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

Statewide Planning and Research Cooperative System

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

- Whether the purpose of the request is consistent with the desired uses of the data
- Whether the applicant is qualified to undertake the study
- Whether the proposed study is technically feasible
- Whether the study uses the SPARCS data in a manner in consistent with SPARCS regulations
- How the data will be secured, 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.

Detailed Instructions for Each Line Item

1. Organization and Individual Requesting the Use of Data

File Type Requested: At the top of the form, check the box corresponding to the file type being requested, either limited or identifiable. To help in making this decision, refer to the Data Dictionary on the SPARCS public website.

A. **Project Director**: This person is in charge of the study, will sign all individual DUAs, will receive the data, and ensure that an experienced analyst or researcher will be working with the data file(s). Provide the name, title, credentials, 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 conducting the study.

C. **Organization Address**: List the address of the organization named in 1.B.

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 this section blank. The person(s) listed as contact(s) and the Project Director are the only individuals 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, be sure 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. For identifiable data requests, this title must match the one in the research protocol and Internal Review Board (IRB) determination letter discussed in 2.E.

B. **Primary Reason/Purpose, Objective, and Benefit**: Please describe at a high level the primary reason and benefits of the proposed study. This section is used to provide an overview of the

main purpose of your application.

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—epidemiological 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.

> **NOTE:** *Use of SPARCS data for promotional, marketing, , or other commercial purposes, or distributing the data as a product or service is not permitted, unless such use is expressly described to and approved by the Department.*

D. **Data Requested**

1. **Data Types and Year(s) Requested**: Select the specific data files and list the calendar years you will need for your study.

   It is permissible to request future years of data up to three (3) years beyond the current calendar year. If you have data in your possession from a previous application/approval, please make a note in the boxes or in your Project Summary document of the approved SPARCS request number, and provide the calendar years, claim type (inpatient/outpatient), calendar years of mortality indicators, calendar years of linked data (VS, Cancer, Sepsis, etc).

   For example: SPARCS request # XXXXX, 2007 – 2014 inpatient & outpatient data, 2007 – 2014 mortality indicators.

   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 with an emergency department flag.

Outpatient Data

Outpatient Data contains ambulatory surgery, emergency department visits, and outpatient services beginning in 1983.

- **Ambulatory Surgery Data (Years Collected: 1983 to Present)**
  Ambulatory surgery data contains only hospital-based ambulatory surgery data from 1983 to 2006. From 2007 to 2010, ambulatory surgery data contains hospital-based, off-site, and free-standing hospital ambulatory surgery site data. Collection of these data from 1983 - 2010 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) and was defined by a range of CPT codes.

  Data from 2011 to current, defined ambulatory surgery with eight specific revenue codes, see table below.

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)**
  Emergency department data contains the treat and release patients, while those admitted to inpatient status are found in the inpatient data. 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. Those patients who are admitted from the ED will have an ED flag.

- **Outpatient Services Data (Years Collected: 2011 to Present)**
  Outpatient services data are described as all other visits to a hospital, 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 January 1, 2011.

2. **Data Updates**: To request a refreshed version of the approved file(s), select the frequency of occurrence. Refreshed files are available on an annual or quarterly basis. If requesting quarterly refreshes, a justification must be provided in the application or project summary document.

   > **NOTE:** *If data refreshes are requested, discounts will not apply. By selecting to have the file refreshed, the requester will be responsible for the full cost of the data.*

3. **HIV/AIDS and Abortion Records** (Identifiable File Requests Only): If requesting access to these highly protected records, the reason must be justified 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. Institutional Review Board (IRB) Waiver or Exemption

Institutional Review Board (IRB) approval is required for all identifiable data requests. 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.

Indicate whether IRB approval has been received. If so, include a copy of the protocol request and the approval letter, if not yet obtained, enter the date when the IRB request was submitted. **The final application must contain the research protocol submitted for IRB review and the determination letter.**

3. Summary of Proposal

Answer items A through C in this section on the application form.

A. Research Method or Data Analysis Plan: All applications must include a separate document that provides an overview of the proposed project, including (1) all research questions to be investigated; (2) your population, research methods, and analysis plan; (3) expected benefits of the research. **Please name the document "Project Summary" when submitting to SPARCS.**

B. Cell Size: The SPARCS Program adheres to the same small cell size policy as the Centers for Medicare & Medicaid Services, which stipulates no cell (e.g., admissions, discharges, patients, services) with a value of 10 or less may be displayed. Also, no percentages or other mathematical formulas may be used if they result in the display of a cell 10 or fewer. Indicate that you and your organization will comply with the SPARCS policy or describe the organization's cell size policy for consideration.

C. Linkages: Indicate whether the proposed study involves linking SPARCS data at the patient level to New York City or New York State Vital Statistics data, or to any other patient-level data source. The application for New York City vital statistics is located on their public webpage: https://www1.nyc.gov/site/doh/data/data-sets/vital-statistics-data.page. You can obtain the New York State application by e-mailing bio-info@health.ny.gov. Submit a copy of the vital statistics application to sparcs.requests@health.ny.gov as confirmation of the request for linkage.

Please identify ALL data sources you will be linking to SPARCS and include the type of data elements you will be linking. Additional files are sometimes reference files such as census data or other survey type data that can be linked by a hospital, provider, or geographic identifier.

Unless expressly approved, linking to any other source is prohibited and constitutes a breach of data security. Approval to link to SPARCS from all data stewards (unless the data is publicly available) must be submitted before any data will be released.

4. Confidentiality of Data

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

Security Guidelines: All data request applications must include an executed copy of the SPARCS Security Guidelines. The document must be reviewed and signed by the organization's Chief Information Security Officer or lead Information Technology administrator. The document is located on the public website: www.health.ny.gov/statistics/sparcs/forms.

B. Contractors/External Project Partners: All organizations that will be working on the proposed project must be listed including a description of their involvement with the proposed project. State whether the organization(s) listed would have access to SPARCS at the line-level or aggregate data level.

> ***Note:*** *Release of data to parties not expressly approved is prohibited and may result in revocation of your organization's approval to use SPARCS data.*

A notarized Organizational Agreement and Individual Data Use agreements must be included from all contractors or external project partners.

C. Data Storage: Indicate if the data will be stored at an alternate location. A notarized Organizational Data Use Agreement (DUA) and Individual Data Use Agreements (DUAs) are required for any organization and/or individuals that will store and have access to SPARCS data.

D. Data Retention: Every data request application is set to expire two (2) years after receipt of the final year of data. If an extension to the project beyond the two-year retention period is needed, a request for extension must be submitted to sparcs.requests@health.ny.gov. Extensions are issued for up to one year. The request must explain why the extension is needed.

Upon completion of the project, data must be destroyed, and destruction must be certified by completing the Affidavit of Data Destruction found on the Department's public website.

E. Data Use Agreements: Every individual accessing SPARCS data must be listed in this section of the application. Each individual must have a properly executed Individual Data Use agreement on file with the Department or their access will be considered a breach. The Project Director's DUA must be signed by the Organizational Representative.

Every request must also be accompanied by a notarized Organizational Data Use Agreement from 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). Individual and Organizational DUAs can be found on the Department's public website on the same page as the application.

F. Release of Data: Use this section to describe any plan to disseminate information or share research results with anyone not listed as a data user in Section 4.E. Data and research results may only be released as described in this section and approved by the SPARCS Administrator or Data Governance Committee.

5. Signatures

A. Project Director: The signature of the Project Director indicates they 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 sign contracts on behalf of the requesting organization.

6. Identifiable Data Elements

If you are requesting identifiable data elements, applicants receive all data elements in the identifiable data category. Your justification for use must be targeted to the specific data elements from the category you intend to use. Some identifiable data elements may not be available for all years requested, please refer to the SPARCS Data Dictionary for information on years available.

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