



*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).*

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](http://msktc.org/sci/model-system-centers) for a complete list of SCI Model System Centers.

## How do I access data from the National SCIMS Database?

The National Spinal Cord Injury Model Systems (SCIMS) Database welcomes the use of data by external researchers who share our goal of improving the lives of persons with spinal cord injury (SCI). Below are the policies for requesting and accessing data.

1. **Download Data Dictionary.** Prior to submitting a data request, download the data dictionary (containing descriptions of all variables) from the NSCISC web site ([www.uab.edu/nsisc](http://www.uab.edu/nsisc) under the "Database" tab) 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 required.
    - Data up to 5 years prior to the request date will be available. However, this requirement may be waived on a case by case basis by a majority vote of the SCIMS Project Directors.
    - Personal data (name, social security number, date of birth, address, geocodes, etc.) of research participants and the identities of the SCIMS Centers will not be released.
  - 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 Executive Committee. Concerns raised by the initial review must be appropriately addressed.
4. **SCIMS Review and Approval.** The final proposal will be forwarded by the NSCISC 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 a mentor to advise the individual or research team who requests the data as needed.
6. **Sign Data Use Agreement.** A Data Use Agreement must be signed by the lead investigator or institutional authority prior to the release of data.
7. **IRB approval.** IRB approval must be obtained prior to the release of data.
8. **Publication Policies:**
  - A copy of the requestor's manuscript must be sent to the NSCISC for review prior to submission for possible publication, and a copy of any related publication must be sent to the NSCISC.
  - Publications must acknowledge the NIDILRR and include a disclaimer (similar to below) stating "the contents of this publication do not necessarily represent the policies of the NSCISC, SCIMS, MSKTC NIDILRR, ACL, and HHS, and endorsement by the Federal Government should not be assumed."

## Source

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