Using the Spinal Cord Injury Model Systems National Dataset

Introduction

This fact sheet is a quick reference on the policies associated with accessing and using data from the Spinal Cord Injury Model Systems (SCIMS) National Database for those who are not a funded data collection site for the SCIMS (i.e., the general scientific community). Topics covered include:

- What is the SCIMS National Database?
- Policy to obtain data from the SCIMS National Database
- Guidelines for Accessing the SCIMS National Database

What is the SCIMS National Database?

The National Spinal Cord Injury Statistical Center (NSCISC), funded by the National Institute on Disability and Rehabilitation Research (NIDRR), supports and directs the collection, management and analysis of the world's largest spinal cord injury database. The SCIMS National Database was originally designed to store information on patients treated at SCIMS centers across the country to demonstrate the efficacy of a comprehensive multidisciplinary care system. As the scope of the SCIMS Program changed, the SCIMS National Database evolved to maintain its relevance based on current needs.

The SCIMS National Database is a prospective longitudinal multicenter database that captures data from an estimated 13% of new spinal cord injury (SCI) cases in the US from 28 federally funded SCIMS since 1973. The database has demographic and condition status data for more than 29,000 people with SCI. For further information, visit our Web site at https://www.nscisc.uab.edu/.

Purpose of the SCIMS National Database

The SCIMS National Database can help researchers and clinicians to:

1. Study the longitudinal course of traumatic SCI and factors that affect that course.
2. Identify and evaluate trends over time in etiology, demographic, and injury severity characteristics of persons who incur an SCI.
3. Identify and evaluate trends over time in health services delivery and treatment outcomes for persons with SCI.
4. Establish expected rehabilitation treatment outcomes for persons with SCI.
5. Facilitate other research such as the identification of potential persons for enrollment in appropriate SCI clinical trials and research projects or as a springboard to population-based studies.

The SCIMS National Database is not intended to study the effectiveness of Model Systems' care as compared to other systems of health care delivery. It is also not by itself intended to gather and maintain population-based data on spinal cord injuries.

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Policy and Procedures for Obtaining Data from the SCIMS National Database

Who can use the SCIMS National Database?

The SCIMS National Database welcomes the use of these data by external researchers who share our goal of improving lives of persons with SCI. Anyone from the scientific community who wishes to use data from the SCIMS National Database can access and use this database. Non-affiliated SCIMS entities who do not have personal and SCIMS center identifiers may gain access to the database following the request guidelines below. A Data Use Agreement must be secured and signed by the lead investigator prior to data transfer.

Guidelines for Accessing the SCIMS National Database

The following procedures have been designed to be simple and to invite participation by external researchers while maintaining the integrity of the data use and confidentiality of the participants.

1. **Submit a Proposal.** Provide a proposal that includes:
   a. Study purpose and brief methodology
   b. Data required
   c. Commercial use and relationship if any
   d. Confidentiality precautions
   e. Responsible party
   f. IRB approval (before the release of data)
2. **Obtain Data Dictionary**. Purchase a copy of the data dictionary (containing descriptions of all variables) or download this document from the NSCISC web site at https://www.nscisc.uab.edu/ prior to formulating the proposal and sending the request for data.
3. **Approval for Students and Trainees**. Students and trainees must have their proposals approved by either their department Chair or research mentor.
4. **Review by NSCISC**. The proposal first will be reviewed by the NSCISC and SCIMS Executive Committee. Concerns raised by the initial review must be appropriately addressed.
5. **Review and Approval by SCIMS Project Directors**. The final proposal will be forwarded by the NSCISC to the current cycle's SCIMS Project Directors and NIDRR Project Officer for review and approval. The decision on data release will be based on a vote of the majority by Project Directors.
6. **Appoint Mentor**. The Model Systems may, at their discretion, appoint a mentor to advise the individual or research team who requests the data as needed.
7. **Sign Data Use Agreement**. A signed Data Use Agreement must be returned to the NSCISC.
8. **Protection of Personal Info**. Personal data (name, social security number, date of birth, address, geocodes, etc.) of research participants and SCIMS centers' identities will not be released.
9. **Available Data**. 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 Project Directors.

10. **Publications**. 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 actual publication must be sent to the NSCISC.

11. **Publication Policy**. All publications must acknowledge NIDRR and include the disclaimer that the opinions expressed are those of the authors and not necessarily those of the NSCISC, Model Systems, or NIDRR.

12. **Fees**. The NSCISC's fee for this service is contingent on the complexity of the request. An estimate will be provided, upon request, based on the provision of all details from the requestor.

Source

Spinal Cord Injury Model System
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A NIDRR Funded Program

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