The Spinal Cord Injury Model System (SCIMS)

Funded by:
National Institute on Disability and Rehabilitation Research (NIDRR)
Office of Special Education and Rehabilitative Services (OSERS)
U.S. Department of Education, Washington, DC

Version date: May 2013
## Contents

<table>
<thead>
<tr>
<th>Topics</th>
<th>Slide Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCIMS Background Information</td>
<td>3</td>
</tr>
<tr>
<td>Current SCI Model Systems</td>
<td>10</td>
</tr>
<tr>
<td>Formerly Funded Centers That Contributed to the National SCI Database</td>
<td>20</td>
</tr>
<tr>
<td>Model Systems Knowledge Translation Center</td>
<td>21</td>
</tr>
<tr>
<td>SCIMS Research Activity Areas</td>
<td>25</td>
</tr>
<tr>
<td>National SCI Database</td>
<td>38</td>
</tr>
<tr>
<td>National SCIMS Descriptive Data Summary 1973–2011</td>
<td>65</td>
</tr>
</tbody>
</table>
**Definition of Traumatic Spinal Cord Injury (SCI)**

- For the purposes of the SCIMS program, a case of SCI is defined as the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and cauda equina), resulting in temporary or permanent sensory and/or motor deficit.

- The clinical definition of SCI excludes intervertebral disc disease, vertebral injuries in the absence of SCI, nerve root avulsions and injuries to nerve roots and peripheral nerves outside the spinal canal, cancer, spinal cord vascular disease, and other nontraumatic spinal cord diseases.
Despite advances in understanding SCI, approaches to treatment remained largely fragmented, and comprehensive rehabilitation failed to become widely adopted in the Western Hemisphere ... until John Young (1919–1990) resolved to correct this.

With the assistance of J. Paul Thomas, then Director of the Medical Sciences Program at the Rehabilitation Services Administration, John Young obtained a Federal grant in 1970 to demonstrate the superiority of comprehensive versus fragmented SCI care in Phoenix, Arizona ... and called this demonstration a “Model System.”

Donovan, 2006
The Genesis of the SCIMS (continued)

• “A Model System must be able to meet the needs of a person with SCI by competently treating the direct injury as well as all organ systems affected (of which there are many); the functional deficits that result, by providing training and equipment; the psychological adjustments that must be made; the vocational/avocational pursuits that must be changed; and the providing of long-term specialized care.

— John Young

Donovan, 2006
Project Design

• The SCIMS program was established by the Rehabilitation Services Administration in 1970, funding Dr. Young’s vision of integrated SCI care.

• Since its inception, a total of 30 centers have been funded by NIDRR, 28 of which have contributed data to the national SCI database.

• The SCI Model Systems are specialized programs of care in SCI that gather information and conduct research with the goal of improving long-term functional, vocational, cognitive, and quality-of-life outcomes for individuals with SCI.

  Stover, DeVivo, & Go, 1999;
  Chen et al., 2011
Project Design (continued)

• The SCIMS grantees contribute patient records to a national database, maintained by a national statistical center, which tracks the long-term consequences of SCI and conducts research in the areas of medical rehabilitation, health and wellness, technology, service delivery, short- and long-term interventions, and systems research.

• Each SCI Model System is charged with disseminating information and research findings to patients, family members, health care providers, educators, policymakers, and the general public.
Project Priorities
Priority One 2011–2016

The SCIMS program is designed to generate new knowledge that can be used to improve outcomes of individuals with SCI. Each SCIMS Center must contribute to this goal by:

a. Providing a multidisciplinary system of rehabilitation care, specifically designed to meet the needs of individuals with SCI;

b. Continuing the assessment of long-term outcomes of individuals with SCI by enrolling at least 30 subjects per year into the SCIMS database;

c. Proposing and conducting at least one site-specific research project to test innovative approaches for treating SCI or assessing outcomes of individuals with SCI;

Federal Register, Volume 76, Number 111
Project Priorities
Priority One 2011–2016 (continued)

d. Participating as research collaborators in at least one module project;
e. Addressing the needs of persons with disabilities, including individuals from traditionally underserved populations;
f. Coordinating with the Model Systems Knowledge Translation Center (MSKTC) to provide scientific results and information for dissemination to clinical and consumer audiences; and
g. Ensuring the participation of persons with disabilities in conducting SCIMS research.

*Federal Register, Volume 76, Number 111*
Current SCI Model Systems
SCI Model Systems Coordinators

Federal Program Management
National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education (Washington, DC)
Project Officer: Theresa SanAgustin, M.D.
http://www2.ed.gov/about/offices/list/osers/nidrr/index.html

National SCI Statistical Center (NSCISC)
University of Alabama at Birmingham (Birmingham, AL)
Principal Investigator: Yuying Chen, M.D., Ph.D.
https://www.nscisc.uab.edu/
SCI Model Systems Grantees
(in alphabetical order by State)

University of Alabama at Birmingham SCI Model System (UAB-SCIMS)
University of Alabama at Birmingham (Birmingham, AL)
Principal Investigators: Amie B. Jackson, M.D., and J. Scott Richards, Ph.D.
http://www.uab.edu/medicine/sci/

Southern California SCI Model System
Ranchos Los Amigos National Rehabilitation Center (Downey, CA)
Principal Investigator: Mindy Lipson Aisen, M.D.
http://www.larei.org/
SCI Model Systems Grantees
(in alphabetical order by State, continued)

The Rocky Mountain Regional Spinal Injury System
Craig Hospital (Englewood, CO)
Principal Investigators: Daniel P. Lammertse, M.D., and Susan Charlifue, Ph.D.
http://www.craighospital.org/Left-Nav/Research/Abstracts/SCIMS

South Florida SCI Model System
University of Miami (Miami, FL)
Principal Investigators: Diana D. Cardenas, M.D., Larry Brooks, Ph.D., and Mark Nash, Ph.D.
http://www.rehabmed.med.miami.edu/
Southeastern Regional SCI Model System
Shepherd Center (Atlanta, GA)
Principal Investigators: David Apple, Jr., M.D., and Lesley M. Hudson, M.A.
http://www.shepherd.org/research/model-system-of-care

Midwest Regional SCI Care System (MRSCICS)
Rehabilitation Institute of Chicago (Chicago, IL)
Principal Investigators: David Chen, M.D., and Allen W. Heinemann, Ph.D.
http://www.ric.org/research/centers/mrscics/
Kentucky Regional SCI Model System
University of Louisville Research Foundation, Inc. (Louisville, KY)
Principal Investigator: Daniel E. Graves, Ph.D.

Spaulding-Harvard SCI Model System
Spaulding Rehabilitation Hospital (Boston, MA)
 Principal Investigators: Leslie Morse, D.O., and Ross D. Zafonte, D.O.
http://www.sh-sci.org/
New England Regional SCI Center (NERSCIC) Network
Boston University Medical Campus (Boston, MA), Gaylord Hospital (Wallingford, CT), and Hospital for Special Care (New Britain, CT)
Principal Investigator: Alan Jette, Ph.D.
http://www.bmc.org/spinalcordinjurycenter/research.htm

University of Michigan SCI Model System
University of Michigan (Ann Arbor, MI)
Principal Investigators: Denise G. Tate, Ph.D., and Anthony Chiodo, M.D.
http://www.med.umich.edu/pmr/modelsci/
SCI Model Systems Grantees
(in alphabetical order by State, continued 5)

Northern New Jersey SCI Model System
Kessler Foundation, Inc. (West Orange, NJ)
Principal Investigators: Trevor Dyson-Hudson, Ph.D., and Steven Kirshblum, M.D.
http://kesslerfoundation.org/researchcenter/spinalcordinjury/modelsystems.php

Regional SCI Center of the Delaware Valley
Thomas Jefferson University (Philadelphia, PA)
Principal Investigator: Ralph J. Marino, M.D.
http://www.spinalcordcenter.org/
University of Pittsburgh Model Center on SCI (UPMC-SCI)
University of Pittsburgh (Pittsburgh, PA)
Principle Investigator: Michael L. Boninger, M.D.
http://www.upmc-sci.org/

Northwest Regional SCI System (NWRSCIS)
University of Washington (Seattle, WA)
Principal Investigators: Charles H. Bombardier, Ph.D., Stephen P. Burns, M.D., and Jeanne M. Hoffman, Ph. D.
http://sci.washington.edu/
Subcontracts by NSCISC:
1. Santa Clara Valley Medical Center (San Jose, CA)
   — Principal Investigator: Stephanie Kolakowsky-Hayner, Ph.D.
2. Mount Sinai School of Medicine (New York, NY)
   — Principal Investigator: Marcel Dijker, Ph.D.
3. The Institute for Rehabilitation and Research (Houston, TX)
   — Principal Investigator: Heather Taylor, Ph.D.

Data collected by NSCISC:
4. University of Missouri (Columbia, MO)
5. Woodrow Wilson Rehabilitation Center (Fishersville, VA)
Formerly Funded Centers That Contributed to the National SCI Database

- Michigan, Detroit: 1982–2000

*Form II center that collects followup data only.
Model Systems Knowledge Translation Center

- Aims to enhance the relevance and visibility of Model Systems research and communicate Model Systems research effectively to stakeholders
- Currently operated by the American Institutes for Research (AIR) (Washington, DC) in collaboration with WETA/Brainline (Arlington, VA) and George Mason University (Fairfax, VA)
- Principal Investigators: Steven Garfinkel, Ph.D., and Lynn Gerber, M.D.
- Project Directors: Cindy Cai, Ph.D., and Cynthia Overton, Ph.D.
- Funded by National Institute on Disability and Rehabilitation Research (Washington, DC)
- Project Officer: Pimjai Sudsawad
MSKTC Goals

Three overarching goals guide the work of the MSKTC:

• **Goal 1:** Enhance the understanding of the quality and relevance of knowledge among researchers and multiple users on the topics of SCI, traumatic brain injury (TBI), and burn injury (Burn).

• **Goal 2:** Enhance the knowledge of advances in SCI, TBI, and Burn research among diverse audience members who need this information.

• **Goal 3:** Create a centralized repository of empirical information and resources on research in SCI, TBI, and Burn areas and actively conduct outreach and dissemination activities to communicate this knowledge.
# MSKTC Activities

<table>
<thead>
<tr>
<th>Service Area 1</th>
<th>Service Area 2</th>
<th>Service Area 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge Production and Synthesis</strong></td>
<td><strong>Knowledge Translation Support to Grantees</strong></td>
<td><strong>Knowledge Dissemination</strong></td>
</tr>
<tr>
<td>• Establish Technical Review Committees</td>
<td>• Provide knowledge translation technical assistance and training</td>
<td>• Redesign and maintain Web site</td>
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<td>• Maintain and update standards for systematic reviews</td>
<td>• Support Communities of Practice</td>
<td>• Develop user-friendly products</td>
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<tr>
<td>• Conduct reviews and publish results</td>
<td>• Conduct consumer-needs research</td>
<td>• Create knowledge translation toolkit</td>
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<tr>
<td>• Conduct quick-turnaround reviews</td>
<td></td>
<td>• Engage in stakeholder outreach and conduct dissemination activities</td>
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</tbody>
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### SCI Highlights of MSKTC Progress

<table>
<thead>
<tr>
<th>Systematic Reviews</th>
<th>Completed</th>
<th>In Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCI and Measures of Major Depression</td>
<td>• SCI and Urinary Tract Infection (UTI) Surveillance&lt;br&gt;• SCI and Measures for Predicting Outcomes of Employment&lt;br&gt;• Prevention and Treatment of Bone Loss in SCI&lt;br&gt;• SCI and Adverse Exercise Effects&lt;br&gt;• Women With SCI&lt;br&gt;• Sleep/Obstructive Sleep Apnea and SCI&lt;br&gt;• Transition from Adolescence to Adulthood&lt;br&gt;• Family Planning After SCI</td>
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<table>
<thead>
<tr>
<th>Consumer Fact Sheets</th>
<th>Completed</th>
<th>In Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin Care and Pressure Sores&lt;br&gt;Pain After SCI&lt;br&gt;Safe Transfer Technique&lt;br&gt;Wheelchair Series&lt;br&gt;Spasticity and SCI&lt;br&gt;Employment After SCI&lt;br&gt;SCI and Depression&lt;br&gt;SCI and Wheelchair Prescription&lt;br&gt;SCI and Transfers&lt;br&gt;Gait Training and SCI</td>
<td>• SCI and Exercise&lt;br&gt;• SCI and Bone Health&lt;br&gt;• Bladder Care and SCI&lt;br&gt;• Bowel Care and SCI&lt;br&gt;• Aging and SCI&lt;br&gt;• Obesity and Nutrition and SCI</td>
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<thead>
<tr>
<th>Knowledge Translation Products</th>
<th>Completed</th>
<th>In Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning for Communities of Practice: A Guide for Model Systems Grantees&lt;br&gt;Newsletter Template and Instructions&lt;br&gt;Press Release Template and Instructions&lt;br&gt;Communities of Practice Webinar</td>
<td>• Knowledge Translation Webinar&lt;br&gt;• Additional tools for the Knowledge Translation Toolkit</td>
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</tbody>
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<thead>
<tr>
<th>Multimedia Products</th>
<th>Completed</th>
<th>In Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment After SCI Slideshow</td>
<td>• SCI Hot Topics Module&lt;br&gt;• Additional multimedia presentations based on SCI factsheets</td>
<td></td>
</tr>
</tbody>
</table>
SCIMS Research Activity Areas

Site-specific research projects
• Research carried out within each center

Module projects
• Collaborative research involving several SCIMS

Contributions to the National SCI Database
• Enrollment of new inpatients
• Followup of discharged patients
## Site-Specific Research Projects

*(in alphabetical order by State)*

<table>
<thead>
<tr>
<th>Center</th>
<th>Project Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UAB-SCI Model System (AL)</strong></td>
<td>Virtual Walking for Reducing Spinal Cord Injury-Related Neuropathic Pain</td>
</tr>
<tr>
<td><strong>Southern California SCI Model System (CA)</strong></td>
<td>A Randomized Clinical Trial to Evaluate Two Prevention Programs for Maintenance of Shoulder Health and Function After Spinal Cord Injury</td>
</tr>
<tr>
<td><strong>Rocky Mountain Regional Spinal Injury System (CO)</strong></td>
<td>Reinventing Yourself After SCI: A Site-Specific Randomized Clinical Trial</td>
</tr>
</tbody>
</table>
## Site-Specific Projects
*(in alphabetical order by State)*

<table>
<thead>
<tr>
<th>Center</th>
<th>Project Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>South Florida SCI Model System (FL)</strong></td>
<td>Longitudinal Study of Changes in Shoulder Pathology in the Year After SCI</td>
</tr>
<tr>
<td></td>
<td>Prospective Randomized Control Trial for Shoulder Pathology and Pain in Chronic SCI</td>
</tr>
<tr>
<td><strong>Southeastern Regional SCI Model System (GA)</strong></td>
<td>Evaluation of an Improved Method to Assess and Follow the Recovery of Motor Control in SCI</td>
</tr>
<tr>
<td></td>
<td>A Longitudinal Study of Gainful Employment 10 Years After SCI Onset: Comparisons of Those Who Do and Do Not Return to the Preinjury Employer</td>
</tr>
<tr>
<td><strong>Midwest Regional SCI Care System (IL)</strong></td>
<td>Mobility, Activity, and Participation in SCI: The MAPS Project</td>
</tr>
</tbody>
</table>
Site-Specific Research Projects  
(in alphabetical order by State, continued)

<table>
<thead>
<tr>
<th>Center</th>
<th>Project Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kentucky Regional SCI Model System (KY)</td>
<td>Baclofen With Locomotor Training: The Effect on Function and Neuroplasticity in Chronic Incomplete SCI</td>
</tr>
<tr>
<td>Spaulding-Harvard SCI Model System (MA)</td>
<td>Effects of tDCS on Chronic Pain in SCI</td>
</tr>
<tr>
<td>New England Regional SCI Center Network (MA)</td>
<td>My Care My Call</td>
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<tr>
<td></td>
<td>Missing Links: SCI-CAT Lifespan</td>
</tr>
</tbody>
</table>
## Site-Specific Research Projects

(in alphabetical order by State, continued 2)

<table>
<thead>
<tr>
<th>Center</th>
<th>Project Title</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>University of Michigan SCI Model System (MI)</strong></td>
<td>Bladder and Bowel Complications and Their Impact on Quality-of-Life Outcomes After SCI</td>
</tr>
<tr>
<td></td>
<td>Applying Health Mechanics to Enhance Bowel and Bladder Health for Persons With SCI</td>
</tr>
<tr>
<td><strong>Northern New Jersey SCI Model System (NJ)</strong></td>
<td>Restoring Lost Functions After SCI: Combination Therapy With Dalfampridine and Locomotor Training in Persons With Chronic, Motor Incomplete SCI</td>
</tr>
<tr>
<td><strong>Regional SCI Center of the Delaware Valley (PA)</strong></td>
<td>Zoledronic Acid to Prevent Bone Loss After Acute SCI</td>
</tr>
</tbody>
</table>
## Site-Specific Research Projects

*(in alphabetical order by State, continued 3)*

<table>
<thead>
<tr>
<th>Center</th>
<th>Project Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Pittsburgh Model Center on SCI (PA)</td>
<td>Investigation of Independent Transfers and Injury Prevention Among Individuals With SCI</td>
</tr>
<tr>
<td>Northwest Regional SCI System (WA)</td>
<td>SCI CARE: Efficacy of Collaborative Care Versus Usual Care for Improving Quality of Life in Outpatient Spinal Cord Injury Rehabilitation: A Patient-Centered Approach</td>
</tr>
</tbody>
</table>
# Module Projects

(in alphabetical order by State of lead center)

<table>
<thead>
<tr>
<th>Module Project Title</th>
<th>Collaborating Centers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnancy, Labor, Delivery, and Post-Partum Outcomes of Women With and Without SCI: An Observational Study</td>
<td><em>UAB-SCIMS (lead) (AL)</em>, <em>Southern California SCIMS (CA)</em>, Kentucky Regional SCIMS (KY), and University of Michigan SCIMS (MI)</td>
</tr>
<tr>
<td>Wearable Technology for Telecare Monitoring of Persons With Subacute and Chronic Spinal Cord Injury</td>
<td><em>Southern California SCIMS (lead) (CA)</em>, Kentucky Regional SCIMS (KY), and Spaulding-Harvard SCIMS (MA)</td>
</tr>
<tr>
<td>Long-Term Followup of Patients With Ventilator Dependent High Tetraplegia Managed With Diaphragmatic Pacing Systems</td>
<td><em>Rocky Mountain Regional Spinal Injury System (lead) (CO)</em>, South Florida SCIMS (FL), Southeastern Regional SCIMS (GA), Midwest Regional SCI Care System (IL), Northern New Jersey SCIMS (NJ), and Regional SCI Center of the Delaware Valley (PA)</td>
</tr>
</tbody>
</table>
## Module Projects

(in alphabetical order by State of lead center, continued)

<table>
<thead>
<tr>
<th>Module Project Title</th>
<th>Collaborating Centers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Extending the SCI Rehab Project—Five-Year Followup</strong></td>
<td>Rocky Mountain Regional Spinal Injury System (lead) (CO), Southeastern Regional SCIMS (GA), and Midwest Regional SCI Care System (IL)</td>
</tr>
<tr>
<td><strong>SCIMS Data Set: Preparing for Future Changes</strong></td>
<td>Midwest Regional SCI Care System (lead) (IL), UAB-SCIMS (AL), Rocky Mountain Regional Spinal Injury System (CO), Kentucky Regional SCIMS (KY), University of Pittsburgh Model Center on SCI (PA), Regional SCI Center of the Delaware Valley (PA), Spaulding-Harvard SCIMS (MA), and Midwest Regional SCI Care System (WA)</td>
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</table>
## Module Projects
(in alphabetical order by State of lead center, continued 2)

<table>
<thead>
<tr>
<th>Module Project Title</th>
<th>Collaborating Centers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enhancement and Evaluation of the SCI-FI Instrument (SCI Functional Index Computer Adaptive Testing)</strong></td>
<td><em>New England Regional SCI Center Network (lead) (MA)</em>, Rocky Mountain Regional Spinal Injury System (CO), Midwest Regional SCI Care System (IL), Spaulding-Harvard SCIMS (MA), University of Michigan SCIMS (MI), Northern New Jersey SCIMS (NJ), University of Pittsburgh Model Center on SCI (PA), and Regional SCI Center of the Delaware Valley (PA)</td>
</tr>
<tr>
<td><strong>Exercise and Breathlessness</strong></td>
<td><em>Spaulding-Harvard SCIMS (lead) (MA)</em>, Southern California SCIMS (CA), Kentucky Regional SCIMS (KY), and University of Pittsburgh Model Center on SCI (PA)</td>
</tr>
</tbody>
</table>
## Module Projects

(in alphabetical order by State of lead center, continued 3)

<table>
<thead>
<tr>
<th>Module Project Title</th>
<th>Collaborating Centers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluating the Sensitivity and Responsiveness of the SCI-QOL CATs</td>
<td>University of Michigan SCIMS (lead) (MI), Rocky Mountain Regional Spinal Injury System (CO), South Florida SCIMS (FL), Southeastern Regional SCIMS (GA), Midwest Regional SCI Care System (IL), Kentucky Regional SCIMS (KY), New England Regional SCI Center Network (MA), and Northern New Jersey SCIMS (NJ)</td>
</tr>
<tr>
<td>Neurological Recovery After Traumatic SCI</td>
<td>Regional SCI Center of the Delaware Valley (lead) (PA), Southeastern Regional SCIMS (GA), Kentucky Regional SCIMS (KY), Spaulding-Harvard SCIMS (MA), and Northern New Jersey SCIMS (NJ)</td>
</tr>
</tbody>
</table>
# Module Projects

*(in alphabetical order by State of lead center, continued 4)*

<table>
<thead>
<tr>
<th>Module Project Title</th>
<th>Collaborating Centers (City)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equity and Quality in Assistive Technology (EQuATe)</td>
<td>University of Pittsburgh Model Center on SCI (lead) (PA), Midwest Regional SCI Care System (IL), Kentucky Regional SCIMS (KY), New England Regional SCI Center Network (MA), Spaulding-Harvard SCIMS (MA), Northern New Jersey SCIMS (NJ), Regional SCI Center of the Delaware Valley (PA), and Northwest Regional SCI System (WA)</td>
</tr>
</tbody>
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Collaborative Projects
Priority Two 2012–2017

• **Collaborative projects** are multisite research projects to conduct research that contributes to evidence-based rehabilitation interventions and clinical practice guidelines that improve the lives of individuals with SCI. Multisite research projects generally involve:

  – Three or more SCIMS centers (and may include non-SCIMS sites), and

  – Research to improve long-term outcomes to answer questions important to SCI rehabilitation.

*Federal Register, Volume 76, Number 111*
Collaborative Project

• Collaboration on Mobility Training (COMIT)
  – **Goal**: To determine the effect of a wheelchair skills training program and wheelchair maintenance training program on participation and quality of life in persons with SCI.
  – **Lead Center, PI**: University of Pittsburgh Model Center on SCI, Michael Boninger, M.D.
  – Collaborating Centers:
    ▪ Northern New Jersey SCI Model System
    ▪ Midwest Regional SCI Model System
    ▪ South Florida SCI Model System
    ▪ Dalhousie University (not a model system)
National SCI Database

• Began in 1975
  – Data obtained retrospectively to 1973 and prospectively since 1975
• Captures approximately 13% of all new SCI occurring in the United States
• National SCI Statistical Center at the University of Alabama at Birmingham has managed the database since 1983
• As of March 2013
  – Registry—12,345 participants (1987–2013)
  – Form I—29,377 participants (1973–2013)
  – Form II—107,742 records (1975–2013) among 24,080 participants, with the longest followup of 40 years post injury
National SCI Database Goals

• Examine the longitudinal course of SCI
• Evaluate trends over time
  – Etiology, demographics, injury characteristics, health services delivery, treatment outcomes, etc.
• Establish rehabilitation outcomes standards
• Facilitate other research
  – Generate research hypotheses
  – Identify study subjects
Internal Requests

• SCIMS centers are requested to share manuscript proposals, using the National SCI Database, via email notification to avoid conflicts and invite collaboration

• Comparing SCIMS centers is prohibited

• A Data Use Agreement must be signed with National SCI Statistical Center

• All publications must acknowledge NIDRR
External Requests

• Requestor must provide a proposal, outlining the study purpose and methods, commercial use/relationships, confidentiality protections, responsible party, data required, and proof of IRB (institutional review board) approval

• The proposal must be reviewed by NSCISC and the Executive Committee; the final proposal is then forwarded to the SCIMS Project Directors and NIDRR

• The decision to release data is made by a majority vote of the Project Directors

• Data up to 5 years prior to the request date will be available

• A copy of the manuscript must be sent to NSCISC for review before submitting it for publication

• All publications must acknowledge NIDRR and have an appropriate disclaimer
Eligibility for the SCIMS

- Presence of an external traumatic event that results in a SCI
- Temporary or permanent loss of sensory and/or motor function as a result of the traumatic event
- Admission to the system within 1 year of the injury
- Discharge from the system as:
  - Inpatient acute rehabilitation is completed,
  - A neurologic status of normal or minimal deficit is achieved, or
  - When deceased
- Must not have completed an organized rehabilitation program before admission to the system
- Signed informed consent and Health Insurance Portability and Accountability Act (HIPAA) forms
National SCI Database Structure

Form I or Registry (inpatient data collection at enrollment)
- Initial hospital care data
- Patients residing outside the catchment area are enrolled in the Registry
  - Less detailed data collection than Form I and no longitudinal followup data are collected for Registry cases

Form II (followup data collection)
- Followup data on Form I participants
- Currently in years 1, 5, 10, and every 5 years thereafter
Data Collection Sources

• Medical record review
  – May be supplemented by site-specific data collection forms completed by clinicians or inpatient interview

• Neurological examination
  – Typically conducted as part of routine SCI care

• Patient interview
  – Telephone, mailed questionnaire, in-person interview

• Death records
Followup Guidelines

• Find participants
  – Check the Social Security Death Index (SSDI), genealogy, or other death search site for record of death
  – Search system (hospital and clinical) records for recent activity and updated contact information
  – Conduct at least two free Internet searches and a fee-based search if available

• Attempt to schedule a clinical followup visit

• Call viable phone numbers at least six times at different times of the day and week

• Mail a Form II survey to a viable address
National SCI Database Variables

- Demographics
- Injury characteristics (severity, etiology, associated injuries, spinal surgery, etc.)
- Hospitalizations
- Medical, functional, and psychosocial outcomes measures
- Use of assistive technology
Demographics
(at the time of injury)

- Age, sex, and race/ethnicity
- English language ability
- Marital status
- Level of education
- Occupational status and job census code
- Primary insurance
- Veteran status
- Family income
- Geographic identifiers (geocode) and ZIP code
- Place of residence at admission and discharge
Injury Characteristics

• Date of injury
• Traumatic etiology
• External cause of injury (ICD-10-CM)
• Work-related injury (yes/no)
• Vertebal injury (yes/no)
• Associated injuries (yes/no)
• Spinal surgery (yes/no)
• Associated TBI: severity
Neurological Exam

• Collected at:
  – Initial system admission (for Day 1 admit patients only)
  – Admission to rehabilitation
  – Discharge from rehabilitation
  – First anniversary of injury

• International Standards for Neurological Classification of SCI:
  – Date of exam
  – Motor scores (C5–S1) and motor levels
  – Presence of anal sensation and/or sphincter contraction
  – Sensory score (C2–S4/5) and sensory level
  – Level of preserved neurologic function (left and right)
  – Category of neurologic impairment
  – American Spinal Injury Association (ASIA) Impairment Scale, A through E
Initial Hospitalization

• Medical history:
  – Diabetes
  – Depression
  – Anxiety
• Alcohol use—Alcohol Use Disorders Identification Test (AUDIT) C
• Length of stay in medical/surgical unit and rehabilitation
• Use of immobilization devices (at rehabilitation discharge):
  – Halo device
  – Thoracolumbosacral orthosis (TLSO)
• Height and weight
• Method of bladder management (at rehabilitation discharge)
• Use of mechanical ventilation (at rehabilitation admission and discharge)
Initial Hospitalization

- Functional status measured using the motor subscale of FIM (Functional Independence Measure)
  - Self-care such as eating, grooming, bathing, dressing, and toileting
  - Bowel and bladder management
  - Transfers such as from bed to chair, toilet, and tub/shower
  - Locomotion such as walking, wheelchair, stairs
- FIM assessed at rehabilitation admission and discharge
Followup Data Collection

• Current sociodemographic information
  – Marital status
  – Level of education
  – Occupational status and job census code
  – Place of residence
  – Primary insurance
  – Family income
  – Geographic identifiers (geocode) and ZIP code
  – Alcohol use
  – Smoking status

• Use of the VA Health System services (yes/no)
Followup Data Collection (continued)

• Impairment and neurological status
  – Neurological exam (required for Year 1 only)
  – Method of bladder management and reason for change
  – Use of mechanical ventilation at Year 1
  – Pain
  – Urinary tract infection
  – Pressure ulcer
  – Depression
  – Anxiety
  – Diabetes
Followup Data Collection (continued 2)

• Rehospitalizations over the last 12 months
  – Length of stay
  – Reason

• Functional status—motor FIM

• Height and weight
Followup Data Collection (continued 3)

- Self-perceived health status (two items from the Short Form [SF] 36, Health Survey)
  - Health rating on a five-point scale, ranging from “Excellent” to “Poor”
  - Current health compared to 1 year ago

- Satisfaction With Life Scale (SWLS)
  - Five-item self-report scale
Followup Data Collection (continued 4)

- Patient Health Questionnaire (PHQ-2)
  - Two items from the PHQ-9 screening for depression

- Craig Handicap Assessment and Reporting Technique—Short Form (CHART-SF)
  - Measure of societal participation
  - Dimensions assessed include physical independence, mobility, occupation, and social integration
Followup Data Collection (continued 5)

• Assistive technology use
  – Mobility aids for ambulation
  – Wheelchair or scooter use
  – Modified vehicle availability and use

• Information/communication technology use
  – Computer
  – Internet/email
  – Mobile phone
  – Key information sources
Record Status

• Vital status date
  – Date of death or date last known alive

• Primary and secondary causes of death

• Participant status: Registry/Form I, neurological recovery, eligibility for future followup

• Participant Form II statistics: total numbers, last Form II anniversary year
Data Quality

- Standard operating procedures and policies
- Data dictionary
- Data collectors’ training conferences
- Software quality control procedures
  - Range and legal value checks
  - Cross-variable and cross-record consistency
- Data quality monitoring reports
  - Followup tracking report
  - Subject recruitment and enrollment report
  - Missing data report
- Supportive site visits to review system-specific procedures
- Onsite quality assurance
- Data collectors certification program
Internal Dissemination

- Annual Statistical Report and Mid-Year Report
  - Produced by National SCI Statistical Center
- Benchmark Reports
- Report Cards (center-specific performance summary)
External Dissemination

- Facts and Figures at a Glance
- Peer-reviewed publications
- National professional meetings
- Compilation of database research contributed by SCIMS investigators
External Dissemination

Systematic reviews (in collaboration with MSKTC)

- Measurement of Depression in SCI
- SCI and UTI Surveillance
- SCI and Measures for Predicting Outcomes of Employment
- Prevention and Treatment of Bone Loss in SCI
- SCI and Adverse Exercise Effects
- Women With SCI
- Sleep/Obstructive Sleep Apnea and SCI
- Transition from Adolescence to Adulthood
- Family Planning After SCI
External Dissemination

Consumer information (in collaboration with all centers)

- Skin Care and Pressure Sores
- Pain After SCI
- Depression and SCI
- Safe Transfer Technique
- Wheelchair Series
- Spasticity and SCI
- Employment After SCI
- Gait Training and SCO
- SCI and Exercise
- SCI and Bone Health and Aging with SCI
- Obesity and Nutrition After SCI
- Bowel Care and SCI
- Bladder Care and SCI
External Dissemination (continued)

Online Data Collection Forms and Data Dictionary
• [https://www.nscisc.uab.edu/nscisc-database.aspx](https://www.nscisc.uab.edu/nscisc-database.aspx)

Facts and Figures at a Glance
• Published annually by the National SCI Statistical Center
• [https://www.nscisc.uab.edu/reports.aspx](https://www.nscisc.uab.edu/reports.aspx)

Annual Statistical Reports - Public Version
• Published annually by National SCI Statistical Center
• [https://www.nscisc.uab.edu/reports.aspx](https://www.nscisc.uab.edu/reports.aspx)

Slide show to educate others about the SCIMS
National SCI Model System Descriptive Data Summary From 1973 to 2012

Source:
The 2012 Annual Statistical Report for the SCI Model Systems National SCI Statistical Center, Birmingham, AL
https://www.nscisc.uab.edu/reports.aspx
Age at Injury and Gender

Males: 23,442 (80.7%)  
Females: 5,610 (19.3%)
Education
(at the time of injury)

- Up to Grade 8: 8.9%
- Grades 9 thru 11: 23.7%
- High School: 48.2%
- Associate's: 2.4%
- Bachelor's: 6.8%
- Master's: 1.7%
- Doctorate: 1.0%
- Other: 0.8%
- Unknown: 6.5%
Marital Status
(at the time of injury)

- Single: 51.6%
- Married: 32.3%
- Divorced: 9.3%
- Separated: 3.4%
- Widowed: 2.5%
- Other: 0.1%
- Unknown: 0.7%
Occupational Status

(at the time of injury)

- Working, 57.1%
- Unemployed, 15.8%
- Student, 15.2%
- Retired, 6.8%
- On-the-Job-Training/Workshop, 0.4%
- Homemaker, 1.9%
- Other, 1.4%
- Unknown, 1.3%
Race

- White: 67.3%
- African American: 22.8%
- Asian: 1.7%
- American Indian: 0.9%
- Other: 1.6%
- Unknown: 5.8%
SCI Grouped Etiology

- **Vehicular Accidents**
- **Falls**
- **Violence**
- **Sports**

Percentage by Year:

- **1973-79**: 14.4% (Vehicular Accidents)
- **1980-84**: 14.2% (Vehicular Accidents)
- **1985-89**: 10.2% (Vehicular Accidents)
- **1990-94**: 7.6% (Vehicular Accidents), 7.0% (Violence), 8.8% (Falls)
- **1995-99**: 8.0% (Falls), 8.0% (Violence), 9.2% (Vehicular Accidents)
- **2000-04**: 8.0% (Falls), 7.0% (Violence)
- **2005-09**: 8.0% (Falls), 8.0% (Violence)
- **2010-12**: 9.2% (Vehicular Accidents)
# Long-Term Survival

(life expectancy in years)

<table>
<thead>
<tr>
<th>Age</th>
<th>Survive first 24 hours: Motor Fx, Any Level</th>
<th>Survive first 24 hours: Para</th>
<th>Survive first 24 hours: Low Tetra (C5–C8)</th>
<th>Survive first 24 hours: High Tetra (C1–C4)</th>
<th>Survive &gt;1 year post injury: Motor Fx, Any Level</th>
<th>Survive &gt;1 year post injury: Para</th>
<th>Survive &gt;1 year post injury: Vent. Dep., Any Level</th>
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<td>33.7</td>
<td>27.2</td>
<td>23.1</td>
<td>19.7</td>
<td>8.4</td>
<td>34.0</td>
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<tr>
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<td>17.5</td>
<td>12.7</td>
<td>9.9</td>
<td>7.8</td>
<td>2.0</td>
<td>17.7</td>
<td>13.0</td>
</tr>
</tbody>
</table>

*Facts and Figures, 2013*
Major Accomplishments of the SCIMS

• Provides critical information about the course of recovery, trends in cause and severity, health service delivery and costs, treatment, and rehabilitation outcomes
  – Benchmark for the judicial system to determine awards for care based on future needs

• Sets standards for the assessment, treatment, and management of persons with SCI nationally and internationally
  – Development of the Clinical Practice Guidelines in collaboration with American Spinal Injury Association and the Paralyzed Veterans of America

_Ditunno et al., 2003_
Major Accomplishments of the SCIMS (continued)

- Research agenda has broadened from emphasis on acute care to include social and environmental factors, physical functioning, and technology.

- Clinical excellence of the SCIMS provided the foundation from which clinical research focusing on key issues about the health of persons with SCI grew dramatically in the last three decades.
  - Development of new measurement tools to capture neurological, psychosocial, and emotional functioning.

  Ditunno et al., 2003
Major Accomplishments of the SCIMS (continued 2)

• National SCI Database—the largest and longest in the world
  – The SCI statistics have been widely used and referenced
    ▪ NSCISC Web site—averages 81 visits per day
    ▪ Google search for “SCI statistics”—NSCISC Web site ranked first

• Produce specific life-expectancy estimates for an average of 25 court cases per year

• Some requests from countries outside the United States, such as Canada, Australia, England, Scotland, Northern Ireland, Ireland, and Hong Kong
Research Contributions of the SCIMS

1970s
• Emergency and acute care outcomes
• Trends in patient demographics and injury characteristics
• Medical rehabilitation treatment outcomes

1980s
• Development of classification systems (ASIA Impairment Scale, pain)
• Preexisting conditions and secondary complications
• Psychosocial and vocational outcomes

Tate & Forchheimer, 2002; Chen et al., 2011
Research Contributions of the SCIMS (continued)

1990s
• Health care cost issues
• Functional independence outcomes
• Pain and sexuality
• Community integration and consumer involvement

2000s
• Health disparity
• Assistive technology and quality of life
• Obesity and physical/psychosocial health
• Outcome measurement

Tate & Forchheimer, 2002; Chen et al., 2011
References


References (continued)

