

Tailoring Your Knowledge Translation Strategies for Your Intended Users

KTDRR's 2023 Virtual KT Conference

November 6, 8, and 9

Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**



MRSCICS Matters Newsletter

**Keeping in Touch with Patients Enrolled in the
National SCI Database**

KTDRR's 2023 Virtual Knowledge Translation Conference

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Disclosures – Funding



Midwest Regional Spinal Cord Injury Care System,
NIDILRR (90SIMS0015)

Learning Objectives

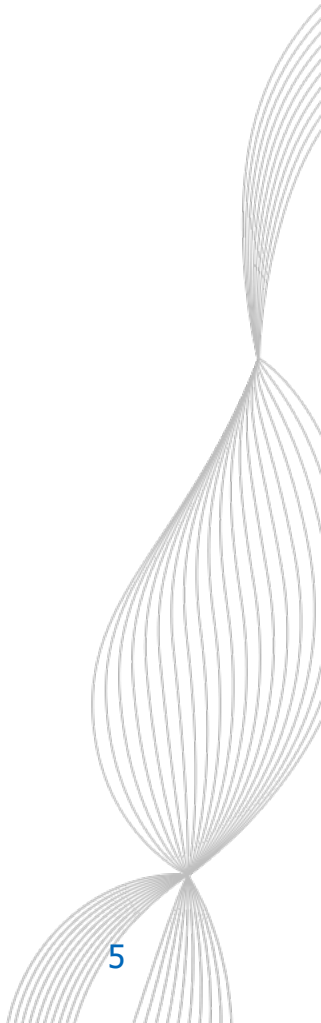


1. What is the National Spinal Cord Injury Database?
2. How is Shirley Ryan AbilityLab involved with the database?
3. Describe the enrollment process and follow-up data collection
4. Why do we need to keep up with enrollees?
5. Describe the MRSCICS Matters newsletter

What does it mean to be a Model System?



1. Highest-quality clinical care
 - Acute care
 - Inpatient rehabilitation
2. Contribute data to the National SCIMS Database
3. Dissemination and knowledge translation



What is the National Spinal Cord Injury Database?



- Established in 1970 to study the long-term outcomes of traumatic spinal cord injury (SCI) and factors that affect that course
 - Demographics
 - Injury characteristics
 - Medical, psychosocial, employment outcomes
- Serves as a research database
 - Centralized, web-based database managed by the National SCI Statistical Center at the University of Alabama, Birmingham
 - 18 SCIMS centers contribute data
 - Deidentified data is available per request

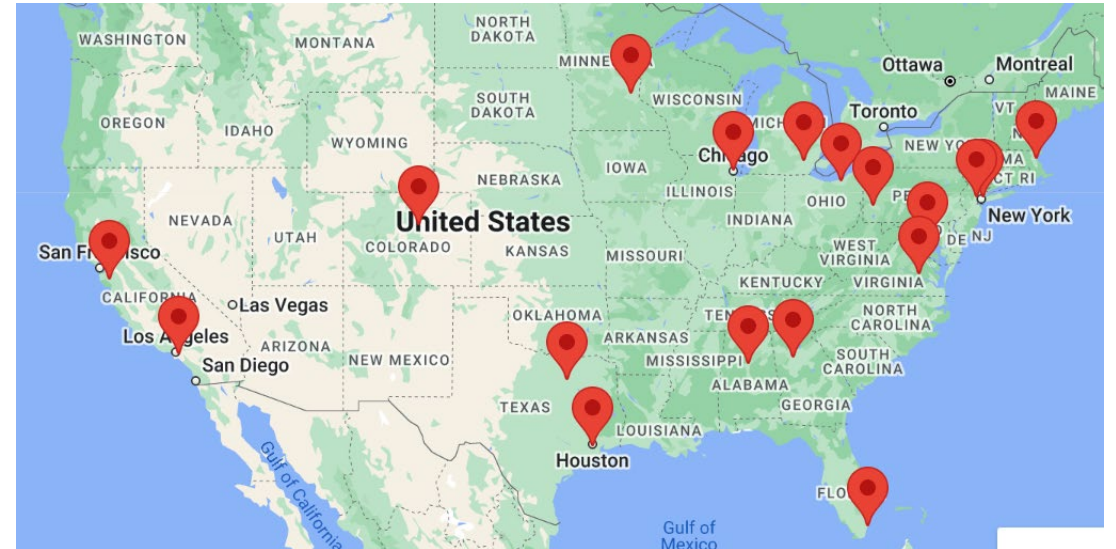
SCI Model System Centers



There are currently 18 active SCI Model Systems of Care.

Shirley Ryan AbilityLab serves as the **Midwest Regional Model System** – involved since 1973.

Centers are funded for 5-year cycles (currently 2021–2026).



SCI Stats from the National Database



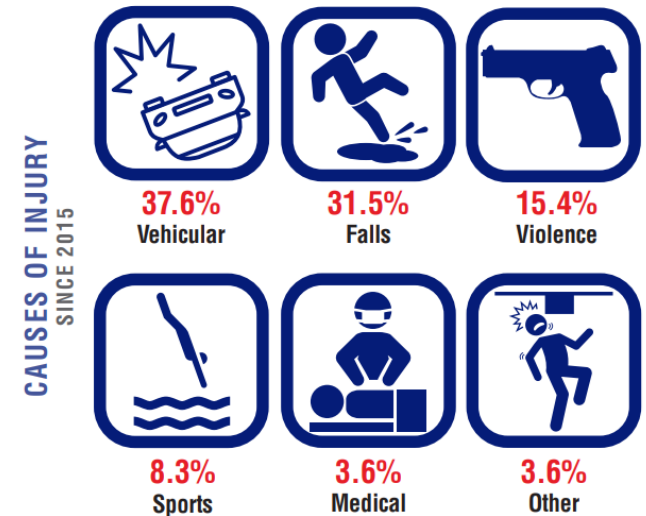
56.1%	Non-Hispanic White
24.7%	Non-Hispanic Black
14.4%	Hispanic
2.6%	Asian
1.7%	Other
.5%	Native American



Between 1970–2022, **36,275** participants enrolled in the national database across **31** total centers.

Estimated 300,000 people living with tSCI in the United States, with approximately 18,000 new injuries per year.

AVERAGE TRENDS OVER TIME		1970s	SINCE 2015
	Age at Injury	29 Years Old	43 Years Old
	Acute Hospital Lengths of Stay	24 Days	12 Days
	Rehabilitation Lengths of Stay	98 Days	31 Days



Citation: National Spinal Cord Injury Statistical Center, Traumatic Spinal Cord Injury Demographics at a Glance 2023. Birmingham, AL: University of Alabama at Birmingham, 2023.

<https://www.nscisc.uab.edu/PublicDocuments/Traumatic%20SCI%20Infographic%20-%20Demographics%20at%20a%20Glance%202023.pdf>

Initial Enrollment during SRAlab Inpatient Rehab



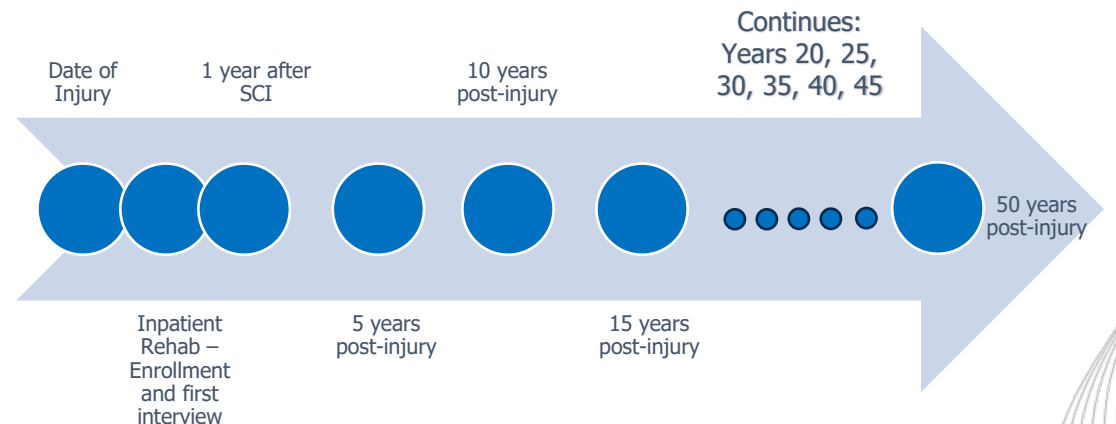
- Approximately 90 new participants each year at SRAlab.
- Patients are enrolled while they complete inpatient rehabilitation.
- After informed consent, research assistants collect information during a brief interview at the time of discharge:
 - Medical history
 - Demographics prior to injury (ex. employment and marital status)
 - Ability to move and feel sensations

Then what?

Long-Term Follow-Up Data Collection



- SRAlab team completes about 200 follow-up surveys per year.
- Enrollees are contacted by phone or email 1 year after their injury, then every 5 years thereafter, for follow-up interviews or surveys.
- Collect information about
 - Socioeconomic status
 - Medical complications
 - Psychosocial well-being
 - Functional abilities
- Participant retention strategies are essential to maintain contact in between 5-year gaps in data collection.
 - People move, change phone numbers/emails, get married/divorced, become incarcerated, require rehospitalization, pass away, etc.



Then what?

Long-Term Follow-Up Data Collection



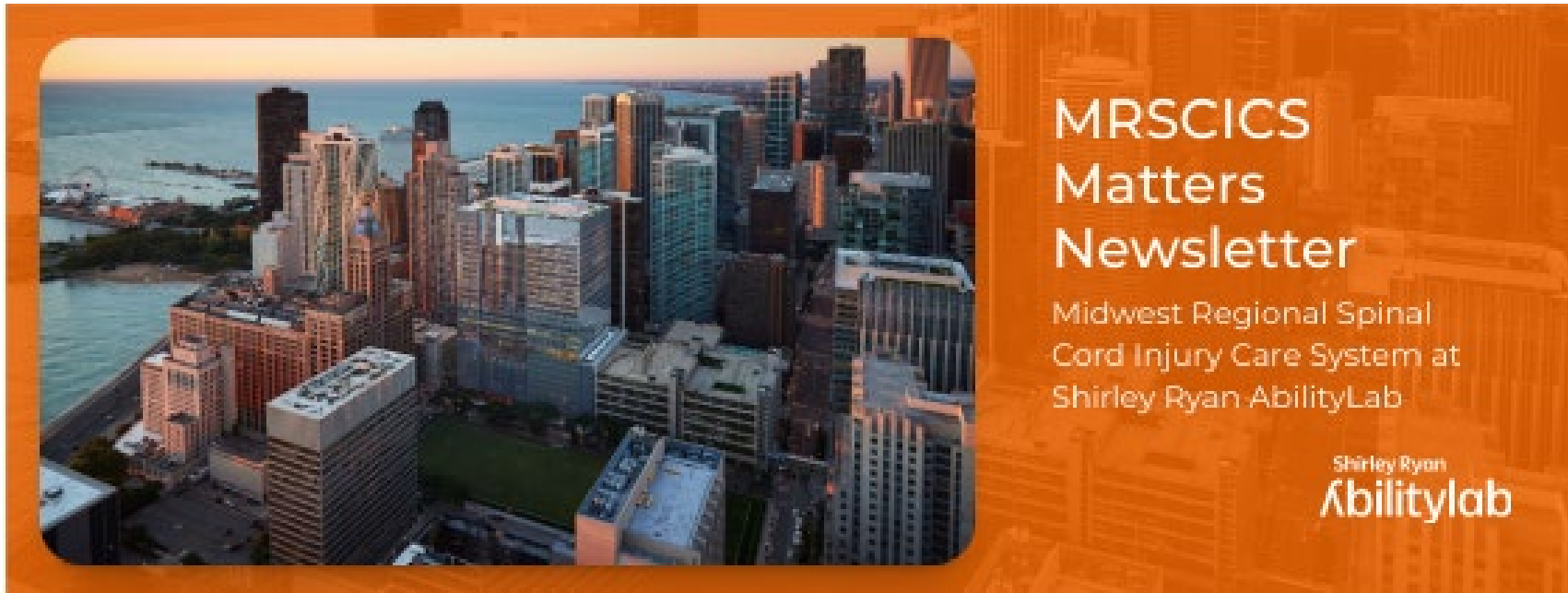
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Staying in Touch



- Birthday and holiday cards
- MRSCICS Matters newsletter
 - Started in 2014 as another way to stay in touch with people in the database in the hope that they would be more likely to complete follow-up interviews





- **About 1,000 subscribers**
 - Mostly participants enrolled in the MRSCICS Database, plus a few collaborators
- **Average open rate of 30% and click rate of 4%**
- Content is:
 - Written in plain language
 - Accessible
 - Interesting and relevant to people living with SCI

<https://www.sralab.org/research/labs/cror/news/mrscics-matters-newsletter-archive>

MRSCICS Matters newsletter content



- Research team member profiles
- New research findings from SCIMS
- MSKTC Factsheets
- SCI research opportunities, current events, educational resources, etc.

New Research Alert!

Have you wondered how researchers use the data that we collect as part of the SCIMS project? These recent papers share new findings that were discovered using information collected from SCIMS participants since 2016.

Robotic supports to help with walking during rehabilitation might be worth the money for people with complete SCI



One of our research scientists, **Dr. Anne Deutsch**, recently published a research paper titled, "Rehabilitation Length of Stay, Body Mass Index, and Functional Improvement among Adults with Traumatic Spinal Cord Injury." The paper used data from the National Spinal Cord Injury Model System Database to



Virtual Support Group for People with SCI, Family and Caregivers

The National Paralysis Resource Center (operated by the Christopher and Dana Reeve Foundation)

Online Fitness Classes for People Living with Paralysis

The National Paralysis Resource Center (operated by the Christopher and Dana Reeve Foundation) is

MSKTC Factsheets



- Factsheets are plain language documents written by SCIMS clinicians and researchers that summarize important topics relevant to people living with SCI.
- Topics include: Depression, Pain, Bladder Management, Driving after SCI, Wheelchair Management, Opioids and Your Health, Aging with SCI, Employment after SCI

<https://msktc.org/sci/factsheets>

Adaptive Sports and Recreation

December 2016 www.msktc.org/sci/factsheets SCI Fact Sheet

This fact sheet explains the important role that adaptive sports and recreation can play after a spinal cord injury (SCI). It also describes different types of sports equipment and points out some health problems to watch for as you participate in sports activities.

Introduction
If you have an SCI, adaptive sports and recreation may be key to your lifelong wellness. These activities may also help you to engage with your community. Many options are available:

- Outdoor recreation activities (for example, adaptive kayaking, fishing, or snow skiing)
- Performing arts (for example, adaptive dance group)
- Individual sports (for example, wheelchair racing or hand cycling)
- Team or competitive sports (for example, wheelchair basketball, wheelchair tennis, quad rugby, or sled hockey)

Even if you have never taken part in sports before, you can find an adaptive activity that is right for you!

Importance of Adaptive Sports and Recreation
An SCI does not have to keep you from being active. Adaptive sports and recreation are good for your health. Without such activity, you may be at higher risk for physical and mental health problems, such as obesity, heart disease, and depression. You may also feel left out if you do not engage in enjoyable activities. Others may assume that you cannot be active just because of your injury.

Adaptive sports and recreation can help you get past these challenges. People with SCI who are involved in adaptive sports and recreation in the community are more likely to

- maintain a positive mood and prevent depression;
- feel more included and empowered in their communities;
- connect with positive mentors and peers with SCI; and
- hold a steady job.

But most of all, adaptive sports and recreation give you a chance to do fun activities with your family and friends.

How To Get Involved in Adaptive Sports and Recreation
You can get involved in adaptive sports and recreation! Here are some tips to make it easier:

1. Think about your goals for participating in adaptive sports and recreation. Goals will be different for everyone. Here are some examples:
 - To do something with your family and friends that everyone will enjoy
 - To make friends by joining a sports team
 - To become physically fit and improve your health
 - To live an active life and enjoy the outdoors
 - To experience the thrill of competing

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/sci/model-system-centers> for more information).





- Access all past editions of the MRSCICS Matters newsletter on our Archives page: <https://www.sralab.org/research/labs/cror/news/mrscics-matters-newsletter-archive>

MRSCICS matters

Winter 2020

Winter 2020 Newsletter

Welcome to the Winter 2020 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at Shirley Ryan AbilityLab, formerly RIC. In this issue, you will read about adaptive sports and fitness, adaptive transportation in Chicago, urinary tract

infections (or UTI's), new research findings, and ongoing research opportunities. If you have any questions, comments, or suggestions, please see the back cover for contact information. Thank you, as always, for participating in spinal cord injury research. Enjoy!



Shirley Ryan AbilityLab Flagship Hospital – Chicago, IL

What is MRSCICS?

MRSCICS is a research study about outcomes after spinal cord injury. When you were an inpatient at Shirley Ryan AbilityLab (formerly RIC), you enrolled in this study and completed your first interview. We contact people one year after their injury for another interview, and then once every five years. The study has been going on since the 1970s, and there are currently

14 hospitals that participate around the United States. The information we collect from you is completely anonymous, and it goes into a big database online that researchers use to collect information about what happens to people after a spinal cord injury. The findings are used to develop treatment plans, community outreach programs, and policies.

Are you due for a follow-up interview?

If your spinal cord injury happened 1, 5, 10, 15, 20, 25, 30, 35, 40 or 45 years ago, it may be time for your next interview! We will contact you by phone, mail or email to schedule a time to complete your interview. If you've moved or changed phone numbers in the past 5 years, we may not have your new information. **To update contact information, please call Jennifer Burns at 312-238-2826, or email jburns03@sralab.org**

INSIDE:

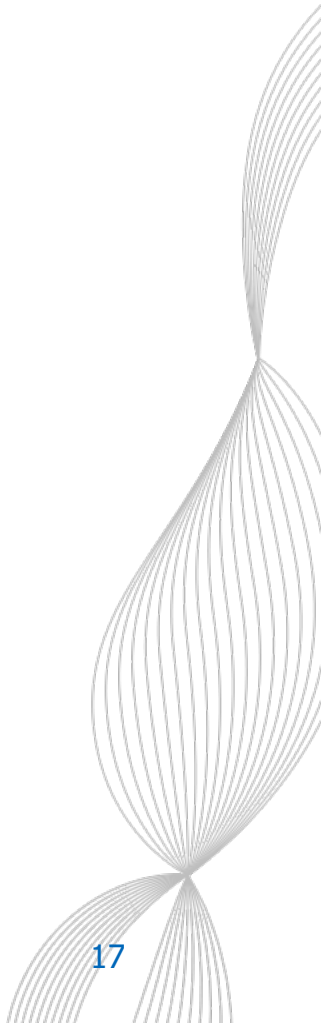
Getting Around Chicago
Accessible transportation options and future projects

Urinary Tract Infections
What are they and why do you get them?

Research Alert
Identifying risk factors for obesity after SCI

Adaptive Sports/Fitness
Why it matters and how to get involved

Questions?





Q&A

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Center on
**KNOWLEDGE TRANSLATION FOR
DISABILITY & REHABILITATION RESEARCH**