

# ACADEMY OF SPINAL CORD INJURY PROFESSIONALS

## Collecting Research Data Internationally: Methodological Challenges and Opportunities

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### Introduction

As money and resources to conduct research in spinal cord injury (SCI) continue to get tighter, it often is necessary for researchers to reach out to their colleagues around the world in order to conduct studies that have adequate sample sizes, neurologically and demographically diverse study participants, and potentially greater generalizability of findings. Worldwide data can facilitate collaboration among a community of scientists to advance knowledge about experiences of people with SCI (and other conditions) as well as treatment effectiveness.

However, barriers arise when collaborating with international partners that can compromise the conduct of a study and may impact interpretation of results. These include conceptual differences in how study materials are presented and interpreted, such as data that are subjective rather than objective (i.e., survey questions vs. lab values). Problems unique to spinal cord injury (SCI) include interpretation and reporting of neurologic status (level and completeness) in the absence of medical record documentation.

One significant hurdle is ensuring that concepts and terms are understood in various languages and cultures. Verbatim translation may not result in clarity or consistency, so additional work is needed to ensure that study participants in other countries have a common understanding of the relevant research materials and terminology.

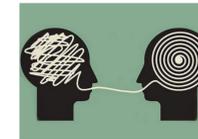


Additional difficulties arise when attempting to capture precise neurological classification data, particularly for those with non-traumatic spinal cord conditions. Timely and accurate medical record documentation is not always readily available and we must rely on participant self-reports of their neurologic status.

This objective of this poster is to describe challenges encountered in an international study, funded by the Craig H. Neilsen Foundation, to validate the SCI Quality of Life Basic Data Set (SCIQLBDS) including translation of the data set items and capturing neurological data via self-report

### Linguistic differences may constitute cross-cultural barriers<sup>1</sup>

An international team of researchers recruited participants from SCI programs in the US, Australia, Brazil and The Netherlands. Cognitive interviews were conducted at each study site ensure that the equivalence of meaning was retained and that the concepts of quality of life (QoL) were understood by all participants in the same way.



#### SCI Quality of Life Basic Data Set Questions

1. *Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied).*
2. *How satisfied are you with your physical health in the past four weeks?*
3. *How satisfied are you with your psychological health, emotions and mood in the past four weeks?*

Participants from all countries consistently defined QoL as the ability to do and enjoy things in life. Those from Brazil and Australia focused more on social and environmental barriers – these same patterns were not noted with the US and Netherlands participants. Those from the Netherlands expressed a greater sense of control over their lives, while the sample from Australia struggled about the value of being alive and societal/religious values. There were notable differences in translating the concept of QoL, particularly in the physical health domain.

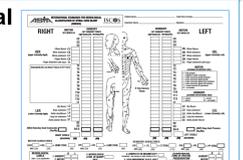
Participants noted that a question regarding satisfaction with social life should be considered. As a result, this question has been added, and the expanded SCIQLBDS is now being tested for validity and reliability by this team of investigators.

**Limitations:** Efforts were made in this small sample of 45 participants to represent those with traumatic and non-traumatic SCI, as well those with paraplegia or tetraplegia (complete and incomplete). This was also a somewhat older sample, with the mean age of 55.5 years (range 32-81). The concept QoL in other languages and in other cultures may not be consistent with these data.

<sup>1</sup>Biering-Sorensen F, Alexander MS, Burns S, Charlifue S, DeVivo M, Dietz V, Krassioukov A, Marino R, Noonan V, Post MWM, Stripling T, Vogel L, Wing P. Recommendations for translation and reliability testing of international spinal cord injury data sets. 2011. Spinal Cord 49:357-360.

### Capturing accurate neurological data by self-report

Since many studies rely on an accurate description of a person's neurological status, it is important to use the International Standards for Neurologic Classification of SCI. In the absence of actual neurological testing, obtaining this information via self-report may be challenging.



In order to obtain the most reliable information from the participants, for the SCIQLBDS validation study we asked the following questions:

*Which of the following best describes where your spinal cord injury (or spinal cord disease) occurred?* (neck, upper back, mid-back, lower back, hip area or below)

*Which parts of your body have been affected to any degree?* (One arm, both arms, trunk, one leg, both legs, bowel function, bladder function and/or sexual function)

*Sometimes a spinal cord injury causes loss of movement in the arms or legs. Which of the following statements best describes you?*

- I have full voluntary movement throughout my arms and legs. (Does not include spasms.)
- I have some voluntary movement in some of the areas affected by my spinal cord injury or disease.
- I have no voluntary movement in the areas affected by my spinal cord injury or disease.

*Sometimes a spinal cord injury causes a change in or loss of feeling (i.e. numbness) in the arms or legs. Which of the following statements best describes you?*

- I have full feeling throughout my body (i.e. my feeling has not changed since my spinal cord injury or disease).
- I have had some change or loss of feeling in the areas affected by my spinal cord injury or disease.
- I have complete loss of feeling in the areas affected by my spinal cord injury or disease.

Analysis of data from 107 inpatients shows that ~15% do not know if they have paraplegia or tetraplegia, which could be a language/translation issue; however only 2% do not know in which area of the neck/back their injury occurred. One individual could not state whether or not there was any loss of *movement* of the arms or legs, but all respondents could indicate whether or not there was any degree of loss of *sensation*.

These results suggest that we can use self-reported information to describe neurological impairment. Additional analyses will focus on the possibilities to use self-report information for a more precise estimation of neurological characteristics.

### Conclusions



Cognitive interviewing is a useful means to ensure appropriate translation and interpretation of terms and tools when research involves multiple countries and languages. Cognitive interviewing helps highlight conceptual differences that may require further clarification during data collection. Interpretation of these data can also be facilitated by understanding linguistic differences. Self-report of neurological status in the absence of clinical testing and documentation is enhanced when participants are given the option to describe their motor and sensory status using simple statements describing presence or absence of movement and sensation in lay terms.