



The Spinal Cord Injury Model Systems

National Institute on Disability, Independent Living, and Rehabilitation Research

The Spinal Cord Injury Model Systems (SCIMS) program began with one center in Phoenix, Arizona in 1970 with original funding from the Rehabilitation Services Administration. Over the years, it has grown to a national program with a total of 30 centers having been funded since its inception and is now sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, U.S. Department of Health and Human Services.

Since its beginning, the goal of the model systems program has been to improve care and outcomes for individuals with spinal cord injury (SCI). The model system approach is based on research that demonstrated the superiority of comprehensive versus fragmented SCI care.

The 14 SCIMS centers currently funded (2016–21) by NIDILRR provide a multidisciplinary system of rehabilitation care ranging from emergency services through rehabilitation and reentry into full community life. SCIMS centers also conduct research, provide education, and disseminate information with the goal of improving long-term functional, vocational, cognitive, and quality-of-life outcomes for individuals with SCI. For information on current centers, please go to <http://www.msktc.org/sci/model-system-centers>.

Research

Each SCIMS center conducts research and contributes data to the National Spinal Cord Injury Statistical Center (NSCISC) (<https://www.nscisc.uab.edu/>), located at the University of Alabama at Birmingham.

- **National SCI Statistical Center:** NSCISC 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 center contributes data on pre-injury, injury, acute care, and rehabilitation services and reports on outcomes at 1 and 5 years post-injury and every 5 years thereafter. The largest SCI database in the world, it currently includes information on more than 28,000 individuals with SCI and is a rich source of data for secondary analytic research and conducting prospective investigations of outcomes.
- **Center-specific research:** Each model system conducts SCI research at its own center. Currently, 14 center-specific studies are underway. Areas of research include bowel and bladder health, bone loss, pain, spasticity, depression, locomotor training, upper limb function, wheelchair skills, exercise, self-efficacy, self-advocacy and employment.
- **Multicenter studies:** SCIMS centers also conduct multicenter research or “module studies.” Currently there are 10 module projects underway covering topics such as women with SCI, assistive technology, exercise, and several outcome measures.
- **Collaborative studies:** SCIMS centers may compete for an additional grant that supports multi-institutional studies of outcomes, rehabilitation interventions, clinical practice guidelines, and service delivery. Currently one collaborative study on mobility training is underway.

Dissemination

The SCIMS program is charged with disseminating evidence-based information to patients, family members, healthcare providers, educators, policymakers, and the general public. Centers do this in a variety of ways:

- Peer-reviewed publications
- National professional meetings
- Compilations of database research contributed by SCIMS investigators in books and special issues of “Archives of Physical Medicine and Rehabilitation”

The SCIMS also collaborate with the NIDILRR-funded Model Systems Knowledge Translation Center (<http://www.msktc.org>) to promote the adoption of research findings by stakeholders including rehabilitation professionals, policymakers, and persons with SCI and their family members. Activities include:

- Conducting systematic reviews
- Publishing evidence-based consumer factsheets on topics of interest to individuals with SCI and their caregivers, such as skin care, preventing pressure sores, and managing SCI-related pain.

Accomplishments

- Data from the SCIMS National Database provide critical information about the course of recovery, trends in cause and severity, health service delivery and costs, and treatment and rehabilitation outcomes. This information has provided benchmarks for the judicial system to determine awards for care based on future needs.
- Research conducted at SCIMS centers has influenced standards for the assessment, treatment, and management of persons with SCI nationally and around the world. In collaboration with the American Spinal Injury Association, the Consortium for Spinal Cord Medicine, and Paralyzed Veterans of America, researchers at SCIMS centers have been actively involved in the development of clinical practice guidelines.
- Over time, the research agenda has broadened from an emphasis on acute care to include social and environmental factors, physical functioning, and technology.
- The clinical excellence of the SCIMS provided the foundation from which clinical research focusing on key health issues of persons with SCI grew dramatically in the last 3 decades.
- SCIMS researchers have developed new measurement tools to capture neurological, psychosocial, and emotional functioning as well as participation in community activities.