

## Module 11 – SCI 101 for Researchers

### Implications for research

The specific physical and psychosocial effects of spinal cord injury present both opportunities and challenges for research. For instance, secondary complications that increase mortality or reduce quality of life are high priorities for people living with SCI. That represents opportunities for new research that can address unmet needs.

On the flip side, in clinical research, the impact of an SCI on daily life can create barriers to participating in a study or using a treatment that may not be apparent to someone who does not understand the lived experience.

Understanding the lived experience is necessary to ensure that research is aligned with the SCI community's needs and priorities.

**Sasha Rabchevsky** – In my own experience, and truth be told I have been doing research with spinal cord injury to promote locomotor recovery, is that we're realizing there's so many other things that we need to be concentrating on: arm function and bowel function and bladder function. And these are not just ancillary, these are very critical and important things. I think that getting people involved makes the researchers understand that, despite the fact that they're making incremental gains--which is good science, doesn't mean it's bad science--it's not addressing the needs of the people that they're really trying to help.

**Anita Kaiser** – People with spinal cord injuries can really share their experiences of living with the spinal cord injury and this can help researchers to gain a better understanding of what people's needs are, what's important to them, and where the gaps are that we need to focus on and address. So in that sense, it can really help researchers to focus and align their research priorities to match the priorities of the SCI community.

**Ed Graver** – For me, and I've thought quite a bit about this, if I couldn't have a cure, something to restore what I once had, I thought the most important thing would be addressing the nerve pain that I have, which at times can be pretty severe. And when I'm having periods of severe pain, that's what I want to address. But when I stand back and look at the overall picture, as a quadriplegic with a C5 injury, I don't have use of my hands. And if I could have use of my hands, I'd probably be willing to live with the pain. So, it's both of those items that I would like to have addressed, but I would have to rate use of my hands first. And that would be followed very quickly by my neurogenic bladder and my bowel program. Those four items constitute the majority of my issues on a daily basis. So those are things that if they could be improved, it would improve my overall quality of life.

**Josh Forbes** – I would love researchers to know how significant even the smallest change that they develop could be. If I could use the washroom, say, on my own. Like the difference in my life that would make. If I could regain some sort of hand function. The changes are astronomical for me, it changes all of my day-to-day routine, it eliminates my PSWs, it limits my exposure to not being able to go and do things with my friends as often as I'd like. The smallest breakthrough could make the hugest difference, so I think that it's super important that we keep fighting for that.

Indeed, 91% of respondents to a NASCIC survey of 1,825 people with lived experience said widely available treatments that restore small amounts of function and improve daily life are highly desirable.

The survey also showed that more than half of respondents believe that chronic SCI is understudied in research.

In addition to illuminating gaps in care and research, people with lived experience are uniquely able to make clinical studies more feasible. For instance, people with lived experience can identify design problems with product candidates before clinical testing begins.

**Dennis Bourbeau** – We had an engineer on the team who was putting forth an idea for how a device is going to be working and how someone would use this device in an experiment in a research study, and two of the people with spinal cord injury on the team were holding it in their hands, looking at it, and then they just started rattling off feedback. And then they call into question the very way this is designed. Those two individuals on the team that had spinal cord injury with lived experience—at that point, they were engineers too. And now we have three engineers, talking very rapidly, very excitedly, about what the design could be and how that would be achieved. It was very gratifying.

People with lived experience also can identify barriers to participation in studies. For instance, will transportation be a barrier? Will participation in the study impose direct or indirect costs on participants? Is the time commitment too great, or could it create unacceptable conflicts with participants' daily routines?

**Claudia Garofalo** – I guess for me the biggest thing is if I have to go someplace. I drive, I have a car with hand controls, but if I have to go somewhere, it's like I have to really plan that out. I have to think about that it's going to take me 15 minutes to get into my car and 15 minutes to get out of my car wherever I go. So I always have to take that into account because there is part of my brain that still thinks I'm a walking person and I can just race out the door and get in my car and go, but that of course is not my reality at all so there's a lot of planning and thinking ahead of doing anything.

**Jerrod Kerr** – Some studies want you to be fasted the night before, so you have to take, taking that into account. You know my bowels and my bladder, and how much I drank before the study begins versus how much—or ate, did I eat—versus my recovery afterwards and getting

on with my day. You know a couple of times a week that might not be a big deal, but if it's four or five times a week for several weeks, that kind of thing has made it challenging as well."

People with lived experience also can and should help interpret and disseminate research findings. Dissemination into the community is important to ensure that research translates into care. *Effective* dissemination requires communicating findings in a way that the community will understand, and avoiding hype and overstatement.

**Anita** – So depending on the study, people with lived experience can really rely on their own experiences to determine if the results actually make sense and if they're applicable to the real world. Especially if the findings are unexpected, people with lived experience can really help to explain why the results were, what they were, you know, for example, you know, why a drug study or a drug trial was ineffective. There was a study I was involved with that was measuring blood pressure in people. And they wanted individuals to wear this blood pressure cuff for it was 48 hours straight, obviously taking it off when you had to take a shower and stuff. But it was measuring it, I think every 10 minutes [cut: for TW] for the 48 hours. And the problem was is that it would often, you know, error out if you're doing a certain activity. So for example, if I was driving whenever my arm was bent, um, it would error out. Whenever it errors out when it tries to take a reading, it'll keep repeating it. Same thing if you're sleeping, your arm is bent in a certain way, or if you're exercising. And so a lot of people afterwards, when I spoke with the investigator, a lot of people ended up not wearing it all the time because it was a nuisance, it was disrupting their sleep and just getting in the way. And so they ended up with a lot of missing data and I think if they had individuals maybe involved, you know, in doing a pilot run or something, they could have sort of figured some of this things out.

**Barry** – One of the greatest disservices that we can do as a community when it comes to communicating research is really how we can overhype things sometimes. We don't have to always mention the 'big breakthrough. When scientists say that it's only five years away, that's really not a responsible statement, because there's a lot of variables and factors that they don't have control over. And sometimes the motivation for these sorts of hyper announcements happen when different researchers are about to publish a paper and want to get the word out. Sometimes it gets picked up by the local PR group of the institution that might want to get some excitement around the issue. Sometimes it's the private industry that wants to get the news out to funders and shareholders. But all of that, when you add it up, really creates a form of false hope for individuals. What happens is people with spinal cord injuries that do get excited about these quote breakthrough announcements and then find out that it doesn't happen in the timeline it's been suggested—or at all—really lose hope or interest in research. So it's important for us in the community, both people with spinal cord injuries and researchers, to be careful about how we make announcements about the research that we are working on together.

So how should researchers engage with people living with SCI? The next video will provide a framework for engagement, followed by a video describing pitfalls and best practices.