NIH Toolbox: Standardized Measures for Assessing Cognitive, Emotional, Motor and Sensory Function

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For more information, please visit www.nihtoolbox.org
Goals

• Describe the need for common measures.

• Increase awareness of five National Institutes of Health common measures initiatives.

• Provide an overview of how cognitive, motor, emotional, and sensory function are assessed using the NIH Toolbox measures.
Disclosures

• NIH Toolbox figures, photos, and information in this presentation are used with permission from Dr. Richard Gershon, PI NIH Toolbox.

• The information presented reflects the view of Dr. Susan Coldwell and is not necessarily the view of the National Institutes of Health.

• Dr. Coldwell served as the project lead for gustatory measure development for the NIH Toolbox.
Progress of Clinical Research

- Single-site studies under a single investigator
- Multi-site studies led by a team of investigators
- Aggregation of data across many studies
Aggregation of Data Requires

- Standardized measures
- High inter-examiner reliability
- Value is dependent on good validity
Examples of Standardized Measures in Dentistry

• International Caries Detection and Assessment System (ICDAS)
  www.icdas.org

• Research Diagnostic Criteria for Temporomandibular Disorders (RDC-TMD)
  www.rdc-tmdinternational.org
Demonstrated reliability and validity plus widespread use
• Demonstrated sensitivity to change in a clinical situation
• Endorsed by an authoritative body or consortium of scientists
National Institutes of Health Measurement Initiatives

- PhenX Toolkit (www.phenxtoolkit.org) funded by National Human Genome Research Institute (NHGRI)

- EXAMINER (http://examiner.ucsf.edu) funded by National Institute of Neurological Disorders and Stroke (NINDS)
NeuroQOL (www.neuroqol.org) funded by National Institute of Neurological Disorders and Stroke (NINDS)

PROMIS® (www.nihpromis.org) funded by NIH Common Fund

NIH Toolbox (www.nihtoolbox.org) funded by NIH Blueprint for Neuroscience
PhenX Toolkit

A repository for researchers for selection of “high-priority measures” and “recommended protocols” for use in genome-wide association studies and other genomics studies.
PhenX Toolkit

• 21 Domains assessed including oral health

• 339 measures in the PhenX Toolkit
PhenX Toolkit
Criteria for Selection

Quoted verbatim from www.phenxtoolkit.org

- Clearly defined
- Well established
- Broadly applicable and generally accepted
- Low burden to participants and investigators
- Broadly validated and demonstrated utility
- Reproducible
- Specific
- Reliable
- Standard measurement protocols exist
## PhenX - Oral Health Measures

<table>
<thead>
<tr>
<th>PhenX Measure</th>
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<tbody>
<tr>
<td>Oral Hygiene</td>
</tr>
<tr>
<td>Malocclusion</td>
</tr>
<tr>
<td>Periodontal Disease</td>
</tr>
<tr>
<td>Dental Fluorosis</td>
</tr>
<tr>
<td>Consumption of Sweet Beverages</td>
</tr>
<tr>
<td>Dental Caries</td>
</tr>
<tr>
<td>Oral Mucosal Lesions</td>
</tr>
<tr>
<td>Tobacco (not cigarette)</td>
</tr>
<tr>
<td>Professional Dental Care</td>
</tr>
</tbody>
</table>
• Test battery for executive function (ability to engage in goal-oriented behavior)

• For wide range of ages

• For wide range of disorders
NeuroQOL

- Consists of self-report measures for adults and children with neurological disorders
- Intended for clinical trials, observational research, and epidemiological surveys
NeuroQOL Item Banks

• Physical Health
  (Mobility, Fine Motor, Fatigue, Sleep)
• Social Health
  (Social Roles & Activities)
• Emotional Health
  (Depression, anxiety, stigma, well-being)
• Cognitive Health
  (General Concerns, Executive Function)
• Patient Reported Outcomes Measurement Information System

• Measures health-related quality-of-life through patient reported outcomes

• Assesses impact of disease and treatment on the patient
PROMIS®

• Adult and Pediatric Item Banks

• Domains include
  • Physical Health (e.g., Pain, Fatigue)
  • Mental Health (e.g., Depression, anger)
  • Social Health (e.g., emotional support, relationships)
NIH Toolbox

• Intended to measure variation in healthy populations
• Includes both self-report and direct assessment
• Covers sensory function in addition to emotion, cognition, and motor
• Intended to be used as a comprehensive battery
## Comparison

<table>
<thead>
<tr>
<th></th>
<th>NIH Toolbox</th>
<th>PROMIS</th>
<th>NeuroQOL</th>
<th>EXAMINER</th>
<th>PhenX</th>
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</thead>
<tbody>
<tr>
<td>Population</td>
<td>General</td>
<td>Patients</td>
<td>Neurology</td>
<td>Neurology</td>
<td>General and Specific</td>
</tr>
<tr>
<td>Cognition</td>
<td>Direct Assessment</td>
<td>Self-Report</td>
<td>Self Report</td>
<td>Direct Assessment</td>
<td>Direct Assessment</td>
</tr>
<tr>
<td>Motor</td>
<td>Direct Assessment</td>
<td>Self-Report</td>
<td>Self Report</td>
<td>- - -</td>
<td>Direct Assessment &amp; Self Report</td>
</tr>
<tr>
<td>Sensation</td>
<td>Direct Assessment</td>
<td>Self-Report</td>
<td>Self Report</td>
<td>- - -</td>
<td>Direct Assessment &amp; Self Report</td>
</tr>
</tbody>
</table>

*Table adapted from NIH Toolbox presentation by Claudia Scala Moy, PhD (National Institute for Neurological Disorders and Stroke), September 10, 2012, Bethesda, MD*
Built Over Six Years

- 2006 contract awarded (Richard Gershon, PI)
- 2007 identification of comprehensive domains and instrument selection criteria
- 2008 instrument development
- 2009 Spanish translation and field testing
- 2010 validation studies
- 2011 norming study with N = 4,705 subjects, English and Spanish, ages 3-85, 1-week retest (N = 500)
- 2012 final instrument roll out with norms
Final Toolbox

- Four 30-minute domain-level batteries
- English and Spanish versions
- Normed for ages 3-85
Toolbox Domains

- Cognition
- Emotion
- Motor
- Sensation
Cognition Areas of Focus

- Executive Function/set shifting
- Executive Function/attention
- Working Memory
- Episodic Memory
- Language
- Processing Speed
Subdomain: Executive Function-Set Shifting
NIHTB Dimensional Change Card Sort Test (DCCS)

Capacity to shift strategy based on instruction

Task: Sort by color; sort by shape; shift according to instructions; 3 sets of trials – shape, color, mixed
Subdomain: Executive Function/Attention
NIHTB Flanker Inhibitory Control and Attention Test

Capacity to focus on relevant information and ignore irrelevant information.

Task: Indicate the direction of a central target flanked by foils in the same (congruent) and opposite (incongruent) orientations
Subdomain: Working Memory
NIHTB List Sorting Working Memory Test

Capacity to process information and hold and manipulate information in a short-term buffer.

Task: List sequentially presented test items in order of size (and within categories, when more than one); establishes working memory span

“Apple” “Cat” “Watermelon” “Bear” “Pumpkin” “Lemon”
Subdomain: Episodic Memory
NIHTB Picture Sequence Memory Test

Capacity to remember events in sequence.

Task: Replicate spatial placement of a previously demonstrated sequence of pictures
Capacity to translate thought into symbols.

Task: Point to/click on picture that shows meaning of the word (picture-word-word matching)

“BABY”
Subdomain: Language
NIHTB Oral Reading Recognition Test

Single words/letter oral reading; may serve as proxy for quality of education

Task: Name letters, read aloud single words

abate
Amount of information processed within a certain time.

Task: Decide as quickly as possible if two items are the same or not
Emotion Domain

Emotion

- Psychological Well-Being
  - Positive Affect
  - Life Satisfaction
  - Meaning & Purpose
    - Positive Social Development

- Social Relationships
  - Social Support
  - Companionship
  - Social Distress

- Stress & Self-Efficacy
  - Perceived Stress
  - Self-Efficacy

- Negative Affect
  - Fear
  - Sadness
  - Anger
Emotion Domain

• Self or Parent Report
• Age - Appropriate Versions
  • Adult (over 18)
  • 13-17
  • 8-12
  • 3-7
• Uses computer adaptive testing or fixed forms (employs item response theory)
Motor Domain Framework

Motor

- Dexterity
- Strength
- Balance
- Locomotion
- Endurance
Dexterity is a central component of hand function.

NIH Toolbox 9-Hole Pegboard Dexterity Measure

- 1 practice and 1 test trial per hand.
- Raw Score: Time in seconds to complete 1 trial
Strength

Strength is central to the ability to move against gravity and provide enough force movements with or without resistance.

NIH Toolbox Grip Strength Measure

- Adapted from protocols from the American Society of Hand Surgery
- 1 sub-maximum practice and 1 test trial per hand
- Raw Score: Grip force in pounds
Balance allows people to orient their body in space and maintain an upright posture under a variety of conditions.

NIH Toolbox Standing Balance Measure

- Uses accelerometer and Bluetooth technology to measure postural sway
- 5 different static standing conditions
- Raw Score: Not provided
Locomotion

Gait speed is a component of locomotion.

NIH Toolbox 4-Meter Gait Speed Test

- Based on the 4m walk test protocol from the Short Physical Performance Battery
- 2 trials, usual pace
- Raw Score: Time in seconds to walk 4-meters at usual pace
Cardiopulmonary and muscle endurance are important components of physical fitness.

NIH Toolbox 2-Minute Walk Test

- Adapted from the American Thoracic Society’s 6-Minute Walk Protocol.
- Raw Score: Distance in feet and inches walked in 2 minutes.
Sensation Domain: Teams

Vision

Olfaction

Audition

Vestibular

Gustation

Somatosensation
**Definition**

The ability to detect sound and use it functionally.

**Toolbox Measures**

**Words-In-Noise** (WIN): English version (*Wilson, 2003*) and Spanish version (*McArdle et al, 2009*)

- monosyllabic, high-frequency words (e.g., red, mouse)
- 7 signal-to-babble ratios (multi-talker)
- ears tested separately, randomized order
Vision

Definition
Sense of light-derived stimuli that provides a personal conscious representation of the environment.

Toolbox Measure
Static Visual Acuity (SVA) – central visual acuity, computerized test
Dynamic Visual Acuity

**Visual acuity**
- head stable
- head rotating L, R @ 180 deg/sec
- score = static – dynamic acuity “level”

**Rate of movement**
- accelerometer, on head band – controls for correct rate

DVA headgear – rate sensor attached to headband
Standing Balance Test

Measures sway velocity – 6 conditions (45 seconds trial)

Eyes open / closed on solid floor or 4” foam pad; tandem stance
# Micro-encapsulated Odor Identification Tests

## Toolbox Measure
Odor identification test – scored as the percent of correctly identified odors.

<table>
<thead>
<tr>
<th>Child Version</th>
<th>Adult Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Lemon</td>
<td>All items in child version plus</td>
</tr>
<tr>
<td>• Play Doh</td>
<td>• Coffee</td>
</tr>
<tr>
<td>• Chocolate</td>
<td>• Smoke</td>
</tr>
<tr>
<td>• Bubble Gum</td>
<td>• Natural Gas</td>
</tr>
<tr>
<td>• Popcorn</td>
<td>• Flower</td>
</tr>
<tr>
<td>(ages 3–9 years)</td>
<td>(ages 10–85 years)</td>
</tr>
</tbody>
</table>
Bubble Gum

Chocolate

Flower

Natural Gas
Gustation (Taste)

- 1 M NaCl (salt) and
- 1 mM Quinine HCl (bitter)

Presented by cotton swab to tongue tip, then whole mouth “sip, spit, and rinse”.

Strongest Sensation of Any Kind

- Very Strong
- Strong
- Moderate
- Weak
- Barely Detectable
- No Sensation at All
Preliminary Norming Data Reveal Declines in Gustation with Age

- Quinine Whole Mouth
- Salt Whole Mouth
- Quinine Tongue Tip
- Salt Tongue Tip
Somatosensation Pain Measures

**Toolbox Pain Intensity Measures**

*In the past 7 days, how would you rate your pain on average?*

**Adults:** 0-10 numerical rating scale

(0 = no pain, …, 10 = worst imaginable pain)

**Toolbox Interference Measures**

**Adults:** PROMIS Pain Interference Scale

**Children:** PROMIS Pediatric Pain Interference Scale
For more information visit

www.nihtoolbox.org

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