

# Person-Centered Outcome Instruments: PROMIS, Neuro-QOL, and NIH Toolbox

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NORTHWESTERN  
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# Patient-Reported Outcomes (PROs)

- Quantification of symptoms, functional status, perceptions of health
- Subjective and multi-dimensional

# Why ask patients?

- Best source of information
  - Symptoms or health-related quality of life (HRQL): pain, fatigue, distress
  - Impact of symptoms on continuing meaningful activities
  - Knowledge, attitudes, behavior
  - Satisfaction
- Same biological value in 2 pts  $\neq$  same impact
- Variability in correlation b/w clinician and pt reports
- HRQL scores (esp physical fx) predicts survival in many conditions<sup>1</sup>

<sup>1</sup>Hahn EA et al (2007) *Mayo Clin Proc*, 82, 1244-1254

# Carrots and Sticks for PROs

- Era of patient-centeredness



## Meaningful Use: Core Objectives

- 3<sup>rd</sup> level health IT meaningful use incentive program
  - CMS gathering info on PRO-based performance measures
- PCORI

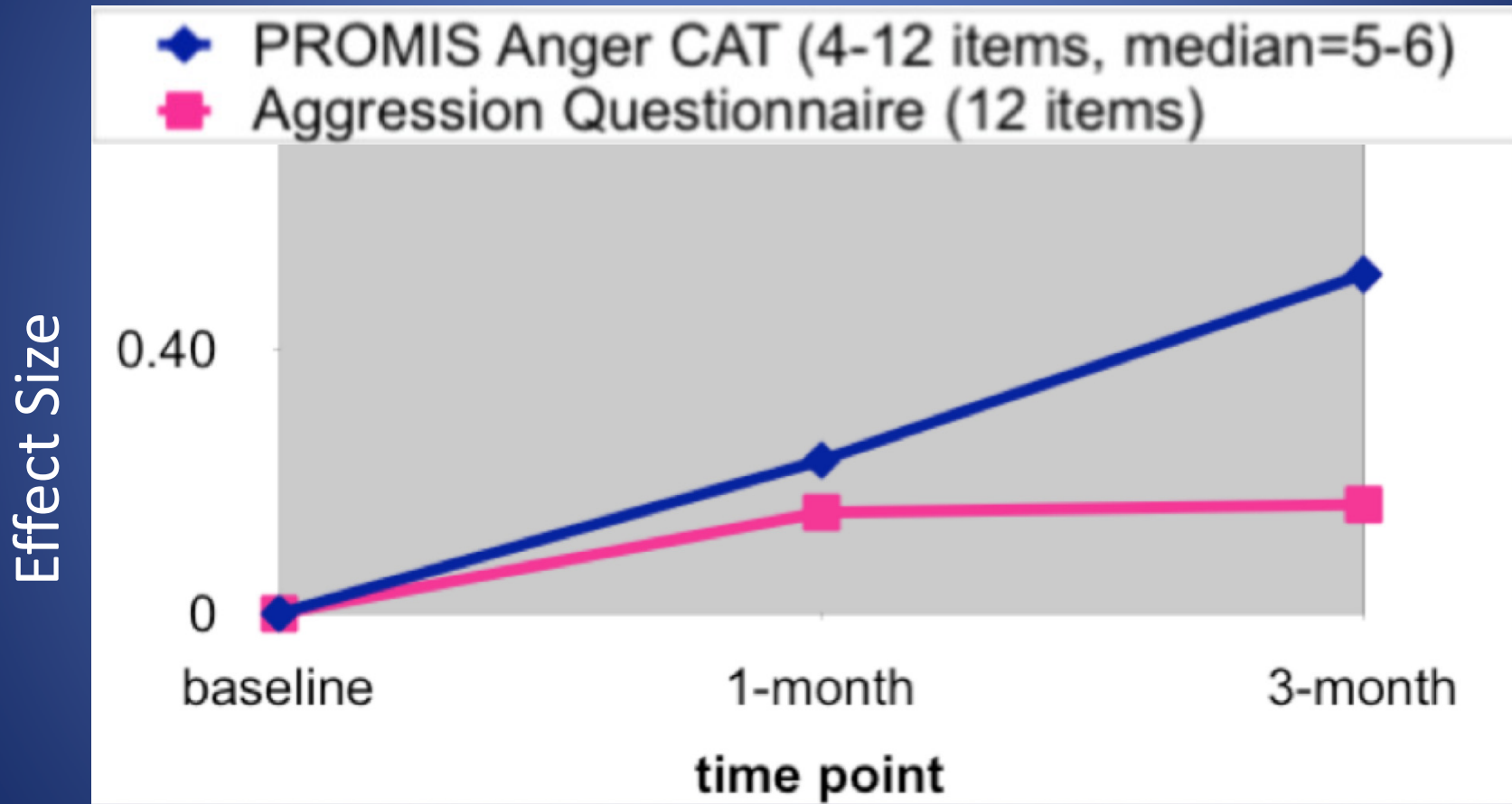
# Problems with PRO Measures

- Ceilings and floors



*Being John Malkovich*  
1999

# Measurement Ceiling



# Problems with PRO Measures

- Ceilings and floors
- Patient burden
- Royalties/costs
- Psychometric limitations
- Scores w/o interpretation guidelines



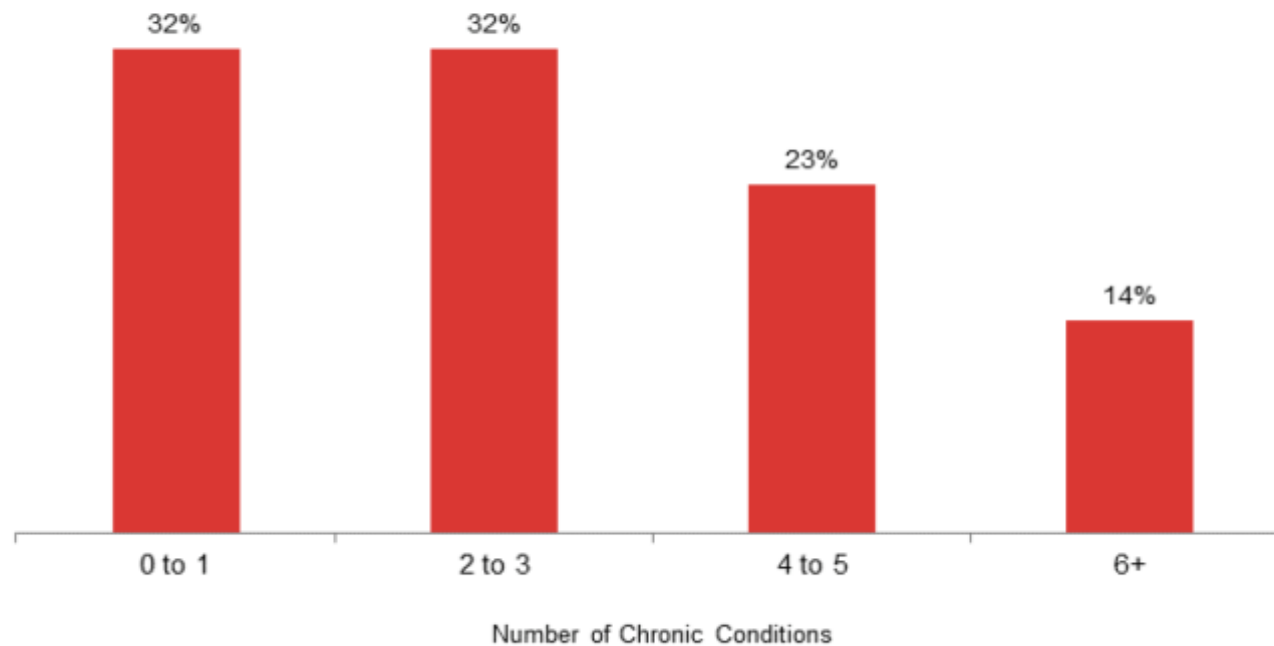
The image features two dark grey silhouettes of human heads facing each other against a background of orange gears. The left head contains a thought bubble with three red question marks. The right head contains a thought bubble with three red exclamation marks. Between them are two white speech bubbles with dashed black outlines. The top speech bubble contains the text 'WOMAC' and the bottom one contains 'SMFA'.

WOMAC

SMFA

# It is impractical to use disease-/condition-specific instruments

## Percentage of Medicare Beneficiaries with Multiple Chronic Conditions



Source: Centers for Medicare and Medicaid Services. Chronic Conditions among Medicare Beneficiaries, Chart book: 2012 Edition Baltimore, MD. 2012.



# New Measurement Initiatives

- Patient-Reported Outcomes Measurement Information System (PROMIS)



- Quality of Life in Neurological Disorders (Neuro-QOL)



- NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox)



# Approach to Measurement

- Non-disease/condition specific (universal)
- Domains of self-reported health
  - NIH Toolbox – also performance measures
- Item Response Theory
- State of the science mixed methods

## Desired Aims

- More widely applicable
- More sensitive
- More efficient

# PROMIS

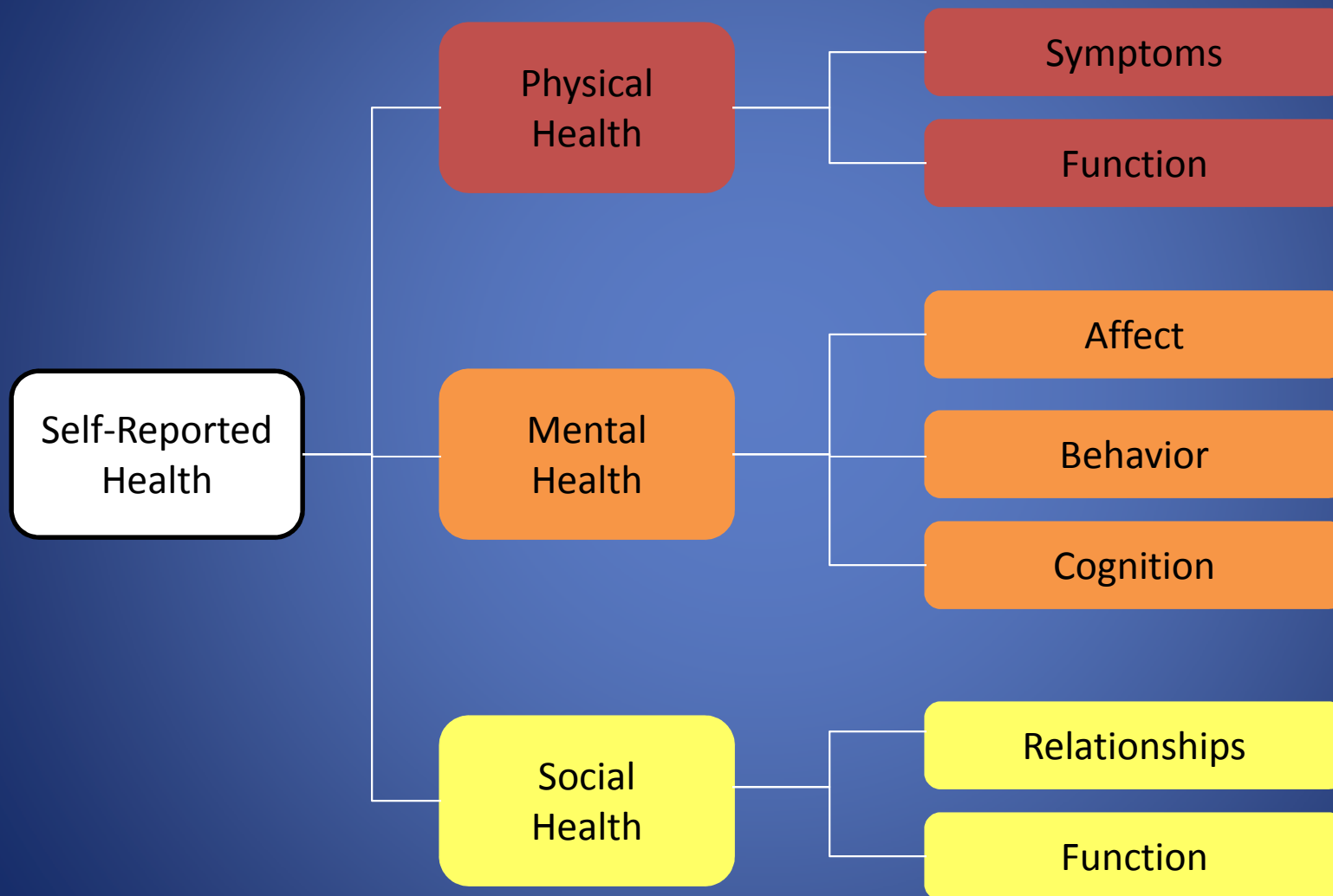
- Item banks – self report physical, mental, social health
- Use across chronic conditions
- Ages 8 – adult (self report). Age 5 proxy.
- CAT, short forms
- Link scores between measures



[www.nihpromis.org](http://www.nihpromis.org)



# PROMIS Domain Framework



# PROMIS Physical Health Item Banks

## Adult

Pain Behavior

Pain Interference

Fatigue

Sleep Disturbance

Sleep-related  
Impairment

Physical Function

Sexual Function

Pain Intensity

## Pediatric

Pain Interference

Fatigue

Upper Extremity

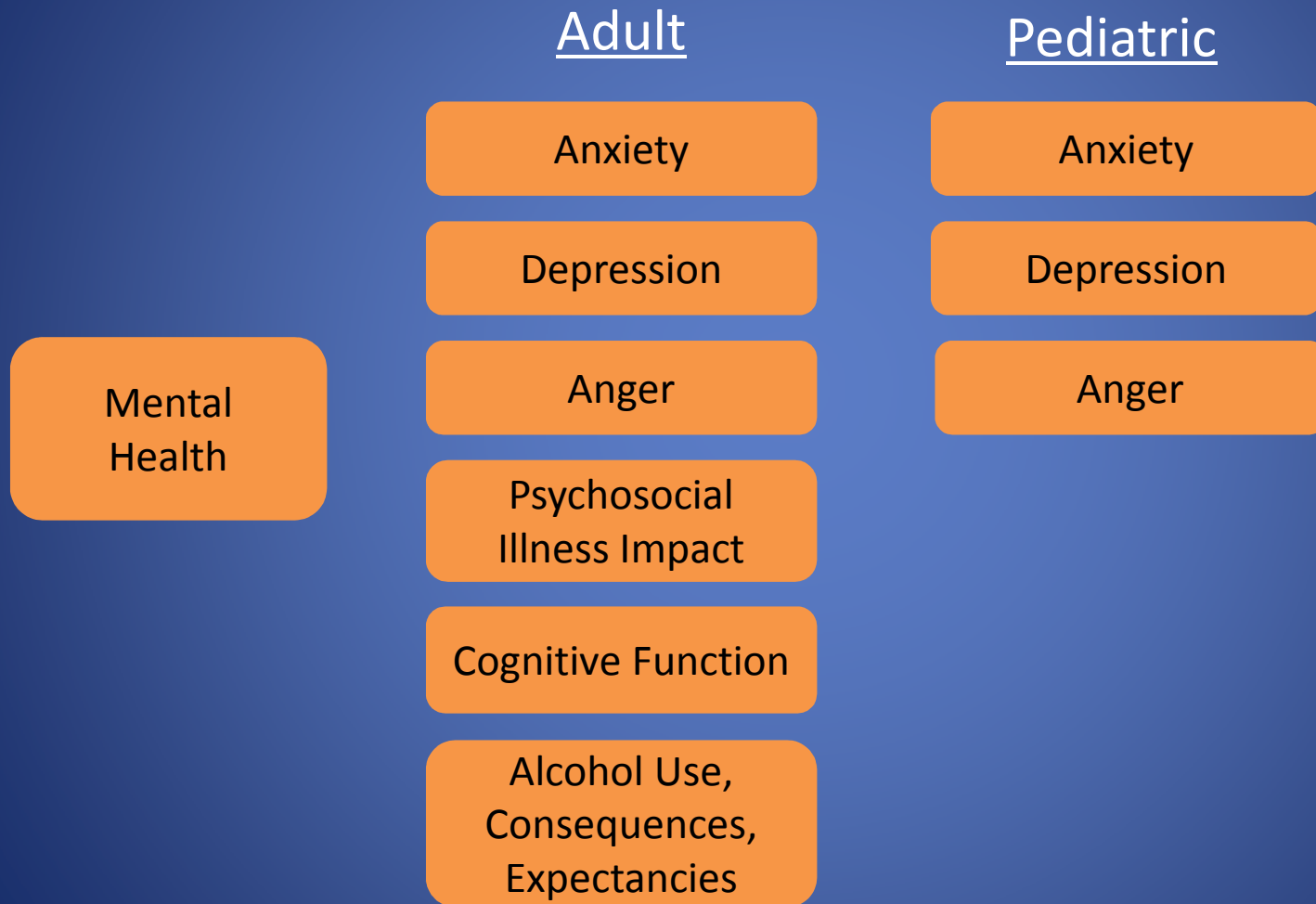
Mobility

Asthma Impact

Physical  
Health

\*Also in Spanish &  
other languages

# PROMIS Mental Health Item Banks



\*Also in Spanish & other languages

# PROMIS Social Health Item Banks

## Adult

Ability to  
Participate in Roles  
& Activities

Satisfaction with  
Roles & Activities

Companionship

Emotional Support

Informational  
Support

Instrumental  
Support

Social Isolation

## Pediatric

Peer Relationships

Social  
Health

\*Also in Spanish &  
other languages

# In Progress



- Adult
  - GI Symptoms
  - Self-efficacy for management of chronic disease
  - v2.0 Sexual Function
- Pediatric
  - Pain Behavior, Quality, Intensity
  - Physical Activity
  - Experience of Stress
  - Subjective Well-being
  - Impact of Child Illness on Family
  - Family Belongingness
  - Global Health

# PROMIS Pain Interference Short Form

**In the past 7 days...**

		<b>Not at all</b>	<b>A little bit</b>	<b>Somewhat</b>	<b>Quite a bit</b>	<b>Very much</b>
1	How much did pain interfere with your day to day activities? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2	How much did pain interfere with work around the home?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3	How much did pain interfere with your ability to participate in social activities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4	How much did pain interfere with your household chores?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5	How much did pain interfere with the things you usually do for fun? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6	How much did pain interfere with your enjoyment of social activities?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5



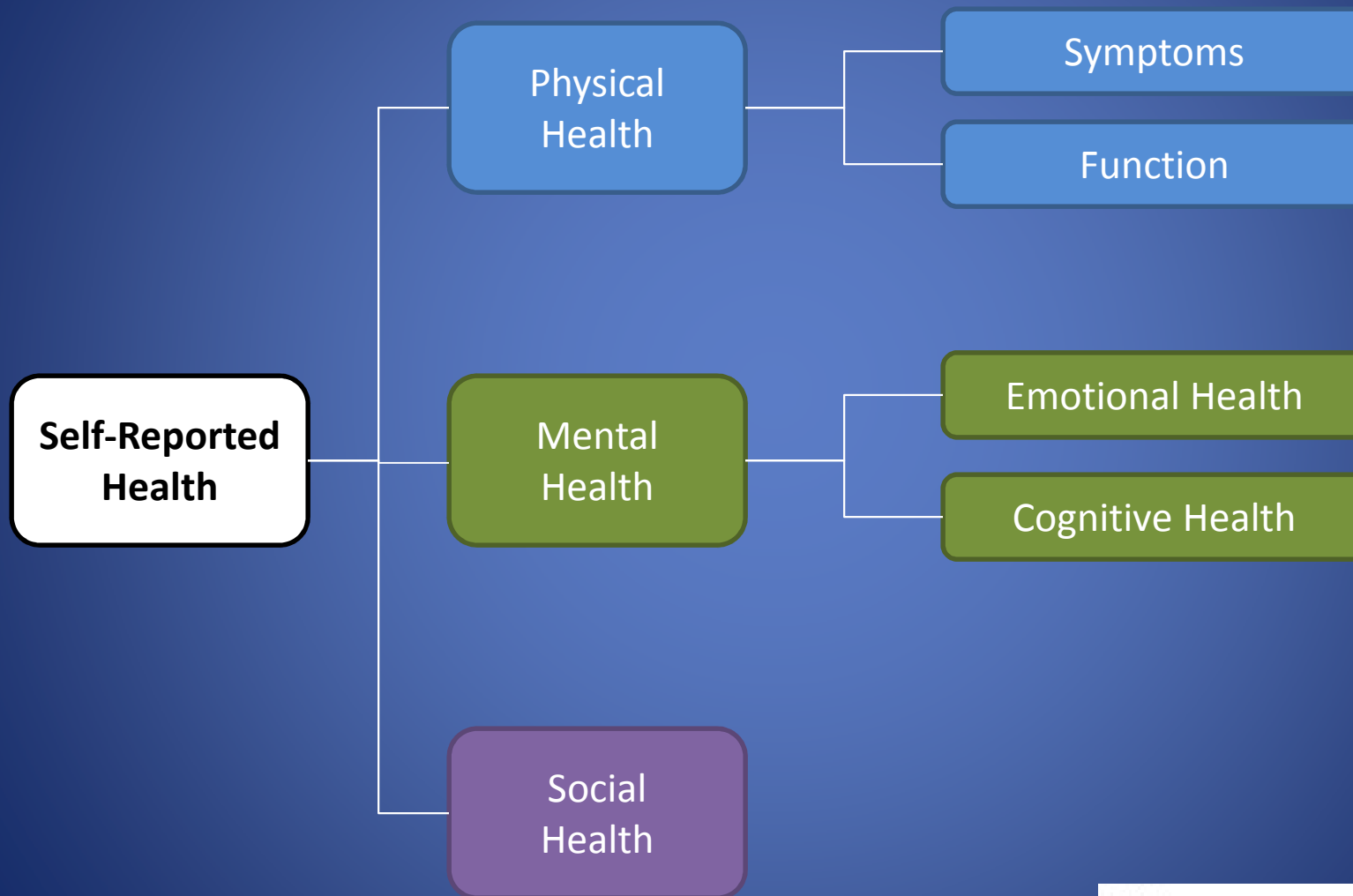
# PROMIS T-score

- Mean = 50
  - Standard Deviation = 10
- Referenced to the US General Population
- High scores = more of domain
- MIDs = 4-6 points (physical function)<sup>1</sup>

# Neuro-QOL

- Item banks – self report physical, mental, social health
- Supplemental domains specific to targeted diseases (e.g., stigma)
- Use in chronic neurologic conditions
- CAT, short forms
- Link scores

# Neuro-QOL Domain Framework



\*Also in Spanish

**Neuro•QOL**

# Neuro-QOL Physical Health Banks

## Adult

Fatigue

Sleep Disturbance

Upper Extremity

Mobility

## Pediatric

Fatigue

Pain

Upper Extremity

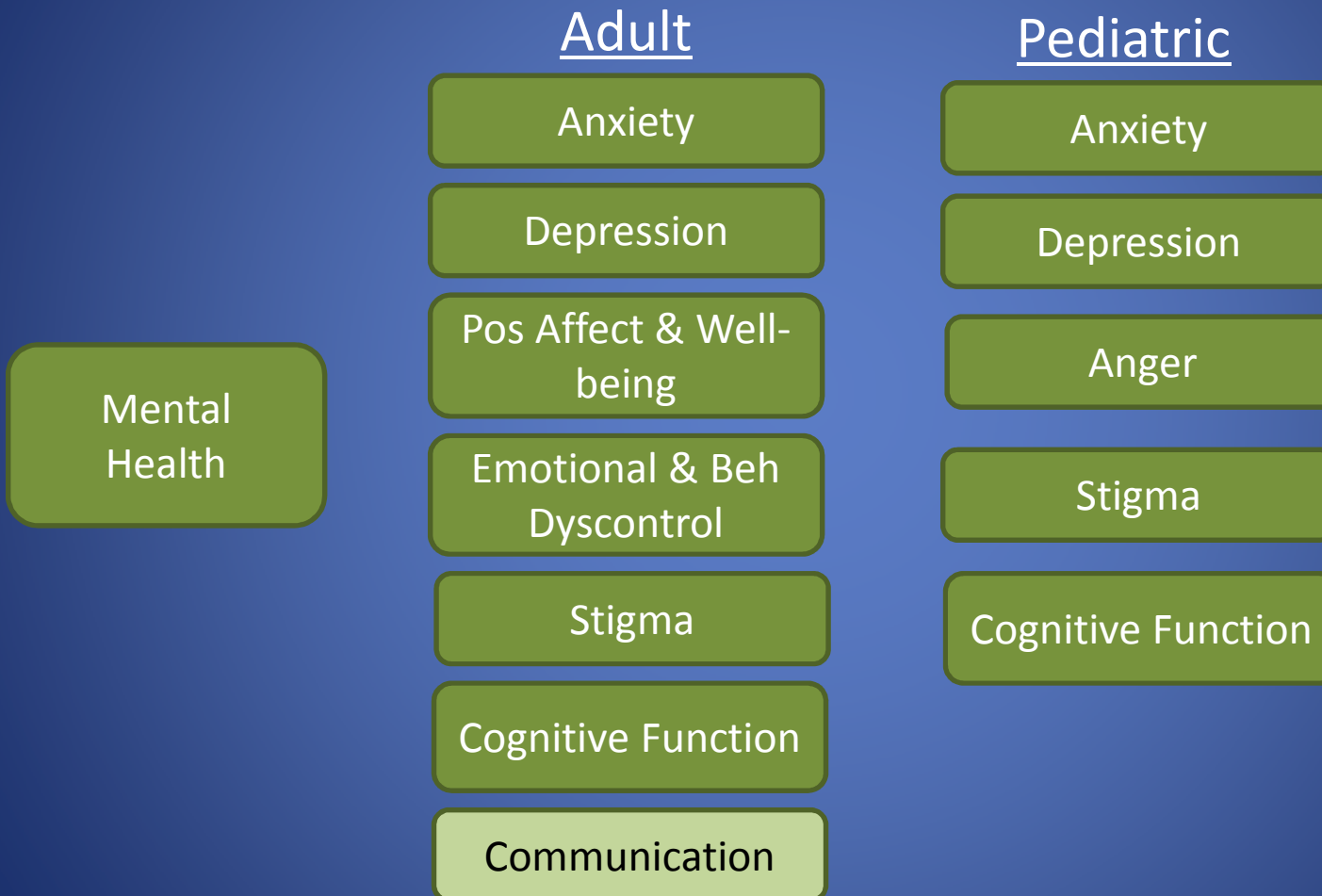
Mobility

Physical  
Health

\*Also in Spanish

**Neuro•QOL**

# Neuro-QOL Mental Health Banks



\*Also in Spanish

**Neuro•QOL**

# Neuro-QOL Social Health Banks

## Adult

Ability to  
Participate in Roles  
& Activities

Satisfaction with  
Roles & Activities

Social  
Health

## Pediatric

Interactions w  
Peers

\*Also in Spanish

**Neuro•QOL**

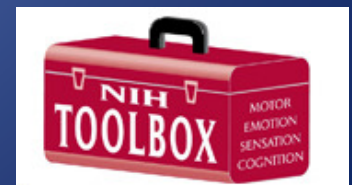
# Neuro-QOL T-score

- Mean = 50
  - Standard Deviation = 10
- Referenced to the US General Population or Clinical Population
- High scores = more of domain

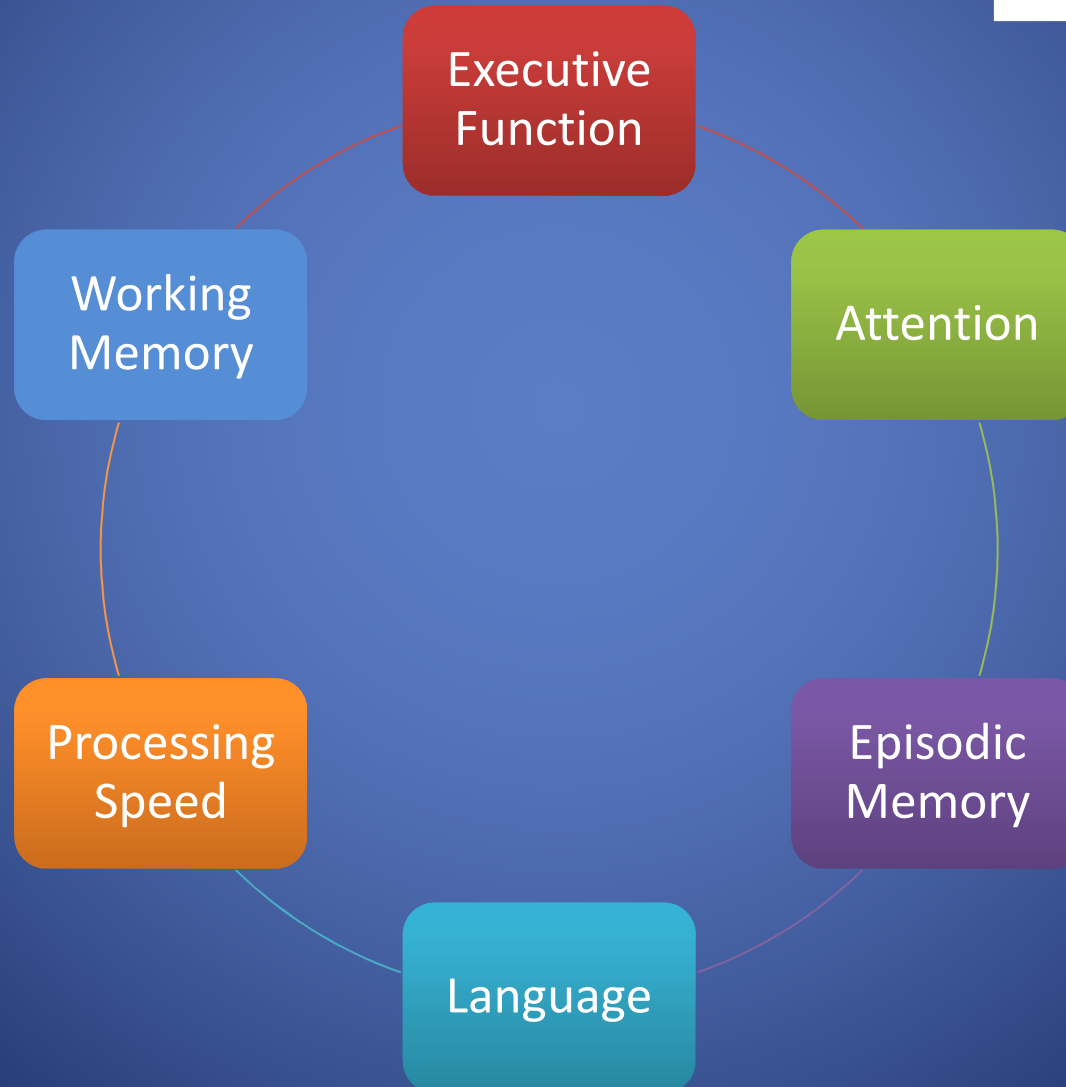
# NIH Toolbox

- Assessment of neurological and behavioral function
- Use across diverse populations
- Ages 3-85
- Batteries (CATs, short forms)
  - Cognition, Motor, Sensation, Emotion
- Objective tests and survey measures
- English and Spanish

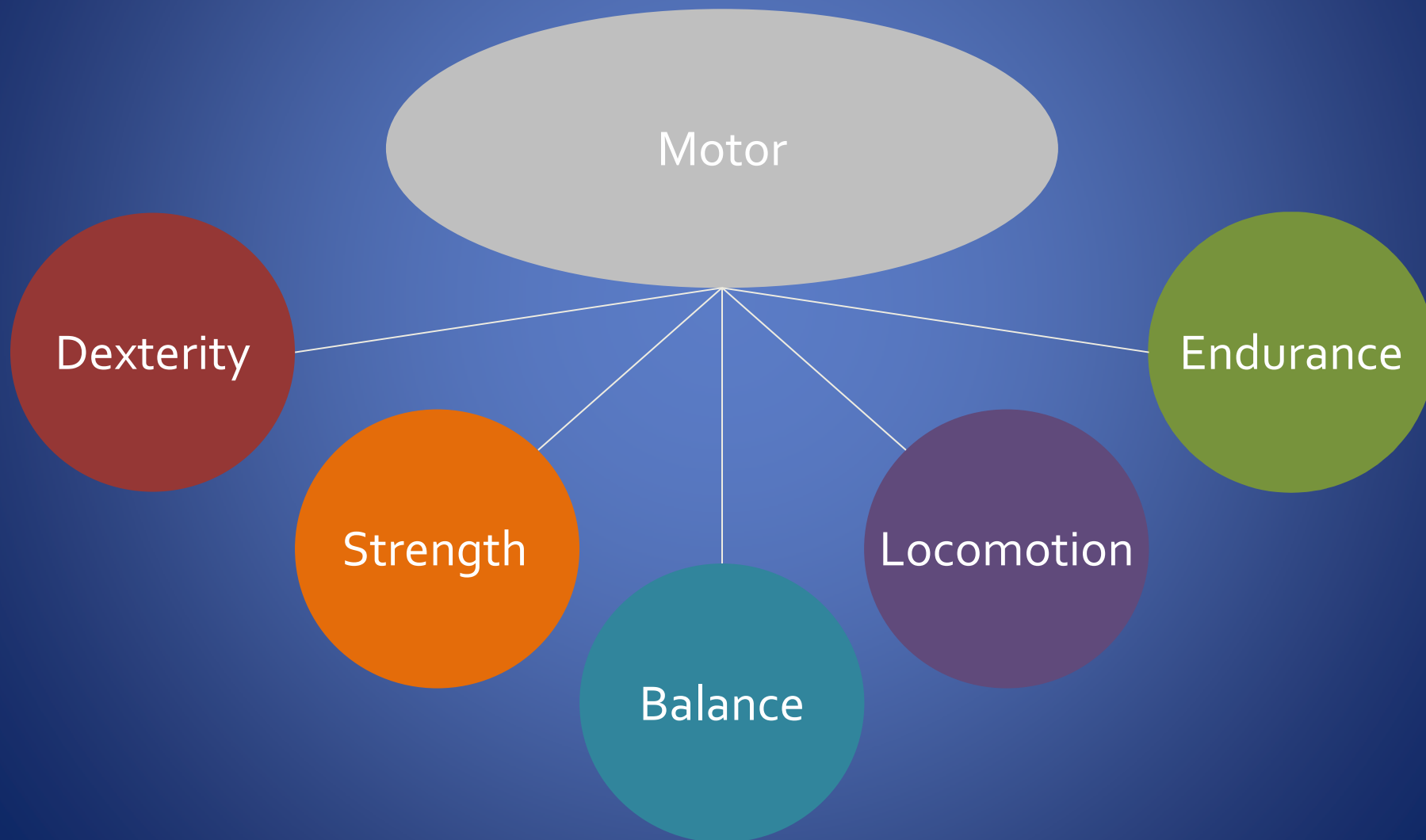
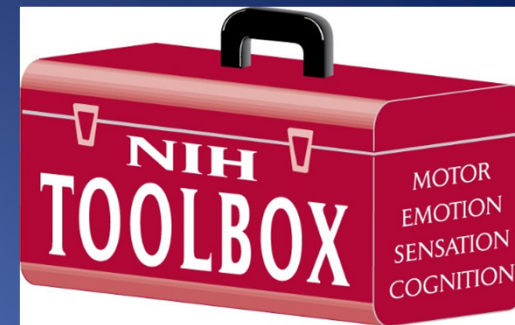
[www.nihtoolbox.org](http://www.nihtoolbox.org)



# Cognition Domains



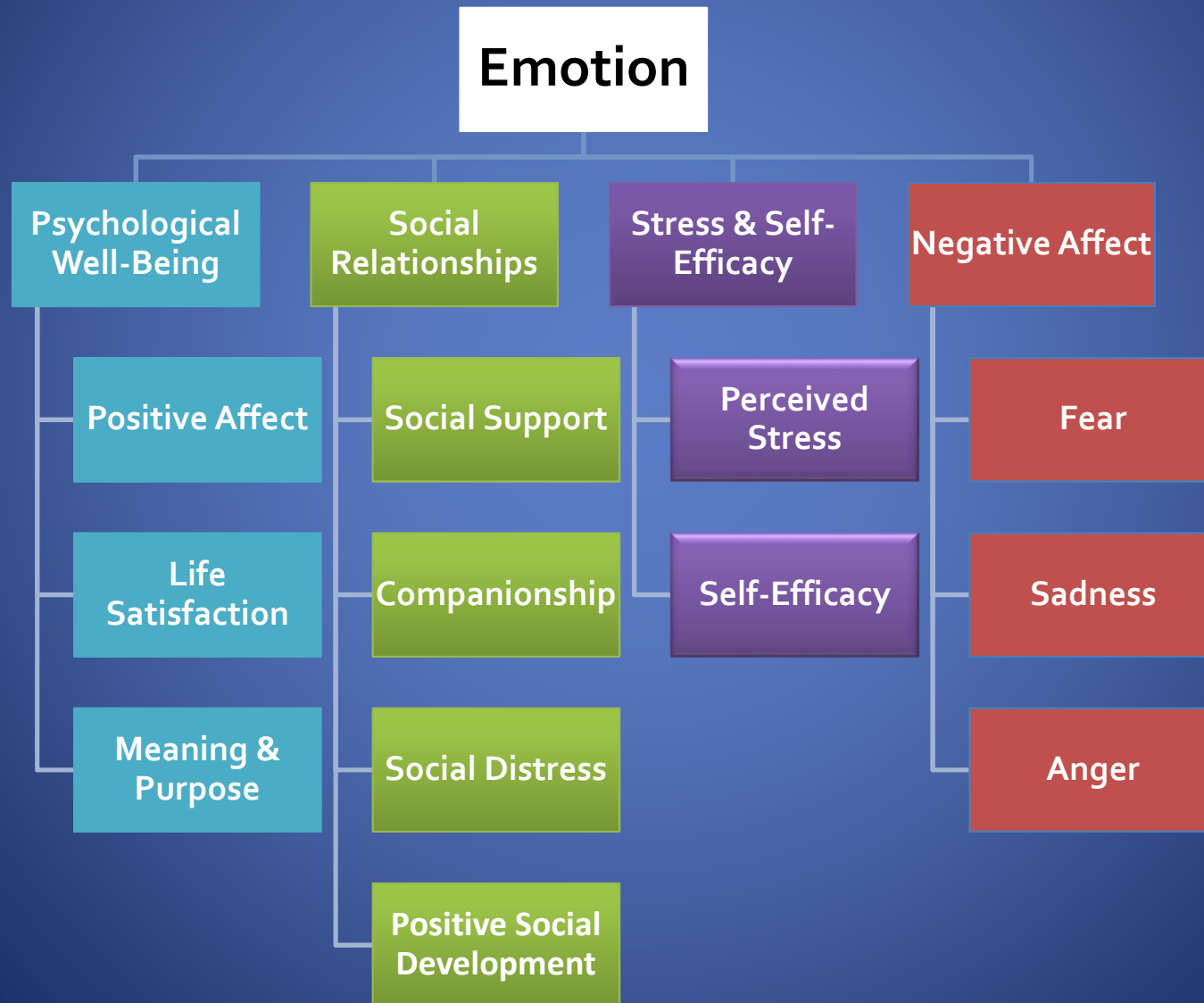
# Motor Domains



# Sensation Domains



# Emotion Domains



# NIH Toolbox Scores

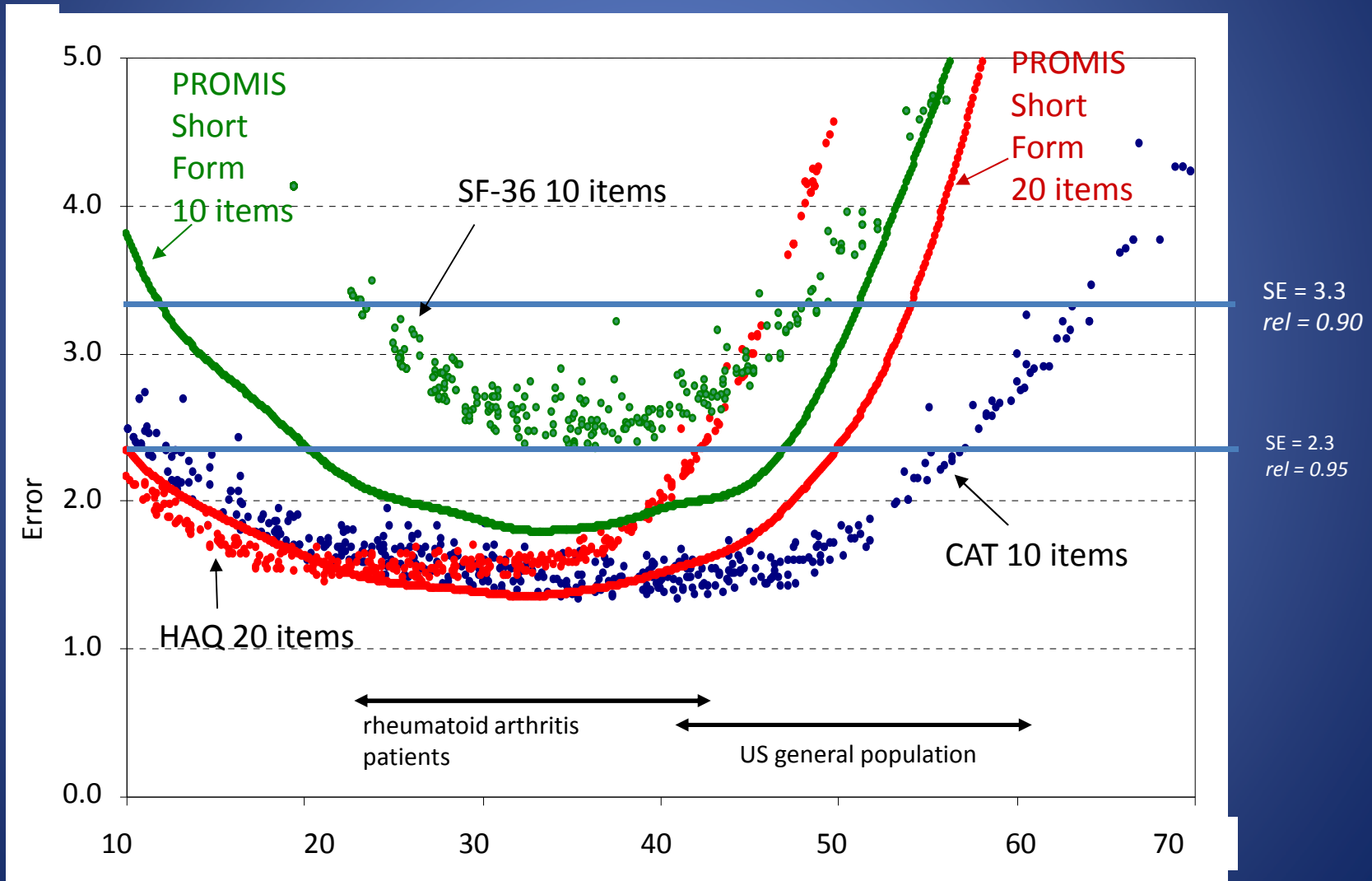
- PRO and Performance Measures
  - Mean = 100 (SD=15)
  - Unadjusted Scale Score
  - Age-adjusted scale score
  - Fully adjusted scale score
- PRO “Raw” scores also available to match PROMIS
  - T-score mean = 50 (SD=10)



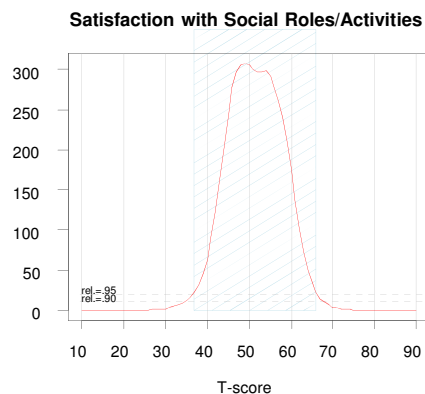
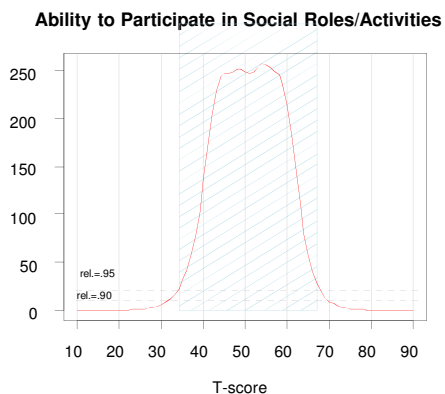
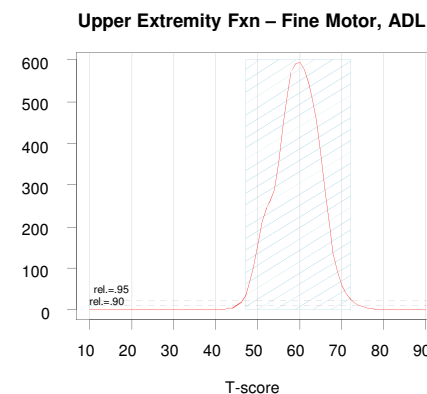
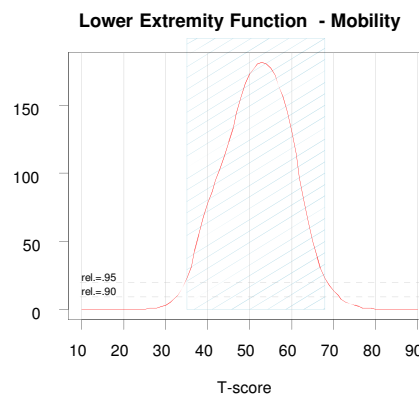
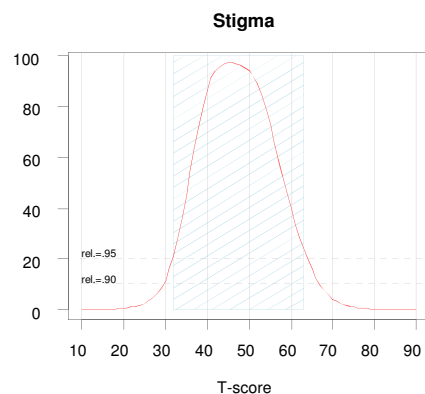
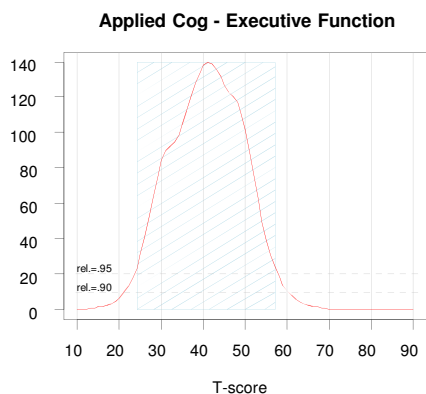
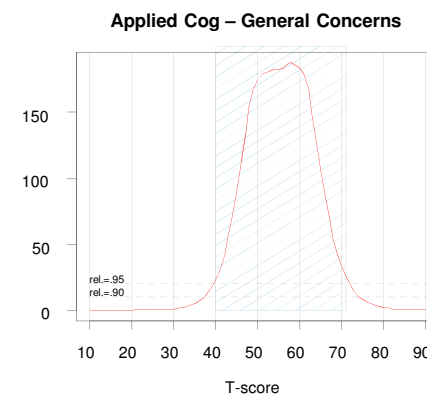
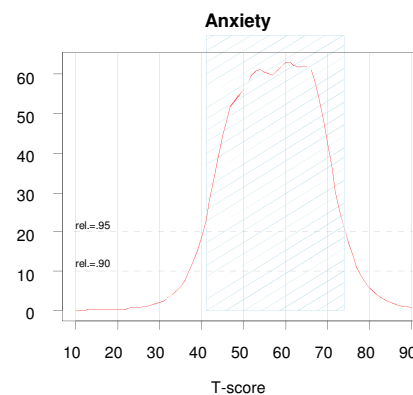
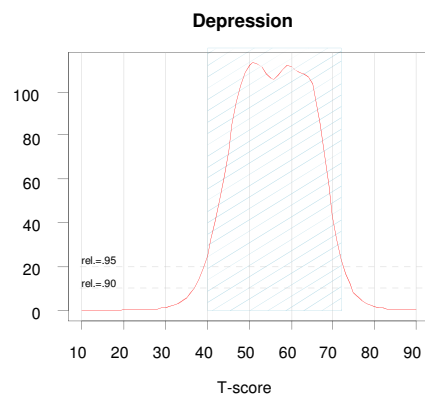
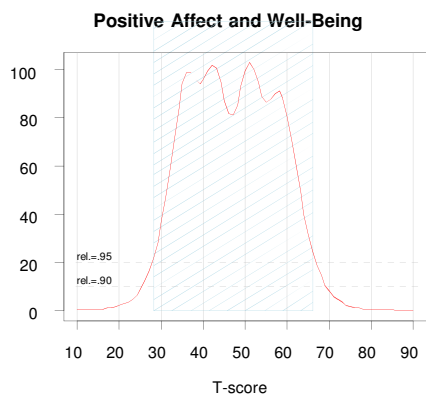
# Advantages to Newer Instruments

- Improved measurement
  - Increased power → reduced sample size
- Adaptability
- Low patient burden
- Comparability
- Royalty-free

# Physical Function Measurement Precision and Range



# NeuroQOL Adult Item Bank Information Functions



The shaded areas represent the effective measurement ranges where a reliability of roughly .95 is attainable.

# Measures of Responsiveness

- Effect size (ES) =  $\frac{\text{Mean change}}{\text{SD at baseline}}$

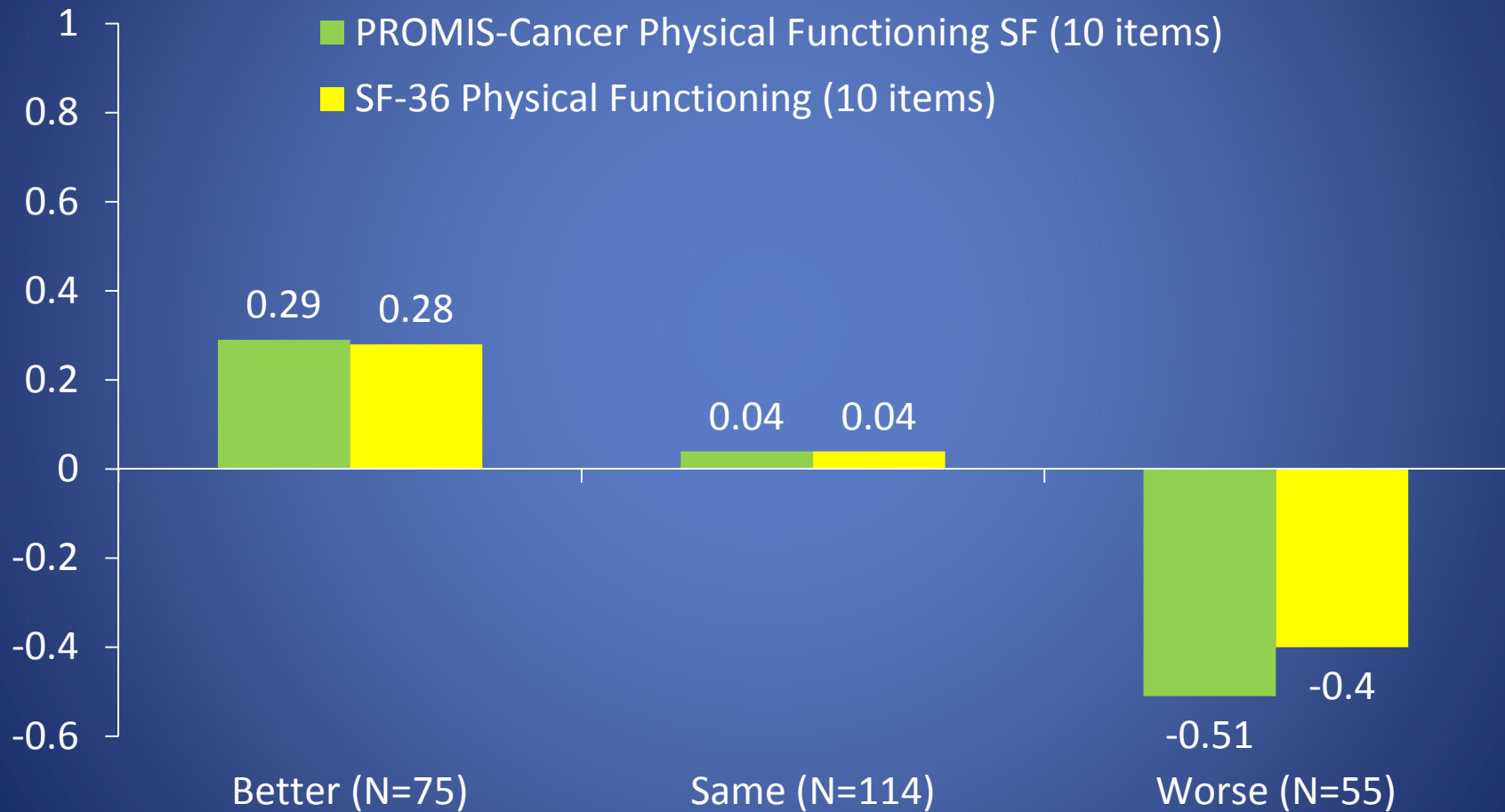
- Standardized response mean

$$(\text{SRM}) = \frac{\text{Mean change}}{\text{SD of change for the sample}}$$

- Responsiveness statistic

$$(\text{RS}) = \frac{\text{Mean change}}{\text{SD of change for group who did not change}}$$

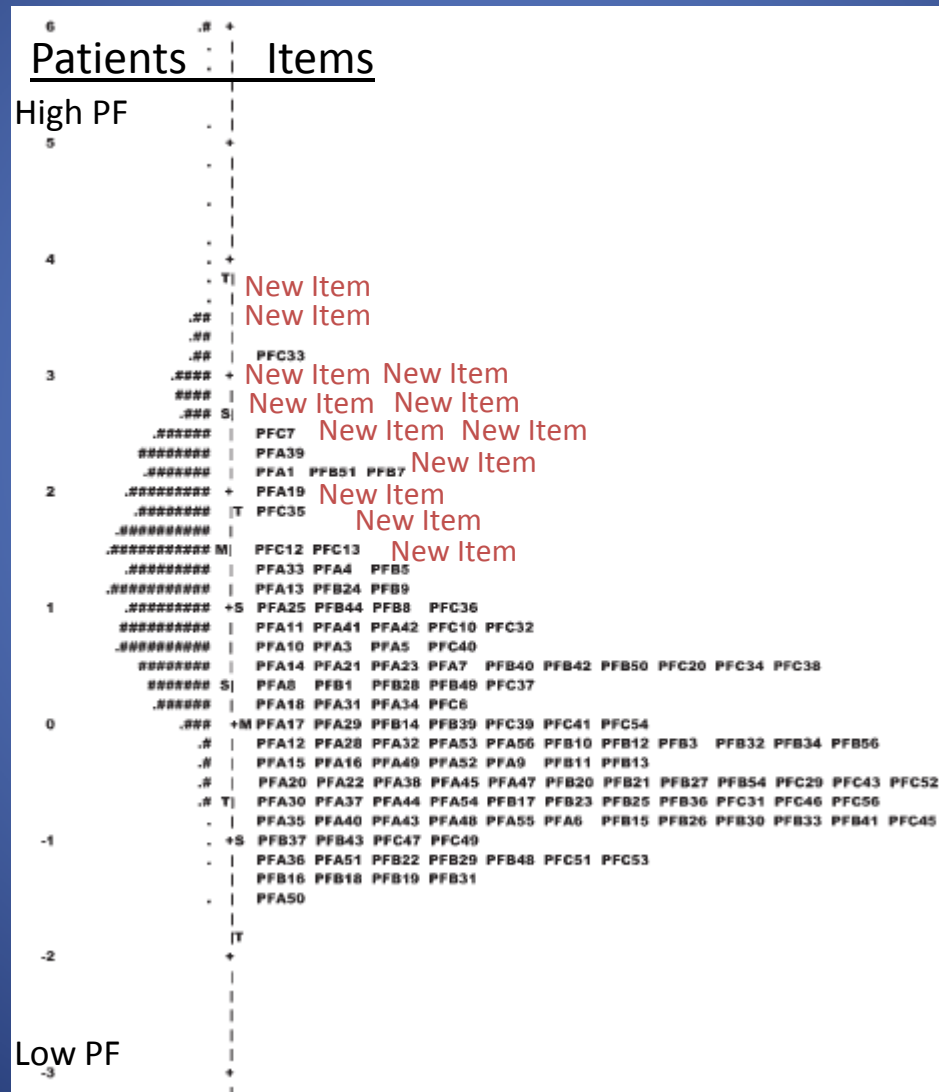
# Physical Function Responsiveness – Effect Sizes



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# Adaptability

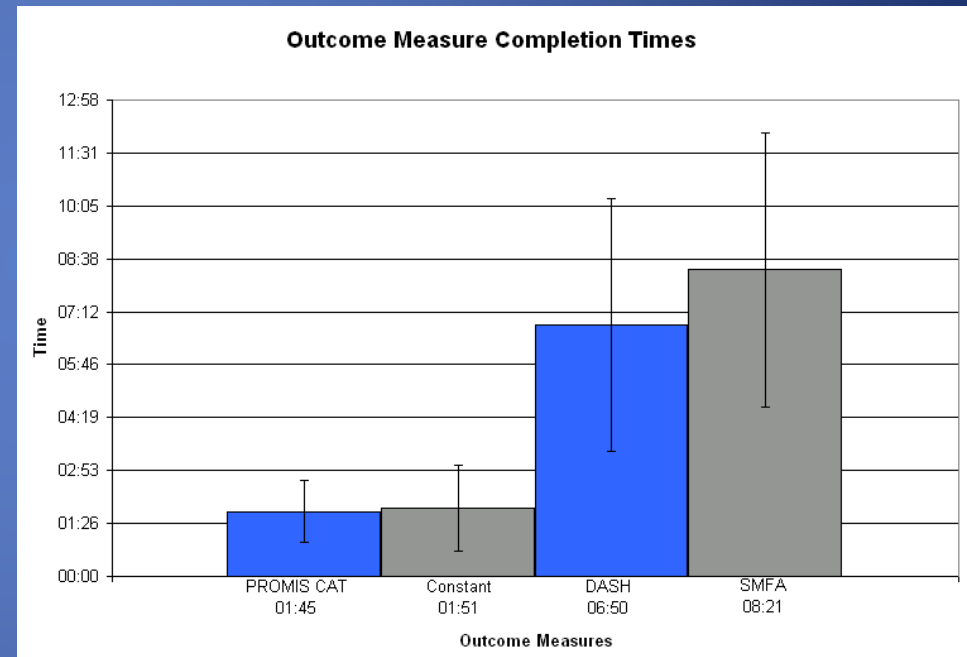


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# Fast Completion Times

- 66 seconds
  - Lower Extremity CAT
  - Patients scheduled for foot and ankle surgery<sup>1</sup>
- 98 seconds
  - Physical Function CAT
  - Proximal humerus fractures in patients > 60 years old<sup>2</sup>



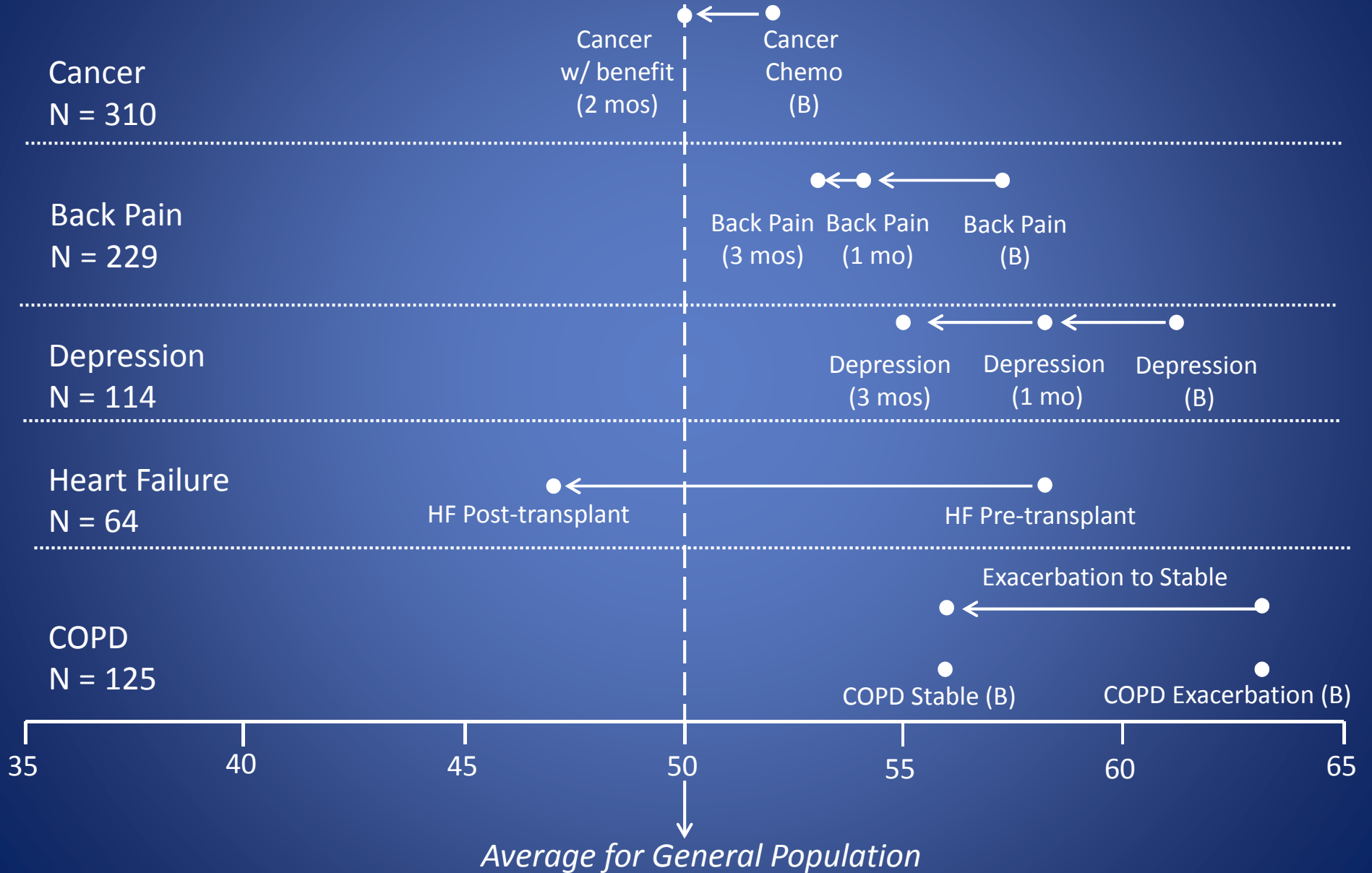
<sup>1</sup>Hung et al 2012

<sup>2</sup>Vrahas under review

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# PROMIS Fatigue Across Five Clinical Conditions



# PROsetta Stone



- Linking tables
  - Legacy instruments to PROMIS metric
- BPI, CES-D, FACIT, HAQ, SF-36, PHQ-9, etc
- [www.prosettastone.org](http://www.prosettastone.org)

SF-36/PF Score	PROMIS T-score	SE
10	24.5	4.0
11	28.3	2.8
12	30.3	2.5
13	32.0	2.2
14	33.4	2.1
15	34.8	2.0
16	36.0	2.0
17	37.2	2.0
18	38.4	1.9
19	39.5	1.9
20	40.7	1.9
21	41.8	1.9
22	42.9	1.9
23	44.1	2.0
24	45.2	2.0

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# How Do I Choose a Measure?

- Population
- Age
- Domains
  - See [definitions](#), review items
  - [PROMIS Scoring Manuals](#)
- Aims of measurement (e.g., screening, primary outcome)
  - Precision
- Completion time

# To Learn More

- [www.nihpromis.org](http://www.nihpromis.org)
- [www.neuroqol.org](http://www.neuroqol.org)
- [www.nihtoolbox.org](http://www.nihtoolbox.org)
- Video tutorials
- Publications
- Manuals

# Acknowledgements

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Thank you!