

Patient Engagement in Research Community of Practice

May 2023: Resource on Engagement in Spinal Cord Injury Research

This document provides a presentation summary about the Spinal Cord Injury (SCI) Research Advocacy Course developed by the North American Spinal Cord Injury Consortium (NASCI).

Key Presentation Points

- The SCI Research Advocacy course is a free online course with 12 modules for people living with SCI, their caregivers, SCI researchers, and health care professionals. The course aims to increase knowledge of research processes so people living with SCI feel more prepared to advise and partner on SCI research. Meanwhile, researchers gain understanding of meaningful engagement and the barriers and facilitators to the participation of people living with SCI.
- Individuals completing the course will have access to supplementary materials and resources. They will also be included in NASCI's Project Engagement database that will help match people living with SCI and researchers to future SCI-related research opportunities.

What did we discuss?

- **Evaluation:** The course has an evaluation component set up to help understand impact. During enrollment, participants can indicate whether they want to participate in the evaluation. An evaluation project is under way with 70 of the 157 enrolled participants. Future partnerships and grant applications are being explored to further investigate the impact of the course.
- **Representation of diverse participants in the SCI community:** NASCI has worked with partners in the United States and the Latinx community to translate the content into Spanish. Other ongoing efforts to increase representation include funding projects that incorporate Equity, Diversity, and Inclusion strategies and identifying phrasing that is acceptable and appropriate for different communities.
- **Barriers to engagement:** Access to internet and community mistrust in the medical system are two barriers to engagement in research. People in rehab have been offered a print version of the course to address barriers to internet or computer access. There are future plans to explore alternative formats to deliver the course (e.g., YouTube).
- **Learnings for people living with SCI:** The process of accepting, learning, and adapting to a new diagnosis requires time. When people feel they are ready to engage, access to information and resources can allow them to feel more confident about engagement in research. During engagement, it is important to share information, constructive feedback, and messages that resonate. This can be more helpful than just focusing on emotions or complaints.

Relevant Resources on Patient Engagement in Research

- [Conference proceedings:](#) A document discussing the meeting proceedings of 'SCI 2020: Launching a Decade of Disruption in Spinal Cord Injury Research' Conference.
- [SCI Research Advocacy Course:](#) A free online course sharing information about the biology of SCI and SCI research.