

Measuring What Matters in Rehabilitation

Allen W. Heinemann, PhD, FACRM



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Learning Objectives

1. Describe the history of rehabilitation outcome measurement
2. Identify sentinel events in the development of rehabilitation outcome measures
3. Describe opportunities to improve rehabilitation services through the routine collection, reporting and aggregating of details about rehabilitation services, processes and outcomes
4. Discuss a research agenda related to rehabilitation outcomes improvement

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In memoriam: David B. Gray



- Developed the Participation and Environment components of the International Classification of Functioning, Disability and Health
- Deputy Director of the National Center for Medical Rehabilitation Research 1990 -5
- Director of the National Institute on Disability and Rehabilitation Research, 1986-7
- BA Lawrence University, 1966
- MA Western Michigan University, 1970
PhD Behavior Genetics: University of Minnesota, 1974

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The view from 30 meters and 30 years



Bubo scandiacus



Buteo jamaicensis

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I. A brief and selective history of rehabilitation outcome measurement

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Outcomes definitions

- Rehabilitation outcomes
 - “Changes produced by rehabilitative services in the lives of service recipients and their environment”
Fuhrer, 1987
- Outcome measures
 - “Intended to quantify a patient’s performance or health status based on standardized evaluation protocols or close ended questions.” *Jette, Halbert, Iverson, Miceli, Shah, 2009*

A selective timeline of key outcome measurement events

- 1987** Marcus Fuhrer: *Rehabilitation Outcomes: Analysis and Measurement*
- 1987** Keith et al: Birth of the FIM and UDsmr
- 1993** Heinemann et al: Application of the Rasch model to functional status measurement
- 1994** Stineman et al: A Case-Mix Classification System for Medical Rehabilitation
- 1997** Fuhrer: *Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research*
- 2001** Stucki et al. Emerging attention to clinically important change
- 2008** John Whyte: Coulter lecture – theoretical frameworks and intervention taxonomies
- 2005** Cella et al: PROMIS item banks



Types of rehabilitation outcome measures

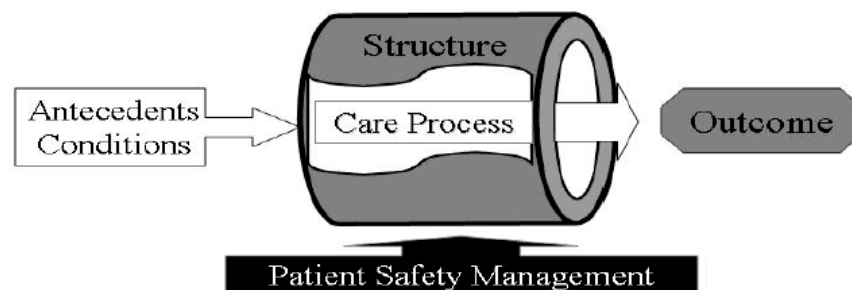
- Patient performance (Timed Up and Go)
 - Ecological validity
- Clinician ratings of patient performance (FIM)
 - Require on-going rater training
- Patient-reported (PROMIS, AM-PAC)
 - Require some method to assure items “add-up” to a meaningful score
 - Contemporary methods include item response theory or Rasch model methods

Uses of outcome measures

- Establish a patient's baseline status, need for services
- Monitor a patient's progress to determine the effectiveness of an intervention
- Inform patients and family of progress in a quantifiable manner
- Justify reimbursement by payers
- Provide data for program evaluation
- Support accreditation decisions
- Define quality measures for provider selection
- Evaluate clinical trial benefits

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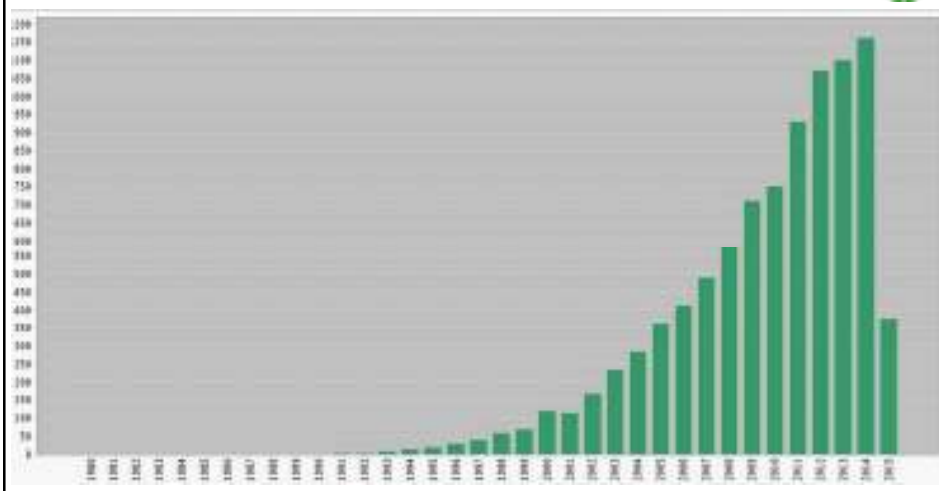
Donabedian's quality improvement model



The Donabedian Model of Patient Safety: Medical Teamwork and Patient Safety: The Evidence-based Relation. July 2005. Agency for Healthcare Research and Quality, Rockville, MD.
<http://www.ahrq.gov/research/findings/final-reports/medteam/figure2.html>

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Rehabilitation + Outcome Measurement Citations: 1975 to 2015 (May)



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Where were these 453 articles published?

- Age and Ageing
- American J of Occupational Therapy
- American J of PM&R
- Aphasiology
- Archives of PM&R
- Brain Injury
- Canadian J Occupational Therapy/Revue Canadienne Ergotherapie
- Cochraine Database
- J Communication Disorders
- J Head Trauma Rehabilitation

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II. Identify sentinel events in the development of rehabilitation outcome measures

- A. Conceptual clarification
- B. Taxonomies
- C. Measurement technology
- D. Measurement resources for clinicians

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A. Conceptual clarification Whyte's 2007 Coulter Lecture

- Theoretical models and taxonomies are crucial in scientific development
- Rehabilitation theories are insufficiently developed
- Medical rehabilitation should develop a body of well-articulated theories



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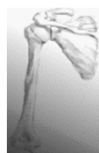
Messick reframes validity considerations

- **Content:** relevance, representativeness, and technical of the measure to the construct
- **Substantive:** empirical evidence for the theoretical construct of interest
- **Structural:** fidelity of the scoring structure to the structure of the construct domain
- **Generalizability:** extent scores generalize across populations, settings, and tasks
- **External:** convergent, discriminant, and criterion-based evidence for the measure. How does this measure perform in comparison to other similar or different measures?
- **Consequential:** positive or negative, and intentional or unintentional consequences of use of the measure

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B. International Classification of Functioning Disability and Health

Body Functions & Structures



Functions
Structures

Activities & Participation



Capacity
Performance

Environmental Factors



Barriers
Facilitators

<http://apps.who.int/classifications/icfbrowser/>



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Body functions and structures

1. Mental Functions
2. Sensory Functions and Pain
3. Voice and Speech Functions
4. Functions of the Cardiovascular, Hematological, Immunological and Respiratory Systems
5. Functions of the Digestive, Metabolic, and Endocrine Systems
6. Genitourinary and Reproductive Functions
7. Neuromusculoskeletal and Movement-related Functions
8. Functions of the Skin and Related Structures



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Activities and participation

1. Learning and Applying Knowledge
2. General Tasks and Demands
3. Communication
4. Mobility
5. Self-care
6. Domestic life
7. Interpersonal Interactions and Relationships
8. Major Life Areas
9. Community, Social and Civic Life



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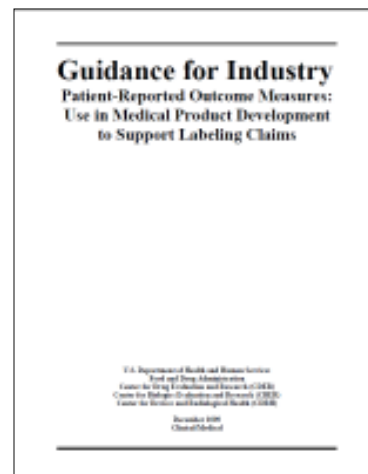
Outcome measures across ICF domains

- Body function
 - Mini Mental Status Examination (performance)
 - Beck Depression Inventory (patient reported)
- Activity and Participation
 - 10 Meter Walk Test (performance)
 - Functional Independence Measure (clinician rated)
 - Community Integration Questionnaire (patient reported)
- Environmental factors
 - Community Health Environment Checklist (user rated)
 - Measure of the Quality of the Environment (patient reported)

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C. Rehabilitation's embrace of patient-reported outcomes

"Any report of status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else"



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What do PROs measure?

- Symptoms
- Health status
- Quality of life
- Satisfaction with services
- Medication use
- Perceived value of treatment



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Why use PROs in clinical practice?

- Patient perspective is essential in comparative effectiveness and patient centered outcomes research
 - When making decisions, patients need to understand experiences of previous patients "like them"
 - Clinicians and payers need to understand how patients experience interventions
 - PROs predict whether patients comply with treatment and use services
- Institute of Medicine
 - "Purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at individual and population levels"



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PROs: Address goals of patient-centered outcomes research

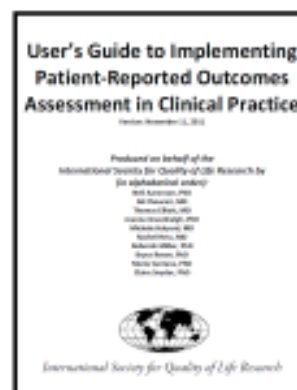
- Patient-Centered Outcomes Research Institute
 - PCOR Definition
 - “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
 - Methodology Report, Standard 4.1.3:
 - “Use patient-reported outcomes when patients or people at risk of a condition are the best sources of information.”



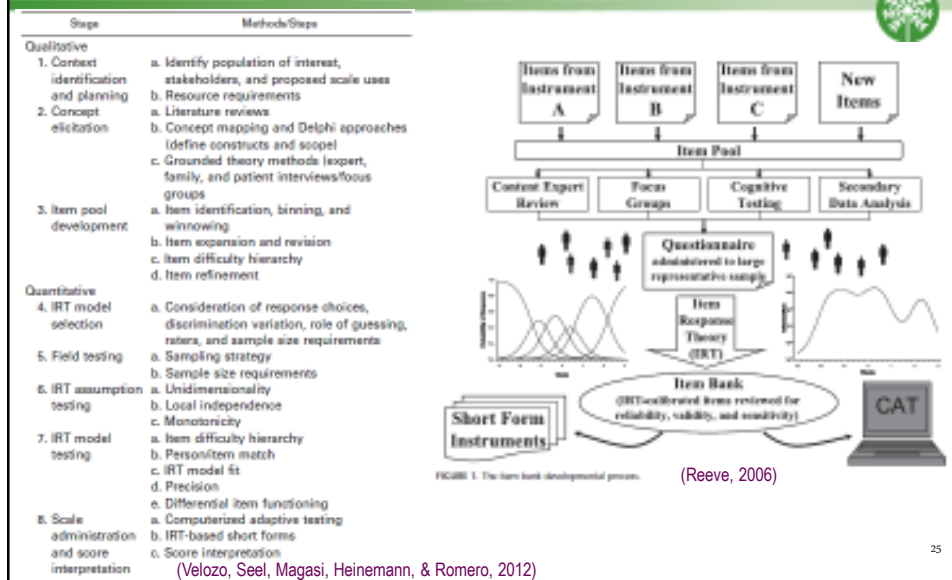
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How PROs can be used in clinical practice

- Identifying goals for collecting PROs in clinical practice
- Selecting patients, setting, and timing for assessment
- Determining which questionnaires to use
- Choosing a mode for administering the PROs
- Reporting PRO results
- Interpreting scores
- Responding to issues identified by the PRO
- Evaluating the impact of PRO intervention on the practice



Standardized methods for measure development that allows CAT administration



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PROs and computerized adaptive testing

- Algorithm development uses psychometric framework of Item Response Theory
- CAT utilizes algorithms to estimate person ability and choose the next best item to administer using test specifications such as
 - Content coverage
 - Desired length
 - Precision

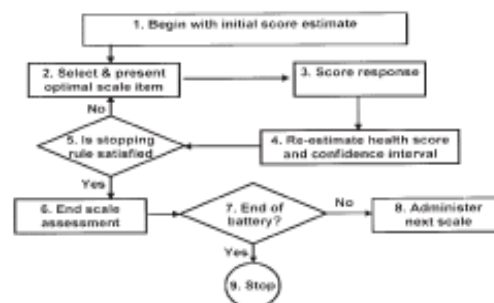


Figure 7. The logic of computerized adaptive testing. From *Computerized Adaptive Testing: A Primer* (2nd ed.), by H. Walter (with N. J. Doran, D. Elgort, R. Flaugher, B. F. Green, R. J. Miesley, L. Steinberg, and D. Thissen), 2000, Hillsdale, NJ: Erlbaum. Copyright 2000 by Lawrence Erlbaum Associates. Adapted with permission.

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CAT advantages

- Reduce patient burden without loss of precision
- Immediacy of feedback
- Communication on a common metric
- Dynamic tailoring of instrument difficulty to the level of patient
- Reduce clerical errors

Spinal Cord Injury-Functional Index: Item Banks to Measure Physical Functioning in Individuals With Spinal Cord Injury

David S. Tulsky, PhD, Alan M. Jette, PT, PhD, Pamela A. Kiada, MA, Claire Kalpakjian, PhD, Marcel P. Dijkers, PhD, Gale Whiteneck, PhD, Pengsheng Ni, MD, MPH, Steven Kirshblum, MD, Susan Charney, PhD, Allen W. Heinemann, PhD, Martin Fuschione, MPP, Mary D. Slavin, PT, PhD, Bethany Houdihan, MSW, MPH, Denise G. Tate, PhD, Trevor Dyson-Hudson, MD, Denise G. Fyffe, PhD, Steve Williams, MD, Jeanne Zanca, MPT, PhD

Both articles below must be read to complete this one 2-hour CME activity.

Article 1: Spinal Cord Injury-Functional Index: Item Banks to Measure Physical Functioning in Individuals With Spinal Cord Injury
David S. Tulsky, PhD, Alan M. Jette, PT, PhD, Pamela A. Kiada, MA, Claire Kalpakjian, PhD, Marcel P. Dijkers, PhD, Gale Whiteneck, PhD, Pengsheng Ni, MD, MPH, Steven Kirshblum, MD, Susan Charney, PhD, Allen W. Heinemann, PhD, Martin Fuschione, MPP, Mary D. Slavin, PT, PhD, Bethany Houdihan, MSW, MPH, Denise G. Tate, PhD, Trevor Dyson-Hudson, MD, Denise Fyffe, PhD, Steve Williams, MD, Jeanne Zanca, MPT, PhD

Article 2: Development and Initial Evaluation of the Spinal Cord Injury-Functional Index
Alan M. Jette, PT, PhD, David S. Tulsky, PhD, Pengsheng Ni, MD, MPH, Pamela A. Kiada, MA, Mary D. Slavin, PT, PhD, Marcel P. Dijkers, PhD, Allen W. Heinemann, PhD, Denise G. Tate, PhD, Gale Whiteneck, PhD, Susan Charney, PhD, Bethany Houdihan, MSW, MPH, Steve Williams, MD, Steven Gashler, MD, Trevor Dyson-Hudson, MD, Jeanne Zanca, MPT, Denise Fyffe, PhD

Statement of Need

A major treatment goal in the rehabilitation of persons with spinal cord injury (SCI) is to maximize the restoration of physical functioning. Documenting the extent of recovery is imperative for: 1) ensuring treatment efficacy; 2) evaluating the cost-effectiveness of treatment interventions; 3) assessing the impact of policy changes on patient outcomes; 4) enhancing the quality of care being provided; and 5) providing appropriate, long-term prognostic information to patients and their families, as well as to insurance carriers. In order to document recovery of mobilization, locomotion, stability and valid tools are necessary to assess physical functioning outcomes in the SCI population.

Several outcome measures are currently used to assess physical functioning in SCI. The most commonly used scales (e.g., Functional Independence Measure) have 2 important shortcomings with respect to their use in the population: 1) the measure is unable to assess the full range of SCI severity and the breadth of content to assess all important aspects of physical functioning are covered, making the proportion of individuals with SCI in scoring extremes 1) is difficult for any single instrument to include the large number of items necessary to cover the range of severity levels seen among persons with SCI.

These 2 articles will describe the development and evaluation of the Spinal Cord Injury-Functional Index (SCI-FI), a new comprehensive outcome measurement tool for persons with SCI.

Accreditation Statement

The journal-based activity has been planned and developed in accordance with the Essential Areas and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the sponsorship of Professional Education Services Group (PESG). PESG is accredited by the ACCME to provide continuing medical education (CME) for physicians.

Credit Designation Statement

PESG designates this journal-based CME activity for a maximum of 2.0 ABA/AMA Category 1 Credits. Physicians should claim only the credit commensurate with the extent of their participation in the activity. All other health care professionals completing continuing education credits for this activity will be issued a certificate of participation.

Educational Objectives

To support the attainment of knowledge, competence, and performance, the learner should be able to achieve the following objectives:

1. Describe the current outcome measurement tools being used with persons with SCI.
2. Discuss the limitations of the current outcome measurement tools being used with persons with SCI.
3. Describe the development of a new outcome measurement tool with the new content and structure being designed specifically for persons with SCI.
4. Explain how the Spinal Cord Injury-Functional Index (SCI-FI) outcome measurement tool improves upon existing outcome measurement tools used with persons with SCI.

Planning Committee

Susan Charney, PhD; Marcel P. Dijkers, PhD; Trevor Dyson-Hudson, MD; Martin Fuschione, MPP; Denise Fyffe, PhD; Allen W. Heinemann, PhD; Steven Kirshblum, MD; MPH; Alan M. Jette, PT, PhD; Claire Kalpakjian, PhD; Steven Kirshblum, MD; Pamela A. Kiada, MA; Pengsheng Ni, MD, MPH; Mary D. Slavin, PT, PhD; Denise G. Tate, PhD; Steve Williams, MD; Gale Whiteneck, PhD; Steve Williams, MD; Jeanne Zanca, MPT, PhD; PESG staff.

Faculty Profile & Disclosure Information

As a speaker accredited by the ACCME, it is the policy of PESG to require the disclosure of any interest in a position to control the content of an educational activity. All relevant financial relationships with any commercial interest within manufacturers must be disclosed to participants at the beginning of each activity. The faculty of this educational activity declare the following:

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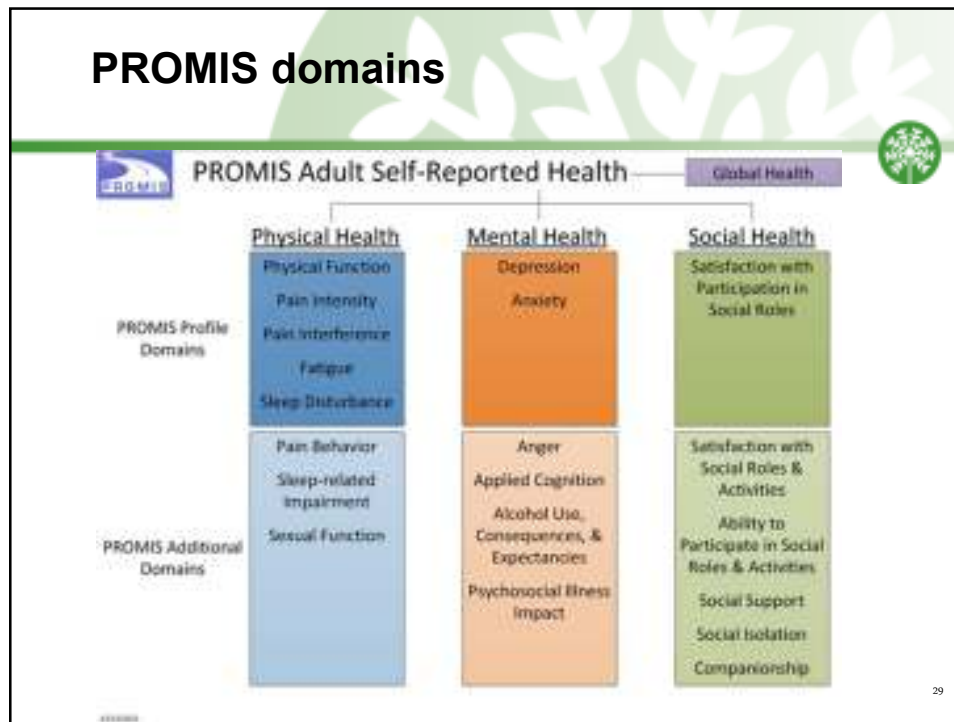
Arch Phys Med Rehabil Vol 93, October 2012

Patient Reported Outcomes Measurement Information System

The screenshot displays the PROMIS (Patient Reported Outcomes Measurement Information System) website. The header features the PROMIS logo and the tagline "Dynamic Tools to Measure Health Outcomes from Six Patient Perspectives". Below the header, there are several sections:

- PROMIS Maturity Model:** A section with a blue background and white text, stating "Check out these revised PROMIS maturity models that outline PROMIS instrument development".
- Research Tools:** A section with a green background and white text, stating "Provides efficient, reliable, and valid assessments of adult and child (pediatric) self-reported health".
- Research Tools:** A section with a green background and white text, stating "Provides data about the effect of therapy that cannot be found in traditional clinical measures".
- PROMIS:** A section with a purple background and white text, stating "Measures what you are able to do and how you feel".

Each section includes a list of links and a small image of a person. The website is designed to be user-friendly and informative for researchers and patients alike.



D. Resources to enhance clinician knowledge of measurement concepts

- Center on Outcome Measurement in Brain Injury (COMBI)
- Evidence-Based Review of Stroke Rehabilitation (EBRSR)
- StrokEDGE
- Spinal Cord Injury Rehabilitation Evidence (SCIRE)
- Rehabilitation Measures Database (RMD)



EBRSR: Evidence-Based Review of Stroke Rehabilitation



Rehabilitation Measures Database



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Archives' measurement "tear sheets"

Additional collaborations:

Rehabilitation Nursing

American Journal of Occupational Therapy

ACRM
Archives of Physical Medicine and Rehabilitation
Journal homepage: www.apmr.org
Archives of Physical Medicine and Rehabilitation 2015.95.2123-6

ORGANIZATION NEWS
Highlights From the Rehabilitation Measures Database
This content is provided as a service by the American Congress of Rehabilitation Medicine and is not peer-reviewed by the database.

Measurement Characteristics and Clinical Utility of the Dizziness Handicap Inventory Among Individuals With Vestibular Disorders
Amy Yorke, PT, NCS, Irene Ward, PT, DPT, NCS, Saloni Yora, PT, Stephanie Combs, PT, PhD, NCS, Tammie Keller-Johnson, PT, DPT, MS

The Dizziness Handicap Inventory (DHI) by Jacobson and Newman¹ is a 25-item self-assessment measuring the functional, emotional, and physical effects of dizziness and vertigo in individuals >19 years of age. The test can be completed in 5 to 10 minutes. Total scores range from 0 to 100 with increasing scores signifying greater perception of handicap because of dizziness. A total score of >10 indicates a handicap for patients with peripheral or central pathology, whereas scores >18 indicate an examination by a balance specialist. The DHI can also be broken down into 3 subscales: physical (29 points), emotional (26 points), and functional (26 points). The DHI is reliable and valid for adults with peripheral and central vestibular pathologies, multiple sclerosis,² posttraumatic brain injury,³ vestibular-associated disorders,⁴ and benign paroxysmal positional vertigo.⁵

The Rehabilitation Measures Database summary provides a synopsis of the psychometric properties of the DHI in individuals with vestibular dysfunction. For a full review of the DHI along with nearly 200 other instruments, please go to www.rehabmeasures.org. Please address correspondence to rehabmeasures@va.gov.

REFERENCES

1. Jacobson G, Newman CW. The development of the dizziness handicap inventory. *Arch Otolaryngol Head Neck Surg* 1990;116:947.
2. Welch RL, et al. Effects of vestibular rehabilitation on multiple sclerosis-related fatigue and upright posture control: a randomized controlled trial. *Phys Ther* 2011;91:295-303.
3. Eastman BE, et al. Comparison of subjective and objective measurements of balance disorders following moderate head injury. *Med Eng Phys* 2006;28:234-8.
4. Torkelson J, All JJ, LutzChay FN. Small-sized neck motion test on otolith-associated dizziness: relationship to self-reports of neck pain and disability, dizziness and activity. *J Rehabil Med* 2005;37:219-23.
5. Whitney ML, Harkness DE, Morris US. Validity of the dizziness handicap inventory in the screening for benign paroxysmal positional vertigo. *Otol Neurotol* 2009;30:1027-33.
6. Whitney ML, Dinkel ME, Harkness DE. The activities-specific balance confidence scale and the dizziness handicap inventory: a comparison. *J Neurosci Nurs* 2004;36:213-8.
7. Alghamdi AA, et al. The development and validation of the vestibular symptoms and participation measure. *Arch Phys Med Rehabil* 2012;93:1822-31.
8. Hanson EE, Harkness DE, Harkness A. Balance performance and self-perceived handicap among dizziness patients in primary health care. *Neurology* 2009;72:215-20.

This instrument summary is designed to facilitate the selection of outcome measures by trained clinicians. The information contained in this summary represents a sample of the peer-reviewed research available at the time of this summary's publication. The information contained in this summary does not constitute an endorsement of this instrument for clinical practice. The views expressed are those of the summary authors and do not represent those of authors' employers, instrument creators, the Archives of Physical Medicine and Rehabilitation, the Rehabilitation Measures Database, the United States Department of Education, or the Retirement Research Foundation. The information contained in this summary has not been reviewed externally.

The Rehabilitation Measures Database and Instrument Summary Worksheets are linked by the National Institute on Disability and Rehabilitation Research, United States Department of Education through the Rehabilitation Research and Training Center on Improving Measurement of Medical Rehabilitation Outcomes (grant no. H121B000024) and the Retirement Research Foundation (grant no. 2011-027).

Quebec Congress in Adaptation-
Rehabilitation Research

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Steps in selecting an outcome measure



Potter, Fulk, Salem, Sullivan, 2011

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Considerations in outcome measure selection

- What to measure
 - Body structure, function, activity, participation, environmental factors
- Purpose of measurement
 - Discriminative, predictive, evaluative
- Types of measure
 - Condition-specific, generic
- Patient and clinical factors
 - Patient ability, goals, clinic requirements
- Psychometric considerations
 - Reliability, validity, diagnostic accuracy, responsiveness, sensitivity
- Feasibility
 - Time, space, equipment, training, cost, burden, culture, language, proprietary restrictions

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Goal: Improved patient care

- Standardized outcomes reported by all disciplines
- Assessment across settings
- Outcomes reported graphically to highlight trends over time
- Incorporates key patient reported factors into treatment planning
- Allows team conference to focus on trends and treatment modifications, not reporting



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Facilitators of outcome measurement

- Individual facilitators
 - Belief in benefits of routine measurement
 - Flexibility in selecting instruments to patients' circumstances
 - Evidence to negotiate with insurers regarding coverage
 - Opportunity to use information for quality improvement
- External facilitators
 - Access to resources about a variety of measures
 - Influential opinion leaders
 - Accrediting organizations
 - Information on selecting, administering, scoring, and interpreting measures

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Barriers to outcome measurement

- Individual barriers
 - Limited time to search, administer, score, interpret measures
 - Limited knowledge on selection and interpretation criteria
 - Limited resources to purchase, set-up, store equipment
 - Belief that outcome measures are unnecessary, contrary to individualized services
- Organizational barriers
 - Perception that return on investment is insufficient
 - No policies promoting routine use of standardized outcome measures, limited compliance monitoring
 - Limited consensus or recommendations from professional organizations

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III. Describe opportunities to improve rehabilitation services through the routine collection, reporting and aggregating of details about rehabilitation services, processes and outcomes

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Example 1: Development of an outcomes dashboard for team conferences

Funding provided by the Rehabilitation Institute of Chicago, Henry B. Betts Innovation Award



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Project goal: Improve patient care with integrated information

Current situation

- Clinicians report patient status verbally: FIM, TUG, behavioral descriptions
- Daily FIM ratings are collected but not used clinically; other ratings are in text notes
- Patient voice is not documented using standard instruments
- No objective measure of patient activity level
- Can't monitor trends over time

Vision

- Clinicians have access to standardized outcomes data
- Clinicians see progress in an easy-to-digest visual display
- The patient's voice is heard during team conferences
- Accelerometers allow documentation of patient activity level
- Team monitors patient trends over time

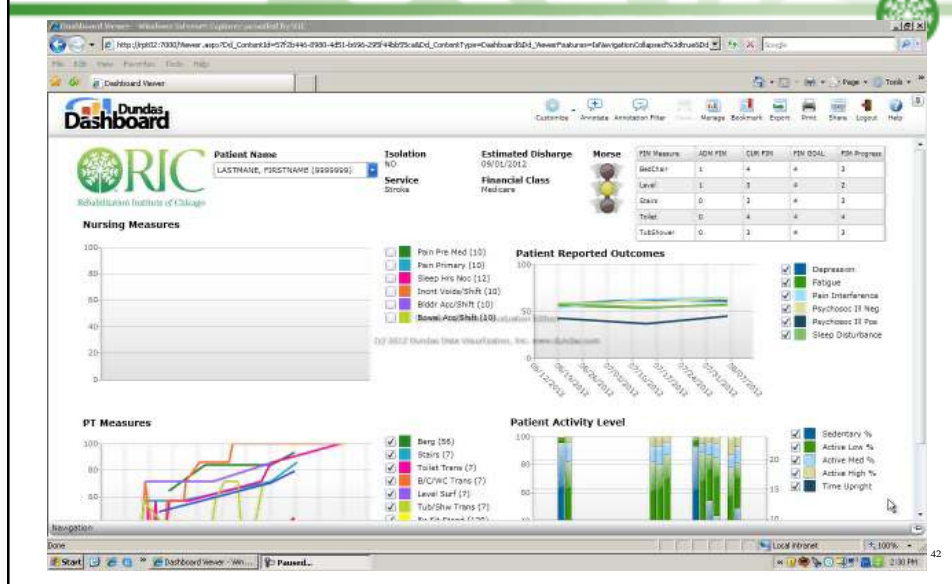
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Project tasks

- Created an outcomes dashboard that can be used in all levels of care
- Extracted nursing and PT-reported performance information from EMR
- Installed local version of NIH PROMIS Center
- Deployed accelerometers using Android phones to collect 3D movement
- Developed a procedure manual to support use of the Dashboard, PROMIS, and accelerometers
- Encouraged the clinical team to reconsider how they organize team conferences
- Compared team conference functioning with a floor not using the Dashboard

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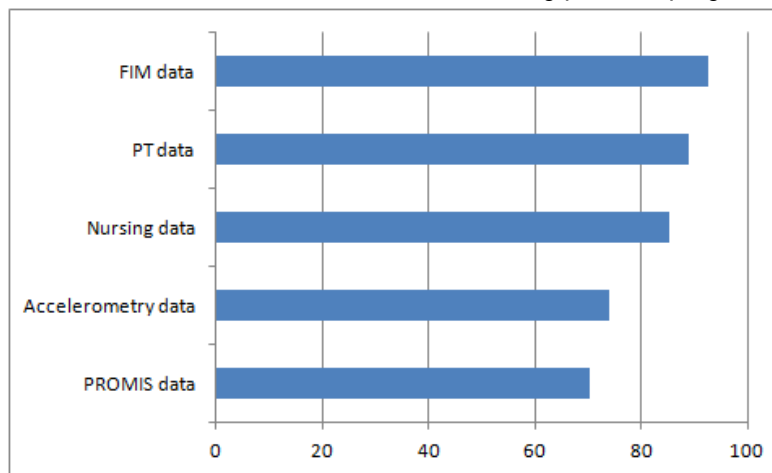
Outcomes dashboard available during team conferences



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Dashboard evaluation

Percent of clinical team members rating each data source as **at least** somewhat useful in understanding patients' progress



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Qualitative feedback

- "I'm excited at the potential impact that the dashboard can have on team communication surrounding patient progress and outcomes. It can also assist with educating patients and families about progress in a way that they can understand" *OT*
- "The visual representation of progress really allows the team to understand whether or not a patient is progressing and how quickly they are doing so" *Clinician*
- "The dashboard has great potential to improve communication and enhance understanding of patient performance and progress by all members of the team." *Physician*
- "I think that this is great. The questions about my sleeping and the way I am feeling about things make me think. It is good to see that I am making progress because sometimes I feel like I am not." *Patient*



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Example 2: A quality improvement demonstration project for prosthetic clinics

Funding provided by the National Institute on
Disability and Rehabilitation Research
Rehabilitation Engineering Research Center on
Prosthetics and Orthotics



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Continuous quality improvement

- CQI seeks to improve healthcare by
 - Monitoring healthcare outcomes
 - Engaging staff
 - Maintaining a patient focus
 - Understanding processes of care
- Factors to consider
 - Patients
 - Clinicians
 - Organization
 - Community
- CQI requires the use of performance indicators
 - specify key desired outcomes
 - enable comparisons across facilities or over time within a facility
 - create the potential for benchmarking

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Benefits of continuous quality improvement

- Improve patient satisfaction
- Reduce or eliminate problems within delivery systems
- Reduce costs while maintaining or improving quality
- Satisfy an existing need more effectively or efficiently
- Identify and meet new needs



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ABC's mission promotes CQI



- ABC's Mission
 - To establish and promote the highest standards of organizational and clinical performance in the delivery of O&P services
- Performance Management & Improvement Standards
 - A set of 10 standards promote tracking of the organization's strengths and weaknesses in providing quality patient care

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Project objectives

- Implement continuous quality improvement (CQI) projects in several prosthetic clinics
- Evaluate the utility of the Orthotic and Prosthetic Users' Survey as a CQI tool
- Describe challenges and strategies used by facilities in implementing CQI projects

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Project methods

- Facilities: Five Midwest prosthetic clinics
- Instrumentation: Orthotic and Prosthetic Users' Survey
- Procedures: Admission, device delivery, 2 month follow-up OPUS administration
- Variation: Facilities selected data collection methods
- Reporting: Investigators provided comparative outcomes information and consulted on quality improvement opportunities

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Data collection forms and timing

- Initial visit
 - Orthotics Prosthetics Users Survey (OPUS)
 - Functional status
 - Quality of life
 - Health status
 - Clinician documentation (K levels, demographic details, goals)
- Device delivery
 - Functional status, quality of life, satisfaction with services and device
- Follow-Up at 2 months post-device delivery
 - Functional status, quality of life, satisfaction with services and device

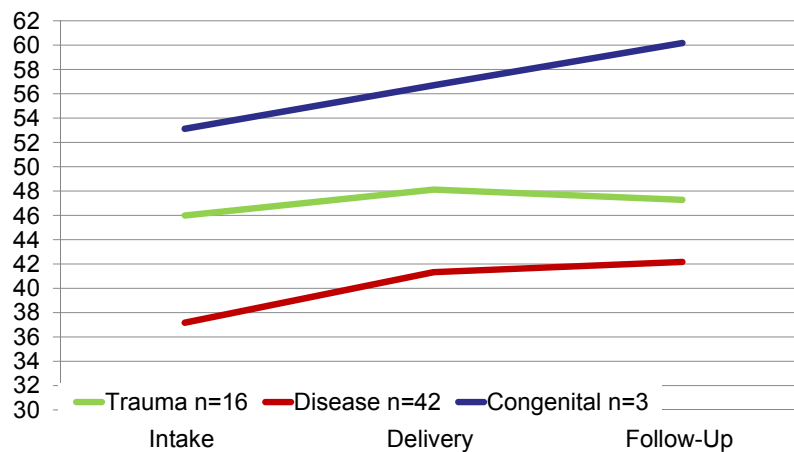
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Consultation process

- Review PRO results
- Discuss ways in which to improve clinical practice
- Develop draft action plans
- Monitor action plan implementation

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Lower extremity functional status by etiology



Higher scores represent greater function.

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Quality improvement foci

- Facilities A and B
 - Identify trends for patients with declining functional status and satisfaction with service
 - Identify patients whose functional status or satisfaction with services decreases over time
 - Conduct follow-up calls using scripted open ended questions
 - Structure staff education to address identified needs
 - Collect follow-up data
- Facility C
 - QI Project planning on hold due to Medicare audits
 - Continue to collect surveys with goal of participating in QI project in the future

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Challenges encountered

- Time limitations
 - “It’s difficult to get any patient to return surveys... Everyone is busy, whether they are high-income, low-income, have a disability, or don’t have a disability.”
 - “Time is the biggest barrier. We have limited staff who have multiple roles.”
- Tracking patient participation over the course of treatment
 - Electronic health record helps
- Obtaining follow-up data when patients do not return for appointments
- Patients not understanding the value in filling out the surveys

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Strategies to collect quality data

- “It is important to structure time for survey completion during a standard clinic visit.”
- “It would be very helpful if the survey was part of our EMR.”
- “We need to work on having our clinicians talk about the survey with patients and encourage the patient to begin filling it out while they are in the waiting room, and then while they are in the evaluation appointment.”
- “We offered a \$50 gift card to the clinician who completed the most complete sets of surveys.”
- “We hand the delivery survey to the patient as they arrive. They bring it back at their follow-up appointment.”
- “Some of our patients live in the country and if they don’t want to come back in for a follow-up appointment, we don’t demand it. We have to rely on them to mail the surveys in.”

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Benefits of CQI activities

- Target the needs of patients and achieve accreditation requirements
 - “To have richer data to show whether the services we provide are actually improving patient’s function and participation.”
 - “We truly understand the value in gathering data about patients’ experience.”
- Enhance patient-centered care
 - “To document our successes and to give patients a chance to specify where we can improve.”
 - “Patients would be valued by seeking their feedback, success and problems.”

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Example 3: Feasibility of Obtaining Patient-Reported Outcomes after Rehabilitation Discharge

Rehabilitation Research and Training Center on Measuring Rehabilitation Outcomes and Effectiveness

(NIDRR Award H133B040032111)

Rehabilitation Research and Training Center on Improving Measurement of Medical Rehabilitation Outcomes

(NIDRR Award [H133B090024](#))



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Project background and objectives

- Background
 - Post-discharge information on participation is critical to improving rehabilitation services and patients' quality of life
 - Telephone interviews are valuable, but costly
 - IRT/CAT methods may save resources, but feasibility is unknown
- Objectives
 - Develop patient-reported outcome measure of participation
 - Implement participation measure CAT
 - Evaluate feasibility of CAT data collection using web and telephonic interface

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Developing a measure of participation

- Conduct literature review
- Conduct focus groups with consumers, caregivers, providers, payers, policy makers
- Develop items and rating scales to operationalize participation
- Conduct cognitive interviews with consumers and general public
- Revise and pilot test participation instrument
- Collect and analyze population data from persons with and without disabilities (BRFSS)
- Refine instrument
- Evaluate instrument as part of routine post-discharge follow-up assessment

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Focus group input from stakeholders

Consumers	<p>"It means to make some sort of contribution in life"</p> <p>"Working and living"</p> <p>"It's important to socialize"</p> <p>"Just being able to do the things that you enjoy"</p>
Caregivers	<p>"Just doing what you want to do"</p> <p>"Being able to go to the store, to school, being able to do all of the things that normal people do"</p>
Providers	<p>"It goes beyond just daily living activities"</p> <p>"What you want when you want with who you want"</p> <p>"You are seen as having something to give"</p>
Payers	<p>"Allowed to fail, take on challenge"</p> <p>"Lack of information can be as isolating as any physical barrier"</p>
Policy Makers	<p>"Just the stuff we do and take for granted"</p>

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What we heard: Participation enfranchisement



- Hammel J, Magasi S, Heinemann AW, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30:19,1445-1460.
- Magasi S, Hammel J, Heinemann AW, Whiteneck G, Bogner J. Participation: A comparative analysis of multiple rehabilitation stakeholders' perspectives. *Journal of Rehabilitation Medicine*, 41, 936-944, 2009.

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Community Participation Indicators

- Frequency of activity
- Importance of activity
- Evaluation of activity frequency
- 48 enfranchisement items
 - Control over participation
 - Involvement in life situations



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Scoring decision: Consider importance of activities

- Avoid creating a "busy-ness" index
- Personal preferences, opportunities, environmental factors influence activity patterns
- Report descriptive information about activity patterns
- Evaluate "percent of important activities performed often enough" as an indicator of participation satisfaction

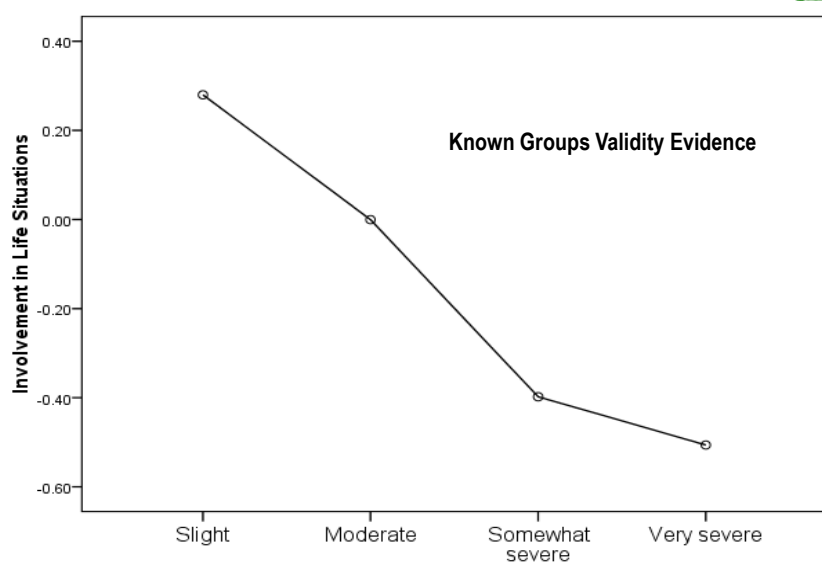
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Rating scale analysis of enfranchisement items

- Control over participation
- Involvement in life situations

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People with more severe disabilities report less involvement in life situations



Participation: Conclusions

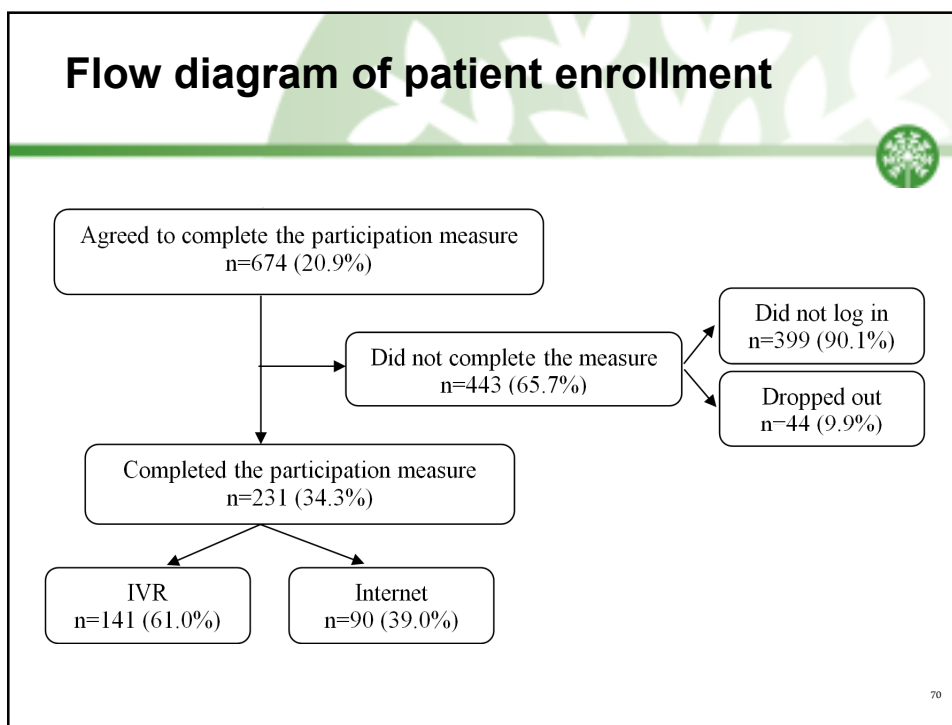
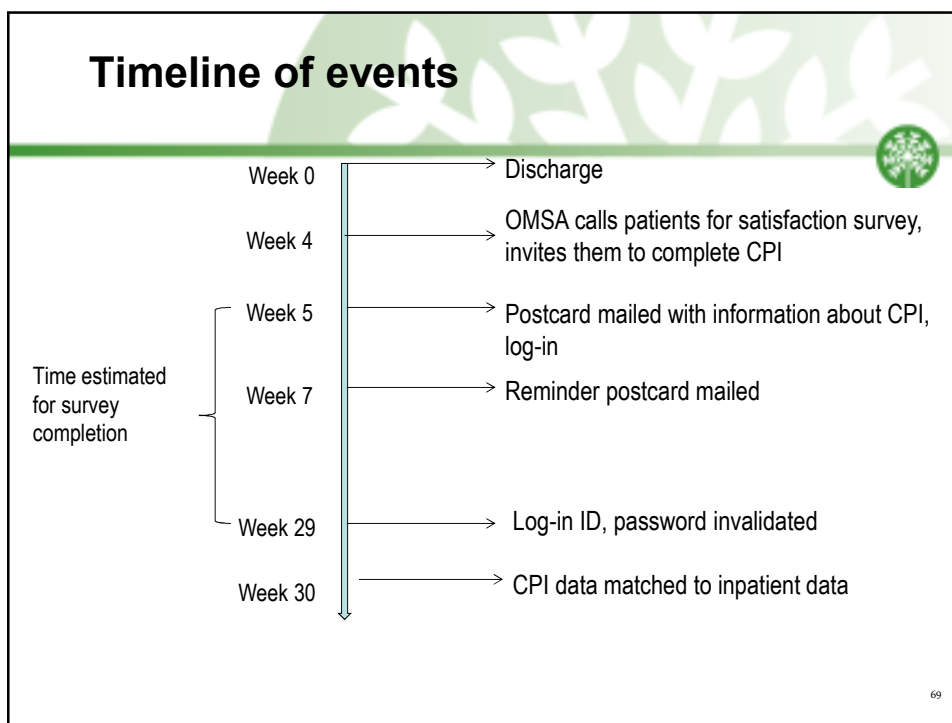
- Participation as measured by activity frequency, evaluation and enfranchisement items is not a unidimensional construct
 - Activity frequency, importance and evaluation are distinct aspects
 - Individuals' preferences and opportunities vary greatly
 - Personal preferences determine individual's participation profile
- Involvement in and control over participation are distinct constructs that can be measured reliably
- Preliminary construct validity of involvement in and control over participation is promising

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Feasibility of collecting post-discharge information using IRT/CAT

- Sample recruitment
 - Outcomes Management Systems and Analysis staff invited discharged adult inpatients to complete study instruments after a 1-month post-discharge telephone satisfaction survey.
- Data collection options
 - Secure web site
 - Interactive voice response (IVR) system
 - Questions administered using a CAT algorithm
- Data analysis
 - CAT data matched to de-identified inpatient data.

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Results

- 674 patients agreed to complete the CAT-CPI.
 - Patients who agreed to complete the CAT-CPI were younger and reported slightly higher satisfaction with overall care than did those who did not participate.
- 34% actually completed the CAT-CPI
 - 61% selected telephonic administration
 - 39% selected internet administration.
- Decreased odds of completing the CAT-CPI associated with
 - black and “other” race; stroke, brain injury, orthopedic and “other” impairments; being a Medicaid beneficiary, shorter LOS, and lower discharge FIM cognition measure
- Increased odds of choosing telephonic administration associated with
 - younger age, retirement status, female gender, lower discharge FIM motor measure

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Conclusions

- CAT administration by internet and telephone is feasible for collecting post-rehabilitation outcomes data
- Incentives required to assure sufficient level of patient follow-up
- Providing alternative ways of answering questions helps assure that a larger proportion of patients will respond
- Patient characteristics influence selection of phone vs. web-based option

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IV. Research agenda

From 20 meters



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Agenda

- Promoting routine outcomes measurement in rehabilitation practice
- Selecting optimal measures across populations and settings
- Measuring what matters
- Measuring what's feasible
- Appreciating policy priorities that influence outcome measurement
- Minimizing the unintended consequences of measurement

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Promoting routine outcomes measurement in rehabilitation practice



- What are clinicians taught?
 - How do they acquire measurement knowledge?
 - How does their training affect practice?
 - How does their training affect the choice of outcome measures they use?
 - How do different disciplines learn to use each others' measures to guide care and place the focus on the patient?
- How do clinicians access outcomes information?
 - Do they have access to Medline, CINAHL, PsychLit?
 - What sources of information do they use?
- What are their training needs?

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Selecting optimal measures across populations and settings



- How many measures are “enough”?
- How do we distinguish between the “good enough,” “better” and “optimal” measures within a domain?
- Institution specific measures
 - Prevent comparisons between institutions
- Challenges quantifying “change” when related but distinct instruments are used
- What criteria are clinicians using when they choose an instrument?

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Measuring what matters

- Neglected areas of assessment
 - Longer term outcomes
 - Environmental factors
- Cultural sensitivity and population specificity
 - Gender differences
 - Racial / ethnic differences
 - Impairment group differences
 - Age differences

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Appreciating policy priorities that influence outcome measurement

- How will national and provincial health priorities affect what is measured?
- How will use of quality metrics affect what's measured?

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Minimizing the unintended consequences of measurement



- Clinician and patient burden
- Risky uses of outcomes data
 - Using validated measures for a different population or setting than which it was evaluated
 - Measuring to impress
 - Provider compensation
 - Third-party payer reimbursements
 - Policy / political decisions
 - Marketing

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At ground level...



- Utilize sensitive, reliable, appropriate instruments in CER studies
- Evaluate methods to promote knowledge translation with clinical end users
- Develop and evaluate quality measures for medical rehabilitation
- Sustain efforts to evaluate promising interventions with carefully targeted endpoints operationalized by instruments that are reflective of and sensitive to clinical investigators' goals



In conclusion

- Measure what matters
- Engage stakeholders in learning what matters
- Consider how measurement information will be utilized

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