Technical Report - The Inclusion of Assistive Technology Outcomes in Current Health and Rehabilitation Outcome Measures (Version 1.0)

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Executive summary

This report presents the results of the field scan effort to clarify how assistive technology (AT) is treated in current and developing health and rehabilitation outcomes assessment instruments. Health and rehabilitation outcome measures vary widely on the basis of their purpose and scope. The number and variety of disciplines that consider the issue of function in their outcome measurement is many. Outcome can be measured in clinical, functional, psychosocial, and cost terms. Regardless of their intent, all outcome measurements contain a complex integration of information designed to capture change. Assistive technology (AT) is one of many potential interventions in the rehabilitation process.

While a primary focus of this review is to look at popular outcome measures in current use, several instruments important from an historical perspective (and widely used in early functional outcome studies) are included. Additionally, several authors of developing instruments consulted with us for feedback regarding assistive technology inclusion in the instruments they have in progress. Review of 100 prominent instruments reveals three primary categories of how AT is treated in the scaling and methodology of current assessments. First, instruments do not mention AT in their scoring procedures. Second, the functional outcome score is lowered when the subject uses AT. Third, the instrument allows the use of assistive technology to obtain a full functional score. This cataloguing of outcome measures reveals the extent to which assistive technology is either ignored or considered as a covariate of function. Overall, the findings suggest that many current assessments totally disregard AT and others fail to appreciate the significance of AT as a positive contribution to health and rehabilitation.

A second purpose of this project was to examine existing instrumentation for potential methodological strategies that might benefit AT outcomes measurement. If there is a system that works, there is no purpose to reinventing the wheel. The three instruments that provide a method for isolating the impact of AT are identified and their methodologies explained. Additionally, trends revealed in the literature reviewed are discussed. The instruments reviewed were published between the years 1957 and 2001. One unfortunate and one positive trend are identified. Finally, the report concludes with recommendations for stakeholders in the process of AT delivery and use.

Rationale for scan

We performed this scan to look at how assistive technology outcomes are currently being assessed in health and rehabilitation instruments. Specifically, we identified three research questions:

1) How is assistive technology considered in the scoring of each instrument?

2) Is there an existing methodology that isolates AT intervention?

3) Are there any trends regarding the consideration of AT in the instruments reviewed?

Description of scope of scan

We identified assessment instruments from the medical rehabilitation, gerontology, occupational and physical therapy, special education, audiology, vision, and speech/language disciplines that measure outcomes for both adults and children across a wide range of disabilities and clinical settings. The intention was to identify instruments in current use, however, we included several instruments important from an historical perspective. The USA, Canada, Europe and Australia are represented. Publication dates of the selected instruments selected spanned 1957 through 2001. From the hundreds of instruments we identified the set of 100 instruments for review.

Data collection procedure: Literature review

a. Sources: We used CINAHL and Medline databases plus health related web page resources for our bibliographical search.

b. Steps and iterations: Keywords included “functional assessment” and “outcome.”

c. Analysis procedures:

Limiting the set: We identified two criteria to narrow the set of instruments for review to 100. Instruments having a high incidence of occurrence in these searches and those with large numbers of references in the outcomes research literature were selected. See Table 1 for the distribution of instruments. Appendix A is the list of 100 instruments in alphabetical order with bibliographical sources.

GENERIC ASSESSMENTS	
Generic Health and Quality of Life	
e.g. SF-36, SIP, Euro-Qol	6
Social Outcome	
e.g., CHART, London Handicap Scale	5
Rehabilitation	
e.g. FIM, PECS, LORS II	13
SPECIFIC ASSESSMENTS	
Age-related Populations	
Geriatric	12
Geriatric-US federal government	3
Pediatric	4
Activity Specific	
e.g., Kenny, AMPS, COPM, FAI	13
Disability Specific	
Sensory: Vision, Language, Communication	7
Stroke	3
Traumatic Brain Injury	1
Multiple Sclerosis	2
Spinal Cord Injury	2
Arthritis	8
Dementia	1
Mobility/Gait	3
Orthopedics	11
Mental Health	6
TOTAL	100

Table 1: Distribution of Instruments Reviewed – Generically by Purpose

Data extraction 1: Initial analysis involved classification of the instruments as to how assistive technology is considered in their scoring processes. Three categories developed: 1) no mention of AT in the scoring, 2) the use of AT lowered the outcome score and, 3) the use of AT was allowed to elevate the functional score.

Data extraction 2: Secondary analysis critically reviewed the instruments for methodologies that isolated the impact of AT from other concurrent interventions.

Data extraction 3: Finally, through critical analysis, we identified trends in functional assessment that were evident over the 33 years represented by the publication dates of the instruments reviewed.

Findings

Research question #1: How is assistive technology considered in the scoring of each instrument?

Figure 1 shows that 30 instruments fail to acknowledge the use of AT in their outcome scoring, 44 instruments incorporate the use of AT in the score but the use lowers the overall functional score, and 22 instruments allow AT to elevate the outcome score, accounting for 96 of the instruments. Four of the instruments did not fit this classification scheme and will be discussed separately, below. Prior to that, examples of instruments where AT lowers a score and where AT use is accepted as "best" performance are provided.

Figure 1

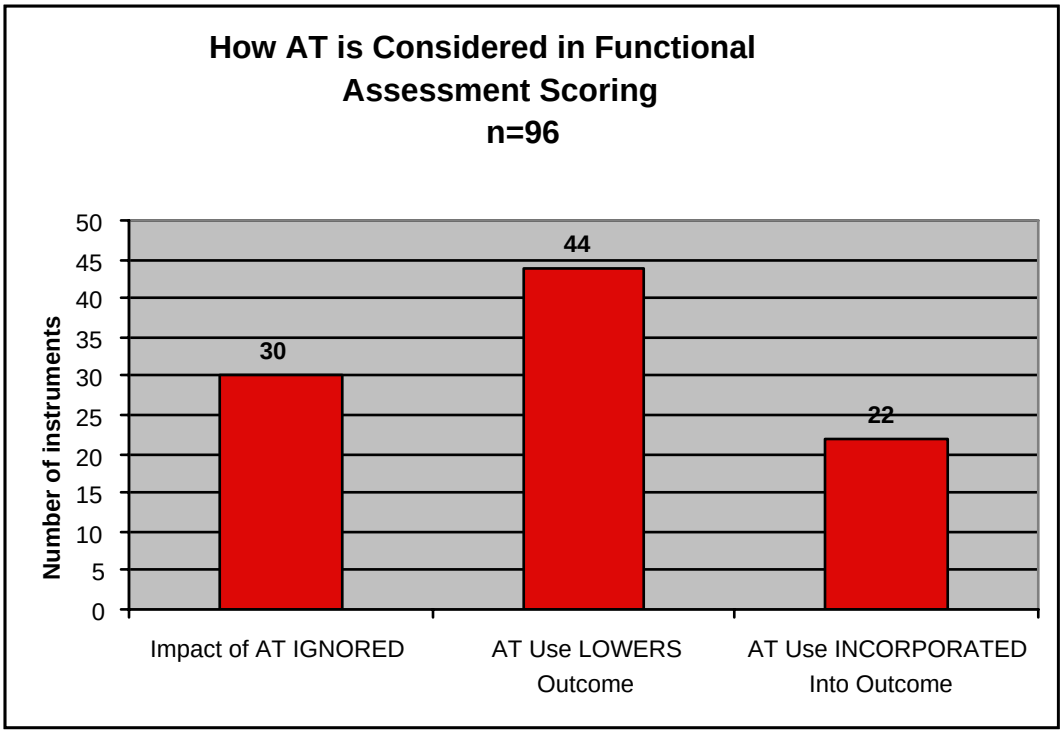

Table 2 shows examples from instruments where the use of AT lowers the total score. In some instruments, like the Functional Independence Measure (State University of New York at Buffalo, 1997), this occurs throughout the scoring of the instrument. Every item has a lower score if assistive devices are used. In other tools, like the Sickness Inventory Profile (Gilson, Gilson, & Bergner, 1975) the use of AT lowering an overall score occurs only in occasional questions. In the SIP, items that are checked by the individual are those that are used to provide a score or an interpretation. An individual who uses a cane or walker would check item 10, whereas an individual who did not use a mobility device would not. In this example, the user of an aid for mobility would have one extra "check" against them in the final score.

Adult FIM (State University of New York at Buffalo, 1997) 7 Complete Independence (Timely, Safely) 6 Modified Independence (Device) 5 Supervision 4 Minimal Assist (Subject = 75% +) 3 Moderate Assist (Subject = 50% +) 2 Maximal Assist (Subject = 25% +) 1 Total Assist (Subject = 0% +) Embedded throughout the instrument
SIP (Gilson et al., 1975) Item #4: I do not maintain balance. Item #7: I kneel, stoop, or bend down *only by holding on to something*. Item #10: I get in and out of bed or chairs *by grasping something for support or using a cane or walker.* (Italics added) Items that lower AT appear in occasional questions

Table 2: Examples of how use of assistive devices lowers scores

Diametrically opposed to this method of scoring are instruments that allow an individual to use assistive technology to obtain a full score. This type of scoring is

usually explained in the instructions. Table 3 provides examples from the Klein-Bell (Klein & Bell, 1982) the Edinburgh Rehabilitation Status Scale (Affleck, Aitken, Hunter, McGuire, & Roy, 1988), and the Standardized Test of Patient Mobility (Jebsen et al., 1970), all of which address assistive device use this way.

Scoring instructions:	
Klein Bell (Klein & Bell, 1982)	"When an individual uses adaptive equipment without verbal or physical assistance, he or she is assigned a full score."
Edinburgh Rehabilitation Status Scale (Affleck et al., 1988)	"May have aids or appliances or has successfully used an adapted house."
Standardized Test of Patient Mobility (Jebsen et al., 1970)	"Ambulation aids are allowed."

Table 3: Examples of how AT is allowed to be used for "best" score

Four of the 100 instruments, however, did not "fit" into this classification system. They are discussed individually as they provide a glimpse into the complexities of considering AT in functional performance.

Two instruments have conflicting views of AT use, depending on the device used. Tables 4 and 5 provide examples of how the use and scoring of AT can be inconsistent *within* an instrument. Both the Katz Index of Activities of Daily Living (1963) and the OASIS (Center of Health Services and Policy Research Center, 1998), the US government required instrument for home healthcare clients, have some items which allow the use of AT in their scoring, and other items in which the use of AT lowers a score. A third instrument where AT use is considered differently *within* the instrument is found in The National Standardized Minimum Dataset (American Foundation for the Blind, 2002, October). It scores functional behaviors by the dual criteria of "Performance" and "Independence." When determining the "Performance" rating of a behavior, the use of AT is not mentioned. However, when determining the "Independence" rating of a behavior, the use of AT lowers the score. Finally, the fourth instrument that escapes the classification used in this review is the Evaluation of Daily Activities Questionnaire (Nordenskiöld, Grimby, & Dahlin-Ivanoff, 1998). It was designed specifically to assess the difficulty of daily activities with and without the use of assistive devices (AD*) or* altered working methods for individuals with rheumatoid arthritis. The effect of altered working methods is not separated from the affect of AD.

AT OK	**(M0650) Ability to dress <u>Upper Body</u>** (with or without dressing aids) including
AT Lowers	**(M0670) Bathing:** Ability to wash entire body… 0 – Able to bathe self in shower or tub independently.

	1 – With the use of devices, is able to bathe self in shower or tub independently 2 – Able to bathe in shower or tub with the assistance of another person

Table 4: Examples from Outcome and Assessment Information Set OASIS-B1
(Center of Health Services and Policy Research Center, 1998)
(only portions of questions reproduced)

AT OK	**Transfer** Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports) Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers
AT Lowers	**Continence** Independent: urination and defecation entirely self-controlled Dependent: partial or total incontinence in urination or defecation; partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans

Table 5: Examples from the Index of Katz Independence in Activities of Daily Living
(Katz, 1963)

Research question #2: Is there an existing methodology that isolates AT intervention?

Overall, 70% of the instruments considered assistive technology. Only three of these, however, provide a method for *isolating* the impact of AT. As mentioned above, Nordenskiöld's Evaluation of Daily Activities Questionnaire, or EDAQ (1998), takes a step in this direction, however, as stated previously, it was designed specifically to capture the impact of a combined intervention strategy. The effects of both AD use and patient education are measured with its administration.

- The Occupational Therapy Functional Assessment Compilation Tool, OT FACT Version 2.0 (Smith, 1995), allows scoring with and/or without the use of adaptive equipment. Memo fields are available for each item to document the type of assistive device or devices used.

- The Pediatric Evaluation of Disability (PEDI), developed to document health status of chronically ill and disabled children in pediatric rehabilitation settings, quantifies the contribution of AT parallel to the functional assessment. It provides a description of functional limitations, caregiver assistance, and modifications for tasks (Haley et al., 1989).

- Finally, the recently developed International Classification of Functioning, Disability and Health Checklist (World Health Organization, 2001b) allows for both capacity and performance qualifiers to be scored with or without assistive devices and with or without personal assistance. "While neither devices nor personal assistance eliminate the impairments, they may remove limitations on functioning in specific domains. This type of coding is particularly useful to identify how much the functioning of the individual would be limited without the assistive devices" (WHO, 2001a, p.15).

  In all cases, repeated scoring of each item is necessary to tease out the impact of the assistive device.

Research question #3: Are there any trends regarding the consideration of AT in the instruments reviewed?

This review identifies two trends. The first is the inconsistent application for scoring of AT within an instrument as previously identified in the Katz Index of Activities of Daily Living (1963) and the OASIS (Center of Health Services and Policy Research Center, 1998). In the OASIS, corrective lenses and hearing aids may be used in their respective categories for a full functional score while augmentative communication is not even considered in the category of hearing. For dressing, toileting, and driving a car, the use of assistive or adaptive devices does not lower a score, but for bathing, transferring, ambulation or ability to use the telephone AT device use "penalizes" the user with a lower score. Does this make sense? Published twenty-five years after the Katz, which also has this inconsistent scoring of AT, it does not appear that the understanding or impact of assistive device use has become less muddled over time. Looking at this issue from another perspective, Table 6 shows how the six most recently published reviewed instruments fared in our classification system. Clearly, the role that assistive technology plays in increasing functional performance remains problematic in outcomes measurement.

Impact of AT ignored	AT use lowers outcome	AT incorporated into outcome
Adelaide Activities Profile (Bond & Clark, 1998)	School Functional Assessment (Coster, Deeney, Haltiwanger, & Haley, 1998)	Occupational Self Assessment (Baron, Kielhofner, Goldhammer, & Wolenski, 1999)
Minimum Data Set 2.0 (Health Care Financing Administration, 1998)	MDS Post-acute Care, (Health Care Financing Administration, 2000)	Subjective Index of Physical and Social Outcome (SIPSO) (Trigg & Wood, 2000)
		National Eye Institute Visual Function Questionnaire (Mangione et al., 2001)

Table 6: Classification of most recently published outcome instruments reviewed.

The second trend identified in this review is the increasing incidence of instruments' taking into account the patient's point of view as central to monitoring healthcare outcomes. Scherer & Galvin (1997) state that outcomes need to demonstrate that goals have been *identified* and then achieved [emphasis added]. Wielandt & Strong (2000) in their review of compliance with prescribed adaptive equipment conclude, "that a more client-centered approach is required during the entire therapeutic process …Compliance with adaptive equipment needs the active participation of the clients" p 206. Newer instruments that take a more subjective approach to functional performance are increasing in popularity. Five of the reviewed instruments base outcome performance on patient preference or consumer goal setting. Additionally, several instruments not included in the set of 100 instruments (because they did not meet both selection criteria, above) are also mentioned here as they are representative of this trend.

- The McMaster Toronto Arthritis Questionnaire, or MACTAR, (Tugwell et al., 1987), is a patient preference questionnaire for assessing disability in patients with rheumatoid arthritis. It asks the patient which activities that are limited by their arthritis would they most like to do, "without the pain or discomfort of your arthritis," (p. 447).

- OT FACT (Smith, 1990, 1994) does not specifically address preference, but with it's computerized branching system for scoring, only categories relevant to the patient are included.

- As part of its scoring, the AIMS2 (Meenan, Mason, Anderson, Guccione, & Kazis, 1992) asks the individual to select three areas of health in which they would most like to see improvement.

- The Canadian Occupational Performance Measure (Law et al., 1998; Law, Baum, & Dunn, 2001), has become a widely used patient preference instrument. It is a formal interview that elicits open-ended patient identified goals and quantitative ratings of those goals.

- The Occupational Self Assessment, or OSA (Baron et al., 1999), asks individuals how well they are able to do a task, how important these tasks are, and then finally, "Choose up to 4 things about yourself that you would like to change", rank ordering the four.

Additional instruments (not part of the 100 because of exclusion criteria).

- The Impact on Participation and Autonomy Questionnaire (IPAQ), recently developed in Amsterdam (Cardol, de Haan, de Jong, van den Bos, & de Groot, 2001) expands on this concept of patient preference to measure perceived participation and perceived problems or restrictions. It asks individuals if they are able to perform activities, "the way one wants", "when one wants".

- Wright & Young (1997) and Wright, Young, & Waddell (2000) developed the Patient Specific Index to focus on the specific concerns of individuals undergoing total hip arthroplasty.

Discussion

The majority of instruments in this review developed parallel to the acceptance and implementation of the WHO's *International Classification of Impairment, Disability, and Handicap (ICIDH) Model of Disablement* (World Health Organization, 1980b). As the process of revision of the ICIDH to the *International Classification of Functioning and Disability: ICIDH-2 Beta-2 draft* (World Health Organization, 1999) and it's most current form of the *International Classification of Functioning, Disability, and Health-ICF* (World Health Organization, 2001a) reflect a broader classification of health and health related states, so too have the authors of outcomes instruments been revising their perspectives as to what it is that is important to measure. As such, the results of this review are not surprising considering the diverse purposes of functional assessment. Many instruments focus on the impairment and disability levels of function, with condition specific foci developed from a medical model that views functioning and health as a consequence of a condition. Other instruments track interdisciplinary rehabilitation efforts or to determine the need for care. Some are unidisciplinary, focusing on a given practice environment. More recently, instruments to track quality of life and satisfaction are developing concurrently with the trends of greater accountability and cost control in healthcare. Considering the broad expectations for most of these instruments it is no wonder that the consideration of AT is not clear.

When AT is considered in outcomes measures, scaling is inconsistent. Assessments that fail to include AT are likely predisposed to the construct that either a) AT makes no difference or significantly interacts with the interventions they are observing, or b) they do not care if AT make a difference. Assessments that include AT, but assess the outcomes score as lower with AT use, convey a construct that better outcomes avoid the use of technology. The implications of this concept are that healthy people do not use technology and that technology use is dichotomous. While these constructs may be valid for specific research studies, the failure to understand the role of technology in the outcomes of people who have a spectrum of types and intensities of disabilities neglects a significant opportunity to scientifically better understand the interaction between technology and human disablement.

Implications for:

A. Next generation outcome measurement system

To adequately include patient preference and goal setting, a "next generation" instrument, tapping the advances in computer technology and measurement theory must be developed to meet the unique outcomes measurement needs that will measure the

increased functionality afforded to individuals with disabilities when they use assistive devices or benefit from universal design.

B. Researchers

Many of the instruments reviewed in this article contain multiple variables. Their outcome scores may be valuable for documenting the average ratings of a group of individuals, but they can lack meaning for individual patients. In these types of instruments, the primary focus of an intervention may be lost. Researchers interested in the effects of an assistive technology intervention need to use instrumentation specific to the targeted behavior and device/s.

C. Policy makers

Considering the muddled consideration of assistive technology in the instruments reviewed, it is crucial that policy makers base decisions on adequate instrumentation. Traditional psychometric measures are the standard for the instrumentation used in most current outcomes studies, however, as the trend to consider outcome from the patient's perspective continues, these traditional psychometric measures may not be adequate. Policy makers need to support instrument development that incorporates other methodologies.

D. Practioners

Assistive technology practitioners could have intuitively predicted the results of this study. The feeling of AT practice has been that health and rehabilitation assessments devalue the impact of AT. Nonetheless, for practitioners using existing health and rehabilitation outcomes measures, it is crucial that they understand the threats to validity and reliability in an instrument that does not include the use of assistive technology in its descriptions of functional performance. Additionally, when instructions for the scoring of AT exist within an instrument, practitioners must understand the theoretical concept of "independence" implicit in the scaling used. The languages used may be similar, but the underlying assumptions may be drastically different.

E. Consumers

Despite the multitude of assessment instruments created by experts or by mathematical models, why should anyone other than the consumer decide what area of performance will be the focus of intervention?

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Appendix A: Bibliography of the 100 Functional Assessment Instruments Reviewed

INSTRUMENT	SOURCE
The Árnadóttir OT-ADL Neurobehavioral Evaluation Instrument (A-1)	Árnadóttir G. The brain and behavior, assessing cortical dysfunction through activities of daily living. St. Louis: C. V. Mosby; 1990.
Adelaide Activities Profile (AAP)	Bond MJ, Clark MS. Clinical applications of the Adelaide Activities Profile. Clinical Rehabilitation 1998; 12:228-37.
The Acute Care Index of Function (ACIF)	Roach KE, Van Dillen LR. Development of an Acute Care Index of Functional Status for patients with neurologic impairment. Physical Therapy 1988; 68 (7):1102-8.
The ADL-Staircase	Sonn U. Longitudinal studies of dependence in daily life activities among elderly persons. Scan J Rehab Med Suppl 1996; 34:2-34.
The Arthritis Impact Measurement Scales (AIMS-2)	Meenan RF, Mason JH, Anderson JJ et al. AIMS2: The content and properties of a revised and expanded Arthritis Impact Measurement Scales Health Questionnaire. Arthritis and Rheumatism 1992; 35 (1):1-10.
Arthritis Self Efficacy Scale	Lorig K, Chastain RL, Ung E et al. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis & Rheumatism 1989; 32 (1):37-44.
Assessment of Motor and Processing Skills (AMPS)	Fischer AG. Assessment of Motor and Processing Skills (AMPS) Research ed. 7.00. Fort Collins: Department of Occupational Therapy, Colorado State University; 1994.
The Bristol Activities of Daily Living Scale (BADLS)	Bucks RS, Ashworth DL, Wilcock GK et al. Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. Age and Ageing 1996; 25 (2):113-20.
The Bay Area Functional Performance Profile (BaFPE)	Bloomer J, Williams S. Task oriented assessment and social interaction scale: BaFPE. San Francisco: Langley Porter Institute, UCSF; 1979.
Barthel Index	Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. Maryland State Medical Journal 1965; 14 (2):61-5.

INSTRUMENT	SOURCE
The Behavior And Symptom Identification Scale (BASIS-32)	Eisen SV, Wilcox M, Leff HS et al. Assessing behavioral health outcomes in outpatient programs: reliability and validity of the BASIS-32. Journal of Behavioral Health Services and Research 1999; 26:5-17.
The Communicative Effectiveness Index (CEI)	Lomas J, Pickard L, S. B et al. The Communication Effectiveness Index: development and psychometric evaluation of functional communication for adult aphasia. Journal of Speech and Hearing Disorders 1989; 54 (1):113-24.
Craig Handicap Assessment and Reporting Technique (CHART)	Whitenenck GG, Charlifue SW, Gerhart KA et al. Quantifying handicap: a new measure of long-term rehabilitation outcomes. Archives of Physical Medicine and Rehabilitation 1992; 73 (6):519-26.
Community Integration Questionnaire (CIQ)	Willer B, Ottenbacher KJ, Coad ML. The Community Integration Questionnaire. American Journal of Physical Medicine and Rehabilitation 1994; 73 (2):103-11.
Canadian Occupational Performance Measure (COPM)	Law M, Baptiste S, Carswell A et al. The Canadian Occupational Performance Measure. 3rd ed. Toronto, Ontario: CAOT Publications; 1998.
The Disability and Impairment Interview Schedule	Bennett AE, Garrad J, Halil T. Chronic disease and disability in the community: A prevalence study. British Medical Journal 1970; 3:762-4.
Disability Rating Scale	Rappaport M, Hall KM, Hopkins K et al. Disability Rating Scale for severe head trauma patients: coma to community. Archives of Physical Medicine and Rehabilitation 1982; 63 (3):118-23.
Dallas Pain Questionnaire (DPQ)	Lawlis GF, Cuencas R, Selby D et al. The development of the Dallas Pain Questionnaire. Spine 1989; 14 (5):511-7.
Nottingham Extended Activities of Daily Living (EADL)	Nouri FM, Lincoln NB. An extended activities of daily living scale for stroke patients. Clinical Rehabilitation 1987; 1:301-5.
Expanded Disability Status Scale (EDSS)	Kurtzke JF. Rating neurologic impairment in multiple sclerosis: an Expected Disability Status Scale (EDSS). Neurology 1983; 33 (11):1444-52.
Evaluation of Daily Activities Questionnaire (EDAQ)	Nordenskiöld U, Grimby G, Dahlin-Ivanoff S. Questionnaire to evaluate the effects of assistive devices and altered working methods in women with rheumatoid arthritis. Clinical Rheumatology 1998; 17:6-16.

INSTRUMENT	SOURCE
Edinburgh Rehabilitation Status Scale	Affleck JW, Aitken RC, Hunter JA et al. Rehabilitation status: a measure of medicosocial dysfunction. The Lancet 1988; 1:230-3.
Euro-Qol (EQ-5D)	Brooks RH, with the EuroQol Group. EuroQol: the current state of play. Health Policy 1996; 37 (1):53-72.
Functional Assessment of Communication Skills for Adults (FACS)	Frattali CM, Thompson CK, Holland AL et al. Functional Assessment of Communication Skills for Adults. Rockville, MD: ASHA; 1995.
Functional Assessment Inventory (FAI)	Crewe N, Athelstan G. Functional assessment in vocational rehabilitation. International Journal of Rehabilitation Research 1979; 2:535-6.
Frenchay Activity Index (FAI)	Holbrook M, Skilbeck CE. An activities index for use with stroke patients. Age and Ageing 1983; 12 (2):166-70.
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