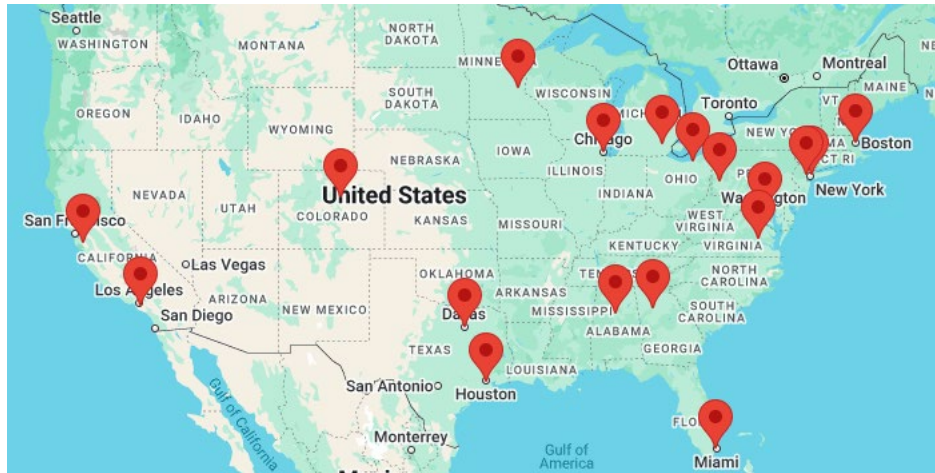


SCI Model Systems Funding (SCIMS)

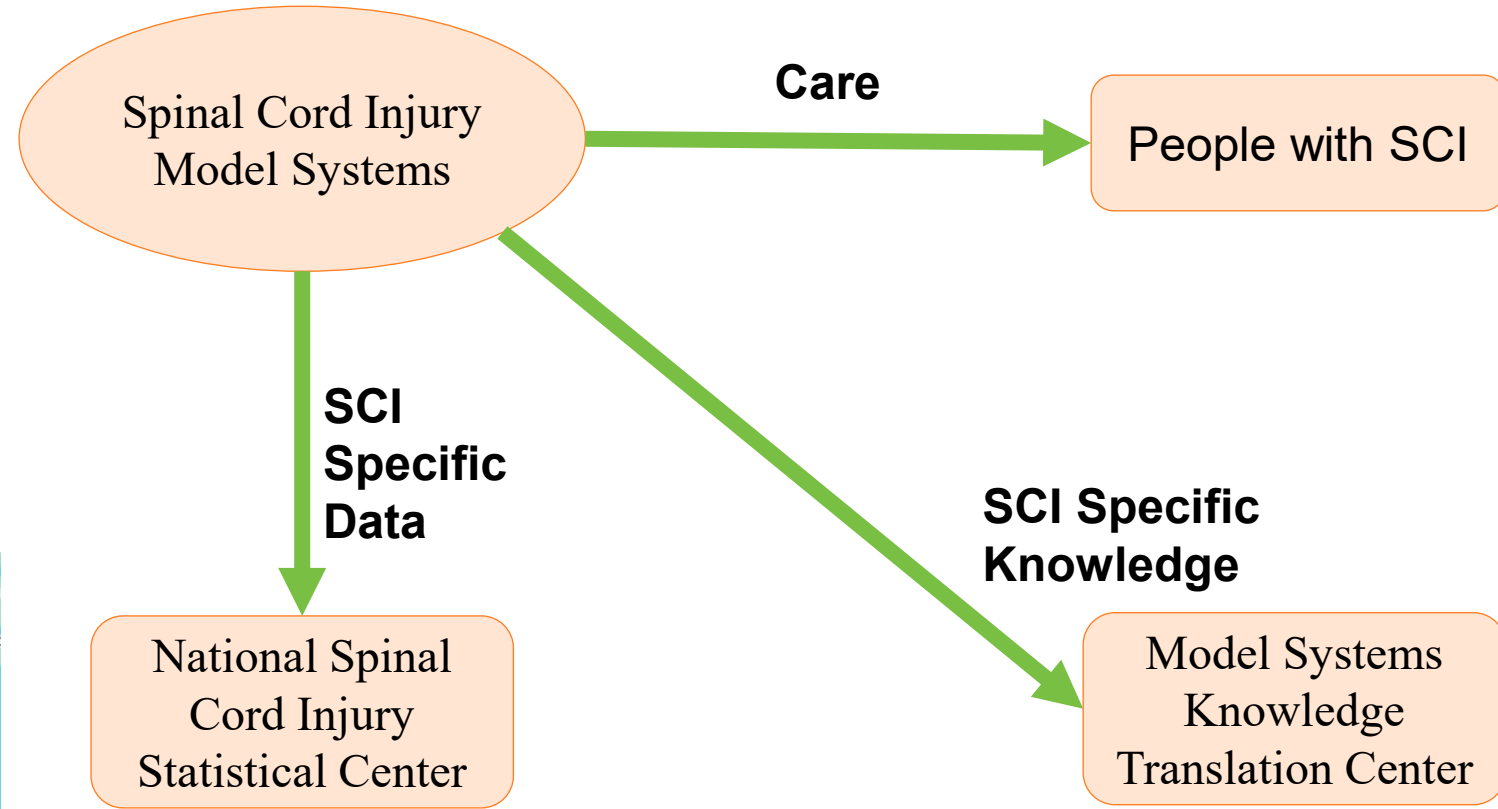
March 25-26, 2025

What is SCIMS?

A network of research and rehabilitation facilities throughout the United States that provide continuous, comprehensive, multidisciplinary care for persons with SCI



What does SCIMS do?



Focus on topics that affect people daily, topics that NIH doesn't focus on.

Current and Previously funded SCIMS centers

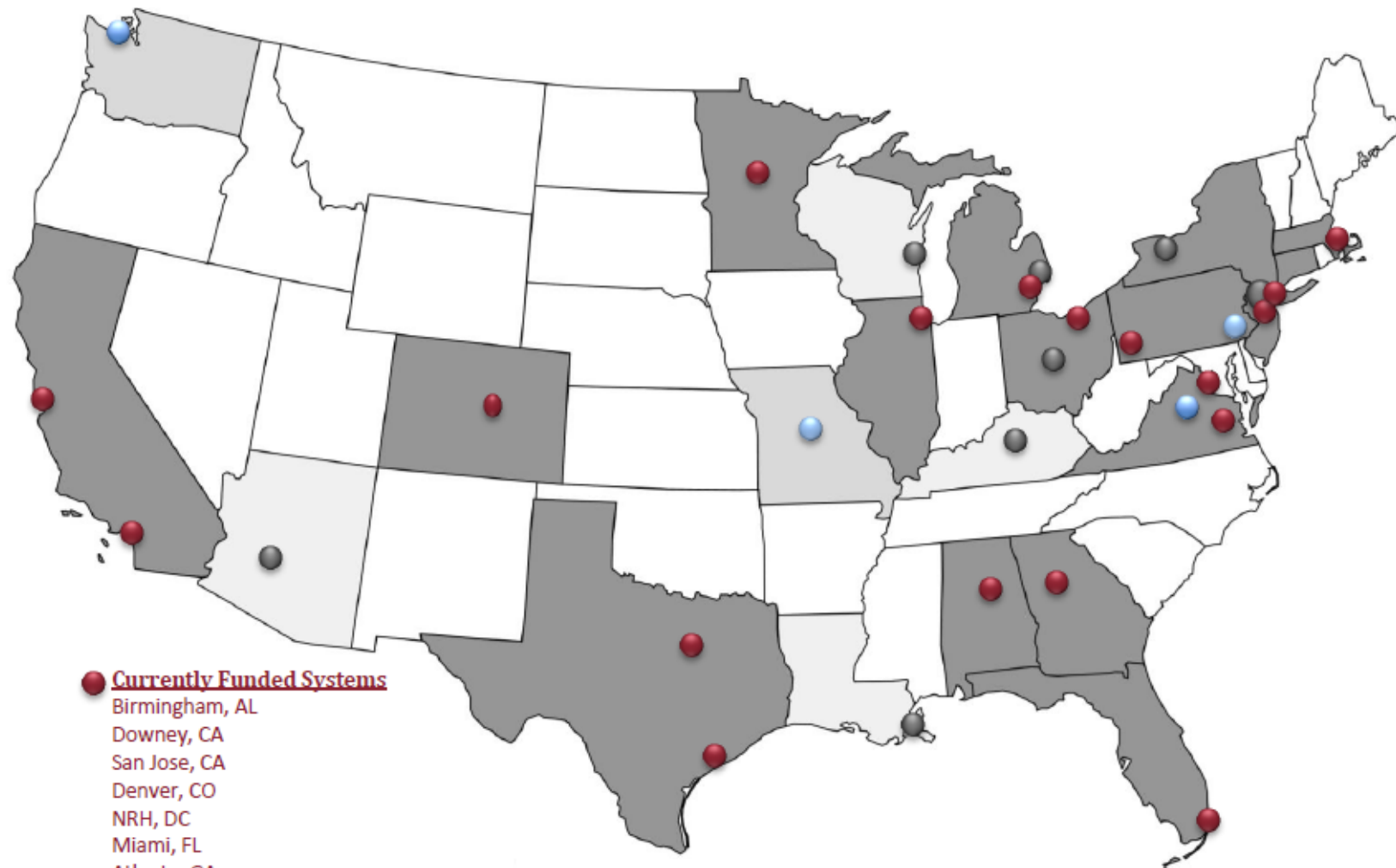
Began in 1970

>50 years of follow-up

>54,000 participants

18 currently funded

32 different centers since 1970



Currently Funded Systems

- Birmingham, AL
- Downey, CA
- San Jose, CA
- Denver, CO
- NRH, DC
- Miami, FL
- Atlanta, GA
- Chicago, IL
- Boston, MA
- Ann Arbor, MI
- Minnesota
- West Orange, NJ
- Mount Sinai, NY
- Cleveland, OH
- Pittsburgh, PA
- Dallas, TX
- Houston, TX
- Richmond, VA

Form II Collection

- Philadelphia, PA
- Seattle, WA
- Columbia, MO
- Fishersville, VA

Previously Funded Systems

- Phoenix, AZ
- Louisville, KY
- New Orleans, LA
- Detroit, MI
- NYU, NY
- Rochester, NY
- Columbus, OH
- Milwaukee, WI

SCIMS Data Use



- Monitor trends over time
 - Causes of injury
 - Age at injury
 - Life expectancy & causes of death
 - Employment, participation, & quality of life
 - Functional outcomes & Independence
 - Length of Stay and Rehabilitation Efficiency
 - Secondary Conditions (ex. Pain, Pressure Injuries)

Defines who & what to focus on to

- PREVENT SCI
- INCREASE Lifespan
- IMPROVE
 - Health, Independence, Quality of Life, Participation, etc...

- Fill SCI Specific Knowledge Gaps
 - Pain, Spasticity, Bladder, Bowel, Wheelchair Skills, Shoulder Pain, etc..

Focus on topics that affect people daily, topics that NIH doesn't focus on.

SCIMS Knowledge Translation & Impact



- Currently 43 Factsheets used daily in Rehab & Outpatient care
- Dissemination & knowledge translation are required for SCIMS centers
- Broad impacts of knowledge
 - Wheelchair, pressure injury, & shoulder pain info is used for ALL wheelchair users
- International Leader in Long-term SCI research

supports and directs the collection, management, and analysis of the National SCIMS Database, the World's largest (>54,000 participants) and longest-running (>50y) SCI research database

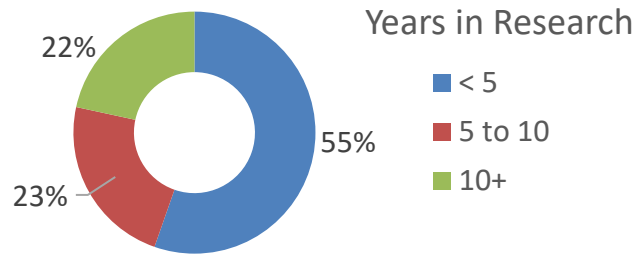
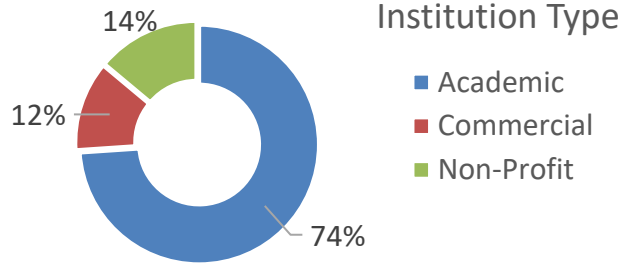


Research & Knowledge Translation

- **Trends over time since 1970s**
 - Who, How, What
 - Prevention & projection (health care needs)
- **Longitudinal course living with SCI**
 - Physical & psychosocial well-being, life expectancy, costs of care
 - Build knowledge to improve care & services,
 - Set rehabilitation standards
 - Inform policy, best practices, and life-care planning
- **Platform for collaboration**

Public Data Access

Research, Education, and Development



Among 560 downloads (Dec 2018-Dec 2024):

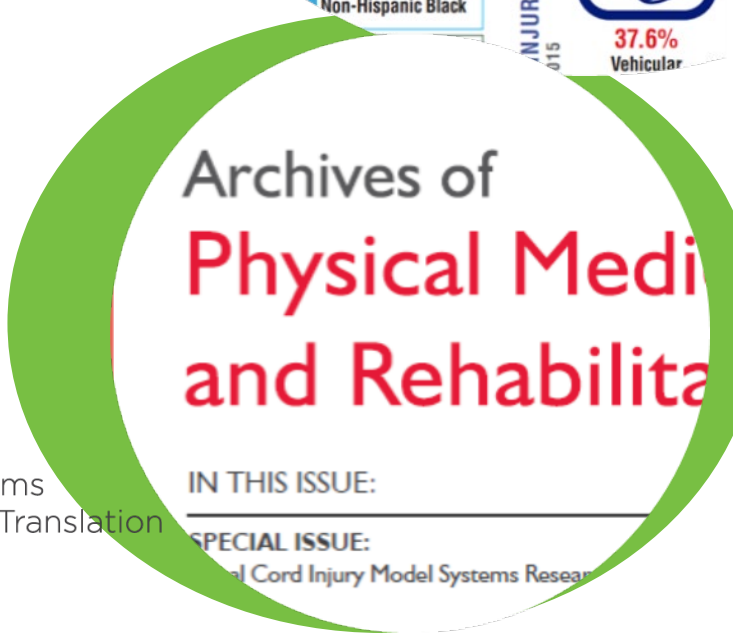
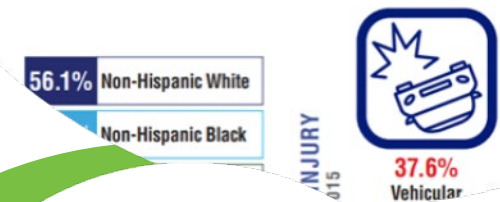
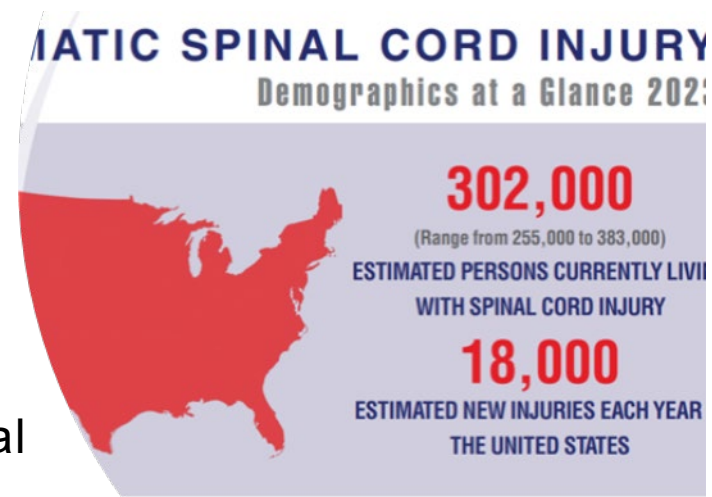
- 83.8% US
- **16.2% Other** – Australia, Brazil, Canada, China, Czech, Finland, Germany, Iceland, India, Iran, Israel, Japan, Korea, Malaysia, Mexico, Romania, Saudi Arabia, Spain, Sweden, Switzerland, Thailand, UK

Community Outreach

- Fact Sheets, Data Sheets, Reports, Special issues
- Online Tool – Life Expectancy Calculator
- Collaboration with MSKTC to develop materials for community outreach



Model Systems
Knowledge Translation
Center



SCIMS Funding History

- Annual funding per center has been flat since 2006
 - Inflation has decreased the purchasing power of 1\$ by 37% since 2006
- Required work per center has increased since FY2000
- SCI Population has increased by 50% since FY2000
 - More annual enrollments and more follow-ups annually
 - Enrollment & follow-up rates are down due to inability to pay for sufficient staff time

SCI Model Systems Funding Asks

Requested Funding at Spinal Cord Injury Model Systems (SCIMS)

SCIMS:

\$17.5 million for 18 centers to account for inflation and 50% growth in SCI population since 2000. Restores funding to 2006 purchasing power

NATIONAL SPINAL CORD INJURY STATISTICAL CENTER:

\$1.9 million - premier source of spinal cord injury-related data in the U.S.

MODEL SYSTEMS KNOWLEDGE TRANSLATION CENTER:

\$2.2 million. MSKTC works with the NSCISC and the SCI Model Systems on research and translating data into useful fact sheets and other products on a range of SCI topics that are used not only in the United States but globally

TOTAL FUNDING REQUEST - \$21.6 million annually