

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

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# Presentation Goals

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

# Research on Social Factors and Health

## **Meta-analyses of social determinants of health (SDOH) and mortality are robust**

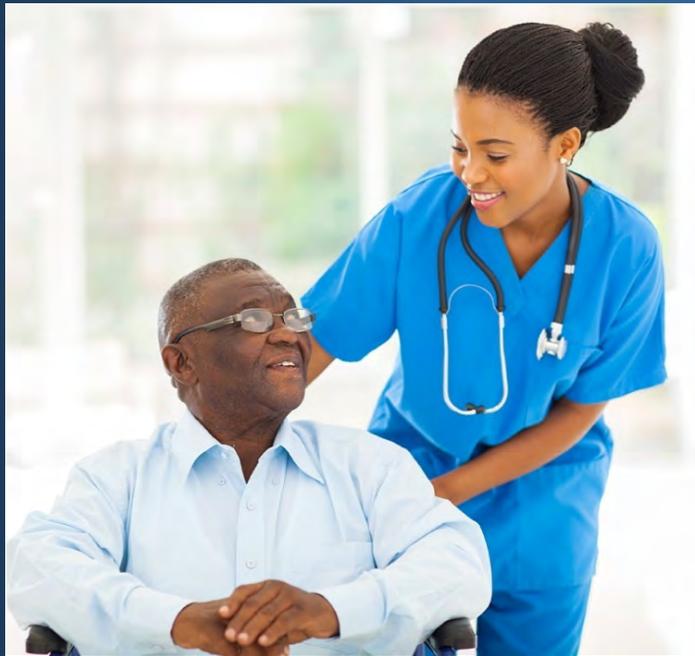
- socioeconomic status (Stringhini et al., 2017)
- income inequality (Kondo, 2012)
- social relationships (Holt-Lunstad et al., 2010)

## **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



# Patient Reported Outcomes Measurement Information System®

**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 (Next item depends on previous answer)

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



# PROMIS Essential Components

## 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



# PROMIS<sup>®</sup> Adult Self-Reported Health

Global Health

## Physical Health

## Mental Health

## Social Health

PROMIS Profile  
Domains

Fatigue  
Pain Intensity  
Pain Interference  
Physical Function  
Sleep Disturbance

Anxiety  
Depression

Ability to  
Participate in Social  
Roles & Activities

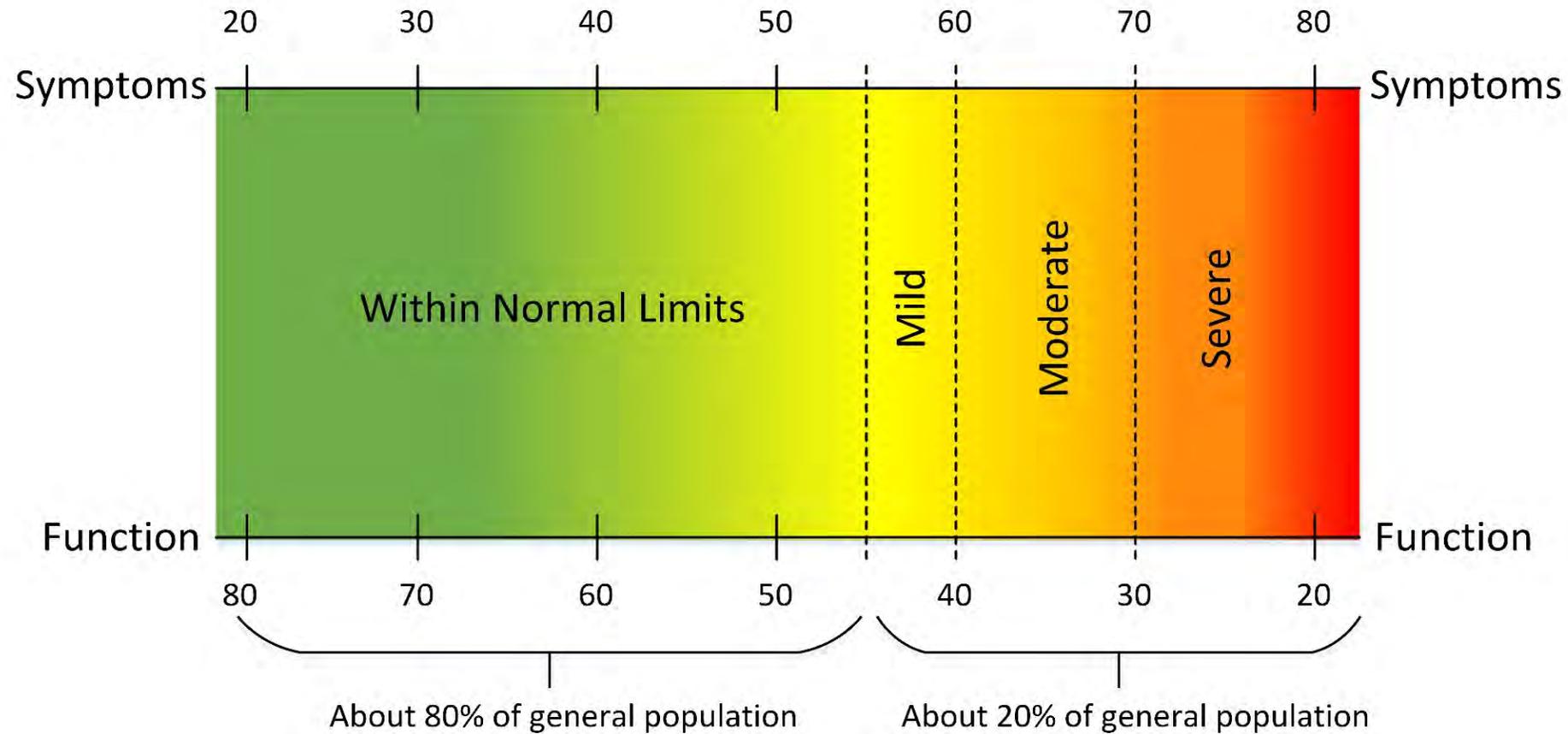
PROMIS Additional  
Domains

Dyspnea  
Gastrointestinal  
Symptoms  
Itch  
Pain Behavior  
Pain Quality  
Sexual Function  
Sleep-related  
Impairment

Alcohol  
Anger  
Cognitive Function  
Life Satisfaction  
Meaning & Purpose  
Positive Affect  
Psychosocial Illness  
Impact  
Self-efficacy for  
Managing Chronic  
Conditions  
Smoking  
Substance Use

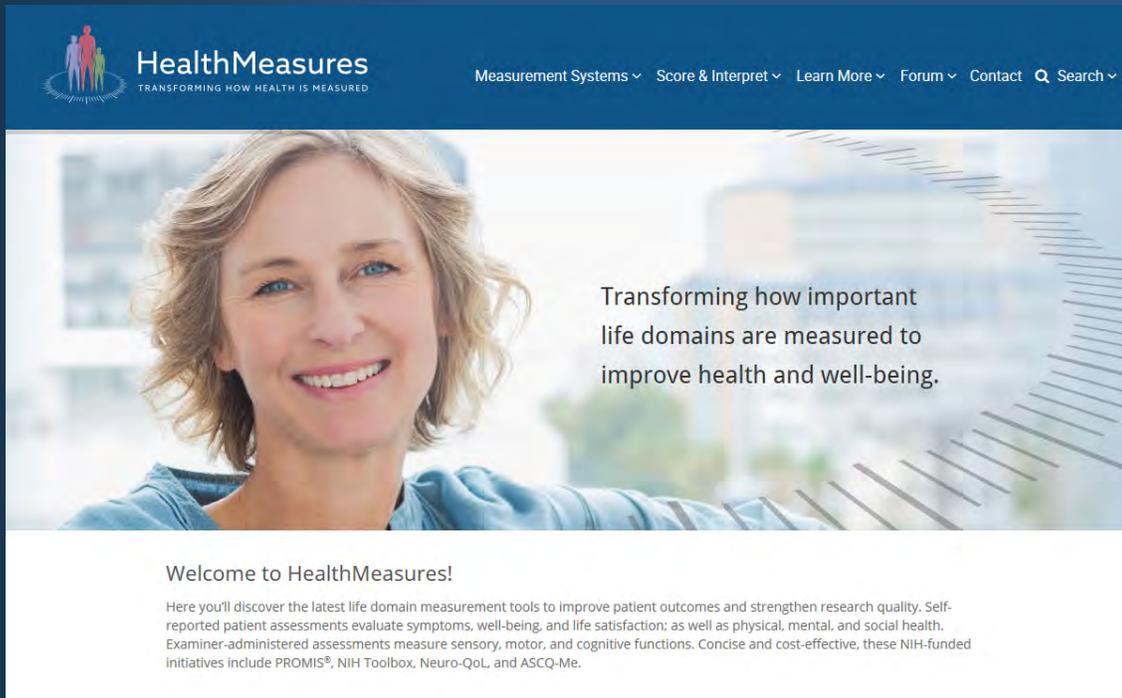
Companionship  
Satisfaction with  
Social Roles &  
Activities  
Social Isolation  
Social Support

# Interpretability: All Scores, One Scale



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

# Available via HealthMeasures



The screenshot shows the HealthMeasures website homepage. At the top left is the HealthMeasures logo with the tagline "TRANSFORMING HOW HEALTH IS MEASURED". To the right of the logo is a navigation menu with links for "Measurement Systems", "Score & Interpret", "Learn More", "Forum", "Contact", and a search icon. Below the navigation is a large banner image of a smiling woman. To the right of the woman, the text reads: "Transforming how important life domains are measured to improve health and well-being." Below the banner, there is a "Welcome to HealthMeasures!" section followed by a paragraph: "Here you'll discover the latest life domain measurement tools to improve patient outcomes and strengthen research quality. Self-reported patient assessments evaluate symptoms, well-being, and life satisfaction; as well as physical, mental, and social health. Examiner-administered assessments measure sensory, motor, and cognitive functions. Concise and cost-effective, these NIH-funded initiatives include PROMIS®, NIH Toolbox, Neuro-QoL, and ASCQ-Me."

[www.healthmeasures.net](http://www.healthmeasures.net)

## 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



Neuro-QoL

ASCQ-Me<sup>SM</sup>  
Adult Sickle Cell Quality of Life Measurement Information System



HealthMeasures  
TRANSFORMING HOW HEALTH IS MEASURED



# What does it provide?

- 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

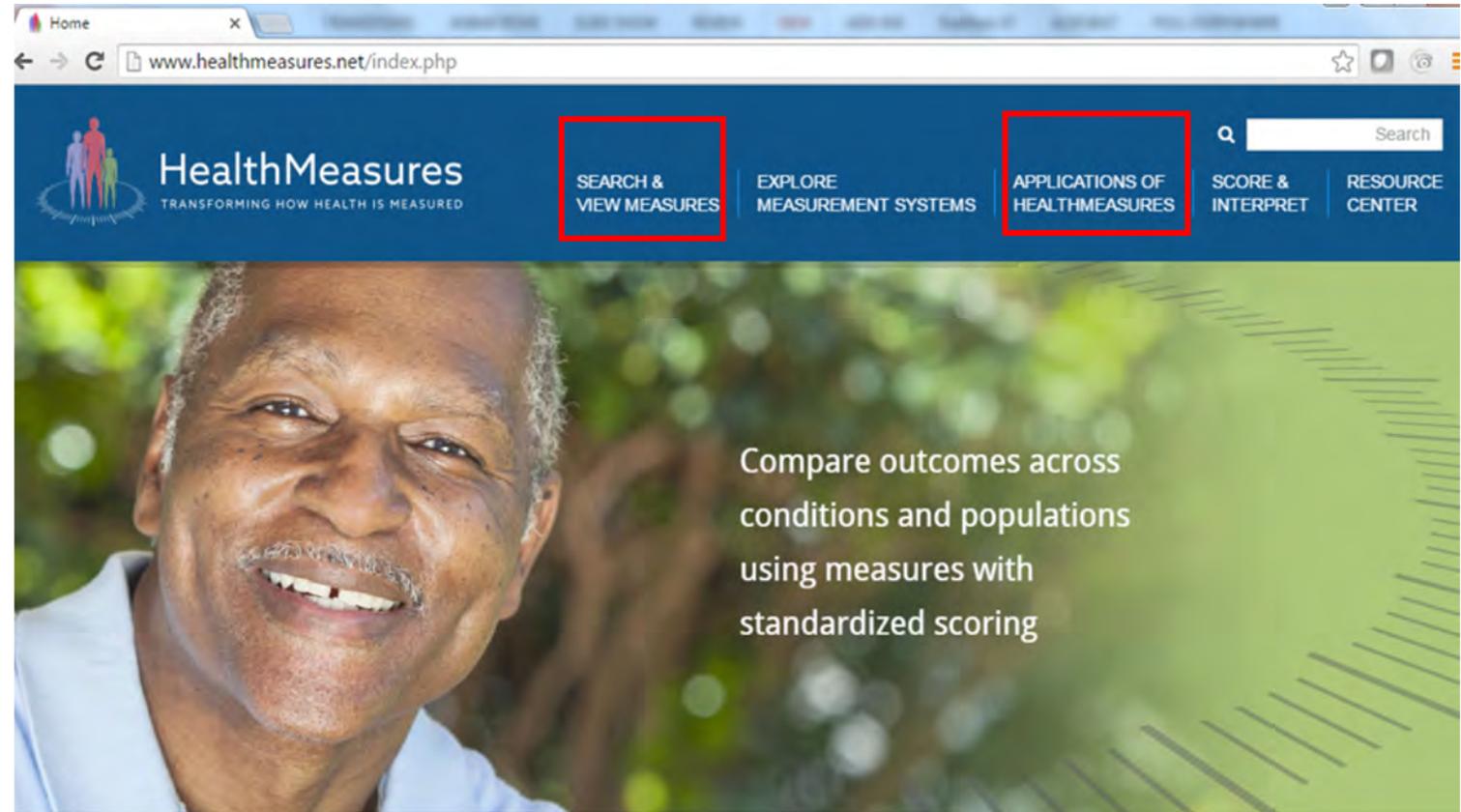
# Information for Accessing PROMIS Tools

## 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.



# Summary and Future Needs

- 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

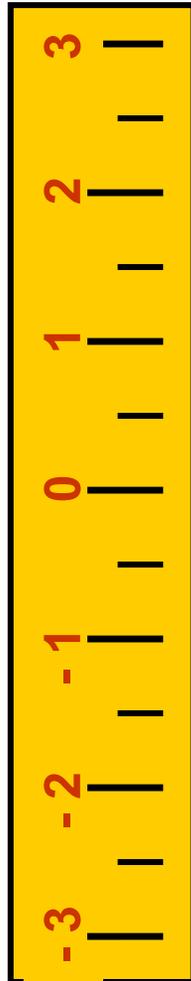
**Questions?**

[Ashley.Smith@nih.gov](mailto:Ashley.Smith@nih.gov)

# Extra Slides

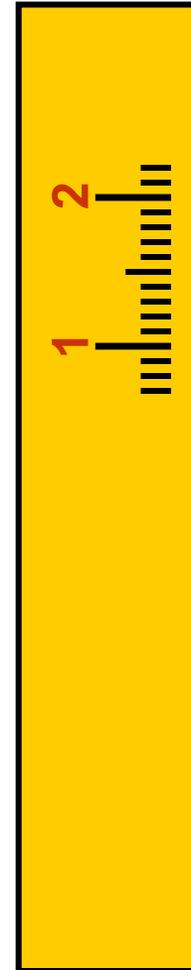
# Fixed Questionnaires vs. Computerized Adaptive Tests (CAT)

high  
physical  
function



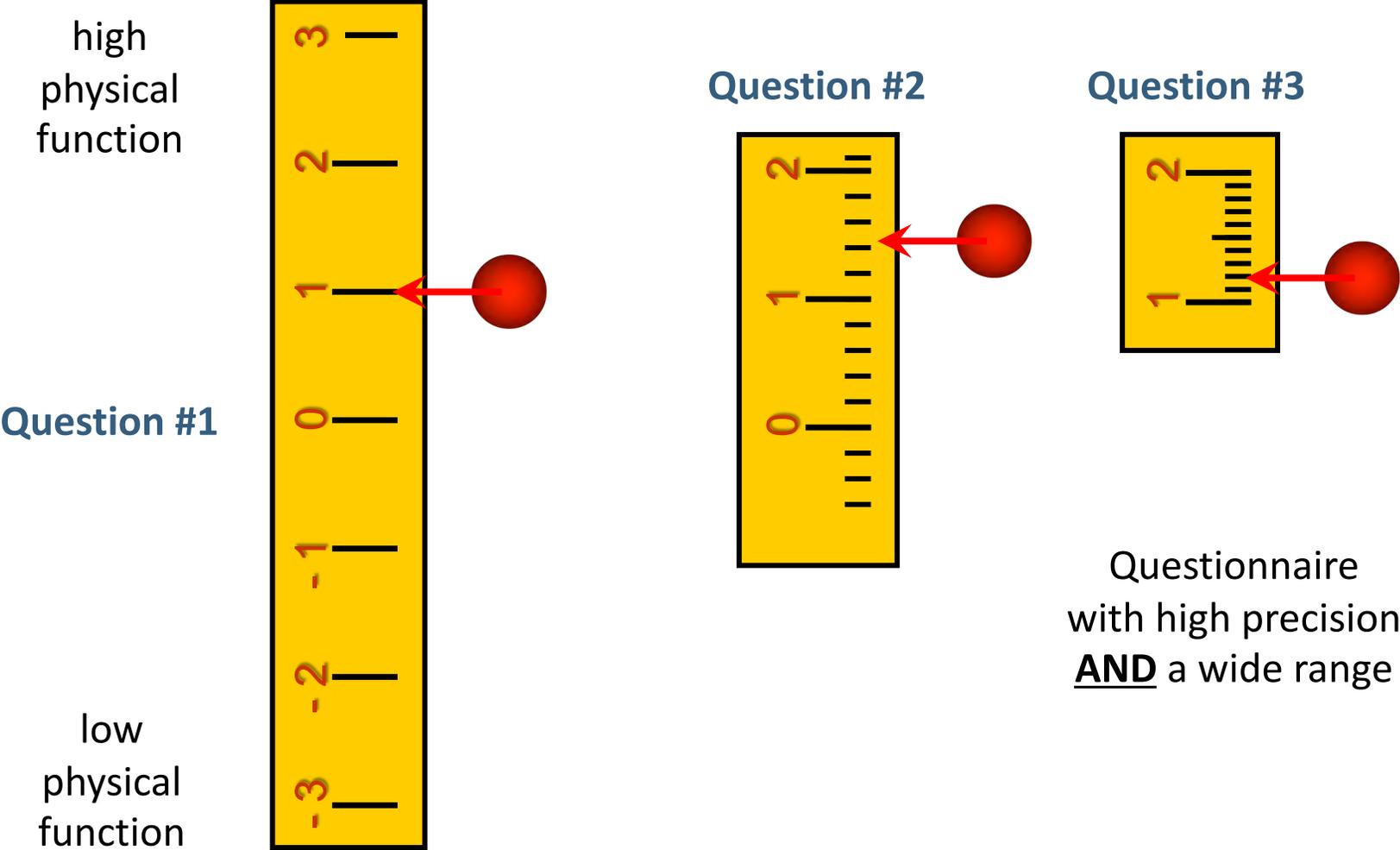
Questionnaire  
with a wide range  
but low precision

low  
physical  
function



Questionnaire  
with high precision  
but small range

# Fixed Questionnaires vs. Computerized Adaptive Tests (CAT)



# 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



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



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



- 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](http://www.HealthMeasures.net)

[www.healthcaresdelivery.cancer.gov/healthmeasures](http://www.healthcaresdelivery.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

**PROMIS I**

## 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

**PROMIS II**

## 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 III”**



**HealthMeasures**

TRANSFORMING HOW HEALTH IS MEASURED



# 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



## NIH Mission

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