Measuring Patient Health with PROMIS®: Applications for Social Integration Research and Care

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1. Discuss need for robust and feasible health outcome data collection for research on social interventions in healthcare

2. Consider standard approach to capture patient health information directly from patients

3. Describe a unique patient-reported outcome assessment system for physical, mental, and social health
Meta-analyses of social determinants of health (SDOH) and mortality are robust
- socioeconomic status (Stringhini et al., 2017)
- income inequality (Kondo, 2012)
- social relationships (Holt-Lunstad et al., 2010)

Mechanisms to explain impact of SDOH on health have been explored
- environmental toxin exposure, risky health behaviors, chronic stress, epigenetic processes (Braveman & Gottlieb, 2014)
- undertreatment among unmarried patients (Aizer et al., 2013)

When conducting interventions in healthcare delivery settings, we need to examine **proximal outcomes**, such as symptoms and functioning

Are there standard ways to capture patient health from patients?
Understanding patient’s health from patients
Patient Reported Outcomes (PROs)

- PROs typically fall into three categories: physical, mental, and social health, based on WHO identified domains of quality of life.
- PRO measures critically inform clinical research and clinical care; may also inform care quality.
- PROs can bring direct experience of patients into clinic to better understand the effect of health conditions and treatments on daily life.
Challenges for PRO Assessment

Historically:
• Clinical research suffered from a lack of comprehensive tools
• Response burden for fixed questionnaires
• Generic vs. disease-specific tools

NIH Vision for Measurement:
• Brief, precise, valid, flexible tools
• Comparisons across diseases
• Shared electronic platforms
• Pediatric and adult
• Low patient-burden

Three waves of NIH Funding over 15 years
Components: brief, precise, valid, reliable fixed or tailored tools for patient-reported health status in physical, mental, and social well-being domains for adult and pediatric populations

Advantages: Disease-agnostic, Domain-based, Flexible, Adaptable, Low burden, Comparable, Accessible

- Short Forms ("Ready made" or "Make your own")
- Individually tailored electronic questionnaires via computer adaptive tests

Standardized: Item Response Theory (IRT) for construction; One metric (T-score, Mean=50, SD=10; ref=US population)
Domain
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

Computer Adaptive Testing (CAT): All items from bank can be used, Next item depends on response to prior item
Interpretability: All Scores, One Scale

Within Normal Limits

Symptoms

Function

Mild
Moderate
Severe

About 80% of general population

About 20% of general population

*These are general guidelines to aid in interpreting PROMIS T-scores. Within a given condition or PROMIS domain, thresholds may differ.
Available via HealthMeasures

Trans-NIH Cooperative Agreement

14 NIH Contributors

- NCI, NINDS, NIA, NHLBI, NCCAM, NIAMS, NIDDK, NIDCD, ORWH, OBSSR, NIMH, NIDA, NINR, NCMRR

Integration, Dissemination, Sustainability

- Curate and provide **four** systems
- Infrastructure and scientific standards
- Funding decrease: transition to independence

www.healthmeasures.net
Automated use of four state-of-the-science measurement systems and the ability to combine with other tools

Supports, administers, and provides integrated platforms for self-report or performance-based measures

Include self-reported quality of life and measures of function
- Reports: Physical, mental, social health; symptoms, well-being
- Performance-based measures: sensory, motor and cognitive function

Applications: outcome measurement, process measurement, prediction, case identification, and population surveillance, monitoring in clinical practice
HealthMeasures Application Program Interface (API)

iPad App (NIH Toolbox and PROMIS)

Research Electronic Data Capture (REDCap)
- For Clinical Trials and Research, free to consortium members

Epic: Short-forms available, CAT available since 2016 release
- 400 assessments, English, Spanish
- via MyChart (appointment based, recurring, Ad Hoc: patient/clinic-driven)

EHR Access to Seamless Integration of PROMIS (EASI-PRO)
- Scalable implementation in Epic, Cerner, Smart on FHIR, others
Information for Accessing PROMIS Tools

Search & View Measures
Download free, respondent-ready PDF short forms.

Applications of HealthMeasures
Free guides to help select measures for use in research, clinical care, and care quality.
Current tools with advanced methods are available to capture patient health with low burden on patient and system.

Future research examining social care interventions in healthcare delivery settings could benefit from standard approaches to allow comparisons across studies.

PROMIS is one option for a standard way to assess PRO data (symptoms and functioning) for mental, physical, and social health.
Questions?

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Extra Slides
Fixed Questionnaires vs. Computerized Adaptive Tests (CAT)

Questionnaire with high precision but small range

Questionnaire with a wide range but low precision

high physical function

low physical function
Fixed Questionnaires vs. Computerized Adaptive Tests (CAT)

- Question #1: high physical function
- Question #2: low physical function
- Question #3: Questionnaire with high precision AND a wide range
Precise, flexible, comprehensive measurement systems

Brief and psychometrically sound patient-centered health 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

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

www.HealthMeasures.net
www.healthcaredelivery.cancer.gov/healthmeasures
Translation Science Continuum for Measurement Development

I: Basic Methods / Tool Development
- Create tools using modern psychometrics
- Item identification/development
- Qualitative studies
- Test in clinical samples and general population
- Analysis, interpretation, refinement

II. Translation
- Validate in clinical samples
- Measure adaptation for language, literacy
- Finalize standards for use
- Develop outside partnerships
- Use in observational studies
- Use in clinical trials
- Methods to allow for clinical application

III. Implementation & Adoption
- Widespread use in extramural studies and trials
- Outcomes/Comparative effectiveness research
- Payment mechanisms to ensure sustained adoption
- Incorporated into training and education curricula
- Dynamic evaluation to inform provider practices

PROMIS Development

**PROMIS I**

- NIH Roadmap 2004-2008
- 6 Research Centers
- 1 Coordinating Center
- Began development of PROMIS domain framework and item banks
- Developed and tested physical, mental, social health domains in several clinical samples and settings
- Primarily Adult
- Sustainability: PHO established

**PROMIS II**

- 2009-2014 NIH Common Fund
- 12 Research Centers
- 3 Network Centers
- Expanded the development of PROMIS with additional domains
- Large-sample validation in adult cancer patients
- Expanded pediatrics
- Sustainability: Public/Private Partnerships, PHO expansion
To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.