



HealthMeasures



ASCQ-Me[®]

NeuroQoL



USER CONFERENCE

Program

2019 HealthMeasures User Conference

June 4-6, 2019

Prentice Women's Hospital Conference Center
250 E. Superior Street, 3rd Floor
Chicago, Illinois

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Tuesday, June 4th

Pre-Conference Learning Day



7:30 am – 8:30 am Registration & Continental Breakfast Location: Harris Atrium

8:30 am – 12:00 pm Full-Day Training Sessions Begin

Introduction to PROMIS[®], Neuro-QoL[™] and ASCQ-Me[®].....Location: Canning Auditorium

Session Leaders: Susan Yount, PhD, Associate Professor, Northwestern University

This 1-day training is appropriate for researchers and clinicians who are new to HealthMeasures, patient-reported outcomes (PROs), item response theory (IRT), and integrating such measures into research and clinical workflows. Participants will receive an overview of three measurement systems (PROMIS, Neuro-QoL and ASCQ-Me) along with an introduction to IRT and computer adaptive tests (CAT). Additional topics will include administration options, the HealthMeasures Scoring Service, free tools and resources available at HealthMeasures.net, and practical considerations for implementation in clinical practice and research settings.

NIH Toolbox[®] iPad App Training.....Location: L-North

Session Leaders: Julie Hook, MBA, PhD, NIH Toolbox Product Manager, Northwestern University; Cindy Nowinski, MD, PhD, Research Associate Professor, Northwestern University

A 1-day, intensive session in which participants will learn how to administer NIH Toolbox performance measures using the NIH Toolbox iPad app. Sessions will teach the basic knowledge and skills to familiarize participants with the administration of the NIH Toolbox iPad app, self- and proxy-report measures of emotional function, and the performance-based tests of cognitive, motor, and sensory function. For this training, an emphasis will be placed on the administration of cognitive tests. Participants are required to bring their own iPad with the NIH Toolbox app installed.

12:00 pm – 1:00 pm Lunch Location: Harris Atrium

1:00 pm – 5:00 pm Full-Day Training Sessions Continue

1:30 pm – 5:00 pm Afternoon Workshop

Implementing Patient-Reported Outcomes in Clinical Practice.....Location: L-South

Session Leader: Nan Rothrock, PhD, Associate Professor, Northwestern University. **Presenters:** Allison McIntyre, MPH, Clinical Program Manager, University of Rochester; Steven Schuetz, MD, Chief Resident, General Surgery, Northwestern Medicine and Founder, PROMIS-Bolivia S.A.; Janel Hanmer, MD, PhD, Assistant Professor of Medicine, University of Pittsburgh; Amy Cizik, PhD, MPH, Research Assistant Professor, Dept. of Orthopaedics and Sports Medicine, University of Washington

Four healthcare organizations—ranging from academic medical centers to private clinics to low-resource settings—describe how they successfully applied principles from implementation science and organizational transformation to integrate PROs into clinical practice. Presenters will address workflow change, provider and staff education, data collection, electronic medical record (EMR) integration, and use of PRO data in shared decision-making.

Wednesday, June 5th Conference Day 1



7:30 am – 8:30 am Registration & Continental Breakfast Location: Harris Atrium

Exhibits, networking, & pre-arranged consultations with HealthMeasures experts.

8:30 am – 11:30 am Welcome & Opening Plenary Location: L-South

Welcome: Susan Yount, PhD, Conference Co-Chair & Associate Professor, Northwestern University;
Dave Cella, PhD, Northwestern University, HealthMeasures PI

Opening Plenary: Turning Insights Action

Patient-centered outcomes assessments hold the potential to deliver actionable insights and improved outcomes across the healthcare system, from clinical research and patient care to population health research and quality evaluation. This session will present a framework for collecting and using outcomes assessments in ways that yield benefits at multiple levels, and will highlight the experiences and perceptions of patients, providers, and payers working with outcomes assessments to achieve important goals.

Moderator:

Zeeshan Butt, PhD, Conference Co-Chair, Associate Professor, and Associate Director, Center for Patient Centered Outcomes, Northwestern University

Presenters & Panelists:

Patricia Franklin, MD, MPH, MBA, Professor, Northwestern University
Nan Rothrock, PhD, Associate Professor, Northwestern University
Allen Heinemann, PhD, Professor, Northwestern University; Director, Center for Rehabilitation Outcomes Research, Shirley Ryan AbilityLab
James (Jim) Poyer, MBA, MS, Director - Division of Value, Incentives and Quality Reporting, Centers for Medicare & Medicaid Services (CMS)
Cynthia Barnard, PhD, MBA, Vice President - Quality, Northwestern Memorial HealthCare
Northwestern Medicine Patient and Family Advisory Council representatives

11:30 am – 12:30 pm Lunch Location: Harris Atrium

12:45 pm – 1:45 pm Concurrent Breakout Session 1 Location: See detail below

PRO Track Option 1: Validation & Interpretation - Oncology and Orthopaedics.....Location: L-South

Measurement invariance of the PROMIS Global Health measure in a large prospective cancer cohort. Elizabeth Fallon MPH, PhD, American Cancer Society

Using PROMIS tools to assess change in patients' experiences of anxiety, depression, and pain among cancer survivors in a survivorship clinic. Erin Peregrine Antalis, PhD, University of Michigan

Construct validity and precision of different patient reported outcome measures during recovery after upper extremity fractures. Prakash Jayakumar MBBS, MRCS, FSEM, DPhil, University of Texas at Austin

More breakout options, next page>>

Wednesday, June 5th Conference Day 1



12:45 pm – 1:45 pm Concurrent Breakout Session 1 *(continued)*

PRO Track Option 2: Validation & Interpretation - PROMIS Profiles.....Location: L-North

PROMIS domain scores are associated with utilization in an outpatient sample of neurology patients. Janel Hanmer, MD, PhD, University of Pittsburgh Medical Center

Examination of the PROMIS-29 health scales in patients with human immunodeficiency virus (HIV). Benjamin D. Schalet, PhD, Northwestern University, Feinberg School of Medicine

Translation and linguistic validation of the 6 PROMIS profile domains for adults in Korean. Juhee Cho, MA, PhD, Center for Clinical Epidemiology, Samsung Medical Center

NIH Toolbox Track: Keynote Presentations.....Location: Canning Auditorium

The current state of the NIH Toolbox. Richard Gershon, PhD, Northwestern University

The NIH Toolbox Cognitive Battery for special populations: The case of intellectual disabilities. David Hessel, PhD, University of California - Davis

1:45 pm – 2:00 pm Break

2:00 pm – 3:00 pm Concurrent Breakout Session 2 Location: See detail below

PRO Track Option 1: Validation & Interpretation – Addiction and Pain Medicine.....Location: L-South

Listening to the stakeholders: Implementing HEAL contextual factor assessments into clinical settings. Nathan E. Dodds, BS, University of Pittsburgh, Northwestern University

Using PROMIS and Neuro-QoL in residential drug treatment facilities for both client assessment and program evaluation. Ann Kerlin, BBA, MDiv, MA, PhD, LPC, Luther Rice College & Seminary

PRO Track Option 2: Methods and Driving the Science.....Location L-North

Multidimensional computer adaptive testing with PROMIS item banks. Michael Bass, MS, Northwestern University

Evaluating clinical impact of a standard error reduction (SER) based stopping rule for PROMIS CAT instruments. Kathleen Fear, PhD, University of Rochester Medical Center

The Neuro-QoL Utility (NQU) Scoring System. Barry Dewitt, PhD, Carnegie Mellon University

[More breakout options, next page>>](#)



Wednesday, June 5th Conference Day 1



2:00 pm – 3:00 pm Concurrent Breakout Session 2 *(continued)*

NIH Toolbox Track: Use of NIH Toolbox in Neurologic Conditions.....Location: Canning Auditorium

Development of embedded performance validity indicators in the NIH Toolbox Cognitive Battery. Christopher Abeare, PhD, University of Windsor

ARMADA: Advancing Reliable Measurement in Alzheimer’s Disease and Cognitive Aging. Devin Peipert, PhD, Northwestern University

Validity and utility of the NIH Toolbox for assessment of prodromal Alzheimer’s and dementia. Katherine Hackett, Temple University

3:00 pm – 3:15 pm Break

3:15 pm – 4:15 pm Concurrent Breakout Session 3 Location: See detail below

PRO Track Option 1: Focus on Implementation –Technology & Communication.....Location: L-South

Building a novel and flexible electronic patient-reported outcome collection system for cellular therapy research. Deborah Mattila, MLIS, CIBMTR / National Marrow Donor Program

Utilizing PROMIS measures for pain management. Mehmet Kazgan, MSc, MBA, cliexa

Implementation and utilization of patient-reported outcomes at the behavioral health point-of-care. Robert Schloesser, MD, Sheppard Pratt Health System

PRO Track Option 2: Works in Progress Feedback Session.....Location: L-North

PROMIS Pediatric sleep-wake function measures correlate with objective sleep disturbance in atopic dermatitis. Anna Fishbein, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

PROMIS(e) of self-efficacy for managing after distal radius fracture: Opportunities and challenges beyond chronic conditions. Brocha Z. Stern, MOT, OTR, CHT

Developing clinically-relevant, patient-centric health status measure for patients with heart failure built on PROMIS. Faraz Ahmad, MD, MS, Northwestern University

NIH Toolbox Track: Use of NIH Toolbox in Special Populations.....Location: Canning Auditorium

Utilization of NIH Toolbox Cognition Battery in a rare disease conference setting. Juliet Monet Torres, Ann & Robert H. Lurie Children's Hospital of Chicago

Using the NIH Toolbox with transgender and non-binary youth. Victoria Kolbuck, MSW, Ann & Robert H. Lurie Children's Hospital of Chicago

Impact of a gluten free diet on celiac disease as measured by the NIH PROs. Jeffrey Cassisi, PhD, Univ. of Central Florida



Wednesday, June 5th Conference Day 1



4:30 pm – 6:00 pm HealthMeasures Poster Reception

Location: Harris Atrium

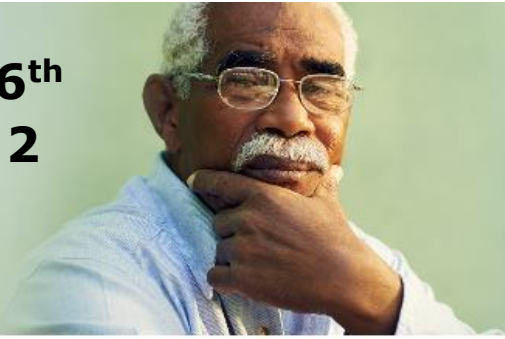
Please join us in the Harris Atrium for:

- *Cocktails and light hors d'oeuvres*
- *Poster presentations*
- *Exhibits and networking*
- *Pre-arranged consultations with HealthMeasures experts*



HealthMeasures
TRANSFORMING HOW HEALTH IS MEASURED

Thursday, June 6th Conference Day 2



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

Exhibits, networking, & pre-arranged consultations with HealthMeasures experts.

8:00 am – 9:00 am Special Topic Sessions **Location: See detail below**

Assessment Center API Roundtable.....Location: Room Q

Session Leader: Michelle Langer, PhD, Assessment Center API Product Manager, Northwestern University

The Assessment Center API is a data collection tool that integrates into electronic health records and other data collection platforms for administration and scoring of over 500 measures (including PROMIS and other HealthMeasures). This session: (1) provides an overview of the software, (2) allows current users to share their experiences and receive support, and (3) engages potential users to learn from current users and the HealthMeasures team.

Gaining a user’s perspective on the NIH Toolbox and our iPad apps.....Location: Room N

Session Leader: Julie Hook, MBA, PhD, NIH Toolbox Product Manager, Northwestern University

This session will begin with an overview of the NIH Toolbox and our iPad apps, to be followed by an interactive session in which users will be asked to provide feedback on their experience with the apps and to comment on future directions.

9:00 am – 10:00 am Concurrent Breakout Session 4 **Location: See detail below**

PRO Track Option 1: Validation & Interpretation in Pediatrics.....Location: L-South

Evaluating the social health of pediatric patients using PROMIS Peer Relationships: Social work intervention thresholds. Shelley Collins, BA, Shriners Hospital for Children-Salt Lake City

Don’t throw the baby out with the bathwater: Creating developmentally-appropriate PROMIS early childhood parent-proxy instruments. Courtney K. Blackwell, PhD, Northwestern University Feinberg School of Medicine

Symptom burden reported by children and adolescents with neurofibromatosis type 1 associated plexiform neurofibroma. Jin-Shei Lai, PhD, OTR/L, Northwestern University

PRO Track Option 2: Focus on Implementation - Shared Decision Making.....Location: L-North

Integrating patient-reported measures and predictive data in a shared decision report for knee and hip arthritis treatment decisions. Hua Zheng, PhD, University of Massachusetts Medical School

Implementing PRO-based patient-clinician shared decision reports in the learning healthcare system. Christina Bond, MS, Patient Research Group

The relationship between the magnitude of limitations and patient experience during recovery from an upper extremity fracture. Prakash Jayakumar MBBS, MRCS, FSEM, DPhil, University of Texas at Austin

More breakout options, next page>>>



Thursday, June 6th Conference Day 2



9:00 am – 10:00 am Concurrent Breakout Session 4 (continued)

NIH Toolbox Track: Use of NIH Toolbox in Non-clinical Populations.....Location: Canning Auditorium

The Spanish version of the NIH Toolbox: Overview and development. Rina Fox, PhD, MPH, Northwestern University.

Use of the NIH Cognition Toolbox with pediatric samples. Natacha Akshoomoff, PhD, University of California – San Diego

Effect of one season of tackle football on young athletes' cognitive function: A novel use of NIH Toolbox Cognition Battery. Carly Strobach, CCRP, Ann & Robert H. Lurie Children's Hospital of Chicago

10:00 am – 10:15 am Break

10:15 am – 11:15 am Concurrent Breakout Session 5 Location: See detail below

PRO Track Option 1: Validation & Interpretation – ASCQ-Me and PROMIS.....Location: L-North

Clinician-reported Inpatient Physical Function: A new measure derived from PROMIS Adult Physical Function. Heather Brown, MSPT, Kaiser Permanente

Longitudinal relationship between hydroxyurea adherence and health-related quality of life among adolescents with sickle cell disease. Sherif M. Badawy, MD, MS, Ann & Robert H. Lurie Children's Hospital of Chicago

ASCQ-Me and PROMIS in the Sickle Cell Disease Implementation Consortium Needs Assessment: Follow-up. Marsha Treadwell, PhD, UCSF Benioff Children's Hospital Oakland

PRO Track Option 2: Validation & Interpretation – PROMIS.....Location: L-South

Characterizing health-related quality of life in narcolepsy: A mixed-methods study. Cameron Moore, BS, Northwestern University Feinberg School of Medicine

Using PROMIS in batterer intervention programs: Towards program evaluation. Colleen E. Crangle, PhD, University of Louisville / Converspeech LLC

Development, validation and interpretation of the PROMIS Itch Questionnaire. Jonathan Silverberg, MD, PHD, MPH, Northwestern University

NIH Toolbox Track 5 – Keynote Presentation.....Location: Canning Auditorium

Using Health Measures instruments with individuals with disabilities. David Tulsy, PhD, University of Delaware
(Note: This session will cover the use of NIH Toolbox, PROMIS and Neuro-QoL in rehabilitation populations.)

11:30 am – 12:30 pm Lunch Location: Harris Atrium



Thursday, June 6th Conference Day 2



12:45 pm – 1:45 pm Concurrent Breakout Session 6 Location: See detail below

PRO Track Option 1: Focus on Implementation – Pediatrics.....Location: L-South

Integrating pediatric PROMIS measures into clinical and technology operations of Shriners Hospitals for Children health system. Maureen Cottom, MBA, PMP, Shriners Hospitals for Children

Planning for a multicenter longitudinal pediatric implementation of PROMIS standard of care data collection. Molly McGuire, MPH, Texas Scottish Rite Hospital for Children

Home-based assessment of patient reported outcome measures using a smartphone app platform: A feasibility study. Sherif M. Badawy, MD, MS, Ann & Robert H. Lurie Children's Hospital of Chicago

PRO Track Option 2: Works in Progress Feedback Session.....Location: L-North

Mindful Measures: Creating item banks of mindfulness using PROMIS® methodology. Stephen J. Suss Jr., BS, University of Pittsburgh

Socio-technical evaluation of PROMIS patient-reported outcome (PRO) measures in the Northwestern Memorial Hospital urology clinic. Therese A. Nelson, MLA, AM, LSW, Northwestern University

Identifying symptoms clusters among pediatric chronic kidney disease patients using PROMIS® computer adaptive tests. Devin Peipert, PhD, Northwestern University

NIH Toolbox Track: Use of NIH Toolbox in Chronic Illness.....Location: Canning Auditorium

NIH Toolbox Cognition Battery is sensitive to HIV-associated neurocognitive disorders: An examination across administration platforms. Kaitlin Casaletto, PhD, University of California – San Francisco

Exploring cognitive dysfunction in older adults living with HIV using the NIH Toolbox Cognition Battery. Judy Frain, PhD, RN, Barnes Jewish College

Using the NIH Toolbox Cognition and Emotion Batteries to predict neural markers of psychopathology. Raluca Petrican, PhD, University of Toronto

1:45 pm – 2:00 pm Break

2:00 pm – 3:30 pm Closing Plenary & Community Town Hall Location: Harris Atrium

Closing Plenary: Focus on the Future

A compelling look at emerging trends in research, technology, clinical care, and patient engagement that are shaping the future of outcomes assessment. The conference will close with an interactive, 30-minute Q&A session.

Moderator: Roxanne E. Jensen, PhD, Program Director, Outcomes Research Branch, National Cancer Institute

Presenters and Panelists:

- Ashley Wilder Smith, PhD, MPH, Chief, Outcomes Research Branch, National Cancer Institute
- Molly Wagster, PhD, Chief, Behavioral & Systems Neuroscience Branch, Div. of Neuroscience, National Institute on Aging
- Karon Cook, PhD, Research Professor, Northwestern University
- Richard Gershon, PhD, Professor, Northwestern University
- Michael Bass, MS, Research Assistant Professor, Northwestern University





HealthMeasures



ASCQ-Me[®]
AMT (AHRQ) Best 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



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