



HealthMeasures



ASCQ-Me™  
Adult Self-Report Quality of Life Measurement Information System

Neuro-QoL



**USER CONFERENCE**

# Detailed Program

## 2017 HealthMeasures User Conference

September 27-28, 2017

Prentice Women's Hospital Conference Center  
250 E. Superior Street, Chicago, Illinois

### Conference Supporters



Bristol-Myers Squibb



RWS  
Life Sciences



*Providing a Voice for Patients Worldwide*

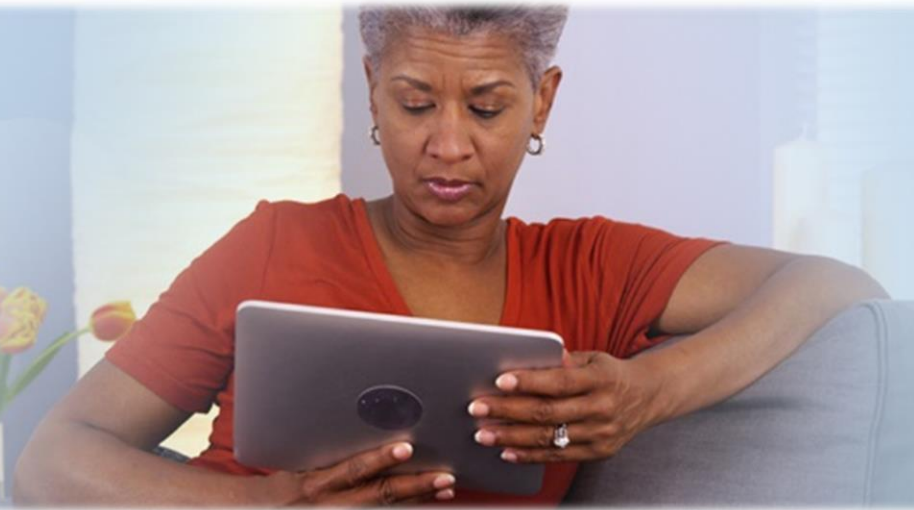
# Wednesday, September 27



<b>7:30 AM – 9:30 AM</b>	<b>Registration &amp; Continental Breakfast</b>	<b>Location: Harris Atrium</b>
<i>Exhibits, networking &amp; pre-arranged consultations with measurement science experts</i>		
<b>8:00 AM – 9:30 AM</b>	<b>Pre-Conference Workshop</b>	<b>Location: Canning Auditorium</b>
<b>Introduction to Person-Centered Assessment</b> <i>Introduction to selecting, administering, scoring and interpreting PROMIS®, Neuro-QoL, ASCQ-Me<sup>SM</sup>, and NIH Toolbox® measures. Appropriate for researchers and clinicians who are new to item response theory (IRT) and using patient-reported outcomes and performance tests of function in clinical care and research.</i>  <i>Complimentary session to be presented on-site at the conference site and via live webcast. Webcast registration details to come.</i>  <b>Presenters:</b> Nan Rothrock, PhD, Northwestern University Karon Cook, PhD, Northwestern University		
<b>9:30 AM – 10:00 AM</b>	<b>Welcome &amp; Announcements</b>	<b>Location: Harris Atrium</b>
<b>Presenters:</b> Ashley Wilder Smith, PhD, MPH, Chief, Outcomes Research Branch, National Cancer Institute David Cella, PhD, Northwestern University, HealthMeasures PI		
<b>10:00 AM – 11:30 AM</b>	<b>Concurrent Breakout Session 1</b>	<b>Location: See track detail below</b>
<b>Track A: Advancing Clinical Care - Location: Room L North</b>  <u><b>Rapid Fire (5 minute) Presentations:</b></u>  <b>PROMIS: American Sign Language.</b> Michael Kallen, PhD, Northwestern University  <b>Health-related Quality of Life in Longitudinal Research on Aging Drivers (LongROAD): PROMIS-29 Profile v2.0.</b> Thelma Mielenz, PhD, Columbia University  <b>Factors Associated with Sleep Disturbance as Individuals Diagnosed with Colorectal Cancer Transition to Early Survivorship.</b> Theresa Coles, MS, University of North Carolina at Chapel Hill, RTI Health Solutions  <b>Disease and Treatment Factors Associated with Lower Quality of Life Scores in Adults with MEN-1.</b> Sneha Goswami, MD Candidate, Northwestern University  <b>Individuals with Knee Impairments Identify Best Items from PROMIS® Pain Interference and Physical Function Item Banks.</b> James Irrgang, PT, PhD, University of Pittsburgh  <b>Practical Considerations for use of the NIH Toolbox in Down Syndrome Research.</b> Alison Pritchard, PhD, Kennedy-Krieger Institute  <b>Linking ASCQ-Me and PROMIS Pain Measures.</b> San Keller, PhD, American Institutes for Research  <b>Relationships Between Psychosocial and Physical Function Scores using PROMIS, ASCQ-Me, or Older, SCD-specific Measures: the SHIP-HU Study.</b> Wally Smith, MD, Virginia Commonwealth University		



# Wednesday, September 27



**10:00 AM – 11:30 AM    Concurrent Breakout Session 1    Location: See track detail below**

**Track B: Enhancing Quality Measurement - Location: Room L South**

**HealthMeasures and the Future of PRO-based Quality Improvement Performance Measures**

Helen Burstin, MD, MPH, Chief Scientific Officer, National Quality Forum

Clifford Ko, MD, Director, Division of Research and Optimal Patient Care, American College of Surgeons

**Track C: Deploying Digital Tools - Location: Room N**

**App-based Administration: Overview & User Experiences**

Cindy Nowinski, MD, PhD, Northwestern University

Molly Losh, PhD, Northwestern University

Seth Elkin-Frankston, PhD, Charles River Analytics

Noelle Carlozzi, PhD, University of Michigan

**Track D: Driving the Science - Location: Room Q**

**Software Alternatives for IRT analyses.** Ron Hays, PhD, UCLA

**Alternative Approaches to Addressing Non-Normal Distributions in the application of IRT Models.**

Steven Reise, PhD, UCLA

**"Real-time" short form development: Applying item information to obtain "live" score-level reliability estimates for evaluating expected short form performance.** Michael Kallen, PhD, Northwestern University

**11:30 AM – 1:00 PM    Lunch & Plenary Session 1    Location: Harris Atrium**

**At the Tipping Point: Driving Change Across Healthcare**

*A recent Annals of Surgery editorial underscored the power of outcome assessments to produce value-based, patient-centered care. Together, we will explore trends and issues impacting the adoption of outcomes assessments as healthcare change agents.*

**Moderator:** Ashley Wilder Smith, PhD, MPH, Chief, Outcomes Research Branch, National Cancer Institute (NCI)

**Panelists:**

Helen Burstin, MD, MPH, National Quality Forum

Christine Dymek EdD, Director, Division of Health Information Technology, Agency for Healthcare Research and Quality (AHRQ)

Lori Frank, PhD, Program Director, Evaluation & Analysis, Patient-Centered Outcomes Research Institute (PCORI)

Peter Meyers, BS, Program Director, Patient-Reported Outcomes, Partners HealthCare

Caleb Stowell, MD, Enterprise Director of Value Based Care, Providence St. Joseph Health



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# Wednesday, September 27



## 1:00 PM – 2:30 PM Concurrent Breakout Session 2 Location: See track detail below

### Track A: Advancing Clinical Care - Location: Room L South

#### **Interpretation of the PROMIS Physical Function CAT Compared to the IKDC-SKF after ACL reconstruction.**

James Irrgang, PT, PhD, University of Pittsburgh

#### **How Much Will I Improve After my surgery and Will I be Normal? The Critical Importance of Collecting and Discussing Patient Reported Outcomes Measures with Adult Spinal Deformity Patients.**

Shay Bess, MD, Presbyterian/St. Luke's Medical Center & Rocky Mountain Hospital for Children

#### **Correspondence of Performance Based Physical Tests and PROMIS Physical Function Scores in Community Dwelling Elderly.**

Ryan Jacobson, DPT, PCS, George Fox University

#### **Trends in PROMIS Scores in the Early Post-Operative Period Following Lateral Ankle Ligament Reconstructive Techniques.**

Allison McIntyre, MPH, University of Rochester Medical Center

### Track B: Enhancing Quality Measurement - Location: Room N

#### **Incorporating PROs into the EMR: The Northwestern Medicine Orthopaedic Surgery Joint Replacement Pilot.**

Surabhi Bhatt, BS, Northwestern Medicine; Begum Kutay, MS, Northwestern Medicine

#### **Incorporating PROMIS Symptom Measures into Primary Care Practice: A Randomized Trial.**

Kurt Kroenke, MD, Indiana University

#### **Implementing PROMIS for Routine Screening in Ambulatory Cancer Care.**

Sofia Garcia, PhD, Northwestern University

### Track C: Deploying Digital Tools - Location: Room Q

#### **The HealthMeasures API: Overview and User Experiences**

Michael Bass, MS, Northwestern University

Jeff Houck, PT, PhD, George Fox University

Rebecca Johnson, MPH, University of Utah

Joshua Spuhl, University of Utah

Heather Gold, PhD, NYU School of Medicine

Raj Karia, MPH, NYU School of Medicine

### Track D: Driving the Science - Location: Room P

#### **Assessing HIV-associated cognitive impairment.**

Bob Heaton, PhD, UCSD

#### **Multi Center Research: Cognitive data in the SEARCH for Diabetes in Youth Study.**

Greta Wilkening, PsyD, University of Colorado

#### **Cognition Assessment in TBI using NIH Toolbox.**

David Tulsky, PhD University of Delaware

#### **NIH Toolbox Equivalency Study.**

Jerry Slotkin, PhD, University of Delaware



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# Wednesday, September 27

## 2:30 PM – 3:30 PM Peer-to-Peer Roundtable Discussions Location: Harris Atrium

*Expert-facilitated small group discussions on issues and topics identified as priorities by HealthMeasures users.*

## 3:30 PM – 5:00 PM Concurrent Breakout Session 3 Location: See track detail below

### Track A: Advancing Clinical Care - Location: Room L South

#### **Validity of the Healing Encounters and Attitudes Lists (HEAL) in Persons with Ongoing Pain.**

Carol Greco, PhD, University of Pittsburgh

#### **Generalizability and Validation of PROMIS Scores to Predict Surgical Success in Foot and Ankle Patients.**

Jeff Houck, PT, PhD, (George Fox University)

#### **Computer-based Administration of Health Literacy and Functional Literacy Measures in Physical Rehabilitation Populations.**

Elizabeth Hahn, Northwestern University

#### **Using PROMIS to Assess QoL for Children with Brain Tumors.**

Jin-Shei Lai, PhD, Northwestern Univ.

### Track B: Enhancing Quality Measurement - Location: Room N

#### **PROMIS-29 V2.0 Physical and Mental Health Summary Scores.**

Ron Hays, PhD UCLA

#### **Introduction to the PROMIS-Preference (PROPr) Summary Score.**

Janel Hanmer, MD, PhD, University of Pittsburgh

#### **Feasibility of Home Health Care Patients' Self-Administration of the PROMIS Global Health Survey.**

Jennifer Riggs, PhD, RN, ABT Associates

### Track C: Deploying Digital Tools - Location: Room Q

#### Applying Custom Technologies: User Experiences

#### **Technical Evaluation of Implementing Patient-reported Outcomes Measures into an Electronic Health Record.**

Heather Gold, PhD, NYU School of Medicine

#### **COMPASS-CP: Precision Health at Its Best.**

Pamela Duncan, PhD, Wake Forest Baptist Health

#### **The Passport to Wellness: Mobilizing the Learner Workforce to Describe Health Determinants of Defined Populations.**

Leah FitzGerald, PhD, Mt. St. Mary's University

#### **Documenting sickle cell disease health-related quality of life in the electronic medical record.**

Lynne Neumayr, MD, UCSF Benioff Children's Hospital Oakland



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TRANSFORMING HOW HEALTH IS MEASURED

# Wednesday, September 27



**3:30 PM – 5:00 PM    Concurrent Breakout Session 3    Location: See track detail below**

**Track D: Driving the Science - Location: Room P**

**Capturing the Effect of COMT Inhibition on Sequelae of Brain Injuries with NIHTB and TBI-QoL.**

Emily Adams Berich, BS, Sheppard Pratt-Lieber Research Institute

**Understanding Patient Reported Outcome Measures in Individuals with Neurodegenerative Diseases that Include Cognitive Decline.** Noelle Carlozzi, PhD, University of Michigan

**PROMIS, Neuro-QoL, SCI-QoL, and TBI-QoL in Neurorehabilitation.** David Tulskey, PhD. University of Delaware

**5:00 PM – 6:30 PM    Poster Reception    Location: Harris Atrium**

- *Cocktail reception*
- *View and discuss more than 20 submitted posters.*
- *View exhibits*
- *Pre-arranged consultations with measurement science experts*



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# Thursday, September 28



**7:30 AM – 9:00 AM    Registration & Continental Breakfast    Location: Harris Atrium**

*Exhibits, networking & pre-arranged consultations with measurement science experts*

**9:00 AM – 10:00 AM    Plenary Session 2    Location: Harris Atrium**

## **Collecting Patient-Reported Outcomes in a Big Way: Challenges & Strategies**

*Healthcare executives and clinical leaders recently surveyed by NEJM Catalyst forecast that patient-generated data will be among the top 3 most useful sources of healthcare data within the next 5 years. This interactive discussion will explore challenges, strategies, and the potential associated with large-scale collection of patient-generated data for clinical and research applications.*

### **Moderator:**

Richard Gershon, PhD, Vice Chair for Research and Professor, Department of Medical Social Sciences, Northwestern University

### **Panelists:**

Paul Harris, PhD, Professor, Department of Biomedical Informatics, Vanderbilt University School of Medicine  
William (Bill) Riley, PhD, Director, NIH Office of Behavioral and Social Sciences Research  
Justin Starren, MD, PhD, Deputy Director, NUCATS Institute; Director, Center for Data Science & Informatics, Northwestern Univ.  
Man Hung, PhD, MEd, MStat, MSIS, Associate Professor, Department of Orthopaedics, University of Utah  
Rebecca Johnson, MPH, Associate Director of Research, Department of Orthopaedics, University of Utah

**10:00 AM – 11:30 AM    Concurrent Breakout Session 4    Location: See track detail below**

### **Track A: Advancing Clinical Care - Location: Room M**

**Characterizing Patients with Patient Acceptable Symptom State (PASS) after Selected Foot and Ankle Orthopedic Procedures Using Patient Reported Outcomes.** Jeff Houck, PT, PhD, George Fox University

**The Distribution of PROMIS Domains among Patients Undergoing Spine Surgery.**  
Amy Cizik, PhD, MPH, University of Washington

**Assessment of Health-Related Quality of Life in Adults Hospitalized with Sickle Cell Disease Vaso-Occlusive Crisis.** Kimberly Esham, MD, Tufts Medical Center

**Understanding the Need for Assistance when Completing Measures of Patient Reported Outcomes in Huntington Disease.** Elizabeth Hahn, Northwestern University

### **Track B: Enhancing Quality Measurement - Location: Room Q**

**PROMIS and the American Joint Replacement Registry: National implementation of PROMIS in a clinical data registry.** Caryn Etkin, PhD, MPH, American Joint Replacement Registry

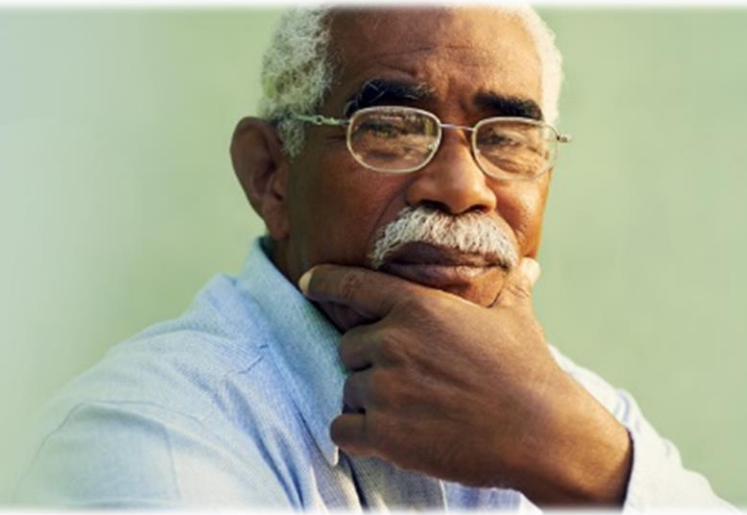
**Making a Swedish PROMIS: A Needs Assessment.**  
J.E. Chaplin, PhD, AFBPsS, Sahlgrenska Academy at University of Gothenburg

**ASCQ-Me and PROMIS in the Sickle Cell Disease Implementation Consortium Needs Assessment and Registry**  
Marsha Treadwell, PhD, Children's Hospital Oakland Research Institute  
Ellen Werner, PhD, MA, National Heart, Lung, and Blood Institute



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# Thursday, September 28



## 10:00 AM – 11:30 AM Concurrent Breakout Session 4 Location: See track detail below

### Track C: Deploying Digital Tools – Location: Room L North

#### Using HealthMeasures in Epic

Richard Gershon, Northwestern University  
Michael Schachter, Epic Business Analyst, Northwestern University  
Christa Martens, MPH, Northwestern University

### Track D: Driving the Science - Location: Room N

#### Advancing the Science of Pediatric Patient-Reported Outcomes for Children with Chronic Diseases: Update from the PEPR Consortium

Brandon Becker, PhD, MPH, Children's Hospital of Philadelphia  
Michelle Campbell, PhD, Center for Drug Evaluation and Research, U.S. Food and Drug Administration (FDA)  
Richard Gershon, PhD, Northwestern University  
Laura Schanberg, MD, Duke University Medical Center  
Carole Tucker, PT, PhD, Temple University  
James Witter, MD, PhD, National Institute of Arthritis and Musculoskeletal and Skin Diseases

## 11:30 AM – 12:30 PM Lunch & Plenary Session 3 Location: Harris Atrium

### HealthMeasures in the Regulatory Setting: The FDA Perspective

*This session will provide insight into the Clinical Outcome Assessment (COA) Qualification Program and what the FDA looks for when evaluating qualification submissions. We will also hear updates on qualification submissions involving HealthMeasures, and discuss how data collected by HealthMeasures users can help inform the FDA perspective.*

**Speaker:** Michelle Campbell, PhD, Center for Drug Evaluation and Research, U.S. Food and Drug Administration (FDA)

## 12:30 PM – 2:00 PM Concurrent Breakout Session 5 Location: See track detail below

### Track A: Advancing Clinical Care - Location: Room N

#### Cross-sectional Investigation of the Effects of Psychiatric Service Dogs on War Veterans with PTSD.

Kerri Rodriguez, MS, Purdue University

#### Performance of PROMIS and Legacy measures Among Advanced Breast Cancer Patients and their Caregivers.

Alla Sikorskii, PhD, Michigan State University

#### Change in CRP, Cortisol, and Quality of Life Among Cancer Survivors Following 26 Weeks of Exercise.

Heather Tarleton, PhD, Loyola Marymount University

### Track B: Special Session:

#### Incorporating HealthMeasures in Population Health Studies - Location: Room M

**Measuring Global Health in Large Population Surveys.** David Cella, PhD, Northwestern University  
**Update on ECHO (Environmental Influences on Child Outcomes)** Courtney Blackwell, PhD, Northwestern University



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TRANSFORMING HOW HEALTH IS MEASURED



# Thursday, September 28

**12:30 PM – 2:00 PM    Concurrent Breakout Session 5    Location: See track detail below**

**Track C: Deploying Digital Tools - Location: Room Q**

**Accessing HealthMeasures in OBERD and REDCap**

Michael Bass, MS, Northwestern University  
Paul Harris, PhD, Vanderbilt University and REDCap  
Otho Plummer, PhD, and Nathan Bleigh, M.Sc., OBERD

**Track D: Driving the Science - Location: Room L North**

**Completing the Circle: Novel Methods for using PRO Scores in Shared Decision-Making and Patient Self-Management.** Karon Cook, PhD, Northwestern University

**Bringing the Clinical Potential of PROMS to Patients Receiving Orthopedic Care.**

Julie Fritz, PT, PhD, University of Utah

**Evaluating Priorities and Interventions in Spinal Cord Injury Rehabilitation.**

Vanessa K. Noonan, PhD, PT, Rick Hansen Institute

**2:00 PM – 3:30 PM    Conference Recap & Community Town Hall    Location: Harris Atrium**

- *Rapid-fire review of key issues and takeaways from the 4 conference breakout tracks:*
  - *Advancing Clinical Care*
  - *Enhancing Quality Measurement*
  - *Deploying Digital Tools*
  - *Driving the Science*
- *Interactive, user-led forum to discuss issues emerging from conference sessions and future directions*
- *Conference closing*



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AMT Study On Quality of Life Measurement Information System

NeuroQoL



## USER CONFERENCE

Thank you for being part of the HealthMeasures community.  
Together, we are transforming how health is measured.

Find copies of measures, helpful resources, and the HealthMeasures User Forum at:

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



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