

ORIGINAL RESEARCH

Measuring Access to Information and Technology: Environmental Factors Affecting Persons With Neurologic Disorders



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Abstract

Objective: To develop and validate a patient-reported measure of access to information and technology (AIT) for persons with spinal cord injury, stroke, or traumatic brain injury.

Design: A mixed-methods approach was used to develop items, refine them through cognitive interviews, and evaluate their psychometric properties. Item responses were evaluated with the Rasch rating scale model. Correlational and analysis-of-variance methods were used to evaluate construct validity.

Setting: Community-dwelling individuals participated in telephone interviews or traveled to the academic medical centers where this research took place.

Participants: Individuals with a diagnosis of spinal cord injury, stroke, or traumatic brain injury (aged ≥ 18 y, English speaking) participated in cognitive interviews (n = 12 persons), field testing of the items (n = 305 persons), and validation testing of the final set of items (n = 604 persons).

Interventions: Not applicable.

Main Outcome Measures: A set of items to measure AIT for people with disabilities.

Results: A user-friendly multimedia touchscreen was used for self-administration of the items. A 23-item AIT measure demonstrated good evidence of internal consistency reliability, and content and construct validity.

Conclusions: This new AIT measure will enable researchers and clinicians to determine to what extent environmental factors influence health outcomes and social participation in people with disabilities. The AIT measure could also provide disability advocates with more specific and detailed information about environmental factors to lobby for elimination of barriers.

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The World Health Organization's *World Report on Disability* proposed requirements for improving the participation and inclusion of people with disabilities, and promoting the achievement of their human rights.¹ Accessibility initiatives should be multi-faceted, taking into account external constraints including the

availability of technology and knowledge. The *International Classification of Functioning, Disability and Health* (ICF) taxonomy of environmental factors that may affect participation includes (1) products and technology and (2) services, systems, and policies.² Limited access to, and usability of, information and technology may prevent people with disabilities from participating effectively in contemporary society.

Individuals living in the community after spinal cord injury (SCI) reported perceiving (1) rehabilitation specialists as ideal sources of information but not easily accessible, and (2) internet

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information as relatively accessible but not necessarily always of high quality.³ People with moderate to severe traumatic brain injury (TBI) had a strong interest in developing their internet and computer skills, but reported limited knowledge and access to computers and the internet.⁴ A systematic review⁵ concluded that there is a lack of research on information and community technology to support self-management needs in people with mild acquired cognitive impairment caused by a head injury or mild stroke. Characteristics that predict internet use in disability groups are the same as those in the general population—for example, ethnicity/race, education, income, and age.^{6–9} Valid measures of access to information and technology (AIT) are essential to capture gaps in needs and variations across subpopulations, and to determine the extent to which limited access affects participation and well-being.

The purpose of this report is to describe the development and validation of a measure of AIT. This work was conducted as part of a large multicenter study to develop and validate a new set of patient-reported measures of environmental factors and their influence on participation for persons with SCI, stroke, or TBI.^{10,11} The investigators developed a conceptual framework with 6 domains: AIT; assistive technology; built and natural environment; economic quality of life; services, systems, and policies; and social environment. These domains parallel the environmental factor chapters of the ICF but are not identical to them.²

Methods

The project used a mixed-methods approach recommended by the Patient-Reported Outcomes Measurement Information System (PROMIS) Network,^{12,13} and is described in detail elsewhere.^{10,11} Briefly, this involved up to 5 phases: (1) a literature review and qualitative methods for concept elicitation, item classification, and creation; (2) item refinement through cognitive interviews; (3) quantitative field testing with individuals with traumatic SCI, stroke, or TBI; (4) item refinement based on field testing results, followed by cognitive interviews; and (5) validation testing with another sample of individuals with traumatic SCI, stroke, or TBI. Institutional review board approval was obtained at each institution before the start of this project. All participants provided informed consent and had the opportunity to raise questions and to withdraw from the study if they wished.

Phase 1: Item development

Working definitions for all environmental factor themes were based on focus group input, review of 107 items in existing instruments,^{14–25} and environmental factor research.¹¹ The AIT Workgroup used these definitions to guide development of items.

List of abbreviations:

AIT	access to information and technology
CHIEF	Craig Hospital Inventory of Environmental Factors
ICF	International Classification of Functioning, Disability and Health
PROMIS	Patient-Reported Outcomes Measurement Information System
SCI	spinal cord injury
TBI	traumatic brain injury

Phase 2: Cognitive interviews and item revision

Cognitive interviews were conducted with 6 community-dwelling people with traumatic SCI (n = 1), stroke (n = 2), or TBI (n = 3) to assess the comprehensibility and relevance of the AIT items. Participants were recruited through a research registry at the Rehabilitation Institute of Chicago. Each participant completed the items during an in-person or telephone interview (20–40min). Participants were asked to explain each question in their own words and describe how they arrived at their answer. They also described their understanding of key concepts, such as the phrase “if I need it.” Interviewers recorded responses verbatim for analysis.

The Workgroup refined items, with feedback from the larger interdisciplinary research team. Revised items underwent a second round of cognitive testing with 6 individuals (n = 2 for each condition) using the same procedures described above. A reading-level analysis was conducted using the Flesch-Kincaid Readability Scale²⁶ and the Lexile Framework,²⁷ targeting a sixth-grade level to maximize accessibility to participants with low reading skills. A translatability review was performed to remove any conceptual or linguistic difficulties that would pose barriers to future multilingual translation and cross-cultural applicability.¹³

Phase 3: Field testing

Participant recruitment

Participants were recruited from the Rehabilitation Institute of Chicago. Eligibility criteria included (1) self-report of SCI, stroke, or TBI; (2) age ≥ 18 years; and (3) the ability to speak English. Target accrual was 100 persons in each impairment group. Participants were interviewed in person (70%) or by telephone (30%). A \$10 incentive was provided for each set of items completed (eg, AIT was 1 set of 25 items).

Psychometric analysis

Preliminary analyses were conducted to identify unused or sparsely used categories, and to examine whether the average measures in response categories increased monotonically. Item responses were evaluated with the Rasch rating scale model as implemented in Winsteps software.^{28–30,a} In the Rasch model, the person’s “raw score” (sum of item responses) is sufficient for estimating the “measure” (the person’s transformed level on the latent trait). A difficulty parameter is estimated for each item, which represents the item’s location on the latent trait. Model fit was evaluated using the infit mean-square statistic, which has an expected value of 1.0 and is less sensitive to outliers compared with other fit statistics.²⁹ Values between 0.6 and 1.4 are most desirable for rating scale data.³¹ Person separation reliability was estimated to evaluate how well people can be differentiated on the measure.²⁹ This estimate is based on the same concept as Cronbach alpha; it is the ratio of person variation to measurement error.³² Values $\geq .80$ were considered optimal. Item separation reliability was evaluated using the same criterion value ($\geq .80$); item separation reliability is an indicator of the potential range covered by the measure.

Phase 4: Item refinement

No further item refinement was needed for the AIT items, based on field testing results.

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