



# Equitable partnerships between scientists and persons living with spinal cord injury will strengthen research scope, quality, and outcomes

*Kim D. Anderson*

## **Purpose of review**

Partnerships across all stakeholders in the research process strengthen the outcomes and ultimate usability of research. The purpose of this review is to discuss the current level of inclusion of people living with spinal cord injury (SCI) in the research process, the science of engagement and benefits of partnerships in research, and emerging resources available to help promote ethical and effective partnerships in SCI research.

## **Recent findings**

Significant strides have been made in interacting with people living with SCI to help identify the problem(s) that are important to study (i.e. the first step in the research process). The SCI research field is lagging in partnering with people living with SCI throughout the rest of the research process despite a plethora of evidence-based principles and strategies for effective partnerships in the broader context of research. There are several emerging resources specific to SCI to help researchers and the community begin to build meaningful partnerships throughout the entire cycle of research.

## **Summary**

The SCI research field already values partnerships with clinicians and promotes the concept of 'bench-to bedside and back again'. Now is the time to take it a step further to 'bench-to bedside-to community and back again'.

## **Keywords**

engagement, partnerships, spinal cord injury

## **INTRODUCTION**

Historically, there has been a gap between those studying spinal cord injury (SCI) and those living with SCI. This could partially be related to the divisive concept of 'care vs. cure', which creates an adversarial relationship over how to invest limited funds – in caring for individuals living with SCI here and now or investing in research that could potentially cure SCI at some point in the future. Both are important. It could also be partially related to the medical model of disability approach to SCI research, in which SCI is a problem that needs to be fixed by the scientists and clinicians and the person with SCI is the object of intervention or the passive patient. The true gap, however, is really rooted in lack of communication and, therefore, lack of partnership. Enhancing communication will enable each side to better understand each other and forge the way for developing meaningful partnerships. This review will discuss the current level of inclusion of people living with SCI in the research process, the science of engagement and benefits of

partnerships in research, and emerging resources available to help promote ethical and effective partnerships in SCI research.

## **CURRENT LEVEL OF INCLUSION OF PEOPLE LIVING WITH SPINAL CORD INJURY THROUGHOUT THE SPINAL CORD INJURY RESEARCH PROCESS**

Generally, there are five broad steps in the research process:

- (1) Identify problem

Department of Physical Medicine and Rehabilitation, MetroHealth System, Case Western Reserve University School of Medicine, Cleveland, Ohio, USA

Correspondence to Kim D. Anderson, MetroHealth Old Brooklyn Health Center, 4229 Pearl Road, Suite SM1-050, Cleveland, OH 44109, USA. Tel: +1 216 957 3682; e-mail: kxa304@case.edu

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## KEY POINTS

- Historically, there has been a gap between those studying spinal cord injury (SCI) and those living with SCI.
- Significant strides have been made in interacting with people living with SCI to help identify the problem(s) that are important to study (i.e. the first step in the research process) but little progress has been made in partnering throughout the rest of the research process.
- There are a plethora of evidence-based principles and strategies for building and maintaining effective partnerships, overcoming challenges, and measuring impact on research.
- There are several emerging resources from leaders in the community living with SCI, funders of SCI research, and champions of SCI research partnerships to help build meaningful partnerships throughout the entire cycle of research.
- Embracing the concept of 'bench-to bedside-to-community and back again' by creating equitable partnerships will strengthen the outcome of SCI research efforts so that all stakeholders can benefit.

- (2) Define research question and secure funding
- (3) Collect data
- (4) Analyze data
- (5) Disseminate results

These steps lead to an iterative cycle of knowledge generation. Over the last 17 years, much progress has been made on interacting with people living with SCI to help identify the problem(s) that are important to study (step 1). This has really revolved around conducting research with people living with SCI as participants and asking their opinions on different topics. This was jump started in 2004 when Anderson published results from a community survey demonstrating that walking was not the most important priority for recovery [1]. There is an ever-growing body of research like this, and it is very helpful in setting priorities broadly as well as refining a particular topic in more depth. Recent examples published in the literature include:

- (1) Kirshblum *et al.* [2] in 2019 – 91 adults with SCI reported on the comfort or discomfort associated with the sensory portion of the International Standards for Neurological Classification of SCI examination. It was determined that light touch was not painful, but pinprick could be considered painful when it was done first and in persons who had not experienced an examination previously.
- (2) Ter Wengel *et al.* [3] in 2020 – 79 adults with SCI (and 77 physicians) reported on the meaningfulness of neurologic recovery based on ASIA Impairment Scale (AIS) grade and lowering of the motor level. It was determined that meaningful recovery does not require a change in AIS grade. It was recommended that detailed neurologic outcomes be used, as opposed to gross outcomes, such as change in AIS grade, so as not to underestimate meaningful recovery.
- (3) Bourbeau *et al.* [4] in 2020 – 370 adults with SCI reported on bladder and bowel priorities for recovery. They also reported on willingness to accept neurostimulation devices targeting bladder or bowel function and on the biggest concerns related to such devices.
- (4) Fekete *et al.* [5] in 2020 – 12591 adults with SCI worldwide reported on the lived experience with SCI as it relates to functioning, health maintenance, and subjective well being.
- (5) Huh and Ko [6] in 2020 – 100 adults with SCI in Korea reported on recovery targets. It was determined that upper extremity, sexual, and bladder and bowel functions remain high priorities for recovery targets.
- (6) Bahsoun *et al.* [7] in 2021 – 159 adults with SCI reported on participating in clinical trials and research studies. It was determined that a large majority of people living with SCI are interested in research but that interest drops precipitously when potential risks are explained. It was recommended that communication between researchers and people living with SCI needs to occur more frequently to help make research more accessible.
- (7) Goldstine *et al.* [8] in 2021 – 12 adults (9 with SCI) helped refine goals created by 6 clinicians in the development of a person-centric goal attainment scale related to neurogenic bladder and bowel dysfunction. It was recommended that talking with individuals with the problem in question is important as they can identify important constructs that may be overlooked by clinicians.

Less progress has been made on steps 2–5. This involves working together with people living with SCI as partners with research teams and valuing their lived experience as equally as any other consultant to a research team. There is a term for this, it is called integrated knowledge translation (IKT). By definition, IKT engages end users throughout the entire research process [9,10]. 'By doing IKT,

researchers and research users work together to shape the research process by collaborating to determine the research questions, deciding on the methodology, being involved in data collection and tools development, interpreting the findings, and helping disseminate the research results' [9]. This is not a new concept. In fact, there is an entire science underlying engagement that is ripe for uptake across the SCI research and lived experience communities.

## SCIENCE OF ENGAGEMENT AND BENEFITS OF PARTNERSHIPS

There are science-based practices for engaging with the public in research partnerships [11]. There are scientific journals dedicated to peer-reviewed publications based on these practices:

- (1) *Progress in Community Health Partnerships: Research, Education, and Action*
- (2) *The Patient: Patient-Centered Outcomes Research*
- (3) *Patient Preference and Adherence*
- (4) *Journal of Participatory Medicine*
- (5) *Research Involvement and Engagement* (journal is co-produced by 'patients' and 'academics')
- (6) *Journal of Community Engagement and Scholarship*
- (7) *Gateways: International Journal of Community Research and Engagement*

There are institutions dedicated to promoting these principles:

- (1) International Association for Public Participation
- (2) Patient-Centered Outcomes Research Institute (PCORI)
- (3) United States Food and Drug Administration:
  - (a) Center for Devices and Radiological Health Patient Science and Engagement Program
  - (b) Center for Drug Evaluation and Research Patient-Focused Drug Development Program
- (4) European Patients Academy for Therapeutic Innovation
- (5) Canadian Institutes of Health Research Partnerships and Citizen Engagement Branch
- (6) National Institute for Health Research, a component of the United Kingdom National Health System, core workstream to partner with patients, service users, carers, and communities across every stage of the research pathway

Recently, an evidence-based definition of 'patient engagement in research' was co-created by the multistakeholder Patient Engagement in

Research Working Group of the International Society for Pharmacoeconomics and Outcomes Research Patient-Centered Special Interest Group [12<sup>■</sup>]. The definition is:

The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their specific experiences, values, and expertise. (p. 682) [12<sup>■</sup>]

Of course, creating partnerships does not come without challenges. An analysis of several hundred partnerships funded by PCORI revealed three domains of engagement challenges [13<sup>■</sup>]. These include: infrastructure to support engagement, building relationships, and maintaining relationships. This in-depth analysis also revealed many actionable strategies to overcome these challenges, which can be quite helpful for research teams beginning engagement activities. Another analysis of a project involving 28 partners identified environmental and procedural facilitators to engagement as well as barriers around logistics, institutions, and aspects of the engagement process [14<sup>■</sup>].

Meaningful engagement is not a quick and easy process and measuring impact takes time. A recent analysis of real-world impact across drug development companies conducting various engagement strategies indicates that some partnership-based strategies that are relatively inexpensive had the most significant impact [15]. Specifically, conducting advisory boards and focus groups with people living with the disease of interest as well as working with advocacy groups during the drug development process led to faster trial planning, regulatory approvals (including Institutional Review Boards), and enrollment, and contributed to fewer protocol amendments. This was in the setting of industry-sponsored drug trials but clinical research is plagued by these problems in the academic setting as well. An analysis of an engagement teams' experience in an academic setting involving the design and development of a randomized controlled trial and clinical service pathway revealed that creating a meaningful engagement experience led to improvements and efficiency in research decision-making, improved selection of research measures, contribution of new ideas to the project, improved service design, and had a substantial impact on the success of the project [14<sup>■</sup>].

From the proceedings of the 'SCI 2020: Launching a Decade of Disruption in Spinal Cord Injury Research' conference [16<sup>■</sup>], we know that the SCI community:

- (1) Feels left out of the research process until researchers are looking for clinical trial participants,
- (2) Wants to be involved in setting research priorities,
- (3) Wants to be involved in designing projects.
- (6) Ability for all partners to benefit in a meaningful way by participating,
- (7) Ethical considerations must be addressed, and
- (8) Respect any practical or financial constraints.

We also know, from a needs assessment survey of the community [17] that people living with SCI most importantly want to partner with research teams as advisors during the conduct of the research projects. In fact, funding agencies are wanting this as well. The Department of Defense SCI Research Program and the Paralyzed Veterans of America Research Foundation have had individuals living with SCI as peer reviewers on their grant panels for many years. Recently, both programs have added a requirement to new grant submissions to include SCI consumer advocates or lived experience consultants as partners with research teams. The National Institute on Disability, Independent Living, and Rehabilitation Research also places great value on the inclusion of people with disabilities throughout the research process and within research teams.

### **EMERGING RESOURCES TO HELP SCIENTISTS AND PEOPLE LIVING WITH SPINAL CORD INJURY ETHICALLY AND EFFECTIVELY PARTNER TO PROMOTE HIGH QUALITY, MEANINGFUL RESEARCH**

There are several emerging resources that are specific to helping establish meaningful partnerships in SCI research. Most importantly are the 'The Integrated Knowledge Translation Guiding Principles for Conducting and Disseminating SCI Research in Partnership' [18<sup>\*\*\*</sup>]. The process of creating these guiding principles is also an excellent example of a meaningful partnership in SCI research as they were co-created by a group of researchers, funders, and individuals living with SCI. A set of eight evidence-based principles were established by a rigorous, consensus-based process to help support meaningful and impactful partnership in SCI research. These guiding principles are paraphrased below:

- (1) Relationships must be based on trust, respect, dignity, and transparency,
- (2) Shared decision-making is involved,
- (3) Communication is enabled that is open, honest, and responsive,
- (4) Diverse expertise and knowledge of all partners is recognized, valued, and shared,
- (5) Flexibility and receptivity are needed to allow the research approach to be tailored to match the project aims and context,

Importantly, the authors define tokenism, which occurs when engagement is not valued as an asset to a research program. Tokenism is 'The practice of making only a minimum or symbolic effort to do a particular thing, especially by recruiting a small number of people from under-represented groups in order to give the appearance of equality. Tokenism happens when a partner is asked to endorse, and therefore, legitimize, research programs over which they have little real influence or control' [18<sup>\*\*\*</sup>]. The guiding principles are intended to help prevent tokenism from happening and enable high quality and ethical research to be conducted that is relevant, useful, and useable.

Insight from champions of SCI research partnerships recommends linking strategies to related principles to develop and maintain meaningful partnerships [19]. It also reveals further areas to be explored to build capacity to support research partnerships [20]. These include an attitude shift toward valuing different perspectives and knowledge, looking to inspirational role models to motivate others to adopt research partnership approaches, and encouraging intrinsic motivators to engage in research partnerships (autonomy, competence, relatedness) [20]. Another area that could contribute to a shift in valuing partnerships would be to begin discussing this at the graduate education level. For example, many medical schools traditionally do not include disability education in their curriculum [21]. However, there are some institutions trying to change this, including the University of Michigan Medical School [22] and the University of California San Francisco [23] as two examples. Graduate education programs for scientists could follow suit. The author is not aware of any PhD training programs that formally provide their students with education about or exposure to individuals living with diseases being studied. Exposing physicians and scientists early on in their training to individuals with lived experience and to the science underlying meaningful partnerships could contribute to significant changes in the culture of research.

Leaders in the community living with SCI are also helping to build capacity so that more individuals living with SCI feel comfortable engaging in research partnerships. The North American SCI Consortium (NASCI) is a collaboration of community-based organizations and individuals with lived experience in SCI. They have already created a



database of individuals interested in engaging in SCI research projects and work to help researchers match up with these individuals. NASCIC understands that building capacity also involves education. The community living with SCI has indicated that they want to learn more about research but they have few opportunities to obtain such information [16<sup>¶</sup>]. NASCIC has begun creating a SCI Research Advocacy course to help overcome this lack of knowledge. A multistakeholder working group composed of individuals living with SCI, caregivers, researchers, physicians, industry representatives, and funders are overseeing this effort. The end result will be a free, online, self-paced course of 12 modules covering multiple aspects of SCI research. Individuals that complete the course of modules will be better equipped to be effective partners and will be matched with researchers seeking to establish partnerships. The initial modules will be released by the end of 2021. Additionally, Unite2Fight Paralysis hosts an annual science and advocacy symposium that creates an environment where people living with SCI and people studying SCI can come together to communicate with each other in an inclusive environment. Unite2Fight Paralysis has also begun working with the International Online SCI Research Seminar (IOSCIRS) group to try to make SCI research accessible to nonscientists.

## CONCLUSION

The entire spectrum of SCI research can benefit from meaningful partnerships with people living with SCI, not just clinical research. We as a field already value partnerships with clinicians and promote the concept of 'bench-to bedside and back again'. Why not 'bench-to bedside-to community and back again'? Since the 1980s, our knowledge about SCI across the entire spectrum of research has grown exponentially. However, one cannot turn a blind eye to the failed landscape of SCI clinical trials and lack of impact on the community. It is imperative that all stakeholders work together – valuing and respecting each other's expertise – if we as a whole want to see SCI research change people's lives. The foundation exists to create meaningful partnerships that are beneficial to all parties and that will strengthen SCI research scope, quality, and outcomes. Now we need to put those foundational principles into practice.

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## Conflicts of interest

*There are no conflicts of interest.*

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- of special interest
- of outstanding interest

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