

Where Are We Now and Where Are We Going?

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November 6, 2018



Patient-Reported Outcomes (PROs) in Healthcare

- Incorporation of patients' health status and values via patient-reported outcomes (PROs) that matter to patients remains of paramount importance
- PRO measures (PROMs): used for clinical care, clinical research and trials, and monitoring quality of health care delivery
- Many metrics – lack of comparability
 - Hinders ability to share, interpret, integrate results
- Variable measure quality
 - Variable participant burden, range of domain coverage



PROs in Healthcare

- Many options of PRO measures to choose from
 - Condition or disease-specific/attribution measures
 - Attributed: items specify etiology of symptom/outcome, require respondents to distinguish among potential causes
 - Generic or universal measures
 - Common symptoms/areas of function can be relevant to multiple conditions, populations, settings
 - Especially relevant in populations with multiple comorbid conditions
 - Enables measurement of relevant outcomes and comparisons of disease burden and treatment impact across chronic conditions using a common metric
 - Challenges: requirements/preference for using legacy measure of specialty organization, institution, developer



Precise, flexible, and comprehensive measurement systems

Brief and psychometrically sound tools for ages 3 to 85

Flexible administration – computer adaptive tests (CATs), short forms, and interactive tests

For use in clinical research, clinical practice, quality improvement, and educational settings



- Self- and parent-report
- Global, physical, mental, and social health
- Adults and children
- General population and those living with a chronic condition

NeuroQoL

- Self- and proxy-report
- Physical, mental, and social health
- Adults and children
- Those living with a chronic condition

ASCQ-Me

- Self-report
- Physical, mental, and social health
- Adults
- Those living with sickle cell disease



- Performance tests
- Cognitive, motor, sensory function, emotion
- Adults and children
- General population, those living with a chronic condition

www.HealthMeasures.net



NeuroQoL

ASCQ-Me



HealthMeasures
TRANSFORMING HOW HEALTH IS MEASURED

What is PROMIS®?

Patient-Reported Outcomes Measurement Information System®

- Measures to assess physical, mental, and social health (adult & pediatric)
- Relevant across multiple conditions
- Psychometrically sound, developed and evaluated using state-of-the science methods (item response theory)
- Developed to cover full range of domain
- Administration options available
- Scored on one standardized 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)

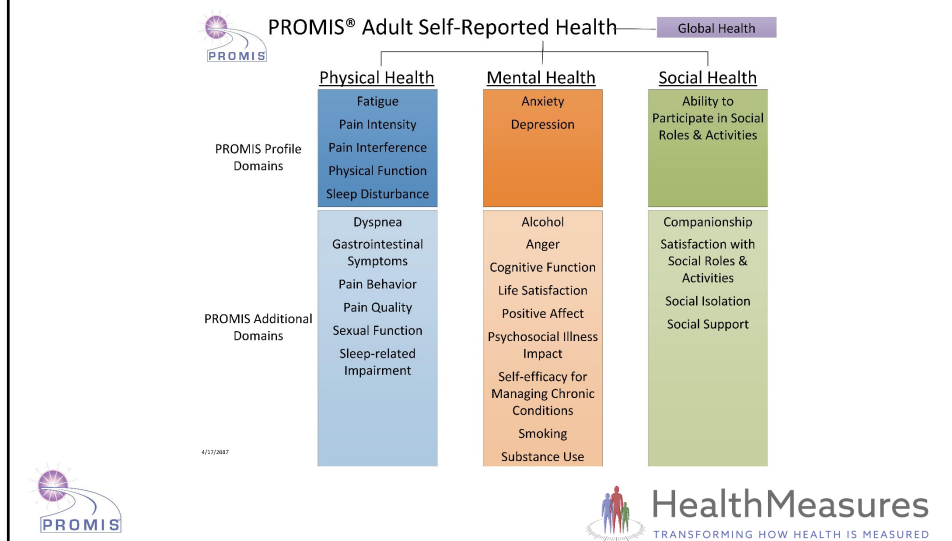
- Individually tailored electronic questionnaires
- Focused on a single domain
- Next item administered from item bank depends on previous answers
- Usually 4-12 items

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)

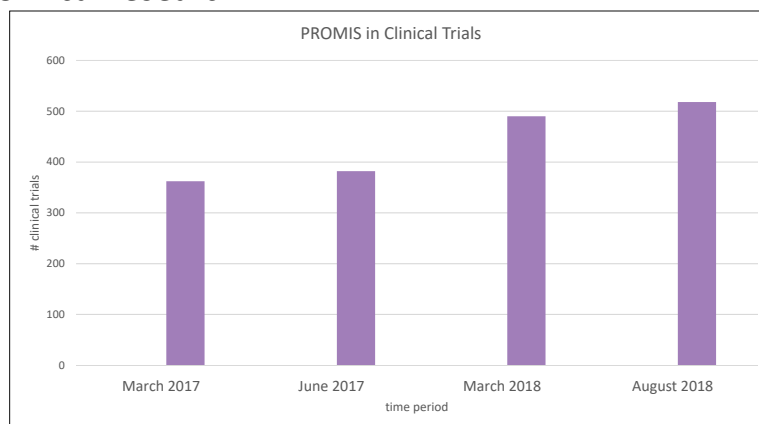


Domains for Adult Assessment



PROMIS at Work in Cardiology

• Clinical research



PROMIS at Work

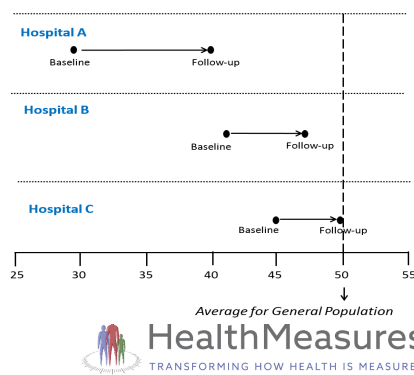
- Clinical practice
 - Symptom management in oncology
 - Shared decision making in orthopaedic surgery
 - Identifying fall risk in orthopaedic patients
 - Measuring outcomes: rehabilitation, cardiac rehabilitation, integrative medicine, cardiology, oncology, orthopedics, pulmonary rehabilitation and spine center
- Quality of Care
 - Recommended among Instruments for Collection of Orthopaedic Quality Data by American Academy of Orthopaedic Surgeons
 - PROMIS Global Health recommended as PRO for Quality of Care Assessment for patients receiving care at Mayo Clinic
- Drug development
 - PROMIS Physical Function included in FDA's Clinical Outcome Assessment Compendium in sarcopenia and oncology



Linking Measures

- Converts score from one measure to PROMIS metric
- Enables comparisons when different measures used

www.prosetastone.org



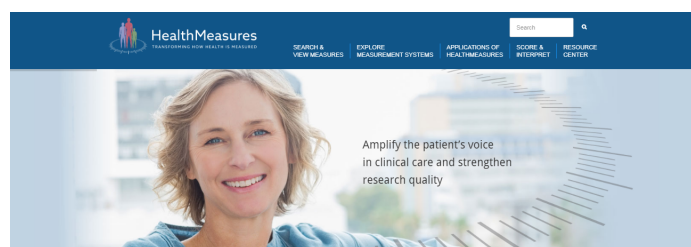
Some Ongoing/Future Directions

- Measure linking
- Disease-relevant extensions
- Clinical quality measurement and certification
- Regulatory submissions
- Disease registries
- Precision medicine phenotyping



Acknowledgments

- Funding for HealthMeasures was provided by the National Institutes of Health grant U2C CA186878



HealthMeasures consists of four precise, flexible, and comprehensive measurement systems that assess physical, mental, and social health, symptoms, well-being and life satisfaction; along with sensory, motor, and cognitive function.

www.healthmeasures.net

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