Where Are We Now and Where Are We Going?
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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/attributed 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

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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

Neuro-QoL
• 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

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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

- Clinical research
- Feasibility of integrating PRO capture into routine clinical practice in large heart failure (HF) clinic
- Screening for depression, anxiety in HF
- Home-based exercise intervention of wearable technology and telephone coaching on walking performance in PAD
- Trial of smoking cessation intervention by vascular surgeons

PROMIS at Work in Cardiology

- Clinical research

![Graph showing PROMIS in Clinical Trials from March 2017 to August 2018](image)
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.prosettastone.org
Some Ongoing/Future Directions

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

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