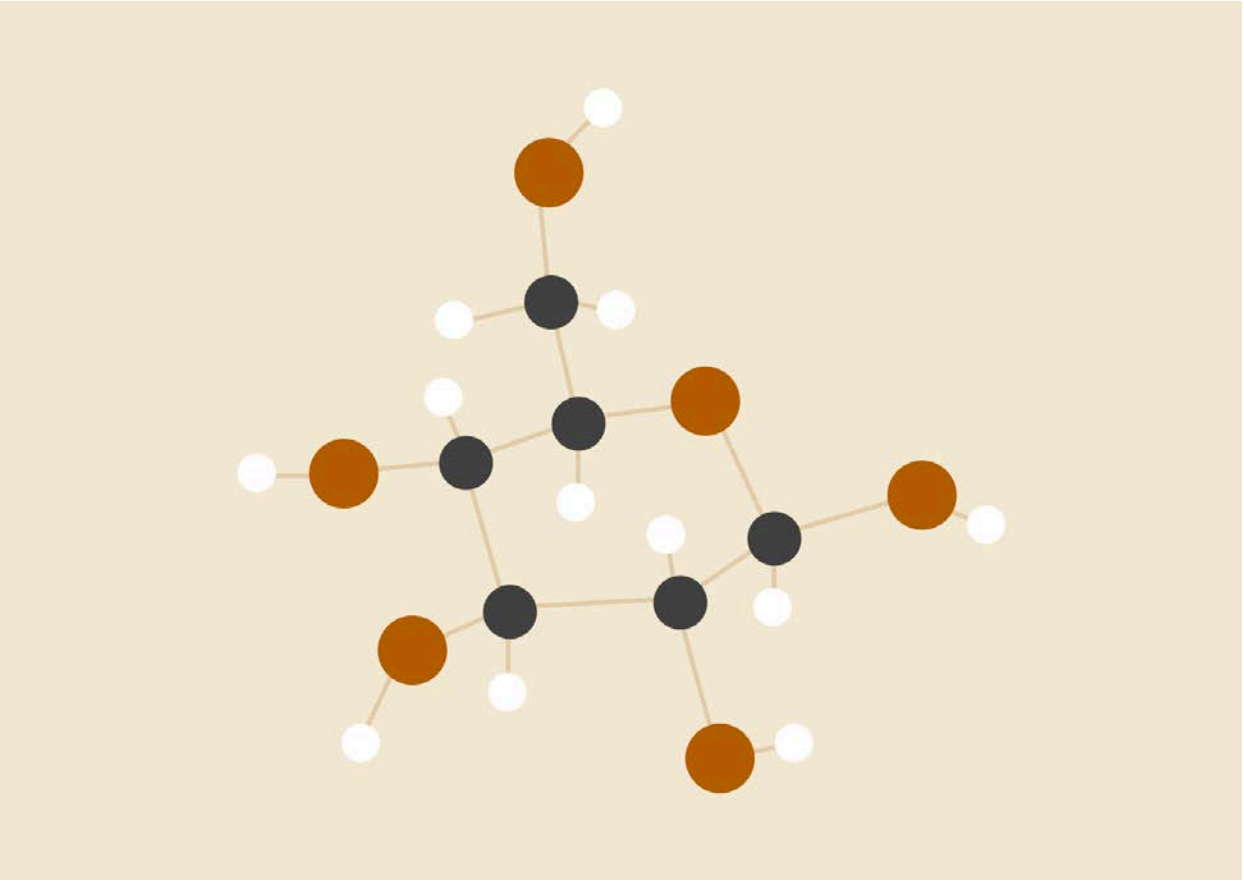
SCI-Powered Network

Information Needs Community Survey



FINAL

04.07.2025

INTRODUCTION

Today people living with SCI are overloaded with information sources; some are good and some are horrible. 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 found 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.

The goal of the SCI Powered Network is to build a community-driven framework of credible and trustworthy spinal cord injury information through exchange and dissemination in an inclusive and engaged manner to serve stakeholders within and outside the SCI community. There are two objectives and three deliverables for this group:

Objective 1: Identification of high-priority health information needs and daily challenges of living with spinal cord injury gathered through a needs assessment designed and conducted with diversity and under-served individuals in mind.

Objective 2: Conduct a landscape search to identify common characteristics of inclusive and trustworthy information and resources.

Deliverable A: Provide a gap analysis between the high-priority needs of spinal cord injury and the identified information and resources.

Deliverable B: Development of metrics of SCI information and resources to create the SCI Powered Network seal of approval.

Deliverable C: Create a design criteria report consisting of solutions definition, system characteristics, and key attributes needed for a community-driven structure for information identification, exchange, and dissemination.

Created through feedback from the SCI lived experience community, NASCIC formed the SCI-Powered Network to begin the first phase 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 one, the Information Needs SCI Community Survey. This specifications document outlines the aims of this project, the methodology, the results, and conclusions of this survey.

PROJECT AIMS

The aims of these efforts are 1) to create a community-driven health information needs survey for the SCI community, 2) to collect and analyze the response from the survey, and 3) to conduct a gap analysis between the high-priority needs of spinal cord injury and the identified information and resources. The final outcome provides an analysis of the SCI community's needs and criteria needed to aid in the development of an information seal of approval for the SCI community.

METHODOLOGY

The efforts for this project were conducted with a diverse Working Group of representatives across the SCI community in the US and Canada. The final Working Group consisted of 20 members representing a wide range of advocacy and information resource organizations specifically for SCI. The Working Group members:

Name		Organization
Reveca	Torres	BackBones
Kim	Anderson	NASCIC
Spring	Hawes	Praxis Institute
Lindsay	Perlman	Paralyzed Veterans of America
Kim	Beer	Christopher & Dana Reeve Foundation
Sarah	Skeels	SCI-Coaches
Peter	Athanasopoulos	SCI-Ontario
Matthew	Queree	SCIRE
Jake	Beckstrom	United 2 Fight Paralysis
Matthew	Castellucio	United Spinal Association
Jose	Hernandez	United Spinal NYC
Bill	Fertig	United Spinal Virginia
Kim	Monden	University of Minnesota
Angela Brian	Rodriguez Denny	South Carolina SCI
Ian	Burkhart	Co-Chair
Jennifer	French	Co-Chair

The Working Group began this effort by first evaluating the known information from previous surveys of the SCI community related to community needs assessment, barriers to information acquisition, and information access and assessment, as well as literature about health information assessment methods. The Working Group also conducted a literature review addressing the gap in information. The list of sources the Working Group referenced are available in the Reference Section of this report. The findings from this literature review informed the development of the 2024 Information Needs SCI Community survey.

The Working Group then composed sections of the survey into various topic areas. They are as follows:

Section	Topic
Opening Questions	Screening
Section 1	Go-to information sources
Section 2	Types of sources of information
Section 3	Info access timing
Section 4	Characteristics Definitions: Credible/ Reliable/Trustworthy, Practical/Useful, Accessible
Section 5	Rank information sources by each characteristic
Section 6	Information Retention & Repeat
Section 7	Information Fatigue/overload
Section 8	Types of filters for health information
Section 9	Access to Care
Section 10	Relation of health & access to care
Section 11	Use of telehealth
Section 12	Demographics

Members of the Working Group were segmented into groups to draft the questions for each section. The questions then went through several iterations and discussions until we finalized the questions. The survey was then built in an online platform, Survey Monkey, and tested among the Working Group members and a small cohort of people with SCI who were not members of the Working Group. Following the testing, the survey was further refined until the final version was approved. A final version of the survey is provided in the references.

The Working Group also agreed to offer gift cards via a lottery to the survey respondents. This was a means to help improve response rates. The team distributed 60 gift cards in the amount of $25 for each gift card.

DATA COLLECTION

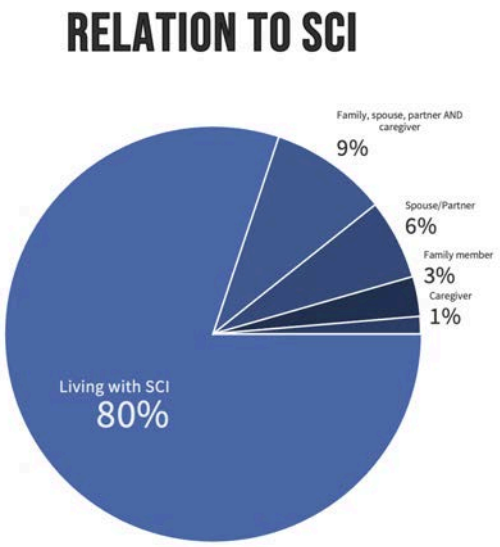
The final survey was opened and began distribution on February 23, 2024, and closed on June 10, 2024. Harnessing the network within the Working Group members and the NASCIC membership, we had a variety of dissemination pathways and methods. The team created a survey press kit including graphics, promotional materials, animated videos, and sample social media posts, which each included a link and QR code to access the survey. We also created some personal short videos as messages from people with lived experience explaining why the survey was important.

We embarked on a variety of dissemination methods including direct email, press releases, news stories, social media posts (including influencers), organization newsletters, and chapter member outreach. Initially targeting the members of the Working Group and their organizations, we quickly expanded to associations such as the Association of Neuro Activity Based Professionals, SCI Model Systems Centers, Activity-based Therapy Centers, Independent Living Centers, and Recreational Sports organizations. We also distributed the survey through a wide social media campaign and specific outreach to peer support groups.

One of the limitations of this survey was the access to people who have no internet connection and who may be living with SCI but are not connected to the SCI community in any way.

RESULTS

When the survey was closed we had 708 survey participants. Once the data was cleaned, the final total of qualified respondents were 448. The majority of the people who responded to the survey were people living with SCI (80%).



The following is a summary of the survey results.

DEMOGRAPHICS

The demographics of the survey respondents are reflective of those known from the National Spinal Cord Injury Statistical Center registry. The respondents did lean slightly toward longer time since injury (median 14 years) and older in age (median 58) (Table 1). The gender distribution was also similar to the overall population with 64% of respondents as male and 33% as female, as was the level and completeness of injury. (Table 2) Most of the respondents were white and many were educated with a majority having education beyond a high school diploma. Income level was disbursed with the majority reporting income between $25,000-$49,000 followed by the income level of $75,000-$124,000. Finally, the majority of respondents reported living in a small city, town, or suburb (45%) closely followed by those in big cities (36%). (Table 3)

	Min, Max	Mean	Median	Mode	SD
Age	17, 94	55	58	63	16
Time Since Injury (Years)	0, 72	19	14	3	16

Table 1: Age and time since injury

Demographic	Survey Respondents	National Sample
Gender		
Male	64%	78%
Female	33%	22%
Other/Prefer not to say	3%	
Race		
White	83%	56%
Black	6%	35%
Asian	2%	2.6%
Other	4%	1.9%
Native American	0%	0.5%
Mixed Race	5%	
Level of Function		
Incomplete tetraplegia	30%	47%
Incomplete paraplegia	31%	20%
Complete tetraplegia	14%	20%
Complete paraplegia	20%	13%
Don't know	4%	
No Impairment		0.5%

Table 2: Gender, Race & Level of function of survey respondents and the U.S. SCI Model Systems National Spinal Cord Injury Statistics Center (2022 national sample)

Demographics	Survey Respondents
Education	
High school	12%
Some college	18%
Associate's degree	11%
Bachelor's degree	24%
Master's degree	17%
Other (<11th grade, technical certify, doctorate/professional)	18%
Income	
Below $25,000	50%
$25,000 to $49,999	97%
$50,000 to $74,999	64%
$75,000 to $124,999	88%
$125,000 or more	74%
I don't know	7%
I prefer not to answer	68%
Area of Residence	
Rural (pop: less than 500)	9%
Small town or Village (pop: 500-10,000)	13%
Town, Small City, or Suburb (pop: 10,000-250,000)	46%
Big City (pop: over 250,000)	36%

Table 3: Education, Income levels, and Area of residence of survey respondents.

When we asked about the level of assistance needed and whether or not the respondents live alone, we received the responses illustrated in Figure 1.

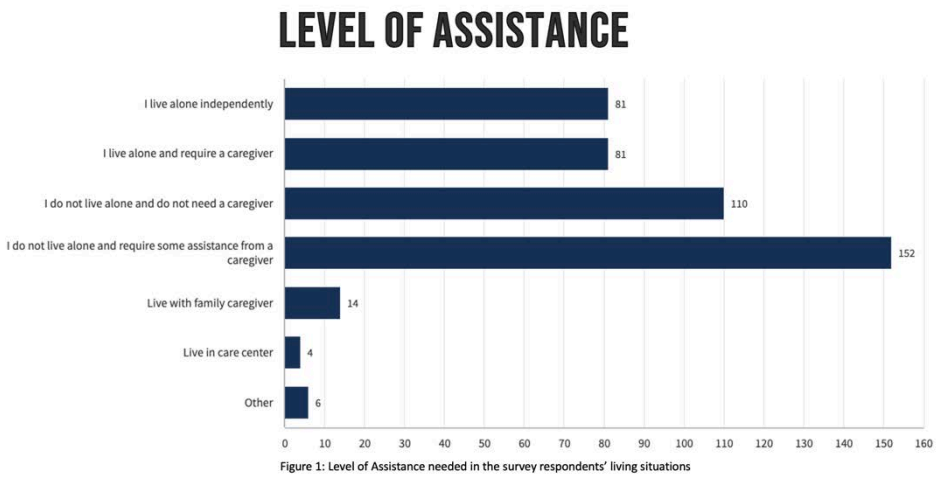


Figure 1: Level of Assistance needed in the survey respondents' living situations

It was also important to understand the level of assistance and how it relates to the level of function or injury. Here we compared these two variables and found that the largest differences across levels of injury were among those who are living with complete quadriplegia. In these cases, 22% of those live alone and 18% do not live alone. Regardless of their living situation, they require some level of caregiver assistance. (Figure 2)

LEVEL OF INJURY & LEVEL OF ASSISTANCE

The biggest differences across levels of injury were among individuals with complete quadriplegia.

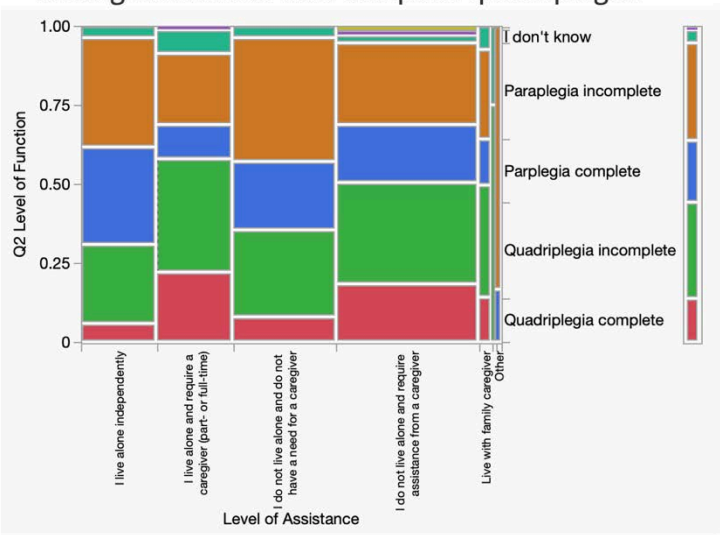


Figure 2: Level of Assistance needed & Level of Function reported from the survey respondents

We also asked about insurance coverage. Since we were addressing respondents from countries with various health insurance systems, we asked the respondents to check all applicable insurance coverage that they had. This did not allow us to view which was the primary insurance of the respondents but we were able to view how many respondents had more than one insurance carrier, which was 49% for both one insurance and multiple insurance sources. (Figure 3)

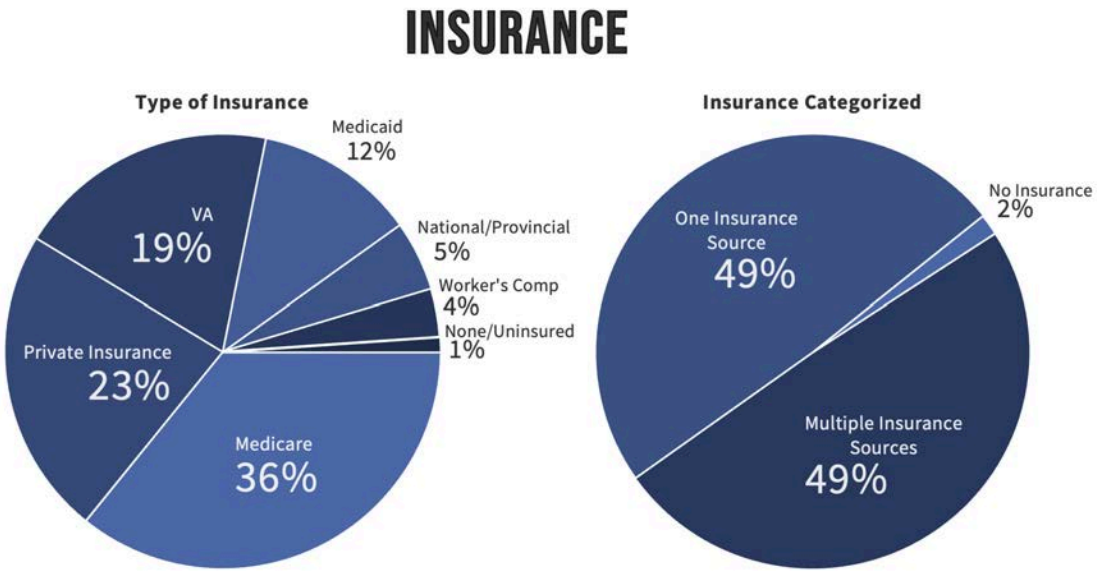


Figure 3: Insurance, types of insurance and insurance source categories

Health Information Sources, Timing & Types of Information

In these sections, we asked about the difficulty people have accessing health information, when they reached out for health information, and the types of information sources they typically reference. We learned that the majority (83%) of the respondents have some level of difficulty accessing SCI health-related information. (Figure 4).

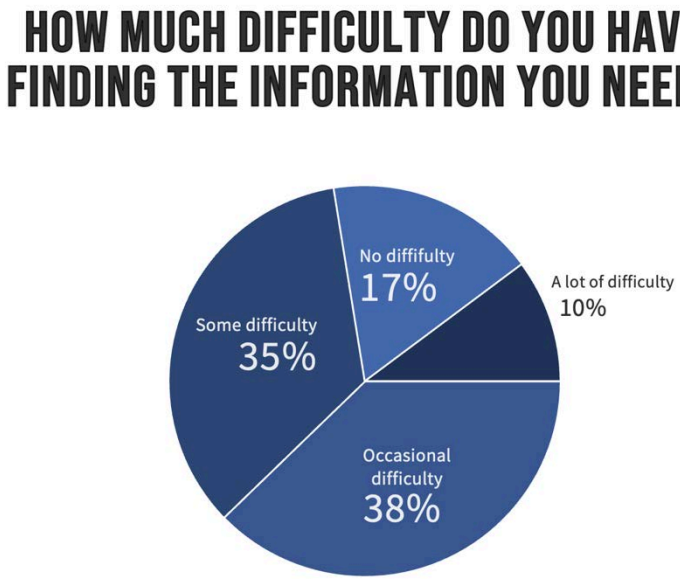


Figure 4: Level of difficulty finding SCI-related health information

To no surprise, most of the respondents reach out for health information when they are experiencing a health problem or issue (followed by wanting information about a new treatment or product), and seeking specialized healthcare. (Figure 5)

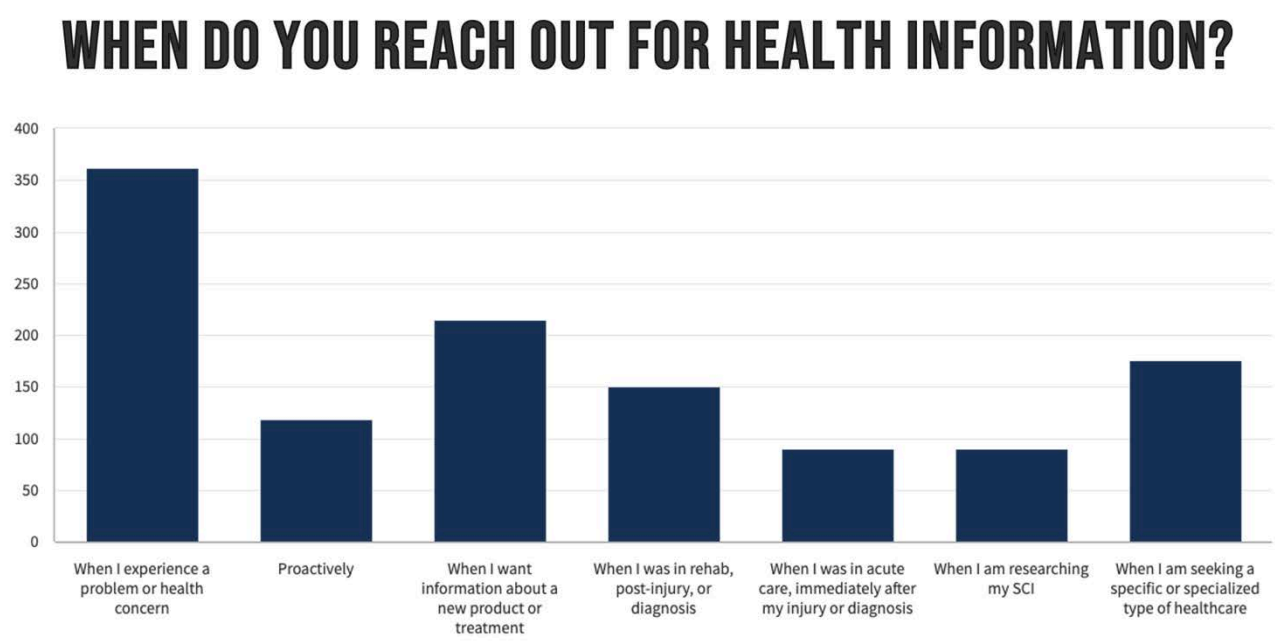


Figure 5: When respondents reach out for health information

When we asked the question "What source types do you use or did you use in the past to get SCI-related health information?", the majority of the responses were to medical professionals followed by websites, SCI organizations, and specialized rehabilitation centers. (Figure 6)

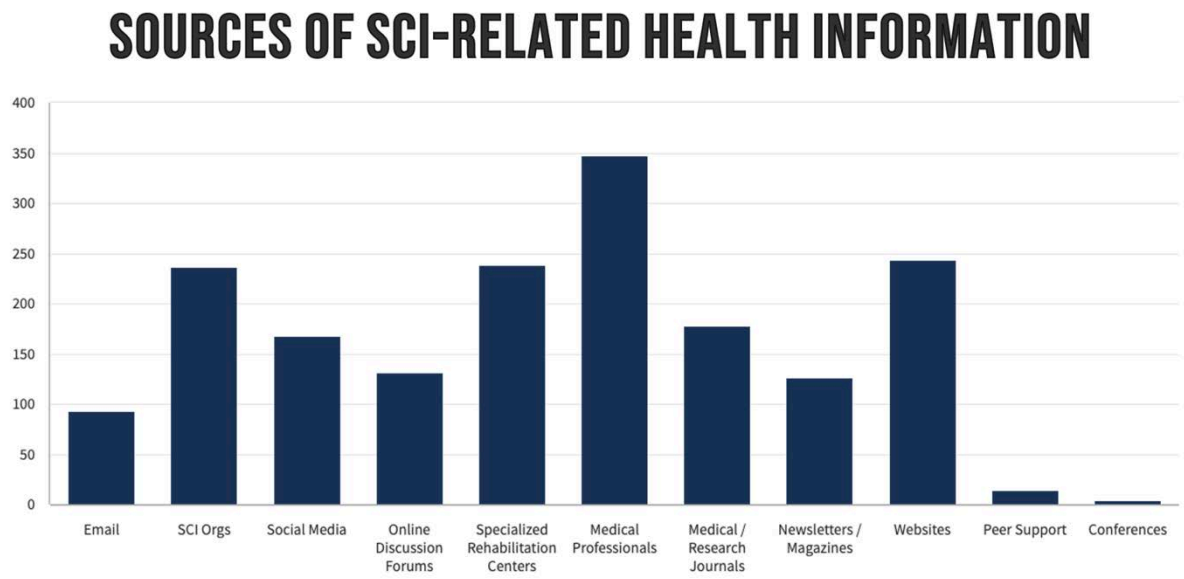


Figure 6: Preferred sources of SCI-related health information

In this context, we also asked an open-ended question "When you have a health problem or question, what are the top 3 information sources that you refer to?" 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. Social media was also a highly mentioned source; however, in some cases it was difficult to distinguish between social media and peer support. For instance, several respondents reported online support which may indicate peer support accessed online or a social media support group. In this instance, it was coded as peer support/others living with SCI. This is the table listing (Table 4) containing only the specific sources named and those that were named specifically more than once. The resources are grouped by format and are in no particular order. It is key to note that the survey respondents' sources include many general sources that are not specific to SCI. Survey respondents also cited reasons for choosing their top sources. Common reasons included terms such as easy, accessible, reliable, trustworthy, knowledgeable, and 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. (Table 4)

SCI Information Needs Survey Response Resource List

Title	Source	Format
Format: Community Forum		
Spinal Cord Injury USA Facebook Group	Social Media	Community Forum
CareCure Forums	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		
A 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 Reeve 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

Table 4: Named sources and categorized from responses to the open-ended question about health related information

A correlation analysis was done by looking at preferred information sources with variables of income, race, and location category for rehabilitation. We did not find any differences in information sources across reported race categories. However, we did find those with reported incomes below $75,000 per year prefer peer support as a preferred information source. (Table 5)

PREFERRED INFORMATION SOURCES BY INCOME

Sources	Below $25,000	$25,000 - $49,000	$50,000 - $74,999	$75,000 - $124,999	$125,000 or more	I don't know	I prefer not to answer
Email Lists	14%	28%	14%	17%	15%	1%	11%
SCI Advocacy Oganizations	11%	20%	17%	22%	13%	1%	17%
Social Media	10%	20%	17%	23%	17%	2%	11%
Online Discussion Forums	13%	18%	13%	19%	21%	2%	15%
Specialized SCI Rehab Centers	11%	19%	11%	19%	19%	2%	19%
Medical Professional	10%	20%	14%	20%	17%	2%	17%
Medical or Research Articles	9%	22%	13%	17%	20%	2%	16%
Newsletters or Magazines	11%	17%	14%	19%	14%	2%	21%
Websites	12%	17%	11%	23%	19%	2%	16%
Peer Support	21%	21%	29%	7%	0%	0%	21%
Conferences	0%	25%	0%	25%	25%	0%	25%

Table 5: Preferred information source ranking by income category

We also found those who either attended a Canadian Rehabilitation Institute/Hospital, a General Rehabilitation Institute/Hospital, or did not attend any Rehabilitation facility preferred peer support as an information source. In addition, those who attended a Military or VA hospital prefer conferences as an information source. This may be due to the various supportive information events hosted by the VA system. (Table 6)

PREFERRED INFORMATION SOURCES BY TYPE OF REHABILITATION FACILITY

Sources	Canadian Rehab Institute/Hospital	General Hospital	Major Health System	Military or VA Hospital	Model System Center	No Rehab	Other	Rehab Institute/Hospital
Email Lists	1%	29%	5%	15%	18%	10%	1%	18%
SCI Advocacy Oganizations	6%	30%	3%	17%	17%	6%	1%	20%
Social Media	4%	32%	6%	10%	18%	10%	1%	17%
Online Discussion Forums	4%	32%	2%	8%	21%	10%	1%	21%
Specialized SCI Rehab Centers	6%	24%	2%	24%	22%	4%	1%	16%
Medical Professional	5%	28%	3%	21%	18%	5%	<1%	18%
Medical or Research Articles	5%	29%	4%	18%	19%	7%	1%	16%
Newsletters or Magazines	3%	28%	1%	25%	16%	7%	1%	18%
Websites	6%	27%	1%	20%	19%	7%	1%	19%
Peer Support	14%	14%	0%	0%	21%	21%	0%	29%
Conferences	0%	25%	0%	50%	0%	0%	0%	25%

Table 6: Preferred information source ranking by type of rehabilitation facility

When people did receive information from their medical professional, they reported not needing assistance to understand the information nor did they express that their culture or religion influenced their decision-making. (Table 7)

ASSISTANCE WITH INFORMATION AND IMPACT OF RELIGION OR CULTURE

	Mean	SD	Mode
How often do you need help understanding information from your doctor (0-100)?	19	27	0
How much does your religion or culture impact your health decision making (0-100)?	26	35	0

Table 7: When people need assistance understanding information and the impact of religion or culture on health decision-making

CHARACTERISTICS OF INFORMATION SOURCES

We also wanted to understand how people distinguish between information sources through the lens of three different characteristic definitions. We provided the same categorized listing and asked the respondents to rank the sources using the provided definition. The rankings and characteristic definitions are provided below. The IQR refers to the interquartile range, which distinguishes the spread of responses. This was only used if there was a tie in the ranking.

Credible, Trustworthy, and Reliable (Table 8)

The questions provided to guide the respondents were:

- Is this source an authority or expert in the field of the information it is reporting?
- Is the information provided by this source able to be consistently relied upon as honest or truthful?

CREDIBILITY, TRUSTWORTHINESS, & RELIABILITY OF SOURCES

Rank	Information Source	Mode	IQR
1	Medical/Healthcare Professionals	1	1
2	Specialty SCI Rehabilitation Centers	1	2
3	Spinal Cord Injury Organizations	3	1
4	Medical or Research Journals	4	3
5	Newsletters	7	2
6	Email	7	3
7	Websites	8	3
8	Social Media	8	3

Table 8: Rankings of information sources based on the provided definition of credibility, trustworthiness & reliability

Practical and Useful (Table 9)

The questions provided to guide the respondents were:

- Can the information be readily applied by an individual?
- Is the information provided at an appropriate level to be used by an individual?

PRACTICALITY & USEFULNESS OF SOURCES

Rank	Information Source	Mode	IQR
1	Speciality SCI Rehabilitation Centers	1	3
2	Medical/Healthcare Professionals	1	3
3	Spinal Cord Injury Organizations	2	1
4	Medical/Research Journals	4	2
5	Newsletters	5	2
6	Email	7	3
7	Websites	8	4
8	Social Media	8	4.75

Table 9: Rankings of information sources based on the provided definition of practicality & usefulness

Accessibility (Table 10)

The questions provided to guide the respondents were:

- Are you able to acquire information, read and understand the information, and enjoy using the source?

ACCESSIBILITY OF SOURCES

Rank	Information Source	Mode	IQR
1	Medical/Healthcare Professionals	1	4
2	Spinal Cord Injury Organizations	2	2
3	Spinal Cord Injury Specialty Rehabilitation Centers	2	4
4	Social Media	2	5
5	Medical/Research Journals	6	2
6	Newsletter	7	3
7	Email	7	4
8	*Websites	8	6.00

*This was a bimodal distribution meaning ~80 people ranked websites #1 and ~120 people ranked websites #8

Table 10: Rankings of information sources based on the provided definition of accessibility

There are a few key limitations to note from the data. First, the information sources are not mutually exclusive. For instance, a Spinal Cord Injury Organization may offer a newsletter, website, email

distribution list, or a social media group. We recognize that there are some overlaps in the offering of the information sources; however, it is important to note the perceived source by the respondents. The respondents were asked to rank the sources related to "health-related information", which may be interpreted as information within the traditional medical system or the context of social determinants of health. Finally, the accessible categorization ranking notes that there is a bimodal distribution for the information source of websites, whereas approximately 80 people ranked websites as #1 (the top ranking), and about 120 ranked it as #8 (the lowest ranking).

For each ranking, we also asked for specific sources. For each question respondents could list as many or as few options as they deemed necessary, therefore these response numbers are different for each category. We received 598 responses for the question about being "Credible, Trustworthy, and Reliable," 515 responses for "Practical and Useful," and 416 responses for "Accessible."

To make sense of the open responses related directly to the ranking category definitions, we sorted them into subcategories of General Resources, Specific Resources, Organizational Resources, and Rehabilitation Center or Hospital Resources. These categories are described below:

- **General Resources** encompasses named sources that fit into the same categories of the above ranking options; Email Lists, SCI Organizations, Social Media, Specialty SCI Rehabilitation Centers, Medical/Healthcare Professionals, Medical or Research Journal Articles, Newsletters/Magazines, and Websites.
- **Specific Resources** include named magazines such as NewMobility, SpinLife, and PVA as well as an online forum, CareCure, and a few named newsletters.
- **Organizational Resources** is a collection of named community-based organizations including Paralyzed Veterans of America, United Spinal, and the Christopher & Dana Reeve Foundation. Also included are the United States Department of Veterans Affairs (VA) and the National Institutes of Health (NIH).
- **Rehabilitation Centers or Hospital Resources** comprise named establishments which include SCI Speciality institutions such as model center hospitals (i.e. Shepherd Center, Craig, Kessler, etc.), activity-based therapy centers, and the Mayo or Cleveland Clinics.

INFORMATION RETENTION, REPEAT & FATIGUE/OVERLOAD

With the majority of respondents reporting some degree of difficulty finding health information, we wanted to understand why people return to information sources and perspectives of information retention. Here we asked a series of questions related to what promotes the respondent to return to information sources. The direct question was "What makes you return to or use an information source again and again?" Overwhelmingly, the aspects of credible and trustworthy sources as well as ease of access and understandability were most highly reported ('Always applies') among the other aspects. It is

key to note that all aspects received a positive response. (Figures 7-11)

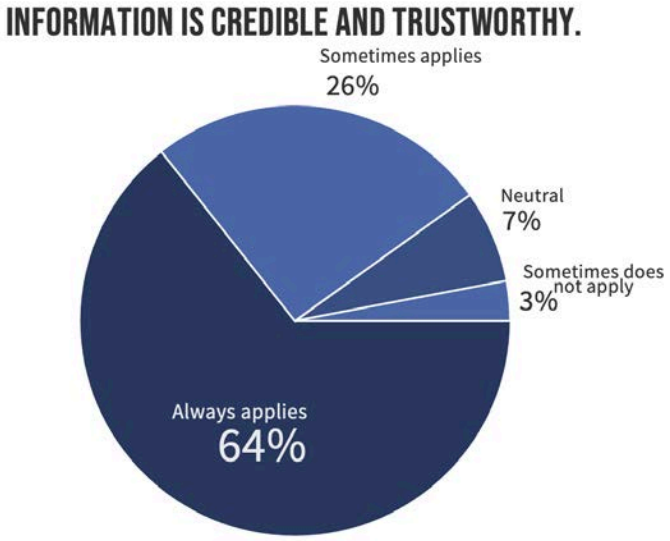


Figure 7: Why respondents returned to an information source: credible & trustworthy

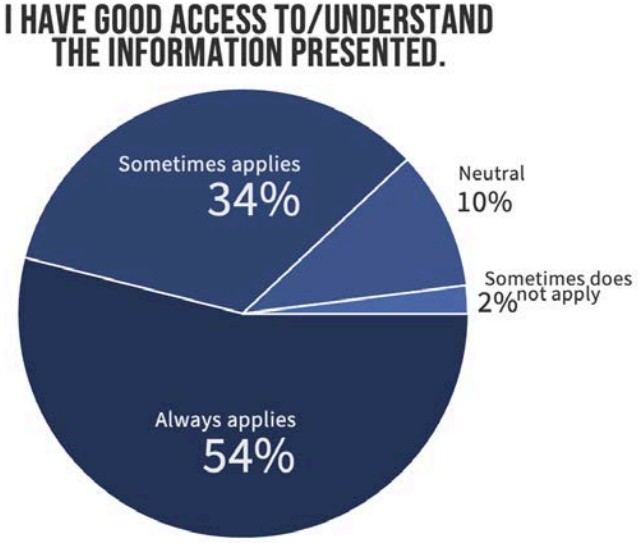


Figure 8: Why respondents returned to an information source: access & understanding

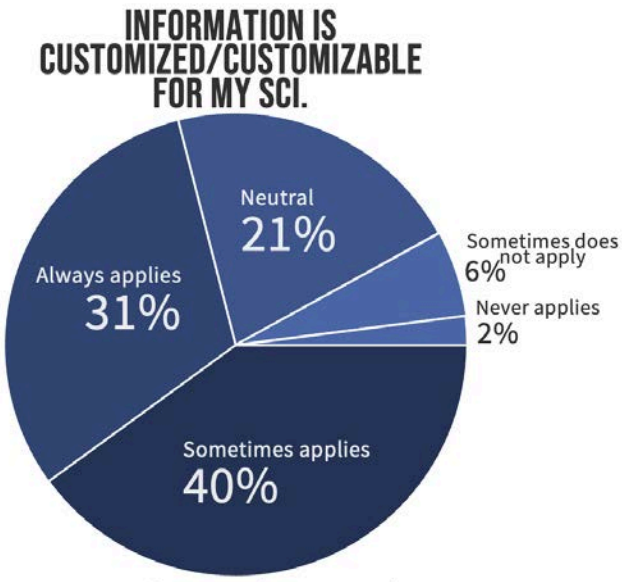


Figure 9: Why respondents returned to an information source: customizable

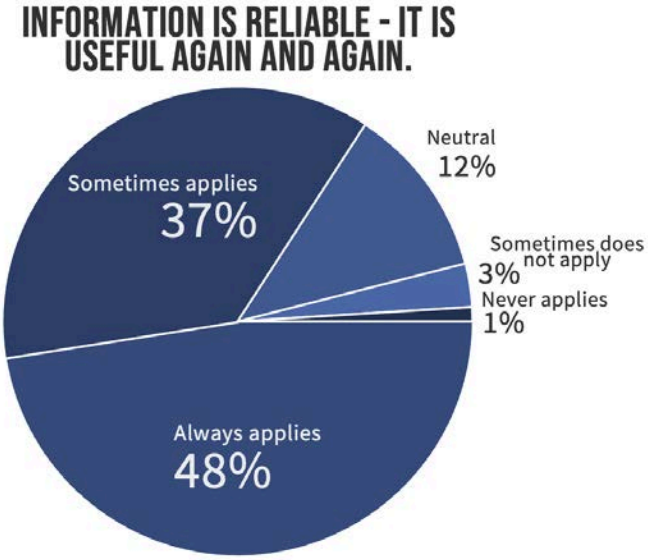


Figure 10: Why respondents returned to an information source: reliable & useful

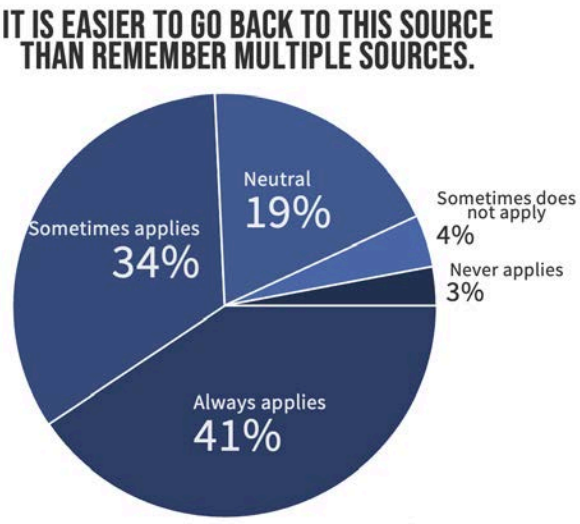


Figure 11: Why respondents returned to an information source: easy

The next series of questions related to information fatigue. The direct question was "We would like to understand your view on SCI health information that you receive. For each statement below rate your agreement." The respondents could rate to what degree they agreed with the statements on a 5-point scale. There were no large differences in the responses; however, most respondents did agree with the statements regarding many recommendations and deciphering which to follow as well as the various SCI information being the same. In addition, the majority disagreed with the statement about SCI information being 'far-fetched'. There were no large differences in responses related to feeling overloaded with information, despite what we learned from the community roundtable discussions prior to the survey, which was with leaders from SCI-community organizations.

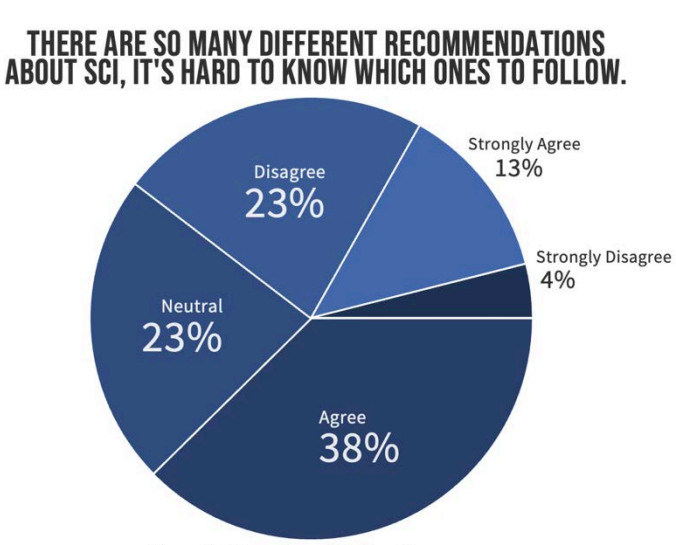


Figure 12: Your view of SCI health information: decipher which to follow.

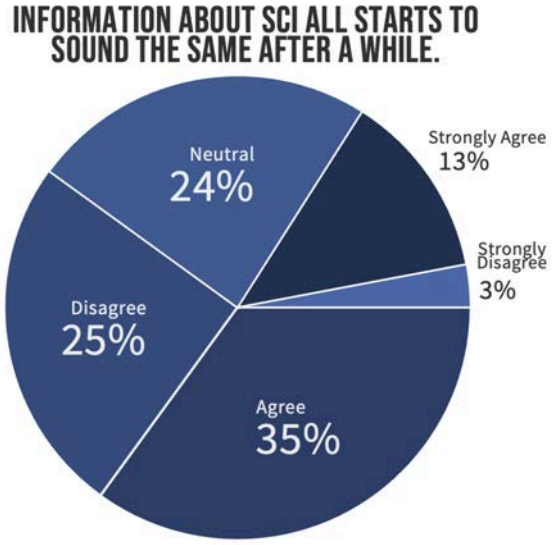


Figure 13: Your view of SCI health information: all sounds the same.

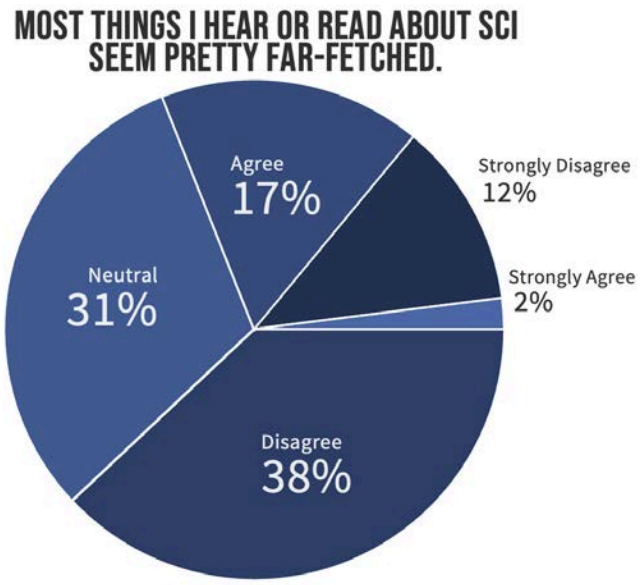


Figure 14: Your view of SCI health information: seems far-fetched.

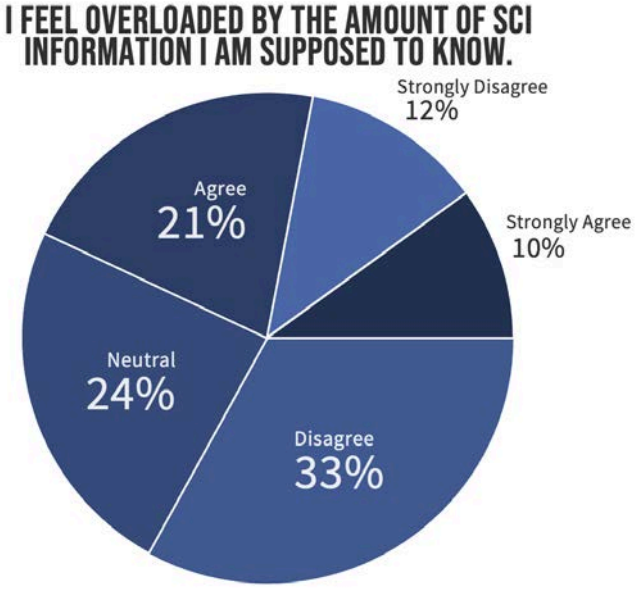


Figure 15: Your view of SCI health information: feeling overloaded.

TYPES OF FILTERS FOR HEALTH INFORMATION

When people are searching for SCI health information, it is important to understand how they would prefer to filter the information. In this single question about information filtering, we provided six options with an additional option to add another means of filtering. We also allowed the respondent to check all that apply. Here the responses may not be viewed as preferred however they do display filtering options that were most frequently chosen.

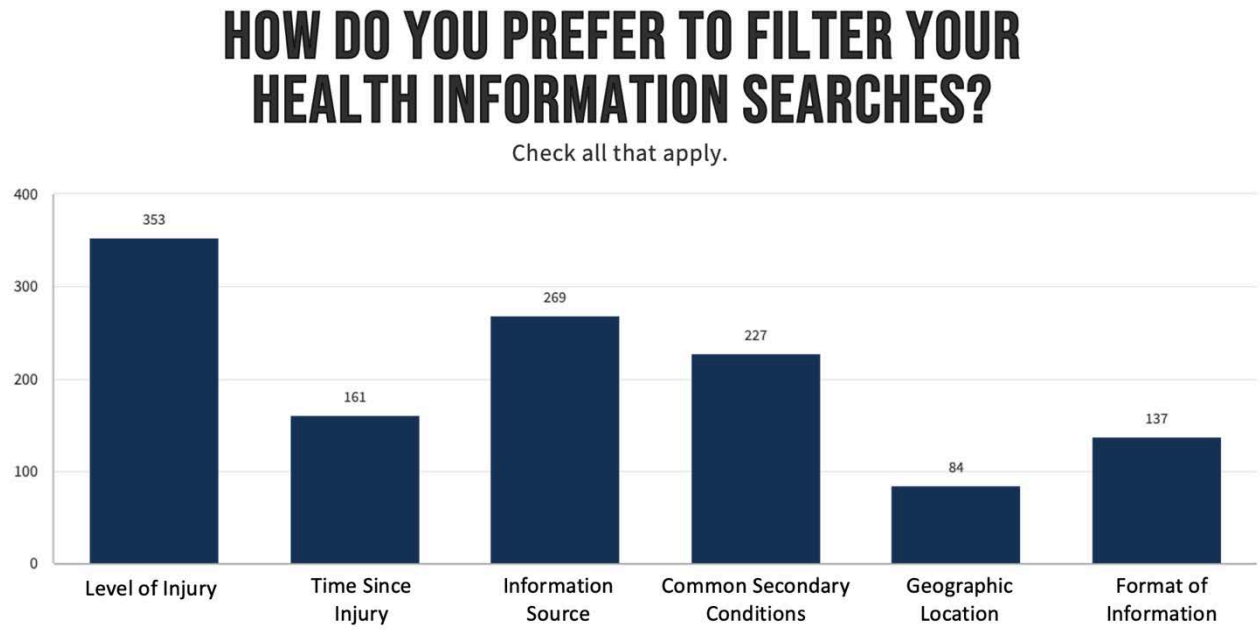


Figure 16: Preferred filtering of health information

ACCESS TO HEALTHCARE AND PERCEIVED CURRENT HEALTH

Within the survey, we asked several questions about access to healthcare and perceived health. On a 5-point scale, we asked the respondents to rate their current access to healthcare with 1 being poor and 5 being excellent. Here, most (65%) respondents reported excellent or good access to healthcare.

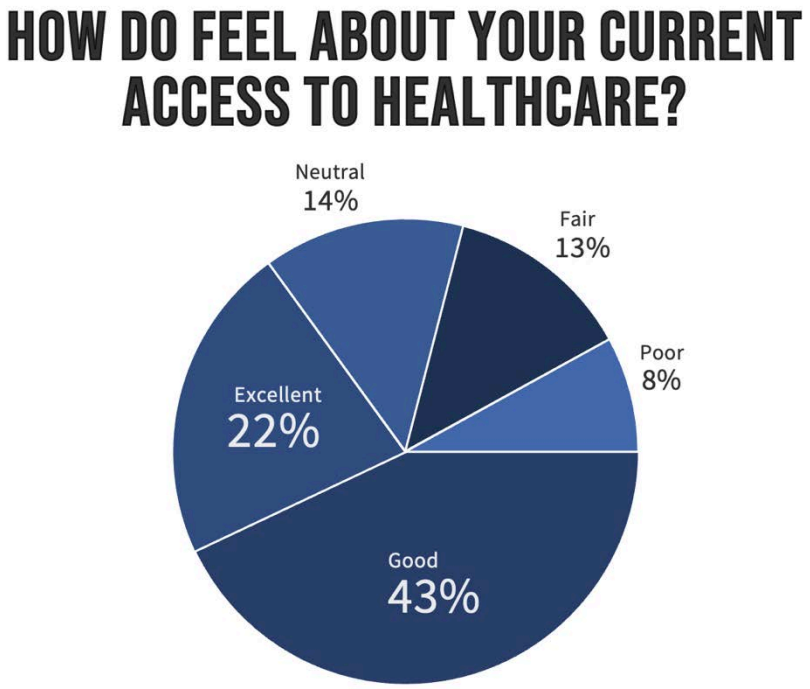


Figure 17: Access to healthcare

We correlated the responses to area of residence and found that 50% of the people who reported poor access to healthcare live in big cities. The data also revealed that there is a larger proportion of respondents living in small towns who reported fair access to healthcare compared to other geographic groups. In addition, the majority of the overall survey respondents (65%) reported good or excellent access to care.

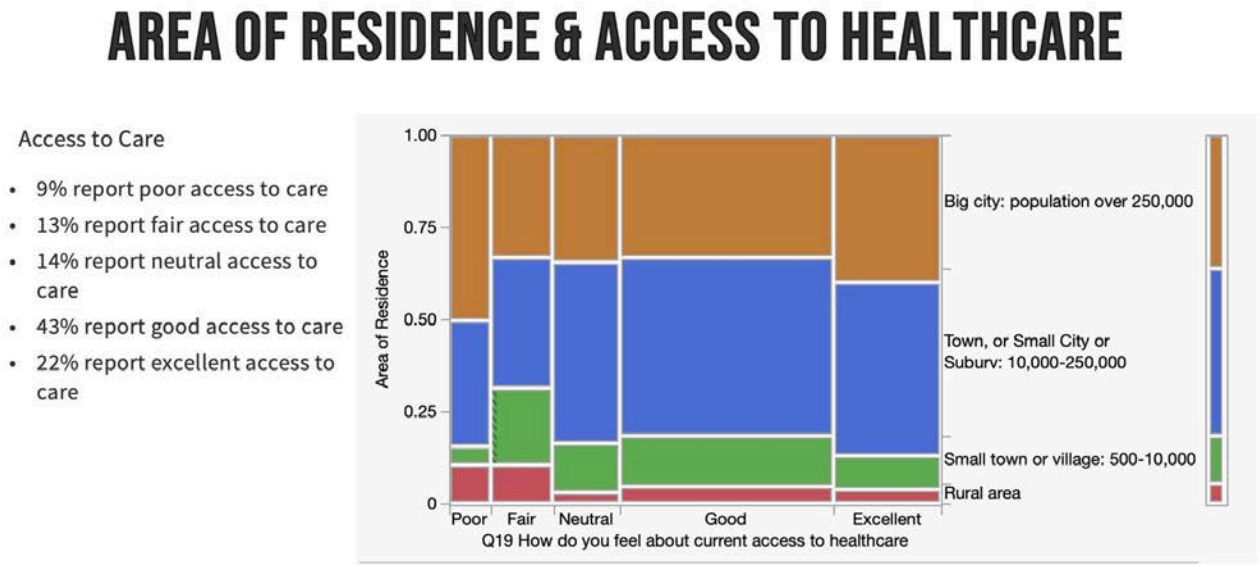


Figure 18: Access to healthcare by area of residence

When we compared income level to access to healthcare, there were no discrepancies found. There were no discrepancies found when we compared insurance coverage to access to healthcare; however, there were very few (7) respondents who reported having no access to insurance.

On a 5-point scale, we asked how the respondent feels about their current health with 1 being poor and 5 being excellent. The majority of respondents (57%) reported their current health to be good or excellent. When we compared this to insurance coverage, no discrepancies were discovered between coverage and perceived current health.

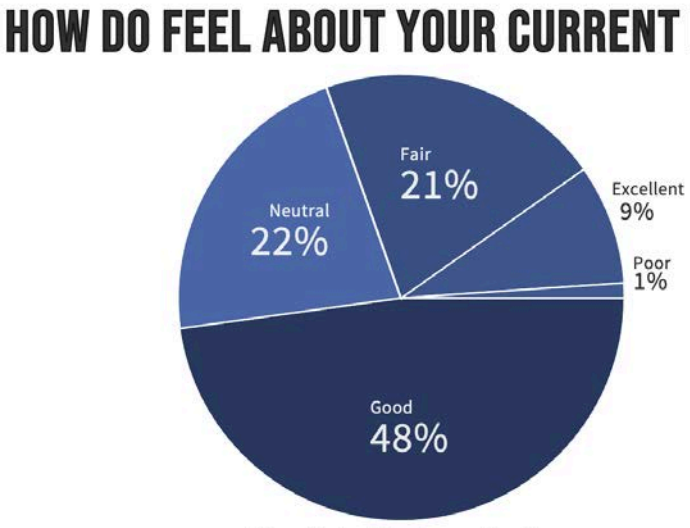


Figure 19: Feel about current health

Within this series of questions, we also asked who people contact if they have a health-related issue. Here we provided options and allowed the respondents to choose all that apply. The most frequently chosen options were a primary care physician (PCP), a clinician with SCI experience, and a clinician from another specialty (such as urology or pain). If they responded with a PCP, we asked if their PCP has SCI experience. The responses to this question were mixed; some did and some did not.

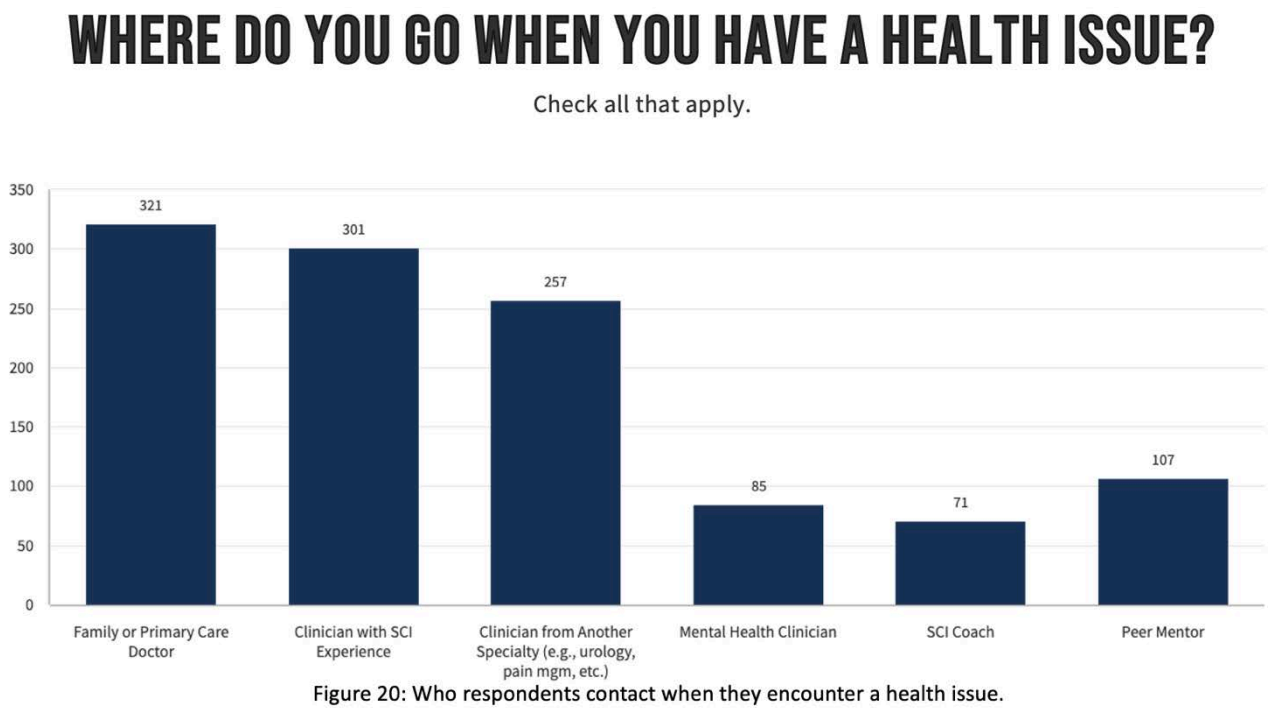


Figure 20: Who respondents contact when they encounter a health issue.

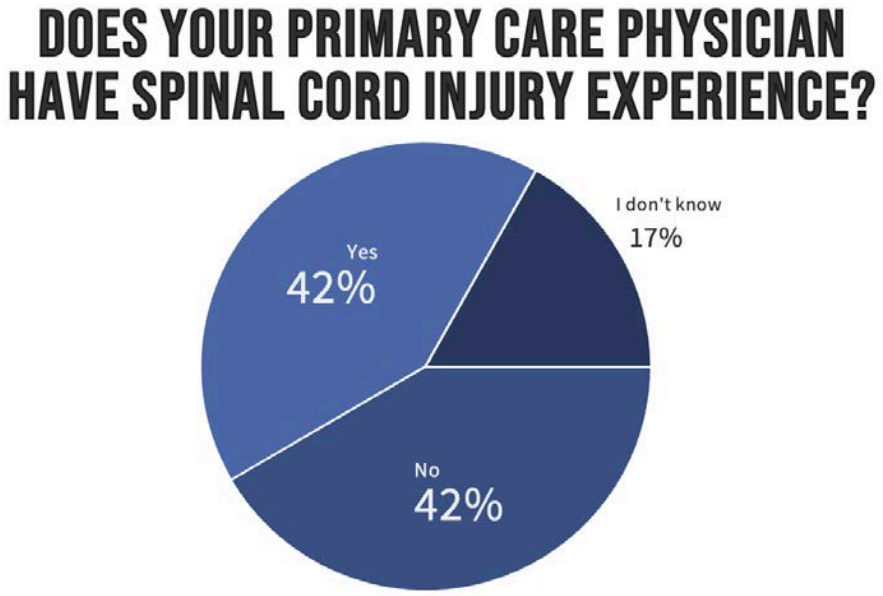


Figure 21: Primary care physician with SCI experience

Finally, in this series of questions, we wanted to understand how the ability to find information influenced people's health and access to healthcare. The majority (58%) reported a very positive or positive influence. It is key to note access to healthcare information can be one driver of health and access to care.

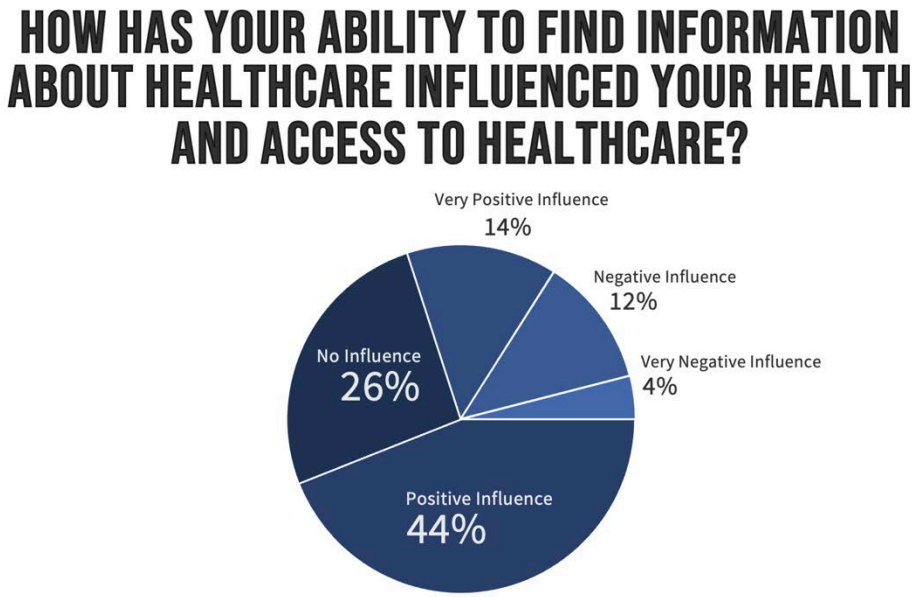


Figure 22: Finding information influenced your health

IMPACT OF REHABILITATION LOCATIONS

Understanding that the rehabilitation landscape is changing and challenging, people's experiences with health, health information, and access may be influenced by where they received their rehabilitation services. Among those who responded, the majority received their rehabilitation at a General Hospital (one without SCI specialty) followed by a Military or VA Hospital. The next category was essentially split between those who attended a Model SCI Center or a Rehabilitation Institute or Hospital (one with SCI specialty). (Figure 23)

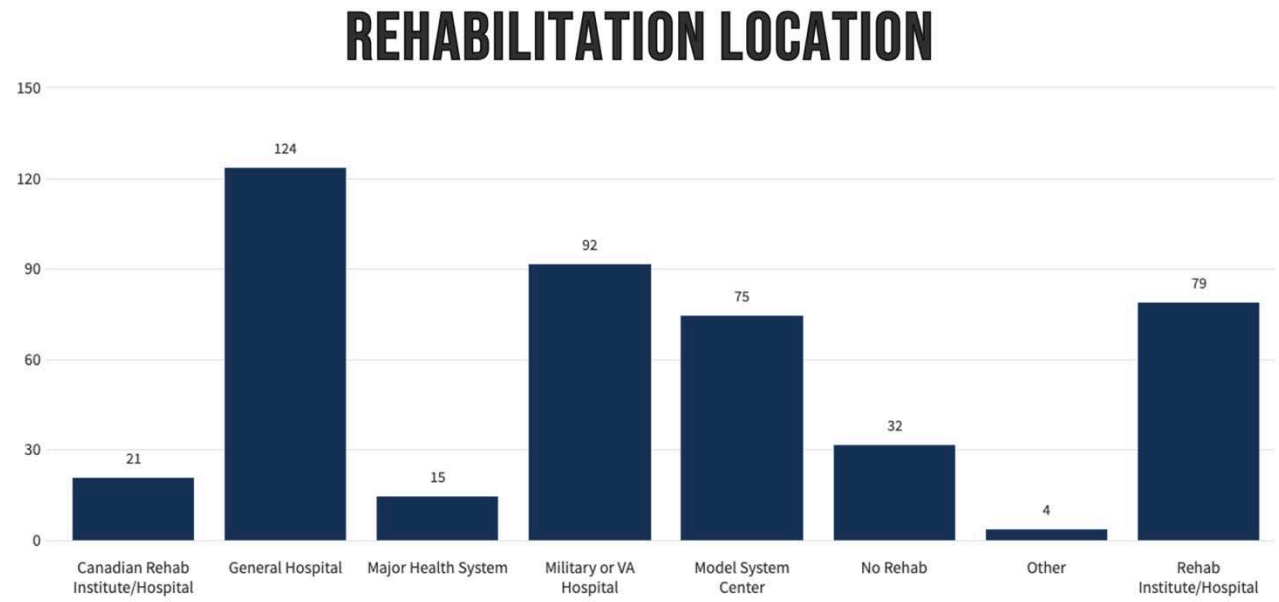


Figure 23: Location where respondents received rehabilitation by category.

When we compare rehabilitation location to access to healthcare, it was not surprising to find the largest difference between those reporting poor access and excellent access to healthcare. Those who reported no rehabilitation also reported poor access to healthcare while those who reported excellent access received their rehabilitation at a Military or VA Hospital. (Figure 24)

REHABILITATION LOCATION & ACCESS TO HEALTHCARE

The primary difference across rehab locations was in the group that rated their access to health care as either *poor* or *excellent*.

32% of people who rated poor access to healthcare received no rehabilitation.

38% of people who rated excellent access to healthcare received rehabilitation from a military or VA hospital.

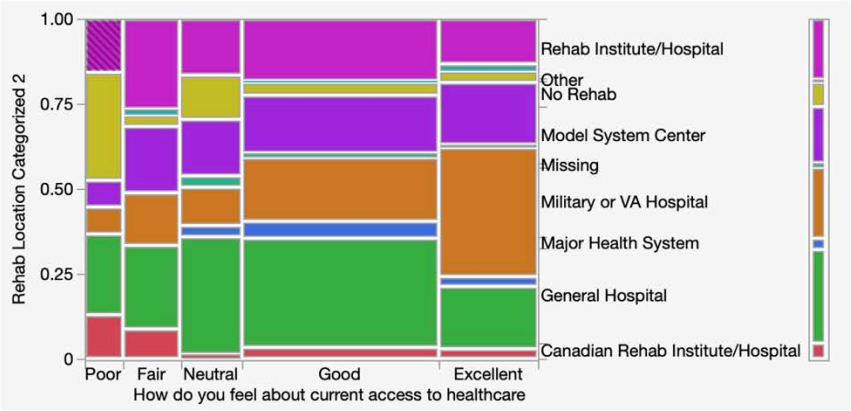


Figure 24: Differences of access to healthcare by location of rehabilitation services

Finally, we wanted to understand how the rehabilitation location can influence difficulty accessing health information. Those who reported having no difficulty finding SCI health information were those who attended a Military or VA Hospital for rehabilitation. It is important to note the small overall number of people who reported having no difficulty accessing SCI health information. (Figure 25)

REHABILITATION LOCATION & DIFFICULTY FINDING INFORMATION

The primary difference across rehab locations is in the *no difficulty* category.

34% of people who reported no difficulty finding nformation received rehabilitation at a military or VA hospital.

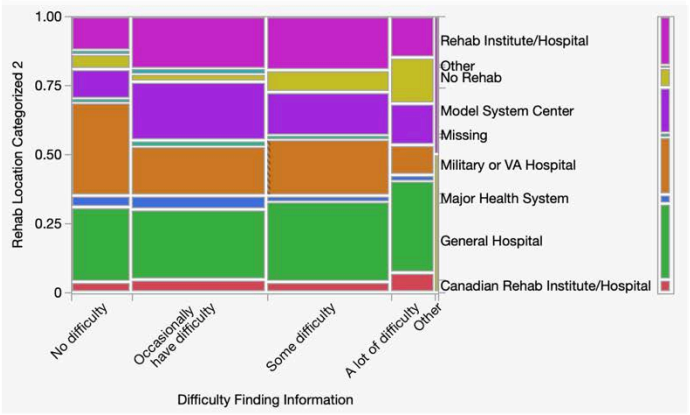


Figure 25: Differences of difficulty finding information by location of rehabilitation services

USE OF TELEHEALTH

It was also important to understand the use of telehealth among people living with SCI. We not only asked whether or not people use telehealth, but how they rate the experience if they use telehealth and the reasons for not using telehealth if they are non-users. The majority of the respondents (82%) use or have used telehealth in the past. Interestingly only 42% of the respondents currently use telehealth. (Figure 26) Through a discussion with our Working Group members, there may be many reasons for this. One reason may be that telehealth visits were subsidized during the COVID-19 pandemic and telehealth is no longer widely subsidized now that the pandemic is over. In addition, many payors are no longer compensating or have changed their compensation structures for telehealth visits. In addition, the healthcare system may have learned the appropriate use of telehealth for specific health-related visits and/or accessibility to telehealth may have changed. One additional insight of the Veterans Administration's use of telehealth. Prior to the pandemic, the VA was promoting the use of telehealth and it became popular among people living with SCI who were not located near an SCI specialty center. In addition, there is a current promoted use of telehealth for mental health services with the VA system.

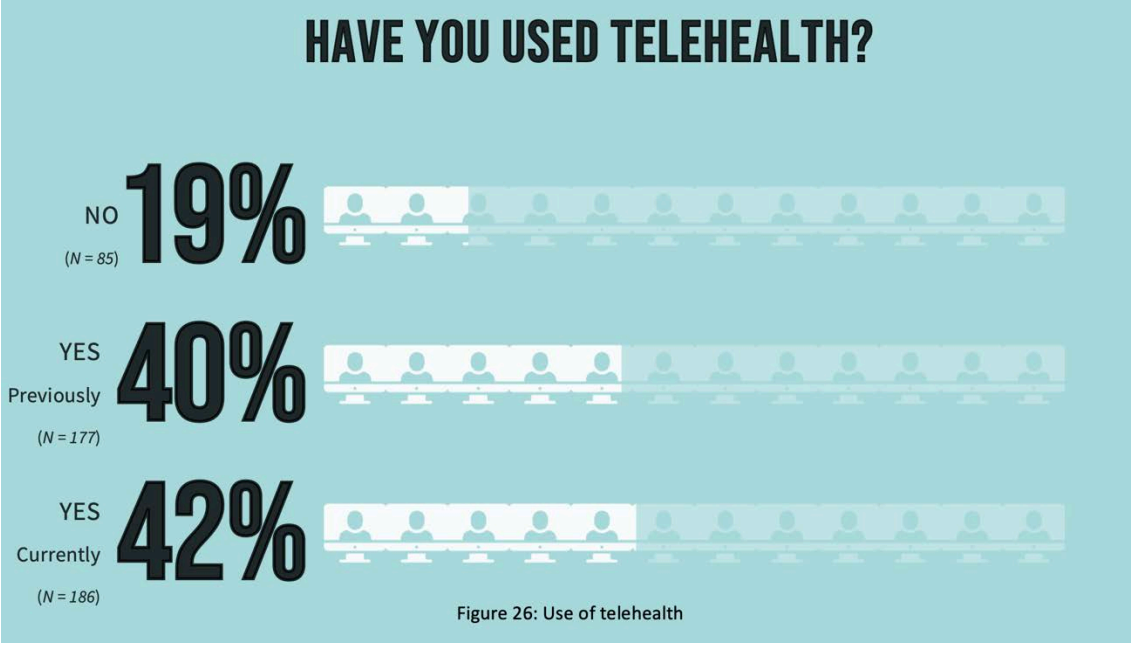


Figure 26: Use of telehealth

We also asked respondents to rate their experiences with telehealth if they used it. (Figure 27) For those who used telehealth, overall they had a positive experience and that was reliable and valuable. (Figure 28) This same cohort reported having telehealth as an option and having access to it. (Figure 29)

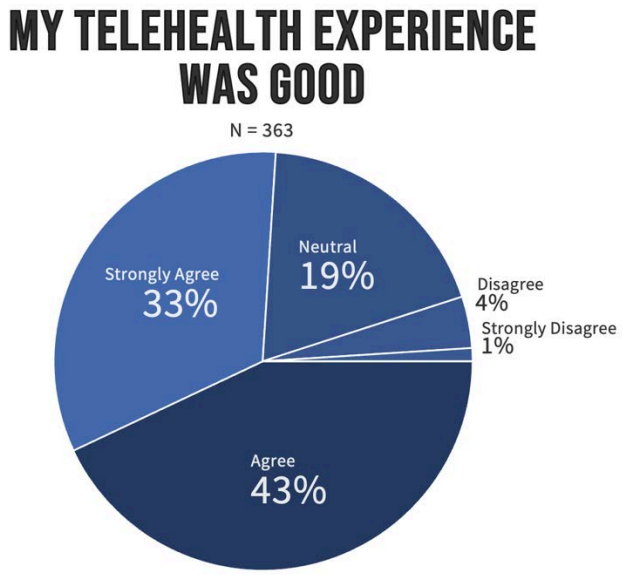


Figure 27: Rate telehealth experience

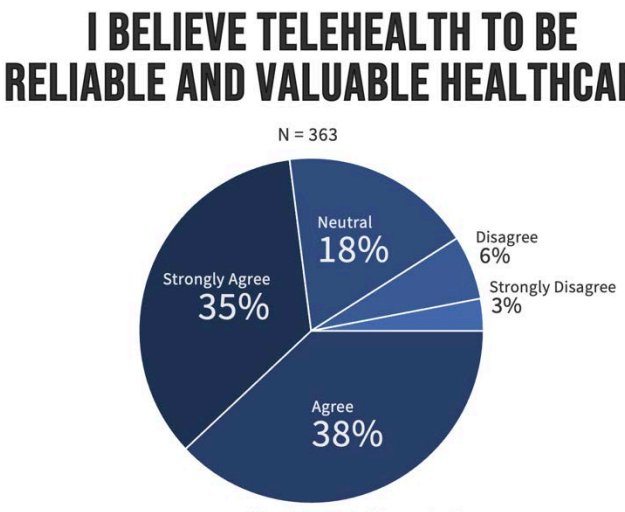


Figure 28: Telehealth as reliable & valuable

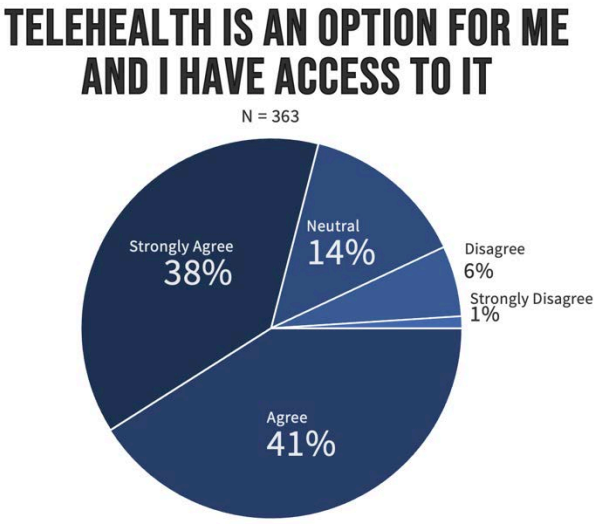


Figure 29: Telehealth an option & access

For those who have not used telehealth, we wanted to understand their reasons. The reasons reported were not technology oriented but were related to the availability/offering of telehealth and the need for in-person visits.

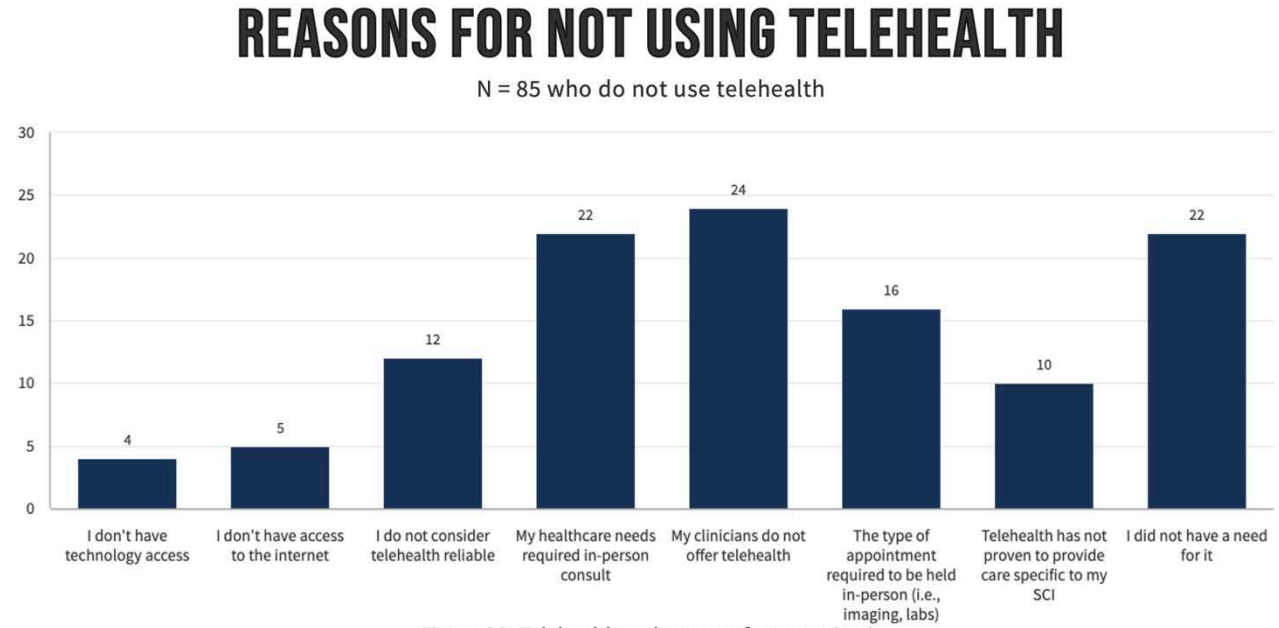


Figure 30: Telehealth and reasons for not using it

Finally, we wanted to understand if there were any correlations between insurance status and the use of telehealth. We found that there were no relationships although there were only seven respondents who

reported no insurance access.

CONCLUSION

From this SCI community survey, there are several important conclusions that can be drawn from the survey responses. Some of them are listed below:

- The majority (83%) of the respondents have some level of difficulty accessing SCI health-related information.
- Medical professionals, SCI Specialty Rehabilitation Centers, and SCI organizations all ranked within the top 3 as trusted, credible, reliable, practical, useful, and accessible sources of SCI information. There may be opportunities for co-branding or partnerships between these organizations to improve access.
- It is key to note that the survey respondents' sources include many general sources that are not specific to SCI.
- Those with SCI view social media as least credible, trustworthy, reliable, practical, and useful, but they use social media often because it is easy to access.
- There is a recognized overlap between the ranking of categories. For instance, a SCI organization may have a website, a peer support group, and a newsletter. In addition, a medical professional and SCI Specialty Rehabilitation Center may also be the same but reported differently.
- Among those who responded, the majority received their rehabilitation at a General Hospital (one without SCI specialty) followed by a Military or VA Hospital.
- People living with SCI mainly seek health information when they have a concern or issue; therefore access to information sources need to be available when needed.
- Access to healthcare information can be one driver of overall health and access to care.
- Telehealth is viewed as a good option when it is appropriate and should remain an available option for people living with SCI.

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. Contents of survey results supporting tables and figures
2. Reference list of literature review of SCI and health literacy
3. Final Survey PDF

SURVEY RESULTS: SUPPORTING TABLES AND FIGURES

Directory

REFERENCE LIST: LITERATURE REVIEW OF SCI AND HEALTH LITERACY

- North American Spinal Cord Injury Consortium 2019 Needs Assessment Survey, https://nascic.org/wp-content/uploads/2021/01/Needs-of-the-Community-Living-with-SCI-in-North-America-AODA.pdf
- Monden K., et al "Stakeholder Evaluation of the Canadian Spinal Cord Injury Physical Activity Guidelines: Barriers and Facilitators to Uptake and Dissemination", poster and presentation at ISCoS 2022 annual meeting, https://az659834.vo.msecnd.net/eventsairwesteuprod/production-zibrant-public/27c420cc1a5e49aaada3c2cd91bbdb09
- Farrehi, Clara, et al. "How individuals with spinal cord injury in the United States access and assess information about experimental therapies and clinical trials: results of a clinical survey." *Spinal cord series and cases* vol. 6,1 103. 23 Nov. 2020, doi:10.1038/s41394-020-00354-6
- Sun, Yalin et al. "Consumer Evaluation of the Quality of Online Health Information: Systematic Literature Review of Relevant Criteria and Indicators." *Journal of medical Internet research* vol. 21,5 e12522. 2 May. 2019, doi:10.2196/12522
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L. R. (2023). Exploring perspectives on assistive technology use: barriers, facilitators, and access. *Disability and Rehabilitation: Assistive Technology*, *19*(4), 1676–1686. https://doi.org/10.1080/17483107.2023.2227235

- Cogley, C., D'Alton, P., Nolan, M., & Smith, E. (2021). *"You were lying in limbo and you knew nothing"*: a thematic analysis of the information needs of spinal cord injured patients and family members in acute care. *Disability and Rehabilitation*, *44*(22), 6804–6814. https://doi.org/10.1080/09638288.2021.1970259
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FINAL SURVEY

Information Needs of People Living with SCI

In this day of information overload, finding the most accurate and updated information is not easy. NASCIC and our principal members are trying to understand and then overcome the information gap experienced by people living with SCI, but we need to hear from you first. This survey is an effort to better understand the health information sources people use and value as well as the health information needs and gaps among the SCI Community. We are seeking input from people with SCI lived experience including those living with SCI, family members, spouses & partners as well as caregivers. The survey takes about 20 minutes to complete. At the end, you can sign-up for a chance to win a gift card as an appreciation for your time.

* What best describes your relation to spinal cord injury?

- ◯ I am a person living with SCI
- ◯ I am a spouse or partner of a person living with SCI
- ◯ I am a family member of a person living with SCI
- ◯ Other (please specify)
- ◯ I am a family member, spouse, or partner AND caregiver of a person living with SCI
- ◯ I am a caregiver of a person living with SCI

Information Needs of People Living with SCI

NOTE: Since you are living with a spinal cord injury, please answer all questions from your personal perspective.

Information Needs of People Living with SCI

NOTE: Since you answered your role as a family member, spouse, partner, and/or caregiver, please answer the questions from your personal perspective. The exceptions to this are a few questions where it is indicated to answer according to the person living with SCI, such as date of injury or diagnosis.

Information Needs of People Living with SCI

* Select your level of function related to your spinal cord injury or diagnosis (if not living with a SCI, please answer about the person with SCI)

- ◯ Quadriplegia complete (paralysis in your hands, arms & legs and no feeling or movement below your injury)
- ◯ Quadriplegia incomplete (paralysis in your hands, arms & legs but you have feeling or movement below your injury)
- ◯ Paraplegia complete (paralysis in your trunk & legs and no feeling or movement below your injury)
- ◯ Paraplegia incomplete (paralysis in your trunk & legs but you have feeling or movement below your injury)
- ◯ I don't know or not sure
- ◯ Other (please specify)

* What year did you have your spinal injury or diagnosis (if not living with SCI, please answer about the person with SCI)?

Information Needs of People Living with SCI

Sources of Information

We would like to ask you a few questions about sources of information that you use related to your spinal cord injury.

* When you have a health problem or question, what are the top 3 information sources that you refer to?

* Why are these your top information sources?

* What source types do you use or did you use in the past to get SCI related health information? (check all that apply)

- [ ] Email Lists
- [ ] SCI Advocacy Organizations
- [ ] Social Media
- [ ] Online Discussion Forums
- [ ] Specialized SCI Rehabilitation Centers
- [ ] Other (please specify)
- [ ] Medical Professional
- [ ] Medical or Research Journal Articles
- [ ] Newsletters/Magazines
- [ ] Websites

* When do you or did you reach out for health information? Choose a maximum of 3 of the choices below.

- [ ] When I experience a problem or health concern.
- [ ] Proactively, before I experience a problem or health concern.
- [ ] When I want information about a new product or treatment.
- [ ] When I was in rehab, post-injury or diagnosis.
- [ ] When I was in acute care, immediately after my injury or diagnosis.
- [ ] When I am researching my SCI or a friend/family member/client's SCI.
- [ ] When I am seeking a specific or specialized type of healthcare.
- [ ] Other (please specify)

* How much difficulty did you have finding the information that you needed?

- ( ) A lot of difficulty
- ( ) Some difficulty
- ( ) Occasionally have difficulty
- ( ) No difficulty at all
- ( ) Other (please specify)

Information Needs of People Living with SCI

What you think about SCI Health Information Sources

Now we will ask your opinion of various types of SCI-related health information. Please rank the following common sources for SCI-related health information that you view as **CREDIBLE, TRUSTWORTHY and RELIABLE**. Rank with 1 being the most Credible, Trustworthy & Reliable and 8 being the least Credible, Trustworthy & Reliable.

Below are questions to guide your choice:

Is this source an authority or expert in the field of the information it is reporting?
Is the information provided by this source able to be consistently relied upon as honest or truthful?

* Please rank the following based on your view of them as CREDIBLE, TRUSTWORTHY and RELIABLE sources.

- Email Lists
- SCI Organizations
- Social Media
- Specialty SCI Rehabilitation Centers
- Medical/Healthcare Professionals
- Medical or Research Journal Articles
- Newsletters/Magazines
- Websites

Please give specific information sources or examples that you like the best.

Please rank the following common sources for SCI-related health information that you view as **PRACTICAL and USEFUL**. Rank with 1 being the most Practical & Useful and 8 being the least Practical & Useful.

Below are questions to guide your choice:

Can the information be readily applied by an individual?
Is the information provided at an appropriate level to be used by an individual?

* Please rank the following based on your view of them as PRACTICAL and USEFUL sources.

- Email Lists
- SCI Organizations
- Social Media
- Specialty SCI Rehabilitation Centers
- Medical/Healthcare Professionals
- Medical or Research Journal Articles
- Newsletters/Magazines
- Websites

Please give specific information sources or examples that you like the best.

Now, please rank the following common sources for SCI-related health information that you view as **ACCESSIBLE**.
Rank with 1 being the most Accessible and 8 being the least Accessible.

Below are questions to guide your choice:

Are you able to acquire information, read and understand the information, and enjoy using the source?

* Please rank the following based on your view of them as ACCESSIBLE sources.

- Email Lists
- SCI Organizations
- Social Media
- Specialty SCI Rehabilitation Centers
- Medical/Healthcare Professionals
- Medical or Research Journal Articles
- Newsletters/Magazines
- Websites

Please give specific information sources or examples that you like the best.

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Information Needs of People Living with SCI

How you Access Information

We would like to ask you a few questions about your sources of health information that you use related to your spinal cord injury.

* What makes you return to or use an information source again and again? (Rate each choice based on your reason to use an information source repeatedly)

	Always applies	Sometimes applies	Neutral	Sometimes does not apply	Never applies
Information is credible and trustworthy.	○	○	○	○	○
I have good access to/understand the information presented.	○	○	○	○	○
Information is customized/customizable for my SCI	○	○	○	○	○
Information is reliable - it is useful again and again	○	○	○	○	○
It is easier to go back to this source other than remember multiple sources	○	○	○	○	○

* We would like to understand your view on SCI health information that you receive. For each statement below rate your agreement.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
There are so many different recommendations about SCI, it's hard to know which ones to follow.	○	○	○	○	○
Information about SCI all starts to sound the same after a while.	○	○	○	○	○
Most things I hear or read about SCI seem pretty far-fetched.	○	○	○	○	○
I feel overloaded by the amount of SCI information I am supposed to know.	○	○	○	○	○

* How would you prefer to filter your health information searches? Please choose your top 3 choices.

- [ ] Level of injury
- [ ] Time since injury
- [ ] Information source
- [ ] Common secondary conditions
- [ ] Geographic location
- [ ] Format of information (i.e. video, article, infographic, etc.)
- [ ] Other (please specify)

North American Spinal Cord Injury Consortium

Information Needs of People Living with SCI

Where Do You Go For Care

We would like to ask where you go when you have a health issue.

* When you have a health related issue, who do you see or contact? (Check all that apply)

- [ ] Family or Primary Care Doctor
- [ ] Clinician with SCI experience/specialized knowledge (Physical Therapist, Occupational Therapist, Physiatrist, etc.)
- [ ] Clinician from a clinical specialty such as urology, pain management, wound care, or nephrology
- [ ] Mental Health Clinician (ie. psychologist, psychiatrist, counselor, etc.)
- [ ] SCI Coach: a trained professional who shares SCI lived experience and knowledge while helping to develop skills for living with SCI.
- [ ] Peer Mentor: a person living with an SCI that shares their life experiences and advice.
- [ ] Other (please specify)

North American Spinal Cord Injury Consortium

Information Needs of People Living with SCI

Where Do You Go For Care: Your Family/Primary Doctor

Above you chose that you go to a Family or Primary Care Doctor. Does your Family or Primary Care Doctor have experience with SCI?

- ◯ Yes
- ◯ No
- ◯ I don't know

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Information Needs of People Living with SCI

Where Do You Go For Care about your Mental Health Clinician

Above you chose that you go to a Mental Health Clinician. Does your Mental Health Clinician have experience with SCI?

- ◯ Yes
- ◯ No
- ◯ I don't know

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Information Needs of People Living with SCI

Where Do You Go For Care about your Experience

* How do you feel about your current health? (Please rate)

Poor	Fair	Neutral	Good	Excellent
☆	☆	☆	☆	☆

* How do you feel about your current access to healthcare? (Please rate)

Poor	Fair	Neutral	Good	Excellent
☆	☆	☆	☆	☆

How has your ability to find information about healthcare influenced your health and access to healthcare? (Please rate)

Very negative influence	Negative influence	No influence	Positive influence	Very positive influence
★	★	★	★	★

Information Needs of People Living with SCI

Understanding your Telehealth Experience

Telehealth is defined as an appointment with a healthcare provider over the phone, video conference, or app.

* Have you used telehealth to access healthcare?

- ◯ Yes, currently
- ◯ Yes, previously
- ◯ No

Information Needs of People Living with SCI

Where Do You Go For Care about your Telehealth Experience

* If yes, thinking of your experience with telehealth, please rate the following statements

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
My telehealth experience was good.	◯	◯	◯	◯	◯
I believe telehealth to be reliable and valuable healthcare.	◯	◯	◯	◯	◯
Telehealth is an option for me and I have access to it.	◯	◯	◯	◯	◯

North American Spinal Cord Injury Consortium

Information Needs of People Living with SCI

Where Do You Go For Care about your Telehealth Experience

If no, then why have you not used telehealth? (Check all that apply)

- [ ] I don't have technology access, such as a cell phone, tablet or computer.
- [ ] I don’t have access to the internet.
- [ ] I do not consider telehealth reliable.
- [ ] My healthcare needs required in-person consult.
- [ ] My clinicians do not offer telehealth.
- [ ] The type of appointment required to be held in-person. (i.e. Imaging or laboratory draw).
- [ ] Telehealth has not proven to provide care specific to my SCI.
- [ ] I did not have a need for it.
- [ ] Other (please specify)

North American Spinal Cord Injury Consortium

Information Needs of People Living with SCI

What About You?

In this section, we would like to learn a little more about you.

* What is your biologic sex?

- ◯ Male
- ◯ Female
- ◯ Non-binary/Third gender
- ◯ Prefer not to say

* With what gender do you identify?

- ◯ Woman
- ◯ Man
- ◯ Transgender
- ◯ Gender neutral
- ◯ Non-binary
- ◯ Two-spirit
- ◯ Prefer not to say

* Please provide your birth year? Enter the 4-digit year.

* What country do you CURRENTLY LIVE in?

- ◯ Canada
- ◯ Mexico
- ◯ United States
- ◯ Other (please specify)

* In what language do you prefer to receive information?

* Where did you receive rehabilitation after your spinal cord injury or diagnosis? Enter a name of a hospital or medical facility. If you never went to rehab, please indicate this below.

* How often do you need to have someone help you understand instructions, pamphlets, or other written material from your doctor or pharmacy.

Never — All the time

* What best describes your area of residence? (Choose one)

- ◯ Big City: population over 250,000
- ◯ Town, or Small City or Suburb: 10,000-250,000
- ◯ Small town or Village: 500-10,000
- ◯ Rural Area: less than 500
- ◯ Other (please specify)

* What is the highest degree or level of education you have completed?

- ◯ Up to and including 11th grade
- ◯ High school degree or GED
- ◯ Technical or Occupational certificate
- ◯ Some college work
- ◯ Other (please specify)
- ◯ Associate's degree
- ◯ Bachelor's degree
- ◯ Master's degree
- ◯ Doctorate or Professional degree

* What is your average household income?

- ◯ Below $25,000
- ◯ $25,000 to $49,999
- ◯ $50,000 to $74,999
- ◯ $75,000 to $124,999
- ◯ $125,000 or more
- ◯ I don't know
- ◯ I prefer not to answer

* What is your race/ethnicity category? (check all that apply)

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Asian or Asian American/Canadian
- ☐ American Indian, Alaska Native or First Nation
- ☐ Other (please specify)
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Middle Eastern or Arabic
- ☐ I don't know
- ☐ I prefer not to answer

* We would like to learn about the assistance you may need in your living situation. Please tell us what best fits your situation.

- ◯ I live alone and independently
- ◯ I live alone and require a caregiver (part-time or full-time)
- ◯ I do not live alone and do not have a need for a caregiver
- ◯ I do not live alone and require assistance from a caregiver
- ◯ Other (please specify)

* What type of health insurance do you have? (check all that apply)

- ☐ Medicare
- ☐ Medicaid
- ☐ National/Provincial Insurance
- ☐ Private Insurance
- ☐ Other (please specify)
- ☐ Veteran/VA
- ☐ Worker's Compensation
- ☐ None/Uninsured

* How much does your religion or culture impact your health decision-making?

No Impact — High Impact

Would you like to sign up for a chance to win a USD $25 gift card?

- ◯ Yes
- ◯ No

Information Needs of People Living with SCI

Gift Card Sign-up

Please provide the following information below to sign up to win 1 of 60 USD $25 gift cards.

Please provide your email address

Email address

Please enter your phone number

Country code

Phone number +1

Please provide an address. We need this to send the gift card.

Street address

Street address line 2

City

State/Province

Zip/Postal code

Country Select country