



The Spinal Cord Injury Model Systems was created in 1970 as a prospective longitudinal multicenter study on demographics and the use of services by people with traumatic spinal cord injury in the United States.

### Consultation, Technical Assistance, and Submission to:

Yuying Chen, MD, PhD,  
NSCISC Director  
(205) 934-3329,  
[yuyingchen@uabmc.edu](mailto:yuyingchen@uabmc.edu)

National SCI Statistical Center  
515 Spain Rehabilitation Center  
1717 6th Avenue South  
Birmingham, AL 35233-7330

For Statistics: 205-934-3342  
TDD: 205-934-4642  
FAX: 205-934-2709  
E-mail: [NSCISC@uab.edu](mailto:NSCISC@uab.edu)  
Website: [uab.edu/NSCISC](http://uab.edu/NSCISC)

© 2023 Board of Trustees, University of Alabama. This is a publication of the National Spinal Cord Injury Statistical Center in collaboration with the Model Systems Knowledge Translation Center (MSKTC). The contents of this data sheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90SIMS0016 and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, and HHS, and you should not assume endorsement by the Federal Government.

Go to [msktc.org/sci/model-system-centers](http://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 September 1, 2021 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 September 1, 2021 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 and dates.

### 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:
  - Study purpose and brief methodology.
  - Data and variables required.
  - Commercial use and relationship, if any.
  - Confidentiality precautions.
  - Name of Lead/Principal Investigator, qualifications, and affiliation.
  - 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 - The final proposal is sent 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.
9. Publication Disclaimer - All publications must include the following:
  - The National Spinal Cord Injury Statistical Center provides access to data under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90SIMS0016). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NSCISC, NIDILRR, ACL, and HHS, and you should not assume endorsement by the Federal Government.