

Needs of the Community Living with SCI in North America

The North American Spinal Cord Injury Consortium (NASCI) has a focus to build collaboration and a unified voice among the spinal cord injury community, mainly those living with the condition and those organizations that represent them, within North America. In order to build a cohesive plan into the near future, we must first have a solid understanding of the priorities within the community. With this in mind, in late 2019 NASCI initiated a needs assessment of the community through an online survey. The purpose of this scouting exercise was clear: to gain input from the community on what is most important to help direct the activities of NASCI and help prioritize the efforts. The survey was not solely meant to steer the directives of NASCI, but to also provide a resource for the various member organizations and individuals to better understand our community and to help focus their efforts into the future.

The survey questions were developed to address three main areas. The first was to gain an understanding of and rank the four key areas of our mission: research, care, cure and policy. This was also instrumental in distinguishing the biggest challenges that people living with SCI face on a daily basis. The second thematic area of the survey centered around involvement in the research process. There are many components of research and traditionally those living with the condition have been limited to clinical trial participation; however, this section directly asked which areas in the research process the members of our community would like to be involved. The final section was a request back to the community regarding the themes identified following the SCI2020 event in February 2019 hosted by the National Institutes of Neurological Disorders and Stroke (NINDS). The organizers of this event identified five areas of potential research emphasis: recovery with assistive technology, health impacts, neuromodulation and neuroplasticity, therapies for repair across the spectrum of SCI as well as care within the acute trauma setting.

Within the survey instrument, these three main sections were presented to the respondents in a random order and all were followed by standard demographic questions. The administration of the survey was through an on-line platform, Survey Monkey, which is accessible via a multitude of electronic platforms. Due to the nature of this platform, those without internet access whether from a computer or a smartphone were excluded from the survey; however, NASCI felt this was the best way to reach out our population most efficiently because the community is highly connected through social media. The survey was open from mid-July to late October 2019. The distribution of the survey instrument was not only to the current NASCI members of all categories, but also through the networks within our members. It was sent via email, newsletters, advertisements, and social media. Upon closing of the survey, there were 644 responses.

Demographics

The survey respondents comprised a representation of the spinal cord injury community (Figure 1). Although we solicited respondents from people living with SCI, their family members and care-partners, an overwhelming majority (90.1%) of the respondents were people living with SCI. The gender distribution of respondents was a relative even split

between male (58.5%) and female (40.2%) along with a small number of those who identify as non-binary and those who preferred not to say. Across the SCI population, the average age of a person living with a spinal cord injury is increasing and this was reflective in the respondents to this survey. The largest age group to respond were ages 46-60 (41.7%) followed by those who are ages 31-45 (26.3%). The survey also asked about the level of injury as well as the duration post injury (or diagnosis for those with non-traumatic SCI). Injury level across the respondents was primarily cervical injuries at C5-8 (33.3%) and thoracic injuries at T7-12 (26.8%); others were distributed evenly with the exception of a low response from those living with sacral injuries (0.8%). Duration since injury or diagnosis was much more distinct with the largest groups of those living with the condition being more than 20 years (36.7%) and between one and ten years (30.1%). Overall, the respondents to this survey were very similar to the overall population profile as reported by the National SCI Statistics Center at the University of Alabama, Birmingham.

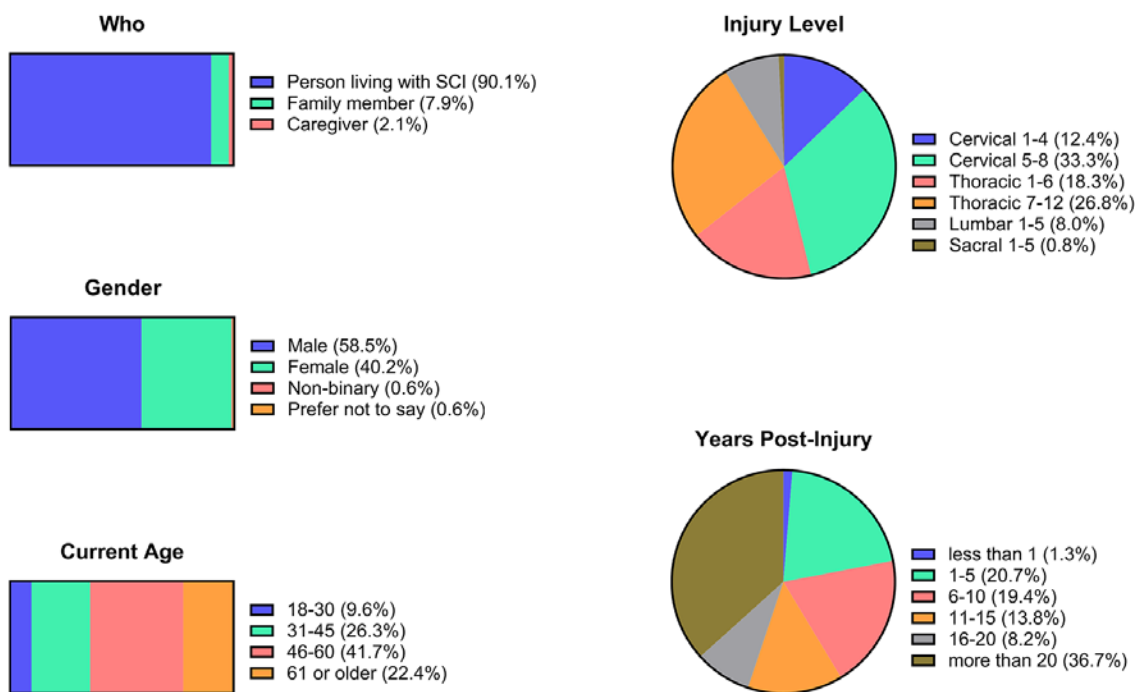


Figure 1

NASCIC Mission-Driven Efforts

The first section of the survey sought input on questions regarding NASCIC’s mission, the community’s level of involvement, and where to direct our efforts. The North American Spinal Cord Injury Consortium (NASCIC) has the mission to bring about unified achievements in research, care, cure, and policy by supporting collaborative efforts across the spinal cord injury community. The community was asked to prioritize the topics of research, care, cure, and policy. Figure 2A shows that the community’s top priority is cure, followed by care and research. Cure will only come about by research, so these two topics may be combined; however, this illustrates the desire across the community for translatable actions from research efforts. Care is very important to the community as

well and could be improved by research if the outcomes of research can be successfully translated. When the community was asked about how active they would like to be in the areas of research, care, and policy the results were fairly even, with a slightly higher percentage of people wanting to receive information about research (Figure 2B). Overall, the community wants to receive information about research and care as well as be active advocates. One could suggest that there have not been the same opportunities created by the community for individuals to be active advocates for research and care as there have been for policies regarding civil rights.

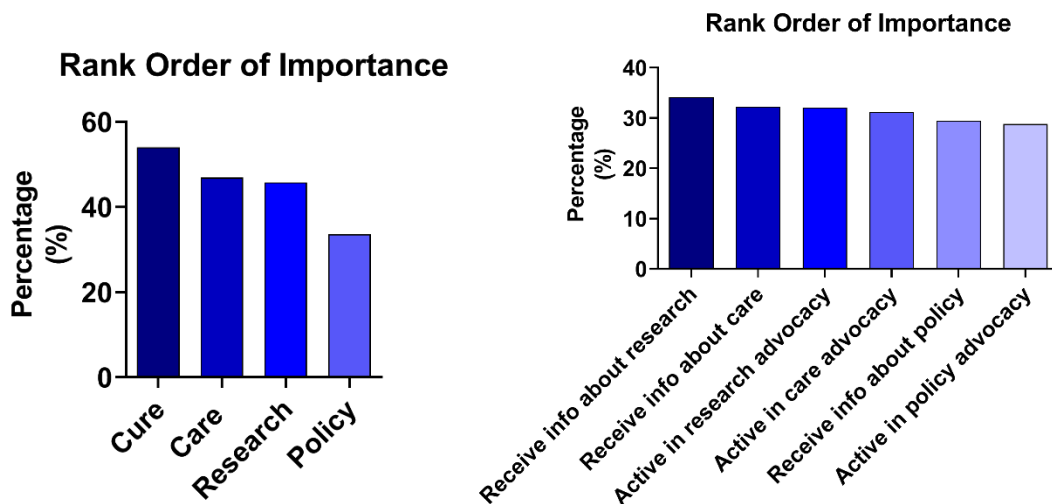


Figure 2

Five topics identified by the NASCIC Executive Council were proposed to the community for them to rank the order of importance. Improving access to SCI-specialized clinical care came out as the top priority, followed by improving access to clinical studies/trials (Figure 3). This indicates that the community continues to struggle with gaining access to the healthcare professionals that truly understand all the consequences and impact that secondary conditions of SCI have on the body. Additionally, these results identify a disconnect between entities conducting clinical studies/trials and the community interested in participating in such activities. The near equal prioritization of the topics involving financial access to therapy/fitness, assistive technology, and personal care attendants illustrates the need for improved access to existing services across the board. These are important topics for advocacy efforts.

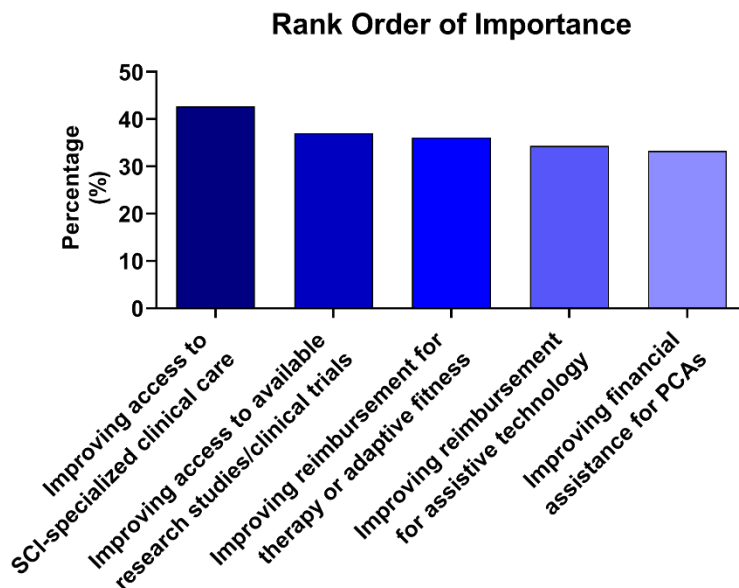


Figure 3

Biggest Challenges Faced by Our Community

As NASCIC is trying to facilitate communication, resource sharing, and the development of effective partnerships so that research, care, cure, and policy activities have a tangible, beneficial impact on our community and families living with SCI, it is critical that we understand the daily challenges people face. We asked the open-ended question “What is the biggest challenge you face on a daily basis related to your spinal cord injury?”.

Of the 644 respondents, 642 provided an answer to this question. Those answers were imported into the qualitative data analysis software program NVivo. Each line was read and coded into a theme. Similar ideas were coded under the same theme. For example, a statement describing challenges with urinary tract infections and a separate statement describing challenges with urine leakage would both be coded under the theme of bladder. A total of 25 unique themes emerged. The number of times each theme was identified by a respondent was counted. The most frequent to least frequently reported themes are ordered in Figure 4.

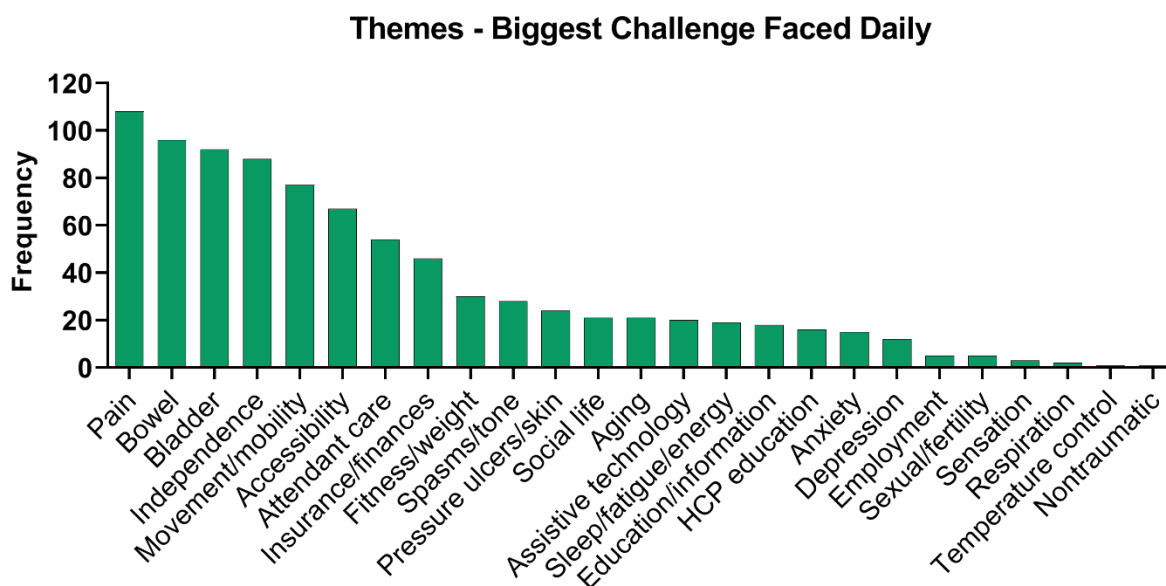
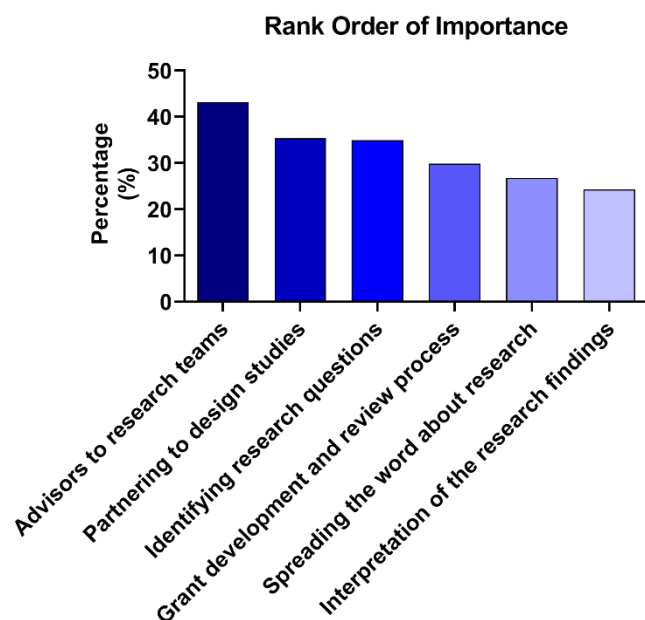


Figure 4

The #1 most frequently cited challenge faced by our community on a daily basis is dealing with pain. This was followed closely by bowel problems, bladder problems, being dependent on other people (coded as the desire to be more independent), and having limitations in movement or mobility (of any kind). Three other themes that emerged as being frequent challenges are problems with accessibility in the environment, finding reliable and affordable attendant care, and many issues involving insurance and financial limitations related to living with SCI. These results are not only helpful for guiding the efforts of NASCIC, but are also incredibly informative for researchers and funding agencies, industry investment, healthcare providers and professional clinical societies, and policy makers and advocacy organizations.

Feedback on Topics Resulting From NIH SCI2020 Conference

The large community survey NASCIC conducted in preparation for SCI 2020 demonstrated that people living with SCI and their families feel left out of the research process until researchers need research participants. As a follow up to that, we asked our community where in the research process they want to be involved. The survey results provide evidence that the SCI community wants to be an active participant in all stages of research planning and execution (Figure 5). Being advisors to research teams



ranked the highest in importance, followed closely by partnering to design studies and identifying research questions. Also ranked above 25% interest was participating in the grant development and review process, dissemination of results, and interpretation of results. By including individuals with SCI as equitable partners throughout the research process the results will be more meaningful and rich and more likely to garner adoption and acceptance from the community.

Figure 5

Following the SCI2020 meeting in February of 2019, the meeting organizers (NINDS) sought public input on the 5 research areas identified as a result of the meeting. We asked survey respondents to rate how important they felt each of the five areas of potential research were and included a request for open comments. The research theme questions were:

- How important is improving functional recovery after SCI with assistive technology?
- How important is improving knowledge of the full range of health impacts of chronic SCI?
- How important is improving evidence for, and implementation of, functional recovery with neuromodulation and use-dependent plasticity?
- How important is accelerating research and development of therapies for repair, plasticity, and improved functional recovery from post-acute to chronic SCI?
- How important is improving care of SCI patients in the acute trauma setting?

As delineated in Figure 6, each potential research area was equally important to 70% of the total respondents to this query, with approximately 10% indicating unsure and less than 10% indicating all areas were very unimportant. Further evaluation showed slight stratification among the research priorities areas, with most importance indicated for 1)

R&D of therapies for repair & plasticity from post-acute to chronic SCI (75%), followed by **2**) improving functional recovery with assistive technology (73%), **3**) full range of health impacts of chronic SCI (70%), and **4**) improving care in the acute trauma setting (65%). The research area ranked with the least importance was **5**) neuromodulation and use-dependent plasticity (55%). However, this area also elicited the most unsure responses (25%).

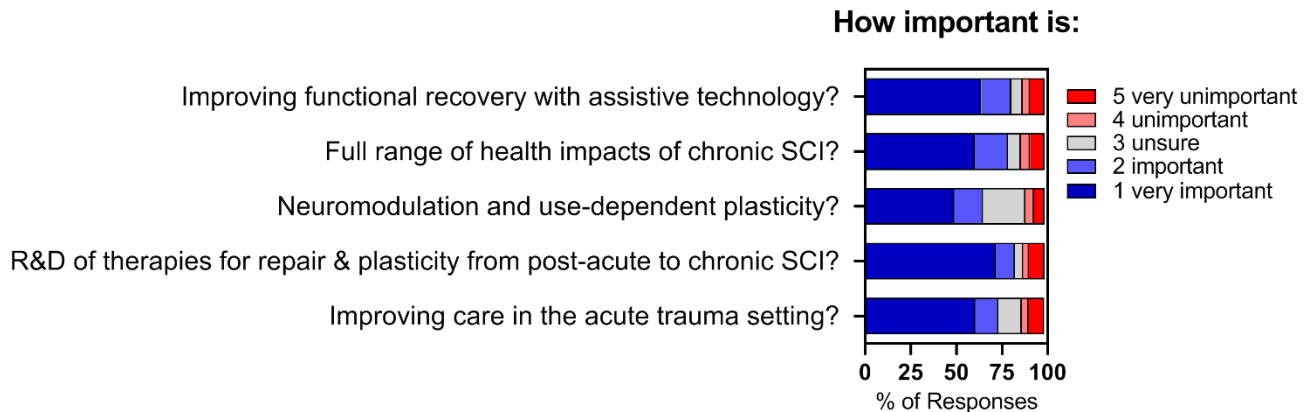


Figure 6

A myriad of responses were provided in the open comments and the following represent comments pertaining to each of the 5 research themes (ranked for importance).

Regarding R&D of therapies for repair & plasticity from post-acute to chronic SCI

"We are hungry for information and access to restorative therapies."

"Everyone needs tech they can use."

"We need robotics assistance to reduce our dependency on caregivers."

WITH RESPECT TO IMPROVING FUNCTIONAL RECOVERY WITH ASSISTIVE TECHNOLOGYS

REGARDING THE FULL RANGE OF HEALTH IMPACTS OF CHRONIC SCI

"Somewhat 'minor' improvements in autonomic function would make a big impact in my opinion."

"Worried that as a person who works hard at wellness and functionality, I am 'aging out' of studies and consideration for adaptive devices."

"My understanding is that the first hours are critical for providing any opportunity for repair."

IMPROVING THE ACUTE TRAUMA SETTING

REGARDING RESEARCH INTO NEUROMODULATION AND USE-DEPENDENT PLASTICITY:

Uncertainty was reflected in the following selected quote, "I have no idea what 'neuromodulation and use dependent plasticity' means?"

There were also open comments that did not fit into the thematic areas above. However, they are worth highlighting since they demonstrate some of the underlying challenges that people living with SCI encounter. Selected excerpts:

“Inclusion of those that have lived with SCI for many years in developing the direction of research into care and cure research is vitally important. These individuals are most well versed in their own needs.”

“The focus needs to be on combination therapies. No single approach will lead to significant improvement. Most likely none of us alive today will live to see any therapy that improves our condition.”

“None of it will matter if insurance won’t pay for the technology & therapy we need. The advances we’ve made have been amazing but the accessibility to those advancements has been slow.”

“More institutions need to work together, combining databases, regarding trials and waitlist to give more SCI people opportunities to participate.”

“I have a master’s degree in psychology and unable to practice, I have only ever been approached to be a participant in a study but never a consultant. I think this reflects the essence of the problem to a large extent. Keep up the good work!”

Summary

Overwhelmingly, **Cure, Research, and Care** are very important to the community living with SCI, but in reality **Research, Cure, and Policy** all **IMPACT CARE**. Therefore, NASCIC will continue to advocate for and facilitate actions targeting the translation of research results into clinical care in a manner that becomes accessible to many people living with SCI. In addition, NASCIC will enhance efforts to share more information about research and care.

Our community living with SCI is facing significant challenges on a daily basis. NASCIC urges researchers and funders to listen to the community and guide their actions to focus research efforts on identifying avenues to reduce the impact of:

- **Pain**
- **Bowel problems**
- **Bladder problems**
- **Improve independence**
- **Improve movement/mobility**

NASCIC will work on connecting groups already working on advocacy efforts to improve **accessibility** and **access to personal care attendants** so that these activities can grow, continue to gain strength, and result in positive change.

The community living with SCI has identified the need to work on improving access to **SCI-specialized clinical care** and **research studies/clinical trials**. In the Fall of 2019,

NASCIC launched the SCI-specialized clinical trial platform www.SciTrials.org . We will focus efforts on continuing to increase awareness of this platform and enhancing the capabilities of the platform to become an effective matching tool between researchers looking for participants and individuals looking to participate in a research study or clinical trial. NASCIC will develop a plan to work with SCI clinical care organizations and providers to try to improve access to specialized care. Part of that plan will include getting tools into the hands of people living with SCI to educate their primary care providers about how to manage the secondary conditions associated with SCI.

Lastly, we need to **build capacity** within our community to enable more engagement in the research process. NASCIC has developed a plan to begin building capacity and we will prioritize efforts as directed by our community. Below are the prioritized activities in which people with SCI want to be involved with in the process of Integrated Knowledge Translation:

- Advisors to research teams
- Partnering to design studies people want to be in
- Identifying research questions
- Grant development and review process
- Dissemination of research results
- Interpretation of data

These efforts are intended to encourage meaningful engagement through the full research process.

Citation: North American Spinal Cord Injury Consortium, Needs of the Community Living with SCI in North America. Niagara Falls, NY. 2019.