

# SPARCS

**Statewide Planning and Research  
Cooperative System**

## **Limited and Identifiable Data Request Form (DOH-5132) Instructions**

SPARCS Program  
Bureau of All Payer Systems and Informatics  
Division of Information and Statistics  
Office of Quality and Patient Safety  
New York State Department of Health

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## OVERVIEW

This instruction manual offers detailed directions on how to complete the **SPARCS Limited and Identifiable Data Request Form** (DOH-5132) for obtaining both limited and identifiable data files. The application form and these instructions are located in the forms area of the SPARCS public website at <http://www.health.ny.gov/statistics/sparcs/>.

The New York State Rules and Regulations, NYCRR Title 10 §400.18, define how requests of SPARCS data will be released. SPARCS data may be used for medical or scientific research or statistical or epidemiological purposes. The SPARCS program will publish and make publicly available the name of the project director, the organization and the title of approved projects. Applications for SPARCS data must provide an explicit plan for preventing breaches or unauthorized disclosures of personal information of any individual who is the subject of the information.

**Limited** data contains indirect identifiers according to HIPAA standards. **Identifiable** data pertains to a individual's facility visit or stay, which, if disclosed, would constitute an unwarranted invasion of personal privacy, as stipulated in Department regulations. A complete description of the data elements contained in the inpatient and outpatient data files can be found in the corresponding output data dictionaries in the Data Access area on the SPARCS public website.

The SPARCS Data Governance Committee is responsible for reviewing all requests for identifiable data. The Committee meets eight times a year to decide whether to recommend the approval or denial of identifiable data requests. The members of the SPARCS Data Governance Committee are posted on the SPARCS public website. The Committee's recommendation is submitted to the Commissioner of Health for ratification. The Commissioner will either agree with or reverse the recommendations of the Committee. All approved data requests are valid for a period of time not to exceed three years. This system of checks and balances helps protect the data, while providing access to needed healthcare information.

Requests for Limited data are reviewed internally and are not submitted to the Commissioner for ratification.

The **SPARCS Limited and Identifiable Data Request Form** (DOH-5132) supplies the SPARCS program with the information necessary to determine whether:

- The purpose of the request is consistent with the desired uses of the data.
- The applicant is qualified to undertake the study.
- The proposed study is technically feasible.
- The data will be secured, while both stored and accessed.

If you would like to request either limited or identifiable data, complete form DOH-5132 and e-mail it to [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov) or mail to the address that appears below.

## PROCESS

1. Following the detailed instructions below, complete the SPARCS Limited and Identifiable Data Request Form (DOH-5132), answering all questions.
2. E-mail the completed form and all supporting documentation to [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov), or mail it to the following address:

SPARCS Program  
Bureau of All Payer Systems and Informatics  
Office of Quality and Patient Safety  
NYS Department of Health  
Corning Tower, Room 1911  
Albany, NY 12237

3. Representatives for identifiable data requests are strongly encouraged to be available by phone or in person during the SPARCS Data Governance Committee meeting to answer questions regarding the request.
4. A notification letter will be sent to the applicant after the request has been reviewed and decided upon.

## DETAILED INSTRUCTIONS FOR EACH LINE ITEM

**File Type Requested:** At the top of the form, you must indicate the file type being requested, either limited or identifiable. To help in making this decision, please refer to the inpatient and outpatient data dictionaries on the SPARCS public website.

### 1. ORGANIZATION AND INDIVIDUAL REQUESTING THE USE OF DATA

- A. **Project Director:** This person will be in charge of the study, sign all individual DUAs, receive the data, and ensure that an experienced analyst or researcher will be working with the raw data file. Provide the name, title, phone number, and e-mail address of the individual in charge of the study. The primary e-mail must be affiliated with the organization.
- B. **Organization Name:** List the organization with which the Project Director is associated when conducting the study. In addition to the name of the organization, include the specific department or unit that the study is being conducted for.
- C. **Organization Address:** List the address of the organization named in 1.B. The data will be shipped to this address.
- D. **Contact Person:** List the name(s) and contact information of the individual(s) who will be responsible for the majority of the correspondence regarding this request. If this is the same person that's listed in 1.A, leave blank. The person(s) listed here and the Project Director are the only ones authorized to discuss this request with the SPARCS Program.
- E. **Type of Requestor:** SPARCS data has costs associated with each request. These costs may be reduced or eliminated depending on the type of organization or person applying. Since multiple discounts can apply to a single request, it's important to select every applicable type to achieve the appropriate discount.

### 2. NATURE OF REQUEST

- A. **Title of Project:** List the title of the study or project for which you are requesting data. This title must match the one in your Internal Review Board (IRB) application approval discussed in 2.D.
- B. **Primary Reason/Purpose, Objective, and Benefit:** The approved data release can only be used for purpose(s) stated in this section.

- Objective(s): Include a description of the main issues to be addressed.
- Benefit(s): Describe the merit(s) of this study.

C. **Type of Request:** SPARCS data may be used for medical or scientific research or statistical or epidemiological purposes.

Check the appropriate boxes indicating the type of request(s):

*Epidemiological*—epidemiology identification of exceptional morbidity or mortality patterns for more in-depth study, or studies of prevalence and incidence of diseases that can be indicated by these data.

*Financial*—investigation of alternate means of paying for hospital, ambulatory surgery, or emergency department services.

*Health Planning and Resource Allocation Studies*—the rational allocation of limited resources to healthcare, provision of adequate healthcare, and article 28 approval processes.

*Quality of Care Assessment*—review of hospital, ambulatory surgery, and emergency departments to assess quality of care.

*Rate Setting*—modeling of rate policies and calculating of reimbursement rates for hospitals, ambulatory surgery, or emergency departments.

*Research Studies*—investigation into a number of healthcare research studies, including variations of length of stay, disease dynamics, and health economics for patient use patterns.

*Surveillance*—surveillance of hospitals, ambulatory surgery, or emergency departments; investigation of fraud and abuse; medical audit or outbreak detection.

*Utilization Review of Resources*—identification of hospital, ambulatory surgery, or emergency department service patterns of utilization to assist in resource or intervention planning.

*Other*—please list other potential possibilities for research and study.

Using the data for promoting, marketing, selling, commercial or competitive purposes; or distributing the data as a product or service is not permitted.

D. **Data Requested**

1. **Data Types and Years:** Select the specific data files and list the years needed.

You are permitted to request future years of data to include up to three years beyond the current year. SPARCS data is updated on a monthly basis. Our annual reconciliation process runs through the end of July, and the previous year of data is not deemed complete until after the annual reconciliation process is over, typically around mid-August of the current year. The closer you are to that date, the more complete the file is. To request a year of data that has already been approved, please e-mail [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov).

**Inpatient Data (Years Collected: 1982 to Present)**

- Inpatient data contains all inpatient discharges from Article 28 licensed hospitals. Available years begin in 1982. With the mandatory collection of emergency department data in 2005, records of patients admitted to inpatient status from the emergency department are in the inpatient data.

## Outpatient Data

Outpatient Data contains both ambulatory surgery and emergency department visits, as well as outpatient services. Available years begin in 1983.

- **Ambulatory Surgery Data (Years Collected: 1983 to Present)**

Outpatient data, which became available in 1983, contained only hospital-based ambulatory surgery data, until voluntary collection of emergency department data began in 2003. SPARCS began collecting data from free-standing and off-site hospital ambulatory surgeries as of January 1, 2007. Collection of these services are based upon the definition of ambulatory surgery in NYCRR Title 10 §755.1, a surgical procedure performed in an operating room on an anesthetized patient with a stay of less than 24 hours.

In 2011, we began defining ambulatory surgery data with eight specific revenue codes, prior to that time, it was defined by a range of CPT codes. The revenue codes are as follows:

Revenue Code	Revenue Code Description
0360	Operating Room Services, General Classification
0362	Operating Room Services, Organ Transplant - Other than Kidney
0369	Operating Room Services, Other Operating Room Services
0481	Cardiology, Cardiac Cath Lab
0490	Ambulatory Surgical Care, General Classification
0499	Ambulatory Surgical Care, Other Ambulatory Surgical Care
0750	Gastro-Intestinal Services, General Classification
0790	Extra-Corporeal Shock Wave Therapy (Formerly Lithotripsy), General Classification

- **Emergency Department Data (Years Collected: 2005 to Present)**

Patient records from a hospital's emergency department visit were voluntarily collected starting in 2003 and became mandatory in 2005. Emergency department data are defined as those outpatient records with a revenue code of 045X. Emergency department data contains the treat and release patients, while those admitted to inpatient status are found in the inpatient data.

- **Outpatient Services Data (Years Collected: 2011 to Present)**

Outpatient services data are described as all other visits to a hospital or a diagnostic and treatment center or hospital extension clinic, licensed to provide ambulatory surgery services, that is not inpatient, ambulatory surgery, or emergency department data. This data collection began as of January 1, 2011.

- **Patient Review Data**

SPARCS also releases Patient Review Instrument (PRI) data. This data details nursing home stays and consists of evaluations of residents in nursing home facilities, and does not contain a unique personal identifier. This file is only available through 2005. If you wish to request this data, please e-mail [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov).

2. **Data Updates:** If you wish to receive refreshes of the file, select the frequency of occurrence. If you require refreshes, discounts will not apply. By selecting to have the file refreshed throughout the year, you will be responsible for the full cost of the data.
3. **HIV/AIDS and Abortion Records (Identifiable Only):** If you are requesting access to these highly-protected records, you must justify the reason on the "Identifiable Data Elements" section on the last page of the form. Complying with the HIPAA Safe Harbor policy, patient identifiers associated with HIV/AIDS and abortion records are redacted from the file, and only some geographical indicators can be added to an approved request.

- In the case of HIV/AIDS records, only the geographical fields, including the 5-digit zip code, will be included.
- In the case of abortion records, the same HIPAA Safe Harbor rule applies. In addition, approval of the request will only be considered if the application is accompanied by a letter of approval from the Commissioner of Health or by signed patient consent forms.

#### E. Protection of Human Subjects

Institutional Review Board (IRB) approval is required for both research and epidemiology studies. IRB approval may also be required for studies that do not include direct patient contact, but require IRB review due to the confidential nature of the patient data involved. Indicate whether or not IRB approval has been received. If so, include a copy of the request and the approval, or enter the date when the IRB request was submitted.

### 3. SUMMARY OF PROPOSAL

You may include additional documentation if you think it will help the reviewer in the decision-making process. However, items A through E must be answered succinctly in the body of this application.

- Research Method** (Identifiable Only): Include a description of your research methodology and techniques to be used in this study.
- Cell Size:** The Centers for Medicare & Medicaid Services have a small size policy which stipulates no cell (e.g. admissions, discharges, patients, services) 10 or less may be displayed. Also, no use of percentages or other mathematical formulas may be used if they result in the display of a cell 10 or less. You must describe your policy here, and the resulting data must be compliant with HIPAA standards regarding de-identification.
- Linkages:** Indicate whether you will require linking SPARCS data to New York City or New York State Vital Statistics data, or if you will be linking to another data source. The application for the city vital statistics is located on their public webpage: <http://www.nyc.gov/html/doh/downloads/pdf/vs/data-request.pdf>. You can obtain the state application by e-mailing [bio-info@health.ny.gov](mailto:bio-info@health.ny.gov).

Unless expressly approved, linking to any other source is prohibited and will result in a breach of security.

Approval from all other sources must be submitted before any data will be released.

### 4. CONFIDENTIALITY OF DATA

- Data Security:** Describe how the confidentiality of the requested data will be maintained. Provide an explanation of how and where the data will be stored, and how access to that data will be regulated.

Complete the Security Guidelines document by having each task initialed by someone that manages your IT network, and signed by an organizational representative (someone that can legally bind the organization). The document is located on the public website: <http://www.health.ny.gov/statistics/sparcs/forms/>.

- Contractors/External Project Partners:** Identify and include a description of anyone not from your organization and their involvement with this project. Please state whether their involvement would be at the raw or aggregate data level.

Release of data to parties not expressly approved is prohibited and will result in a breach of security.

You must include a notarized organizational agreement and individual agreements from all contractors or external project partners.

- C. **Data Storage:** Indicate if the data will be stored at an alternate location. If so, a notarized organizational DUA and individual DUAs are required (refer to Data Use Agreement forms).
- D. **Data Retention:** Every data request is set to expire two years after receipt of the final year of data. If your project is extended beyond this time a request for extension must be submitted to [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov). Extensions are issued for one year. Your request must explain why the extension is needed.

Upon completion of the project, you must certify the destruction of the data by completing the Data Destruction Certification letter found on the Department's public website.

- E. **Data Use Agreements:** Every individual requiring access to SPARCS data must be listed in the section of the application. Each individual must have a properly executed Individual agreement (DOH-5132IA) on file with the Department or their access will be considered a breach. The Project Director's DUA must be counter-signed by the Organizational Representative.

Every request must also be accompanied by a notarized Organizational Data Use Agreement (DOH-5132OA). Only persons authorized to legally sign on behalf of the organization can sign this form. The person that signs this agreement is also the person that signs the application as Organizational Representative (5.B).

This documentation can also be e-mailed to [sparcs.requests@health.ny.gov](mailto:sparcs.requests@health.ny.gov). Individual and Organizational DUAs can be found on the Department's public website on the same page as the application.

- F. **Release of Data:** Check if disseminating aggregate data to anyone or re-releasing data to project partners. List the organization(s) or person(s) receiving the information or data. Describe what will be released and in what format. The re-release of data is forbidden unless explicitly approved.

## 5. SIGNATURES

- A. **Project Director:** The signature of the **Project Director** indicates that he/she will abide by the rules and policy as indicated in the DUA, and throughout the application, regarding the release of the SPARCS data. The project director will also sign all other individual data use agreements.
- B. **Organizational Representative:** The signature of an **Organizational Representative** is required. This person attests to the fact that confidential data is being requested for certain usage by the Project Director and that there are special confidentiality requirements regarding the use, maintenance, storage, and destruction of this data. This person must be authorized to legally sign on behalf of the organization.

## 6. IDENTIFIABLE DATA ELEMENTS

If your request is for identifiable data elements, you must provide a justification for each specific data element being requested. There must be a need for each identifiable data element. If the data element requested is not adequately justified then that data element will be denied. The definitions of the data elements can be found in the output data dictionaries on the public website.