



## NQF Measure Incubator™ Innovation Challenge

*December 14, 2016*

WELCOME

## NQF Measure Incubator™ Innovation Challenge

- NQF is hosting a series of webinars to explore innovative solutions to improve measure development and address areas that have too few or no meaningful measures, as part of initial steps to the launch of the NQF Measure Incubator Learning Collaborative.
- The featured speakers on today's webinar are winning recipients of the recently announced the NQF Innovation Challenge. Please register for our final webinar on:
  - *January 11 1:00 – 2:00pm ET*
  - *or, visit our website to see a recording of our November 17 Innovation Challenge presentation*  
[http://www.qualityforum.org/Measure\\_Incubator\\_Webinar\\_Series.aspx](http://www.qualityforum.org/Measure_Incubator_Webinar_Series.aspx)

## Today's Speakers

**Michelle Langer, PHD** senior psychometrician, American Institutes for Research

**Ellen Schultz, MS** senior researcher, American Institutes for Research

*Moderated by Ronald Walters, MD, MBA, MHA, MS  
associate vice president of medical operations and  
informatics at The University of Texas MD Anderson Cancer  
Center*

# Patient and Family Engagement in Measure Development

Developing Severity and Functional Status Categories for Patient-Reported Outcome Measure Scores

Michelle Langer, PhD  
Senior Psychometrician  
American Institutes for Research

Ellen Schultz, MS  
Senior Researcher  
American Institutes for Research



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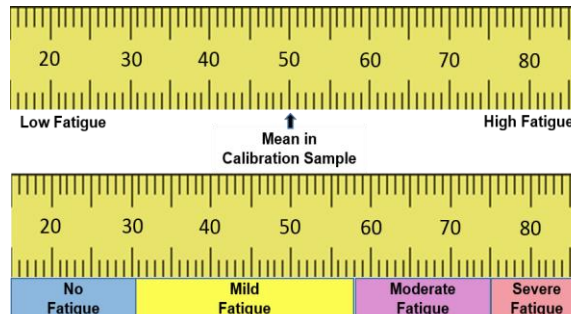
## Special Thanks

Bryce Reeve, PhD  
Co-Investigator for this research  
Professor, UNC-CH School of Public Health

## Measurement Challenge

Divide the score scale of patient-reported outcome measures into categories that are:

- Meaningful to patients and their families
- Useful to clinicians
- Psychometrically sound



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## Addressing the Incubator Challenge

### INCUBATOR PRIORITY AREAS

- Apply innovations from other industries to healthcare measurement
- Patient and family engagement
  - Innovative ways to introduce the patient and family voice into measure development
- Patient-reported outcome measures (PROMs)

### INNOVATIONS OF THIS RESEARCH

- Innovative application of “bookmarking” methods developed in the education field to identify score cut-points for PROMs of mobility, fatigue, pain, depression & psychological stress
- New types of materials (vignettes)
- New types of stakeholders (adolescents, parents, and providers)

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## Bookmarking

- Most widely-used type of standard setting in education field
- “Books” of test items ordered by difficulty
- Experts place “bookmarks” between items to identify the location of the cut-scores that distinguish different levels of proficiency

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## Adapting Bookmarking to PROMs

- “Books” or vignettes about patient symptoms or functioning ordered by severity/functional status
- Experts place bookmarks between vignettes to identify the location of the cut-scores that distinguish different levels of symptoms or functioning

WHOSE expertise should inform bookmarks for PROMs?

- **Patients** who are experts in lived experience
- **Caregivers** who are experts in lived experience
- **Clinicians** who are experts in treatment, management

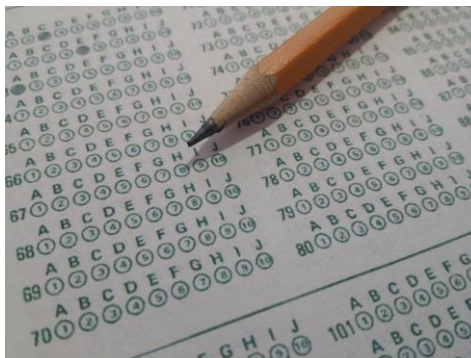
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# Bookmarking Overview

## Standard Setting

- Method in educational testing to identify valid, defensible cut-scores, such as for “high stakes decision making” (pass or fail)
- Bookmarking is one of several standard setting methods
- Used for example, in National Assessment of Educational Progress (NAEP)



## Standard Setting

- For the National Assessment of Educational Progress (NAEP), bookmarking is implemented with the following steps:
  1. A panel of content experts is assembled: classroom teachers in the subject and grade being assessed, college faculty, and curriculum directors.
  2. A description of what students should know and be able to do to qualify for performance at each of the three NAEP achievement levels is developed.
  3. The panelists read through each item, ordered by difficulty. They judge whether students who just meet the requirements for a given achievement level would have the knowledge required to answer the item correctly.
  4. The cut score is set to represent the minimal performance required for each achievement level: Basic, Proficient, Advanced

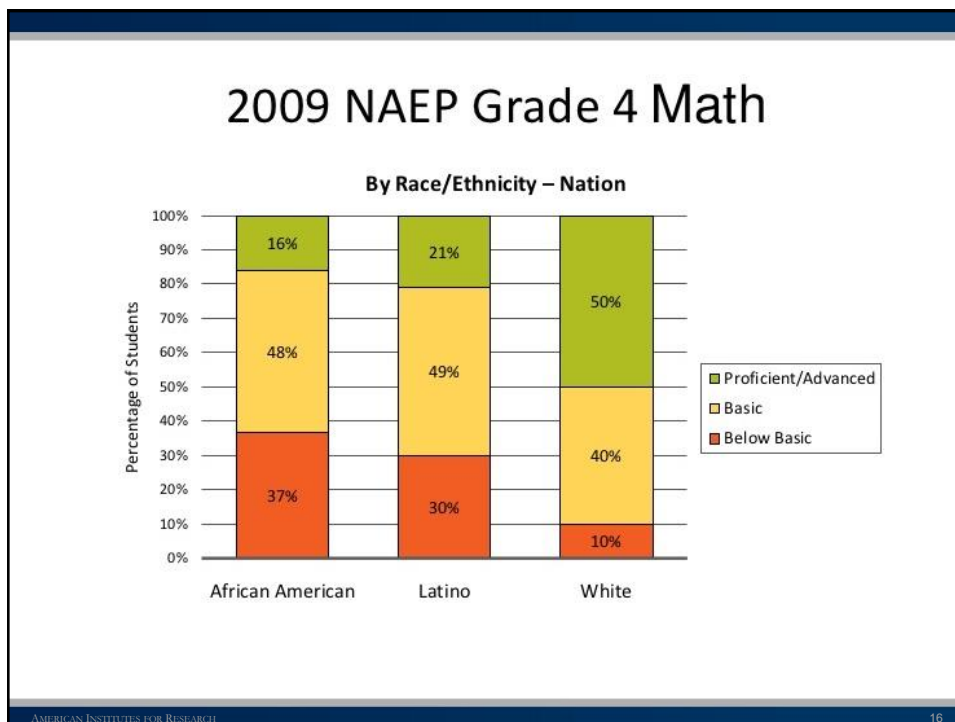
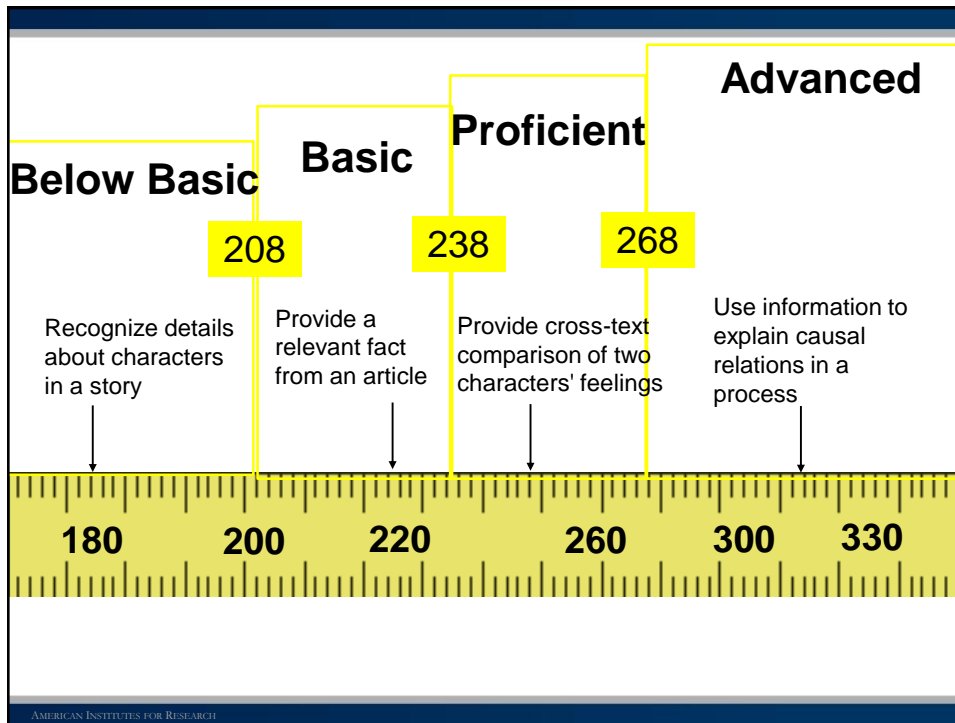
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## Examples of NAEP performance level descriptors in Reading for Grade 4

- **Basic:** Students should demonstrate an understanding of the overall meaning of what they read. When reading, they should be able to make relatively obvious connections between the text and their own experiences and extend the ideas in the text with simple inferences.
- **Proficient:** Students should be able to demonstrate an overall understanding of the text, providing inferential as well as literal information. When reading, they should be able to extend the ideas in the text by making inferences, drawing conclusions, and making connections to their own experiences. The connection between the text and what the student infers should be clear.
- **Advanced:** Students should be able to generalize about topics in the reading selection and demonstrate an awareness of how authors compose and use literary devices. When reading, they should be able to judge text critically and, in general, give thorough answers that indicate careful thought.

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# Using Bookmarking to Improve PROM Interpretation



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## Project Overview

### **Enhancing Meaningfulness and Usefulness of Pediatric PROMIS® Measures**

- Aim: Adapt bookmarking method to identify clinical cut scores (e.g., thresholds) that divide the PROMIS Pediatric T-scores into meaningful categories of symptom severity or functional status
- To identify these cut scores, engage with key stakeholders:
  - Adolescents living with cancer or arthritis
  - Parents of adolescents living with cancer or arthritis
  - Clinicians who treat pediatric cancer or arthritis
- Support from NIH

## Rationale

- Normative comparisons provide helpful context but not informative with respect to clinical decision-making
  - What severity level requires intervention?
  - What is an improvement?
- Other studies had looked at 0-10 NRS (pain, fatigue) against clinical anchors
  - no clinician input, not multi-item measures

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## PROMIS Measures

- PROMs for:
  - Mobility limitations
  - Fatigue
  - Pain
  - Psychological stress
  - Depression
- T-scores are standardized so that:
  - Score of 50 is mean of reference population
  - 10 score scale points represents one SD of reference population
  - Higher scores = more symptoms or greater functionality

**How do you interpret a T-score? What does it mean for making treatment decisions?**

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## Adapted Bookmarking Procedures

- 4-hour workshops conducted separately with each stakeholder group:
  - Adolescents with cancer or arthritis
  - Parents of adolescents with cancer or arthritis
  - Clinicians who treat children with cancer or arthritis
- 8 participants per stakeholder group
- Orient to task, process
  - Fanciness of dessert example

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## Workshop Steps

1. Participants complete warm-up exercise.
2. Discuss labels of bookmarks:
  - “none/normal,” “mild,” “moderate,” “severe” symptoms
  - “no problems,” “mild problems,” “moderate problems,” “severe problems” functioning
3. For each domain:
  - » Lay out vignettes in order of PROMIS T-score.
  - » Individually place bookmarks between vignettes.
  - » Seek consensus on location of bookmarks.
  - » For clinician stakeholders, consequential validity results provided (proportion of patients who would be classified into each category based on their choices, a “reality check” given their bookmarks)

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# Adapted Bookmarking Procedures

## • Introduction

- Introduce Moderator and assistants and participants names.
- Why are we here? (explain bookmarking exercise goals)
- Warm-up exercise: “Fanciness of Desserts”

- Graham cracker
- Vanilla ice cream
- Chocolate chip cookie
- Angel food cake
- Chocolate pie
- Apple cobbler
- Bananas foster
- Peach Flambé
- Baked Alaska
- Crème Brûlée

Very  
Plain

Plain

Fancy

Extra  
Fancy



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## Example vignette

### Kelly's Energy

In the last 7 days, Kelly was never so weak that she had to limit her social activities, was unable to leave the house, or needed help doing her usual activities.

In summary, Kelly reports during the past 7 days:

How often did you have to limit your social activities because of your fatigue?

**Never** Rarely Sometimes Often Always

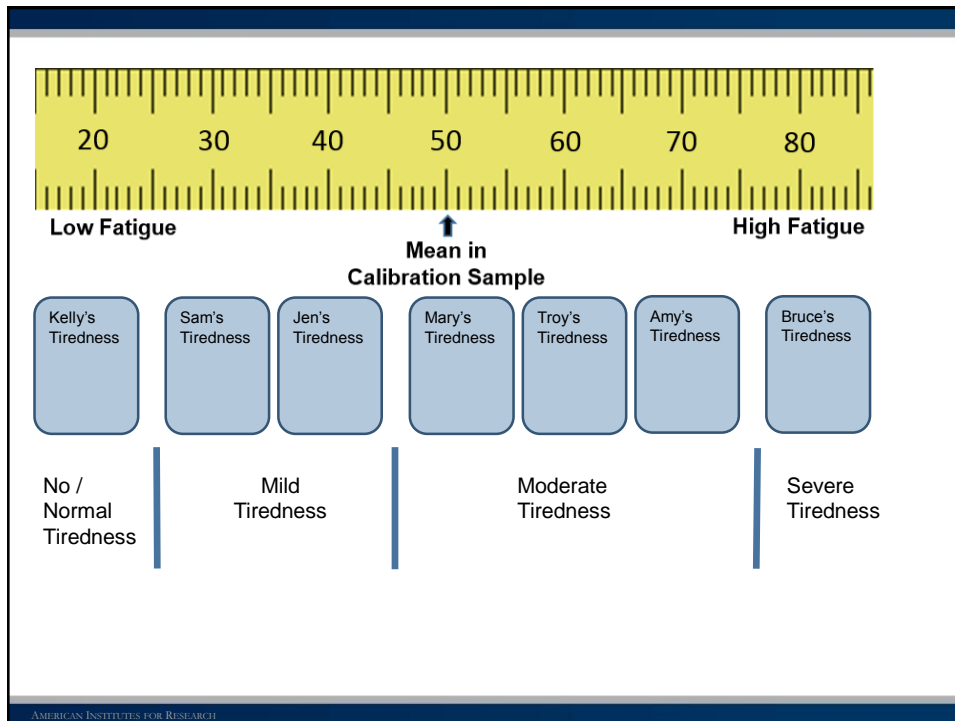
How often were you too tired to leave the house?

**Never** Rarely Sometimes Often Always

I need help doing my usual activities.

**Not at all** A little bit Somewhat Quite a bit Very much

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## Progress to Date

- Vignettes finalized.
- Discussing the order of bookmark placement for participants.
  - In education, bookmarks are usually placed from easiest to most difficult
  - In the PROM context, it may be easier to place most extreme bookmarks (no symptoms, severe symptoms) before the intermediate bookmarks (mild, moderate)
  - Whatever order is chosen, subsequent bookmarks are dependent on initial choices
- Participant recruitment to begin soon.

## Discussion Points

- Handling differences between stakeholders
  - Do we reconcile or choose?
  - Dependent on a given use?
- How will resulting severity/functional status PROM categories be put into practice?
  - Treatment decisions
  - Patient education
  - Research
  - Performance measurement

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## American Institutes for Research

Established in 1946, with headquarters in Washington, D.C., American Institutes for Research (AIR) is an independent, nonpartisan, not-for-profit organization that conducts behavioral and social science research and delivers technical assistance both domestically and internationally.

As one of the largest behavioral and social science research organizations in the world, AIR is committed to empowering communities and institutions with innovative solutions to the most critical challenges in education, health, workforce, and international development.

## Questions

## Upcoming Events

Wednesday Jan 11

1:00-2:00pm ET

**Charlotta Lindvall, MD, Dana-Farber Cancer Institute**

Proposes using natural language processing to develop quality measures in palliative surgery using electronic health record (EHR) data

**Tracy Spinks, MD Anderson Cancer Center**

Outlines a new, streamlined, standardized approach to implementing PRO measure sets in EHRs

*Moderated by Ed Septimus, MD, medical director, Infection Prevention and Epidemiology, Hospital Corporation of America*

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