

Neuro-QoL ASCQ-Me

# An Introduction to PROMIS®

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## What is PROMIS®?

Patient-Reported Outcomes Measurement Information System®

- Over 300 measures used to evaluate and monitor physical, mental, and social health in adults and children
- Relevant across all conditions
  - General population
  - Chronic conditions
- Developed and evaluated using state-of-the science psychometric methods
- Scores on one metric
- Translations available in Spanish and 42 other languages





# Essential Components of PROMIS

#### **DOMAIN**

The feeling, function, or perception you wish to measure

Cuts across different diseases and settings. E.g., physical function, depressive symptoms



#### **ITEM BANK**

Collection of items that each measure the same domain

Used to create different measure types, all producing a score on the same metric





## PROMIS Measure Types

#### **SHORT FORMS**

- Subsets of item banks
- Focused on a single domain
- Off-the-shelf or custom
- Usually 4-10 items

#### COMPUTER ADAPTIVE TESTS (CATs)

- Individually tailored electronic questionnaires
- Focused on a single domain
- Next item administered from item bank depends on previous answers
- Usually 4-12 items

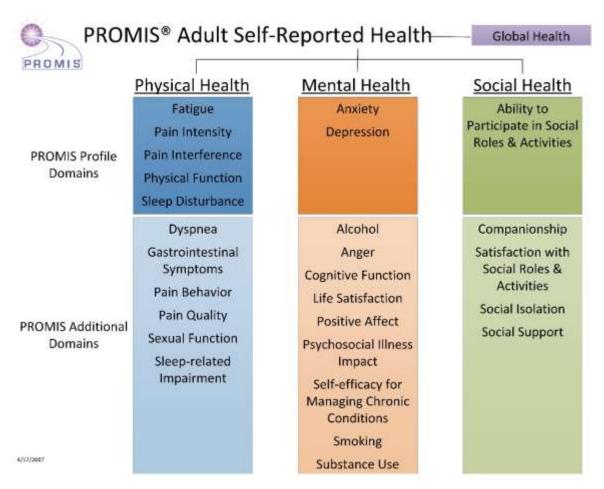
#### **PROFILES**

- Collection of short forms covering multiple domains (e.g. depression, physical function, pain interference)
- Adult profiles (29, 43, and 57 item versions), Pediatric and Parent-Proxy profiles (25, 37, 49 item versions)





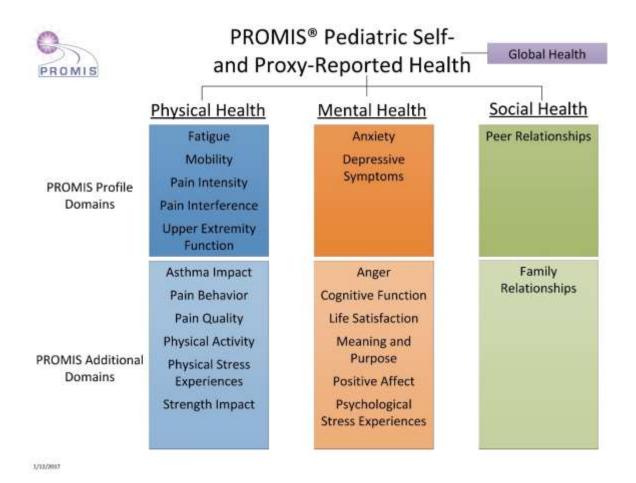
#### Domains for Adult Assessment







### Domains for Pediatric Assessment







# Computerized Adaptive Testing (CAT)

- PROMIS measures were developed using item response theory, which estimates parameters for each PRO question: how related is it to the domain being measured & "where" does it measure best?
- As a result, item banks were developed which can be used with CAT algorithms to tailor questions to how a person is feeling and functioning
- Advantages:
  - Brief 4-12 items; can be completed in under a minute
  - Precise Low error
  - Tailored content CATs don't ask questions that aren't relevant to the respondent
  - Cover a wide range of function or symptoms











# How often did you have to push yourself to get things done because of your fatigue? Never Rarely Sometimes Often Always

Exit

Next

In the past 7 days

Previous

# During the past 7 days: I have trouble starting things because I am tired Not at all A little bit Somewhat Quite a bit Very much Previous Next Exit

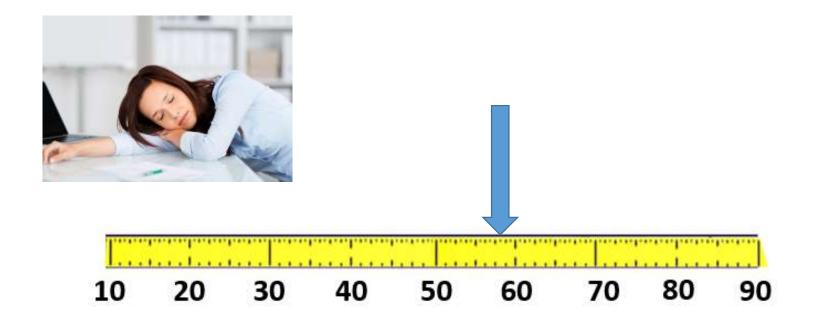
# In the past 7 days How run-down did you feel on average? Not at all A little bit Somewhat Quite a bit Very much

# In the past 7 days How much were you bothered by your fatigue on average? Not at all A little bit Somewhat Quite a bit Very much Previous Next Exit

Your score on the Fatigue CAT is 59. The average score is 50.

Your score indicates that your level of Fatigue is higher (worse) than:

- · 80 percent of people in the general population
- · 75 percent of people age 35-45
- · 76 percent of females



https://www.assessmentcenter.net/ac1/Assessments/CATDemo

#### Administration & Data Collection

#### **Using Paper**

- Respondent-ready PDFs for short forms & profiles on HealthMeasures.net
- Minimal technology needed; staff time required for data entry and scoring

#### Using a Computer

- Required for administration of CATs
- PROMIS measures available in REDCap, Epic, Assessment Center<sup>SM</sup> and OBERD (Outcomes Based Electronic Research Database)
- For a custom solution, the Assessment Center API integrates into your data collection system to administer CATs and fixed forms, both with automatic IRT-based scoring

#### Using the PROMIS iPad App

- Enables on-demand assessments. An administrator can select any PROMIS measure and hand the iPad over to a respondent for completion
- Available in the iTunes Store





## PROMIS SCORING OPTIONS

#### HealthMeasures Scoring Service

- Free, web-based application
- Upload Excel file w/ raw responses to short form or profile items
- Receive scored file by email
- Most accurate and preferred method for calculating scores

Automatic Scoring via Data Collection Tool

- Our data collection tools, including the API, REDCap, Epic, and Assessment Center, automatically score responses & deliver results
- Most accurate and preferred method for calculating scores

#### **By Hand**

- Scoring Manuals provide details and instructions for scoring individual PROMIS measures
- Accessed using the Search & View Measures feature and Calculate Scores page on HealthMeasures.net
- Less accurate and a challenge for missing data





# Understanding PROMIS Scores

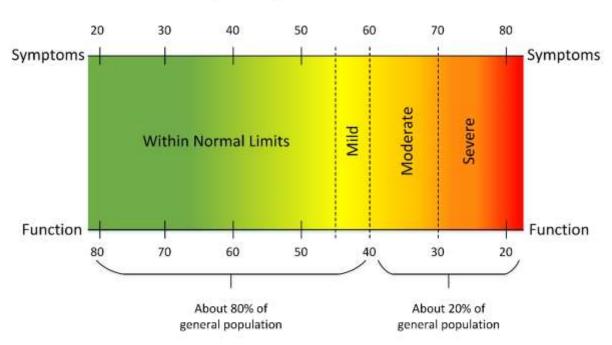
- PROMIS measures use a T-score metric
  - 50 is the mean for a relevant reference population
  - 10 is the standard deviation (SD) of that population
- Meaning of the score is defined by how it compares to the scores of others in a reference population
- High scores equal more of the domain being measured (e.g., more fatigue, more physical function)





## PROMIS Score Ranges

#### Interpreting PROMIS® T-Scores\*



\*These are general guidelines to aid in interpreting PROMIS\* T-scores.

Within a given condition or PROMIS domain, thresholds may differ.

Different thresholds are used for pediatric and parent proxy Anger, Anxiety, Asthma Impact,
Depressive Symptoms, Fatigue, Pain Behavior, Pain Interference, Pain Quality, as well as
adult, pediatric, and parent proxy Global.





# Linking Measures



Converts score from one measure to PROMIS metric

• Enables comparisons when different measures

used

www.prosettastone.org

SF-36/PF	PROMIS	·
Score	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	15.2	2.0





# Support of PROMIS

- PCORI has awarded over \$30 million to studies using PROMIS
- Over 100 NIH grants using PROMIS
- Over <u>700 clinical trials</u> currently in progress using PROMIS
- The American Academy of Orthopaedic Surgeons recommends
   PROMIS for collection of Orthopaedic Quality Data
- The Mayo Clinic recommends and uses the PROMIS Global Health scale as a PRO for Quality of Care Assessment
- The FDA's Clinical Outcome Assessment Compendium, a resource to foster patient-focused drug development, includes PROMIS Physical Function in sarcopenia and oncology





#### PROMIS API Users

- Epic PROMIS application in App Orchard
  - Score interpretation and data visualizations, full native integration into Epic and MyChart
  - <u>35 Hospital systems</u> have licensed in last 18 months
- Non-profit research (NIH, National Marrow Donor Program, etc.)
- 20 hospital systems with custom API integrations
  - ~1 million annual administrations per hospital
  - ~80% completion rates
- 30 vendors
- PASTOR, screening tool and outcomes registry for beneficiaries enrolled in the military health care system





PROMIS has stimulated me to have more in-depth conversations with my patients. The tool is <u>helping</u> me become a better doctor. I also find that I am ordering more OT consults. I believe it is improving the care of the whole child. – Dr. Mielke, Twin Cities

PROMIS scores are tracking with things that you and I are familiar with...over time, patients getting better on therapies that we would expect them to. I think this is additional validation – not just from the National Institutes of Health and a decade of research by lots of different groups, but in our own field – that these actually correlate with disease activity and that when you start an effective therapy they're going to improve as you would anticipate.

-Dr. Curtis, Birmingham



PROMIS results give me a good idea of how a patient is doing before I enter the room. I have noticed that adolescents are more willing to tell an iPad that they are struggling with peer relationships than to volunteer this information in response to in-person questioning. PROMIS has helped me uncover issues that I would have otherwise missed.

-Dr. Luhmann, St. Louis

What has come across as most powerful so far is that <u>patients</u> seem to be very grateful that someone is actually addressing these topics and is going to the lengths to try to help them as a whole person.

Dr. Bridge, Newberg OR





### PROMIS in Medical Education/Certification

- Demonstrate medical expertise by measuring outcomes that matter most to patients
  - Obtain additional information for patient care
  - Use to meet quality measurement demands (bundled payments, PQRS, PRO-PMs)
  - Use for benchmarking among clinicians
- Implement in Certification or Maintenance of Certification



