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**Disclosures:**

Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article. Supplemental digital content is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site ([www.ajpmr.com](http://www.ajpmr.com)).

0894-9115/11/9011(Suppl)-0S66/0  
*American Journal of Physical  
 Medicine & Rehabilitation*  
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 Williams & Wilkins

DOI: 10.1097/PHM.0b013e318230fbf9

**INVITED REVIEW**

## Domain Sets and Measurement Instruments on Participation and Environmental Factors in Spinal Cord Injury Research

**ABSTRACT**

Escorpizo R, Graf S, Marti A, Noreau L, Post MWM, Stucki G, Reinhardt JD: Domain sets and measurement instruments on participation and environmental factors in spinal cord injury research. *Am J Phys Med Rehabil* 2011;90(suppl): S66–S78.

The understanding and measurement of participation and environmental context in spinal cord injury (SCI) is critically important. However, there is limited understanding of the environment-participation relationship in SCI research. There is little consensus on what is and on how to measure participation and its environmental determinants in the SCI. The objective of this article is to develop a set of International Classification of Functioning, Disability and Health (ICF)-based SCI Participation and Environment Domain Set and measurement instruments that intend to measure those domains. ICF categories from the ICF components of activities and participation and environmental factors based on the comprehensive ICF Core Set for SCI and the ICF Core Set for vocational rehabilitation were merged. Measurement instruments were selected based on published systematic reviews of measurement instruments in SCI. There were 128 ICF categories or domains in total (38 for environmental factors and 90 for activities and participation). There were six measurement instruments on environmental factors and six for participation based on existing systematic reviews. This article presents a domain set that is relevant to conducting research on the social and environmental perspectives, in an effort to understand and measure functioning in SCI (i.e., “SCI participation domain set” and “SCI environment domain set,” respectively). The sample of SCI Participation and Environment Measurement Instruments gathered indicate the comprehensiveness and depth of the different domains. Guiding principles on the utilization of these measurement instruments depending on the purpose and design of a research study are highly recommended to investigators.

**Key Words:** ICF, Spinal Cord Injuries, Environment, Participation

**S**pinal cord injury (SCI) has a major impact on body functions and body structures and, in the interaction with particular environmental contexts, has a tremendous impact on how people will act in their social life after returning to community living. The concept of participation seen as one's involvement in life situations<sup>1</sup> is essential to appreciate the lived experience of persons with SCI<sup>2</sup> and is of major importance from a social perspective with respect to the diversity of environments where people live.

Although studies in SCI address participation as at least one major outcome nowadays,<sup>3,4</sup> in contrast, only a few studies address environmental factors that are relevant to the participation of people with SCI.<sup>5-8</sup> Therefore, there remains a limited understanding of the environment-participation relationship in the field of SCI.<sup>7,9,10</sup> In addition, there is currently no agreement on what is and on how to measure participation and its environmental determinants in the SCI population.<sup>6,7,10</sup>

A useful starting point for robust outcome measurement in SCI would be to provide researchers with a selection of domains (domain set) in participation (SCI Participation Domain Set) and environmental factors (SCI Environment Domain Set) that are most relevant in SCI. A comprehensive classification of such domain is provided by the International Classification of Functioning, Disability and Health (ICF),<sup>1</sup> which is intended to describe and measure the functioning of individuals.<sup>1</sup> ICF Core Sets are lists of categories from the ICF that are relevant to a health condition or a health-related event<sup>11</sup> such as the ICF Core Sets for SCI.<sup>12,13</sup>

In the perspective of full community integration after SCI, examining the importance of participation in working life could be an added value<sup>14</sup> because work and employment are major life areas to most people with SCI. Therefore, for the purpose of portraying work life after SCI, a core set of (activities and) participation and environmental measures such as the ICF Core Set for vocational rehabilitation<sup>15</sup> would be helpful in designing interventions aimed at enhancing vocational life.

With the ICF and the ICF Core Sets (for SCI and vocational rehabilitation), we now have a so-called SCI Participation Domain Set and an SCI Environment Domain Set along a continuum of care that will also consider the vocational aspect of community living. The next step would be to identify suitable measurement instruments<sup>16</sup> relating to the domain sets. These two steps can be made based on ICF Core Set development, the linkage of

measurement instruments to the ICF,<sup>17-19</sup> and the evaluation of measurement instruments on their psychometric properties and feasibility.

The objective of this article was to develop a domain set (i.e., ICF categories) on activities and participation and environmental factors and to identify measurement instruments to measure these domains and to provide a starting point for developing potential measurement instruments in the future. The specific aims were (1) to develop the SCI Participation Domain Set and SCI Environment Domain Set based on the ICF Core Sets for SCI, (2) to propose a pool of potential measurement instruments of these domains (i.e., SCI Participation and Environment measurement instruments) based on the linkage of existing measurement instruments with the ICF-based Domain Sets, (3) to illustrate how this can inform the selection of measurement instruments for research, and (4) to identify items that can serve as the basis for developing measurement instruments in the future. Overall, this article provides added value in terms of strengthening the link between (activities and) participation and environment, the link between domains and measurement instruments, and generating a pool of potential items for research investigators interested in SCI.

## **METHODS**

### **SCI Participation and Environment Domain Sets**

To form the domain sets from the social and environmental perspectives, categories from the ICF components of activities and participation and environmental factors found in the comprehensive ICF Core Set for SCI<sup>12,13</sup> and categories from the ICF Core Set for vocational rehabilitation<sup>15</sup> were merged. In this article, all categories belonging to the activities and participation component of the ICF were considered because they relate to "participation." The core set for vocational rehabilitation was chosen because of the pivotal position of labor market integration in the participation of persons with SCI. This holds true from the perspective of people with SCI who consider work as a main resource of income on one hand and self-realization on the other.<sup>14,20</sup>

### **SCI Participation and Environment Measurement Instruments**

To select measurement instruments that capture the SCI Participation and Environment Domain Sets, measurement instruments were selected based on a

reanalysis of published systematic reviews of measurement instruments in SCI. The measurement instruments were relevant to participation<sup>4,21</sup> and environmental factors.<sup>7</sup> There were six measurement instruments for participation and six for environmental factors based on the systematic reviews. The psychometric properties of these measurement instruments are presented in both systematic reviews.<sup>4,7</sup> Items of the measurement instruments were linked to the SCI Participation and Environment Domain Sets, applying the linking rules suggested by Cieza et al.<sup>17</sup> Two coders independently linked the items to the domain sets. If there was disagreement between the two coders, a consensus was sought. If no consensus could be found, a third person was consulted. Psychometric studies of the measurement instruments found in the systematic reviews were reported. Qualifiers (i.e., response options or scales of the item in the measurement instrument) used in the different measurement instruments were obtained as well to illustrate the measurement options available.

As previously stated, the items of these measurement instruments have been linked to the ICF and were tagged to the categories of the SCI Participation and Environment Domain Sets. Electronic appendices are made available depicting the list of measurement instruments and their specific items and the corresponding ICF category that the items have been linked to in the SCI Participation and Environment Domain Sets. Appendix A (<http://links.lww.com/PHM/A46>) is for environmental factors, and Appendix B (<http://links.lww.com/PHM/A47>) is for participation. Both electronic appendices could serve as an item pool, which is a collection of items from the different measurement instruments.

## RESULTS

### SCI Environment Domain Set and Measurement Instruments

The SCI Environment Domain Set is displayed in Table 1. ICF categories listed on the first column were all those that have been identified in one or more of the three selected ICF Core Sets,<sup>12,13,15</sup> which includes 38 elements covering the five ICF environmental factor chapters (e1 to e5). Except for one factor (Drugs, third level), the other elements fall into the second level of the ICF taxonomy system. More than 50% of elements take part in the category “Product and Technology” ( $n = 9$ ) and “Services, Systems, and Policies” ( $n = 11$ ). Regarding the specific aspect of working life, it is important to notice that 16 of 38 environmental

factors came from the ICF Core Set for vocational rehabilitation, suggesting the importance of delimiting (i.e., design) of such a specific core set. Sixty-four percent (7 of 11) of the “Services, Systems, and Policies” factors were part of this specific core set. Moreover, three factors from the “Natural Environment and Human-made Changes to Environment” (light, sound, and air quality) came from the core set for vocational rehabilitation only.

Table 1 shows to what extent measures cover the ICF environmental categories. Measurement instruments like the Craig Hospital Inventory of Environmental Factors<sup>8</sup> and Measure of the Quality of the Environment<sup>27</sup> were designed to cover most of the environmental dimensions, which explains that they include items on most of the ICF categories, whereas other measurement instruments were designed from a more specific perspective (e.g. Facilitator and Barriers Survey–Mobility<sup>28</sup> and Community and Home Environment Checklist<sup>29</sup>) with few or no factors in some environmental dimensions.

Table 2 provides an illustration where sample items from measurement instruments are linked to an ICF category on environmental factor (e310 Immediate Family).

### SCI Participation Domain Set and Measurement Instruments

Listed in Table 3 are the ICF categories of the activities and participation chapters (d1 to d9) that includes 90 elements among them; 31% ( $n = 28$ ) are from the third level of the ICF taxonomy system. Not surprisingly, given the physical consequences of SCI, 43% ( $n = 39$ ) of the elements are from the Mobility ICF chapter (d4), with a substantial number of more precise (third level) items. The numbers of elements in the other participation chapters were comparable, varying from 4 to 10. Despite the importance of mobility in people with SCI, with respect to vocational life, the overall participation SCI Core Set (item pool) was improved through the addition of 21 items coming from the core set for vocational rehabilitation. The enhancement was particularly noticeable in the “Learning and Applying Knowledge” chapter, in which seven items were added (33% of the total addition from the core set for vocational rehabilitation), including thinking, reading, writing, and making decisions.

Measurement instruments focusing on participation varied significantly in terms of ICF categories that they cover because of the purpose of their development (Table 3). However, it remains worrying



**TABLE 1 (Continued)**

ICF Categories	ICF Core Set for SCI in Early Postacute <sup>13</sup>			ICF Core Set for SCI in Long-Term Context <sup>12</sup>		ICF Core Set for Vocational Rehabilitation <sup>15</sup>		Series of Environmental Measurement Instruments that Address Specific ICF Categories of Environmental Factors as Marked by an "x"														
	SCI in Early Postacute <sup>13</sup>	ICF Core Set for SCI in Long-Term Context <sup>12</sup>	ICF Core Set for Vocational Rehabilitation <sup>15</sup>	CHIEF	FABS/M	MQE	CHEC	BHADP	AIMFREE													
e4 Attitudes																						
e410 Individual attitudes of immediate family members	x				x				x													
e420 Individual attitudes of friends	x																					
e425 Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	x																					
e430 Individual attitudes of people in positions of authority																						
e450 Individual attitudes of health professionals	x				x																	
e460 Societal attitudes	x				x																	
e465 Social norms, practices and ideologies																						
e5 Services, systems, and policies																						
e525 Housing services, systems, and policies																						
e535 Communication services, systems, and policies																						
e540 Transportation services, systems, and policies	x				x																	
e550 Legal services, systems, and policies																						
e555 Associations and organizational services, systems, and policies																						
e565 Economic services, systems, and policies																						
e570 Social security services, systems, and policies	x <sup>a</sup>																					
e575 General social support services, systems, and policies																						
e580 Health services, systems, and policies	x <sup>a</sup>																					
e585 Education and training services, systems, and policies																						
e590 Labour and employment services, systems, and policies																						

<sup>a</sup>Included in the Brief Core Set.

SCI, spinal cord injury; ICF, International Classification of Functioning, Disability and Health; CHIEF, Craig Hospital Inventory of Environmental Factors<sup>8</sup>; FABS/M, Facilitator and Barriers Survey–Mobility<sup>28</sup>; MQE, Measure of the Quality of the Environment<sup>27</sup>; CHEC, Community Health Environment Checklist<sup>28</sup>; BHADP, Barriers to Health Activities for Disabled Persons<sup>35</sup>; AIMFREE, Accessibility Instruments Measuring Fitness and Recreation Environments.<sup>36</sup>

**TABLE 2** An example where an item of a set of applicable measurement instruments is linked to an ICF category of environmental factors (e310 Immediate family)

Name of Measurement Instrument	Item in the Measurement Instrument
FABS/M	How does the help of family members influence your participation in daily activities?
FABS/M	If you had physical assistance from another person in completing this survey, what is that person's relationship to you? -Family member
MQE	While taking into account your abilities and personal limits, indicate to what extent the situations or factors generally influence your daily life: support from members of your family or close friends who take the place of family (presence, physical assistance, household assistance, encouragement).
CHIEF	In the past 12 mos, how often has a lack of support and encouragement from others in your home been a problem?
BHADP	Please circle the number that best indicates how much each of these problems keeps you from taking care of your health: Lack of support from family/friends.
FABS/M	How often do you ask for help from family members?

Appendix A (<http://links.lww.com/PHM/A46>) provides the full version with all the SCI participation and environment measurement instruments.

SCI, spinal cord injury; ICF, International Classification of Functioning, Disability and Health; FABS/M, Facilitator and Barriers Survey–Mobility<sup>28</sup>; MQE, Measure of the Quality of the Environment<sup>27</sup>; CHIEF, Craig Hospital Inventory of Environmental Factors<sup>3</sup>; BHADP, Barriers to Health Activities for Disabled Persons.<sup>35</sup>

that a substantial number of ICF elements (second- or third-level) are not included in any of the selected measurement instruments for the present study, particularly into specific chapters: “Learning and Applying Knowledge” and “Mobility.”

Table 4 provides an illustration where sample items from measurement instruments are linked to an ICF category on activities and participation (d460 Moving around in different locations).

## DISCUSSION

SCI is associated with great burden to the patient, their families and caregivers, and the society

in general. Therefore, there is a critical need to understand SCI in the context of functioning, and one way is through the ICF by the World Health Organization. In this article, we compiled comprehensive SCI Participation and Environment Domain Sets. We also identified SCI Participation and Environment Measurement Instruments to capture aspects of functioning. They relate to the participation and environmental factor components of the ICF. Therefore, they can provide a valuable starting point for researchers who are interested in SCI-related studies, such as the Swiss Spinal Cord Injury Cohort Study, which is a large cohort study on SCI in Switzerland,<sup>31,32</sup> from the participation and environmental perspective and who need to define the domain sets to be measured in the study and the measurement instruments to use. The sets may, furthermore, be useful for ICF-based descriptive reporting of study populations with SCI in papers that focus on the social and/or environmental perspectives of functioning.

The ICF categories of the SCI Participation and Environment Domain Sets based on three existing core sets<sup>12,13,15</sup> varied widely from each other, covering different domains of functioning at different levels. There were hardly any categories in the SCI Core Sets in the areas of applying knowledge and making decisions and in carrying out tasks and routines, which were predominantly identified in the Vocational Rehabilitation Core Set.<sup>15</sup> This difference is expected because of the nature of the health condition and setting that the core sets looked at—purely SCI health condition *vs.* various other conditions in the Vocational Rehabilitation Core Set. An SCI does not result in cognitive deficits by itself; however, persons with SCI may have cognitive deficits caused by concomitant head injury or by pre-existing health conditions. Considering these participation areas in general (d1–d2), they present categories that are intimately related to work performance; therefore, they must be included in an SCI Core Set. However, it is also interesting to note some similarities in the ICF categories across the core sets; among them were products and technology and support and relationships with family, friends, and healthcare providers for the environmental factors. Similarities were also evident in the areas of carrying out daily routine, handling stress, mobility with the use of equipment, transportation, employment, and economic self-sufficiency for participation—a finding that could reflect the consequences of disabilities relevant to both SCI and vocational rehabilitation. This common interface can be explored, for example, through research studies

**TABLE 3** SCI participation domain set for (activities and) participation, which is included in selected ICF core sets (setting-specific such as vocational rehabilitation and super setting-specific such as early postacute and long-term settings)

ICF Categories	ICF Core Set for SCI in Early Postacute <sup>13</sup>	ICF Core Set for SCI in Long-Term context <sup>12</sup>	ICF Core Set for Vocational Rehabilitation <sup>15</sup>	Participation Measurement Instruments that Address Specific ICF Categories of Activities and Participation as Marked by an "x"																
				CHART	LIFE-H	IPA	RNLI	OPHI	PARA-SCI											
d1 Learning and applying knowledge																				
d155 Acquiring skills		x	x <sup>a</sup>																	
d160 Focusing attention			x																	
d163 Thinking			x																	
d166 Reading			x																	
d170 Writing			x																	
d172 Calculating			x																	
d175 Solving problems			x																	
d177 Making decisions			x																	
d2 General tasks and demands																				
d210 Undertaking a single task			x																	
d220 Undertaking multiple tasks			x																	
d230 Carrying out daily routine	x	x <sup>a</sup>	x																	
d240 Handling stress and other psychological demands	x	x <sup>a</sup>	x																	
d3 Communication																				
d310 Communicating with- receiving- spoken messages																				
d315 Communicating with- receiving- nonverbal messages																				
d345 Writing messages																				
d350 Conversation																				
d360 Using communication devices and techniques	x	x	x																	
d4 Mobility																				
d410 Changing basic body position																				
d4100 Lying down	x	x <sup>a</sup>	x																	
d4103 Sitting	x <sup>a</sup>	x <sup>a</sup>	x																	
d4102 Kneeling	x <sup>a</sup>	x <sup>a</sup>	x																	
d4104 Standing	x <sup>a</sup>	x <sup>a</sup>	x																	
d4105 Bending	x <sup>a</sup>	x <sup>a</sup>	x																	
d4106 Shifting the body's center of gravity	x <sup>a</sup>	x <sup>a</sup>	x																	
d415 Maintaining a body position																				
d4155 Maintaining a body position																				







that look at the evaluation of patients with SCI along a continuum of care (e.g., acute care setting after SCI to vocational rehabilitation program) using common aspects of functioning to be evaluated.

The SCI Participation and Environment Measurement Instruments for participation and environmental factors also varied greatly in terms of the functioning domains covered based on the ICF categories. At a first glance, it seems that the comparison of results obtained from different measurement instruments will be difficult given that the measurement instruments were developed to capture domains to a different extent and with different qualifiers or types of responses. We do recognize that the SCI Participation and Environment Domain Sets provide ICF categories from the component activities and participation, whereas the measurement instruments were based on participation only.<sup>4,21</sup> This means that the SCI Participation and Environment Domain Sets actually have an added value in that it provides domains that relate to activities (e.g., mobility) and also participation (e.g., community life), resulting in a more comprehensive catalog of functioning.

This study provides the scientific community involved in SCI with multiple options of domain sets and measurement instruments from which they can choose from, specific to their need. In addition, the combination of domain sets and measurement instruments allows for communication through ICF categories, which might prove particularly useful for meta-analysis. In principle, it is possible to cross-calibrate items from various measurement instruments to a particular ICF category on a common reference scale based on the generic ICF categories.<sup>23</sup> The same holds true for summary scores within one dimension of functioning.<sup>22</sup> The cross-calibration of items can then be based on item frequencies within suitable samples and corresponding Rasch statistical analysis.<sup>23</sup>

The measurement instruments presented in this article may be used for the selection of appropriate measurement instruments in a specific study. Indeed, the ICF-linked items of the measurement instruments may be used as an item pool that can inform the construction of community survey instruments in SCI—similar to a sophisticated system such as the Patient-Reported Outcomes Measurement Information System ([www.nihpromis.org](http://www.nihpromis.org)) but with the addition of providing a better link between environment and participation. Selected items may be cognitively tested in the population to make decisions on what works best when single-item specifications of ICF categories are needed. Items from the pool can be

updated regularly as new measurement instruments are being developed. No measurement instrument totally covers the list of SCI Participation and Environment Domain Sets based on the core sets, but as in any instrument development (especially if a new measurement instrument is to be developed), psychometric properties of single items or the measurement instrument as a whole is another important prerequisite. Based on the accompanying article by Fekete et al.<sup>24</sup> in this series, the SCI Participation and Environment Measurement Instruments and their items can also be assessed using a list of guiding principles in the selection of measurement instruments for a specific research question.

We found no single measurement instrument for the measurement of all relevant ICF categories in (activities and) participation or environmental factors as considered by the ICF Core Sets for SCI and vocational rehabilitation. Measurement instruments differ largely not only in terms of psychometric quality but also in terms of qualifiers used so that a combination of measurement instruments or items would not be easy. Moreover, the relation of measurement instruments of self-reported participation and environmental factors is far from being clear in theory or empirically and may be dependent on the item formulation or type of qualifier used.<sup>7</sup> In addition, it is currently unclear how different types of qualifiers on environmental factors (i.e. recording the perception of barriers or the presence of environmental features) are related to each other. Moreover, the relation of rather objective features of the environment that are, for instance, documented in the so-called Geo Information Systems with self-reported measurement instruments relying on the perception of persons with SCI, has rarely been studied. In fact, the use of Geo Information Systems data and their link with study participants' neighborhoods (e.g., via zip codes) may be a promising and most parsimonious approach to measure environmental factors from an aggregate perspective in the future. The predictive quality of such data in forecasting participation levels of persons with SCI has yet to be explored.<sup>33</sup> It is important to recognize that the selection of which domain sets to use does not exclusively depend on whether or not a measurement instrument is available. The measurement instruments presented here are not exhaustive; therefore, other measurement instruments (and their corresponding qualifiers) may be used if it best suits a particular research question or design, also keeping in mind the psychometrics. However, the proposed domain sets and measurement instruments on functioning in SCI from the social and

environmental perspectives provides a promising starting point and basis for the study of determinants and contexts of participation in SCI and for the study of the relations between subjective and objective assessments of participation and environmental factors.

Furthermore, the SCI Participation and Environment Domain Sets may, in addition of theoretical considerations on the environment-participation link,<sup>7,9</sup> provide guidance on what aspects to cover in innovative measurement instruments for the measurement of participation and/or environmental factors. The Nottwil Environmental Factors Inventory<sup>34</sup> for SCI currently being developed is an example of an ICF-based measurement instrument on the environment. The structure of the measurement instrument was based on theoretical considerations on the perception of environmental factors. The choice of the domain set of the measurement instrument considered the ICF Core Set for SCI (i.e., list of included ICF categories in the core set).

To summarize, in this article, the suggested SCI Participation and Environment Domain Sets and measurement instruments for the study of functioning in SCI provide the scientific community on SCI research with focal points on participation and the environment, with the possibility to examine functioning in a comprehensive and systematic manner using the ICF as the language and framework. Our proposal could facilitate the comparability of SCI studies across settings and even possibly between countries by having a common understanding of relevant domains of functioning and their measurement.

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