use of SPARCS data, either by a person without an individual affidavit on file, or by using the data in a manner, or for a purpose not approved by the Data Governance Committee. |
| **Data Governance Committee** | A group of people experienced with SPARCS data, and/or research and that will review the application for identifiable data and make a recommendation to the Commissioner whether to allow the release of the data. Recommendations must be ratified by the Commissioner and the group's decisions can be overturned. |
| **Data Protection Review Board** | The previous Board that presided over the request and presentation of SPARCS data applications through June 2014. They ensured that SPARCS data was released only to researchers with a proven ability to maintain a secure environment for the data, and that they were able to effectively perform the research. |
| **Data Queue** | After being approved to use the data, the applicant is placed in the queue with other data requesters. |
| **Data Retention & Application Expiration Date** | The expiration date at which each applicant is allowed to use SPARCS data. This date is set programmatically to two (2) years after the last calendar year of data is received. Retention can be extended for up to one (1) additional year by e-mailing a request to sparcs.requests@health.state.ny.gov (include the reason for the extension). |
| **Data Use Agreement: Individual** | The individual data use agreement that must be signed by the Project Director, and all individuals that will be working with SPARCS data. |
| **Data Use Agreement: Organizational** | A binding document that is required to be signed by a representative of the organization who is authorized to sign on behalf of said organization. This person is usually a Corporate Officer, or Department Chair. |
| **De-identified Data (Public Use)** | Unlike the identifiable data, this file does not contain data that can be used (alone, or linked to other data), to identify a patient. An inpatient public use file is located on www.health.data.ny.gov simply by searching for keyword "SPARCS" |
| **Identifiable Data** | SPARCS data elements, which if used inappropriately, could identify a patient. This type of data is also referred to as Protected Health Information (PHI) or Personally Identifiable Information (PII). All identifiable data requests are reviewed by the Data Governance Committee. |
| **IRB** | Institutional Review Board. |
| **Inpatient** | SPARCS currently collects patient level detail on characteristics, diagnoses and treatments, services, and charges for inpatient stays in New York State from 1982-present. |
| **Limited Data** | Limited data contains indirect identifiers that are deemed potentially identifiable according to HIPAA standards. |

| Term | Description |
|---|---|
| NYCRR 400.18 | The section of the New York Codes, Rules and Regulations that allow SPARCS to collect data from facilities, and the manner in which they are allowed to release that data. |
| NYSDOH | The New York State Department of Health |
| Outpatient | SPARCS currently collects patient level detail on characteristics, diagnoses and treatments, services, and charges for outpatient visits in New York State for the following types:<br>• Ambulatory Surgery (1983-present)<br>• Emergency Department (2005-present)<br>• Expanded Outpatient Data Collection (EODC) (2011-present) |
| Public Health Law (PHL), 2816 | The New York Public Health Law that defines SPARCS. |
| Ratification | The Commissioner of Health's decision on the Committee's recommendations to release SPARCS data to the requesting researcher. |
| Review and Recommendation (R&R) | The document created by the SPARCS program while reviewing an applicant's request (Attachment A). It is used to assist the Committee with their recommendation. |
| Safe Harbor | HIPAA "Safe Harbor" is the de-identification of Medical Record Information requiring that certain identifiers of the individual or of relatives, employers, or household members of the individual must be removed from medical record information in order for the records to be considered de-identified. |
| SPARCS Administrator | Person responsible (or their designee), for assuring that NYCRR Title 10 Section 400.18 is adhered to when requesting access to SPARCS identifiable data. |
| SPARCS program | The program area within the Office of Quality and Patient Safety that oversees all SPARCS program functions, including the collection and release of SPARCS data. |
| Transparency | The Department of Health is committed to creating a level of openness that builds trust and accountability. |
| Data Set Sheet | A document that is created upon finalizing an applicant's request. It contains the information necessary to create the specific data file. |

# Attachment A: Review and Recommendations Document

| New York State Department of Health SPARCS Program Memorandum | Reviewer: |
|---|---|

| Applicant: |
|---|

| Organization: |
|---|

| Request Type: ☐ New ☐ Amended ☐ Streamlined |
|---|

| Date: |
|---|

| PROJECT TITLE: |
|---|

| Previous Applications: ☐ Yes ☐ No<br>Application number:<br>Data in applicant's possession: | ☐HIV/AIDS ☐ Data Linkages<br><br>☐Abortion ☐ Secondary Release |
|---|---|

Data Requested:

     Type:       Years:
    Inpatient
    Outpatient
    Extraction
    Cohort Match
    Mortality Indictors

1. If approved for HIV/AIDS, the address will include the 5-digit zip, county, and regional elements only.
2. Data approved for release to the requestor cannot be secondarily released to any other person unless expressly approved.
3. The Department must be kept apprised of all publications, website postings, etc. derived from SPARCS data.
4. Statistical tabulation of facility records will have no single grouping or tabulation based upon fewer than six facility patient records. Such groupings will be eliminated or combined with other groupings.

## REVIEW

| Documentation Received: | Elements Recommended: |
|---|---|
| ☐ IRB Waiver | ☐ Dates |
| ☐ IRB Approval | ☐ DOB |
| ☐ Organizational affidavit(s) | ☐ Address |
| ☐ Signature-Organizational Rep | ☐ Numbers |
| ☐ Signature-Project Director | ☐ Policy Number |
| ☐ Individual Affidavit | ☐ Unencrypted UPI |
| ☐ Security Requirements | ☐ Encrypted UPI |
| ☐ Certification of Destruction Agreement | ☐ Enhanced Encrypted UPI |
| ☐ Vital Statistics Approvals | **Extraction criteria: (Extraction options**: Claim, Patient County, Hospital County, Age, Gender, PFI) |
| ☐ Tax Exempt Number | **Mortality indicators requested:** |
| ☐ Vendor/Contractor Affidavit(s) | **Data sets to be linked:** |
| ☐ Qualifications | **Party responsible for linking data:** |