

The Spinal Cord Injury Model Systems

National Institute on Disability and Rehabilitation Research

The Spinal Cord Injury Model Systems (SCIMS) Centers Program was established in 1970 with original funding from the Rehabilitation Services Administration (RSA). Twenty-six centers received RSA funding until 1995 when funding was moved to the National Institute on Disability and Rehabilitation Research (NIDRR) (Office of the Special Education and Rehabilitative Services (OSERS), U.S. Department of Education). Since 1995, a total of 48 centers across the country have been funded.

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 (2011-2016) by NIDRR provide a multidisciplinary system of rehabilitation care ranging from emergency services through rehabilitation and re-entry 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 a map of 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 (<https://www.nscisc.uab.edu/>) located at the University of Alabama, 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 of outcomes at one and five years post injury and every five years thereafter. The largest SCI database in the world, it currently includes information on more than 26,000 individuals with SCI and is a rich source of data for secondary analytic research and for 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 neuro-pathic bladder, pain, depression, pressure ulcers, respiratory complications, upper limb function and wheelchair seating.
- Multi-center studies: SCIMS centers also conduct multi-center research or “module studies.” Currently there are seven module projects underway covering topics such as employment, assistive technology, depression 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 there are two collaborative studies underway.

Dissemination

The SCIMS is charged with disseminating evidence-based information to patients, family members, health-care 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 NIDRR-funded Model Systems Knowledge Translation Center (<http://www.msktc.org>) to promote adoption of research findings by stakeholders, including rehabilitation professionals, policy-makers 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 provides critical information about the course of recovery, trends in cause and severity, health service delivery and costs, 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 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 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 health issues of persons with SCI grew dramatically in the last three decades.
- SCIMS researchers have developed new measurement tools to capture neurological, psychosocial and emotional functioning as well as participation in community activities.