

Module 11 – SCI 101 for Researchers

Learning from the Experts

This module is designed specifically for researchers working in the lab, the clinic, and the community. The goal is to encourage and support researchers to routinely engage people living with SCI in all types and phases of SCI research.

If you think your research could one day be translated into therapies, products, services, or guidelines that improve life for people with SCI—even if it is early research and you won't be translating the work yourself—you and your team can benefit from engaging people living with SCI. For example:

- Research developed with input from people with lived experience is more likely to be funded. In fact, many funders require it.
- Research that includes the perspectives of people with SCI is highly cited.
- It is more likely to address the real-world priorities of people living with SCI, which improves the chances that it will move to the next step, be patentable, or get licensed.
- Engaging with people who have an SCI can make your work more satisfying and meaningful.

People who live with an SCI know best what daily challenges and medical problems need to be solved. They know what improvements can really make a difference. They bring a practical perspective to the design of preclinical experiments, clinical studies, treatment protocols, and medical products. And they have tremendous insight into problems that more foundational science seeks to address.

In short: people who live with SCI can tell you what is important to the community, where there will be problems with implementation or translation, and where there are opportunities that nobody else will see. Therefore, it is important to include this expertise at all stages of research and development.

NASCIC acknowledges that in basic research examining fundamental neuroscience questions, the best and most meaningful role of people with lived experience is not as clear. Together, researchers and people with lived experience can define what partnership in basic research can be.

Engagement is a skill that needs to be developed, and effective engagement requires as much thoughtfulness and planning as any other aspect of research. The manner of engagement may

be different depending on the needs of the project. This module will provide you with a foundation for effective engagement with the SCI community.

Through video interviews with people who have spinal cord injuries, and with researchers who do engage people with lived experience, you will gain insights into:

- What life with an SCI is like, and why that matters in research,
- How to work with people with an SCI to develop research projects, and
- How these collaborations have improved science, lab culture, and researchers' sense of satisfaction.

Before we dive in—the perspectives in this module are unique to the people who were interviewed. No two people with spinal cord injury are alike, even if they have injuries in the same place in the spinal cord. Factors including the severity of the injury, a person's health, skills they have learned over time, their age, and the length of time since their injury all combine to affect their experience of a spinal cord injury.

While this module will provide a foundation, it cannot substitute for engaging people who live with an SCI and their caregivers.

We hope you will use these examples to:

- Think about how individuals with SCI can help *you* in *your* research,
- Ask questions that will drive your work forward, and
- Plan for engagements with people who have SCIs that will be productive for you and for them.