

## NASCIC Report of SCI 2020 Panel and Consumer Survey

“Alone we can do so little, together we can do so much.” – Helen Keller

The North American Spinal Cord Injury Consortium (NASCIC) has been designed to identify gaps, communicate resources, and be a conduit for collaboration between the community of people living with SCI and the many stakeholders. NASCIC has the mission to bring about unified achievements in research, care, cure, and policy by advocating for collaborative efforts across the SCI community. Our purpose is an organized and intentional response to the growing recognition of the need for strong and trusting partnerships between those living with SCI and the SCI stakeholder community. Through NASCIC we seek to improve research, care, cure, and policies that impact people living with SCI, their families, and their community. Working collaboratively, the organization is structured to effectively bring about collective change through approved projects.

This report describes an example of how multiple SCI-led organizations, individuals living with SCI, and families living with SCI came together on an effort that had a stronger impact **UNITED** than if they had been separated.

The National Institutes of Health (NIH) is the largest funder of SCI research in the United States. In February of 2019, the NIH brought together the SCI research community, members of the SCI community, and many other SCI research funding organizations. According to the NIH meeting organizers:

***“The goal of the ‘SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research’ conference is to initiate discussion across the SCI research community to launch a new decade of research that disrupts traditional barriers and brings about collaborative efforts to address the key research questions in spinal cord injury research. This conference is designed to be a comprehensive stakeholder’s meeting to bring diverse experience and voices together with this common goal. The participants will be challenged to critically evaluate the state of the science, assess areas of scientific, technological and community readiness, and identify the collaborations needed to change the trajectory of research and clinical opportunities for people with SCI.”***

The meeting agenda was segmented into six sessions, five of which were addressing various areas of SCI research including acute care, subacute and chronic, neuromodulation, technology, and secondary health effects. Each of the five research sessions had expert panelists in their specific areas along with discussion facilitators. The sixth session was focused on input from the community living with SCI, described below.

The NASCIC Executive Council (EC) was asked to lead one session in the SCI 2020 meeting by providing input from the community living with SCI; this session was called “With Us, Not For Us”. The EC selected two members to participate on the SCI 2020 Steering Committee, which was comprised of the NIH meeting organizers and representatives of the other 5 sessions. The Steering Committee’s first task was to craft the central questions our session would address. It was an attempt by NIH/NINDS to identify critical blocks in developing innovative treatments for paralysis and to garner solutions. The questions given to the NASCIC EC by the Steering Committee were:

1. How can SCI consumers participate and provide meaningful input to help researchers as they set priorities and design projects?
2. What does “ready for translation” mean? At what point should research discoveries be moved to clinical implementation and when is additional mechanistic work essential vs. a luxury; what is the acceptable level of evidence and why? Where do the opinions of consumers align or differ from the opinions of scientists and funders?
3. What is the appropriate balance between investments for acute and chronic SCI therapies? Where is that balance now and why? How can we shift it?

In order for the NASCIC EC to begin to address these 3 questions during our session, we felt it was essential to get input from our community living with SCI and their families. We developed a series of questions that would inform our approach to the panel session and cast them out to our community to answer (see Appendix I for a list of all questions). In 37 days we received 1,825 responses! How clear can it be that the community living with SCI wants its voice heard? We took this opportunity very seriously and we hope we represented our community by bringing your collective voice to this forum.

### Summary of Panel Session with Survey Results Included

Kim Anderson-Erisman, NASCIC President, opened up the session to set the stage for the presentations that would follow. She stated that we are here to start an ongoing dialogue to share our reality. In order to do that we need to be able to talk openly and honestly – all of us, no qualms. Our intent is to be disruptive, but in a productive way.

Our reality is that we are living in a system that is broken. **Research** is driven so much by **innovation** that studies needed for translation are considered not innovative and don't get funded. The **clinical** realm is focused on **standard of care**, but there are no standards across centers and no process to inject new knowledge into care, and too many times access is dictated by insurance coverage. **Businesses** are driven by **profit** and many do not invest in SCI because of low expected revenue. People in the audience may think this system



is working, and in the research, clinical, and business realms that's true – **on a day-to-day level everyone is successfully operating in their silos**. But this system is broken in our eyes because nothing is delivered widespread to people living with SCI – **our reality** is that we are **treading water just to survive**.

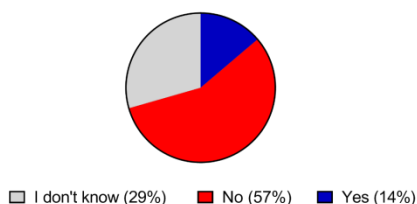
**every single day**, and you can only tread water for so long before you drown. With that thought in mind, we expressed the need to make this meeting meaningful!!

Kim then introduced the survey and that the audience would not just hear from the 7 panelists on stage, but also the 1,825 respondents of the survey. The survey comprised of a series of statements and questions developed from the original 3 questions posed to us by the NIH/NINDS and listed in the previous section. The NASCIC-initiated survey was distributed throughout the SCI community network and was administered on-line. The results from this survey were presented during this session to highlight and represent some of the voices within the SCI community.

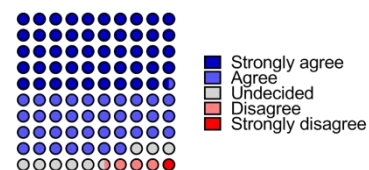
Dr. Anderson-Erisman kicked off the session with some of the survey results. She pointed out how many people are living with **high cervical** and **lumbosacral** injuries (28%), who are often excluded from research clinical trials. She also highlighted how many people are **more than 20 years' post-injury** (34%) and aging with SCI. She went on to point out that those living with SCI do, in fact, **want all functions back**, but we understand that a combination of treatments will likely be required to accomplish that. In the meantime, treatments that restore **small improvements** that positively improve daily life now are **highly desirable**. Furthermore, restoring bladder, bowel, and sexual function are still important. In fact, 98% of the 1,825 people agreed with this statement, and of all the questions in our survey this was the most agreed upon statement from the community! This relays a clear message to the scientific community that there is an obligation to address this area, regardless of the level of difficulty.

Kim ended her introduction stating that we are not here to complain, we are here to share responsibility in creating

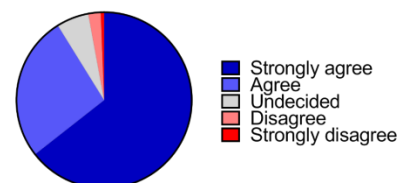
Do you feel like **researchers, clinicians, people living with SCI and their families, funders, industry, insurers, and regulatory agencies** are **CURRENTLY WORKING TOGETHER** to develop a **SUCCESSFUL PATHWAY** to move research findings from the **laboratory all the way out to the community** and ensure that large numbers of people have access to new treatments?



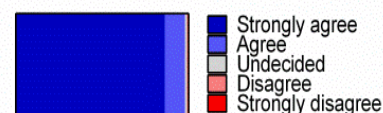
People living with SCI and their families want **all functions** restored, but **understand** that a **combination of treatments** may have the most promise to be able to restore all functions



**Widely available** treatments that restore **small** amounts of function that **positively improve** daily life **NOW** are highly desirable



Restoring **bladder, bowel, and sexual** function are **STILL** important

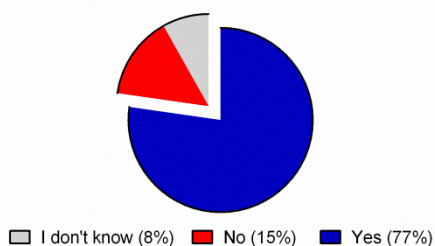


solutions. We want and need to be part of the team. We understand that this is a huge process and that not any one group can do it all. It can't be just scientists, it can't be just clinicians, industry, funders, and it can't be just people with SCI. We have to do it all together. At this moment, our community is telling us that we are not working together to create a successful pathway to ensure all the things being done in research are getting out to all of us who are living with SCI and treading water... on the precipice of drowning.

Matthew Rodreick, NASCIC Delegate, and John Chernesky, NASCIC Vice-President, addressed the 1<sup>st</sup> of 3 questions for our session: *How can SCI consumers participate and provide meaningful input to help*

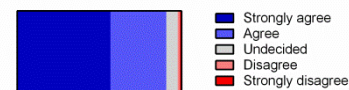
researchers as they set priorities and design projects? Matthew started out with asking “Are **We** in the System?”, we meaning people living with SCI and their families. If you look at the system of science, there are competing institutional incentives ingrained into funding, peer review, publication, biases or conventions in the science, the iterative nature of science, etc. This leads to a system which encourages scientists to be risk averse. The community living with SCI, however, has little to no effective mechanism to influence any of that. **What we need is a transformation of the relationship between those living with a SCI and those who research it.** Our community tells us that they want

Do you feel like you need to increase your own knowledge about or have a better understanding of research and the research process?

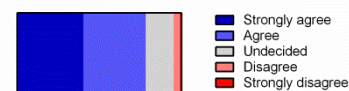


to be involved in the setting of research priorities and in the designing of projects. Our community also tells us that they need to understand more about research and the research process because there are very few avenues or resources by which they know how to obtain this information. Translated by Rodreck, “**We do know what we know**”. We know what it’s like to live with SCI, which is something that no one else knows.” This knowledge and expertise is of value within the research process.

People living with SCI and their families want to be involved in setting of research priorities



People living with SCI and their families want to be involved in designing projects

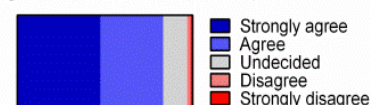


This led into the transition to John Chernesky’s talk about how to include people with lived experience in research. Our community told us that they currently feel left out of the research process until researchers are looking for clinical trial participants.

There is precedence for including people with lived experience of health conditions as research partners and there are multiple funding organizations that require this. They encourage or require the engagement of people in governance, priority setting, as expert reviewers, and increasingly require them to be partners on research projects.

**Integrated Knowledge Translation** is the “meaningful engagement of the right research users throughout the SCI research process at the right time,” expressed Chernesky. He shared an example of a framework that we can use to include people with SCI throughout the research process. It is important to not just include people with SCI when trying to secure funding, when research participants are needed, or for assistance with dissemination. Their input should be sought when developing research questions, choosing methods, conducting the research, analyzing the results, and then with dissemination. John concluded with, “**Those affected by a decision have a right to be a part of the decision-making process**”.

**Currently, people living with SCI and their families are left out of the research process** until researchers are looking for clinical trial participants

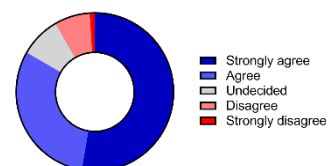


Jennifer French, NASCIC Delegate, and Sasha Rabchevsky, NASCIC Delegate, addressed the second of the 3 questions: *What does “ready for translation” mean? At what point should research discoveries be moved to clinical implementation and when is additional mechanistic work essential vs. a luxury; what is the acceptable level of evidence and why? Where do the opinions of consumers align or differ from the opinions of scientists and funders?* They started out their section bringing up the multiple media

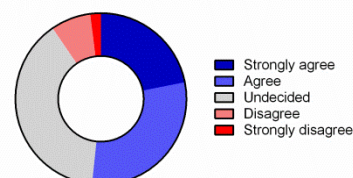


headlines of research studies. The messages through the media imply that there is a cure for SCI when, in fact, there is not. We asked our community and they **are overwhelmingly tired of media hype about research results that are not yet available treatments** clinically available. They cautioned the research community by stating “If you are involved with a press release about your research findings, stop for a minute and think about the people with SCI and their families who will be reading it – are you over promising the impact of your research? Is what you’re saying misleading in terms of delivery and availability?” This transitioned into the topic of ready for translation. The questions posed to those living with SCI were: Does ready for translation mean moving from animal to human? Or does ready for translation mean moving from research to healthcare? Our community’s responses were evenly split. This tells us that there is not a clear answer for the definition of ‘ready for translation’. In fact, one person commented “I chose “undecided” for the first two questions because I have no idea what “ready for translation” means.” **The fact is that translation is a process, not a single step and it goes from the most basic animal research through population-based studies.** No one in the SCI community is an expert on the entire process. We need to work together to bring new discoveries all the way though to people living with SCI.

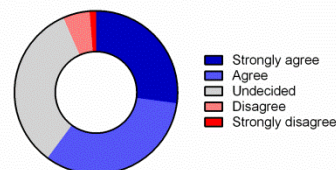
People living with SCI and their families are tired of media hype about research results that are not yet available treatments



Ready for Translation = move from animal to human



Ready for Translation = move from research to healthcare

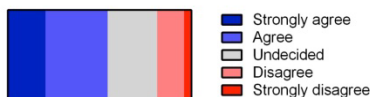


The next section focused on safety versus efficacy and the attitude of those living with SCI. The questions posed were:

- How much research in animals is enough before we move to humans?
- Do we need to know every detail about a treatment’s mechanism of action before we move to humans?

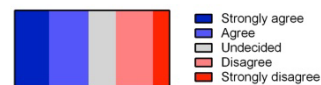
We asked our community about their opinion on this topic and about half of the people felt that safety was more important than effective treatments to restore function. We also asked their opinions on whether we needed to know everything about a treatment as long as the effectiveness outweighs the safety.

Safety is more important than effective treatments to restore function



About half the people agreed and half disagreed. The responses to these two questions show the diversity of our community. **We have**

We do not need to understand everything about a treatment as long as the effectiveness outweighs the safety



**people very concerned about safety and we have people very interested in efficacy, and every point in between.** Rabchevsky and French highlighted this point with examples of the histories of clinical Schwann cell transplantations and Brain Computer Interfaces. These served as examples of extensive animal research before moving to humans versus assuring safety and moving quickly to humans. Overall, this highlights the various levels of acceptable risk among people living with SCI.

They concluded their section talking about financial investment in translation for SCI. **The current paradox is that discoveries based on public investment in research lead to false hope by punting**

**translation to the private industry sector.** There already exist mechanisms to help translate science into clinical practice, and some examples were provided such as the NINDS CREATE and the NSF Innovation Corp programs. The presenters stressed the need to have an ecosystem that will help nurture discoveries by including the SCI community, de-risk discoveries to be ready for investment, and to provide seed funding to kick-start the translation process into the marketplace.

Barry Munro, NASCIC Treasurer, and Rob Wudlick, NASCIC Delegate, addressed the third of three questions for our session: *What is the appropriate balance between investments for acute and chronic SCI therapies? Where is that balance now and why? How can we shift it?* The underlying topic is of balance. **There is a presumption and perception that the majority of research focuses on acute SCI rather than chronic.** We are still lacking the hard data to confirm this presumption and perception,

including  
Current research focuses too much on  
acute injuries [within 1-week post-injury]



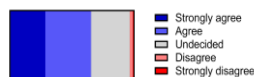
Chronic injuries [6 months or longer post-injury] are under studied in research



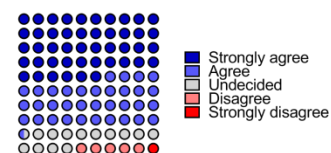
data from the NIH regarding what is funded. At this point, the community, who are also the tax payers, includes people who have this presumption and perception. The results from the survey reflect this, where over half of the respondents agree or strongly agree that research focuses on acute injuries, as well as represents a low level of research for chronic injuries. We do know that between the 1980's and now there has been significant investment of time and money in neuroprotection, both on the basic science side and in clinical trials, with over 20 trials having been conducted in this period. How many approved products have resulted from this investment? None.

Munro expressed, "It's time we step back and look at what we're doing. Using a baseball analogy, **let's stop trying to hit ALL home runs and win a championship.** Seeking a home run every time isn't working anymore, hitting the home run isn't all we have to do. Let's start playing little ball – get on base, advance the runner, steal a base, get a walk, bunt the ball...it doesn't have to get over the fence...or be a grand slam." Our community told us through this survey that we need to **improve access** to existing care and equipment, reduce the cost of living with SCI, and increase life expectancy. These are all **important short-term goals** while new treatments are waiting to be discovered and translated. They are also telling us that they are interested in a **variety of treatments**, including medications, cells, devices, and rehabilitation, not just one.

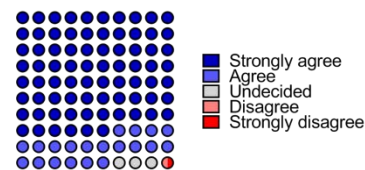
There are 'simple solutions' to **improve practice of care** for brand new [acute] injuries (blood pressure control protocol, hypothermia, early surgery, nutrition protocols, etc) that could be easily **researched and implemented** into clinical care.



Improving access to **existing care and equipment, reducing the cost of living with SCI, and increasing life expectancy** are **more important short term goals** while new treatments are waiting to be discovered



People living with SCI and their families are interested in a **variety of treatments**, including those that involve **medication, cells, devices, and/or rehabilitation**

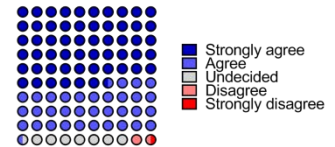


In reference to acute or chronic research investments for the community of people living with SCI, within 12 months all acute injuries will become chronic injuries. For those individuals in the acute window, the community feels that there are some simple solutions to improve the practice of care in the acute

setting that could be easily researched and implemented into clinical care, such as blood pressure control or nutrition to name a few.

So how can we shift this presumption and perception that exists? Munro concluded with this advice, **“Invite the SCI Community as a partner and resource. The whole is greater than the sum of the parts. We are motivated and united because the status quo is not working. Recognize that SCI is a terminal condition. Funding needs to align with the priorities of the people living with SCI.”** Our community tells us, very strongly, that funders should do more to direct researchers to design treatments that reflect the needs of people living with SCI and their families.

Funders should do more to **direct researchers** to design **treatments that reflect the needs** of people living with SCI and their families



The panelists closed the session with these discussion points for the audience.

- What mechanisms can you suggest to effectively align research activities with the priorities of the SCI community?
- What are the means to incentivize meaningful consumer engagement? Funder requirements? Standard design practices?
- What type of common language do we need to create effective communication among the many stakeholders?
- How do we make a systemic change to support promising therapies through the translational spectrum?
- Are we expecting VC/Industry to do the heavy lifting of translation, not from NIH!?
- How can we expect consumers to be aligned if the science communities are not?
- How do we create the urgency in the research community?
- What are the “low hanging fruits” or “simple solutions” that we can quickly bring to the SCI Community?
- How do we combine the great resources of both the scientific & SCI communities to yield impactful outcomes?
- How much of NINDS funding is allocated to Acute versus Chronic SCI?

## Conclusion and the Future

**The overwhelming message from those living with SCI is that the status quo is not working for us or our families.**

We propose three disruptions to the current status quo:

1. People living with SCI need to be engaged at all points in the system from discovery to clinical implementation.
2. Funded research portfolios need to reflect the needs of people living with SCI.
3. Investments in research have to yield tangible impacts in the lives of people living with SCI...NOW.

It is our hope that the NIH and other stakeholders in the research communities will take this information and include the will of the SCI Community in setting their priorities for the next decade. Whether this happens remains to be seen. The most important message that we gave was that the community is **a strong, viable potential partner** that can only enrich and bring great resources to the scientific community and SCI research going forward. We implore that people with lived experience be partners in all aspects of research and we stress that there is a sense of urgency while we work towards these advances.

The most sobering point we made was the following statistic: **according to life-expectancy estimates for people living with SCI, those who have been injured for more than 30 years might not be alive for the next decade's conference.** To put it bluntly, people are dying from the secondary complications of SCI. And **we need to continue to stress this urgency in order for a true disruption in the way we as a society fund and conduct SCI research.**

What will be the next steps carried out by the NIH and the other stakeholders in the research community in response to this urgency? Will they be disruptive in a manner that promotes positive change for people living with SCI? Time will tell. But the clock is ticking and those of us with lived experience of SCI shouldn't wait to find out. We as a community living with and caring for people with SCI need to:

- Take the lead and forge ahead together with our voice growing in strength;
- Support technological advances that can provide function on a faster timeframe while continuing to support biologic, pharmaceutical, rehabilitation, or combinatorial advances that are on an inherently slower timeframe; and
- Strengthen our partnerships with industry and healthcare providers to ensure that outcomes of research actually make it out into the real world – our world.

**Citation:** North American Spinal Cord Injury Consortium, NASCIC Report of SCI 2020 Panel and Consumer Survey. Niagara Falls, NY. 2019.



## Appendix I

### SCI 2020 Community Survey by NASCIC

Here is an opportunity for multiple SCI-led organizations, individuals living with SCI, and families living with SCI to come together on a topic where **UNITED** they can have a stronger impact than separately.

The National Institutes of Health (NIH) is the largest funder of SCI research in the United States. They are hosting a meeting in February 2019 bringing together the SCI research community and many other SCI research funding organizations. According to the NIH meeting organizers:

*"The goal of the 'SCI 2020: Launching a Decade for Disruption in Spinal Cord Injury Research' conference is to initiate discussion across the SCI research community to launch a new decade of research that disrupts traditional barriers and brings about collaborative efforts to address the key research questions in spinal cord injury research. This conference is designed to be a comprehensive stakeholder's meeting to bring diverse experience and voices together with this common goal. The participants will be challenged to critically evaluate the state of the science, assess areas of scientific, technological and community readiness, and identify the collaborations needed to change the trajectory of research and clinical opportunities for people with SCI."*

The North American SCI Consortium has been asked to lead one session in the SCI 2020 meeting to voice concerns of the community living with SCI. Below are 3 questions/topic areas that your input in being sought.

To participate in this survey you must have a spinal cord injury and be at least 18 years old.

Do you feel like need to increase your own knowledge about or have a better understanding of research and the research process?

YES	NO	I DON'T KNOW
77.26%	14.58%	8.16%

#### Question 1:

How can SCI consumers participate and provide meaningful input to help researchers as they set priorities and design projects?

1. People living with SCI and their families want to be involved in setting of research priorities.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
56.75%	34.08%	7.00%	1.36%	0.81%

2. People living with SCI and their families want to be involved in designing projects.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
40.21%	37.98%	17.04%	3.84%	0.93%

3. Currently, people living with SCI and their families are left out of the research process until researchers are looking for clinical trial participants.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
47.27%	35.94%	13.69%	1.92%	1.18%

4. People living with SCI and their families want all functions restored, but understand that a combination of treatments may have the most promise to be able to restore all functions.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
49.38%	37.67%	8.36%	3.35%	1.24%

5. Widely available treatments that restore small amounts of function that positively improve daily life now are highly desirable.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
64.44%	26.70%	5.95%	2.29%	0.62%

6. Restoring bladder, bowel, and sexual function are still important.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
86.31%	11.59%	1.18%	0.37%	0.56%

7. People living with SCI and their families are interested in a variety of treatments, including those that involve medication, cells, devices, and/or rehabilitation.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
75.90%	20.32%	2.66%	0.50%	0.62%

## Question 2

What does “ready for translation” mean? At what point should research discoveries be moved to clinical implementation and when is additional mechanistic work essential vs. a luxury; what is the acceptable level of evidence and why? Where do the opinions of consumers align or differ from the opinions of scientists and funders?

1. ‘Ready for Translation’ means ready to move from animal to human research.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
21.88%	29.77%	38.79%	7.56%	1.99%

2. ‘Ready for Translation’ means ready to move from research to healthcare.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
27.12%	33.02%	33.29%	5.31%	1.26%

3. People living with SCI and their families are tired of media hype about research results that are not yet available treatments.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
52.65%	30.64%	8.36%	7.29%	1.06%

4. We do not need to understand everything about a treatment as long as the effectiveness outweighs the safety.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
22.21%	25.53%	17.77%	24.07%	10.41%

5. Safety is more important than effective treatments to restore function.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
20.62%	33.82%	27.12%	14.66%	3.78%

6. Do you feel like researchers, clinicians, people living with SCI and their families, funders, industry, insurers, and regulatory agencies are working together to develop a successful pathway to move research findings from the laboratory all the way out to the community and ensure that large numbers of people have access to new treatments?

YES	NO	I DON'T KNOW
13.79%	56.76%	29.44%

## Question 3

What is the appropriate balance between investments for acute and chronic SCI therapies? Where is that balance now and why? How can we shift it?

## 1. Current research focuses too much on acute injuries [within 1-week post-injury].

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
27.87%	29.72%	33.22%	7.89%	1.30%

## 2. Chronic injuries [6 months or longer post-injury] are under studied in research.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
38.64%	31.43%	24.16%	4.67%	1.10%

## 3. Funders should do more to direct researchers to design treatments that reflect the needs of people living with SCI and their families.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
56.35%	34.04%	7.69%	1.58%	0.34%

## 4. Improving access to existing care and equipment, reducing the cost of living with SCI, and increasing life expectancy are more important short term goals while new treatments are waiting to be discovered.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
46.19%	34.11%	13.66%	4.87%	1.17%

## 5. There are simple solutions to improve practice of care for brand new [acute] injuries (blood pressure control protocol, hypothermia, early surgery, nutrition protocols, etc) that could be easily researched and implemented into clinical care.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
28.55%	36.93%	31.23%	2.40%	0.89%

**Demographics**

Person living with SCI	Family member	Caregiver
85.07%	11.15%	3.79%

Male	Female
65.24%	34.76%

Current Age 18-30	Current Age 31-45	Current Age 46-60	Current Age 61 or older
9.15%	22.16%	39.50%	29.18%

Cervical 1-4	Cervical 5-8	Thoracic 1-6	Thoracic 7-12	Lumbar 1-5	Sacral 1-5
15.02%	31.09%	16.15%	24.51%	12.09%	1.14%

<1 year post-injury (YPI)	1-5 YPI	6-10 YPI	11-15 YPI	16-20 YPI	21 or more YPI
1.62%	21.43%	19.32%	13.72%	9.74%	34.17%