

Smart Policy Works LLC

Patient Empowerment for “Research Readiness”

We spend a great deal in this country on medical research that often does not reflect the interests of people living with chronic disease. The push for evidence-based medicine in the 1970s came hand-in-hand with empowering patients as partners as a way to both improve outcomes and to curb wasteful spending.

In 2016, we led an effort funded by the Patient Centered Outcomes Research Institute (PCORI) to engage people with trauma induced spinal cord injury in the design, implementation and dissemination of research. (The award was to Health & Disability Advocates; Barbara Otto, Joe Entwisle and Melissa Turner led the initiative.)



A spinal cord injury, like most chronic conditions, has implications for many other aspects of a person’s health, including increased risks for cardiovascular disease, mental health issues and diabetes. Nearly a quarter of a million Americans live with “SCI,” and almost 12,000 a year experience such injuries.

Our aim was to prepare patients with trauma-induced SCI to become “research ready” and play active roles in research to improve their health and quality of life. We recruited a cohort of patient stakeholders and worked with them on how to use their own experiences to improve future studies.

What made this project unique was its deep roots in lived experience among the cohort, the panel and the team. We assembled a project team with strong representation of SCI and convened an expert panel who were themselves living with the injury or had one-on-one experience with it. We also made a strong effort to foreground the cohort’s own research interests and range of concerns.

Our findings challenge the wheelchair stereotype. People with SCI are a diverse population with a range of ability and unequal opportunities for education, employment and community participation. Our deep commitment to documenting the work led us to creating profiles for each of the participants. We are excited to make this work available to serve as a model and inform future projects. It is our sincere hope that others will be able to use, adapt and build on the curriculum we developed in this path breaking project.

[Read the full report](#)