



This data sheet is a quick reference on the policies associated with accessing and using data from the National SCIMS Database for those who are not a funded data collection site for the SCIMS (i.e., the general scientific community). For information on Database use, visit www.uab.edu/nscisc and click the "Database and Public Access" tab.

The National Spinal Cord Injury Statistical Center (NSCISC), located at the University of Alabama at Birmingham (UAB) Department of Physical Medicine and Rehabilitation, supports and directs the collection, management and analysis of the National SCIMS Database.

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Go to msktc.org/sci/model-system-centers for a complete list of SCI Model System Centers.

The National Spinal Cord Injury Model Systems (SCIMS) Database welcomes the use of data for the purposes of improving the lives of persons with spinal cord injury (SCI).

- The Health Insurance Portability and Accountability Act (HIPAA) establishes the conditions under which protected health information may or may not be used or disclosed.
- Please contact NSCISC for instructions on properly interpreting data and data use.

Public Access to De-Identified Data

De-Identified Data collected before October 1, 2016 are freely available for download. De-Identified Data are stripped of all HIPAA-defined identifiers, including names, geographic subdivisions smaller than a state, elements of dates (except year) related to an individual, telephone numbers, fax numbers, email addresses, social security numbers, and medical record numbers.

Limited Data Set with a Data Use Agreement

A Limited Data Set collected before and after October 1, 2016 is available to independent researchers and those seeking SCIMS comments or collaboration. A Limited Data Set is stripped of all HIPAA-defined identifiers except age, dates, city, state or zip.

Requirements for obtaining a Limited Data Set:

1. **Download Data Dictionary.** Prior to submitting a data request, download the data dictionary (containing descriptions of all variables) from the NSCISC web site to ensure the data being sought is available from the National SCIMS Database.
2. **Formulate and Submit a Proposal.** All proposals must include:
 - a) Study purpose and brief methodology.
 - b) Data and variables required.
 - c) Commercial use and relationship, if any.
 - d) Confidentiality precautions.
 - e) Name of Lead/Principal Investigator, qualifications, and affiliation.
 - f) Student/Trainee proposal approval, if applicable, signed by the affiliated department Chair or research mentor prior to submission.
3. **NSCISC Review.** The proposal will first be reviewed by the NSCISC and SCIMS committee. Concerns raised by the initial review must be appropriately addressed.
4. **SCIMS Review and Approval.** NSCISC will forward the final proposal to the current cycle's SCIMS Project Directors and NIDILRR Project Officer for review and approval. The decision to release data will be based on a majority vote of the SCIMS Project Directors.
5. **Appoint Mentor.** The SCIMS may, at their discretion, appoint an advisory mentor.
6. **Sign Data Use Agreement.** A Data Use Agreement must be signed by the lead investigator and institutional authority prior to the release of data.
7. **IRB approval.** IRB approval must be obtained prior to the release of data.
8. **Publications.** A copy of the requestor's manuscript must be sent to NSCISC for review prior to submission for possible publication, and a copy of any related publication must be sent to NSCISC.
 - All publications must include the Publication Disclaimer provided below.

Source

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