NASCIC
SCI RESEARCH
ADVOCACY COURSE

Module 11 – SCI 101 for Researchers

Dos and Don'ts of Engaging the SCI Community in Research

Collaborations in research can take many forms, depending on the individuals involved and the aims of the research. There's no one right way to engage, but there are best practices to consider, and pitfalls to avoid.

In the last video, we introduced a pitfall called tokenism. Examples the community has actually experienced include:

- Asking individuals living with SCI or SCI organizations to endorse or legitimize research programs without asking for, or listening to, input or recommendations;
- Asking for input or recommendations, but only after decisions have already been made; and
- Failing to support active participation with information and communication.

Another pitfall is bias—often unintentional—either from researchers seeking confirmation of their intentions instead of meaningful input, or from advocates speaking out of self interest instead of representing the community.

Following best practices is the best way to avoid these pitfalls, including:

Involving people with lived experience in all points of the research process. This includes:

- Seeking input into the most important research topics,
- Collaborating to develop and refine a research question that matters,
- Developing and reviewing grants,
- Developing methods and designing studies that people want to participate in,
- Conducting research as equitable members of the research team,
- Interpreting results, and
- Disseminating results to reach end users and have impact

Best practices also include involving participants with perspectives relevant to the research questions being addressed; for instance:

- Levels of injury;
- Severity of injury;
- Cause of injury;
- Time since injury; and

- Demographics including age, sex, gender, ethnicity, socio-economic status, etc.

Encouraging bi-directional learning and communication is another best practice for successful engagement.

Dennis Bourbeau – It is incumbent on me to create and environment and a culture that welcomes everyone and empowers everyone on the team to speak and ask questions and make comments. It is possible that someone with some letters after their name may feel a it like they're the expert, right, and they may be less likely to listen, or they may have a blind spot they're not aware of. So we have to make sure that we foster that culture to make sure that everyone's opinion is valued and heard. What it comes down to is to be able to go into the lab and have scientists, engineers, clinicians, administrators, but also people with spinal cord injury. Everyone has their expertise that they need to bring in to make sure that what we've done has meaning and has an impact.

Similarly, respecting everyone's expertise and contribution is essential.

Dennis Bourbeau – Having a group of people that are motivated by different things, but also having an interaction to get something done, makes the lab vibrant, lively, interesting. It gives our work meaning. We bring in undergraduate students and graduate students and postdocs, we work with nurses and therapists, we work with medical doctors and PhDs, you know, just all over the spectrum of levels of education and experience. And everyone has something to offer, and everyone has something to learn.

Collaborators should be compensated for their time and contribution. This can be tricky for people who receive disability benefits, and needs to be managed with care.

Dennis Bourbeau – One surprising thing to me was, how to pay them? Do I get them employed at our institution, or do we set them up as a private [cut: as a private] contractor? I didn't appreciate at first what it would take as far as administrative effort to have them on the team, and then second I didn't appreciate some of the economic consequences that there could be for some people, so if they've got Medicare we can't pay them so much that their salary is over some threshold and their benefits are taken away.

There are many resources available to help you plan and launch successful collaborations with people living with SCI. We'll provide details on how NASCIC can help both researchers and SCI research advocates develop effective partnerships in the module on Getting Started. In addition, you can visit the supplemental resources section of this module, which includes links and documents describing additional best practices, such as:

- Guidelines from the NASCIC Project Review Committee;
- An Engagement Rubric from the Patient-Centered Outcomes Research Institute (PCORI);

- A Guide to Researcher and Knowledge User Collaboration from the Canadian Institutes of Health Research; and
- Other SCI community-based organizations who connect advocates with lived experience and research teams.

The next video will describe a case study on collaboration from the Lane Lab.