Inaugural Conference Program

May 15, 2015

Philadelphia Marriott
Philadelphia, PA
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Morning Plenary
8:00 am-9:30 am Liberty Ballroom

8:00 Welcome on Behalf of the PHO
Christopher Forrest, MD, PhD & Karon Cook, PhD
Children’s Hospital of Philadelphia, Northwestern University
Conference Chair, Co-Chair

8:10 Welcome on Behalf of the National Institutes of Health
Ashley Wilder Smith, PhD, MPH
Chief, Outcomes Research Branch
National Cancer Institute, National Institutes of Health

8:15 THE STATE OF PROMIS®
David Cella, PhD
Northwestern University

9:00 GLOBAL PERSPECTIVE - PROMIS INTERNATIONAL
Jordi Alonso, MD, PhD
Director, Epidemiology & Public Health Program
IMIM - Hospital del Mar Medical Research Institute
Barcelona Spain

9:15 Karon Cook, PhD Discussion Moderator

9:30 am - 9:45 am Break
Concurrent Session #1
9:45 am-11:00 am
Room: Liberty Ballroom
Advances in Patient-Centered Outcomes Research

9:45  Clifton Bingham, MD  Using PROMIS in PCOR: Lessons from PCORI’s Pilot Projects
10:00  Amy Eisenstein, PhD  Standardizing and Personalizing Patient-Centered Rheumatoid Arthritis Treatment Targets
10:15  Ana Maria Rodriguez, PhD MSc, PT & Ari Gnanasakthy, PhD  The Future of PRO Development: Using Technology to Advance Patient-Centered Measure Development - Part 1
10:30  Tamara Kear, PhD, RN  The Future of PRO Development: Using Technology to Advance Patient-Centered Measure Development - Part 2
10:45  David Cella, PhD  Moderated Discussion

Room: 302/303
Clinical Validity of PROMIS: Musculoskeletal Disorder

9:45  Susan Bartlett, PhD  How Well Do Generic Patient PROMIS Instruments Capture Health Status in Rheumatoid Arthritis?
10:00  Dinesh Khanna, MD, MS  The PROMIS-29 In Systemic Sclerosis: Associations With Clinical Characteristics
10:15  Constance Mara, PhD  Establishing Clinical Meaning and Severity Cut-points on Patient Reported Outcome Measures in Juvenile Idiopathic Arthritis
10:30  Dennis Revicki, PhD  Developing The Fibrodysplasia Ossificans Progressiva -Physical Function Questionnaire For Adults: Intelligent Test Design Using A PROMIS Item Banks
10:45  David Tulsky, PhD  Moderated Discussion
Room: 304/305

New Item Bank Development

9:45  Brandon Becker, MPH  Estimating Pediatric PROMIS Item Bank Item Parameters Representative of the US Population
10:00  Carol Greco, PhD  New Patient-Reported Measures of Contextual Factors in Healing
10:15  Ann Gruber-Baldini, PhD  Calibration and Validation of the PROMIS Self-Efficacy for Managing Chronic Conditions Measures
10:30  Karen Schifferdecker, PhD, MPH  Creating Condition-Specific Patient Reported Outcome Measures
10:45  San Keller, PhD  Moderated Discussion

11:00 am-11:15 am Break

The mission of the PHO is to improve health outcomes by developing, maintaining, improving, and encouraging the application of the Patient Reported Outcomes Measurement Information System (PROMIS).

The four main goals of the PHO, which complement both the PHO’s mission and values, are the following:

1. Advance the science of health outcomes assessment,
2. Disseminate standardized and validated health outcome metrics,
3. Foster the development of new patient-reported health outcomes for diverse populations, and
4. Educate the scientific and clinical communities on the science of patient-reported outcomes.

Interested in learning more about PHO?

Send us an email:  Julie-Kay@northwestern.edu
### Concurrent Session #2
11:15 am-12:30 pm

**Room: Liberty Ballroom**

**Digital Innovations: Web-Based Scoring, EHRs, mHealth, and CAT**

<table>
<thead>
<tr>
<th>Time</th>
<th>Speaker</th>
<th>Title</th>
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<tbody>
<tr>
<td>11:15</td>
<td>Michael Kallen, PhD, MPH</td>
<td>Grooming a CAT: Customizing CAT Administration Parameters to Increase Response Efficiencies in Specific Research and Clinical Settings</td>
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<tr>
<td>11:45</td>
<td>Heidi Crane, MD, MPH</td>
<td>Lessons From Implementing and Collecting PROs for HIV Care and Research: Results From 10,000 Patients</td>
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<tr>
<td>12:00</td>
<td>James Willig, MD, MSPH</td>
<td>Basic PROMIS Panel: A Proposal for a Unified Visual Interface to Summarize Multiple PROMIS Domains</td>
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<td>12:15</td>
<td>Karon Cook, PhD</td>
<td>Moderated Discussion</td>
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**Room: 302/303**

**Cross-Cultural Issues and Vulnerable Populations**

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<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td>11:15</td>
<td>Christopher Forrest, MD, PhD</td>
<td>Profile of Subjective Well-Being Among Children on The US</td>
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<tr>
<td>11:30</td>
<td>Elizabeth Hahn, MA</td>
<td>Health Literacy and Patient-Reported Outcomes In Underserved English- and Spanish-Speaking Diabetes Patients</td>
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<tr>
<td>11:45</td>
<td>Ulrike Ravens-Sieberer, PhD, MPH</td>
<td>Translation of eight Pediatric PROMIS item banks into Spanish and German</td>
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<tr>
<td>12:00</td>
<td>Gemma Vilagut, MSc</td>
<td>The Spanish PROMIS® Depression measures a-Clinical Sample of Mental Health Patients</td>
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<tr>
<td>12:15</td>
<td>Dagmar Amtmann, PhD</td>
<td>Moderated Discussion</td>
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Room: 304/305

Clinical Validity of PROMIS: Cancer and Orthopedics

11:15  Roxanne Jensen, PhD  Evaluation of Responsiveness of Eight PROMIS Measures in a Community-Based Sample of Cancer Patients
11:30  George Stukenborg, PhD  PROMIS Assessment for Patients Undergoing Colorectal Surgery in Enhanced Recovery Protocol
11:45  Nan Rothrock, PhD  Validation of PROMIS Mobility Computer Adaptive Test and Short Form in Patients with Orthopedic Trauma
12:00  Nan Rothrock, PhD  Validation of PROMIS Computer Adaptive Tests in Lumbar Stenosis Patients
12:15  Dinesh Khanna, MD, MS  Moderated Discussion

Lunch Plenary
12:30 pm - 1:30 pm
Liberty Ballroom

1:00  PROs: The Patient’s Voice Realized - The Pain Care Experience

Ivan Lesnik, MD

Chief of Pain Services
Department of Anesthesiology and Pain Medicine
Harborview Medical Center
Seattle, WA

1:15  Karon Cook, PhD Discussion Moderator
# Concurrent Session #3
1:30 pm-2:45 pm

## Room: Liberty Ballroom

### Integration of PROs into Clinical Practice

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<tr>
<th>Time</th>
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<th>Title</th>
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<tbody>
<tr>
<td>1:30</td>
<td>Yvonne Lee, MD, MMSc</td>
<td>PROMIS Pain, Fatigue, Sleep, Fatigue, Anxiety and Depression in Patients with Active Rheumatoid Arthritis</td>
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<tr>
<td>1:45</td>
<td>Karon Cook, PhD</td>
<td>Uncle Sam Wants PROMIS: Leveraging PROMIS to Build and Pilot the DoD’s Pain Assessment Screening Tool and Registry (PASTOR)</td>
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<tr>
<td>2:00</td>
<td>George Stukenborg, PhD</td>
<td>Collection And Use of PROMIS Measures for Palliative Care Cancer Patients</td>
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<tr>
<td>2:15</td>
<td>James Willig, MD, MSPH</td>
<td>PRO Implementation In Clinical Practice: Failure as a Steppingstone To Success</td>
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<tr>
<td>2:30</td>
<td>Chris Forrest, MD, PhD</td>
<td>Moderated Discussion</td>
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## Room: 302/303

### EQ-5D and PROMIS and PROMIS en Français

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<tbody>
<tr>
<td>1:30</td>
<td>Susan Bartlett, PhD</td>
<td>PROMIS-29 en Français: Coordinating Translation Efforts in Canada and France for a Universal Approach</td>
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<tr>
<td>1:45</td>
<td>John Hartman, MA</td>
<td>Comparison of PROMIS-29 and EQ-5D-3L Quality-Adjusted Life Years</td>
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<td>2:00</td>
<td>Irene Katzan, MD</td>
<td>Predicting EQ-5D Utility Index from the PROMIS-10 Global Form – Ready for PrimeTime?</td>
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<tr>
<td>2:15</td>
<td>Shannon Runge, MA</td>
<td>Choosing between the PROMIS Global and EQ-5D for Comparative Effectiveness Research: Are they really different?</td>
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<td>2:30</td>
<td>Kathleen Lohr, PhD</td>
<td>Moderated Discussion</td>
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PROMIS and Behavioral Health

1:30  Jason Colditz, MEd  Social Media Use and Anxiety as Measured by the PROMIS Anxiety Short Form

1:45  Paul Crane, MD, MPH  Measurement Precision and Differential Classification of At-Risk Alcohol Use with AUDIT-C vs. PROMIS in HIV

2:00  Sherri LaVela, PhD, MPH, MBA  Assessing Physical and Mental Health of Veterans Receiving VA Health Care Using a PROMIS Profile

2:15  Priscilla Schulz, MSW, LCSW-C  PROMIS®29: A Tool for Improving Mental Healthcare and Well-Being of US Peace Corps Volunteers

2:30  Lisa Shulman, MD  Moderated Discussion

2:45 pm-3:00 pm Break

Closing Plenary

3:00 pm-4:00 pm Liberty Ballroom

Visioning the Future of Person-Reported Outcomes

3:00  Lori Frank, PhD
      Program Director, Science, PCORI

3:10  Sean McCormick, MD
      Epic PRO initiative

3:20  Nancy Santanello, MD, MS, FISPE
      Retired VP Epidemiology
      Merck Research Laboratories

3:30  Elektra Papadopoulos, MD, MPH
      Medical Officer
      US Department of Health and Human Services

3:40  David Cella, PhD  Discussion Moderator
Join us in the Independence Ballroom for the Poster Reception

4:00 pm - 6:00 pm

Thank you to the Conference Committee:

Chris Forrest, Chair & Karon Cook, Co-Chair
Dagmar Amtmann Dinesh Khanna
David Cella Kathleen Lohr
Julie Kay Lisa Shulman
San Keller David Tulsky