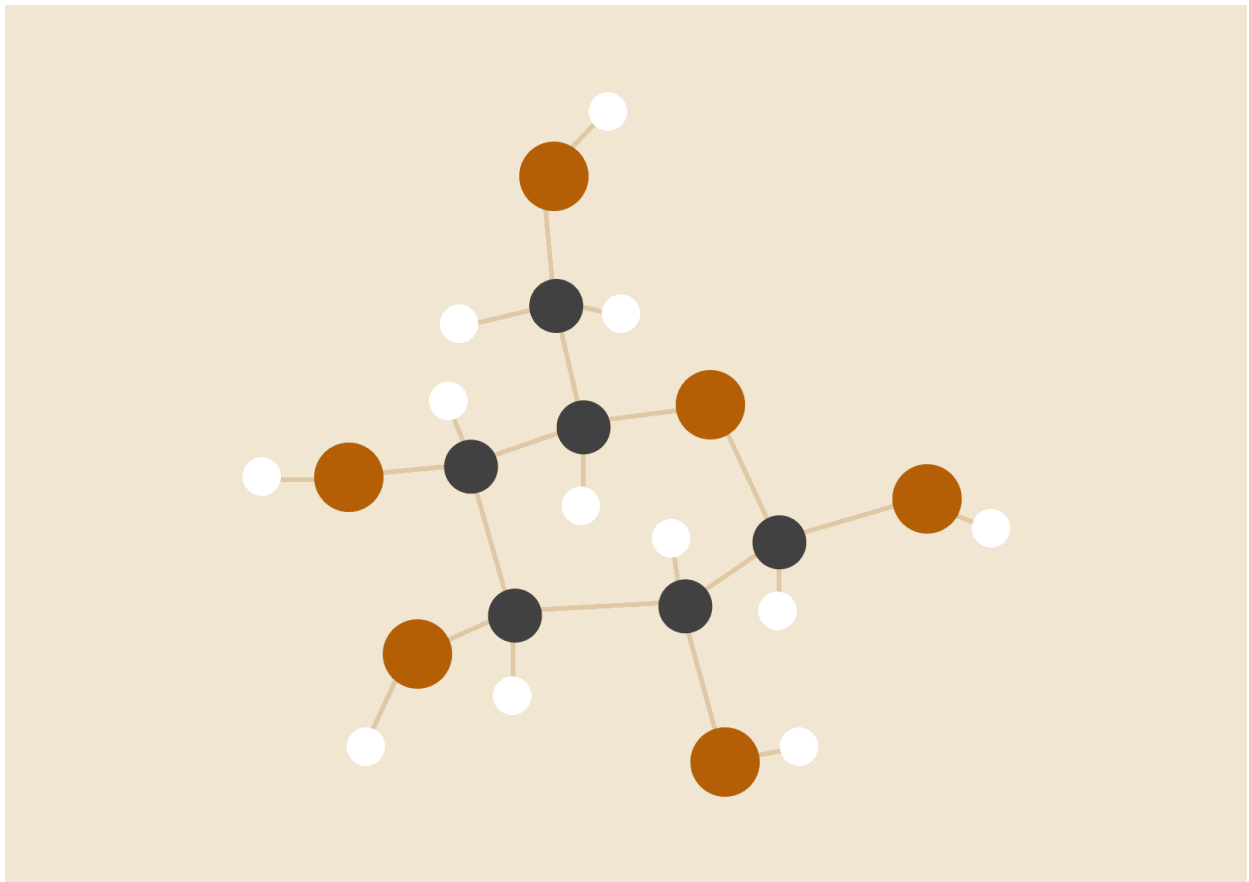


SCI-Powered Network

Information Tools for SCI Artificial Intelligence/LLM Learning



FINAL

04.07.2025

INTRODUCTION

Today, people living with SCI are inundated with information, some of which is helpful or accurate while others can be misleading or harmful. From a one-year series of roundtable discussions with SCI advocacy and resource organizations, NASCIC uncovered this real-world experience as well as the need to harmonize information across groups to identify what can be trusted quickly and efficiently. NASCIC also uncovered that despite the breadth of resources currently available, people living with SCI still feel information-deprived and have difficulty finding trustworthy, credible, practical, and accessible information.

Created from feedback from the SCI lived experience community, NASCIC formed the SCI-Powered Network to begin the first stages of addressing the information gap. There are 3 elements to this overall effort:

1. Information Needs SCI Community Survey
2. SCI Seal of Approval
3. Design Criteria Report - Information tools for SCI Artificial Intelligence (AI)/LLM Learning attributes

This report highlights element three, Information tools for SCI AI/LLM learning attributes. After discussions with the SCI-PN Working Group, it was apparent that any modern information source will need to use AI/LLM tools to remain updated, search and help evaluate resources for people living with SCI. These sources can then be used by information dissemination professionals to aid the SCI community. This exercise is to build community-driven resources to help train AI/LLM tools for the future. This specifications document outlines the aims of this project, the methodology, and the results to help inform SCI-specific health information dissemination.

PROJECT AIMS

The aims of these efforts are two-fold. First, we identified key attributes for a resource dissemination solution. Second, we identified and vetted important features for the SCI community. The community-driven framework used to comprise the SCI Seal of Approval was also used for the SCI AI/LLM learning attributes.

METHODOLOGY

The information provided in the results section was derived from two sources. The first was an initial framework of a condition repository. Information was initially gathered and then vetted

through the Working Group. The vetting process was done through a series of e-Delphi surveys with the group followed by group discussions. We also gathered the most commonly referenced resources from our community leaders. The intent was not to be exhaustive but to provide resources that the community finds useful. The second source for the results is the community survey. Through this exercise, we added to the results for any items that were missing from the Working Group.

HOW TO USE

It is important to understand how to use the results. The information is segmented into categories, which have data listed. These categories and data sets should be used to train an AI/LLM algorithm to learn from the community-driven data to find new and old resources that meet the criteria listed in Part II of this project.

However, the AI/LLM tool cannot be left unmonitored or unsupervised. The AI/LLM tools should be designed for efficiency and not for validation. The resources found with the AI/LLM tool must be vetted by at least one member of a review panel to confirm that nefarious information is excluded.

The following are the categories of information:

Category Name	Description
SCI Conditions & Symptoms	Common primary and secondary conditions and symptoms related to SCI
Categorization/Tags	Groupings of information for people living with SCI to easily find
Specialists seen by people living with SCI	Common clinicians seen by people living with SCI
Frequently Asked Questions by people living with SCI	Common questions asked by people living with SCI at various stages of injury/diagnosis: ICU/Acute, Subacute/Rehab, Transition Home, Community living
Treatments	Common treatments for spinal cord injury at various classifications
SCI Clinics	Clinics for SCI both in the U.S. and Canada

Common Useful Products	These are common everyday products used by people with SCI. This list is not exhaustive but intended as an AI/LLM training tool.
Common SCI Information Resources	Resources gathered from the SCI Powered Network Working Group and Community Survey

RESULTS

Each section of the results includes a category or label along with recommended attributes for each category. These attributes and categories may be used to inform or train AI/LLM tools for the SCI community.

SCI Conditions/Symptoms

This category includes health consequences, symptoms, and secondary health effects of spinal cord injury. The 64 listings are in no particular order:

- Spasticity (Muscle spasms, muscle stiffness, involuntary muscle contractions)
- Joint and muscle pain (arthralgia, myalgia)
- Contractures (joint stiffness, limited range of motion)
- Heterotopic ossification (formation of bone in soft tissues)
- Osteoporosis (bone density loss)
- Postural orthostatic tachycardia syndrome (POTS)
- Orthopedic issues (scoliosis, fractures)
- Gait disturbances
- Reduced muscle mass (muscle wasting)
- Upper limb paralysis or muscle weakness
- Lower limb paralysis or muscle weakness
- Trunk/Core paralysis or muscle weakness
- Neurogenic bladder (dysfunction of the bladder due to nerve damage, including urinary retention, incontinence)
- Urinary tract infections
- Kidney stones or infections
- Bowel dysfunction (including constipation, bowel incontinence)
- Neurogenic bowel (loss of bowel control due to nerve damage)
- Gastrointestinal problems (gastroesophageal reflux disease, peptic ulcers)
- Sexual dysfunction (erectile dysfunction, loss of libido)
- Loss of sensation and/or proprioception

- Chronic pain (musculoskeletal pain, neuropathic pain)
- Neurogenic pain (pain due to nerve damage)
- Chronic inflammation
- Edema
- Depression
- Anxiety
- Anger, frustration, or distress
- Isolation (social withdrawal, loneliness)
- Cognitive health (memory problems, difficulty concentrating)
- Post-traumatic stress disorder (PTSD)
- Mental Health Adjustments/Coping to or with SCI
- Substance abuse disorders
- Cognitive fatigue
- Impaired executive function
- Adaptive coping strategies
- Reduced quality of life
- Relationship issues (marital, children, family, caregivers)
- Autonomic Dysreflexia
- Hypertension (high blood pressure)
- Orthostatic hypotension (low blood pressure when changing positions)
- Impaired temperature regulation (heat and/or cold intolerance, inability to sweat)
- Physical Fatigue
- Excessive sweating (hyperhidrosis)
- Autonomic dysfunction (dysregulation of autonomic nervous system)
- Syringomyelia (cyst formation in the spinal cord)
- Tethered spinal cord (abnormal attachment of the spinal cord)
- Reactions to medications (side effects, adverse drug reactions)
- Visual impairment (blurred vision, double vision)
- Hearing loss (sensorineural hearing loss, conductive hearing loss)
- Speech difficulties (dysarthria, aphasia)
- Sleep problems (insomnia, sleep apnea)
- Respiratory muscle weakness (difficulty breathing)
- Respiratory problems (including pneumonia, atelectasis)
- Cardiorespiratory complications
- Cardiovascular disease (heart disease, stroke)
- Deep vein thrombosis (blood clots in deep veins)
- Endocrine disorders (thyroid dysfunction, adrenal insufficiency)
- Dysphagia (difficulty swallowing)

- Weight or eating problems (malnutrition, obesity)
- Falls or other injuries (fractures, traumatic brain injury)
- Burns (thermal burns, chemical burns)
- Skin problems (pressure sores, ulcers, dermatitis)
- Increased risk of infections
- Aging Complications

Categorization/Tags

This category includes labels or tags that may be used to classify or organize information.

- Physical Health: Mobility
- Physical Health: Autonomic Health
- Physical Health: Pediatrics
- Physical Health: Women
- Physical Health: Other
- Mental Health
- Lifestyle
- Sports, Recreation & Fitness
- Tools & Technology
- Home Modifications & Adaptive Equipment
- Life with SCI (replaced Health Journey)
- Advocacy
- Aging
- Caregiver
- Finances/Employment
- Relationships
- Mobility Equipment
- Nutrition & Wellness
- Adaptive Driving
- Travel
- Support Network
- Alternative Rehabilitation Services
- Parenting with SCI
- Sexual Health
- Social, Cultural, and Environmental Barriers (social determinants of health)
- Miscellaneous (replaced Resources)

Specialists seen by people living with SCI

This category includes medical or technical specialists seen or consulted by people living with spinal cord injuries.

- Physical Therapists
- Occupational Therapists
- Rehabilitation Physicians or Psychiatrists
- Registered Nurse
- Neurologists
- Neurosurgeons
- Orthopedic surgeon
- Urologists
- Gastroenterologist
- Pain Management Specialists
- Registered Respiratory Therapists
- Speech Language Pathologist
- Psychologists/ Psychiatrist
- Case Managers
- Dietitians/ Nutritionists
- Vocational Rehabilitation Counselor
- Social worker
- Recreation Therapists
- Clinical Pharmacists
- Sexual Health Specialists
- Wound Care Specialists
- Endocrinologists
- Assistive Technology Specialist

Frequently Asked Questions by people living with SCI

This category includes frequency asked questions that are posed by people living with spinal cord injury at various stages of their journey.

Question		Stage
What is a spinal cord injury?		ICU/Acute
What is the difference between complete and incomplete spinal cord injuries?		ICU/Acute
How long will I be in the hospital/rehabilitation center?		ICU/Acute

What immediate interventions can I expect?		ICU/Acute
Can you help me understand what my injury means?		ICU/Acute
How might my health be impacted?		ICU/Acute
How do I choose a Rehabilitation Center?		ICU/Acute
I have no health insurance; how can I get care?		ICU/Acute
How will my injury affect my bladder and bowel control?		Subacute/Rehab
Are there clinical trials I can qualify for?		Subacute/Rehab
How can I locate funding for rehabilitation and equipment?		Subacute/Rehab
What are the risks of secondary complications?		Subacute/Rehab
How will this injury affect my sexual function?		Subacute/Rehab
How will my injury impact my mental health?		Subacute/Rehab
Are there any new treatments or research developments I should know about?		ICU/Acute
How do I manage chronic pain?		Subacute/Rehab
What are the signs of autonomic dysreflexia and how do I manage it?		Subacute/Rehab
What role does family support play in my recovery?		Subacute/Rehab
How do I manage my energy levels and avoid fatigue?		Subacute/Rehab
Will I ever regain sensation or movement?		ICU/Acute
How will my daily routine change?		Subacute/Rehab
How do I tell my family and friends about my injury?		ICU/Acute
What is spinal shock and how long will it last?		ICU/Acute
How soon can I start rehabilitation?		ICU/Acute
What can I expect during my hospital stay?		ICU/Acute
How do I manage my relationship with my partner? family? children? friends?		Subacute/Rehab

Is this permanent?		ICU/Acute
What changes will I need to make to my home?		Transition Home
Can I drive a car?		Transition Home
When should I apply for social assistance?		Transition Home
Will I be able to have children?		Transition Home
What kind of support will I need at home?		Subacute/Rehab
What financial resources are available to help with my care?		Transition Home
What kind of equipment will I need?		Transition Home
Can I return to work or school?		Transition Home
How will this injury affect my life expectancy?		Subacute/Rehab
What should I do if I experience severe pain or new symptoms?		Subacute/Rehab
How can I stay active and maintain my health?		Transition Home
How can I connect with a peer-to-peer support group?		Transition Home
How can I prevent pressure sores?		Subacute/Rehab
How do I manage spasticity?		Subacute/Rehab
Can I travel with a spinal cord injury?		Transition Home
How can I improve my independence at home?		Subacute/Rehab
What should I do in case of an emergency?		Subacute/Rehab
How can I stay connected with others?		Transition Home
What are my options for home health care?		Transition Home
How do I handle changes in my body image and self-esteem?		Transition Home
What vocational training and education opportunities are available?		Transition Home
How can I ensure my caregivers are properly trained?		Subacute/Rehab
What are the signs of complications I should watch for?		Subacute/Rehab
How can I stay motivated during my recovery?		Subacute/Rehab
How do I transition from hospital to home?		Transition Home

How do I choose the right wheelchair?		Subacute/Rehab
How do I adapt my home and/or vehicle?		Subacute/Rehab
Are there funding sources to help with adaptations of my home or vehicle?		Subacute/Rehab
How do I manage my relationship with PCAs?		Transition Home
How do I get a ramp quickly for low cost so I can go home?		Transition Home
How do I get/pay for care so I can go home instead of a facility?		Subacute/Rehab
How will I get my needs met w/o feeling like a problem/burden?		Subacute/Rehab
Will I have a good quality of life?"		Transition Home
How will I be able to parent my children?		Subacute/Rehab
Will I need to live in a facility?		Subacute/Rehab

Treatments

This category includes a sample of possible treatments for people living with spinal cord injury at various stages of their journey.

Treatment Phase	Broad Treatment Description
Acute Phase Treatments	Immobilization and Stabilization: Immediate immobilization of the spine to prevent further damage.
Acute Phase Treatments	Medications: Corticosteroids: Such as methylprednisolone, to reduce inflammation and swelling
Acute Phase Treatments	Medications: Pain Management: Medications to manage pain and discomfort
Acute Phase Treatments	Surgical Interventions: Decompression Surgery: To relieve pressure on the spinal cord.
Acute Phase Treatments	Stabilization Surgery: Using rods, screws, or bone grafts to stabilize the spine.
Acute Phase Treatments	DVT prevention

Acute Phase Treatments	Neuroprotection
Rehabilitation Phase	Physical Therapy: Exercises to improve strength, flexibility, and mobility.
Rehabilitation Phase	<u>Occupational Therapy</u> : Training to help perform daily activities independently
Rehabilitation Phase	<u>Assistive Devices</u> : Use of wheelchairs, braces, and other devices to aid mobility and function.
Rehabilitation Phase	<u>Electrical Stimulation</u> : Techniques such as functional electrical stimulation (FES) to stimulate muscle movement and improve function
Rehabilitation Phase	<u>Activity-based Therapy</u> : Techniques used for repetitive mobility or assistive mobility such as robotic-assisted exercise or exoskeletons.
Rehabilitation Phase	Respiratory Therapy
Rehabilitation Phase	Assistive Technology
Long-term Treatments and Emerging Therapies	<u>Neurorehabilitation</u> : Advanced rehabilitation methods, including robotic exoskeletons and virtual reality training.
Long-term Treatments and Emerging Therapies	<u>Pain Management</u> : Ongoing management of chronic pain through medications, physical therapy, and psychological support.
Long-term Treatments and Emerging Therapies	<u>Bladder and Bowel Management</u> : Techniques and devices to help manage bladder and bowel function.
Long-term Treatments and Emerging Therapies	<u>Spasticity Management</u> : Medications and therapies to manage muscle spasticity and improve comfort and function.
Long-term Treatments and Emerging Therapies	<u>Neuroprosthetics & Neuromodulation</u> : Use of electrical stimulation to modulate systems, muscles or nerves for functional use.
Long-term Treatments and Emerging Therapies	<u>Alternative Therapies</u> : Non-conventional therapies such as acupuncture, yoga, hyperbaric oxygen therapy
Long-term Treatments and Emerging Therapies	Sexuality/Fertility

Long-term Treatments and Emerging Therapies	Cardio and Strength Fitness
Long-term Treatments and Emerging Therapies	Nutrition
Long-term Treatments and Emerging Therapies	Nutrition
Psychosocial Support	Counseling and Therapy: To address the emotional and psychological impact of SCI.
Psychosocial Support	Support Groups: Connecting with others who have experienced similar injuries for mutual support and encouragement.
Psychosocial Support	Relationship Counseling: To address relationships with partners, family, children or other loved ones
Psychosocial Support	Vocational Rehabilitation: Training and support to return to work or school.
Psychosocial Support	Adaptive recreation
Psychosocial Support	Cognitive Behavior Therapy
Research and Future Directions	<u>Gene Therapy</u> : Investigating genetic approaches to repair or compensate for spinal cord damage.
Research and Future Directions	<u>Biomaterials</u> : Development of scaffolds and other materials to support tissue regeneration.
Research and Future Directions	<u>Neuroprotective Agents</u> : Research into drugs that can protect nerves and promote recovery.
Research and Future Directions	<u>Stem Cell Therapy</u> : Research is ongoing into the use of stem cells to repair spinal cord damage.
Research and Future Directions	<u>Regenerative Medicine</u> : Techniques aiming to regenerate damaged spinal cord tissue.
Research and Future Directions	Neuromodulation: epidural stimulation, vagus nerve stimulation

SCI Clinics in Canada and the U.S.

This category includes clinics with some form of expertise in spinal cord injury rehabilitation.

Name of Clinic	Location	Website
Adventist HealthCare Rehabilitation at White Oak	Maryland, USA	https://www.adventisthealthcare.com/locations/profile/rehabilitation-inpatient-white-oak/
Alta Bates Summit Medical Center - Acute Rehabilitation Center (ABSMC)	California, USA	https://www.sutterhealth.org/absmc/services/physical-therapy-rehabilitation/alta-bates-summit-regional-acute-rehabilitation-center
BAPTIST HEALTH Rehabilitation Institute (BHRI)	Arkansas, USA	https://www.baptist-health.com/
Baylor Scott & White Spinal Cord Injury Model System	Texas, USA	https://www.bswrehab.com/professionals/research-and-innovation/scims-research-page/
Baylor Scott and White Institute for Rehabilitation Dallas (BSWIR-Dall)	Texas, USA	https://www.bswrehab.com/
Blusson Spinal Cord Centre	British Columbia, Canada	https://www.vch.ca/en/location-service/spinal-cord-injury-outpatient-program-blusson-spinal-cord-centre
Brooks Rehabilitation Hospital	Florida, USA	https://brooksrehab.org/
Bryn Mawr Rehabilitation Hospital (BMRH)	Pennsylvania, USA	https://www.mainlinehealth.org/specialties/rehabilitation
California Pacific Regional Rehabilitation Center (CPRRC)	California, USA	https://www.sutterhealth.org/cpmc/services/physical-therapy-rehabilitation
California Rehabilitation Institute	California, USA	https://www.californiarehabinstitute.com/
Carolinas Rehabilitation (CR)	North Carolina, USA	https://atriumhealth.org/medical-services/specialty-care/rehabilitation
Central Virginia VA Health Care System - Spinal Cord Injury and Disorders Service (VAMC)	Virginia, USA	https://www.va.gov/richmond-health-care/
Central Virginia VA Health Care System (CVHCS)	Virginia, USA	https://www.vcuhealth.org/services/physical-medicine-and-rehabilitation/our-care/spinal-cord-medicine
Centre for Neuro Skills – Sweet Grass	Texas, USA	https://www.neuroskills.com/
Charlie Norwood VA Medical Center - SCI (SCI)	Georgia, USA	https://www.va.gov/augusta-health-care/
CHI Health - Immanuel Rehabilitation Institute (IRI)	Nebraska, USA	https://www.chihealth.com/services/rehabilitation

Clement J. Zablocki VA Medical Center Spinal Cord Injury Program (VAMC-SCI)	Wisconsin, USA	https://www.va.gov/milwaukee-health-care/
Cleveland Clinic Rehabilitation Hospital, Beachwood	Ohio, USA	https://my.clevelandclinic.org/locations/rehabilitation-hospital
Cottage Rehabilitation Hospital of Santa Barbara Cottage Hospital (CRH)	California, USA	https://www.cottagehealth.org/services/rehabilitation/
Craig Hospital	Colorado, USA	https://craighospital.org/research
DMC Rehabilitation Institute of Michigan (RIM)	Michigan, USA	https://www.rimrehab.org/
ECU Health – ECU Health Medical Center (VMC-Rehab)	North Carolina, USA	https://www.ecuhealth.org/
Foothills Medical Centre	Alberta, Canada	https://www.albertahealthservices.ca/findhealth/Service.aspx?id=1791&serviceAtFacilityID=1047469
Frazier Rehab Institute	Kentucky, USA	https://uoflhealth.org/locations/Frazier-rehabilitation-institute/
Gaylord Hospital, Inc. - Rehabilitation Division	Connecticut, USA	https://www.gaylord.org/
GF Strong Rehabilitation Centre	British Columbia, Canada	https://www.vch.ca/en/location-service/inpatient-spinal-cord-injury-program-gf-strong-rehabilitation-centre
Glenrose Rehabilitation Hospital	Alberta, Canada	https://www.albertahealthservices.ca/findhealth/Service.aspx?id=4139&serviceAtFacilityID=1006209
GlobalRehab dba HonorHealth Rehabilitation Hospital (HHRH)	Arizona, USA	https://www.honorhealth-rehab.com/
Good Shepherd Rehabilitation Hospital (GSRH)	Pennsylvania, USA	https://www.goodshepherdrehab.org/
Grace Hospital (acute and rehab)	Manitoba, Canada	https://gracehospital.ca/about/patient-care-programs/
Hamilton General Hospital	Ontario, Canada	https://www.hamiltonhealthsciences.ca/about-us/our-organization/our-locations/hamilton-general-hospital/
Hamilton Regional Rehabilitation Centre	Ontario, Canada	https://www.hamiltonhealthsciences.ca/areas-of-care/rehabilitation/inpatient/spinal-cord-injury-program/
HMH JFK Johnson Rehabilitation Institute	New York, USA	https://www.hackensackmeridianhealth.org/en/locations/hackensack-meridian-jfk-johns

		on-rehabilitation-institute
Hôpital de l'Enfant-Jésus	Quebec, Canada	https://www.chudequebec.ca/centre-hospitaliers/hopital-de-l-enfant-jesus.aspx
Hôpital du Sacré-Cœur de Montréal	Quebec, Canada	https://www.ciusssnordmtl.ca/installations/hopitaux/hopital-du-sacre-coeur-de-montreal/
Hospital of the University of Pennsylvania/Penn Medicine Rehabilitation (Penn Rehab)	Philadelphia, USA	https://pennrehab.org/
Inpatient Acute Rehab Unit at Syracuse VA Medical Center	New York, USA	https://www.visn2.va.gov/
Institut de réadaptation en déficience physique de Québec	Quebec, Canada	https://www.ciusss-capitalenationale.gouv.qc.ca/jhsb/services/services-linguistiques/accs-services-anglais/readaptation
Jackson Memorial/Miami Project/South Florida SCIMS	Florida, USA	https://med.miami.edu/programs/sfscims
James A. Haley Veterans Hospital - SCI/D (JAHVH SCI)	Florida, USA	https://www.va.gov/tampa-health-care/
James J. Peters VAMC - Spinal Cord Injury Service (JJP VAMC)	New York, USA	https://www.va.gov/bronx-health-care/
Kaiser Foundation Rehabilitation Center (KFRC)	California, USA	https://thrive.kaiserpermanente.org/care-near-you/northern-california/napasolano/departments/kaiser-foundation-rehabilitation-center/?kp_shortcut_referrer=kp.org/rehabilitationcenter
Kessler Foundation	New Jersey, USA	https://kesslerfoundation.org/NNJSCIS
L.A. Miller Rehabilitation Centre	Newfoundland and Labrador, Canada	https://www.easternhealth.ca/facilities/dr-la-miller-centre/
l'Institut deréadaptation Gingras-Lindsay-de-Montréal Rehabilitation Institute (IRGLM)	Quebec, Canada	https://ciusss-centresudmtl.gouv.qc.ca/etablissement/institut-de-readaptation-gingras-lindsay-de-montreal-darlington
Lovelace UNM Rehabilitation Hospital, LLC (LUNMRH)	New Mexico, USA	https://lovelace.com/
Lt. Col. Luke Weathers Jr. VA Medical Center - SCI/D	Tennessee, USA	https://www.va.gov/memphis-health-care/
Lynn Rehabilitation Center (LRC)	Florida, USA	https://rehabilitation.jacksonhealth.org/location/christine-e-lynn-rehabilitation-center/

Madonna Rehabilitation Hospital-Lincoln and Madonna Rehabilitation Specialty Hospital-Omaha (MRH)	Nebraska, USA	https://www.madonna.org/
Magee Memorial Hospital for the Convalescents aka Magee Rehabilitation Hospital	Philadelphia, USA	https://www.jeffersonhealth.org/locations/moss-magee-rehabilitation-hospital-center-city
Mary Free Bed Rehabilitation Hospital (MFB)	Michigan, USA	https://www.maryfreebed.com/
MedStar National Rehabilitation Hospital	Columbia, USA	https://www.medstarhealth.org/services/spinal-cord-injury-rehabilitation
MI-SCIMS Michigan Spinal Cord Injury Model System	Michigan, USA	https://disabilityhealth.medicine.umich.edu/research/mi-scims
Michael E. DeBakey Veterans Affairs Medical Center - Spinal Cord Injury Care Line (SCIMEDVAMC)	Texas, USA	https://www.va.gov/houston-health-care/
Minneapolis VA Health Care System - Spinal Cord Injury and Disorders Center (MVAHCS)	Michigan, USA	https://www.va.gov/minneapolis-health-care/health-services/spinal-cord-injury-and-disorder-center-at-minneapolis-va-medical-center/
Minnesota Regional Spinal Cord Injury Model System	Minnesota, USA	https://mnsccms.umn.edu/
Orlando Health Advanced Rehabilitation Institute	Florida, USA	https://www.orlandohealth.com/services-and-specialties/advanced-rehab-institute
Ottawa General Hospital	Ontario, Canada	https://www.ottawahospital.on.ca/en/clinical-services/deptpgmcs/programs/neurospinal-service/
Ottawa Hospital Rehabilitation Centre	Ontario, Canada	https://www.ottawahospital.on.ca/en/clinical-services/deptpgmcs/departments/rehabilitation-centre/about-the-rehabilitation-centre/
Parkwood Hospital	Ontario, Canada	https://www.sjhc.london.on.ca/areas-of-care/spinal-cord-injury-rehabilitation
Prisma Health - Roger C. Peace Rehabilitation Hospital	South Carolina, USA	https://prismahealth.org/locations/hospitals/roger-c-peace-rehabilitation-hospital
Queen Elizabeth II Health Sciences Centre, Halifax Infirmary	Nova Scotia, Canada	https://www.nshealth.ca/clinics-programs-and-services/spine-assessment-clinic
Queen Elizabeth II Health Sciences Centre, Nova Scotia Rehabilitation Centre (rehab)	Nova Scotia, Canada	https://www.nshealth.ca/clinics-programs-and-services/neurology-spinal-cord-injury-program

Rancho Los Amigos National Rehabilitation Center	California, USA	https://www.socalscims.org/
Regional One Health Rehabilitation Hospital (ROH Rehab)	Tennessee, USA	https://www.regionalonehealth.org/
Regions Hospital/Rehabilitation Center	Michigan, USA	https://www.healthpartners.com/care/hospitals/regions/
Rehab Without Walls	Georgia/S. Carolina, USA	https://www.rehabwithoutwalls.com/
Rehab Without Walls - Salt Lake City (RWW)	Utah, USA	https://www.rehabwithoutwalls.com/
Rehabilitation Hospital of Indiana, Inc. (RHI)	Indiana, USA	https://www.rhirehab.com/
Roper Rehabilitation Hospital (RRH)	South Carolina, USA	https://www.rsfh.com/
Royal Alexandra Hospital	Alberta, Canada	https://www.albertahealthservices.ca/findhealth/Service.aspx?id=4195&serviceAtFacilityID=1008522
Saint John Regional Hospital	New Brunswick, Canada	https://horizonnb.ca/facilities/saint-john-regional-hospital/
Santa Clara Valley Medical Center	California, USA	https://scvmc.scvh.org/health-care-services/trauma-center
Shepherd Center	Georgia, USA	https://www.shepherd.org/
Shirley Ryan AbilityLab	Illinois, USA	https://www.sralab.org/conditions/spinal-cord-injury
South Texas Veterans Health Care System - Spinal Cord Injury Center (STVHCS-SCI)	Texas, USA	https://www.va.gov/south-texas-health-care/
Spaulding New England Regional SCI	Massachusetts, USA	https://www.snerscic.org/
Special Tree Neuro Care Center (STNCC)	Michigan, USA	https://www.specialtree.com/
Spinal Cord Injury Research Center at Mount Sinai	New York, USA	https://labs.icaahn.mssm.edu/brycelab/
Spine Center at MetroHealth	Ohio, USA	https://www.metrohealth.org/spine-center
sRIM at Sterling Heights	Michigan, USA	https://www.dmc.org/locations/detail/rehabilitation-institute-of-michigan-sterling-heights-center
St. Joseph's Hospital and Medical Center/Barrow Neurological Institute (SJHMC/BNI)	Arizona, USA	https://www.barrowneuro.org/centers-programs/neurorehabilitation/

St. Michael's Hospital	Ontario, Canada	https://unityhealth.to/areas-of-care/programs-and-clinics/trauma-and-neurosurgery/
Stan Cassidy Centre for Rehabilitation	New Brunswick, Canada	https://horizonnb.ca/horizon-services/provincial-program/stan-cassidy-centre-for-rehabilitation/
Summa Rehab Hospital (SRH)	Ohio, USA	https://summarehabhospital.com/
Sunnybrook Health Sciences Centre	Ontario, Canada	https://sunnybrook.ca/content/?page=centre-spinal-trauma-back-spine-surgery
Texas Rehabilitation Hospital of Fort Worth (TRH)	Texas, USA	https://www.texasrehabhospital.com/
The Ohio State University Wexner Medical Center, Rehabilitation Services (OSUWMC)	Ohio, USA	https://wexnermedical.osu.edu/
The Winifred Masterson Burke Rehabilitation Hospital	New York, USA	https://www.burke.org/medical-services/spinal-cord-injury-medicine-rehabilitation/
TIRR Memorial Hermann	Texas, USA	https://memorialhermann.org/services/treatments/spinal-cord-injury-rehabilitation
Toronto Rehabilitation Institute – Lyndhurst Centre	Ontario, Canada	https://www.uhn.ca/TorontoRehab/Spinal-Cord-Rehab
Toronto Western Hospital	Ontario, Canada	https://www.uhn.ca/Krembil/Inpatient Units/Spinal Neurosurgery
UAB Spinal Cord Injury Model System	Alabama, USA	https://www.uab.edu/medicine/sci/
University Hospital - London	Ontario, Canada	https://www.lhsc.on.ca/icu/brain-spinal-cord-and-nerves
University of Alberta Hospital	Alberta, Canada	https://www.ualberta.ca/rehabilitation/programs/professional-development/microcredential-courses/spinal-cord-injurymanagement-for-healthcare-professionals.html
University of Maryland Rehabilitation & Orthopaedic Institute (UM Rehab)	Maryland, USA	https://www.umms.org/rehab
University of Pittsburgh Model Center on Spinal Cord Injury (UPMC-SCI)	Pennsylvania, USA	https://www.upmc-sci.pitt.edu/
University of Saskatchewan Department of Physical Medicine and Rehabilitation	Saskatchewan, Canada	https://medicine.usask.ca/departments/clinical/physical-medicine.php
UT Southwestern Inpatient Rehabilitation (UTSW)	Texas, USA	https://www.utsouthwestern.edu/

VA Long Beach Healthcare System - Spinal Cord Injury/Disorders Health Care Group (SCI/D HCG)	California, USA	https://www.va.gov/long-beach-health-care/
VA Palo Alto Health Care System, Spinal Cord Injury Service (VAPAHCS)	California, USA	https://www.va.gov/palo-alto-health-care/
VA San Diego Healthcare System - Spinal Cord Injury (VASDHS/SCI)	California, USA	https://www.va.gov/san-diego-health-care/
Veterans Healthcare Administration - Edward Hines Jr. VA Hospital	Illinois, USA	https://www.va.gov/hines-health-care/
WakeMed Rehab	North Carolina, USA	https://www.wakemed.org/
Wascana Rehabilitation Centre and Saskatoon Rehabilitation Centre	Saskatchewan, Canada	https://www.saskhealthauthority.ca/your-health/conditions-diseases-services/rehabilitation-provincial-department-physical-medicine-and-rehabilitation
WellSpan Surgery and Rehabilitation Hospital	Pennsylvania, USA	https://www.wellspan.org/
Winnipeg Health Sciences Centre	Manitoba, Canada	https://hsc.mb.ca/adults/our-services/rehabilitation/

Useful Products

This category includes a broad range of products that people living with spinal cord injury may find useful in their daily lives. This is not an exhaustive list but one to help train a model.

Customized Wheelchairs
Head rest
Head array control
Joystick control
Sip-n-puff control
Lateral supports
Seating systems, pressure relief
Seat elevator
Power leg rests
Standing power chairs
Off road wheelchairs

Natural fit hand rims
Clothing guards
Free Wheel off-road device
Power assist: Smart Drive, Smoove, Navione, etc
Wheelchair brakes, scissor brakes, D-Lock Braking System
Manual standing wheelchair
Beach wheelchairs
Sports wheelchairs
High profile, cushions
Low profile cushions
Customized, often after 'pressure mapping'
Sports cushions
Lapstacker for manual rigid, manual folding & power wheelchairs
Wheelchair backpacks
GRIP Solutions lapboard
Wheelchair luggage carrier
Free Wheel off-road attachment
Lap board
Home, Daily Care, and Lifestyle products
Entry ramps-portable wheelchair suitcase ramps---permanent wheelchair ramps
External/porch wheelchairs lifts
Wheelchair elevators both framed, add on or internal elevators like through the floor wheelchair elevator,
Inclined platform lifts
Roll-in-shower is best overall —built in, tile or modular panels

Shower/commode combination chair such as Invacare Mariner
Swing-away hinges to significantly increase door width for interior wheelchair access
Self-closure spring hinges for both exterior and selected interior doors
Split king adjustable beds with firm mattress for transfer ease or pillow-top for comfort and added pressure relief
ROHO bed toppers for maximum pressure relief
Adjustable bed rails
Full size and minivan modified wheelchair vans, rear and side entry
Vans, SUV's and sedans used for self-transfer
Self-transfer as in standard van transfer
Vehicle hand controls, options include Veigel Compact II
Scott Driving System for high level quads who wish to drive
Portable hand controls
Home automation like Alexa
ADL splints and devices
Door lip thresholds
Adaptive kitchen equipment like electric can openers
Right angle knives
Home environmental controls
Adaptive beds and mattress (like tempurpedic or egg crate)
Walkers
Standing frames
FES bikes

RESOURCES LIST (not exhaustive)

For the resources list, we took a dual approach. First, we asked the SCI-PN Working Group to provide common health resources for SCI. This is the first table listing. Second, we took the responses to the question, “When you have a health problem or question, what are the top 3 information sources that you refer to?” from the SCI Information Needs Assessment survey. This is the second table listing. The resources are grouped by format and are in no particular order.

There are some key distinctions and observations between these listings. The Working Group listing was not provided in the context of a ‘health problem’ but rather key health resources for people living with spinal cord injury. For the survey responses, the question was within the context of a ‘health problem’. While the most common categorized open-ended responses were clinician/doctor, internet search, and peer/support/others living with SCI group (in that order), people also provided specific responses of name resources. The resources highlighted in green are those listings in both tables. It is key to note that the survey respondents identified many general sources that are not specific to SCI. Survey respondents also sighted reasons for choosing their top sources. Common reasons included terms such as easy, access, reliable, trust, knowledgeable, available. It is important to note that regardless of the method of providing information to people living with SCI, it must meet their information appetite and appeal to these specific reasons.

Working Group Resource List

Title	Source	Format	URL or References
Format: Community Forum			
SCIRE Community	Non-profit, evidence-based info for people with SCI and families UBC/Canada	Community Forum	community.scireproject.com
Care Cure Forums	Medically vetted by SCI nurse moderators	Community Forum	https://www.carecure.net/
Spinal Cord Peer Support USA	Facebook	Community Forum	https://www.facebook.com/groups/SCPSUSA

You are not Alone - Dealing with Spinal Cord Injury (Facing Disability)	Facebook	Community Forum	https://www.facebook.com/groups/FacingDisability
Drop Foot and Spinal Cord Injury Support Group	Facebook	Community Forum	https://www.facebook.com/groups/256932597794403/about
The International Network of Spinal Cord Injury Physiotherapists (SCIPT)	Facebook	Community Forum	https://www.facebook.com/groups/190135057682678
Spinal Cord Injury	Facebook	Community Forum	https://www.facebook.com/groups/6173146988/about
Spinal Cord Injury Support Group	Facebook	Community Forum	https://www.facebook.com/groups/1575256319434654
Spinal Cord Injury USA Group	Facebook	Community Forum	https://www.facebook.com/groups/2014869075503756
Spinal Cord Injury Rehabilitation & Recovery	Facebook	Community Forum	https://www.facebook.com/groups/408056109595258
Spinal Cord Injury Walkers	Facebook	Community Forum	https://www.facebook.com/groups/1311153908905293
Women's Spinal Cord Injury Support Group	Facebook	Community Forum	https://www.facebook.com/groups/2113302995648136
United Spinal Association Spinal Cord Injury Support Group	Facebook	Community Forum	https://www.facebook.com/groups/511472059482754
Stem Cell Treatment For Spinal Cord Injury	Facebook	Community Forum	https://www.facebook.com/groups/162913224263321
Wives & Girlfriends of Spinal Cord Injury (SCI) Survivors	Facebook	Community Forum	https://www.facebook.com/groups/wivesgirlfriendsSCIsurvivorsupport
SPINAL CORD PEER SUPPORT USA	Facebook	Community Forum	https://www.facebook.com/groups/SCPSUSA

Spinal Cord Stimulator Support Group	Facebook	Community Forum	https://www.facebook.com/groups/302200546779488
Paralyzed Veterans of America Members	Facebook	Community Forum	https://www.facebook.com/groups/pvamembers
Quadriplegic Life	Facebook	Community Forum	https://www.facebook.com/groups/QuadLife
Quadriplegics Anonymous [The Group]	Facebook	Community Forum	https://www.facebook.com/groups/cripinexile
Reddit Spinal Cord Injuries	Redditt	Community Forum	https://www.reddit.com/r/spinalcordinjuries/
Format: Hard copy & online			
PVA Clinical Practice Guidelines	PVA	Hard copy & online	https://pva.org/research-resources/publication/
PVA Consumer Guides	PVA	Hard copy & online	https://pva.org/research-resources/publication/
Eat well live well w/ SCI	Non-profit, evidence-based information	Hard copy & online	https://www.eatwelllivewellwithsci.com/
PN Magazine	Community-based SCI organization	Hard copy & online	https://pnonline.com/
National Paralysis Resource Center Christopher & Dana Reeve Foundation	Community-based SCI organization	Hard copy & online	https://www.christopherreeve.org/todays-care/paralysis-help-overview/about-the-paralysis-resource-center/
Format: in-person and online			

SCI Nurse Advice Line	Non-emergent SCI medical facility	in-person and online	https://craighospital.org/resources/nurse-advice-line
Kessler Foundation	Academic medical center	in-person and online	https://www.kflearn.org/collections/spinal-cord-injury
Striverts		in-person and online	https://striverts.com
Chanda Center for Health	Community-based SCI organization	in-person and online	https://chandacenter.org/community-resources/
United Spinal Resource Center	knowledge books, peer mentoring, etc.	in-person and online	https://unitedspinal.org/spinal-cord-resources/
Reeve Foundation Paralysis Support	Community-based SCI organization	in-person and online	https://www.christopherreeve.org/todays-care/get-support/
Format: Online			
ASIA Actionable Nuggets	Non-profit, evidence-based information	Online	https://actionnuggets.ca/actionable-nuggets-4th-ed-2019/
SCIRE Project	Non-profit, evidence-based information - UBC/Canada	Online	www.scireproject.com
SCI-BC	Community-based SCI organization	Online	www.sci-bc.ca
Physiopedia	Community based PT evidence (UK)	Online	www.physio-pedia.com
Model System Knowledge Translation Center (MSKTC) SCI factsheets	Gov funded- English & Spanish	Online	https://msktc.org/sci/factsheets

Northwest Regional SCI Center	Academic medical center	Online	https://sci.washington.edu/info/index.asp
Chronic pain toolkit	Gov funded organization or institute	Online	https://aci.health.nsw.gov.au/chronic-pain
FAAST	Gov funded organization or institute	Online	https://faast.org/
Facing Disability	Community-based SCI organization	Online	https://facingdisability.com/
Florida Brain and SCI Resource Center	Community-based SCI organization	Online	https://www.floridahealth.gov/provider-and-partner-resources/brain-and-spinal-cord-injury-program/resource-center/a-z-resources.html
National center on health, physical activity, and disability	Gov funded-English & Spanish	Online	https://www.nchpad.org/
Rehab tool	Community-based SCI organization	Online	http://www.rehabtool.com/resources.html
SCI zone	Community-based SCI organization	Online	https://spinalcordinjuryzone.com/category/info
SCI info pages	Community-based SCI organization	Online	https://www.sci-info-pages.com/
SCI sexual health	Community-based SCI organization	Online	https://scisexualhealth.ca/
SCI/D resource page	Community-based SCI organization	Online	https://makoa.org/sci.htm
SCI health maintenance tool	Non-profit, evidence-based information	Online	https://healthmaintenancetool.com/

Healthcare resources for women w/ SCI	Community-based SCI organization	Online	https://www.hereforwomenwithsci.org/Home
Miami Project healthy living info	Academic medical center	Online	https://www.themiamiproject.org/participant/healthy-lifestyle/
SeePain chronic pain management tool	Non-profit, evidence-based information	Online	https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2023.1197944/full
Backbone	Community-based SCI organization	Online	https://backbonesonline.com/blog/
SCITrials.org	Clinical trials	Online	https://scitrials.org
SCITrialsfinder.net	Clinical trials	Online	https://scitrialsfinder.net/trials
Active Project	Kelly Brush foundation	Online	https://activeproject.kellybrushfoundation.org/programs/
Adapt to Perform	Community-based SCI organization	Online	https://www.youtube.com/channel/UClosZzwrXmjPzDCwD9OcC0A
The Quadcast	Community-based SCI organization	Online	https://www.podchaser.com/podcasts/the-quadcast-1217226
Triumph Foundation Resources	Community-based SCI organization	Online	https://triumph-foundation.org/resources/
Help Hope Live	Community-based SCI organization	Online	https://helphopelive.org

SCI Information Needs Survey Response Resource List

Title	Source	Format
Format: Community Forum		

Spinal Cord Injury USA Facebook Group	Social Media	Community Forum
CareCure	Social Media	Community Forum
Reddit	Social Media	Community Forum
WAGS Facebook Group	Social Media	Community Forum
Spinal Cord Injury Facebook Group	Social Media	Community Forum
YouTube	Social Media	Community Forum
Format: Hardcopy or online		
Book received in Rehab, ie. Yes, you can	Other	Hardcopy or online
Paraplegia News	Community-based SCI organization	Hardcopy or online
Format: in-person		
Friends & Family	Other	in-person
Format: in-person and online		
Shirley Ryan	SCI Medical Center	in-person and online
SCI Organizations (non-specific)	Community-based SCI organization	in-person and online
PVA	Community-based SCI organization	in-person and online
Craig Hospital	SCI Medical Center	in-person and online
SCI Alberta	SCI Medical Center	in-person and online

Shepherd Hospital	SCI Medical Center	in-person and online
Mayo Clinic	Medical Center	in-person and online
Kessler Institute	SCI Medical Center	in-person and online
Christopher & Dana Reeves Foundation	Community-based SCI organization	in-person and online
Triumph Foundation	Community-based SCI organization	in-person and online
United Spinal Association	Community-based SCI organization	in-person and online
Mount Sinai	Medical Center	in-person and online
Kennedy Krieger	SCI Medical Center	in-person and online
Magee	SCI Medical Center	in-person and online
Format: Online		
Medical Journals, such as PubMed searches	Gov funded organization or institute	Online
WebMD	General Health Source	Online
NIH	Gov funded organization or institute	Online
Myhealthyvet	Medical Center	Online
Medline.com	General Health Source	Online
Healthline.com	General Health Source	Online
Spinalcord.com	Community-based SCI organization	Online

MSKTC	Gov funded organization or institute	Online
New Mobility	Community-based SCI organization	Online
UptoDate (Wolters Kluwer)	General Health Source	Online
CDC	Gov funded organization or institute	Online
SCIRE	Community-based SCI organization	Online
NIH	Gov funded organization or institute	Online

CONCLUSION

The objective of this effort was to identify health information attributes, categories, and resources from the SCI community that may be used to build health information distribution methods. These listings can be used to train AI/LLM information source systems. Our team recognizes that in the current environment, a static database or source will never be sufficient to evolve with rapidly changing information. This project was designed to identify key features and attributes that can train an AI/LLM tool to become an evolving information source for people living with SCI. These listings should be used in combination with the findings provided in Part I - SCI Information Needs Survey. In addition, AI/LLM tools need to be combined with human assessment to provide a comprehensive resource tool.

OVERALL SCI-POWERED NETWORK EFFORT

SCI-Powered Network was created through feedback from the SCI lived experience community. This first effort focused on listening to members of the community and gaining feedback for a framework to improve SCI information dissemination. A Working Group of representatives from the SCI lived experience community and community organizations was formed and drove the development and input for the results. There are 3 elements to this overall effort. These are listed below with a brief description.

- Part I - Information Needs SCI Community Survey: This is a survey created by representatives from the SCI community. The survey focused on how people find SCI information, their challenges and suggestions, and impressions of information. Data collection took place from February-June 2024 with 448 qualified responses. Insights from the survey results can help us understand the information needs of people living with SCI.
- Part II - SCI Seal of Approval: This effort is to find a way to help people evaluate information. Here we developed guidance on the framework, ranking criteria, review process, and identification for developing information dissemination tools for the SCI community. A future goal is to create an easily identifiable mark to signal which resources are best for people living with SCI.
- Part III - Information Tools for SCI Artificial Intelligence/LLM Learning: This information was directed by the premise that we can no longer use static databases; the combination of artificial intelligence with human involvement is the tool for the future. Provided in this effort are categories and tools to use to train AI tools and harness human input collaboratively to ensure the right resources are available to the right person at the right time.

All of these elements of the initial effort are interconnected and should be used together.

POSSIBLE ACTIONS

- Explore opportunities for co-branding or partnerships between these organizations to improve access.
- Create methods for access to information sources when and where it is needed.
- Advocate for Telehealth to remain an available option for people living with SCI.
- Build an identifier, like the SCI Seal of Approval, can help people with SCI decipher trusted information.
- Execute a framework for building a system directly for the SCI community should be implemented while including the voice of those from the SCI community.
- Train AI tools with concerted and continuous input from members of the SCI community.
- Combine AI/LLM tools with human assessment to provide a comprehensive resource tool.
- Officer information resource tools should include a combination of key trusted sources for people living with SCI: medical professionals, SCI organizations and SCI peers.
- Address trust-building and community adoption as critical factors, requiring collaboration among organizations and consideration of diverse SCI experiences.
- Implement strategies to focus on usability and leveraging existing trust relationships within the SCI community.

REFERENCES

1. July Summary Notes:
https://docs.google.com/document/d/1wXsZLwi8PuONHuwMTV9DdcxxRVIWdidn/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
2. July Discussion Slides:
https://drive.google.com/file/d/1j55m69EsUmHBNU6X0UZm0U17_lEi0Eql/view?usp=share_link
3. August Summary Notes:
https://docs.google.com/document/d/1PvBLp007VnMKshEM2GBsHfD5zMvSZuPO/edit?usp=share_link&ouid=114323796969939703931&rtpof=true&sd=true
4. August Discussion Slides:
https://drive.google.com/file/d/1-BV1rQ06dOKnOvzAdYCeyUnHtLZKjMrg/view?usp=share_link
5. SCI Part I - Information Needs Community Survey