Goals of PROMIS

• Develop system of measures of patient–reported health status for physical, mental, and social well–being.
• Measure outcomes across chronic diseases and conditions
PROMIS Current (2012) Physical Health Banks

Physical Health

Adult
- Pain Behavior
- Pain Interference
- Fatigue
- Sleep Disturbance
- Sleep-related Impairment
- Physical Function
- Sexual Function

Pediatric
- Pain Interference
- Fatigue
- Upper Extremity
- Mobility
- Asthma Impact
PROMIS Current (2012) Mental Health Banks

Mental Health

Adult
- Anxiety
- Depression
- Anger
- Illness Impact Neg, Pos
- Applied Cog – Concerns, Abilities
- Alcohol Use, Consequences, Expectancies

Pediatric
- Anxiety
- Depression
- Anger
Measuring with Item Banks

• An item bank is a large collection of items measuring a single domain.
  • “Calibrated” on a common metric (arranged by difficulty)

• Any and all items can be used to provide a score for the domain that is being measured.
Qualities of High Quality Item Banks

• Questions are easy to understand
• Shared understanding across individuals
• Measure what you think it should measure
• To get there, utilize rigorous qualitative and quantitative methods
Qualitative Methods

- Definition of construct
- Identification of existing measures
- Patient focus groups
- Expert review/consensus/revision
- Cognitive interviews
- Cultural sensitivity and translatability
- Repeat as necessary
Quantitative Methods

- Large scale testing (500/item)
- Statistical analysis
  - Dimensionality
  - Differential Item Function
  - Fit to item response theory model (IRT)
- Final decisions about inclusion/exclusion
Many formats, one metric

- Short Forms
- Long Forms
- Computer Adaptive testing
Each measures a single domain (e.g. physical function, pain interference)
Example: PROMIS Item Bank for Measuring Physical Function

Covers the whole range of the domain

Items are “calibrated” (arranged by difficulty)
An Example Item Bank

Physical Function
Computer adaptive testing
An Example Item Bank
An Example Item Bank
An Example Item Bank
An Example Item Bank
An Example Item Bank
An Example Item Bank

Specified # of items
Specified level of precision

Continues

Low
High
Why bother?

- Reduce burden of responding
- Make room for measuring more domains

Max (Efficiency) = \frac{\text{precision}}{\# \text{ of items}}
One more advantage of PROMIS

Scores have inherent meaning

Mean = 50 (SD=10)

Low

50 ≈ Mean of U.S. Population

60 ≈ 1 SD > Mean of U.S.

40 ≈ 1 SD < Mean of U.S.

High

2010 US Census
Free, online data collection tool

Creates secure, study-specific websites for capturing participant data
NIH Toolbox
Assessment of Neurological and Behavioral Function
http://www.nihtoolbox.org
Toolbox Scope

- Multidimensional set of brief measures
  - assess cognitive, emotional, motor and sensory function
  - ages 3-85

- NIH Toolbox monitors neurological and behavioral function
  - over time
  - across developmental stages
Toolbox Strategy

- Uses existing measures where possible
  - Familiarity to research community
  - Avoid duplication of effort

- Develop novel measures where needed
Toolbox Methods

- Employs modern psychometric approaches and methods
  - Item Banking
  - CAT; Fixed-Forms
FOR A FAIR SELECTION 
EVERYBODY HAS TO TAKE 
THE SAME EXAM: PLEASE 
CLimb THAT TREE
Across the lifespan

- Battery Approach: Self or Parent Report
- Age - Appropriate Versions
  - Adult (over 18)
  - 13-17
  - 8-12
  - 3-7
Toolbox Domains

Sensation

Motor

Cognition

Emotion

Sensation

Motor

Cognition

Emotion
Toolbox Measures

- Four 30-minute domain-level batteries
- English and Spanish versions
- Fully normed for ages 3-85
- 108 instruments in total
Qualitative Standards

- Expert Survey of selection criteria (152 responses)
- Focus group interviews with patients
- Expert Interviews (44 interviews)
- Surveys to nominate and rank sub-domains and constructs
# Cognition Domain Framework

<table>
<thead>
<tr>
<th>Subdomain</th>
<th>NIH Toolbox Tests</th>
<th>Validation Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Function (Set Shifting)</td>
<td>NIHTB Dimensional Change Card Sort Test (DCCS)</td>
<td>DKEFS Measures, WCST</td>
</tr>
<tr>
<td>Executive Function/Attention (Visual, inhibitory)</td>
<td>NIHTB Flanker Inhibitory Control and Attention Test</td>
<td>NINDS EXAMINER Dot Count, WCST, Children’s Behavior Questionnaire</td>
</tr>
<tr>
<td>Working Memory</td>
<td>NIHTB List Sorting Working Memory Test</td>
<td>Wechsler Letter-Number Sequencing, PASAT</td>
</tr>
<tr>
<td>Episodic Memory</td>
<td>NIHTB Picture Sequence Memory Test</td>
<td>RAVLT Word List, Brief Visuospatial Memory Test-Revised, NEPSY Sentence Repetition</td>
</tr>
<tr>
<td>Language</td>
<td>NIHTB Picture Vocabulary Test NIHTB Oral Reading Recognition Test</td>
<td>Peabody Picture Vocabulary Test-4, Wide Range Achievement Test-4</td>
</tr>
<tr>
<td>Processing Speed</td>
<td>NIHTB Pattern Comparison Test</td>
<td>Wechsler Processing Speed Index</td>
</tr>
</tbody>
</table>
Language Subdomain: NIHTB Picture Vocabulary Test

• Task: Point to/click on picture that shows meaning of the word (picture-word matching)
• Total trials: CAT-administered (~25-30 items)
• Total time: 4 minutes

“BABY”
Emotion Domain Framework

- **Psychological Well-Being**
  - Positive Affect
  - Life Satisfaction
  - Meaning & Purpose

- **Social Relationships**
  - Social Support
  - Companionship
  - Social Distress
  - Positive Social Development

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

- **Negative Affect**
  - Fear
  - Sadness
  - Anger
Motor

- Dexterity
- Strength
- Balance
- Locomotion
- Endurance
Dexterity

- NIH Toolbox 9-Hole Pegboard Dexterity Measure
- 1 practice and 1 test trial per hand.
- Raw Score: Time in seconds to complete 1 trial
Sensation Domain

Vision

Olfaction

Audition

Vestibular

Gustation

Somatosensation
Audition (Hearing)

- 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)
  - Hearing tested separately in each ear, randomized order
Toolbox Particulars

- The measures do not have any licensing fees
- Some have equipment and supply costs.
- More information on the website http://www.nihtoolbox.org/WhatAndWhy/Materials/Pages/default.aspx
Publications

• Neurology Special Issue
  • highlights development and Validation Results for all Toolbox Domains Society for
• Research in Child Development Monograph
  • highlights pediatric use of the cognition battery
• Journal of the International Neuropsychological Society – 2013
  • Issue highlights adult use of the cognition battery
Quality
Efficient
Normed
Broad

NIH TOOLBOX
PROMIS