

New York State Cardiac Data Request

Resource Document for Potential Data Applicants

GENERAL INFORMATION

Matching Data to Outside Data Sources

The standard process for data release under PHL 2816(a) does not include matching cardiac data to other data sources (for example, SPARCS, vital statistics, etc.). However, the Department has determined that projects involving matched data may be considered when the potential benefits of the project are substantial, the topic area is one of high priority for the Department, and the applicant provides resources to support the matching activity.

Applicants should be aware that due to the stringent criteria for recommendation and requirement for additional resources, approval of this type of project has been extremely rare.

Technical Notes Regarding Data File Type

Data will be provided as a SAS dataset, a fixed width text file, a .csv file, or an excel file. Other file formats may be provided if requested.

Affidavits

All project participants **MUST** sign an individual affidavit before data sets are released. Project participants include all individuals who will have access to the cardiac data set in any form as well as study partners, contractors, consultants, collaborators, assistants, associates, etc. Please note that anyone who is the author of a publication resulting from this study is also regarded as a project participant.

In the event that the list of project participants changes after initial approval, an updated list of project participants must be provided in writing to the Cardiac Services Program. No individual may be granted access to the cardiac data set without completing an affidavit and first obtaining approval of NYSDOH.

Fee Structure

There is a fee of \$2,500.00 per data set, per discharge year. For example, if an applicant requests 2010-2012 CSRS data, the applicable fee would be \$7,500.00. [3 discharge years of CSRS data (2010, 2011, 2012) × \$2,500.00] However, if an applicant requests 2010-2012 CSRS data and 2010-2012 PCIRS data, the applicable fee would be \$15,000.00. [3 discharge years of CSRS data (2010, 2011, 2012) × \$2,500.00 + 3 discharge years of PCIRS data (2010, 2011, 2012) × \$2,500.00]

DATA ELEMENT SPECIFIC INFORMATION

Hospital/Physician Identifiers

Data Elements: PFI, TRANS_PFI, CATHPFI, PHYSNUM, ANESNUM1, ANESNUM2, CARDNUM

Hospital and physician identifiers will only be released in encrypted format when necessary to conduct a research study. Applicant must provide written assurance that specific hospitals and/or physicians will not be identified in publications.

Patient Information

Data Elements: LASTNAME, FIRSTNAME, MEDRECNO, SSNO, DOB

Public Health Law 2816-a states that no cardiac data set shall be released that contains patient names, social security numbers, or other data elements that directly identify any patient; the data elements listed above are not releasable.

Multiple records for the same patient may be linked within and between datasets by a unique personal identifier created by the Cardiac Services Program. Need for patient linking must be described in the data application.

Medicaid/PRIMEPAY

Data Elements: MEDICAID, PAYER, PRIMEPAY

Recent data matching activities with the Medicaid database call into question the accuracy of payer information as reported in CSRS and PCIRS. Use of these data elements should be avoided.

Date and Time Fields

Data Elements: ADMIDATE, SURGDATE, SURGHOUR, SURGMIN, PRIODATE, CLOSEHOUR, CLOSEMIN, DISDATE, PCIDATE, PCI_HR, PCI_MIN, SAMEDATE, PRIODATEADM, CHESTPDATE, TRANARRDATE, PCIARRDATE

Exact dates and times will not be released in a standard dataset. They could potentially be used in combination with other information to identify a patient. However, calculated variables such as age, pre-procedure length of stay, post-procedure length of stay, door to balloon time and others may be provided upon request. Please see the “Calculated Variables” section of the master data element list for other examples. Calculated time intervals not already listed may be created if required for a research project.

Pre-Procedural Risk Factors

Data Elements: PRIORITY

“PRIORITY” is not an audited variable. Reporting on this variable is highly subjective and not uniformly reported across hospitals. This variable is not used in New York State annual reports and has been avoided in published studies.

Data Elements: SHOCK, NEUROSTAT

NYS does not include in the publicly released reports data for patients with the risk factors of “shock” or mortalities under certain circumstances when the patient has “anoxic brain injury” prior to PCI. This decision was implemented after careful consideration and was intended to remove unintended barriers to revascularization for these patients. Cases with these exclusion criteria will not be released.

Data Elements: OLD_2B3A, OLD_2B3A_OTH, OLD)2B3A_IND, OLD_MED_TIME, OLD_2B3A_DURING4, OLD_2B3A_ORAL4

At the time of data collection data elements related to IIbIIIa medications were found to be extremely unreliable and not suitable for use in publications. In particular, issues surrounding the timing of administration of these agents resulted in suspect findings. The data on this drug administration will not be included in any released dataset.

Post-Procedure Major Events

Post procedure major event data should be used with extreme caution as these elements are not audited and believed to be substantially under-reported. Use of in-hospital complications as

reported in the registries has been avoided in NYS publications using this data. If released for research purposes, it is required that any publication include a disclaimer that the in-hospital complication data is believed to be under-reported and may not be accurate. Applicants requesting these fields should include in their application an agreement to make such a disclaimer concerning data quality in any and all publications / presentations/ manuscripts, etc.

Discharge Related

Data Elements: THIRTYDAY, DISWHERE

Mortality status at 30-days post-procedure as reported by hospitals is not validated and comparisons to outside data sources (i.e. Vital Statistics / NDI data) have indicated that this information is extremely unreliable. It is technically considered an optional field on the data collection report. This data element will not be released.

Data Element: STATUS

Status will not be released but Discharge Status (live/dead) may be released.

Open Text Fields

Data Elements: RACESPEC, STATE, STAT_SPE, DISWHERE

Open text description of race “other,” “state,” and hospital discharge status “other.” These variables should not be released due to unique and potentially identifying nature of open-text responses. They could potentially be used in combination with other information to identify a patient.