

# Identifying an Improved Measure of Participation: A Methodology Implemented in a Population with Spinal Cord Injury

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# Collaborating Partners

- Mt Sinai Medical Center, NYC, NY
- Kessler, West Orange, NJ
- Boston Medical Center, Boston, MA
- University of Michigan, Ann Arbor, MI
- Shepherd Center, Atlanta, GA
- Metro Health, Cleveland, OH
- Rehabilitation Institute of Chicago, IL

# Rationale

- Participation is a key concept in all models of disability
  - World Health Organization's ICF
  - Institute of Medicine's Models of Disability
  - NIDRR's New Paradigm of Disability
  - NIDRR's Long-Range Plan
- Participation is the broader construct that encompasses employment
- Participation is the rehabilitation outcome that is most desired by people with disability and their families

# The Problem

- There is no accepted standard method of measuring participation in SCI
- Current measures, particularly CHART, have been criticized for ceiling effects, skewed distributions, and being based on societal norms
- A standard measure of participation is needed to test disability modules and new interventions to improve participation among people with SCI and other disabilities

# Purpose

- To identify a psychometrically sound, comprehensive measure of participation that can be agreed upon as the standard measure of participation for use in the SCI Model Systems National Database, SCI interventional research targeting improvements in participation, and other future SCI outcomes research

# Methodology

- A pool of participation items was formed from questions contained in:
  - PART-OS
  - CPI
  - CIM
  - PM-PAC

# Methodology

- NSCIDB variables used in the study analyses will include
  - CHART-SF social integration, mobility, and occupation subscales
  - FIM
  - SWLS
  - Age, years post injury, gender, marital and education status
  - AIS and level of injury

# Research Questions

- Which existing tool is the best measure of participation for SCI?
- What dimensions of participation are identified in the pool of items from established participation measures?
- Is a new combination of items from existing tools the best measure of participation in SCI?
- What is the relationship between objective and subjective participation measures in SCI?
- Can procedures be developed to convert scores among existing participation measures?

# Procedures

- Study questionnaire is administered in conjunction with routine SCIMS data collection
- Questionnaire administered using a CATI program with a live syllabus and associated database
- Training via teleconference and Web-X

# Sample

- 625 individuals with SCI at all sites combined
- 100 test/re-test interviews performed at RMRSIS for reliability
- 100 proxy interviews performed at RMRSIS to test subject/proxy agreement

# Analysis Plan

- Six hypotheses to be tested using
  - Exploratory factor analysis to assess dimensionality of participation
  - Rasch analysis to assess psychometric properties of scales, subscales, and new tools
  - Test-retest reliability & subject-proxy agreement
  - Correlation to assess relationships among tools
  - Rasch analysis with anchoring to compare measures

# Progress to date

- As of August 20, 2008:
- 618 interviews completed
- 100 test/re-test interviews completed
- 100 proxy interviews completed

# Next Steps

- All sites to complete data upload to NSCISC when data collection completed the end of August
- Data from NSCIDB and study combined for analysis
- Analysis during FY 2008-2009
- Manuscript preparation in FY 2008-2009
- Presentation of findings at SCI meetings in FY 2009-2010

# Questions?

- Contact Gale:
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