

# NIH Toolbox

Assessment of Neurological and Behavioral Function

www.nihtoolbox.org

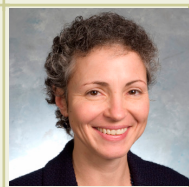
Fall, 2011 Volume 3 Issue 3

Sensation

Motor

Emotion

Cognition



Cindy Nowinski, MD, PhD, Northwestern University  
c-nowinski@northwestern.edu

*Dr. Cindy Nowinski is co-investigator and Scientific Director of the NIH Toolbox project. As such, she oversees the general efforts of the 6 domain teams.*

In this issue we look at grants that include NIH Toolbox measures in their research. Among other objectives, the data from these projects will increase our understanding of NIH Toolbox applications in certain clinical groups such as Parkinson's disease and acute neurorehabilitation populations.

Future newsletter issues will continue to include updates and reports from these and other studies using the NIH Toolbox, such as a project that is building upon the accessibility and usability findings reported below in order to evaluate and validate the NIH Toolbox for use with people with Traumatic Brain Injury, Spinal Cord Injury, and stroke.

## Enhancing the NIH Toolbox Accessibility and Usability to Support Inclusion of People with Disabilities

Principal Investigator: Susan Magasi, PhD  
Northwestern University  
s-magasi@northwestern.edu

The NIH Toolbox mandate to develop a standard set of measures of cognitive, motor, sensory and emotional health for use across the span of people 3 to 85 years, in English and Spanish, is ambitious. Early in the instrument development process, an accessibility committee was formed to help ensure that the NIH Toolbox was compliant with federal accessibility laws and to guide the development team as they sought to embrace principles of universal design to ensure that the Toolbox would be accessible to as many users as possible. As interest in the NIH Toolbox has grown, researchers and clinicians have expressed interest in moving the NIH Toolbox from its focus on the general population to clinical populations, including people with disabilities. Before the NIH Toolbox can be used in research and clinical practice with people with disabilities, we must ensure that they can use and access the measures as intended by the test developers.

To evaluate the usability and accessibility of the NIH Toolbox in people with spinal cord injury, traumatic brain injury, and stroke, we implemented two phases of contextual usability testing in a sample of community-dwelling adults with spinal cord injuries, traumatic brain injuries and stroke. In phase one, 30 participants completed individual NIH Toolbox measures with cognitive debriefing after each measure. In phase two, 27 participants completed NIH Toolbox domain batteries followed by cognitive debriefing. All NIH Toolbox sessions were observed by expert accessibility auditors who documented objective and subjective aspects of performance. Data were analyzed qualitatively and descriptively. In accordance with the NIH Toolbox's established exclusions for individual measures, participants were able to complete the majority of the measures and reported generally favorable experiences.

*Continues on pg. 3*



## New NIH Clinical Tools in Parkinson's Disease

Principal Investigator: Mustafa M. Husain, MD  
University of Texas Southwestern Medical Center  
mustafa.husain@utsouthwestern.edu

### *Recent Toolbox Publications*

Wang Y-C, et al.  
Assessing Dexterity  
Function: A Comparison  
of Two Alternatives  
for the NIH Toolbox.  
Journal of Hand Therapy,  
(2011) Epub ahead of  
print.

Bohannon, RW, et al.  
Adequacy of Belt-Sta-  
bilized Testing of Knee  
Extension Strength.  
Journal of Strength and  
Conditioning Research..  
(2011) 25(7), 1963-1167.

Nowinski, Cindy J., et al.  
Neuro-QOL and the  
NIH Toolbox: Impli-  
cations for Epilepsy.  
Therapy, (2010) 7(5),  
533-540.

Mennella, J. A., et al.  
Evaluation of the Monell  
Forced-Choice, Paired-  
Comparison Tracking  
Procedure for Determin-  
ing Sweet Taste Prefer-  
ences across the Lifespan.  
Chemical Senses, (2011)  
36(4), 345-55.

The clinical impact of Parkinson's disease (PD) and depression are well recognized and of considerable clinical significance, but less understood is their unique role and complex interaction in terms of quality of life and cognitive outcomes.

As such, measurement of quality of life and neurocognitive function in patients with PD, particularly in the presence of comorbid depression, may have prognostic significance. Standard assessment tools have been used to evaluate quality of life and neurocognitive effects of PD and depression, but their use has been limited by poor psychometric properties and more importantly, lengthy administration time.

To overcome these limitations, NIH developed two important tools - the NIH Toolbox Assessment for Neurological and Behavioral Function (NIH Toolbox) and the Health-Related Quality of Life (Neuro-QOL) measure. However, Neuro-QOL and the NIH Toolbox have not been standardized in patients with Parkinson's disease. This research study is using the NIH Toolbox and Neuro-QOL in a representative and well described cohort of 160 patients with Parkinson's disease to discern the effects attributable to Parkinson's or depressive symptomatology. We are currently in year 2 of our project. We have completed 81% of our study enrollment and have a retention rate of 98%. Specifically, we have enrolled 130 participants within a time frame of 16 months.

We developed a unique scientific infrastructure comprised of experts from neurology, psychiatry, neuropsychology, and biostatistics. With our study population of patients with Parkinson's disease, with or without depression, we have found that many patients do not present with depressive symptomatology, and are able to complete a comprehensive assessment battery of clinical, neurocognitive, and quality of life measures in a timely manner. We have also found that many patients with PD may also present with some cognitive impairment. For instance, 26% of patients we screened for possible study enrollment were excluded due to the presence of cognitive impairment.

We presented data at the 10th Annual International Conference on Alzheimer's and Parkinson's Disease regarding the neurocognitive performance on the NIH Toolbox cognitive domain of our first 42 patients with PD. We have learned that the application of the NIH Toolbox and the Neuro-QOL in clinical practice are feasible in patients with Parkinson's disease. The patients are able to complete most portions of the NIH Toolbox including the cognitive, emotion, sensory, and motor batteries (excluding certain tests requiring balancing), with small adaptations.

## Creating a Pediatric Imaging/Genomics Data Resource

Principal Investigator: Terry Jernigan, PhD  
 University of California, San Diego  
 tjernigan@ucsd.edu

The Pediatric Imaging Genomics project (PING) is a “Grand Opportunity” (GO) grant for an ongoing project conducted by investigators at 9 sites distributed throughout the U.S. The aim is to assemble, over a period of 2 years, a large, cross-sectional imaging-genomics dataset to be used as a shared resource.

This project will address the discrepancy between currently available imaging-genetics data in children of different ages and those available in adults. We are currently in the second year of the project. Data from the NIH Toolbox are currently available from over 500 typically developing children (ages 3 to 20).

Results thus far indicate that some of the available NIH Toolbox output variables are sensitive to developmental changes in performance as well as individual variability while other measures may be more sensitive to developmental changes in performance during early childhood with a relative plateau in performance in adolescence. Completion of the NIH Toolbox tests can be challenging for the youngest participants. We are anticipating the availability of scores for the Reading Recognition test as well as additional information about interpretation of NIH Toolbox scores.

### NIH Toolbox Accessibility and Usability ...continued from page 1

Our testing did reveal that some design features may affect participants’ performance and subsequent interpretation of results. Measures could be categorized into four broad groups based on their accessibility and ability to be implemented with accommodations.

1. **Measures inaccessible to some users:** Within the motor domain, endurance is measured using a 2-minute walk test. Therefore, we are currently unable to measure endurance among people who are non-ambulatory. Future research can seek to develop alternate measures.
2. **Measures inaccessible to some users in current form, but can be made accessible with reasonable accommodations in a nonstandard administration:** Emotional health is measured using patient reported outcome measures. Items are presented in written format one at a time on the computer screen. In its current format these measures are inaccessible to people with visual and reading impairments. A reasonable accommodation involves the administrator reading each item aloud. This accommodated version is considered a non-standard administration because reading sensitive items out loud may influence participant responses. Future NIH Toolbox development may seek to increase accessibility by providing an option for text to speech.
3. **Measures inaccessible to some users in current form, but can be made accessible with reasonable accommodations in a standard administration:** The olfaction measure asks participants to smell a scratch and sniff card and click a picture on the computer that corresponds to the scent. Participants who are unable to use their upper extremities may be unable to complete the measure independently but may direct the administrator to scratch the card, hold it to the participant’s nose and enter their response on the computer. In spite of the administrator’s involvement this would be considered a standard administration because the accommodation is not hypothesized to change the construct being measured.
4. **Measures accessible to users but in a way that was not intended by developers:** In the cognitive measure of processing speed, participants press the left arrow key if two pictures are the same and the right arrow if the two pictures are different. Scoring is based on both accuracy and speed. People with impaired upper extremity function, such as our participants with spinal cord injuries between the C5 and T1 levels, have functional but incomplete use of their arms and hands. Therefore while they may be able to depress the keys using the prescribed finger, the movement is often more complex and slower than isolated finger movement that was used in validation and norming. This category is perhaps the most challenging to identify and poses some of the greatest challenges to the interpretation of test scores.

## NIH Toolbox in the Acute Neurorehabilitation Setting

Principal Investigator: Victor William Mark, PhD  
University of Alabama – Birmingham  
vwmark@uab.edu

An important objective for NIH Toolbox research will be to determine how applicable it can be in hospital settings. In the inpatient rehabilitation environment, neurologic disorders are common as well as a major source of enduring disability and reason for admission. An unfortunate limitation for most general neurological assessments is that they are not comprehensive, while assessments that are tailored for one kind of neurologic disorder (such as stroke) may not translate well to other disabling neurologic disorders (such as spinal cord injury).

Because the hospital rehabilitation setting encounters a wide variety of neurological disorders, the NIH Toolbox could be valuable for comprehensively measuring broad neurological deficits across the various illnesses that are typically encountered. If such assessment were to become routine in rehabilitation hospitals, then the NIH Toolbox would provide a basis for gauging the severity of neurologic impairment across various hospitals (thus providing a way to stratify hospitals according to the severity of illnesses that they encounter), and assessing treatment outcomes.

The objective of our research is to evaluate the feasibility of NIH Toolbox testing for persons who are commonly encountered in the rehabilitation hospital. Not only do we enroll persons with known disabling neurological illness, but we also enroll inpatients who are not known to have brain disease, as a way to control for the aspects of hospitalization that could affect NIH Toolbox performance not directly attributable to brain disease effects, such as multiple medications, depression, being

confined away from home for extended periods, and common infections. We also enroll caregivers of our patients to provide normative data ranges for persons with similar socioeconomic background and ethnicity.

Our research is ongoing, but as of now we have enrolled about 100 participants. Only rarely have we found that persons declined to participate. Because rehabilitation inpatients are more often impaired in their locomotion than in cognitive, emotional, or sensory functions, we have found so far that few patients can (or are cleared to) comply with NIH Toolbox tests that stress the legs, particularly balance. In addition, because acutely hospitalized patients have new illnesses and are required to undergo 3 hours/ day of rehabilitation, they are often fatigued during NIH Toolbox testing, which as a result must be given in short amounts (typically 30 minutes per session), which in turn can extend the total amount of testing to close to 3 hours. On the other hand, our preliminary data review indicates that the NIH Toolbox is sensitive to brain illness, as predicted (J Int Neuropsychol Soc, in press). Brain illness patients perform significantly worse on NIH Toolbox tests than do healthy control subjects. Further data reviews are planned to determine to what extent persons with brain illness differ from patients without brain illness on the NIH Toolbox assessments.

Although adjustments must be made for NIH Toolbox testing in the inpatient setting, particularly with the amount of time that a patient can undergo testing at a single session, the high rate of compliance indicates good prospects for the NIH Toolbox to become a standard clinical and research tool for evaluating acutely hospitalized persons with neurological disorders.

## Steering Committee

Richard Gershon, PhD, PI  
Northwestern University

Thomas Bleck, MD  
Rush University Medical Center

David Cella, PhD  
Northwestern University

Susan Coldwell, PhD  
University of Washington

Pamela Dalton, PhD, MPH  
Monell Chemical Senses Center

Sureyya Dikmen, PhD  
University of Washington

Winnie Dunn, PhD, OTR  
University of Kansas

Nathan Fox, PhD  
University of Maryland

Richard Havlik, MD, MPH  
Westat, Inc.

Robert Heaton, PhD  
University of California - SD

Hugh Hendrie, MB, ChB, DSc  
Indiana Univ./Purdue Univ.

Dan Mungas, PhD  
University of California-Davis

Cindy Nowinski, MD, PhD  
Northwestern University

Paul Pilkonis, PhD  
University of Pittsburgh

David Reuben, MD  
University of California-LA

Rose Marie Rine, PhD, PT  
University of North Florida

W. Zev Rymer, MD, PhD  
Rehabilitation Institute of Chicago

David Tulskey, PhD  
University of Michigan

Rohit Varma, MD, MPH  
University Southern California

Molly Wagster, PhD  
National Institute on Aging

Margaret Wallhagen, PhD  
University of California-SF

Sandra Weintraub, PhD  
Northwestern University

Steven Zecker, PhD  
Northwestern University

### CONFERENCE PRESENTATIONS IN 2011

American Academy of Neurology  
Thomas P. Bleck, MD FCCM, April 9–16, 2011

Symposium at Society for Research on Child Development  
Kathleen Wallner- Allen, PhD et al, March 31, 2011