

# PROMIS TERMS AND CONDITIONS

**3/28/2014**

You understand and agree that the PROMIS Health Organization and PROMIS Cooperative Group provide access to PROMIS instruments (e.g., item banks, short forms, profile measures) subject to the PROMIS Terms and Conditions (PTAC). The PROMIS Health Organization/Cooperative Group reserves the right to update the PTAC at any time. Changes in the PTAC will apply to new users, new instruments and to new projects created by existing users after these changes are posted. The most current version of the PTAC can be reviewed by clicking on the Terms of Use hypertext link located in Assessment Center or on the Assessment Center Homepage.

## TERMS FOR USE OF PROMIS INSTRUMENTS

PROMIS instruments measuring a variety of domains (see [nihpromis.org](http://nihpromis.org) for full domain framework) are available for adult and pediatric self-report and parent proxy report. These tools were developed in the English language using extensive qualitative methods to ensure conceptual and semantic clarity. They have been tested for reliability and comparability to more established measures of these same content areas. Calibration testing was conducted in adult, pediatric, and parent proxy samples. A full description is available at <http://nihpromis.org/science/sciencehome>. The item calibrations and test statistics provided are all based upon cross-sectional data collection. Use of PROMIS instruments in clinical research is encouraged, with the understanding that data collected from that use will contribute to knowledge about the validity of PROMIS measures. **USERS OF PROMIS TOOLS ARE STRONGLY ENCOURAGED TO SUBMIT A BRIEF REPORT INCLUDING SAMPLE DEMOGRAPHIC INFORMATION, CLINICAL DATA SUFFICIENT TO DEFINE THE SAMPLE WITHOUT INDICATING TREATMENT RESPONSE DATA, AND PROMIS SCORE DISTRIBUTIONS (E.G., BASELINE MEAN AND STANDARD DEVIATIONS OR CHANGE SCORES BLINDED TO TREATMENT INFORMATION).** This brief report should be submitted to [help@assessmentcenter.net](mailto:help@assessmentcenter.net) for internal review. None of this submitted information will be published without the written consent and participation of the submitter. In addition to the brief report, clinical researchers are encouraged to submit de-identified data for collaborative analysis and reporting. Data ownership would remain with the submitter. Clinical researchers are strongly encouraged to collaborate with PROMIS investigators when applying these items and banks to their research.

**ANY PUBLICATION OR PRESENTATION OF RESULTS OBTAINED FROM STUDIES CONDUCTED USING THESE INSTRUMENTS SHOULD INCLUDE A STATEMENT THAT INDICATES WHICH PROMIS INSTRUMENTS (INCLUDING VERSION NUMBER) WERE USED, AND REFERENCE THE PROMIS SITE ([WWW.NIHPROMIS.ORG](http://WWW.NIHPROMIS.ORG)) FOR FURTHER INFORMATION.**

PERMISSION TO USE PROMIS INSTRUMENTS DOES NOT GRANT PERMISSION TO MODIFY THE WORDING OR LAYOUT OF ITEMS, TO DISTRIBUTE TO OTHERS, OR TO TRANSLATE ITEMS INTO ANY OTHER LANGUAGE. SUCH PERMISSION TO MODIFY, DISTRIBUTE, OR TRANSLATE MUST BE REQUESTED FROM THE PROMIS HEALTH ORGANIZATION OR THE OWNER OF THE COPYRIGHTED MATERIALS FROM WHICH PROMIS HAS BEEN DERIVED.

## COPYRIGHT NOTICE AND CLAIMS OF COPYRIGHT INFRINGEMENT

**Information and materials contained herein are ©2008-2014 PROMIS Health Organization and PROMIS Cooperative Group or other individuals/entities that have contributed information and materials to Assessment Center, and are being used with the permission of the copyright holders.**

The table set forth below identifies individuals and entities who have contributed items in support of building PROMIS item banks and the copyrighted information and materials employed by such persons. As a user of PROMIS you are entirely responsible for respecting the proprietary rights of such persons, and for complying strictly with the requirements set forth herein. If you have questions about these requirements and your legal obligations, you may wish to consult an attorney.

Thomas M. Achenbach, PhD Child Behavior Checklist for Youth
Torbjörn Åkerstedt Karolinska Sleep Diary
Stanley E. Althof Center for Marital and Sexual Health Sexual Functioning Questionnaire
Julie Barroso, PhD HIV-Related Fatigue Scale
Dorcas Beaton Disabilities of the Arm, Shoulder and Hand (DASH)
Basia Belza Multidimensional Assessment of Fatigue
Jill Binkley, PT Lower Extremity Functional Scale
Thomas Borkovec Penn State Worry Questionnaire
Lynn Breau Non-communicating Children's Pain Checklist
Bengt Brorsson Swedish Health Related Quality of Life Survey
Richard Brown, PhD Parkinson Fatigue Scale
Elly Budiman-Mak, MD Foot Function Scale
Arnold Buss Buss-Durkee Hostility Inventory
Daniel J. Buysse Pittsburgh Sleep Quality Index
Andrei Calin, MD Bath Ankylosing Spondylitis Function Index (BASFI)
David Cella, PhD Functional Assessment of Chronic Illness Therapy (FACIT) Center on Outcomes, Research, and Education Item Banks
Larry Chambers, PhD

McMaster Health Index Questionnaire
Trudie Chadler 14-Item fatigue scale
Ann Coscarelli, Cancer Rehabilitation Evaluation System (CARES)
Kimberly A. Cote Brock Sleep and Insomnia Questionnaire
Laura Creti Sexual History Form
Peter Dent, MD Juvenile Arthritis Self-Report Index (JASI)
George Domino Assessment of Sleep Sleep Questionnaire
Maxime Dougados, MD Dougados Functional Index (DFI)
Alan B. Douglass Sleep Disorders Questionnaire
M Tuncay Duruoz, MD Duruoz Hand Index
Jack D. Edinger Edinger's Sleep History Questionnaire
Colin A. Espie Beliefs and Attitudes about Sleep Scale Dysfunctional Beliefs and Attitudes about Sleep Scale - 10 Glasgow Content of Thoughts Inventory Insomnia Impact Scale Sleep Disturbance Questionnaire
Jeremy Fairbank, MD Oswestry Low Back Pain Disability Questionnaire (OLBPDQ)
Catherine S. Fichten Sleep Diary Sleep Questionnaire
Robert Ficke Performance Outcomes Measures Project
J.D. Fisk Fatigue Impact Scale
James F Fries, MD Health Assessment Questionnaire (HAQ)
Richard Gracely Descriptor Differential Scale of Pain Affect (DDS - Pain Affect item)
Johanna CJM de Haes, PhD Rotterdam Symptom Checklist
Stephen Haley, PhD Late Life Function and Disability Instrument: Function Component
Danete Hann, PhD and Paul Jacobsen, PhD Fatigue Symptom Inventory

Philip S Helliwell, MD, PhD Revised Leeds Disability Questionnaire
Ian Hindmarch Quality of Life of Insomniacs Leeds Sleep Evaluation Questionnaire (LESQ)
Mark Hlatky, MD Duke Activity Status Index (DASI)
Timothy J. Hoelscher Insomnia Impact Scale
William L. Holzemer PPBL
E. Scott Huebner, PhD Multidimensional Students' Life Satisfaction Scale (MSLSS)
Paul Jacobsen Fatigue Symptom Inventory
Alan Jette AMPAC
Jeffrey G. Johnson, PhD Patient Health Questionnaire for Adolescents (PHQ-A)
Robert Kerns WHYMOI
Lauren Krupp Fatigue Severity Scale Sleep Symptom Questionnaire
Jin-Shei Lai, PhD Pediatric Fatigue Item Bank
Kathryn A. Lee Numerical Rating Scale for Fatigue
Stephen J. Lepore Social Constraint Scale
Debra Lerner, PhD Work Limitations Questionnaire
Kenneth Lichstein Sleep Questionnaire
Mark S. Litwin UCLA Prostate Cancer Index
Daniel Lovell, MD Juvenile Arthritis Functional Assessment Scale Juvenile Arthritis Functional Assessment Report for Children (JAFAR-C)
Ayala Malach-Pines Burnout Measure
Ralph Marino, MD Capabilities of Upper Extremity (CUE)
Robert Meenan, MD Arthritis Impact Measurement Scales 2 (AIMS2)
Tito Mendoza, Charles Cleeland MD Anderson Symptom Inventory

Charles M. Morin Insomnia Interview Schedule Sleep Diary
Douglas E. Moul Pittsburgh Insomnia Rating Scale
Nikolaus Netzer Berlin Questionnaire
Geraldine Padilla Quality of Life Scale – Cancer
Tonya M. Palermo, PhD Child Activity Limitations Interview (CALI)
George Parkerson, MD Duke Health Profile
Donald Patrick, PhD WHOQOL-100 US Version
Arnold L. Potosky Prostate Cancer Outcomes Study
Jack D. Edinger, Professional Resource Exchange Edinger's Sleep History Questionnaire
Quentin R. Regestein Hyperarousal Scale
Robin Richards, MD American Shoulder and Elbow Surgeons Shoulder Form (ASES)
J. Scott Richards UAB Pain Behavior Scale
Tracey Riseborough Hospital Anxiety and Depression Scale (HADS)
Kathryn Roach, PhD Shoulder Pain and Disability Index
Martin Roland, MA, MRCP Roland-Morris Low Back Pain and Disability Questionnaire
Raymond Rosen and Jules Mitchell Brief Index of Sexual Functioning for Women Female Sexual Function Index
Thomas Roth Global Sleep Assessment Questionnaire
Daniel W. Russell UCLA Loneliness Scale
Debra Sciabarrasi Barthel Index
Cathy Sherbourne, Robert Brook, Brent Bradley Rand-36 Index of Vitality
Judith Siegel, PhD Multidimensional Anger Inventory
Ann Skinner Sickness Impact Profile (SIP)
John Spertus, MD, MPH

Seattle Angina Questionnaire
Charles D. Spielberger, PhD State-Trait Anger Expression Inventory (STAXI)
Barbara Starfield, MD, MPH Child Health and Illness Profile – Adolescent Edition (CHIP-AE)
Kevin Stein Multidimensional Fatigue Symptom Inventory
K.L. Syrjala Sexual Function Questionnaire
Peter Tugwell, MD McMaster Toronto Arthritis
David Tulskey, PhD SCI-QOL TBI-QOL
James W. Varni, PhD PedsQL™ Arthritis Module Version 3.0 Child Report (ages 8-12) PedsQL™ Asthma Module Version 3.0 Child Report (ages 8-12) PedsQL™ Cerebral Palsy Module Version 3.0 Child Report (ages 8-12) PedsQL™ Multidimensional Fatigue Scale Standard Version Child Report (ages 8-12) PedsQL™ Pediatric Quality of Life Inventory Version 4.0 Child Report (ages 8-12)
Johan W. S. Vlaeyen Checklist for Interpersonal Pain Behavior
John Ware, PhD PIQ-6 SF-36 v2 Medical Outcomes Study Sexual Functioning Scale
Terri E. Weaver Functional Outcomes of Sleep Questionnaire
Wilse B. Webb Post-Sleep Inventory
Nadine Weisscher AMC Linear Disability Score (ALDS)
Nick Wetton Crown-Crisp Experiential Index
Hornng-Shiuann Wu, PhD Cancer-Related Fatigue Instrument