

# HealthMeasures Terms of Use

## **Definitions:**

- HealthMeasures: a resource encompassing four measurement systems: PROMIS<sup>®</sup>, NIH Toolbox<sup>®</sup>, Neuro-QoL, and ASCQ-ME<sup>SM</sup>
- Measurement System: a collection of health measurement instruments under one brand, such as PROMIS or NIH Toolbox
- Provider: the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine
- User: anyone who employs a HealthMeasures Measurement System or Instrument in a research, clinical, educational, or other setting
- Publicly Available: HealthMeasures Instruments which are available for download at [healthmeasures.net](http://healthmeasures.net)

Thank you for your interest in HealthMeasures. Please read our Terms of Use carefully as we include information which applies universally to all of our measurement systems as well as information specific to individual measurement systems.

You understand and agree that the Provider gives access to HealthMeasures Instruments (e.g., item banks, short forms, profile measures) subject to these Terms of Use. Provider reserves the right to update the Terms of Use at any time. Changes to the Terms of Use will apply to new users, new instruments, and to new projects created by existing users after these changes are posted.

Use of HealthMeasures Measurement Systems, instruments, related materials, and services requires acceptance of all terms and conditions stated herein. You agree to abide by all of the HealthMeasures Terms of Use as a condition of using HealthMeasures. No modifications or additions to these Terms of Use are binding upon Provider unless previously agreed to in writing by an authorized representative of Provider.

## **Single Use, Reproducibility, and Distribution**

- All HealthMeasures Instruments are copyrighted. All English and Spanish versions of PROMIS and Neuro-QoL and some NIH Toolbox self- and parent-proxy report instruments (NIH Toolbox Emotion and select Sensation) are publicly available for use without licensing or royalty fees for individual research or individual clinical use. Such use of HealthMeasures Measurement Systems and Instruments is “single use,” meaning solely for User’s research, clinical, educational, or other application.
- User shall not reproduce HealthMeasures Instruments except as needed to conduct the authorized single use research, clinical, educational, or other activity. User shall not distribute, publish, sell, license, or provide HealthMeasures products, by any means whatsoever, to third parties not involved with the authorized single use as stated above,

without the prior written agreement of the Provider. Users must request permission to reprint HealthMeasures Instruments for reasons not included in the single use case.

- Commercial Users must seek permission to use, reproduce, or distribute any HealthMeasures Measurement Systems and Instruments, regardless of purpose, at all times.
- Users wishing to integrate instruments into proprietary technological systems, including in the Single Use case, must seek written approval. Proprietary technological systems include, but are not limited to, computerized adaptive tests, apps, and web portals used for data collection. Provider may incur costs in providing the permission to integrate, and those costs may be passed along to the User.
- Users who secure license agreements to deliver HealthMeasures instruments through technological systems owned and supported by Provider do not need additional licenses to use the HealthMeasures instruments provided with the technological system to which User has been granted license. If the license agreement for the technology owned and supported by Provider includes reproduction and distribution rights, the license agreement itself is sufficient permission for reproduction and distribution and covers all requirements to seek permissions or consent required herein.
- User agrees not to adapt, alter, amend, abridge, modify, condense, make derivative works, or translate HealthMeasures Instruments without prior written permission from the Provider. In cases where permission is granted, User will be expected to evaluate the impact of approved modifications.
- User agrees and undertakes not to sell or incorporate HealthMeasures Measurement Systems and Instruments into materials that could be sold without prior written consent from the Provider.
- To inquire about permissions, email [help@healthmeasures.net](mailto:help@healthmeasures.net).

## **Indemnification**

- User agrees and undertakes to indemnify and hold Provider harmless against any and all claims, loss or damage, including fees, penalties or fines and third party claims, and attorneys' fees arising from User's use of any HealthMeasures Measurement System or Instrument. Further, User shall be obliged to indemnify, defend and/or hold harmless Provider and its agents, trustees, officers, medical affiliates, employees, and their respective successors, heirs, and assignees against any liability, damage, loss or expense incurred in connection with User's use of any HealthMeasures Measurement System or Instrument.
- Consent to User's use of HealthMeasures Measurement System or Instrument is given 'AS IS', without any accompanying services or improvements. Provider does not accept any liability resulting from User's use of any HealthMeasures Measurement System or Instrument. All HealthMeasures Measurement Systems and Instruments are supplied to User with no warranties or representations of any kind as to the accuracy, currency, or the

merchantability or fitness of the HealthMeasures Measurement Systems or Instruments for a particular purpose.

- Neither Provider nor any party involved in creating, producing, or delivering any HealthMeasures Measurement System or Instrument shall be liable for any damages, including without limitation, direct, incidental, consequential, indirect, or punitive damages arising out of access to, use of, alterations of, or inability to use any HealthMeasures Measurement System or Instrument, or any errors or omissions in the content thereof.

## **Trademarks**

- User will include Provider's trademark ownership statement on all printed copies of any HealthMeasures Measurement System or Instrument in the same form as it appears on the document that User is downloading from this website.
- User agrees and undertakes not to remove the trademark notices which appear on any printed HealthMeasures Measurement System or Instrument. Use of HealthMeasures Measurement Systems and Instruments does not and will not create any right, title or interest thereof for User, other than the right to use HealthMeasures Measurement Systems and Instruments under these Terms of Use.

## **Publications and Presentations**

- Any publication or presentation created from research, clinical, educational, or other applicable use of any HealthMeasures Instruments should include a statement that indicates which instruments (including version number) were used and provide an appropriate citation.
- For precise copyright citation, see the measurement system of interest below.

## **Furthering Research**

- Use of HealthMeasures Instruments in clinical research is encouraged, with the understanding that data collected from that use will contribute to knowledge about the validity of HealthMeasures measures. USERS OF HealthMeasures TOOLS ARE STRONGLY ENCOURAGED TO SUBMIT A BRIEF REPORT INCLUDING SAMPLE DEMOGRAPHIC INFORMATION, CLINICAL DATA SUFFICIENT TO characterize THE SAMPLE, AND SCORE DISTRIBUTIONS (E.G., BASELINE MEAN AND STANDARD DEVIATIONS OR CHANGE SCORES). This brief report should be submitted to [help@healthmeasures.net](mailto:help@healthmeasures.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 HealthMeasures investigators when applying these items and banks to their research.

## **Additional Terms and Conditions of Use for PROMIS**

The PROMIS Terms and Conditions contained in this document serve as an agreement between Provider and Users of any and all aspects or components of PROMIS.

### **COPYRIGHT NOTICE AND CLAIMS OF COPYRIGHT INFRINGEMENT**

**PROMIS tests, test protocols, test items, norms, norms tables, scoring programs, scoring keys (including scoring algorithms, scale definitions, scale membership, and scoring directions), score reports, software, and other PROMIS-related materials** are ©2006-2017 PROMIS Health Organization or other individuals/entities that have contributed information and materials, and are being used with the permission of the copyright holders. For a table of PROMIS copyright holders and the copyrighted information and materials employed by the copyright holders, see Appendix A.

## **Additional Terms and Conditions of Use for NIH Toolbox**

### **NIH Toolbox Terms and Conditions**

The NIH Toolbox Terms and Conditions contained in this document (hereinafter referred to as "NTAC") serve as an agreement between Provider and Users of any and all aspects or components of the NIH Toolbox.

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### **CONFIDENTIALITY.**

User acknowledges and agrees that the contents of the NIH Toolbox may constitute trade secrets, which include confidential and proprietary material, information, and procedures. User will not resell or otherwise distribute materials, or authorize or allow disclosure of the contents of a test instrument protocol, including test questions and answers, or normative data, except under the limited circumstances described in the section titled, "Maintenance of Test Security and Test Use," or as otherwise contemplated in the published manual associated with the test. User acknowledges and agrees that the use or disclosure of trade secrets in a manner inconsistent with the provisions of this Agreement may cause Provider irreparable damage, for which remedies other than injunctive relief may be inadequate. Accordingly, User agrees that in any request by Provider to a court of competent jurisdiction for injunctive or other equitable relief seeking to restrain such use or disclosure, User will not maintain that such remedy is not appropriate under the circumstances.

## **PERMISSIONS AND LICENSING POLICY**

Reproduction of any NIH Toolbox materials, except for authorized single use of publicly available NIH Toolbox measures, requires the prior written consent of Provider. Questions and answers, including practice questions and answers, may not be reproduced without written permission, regardless of the number of lines or items involved. Test copies may not be bound in theses or reports placed in libraries, generally circulated, or accessible to the public, or in any article or text of any kind.

## **PERMISSION TO USE COPYRIGHTED TEST NORMS**

Provider has the sole right to authorize reproductions of any portion of their published tests, including test norms. Copying of test norms without authorization is a violation of federal copyright law. The term "copying" includes, but is not limited to, entry of NIH Toolbox test norms into a computer's memory for purposes of test processing, scoring, or reporting. Any person or organization wanting to use NIH Toolbox test norms outside of official NIH Toolbox software must submit a written request to [help@healthmeasures.net](mailto:help@healthmeasures.net). If permission is granted, a fee may be charged. For the avoidance of doubt, permission from Provider for use of test norms does not imply endorsement of, or responsibility for, the accuracy or adequacy of any test processing, scoring, or reporting service.

## **MODIFICATION OF NIH TOOLBOX COMPONENTS**

Provider recognizes the importance of continued scientific development of the NIH Toolbox measures to meet the needs of researchers, but emphasizes the importance of maintaining rigorous measurement standards. Therefore, User may make modifications to NIH Toolbox Cognition, Motor, Emotion and Sensation tests and test items if, and only if, the following conditions are met:

1. Specific modification plans must be enumerated and submitted *in writing* to Provider for approval. This request must include the specific changes to be made and the rationale for the changes. This written request must be signed by the lead researcher.
2. User may not make modifications to any component of NIH Toolbox without written consent of Provider.
3. All modifications should be fully validated against the existing NIH Toolbox measure(s) on which they were based. Plans for a concurrent validation study should be included in the written request for modifications. If no validation study is planned, this must be noted in the written request, along with an explanation.
4. User must send validation study results to Provider for review prior to publication citing any results of said study or any results citing use of NIH Toolbox.
5. Provider will review validation study data and will inform User if modification to NIH Toolbox measure(s) constitute an "Approved Adaptation" or a "Non-Validated Adaptation" of NIH Toolbox. Provider will update HealthMeasures.net accordingly to inform other users and prospective users of these modifications, along with contact information for the lead researcher.
6. User must cite NIH Toolbox in any and all presentations, publications, or other third-party sharing of research data, indicating whether any measures used constitute Approved Adaptations or Non-Validated Adaptations.
7. **Provider maintains all rights to Approved Adaptations as well as Non-Validated Adaptations of NIH Toolbox tests and test items made by User. User may under no circumstances license,**

**distribute, or share any components of NIH Toolbox with third parties, regardless of the extent of modifications, without official, written consent of PROVIDER. User is entitled to no ownership claim of intellectual property as a result of making any NIH Toolbox modifications, and is hereby enjoined from communicating or stating any such claims.**

## **MAINTENANCE OF NIH TOOLBOX TEST SECURITY AND TEST USE**

- Each person or institution using the NIH Toolbox Measures must agree to comply with these basic principles of test security.
- Test takers must not receive test answers before beginning the test. Test questions are not to be reproduced or paraphrased in any way.
- Access to test materials must be limited to qualified persons with a responsible, professional interest who agree to safeguard their use.
- Test materials and scores may be released only to persons qualified to interpret and use them properly.
- If a test taker or the parent of a child who has taken a test wishes to examine test responses or results, the parent or test taker may be permitted to review the test and the test answers in the presence of a representative of the school, college, or institution that administered the test. Such review should not be permitted in those jurisdictions where applicable laws require the institution to provide a photocopy of the test subsequent to review. If User is not certain of the effect of the laws in User's jurisdiction, the User should contact their jurisdiction's professional organization.

## **USER QUALIFICATIONS**

Test users must have the appropriate knowledge, skills, training and experience to responsibly use NIH Toolbox measures. "Test users" are those persons responsible for the selection, administration, scoring and interpretation of tests and the communication of results. Provider reserves the right to ask individuals requesting access to NIH Toolbox Cognition measures to provide documentation that they have the experience and training necessary to use those measures, or are working under the supervision of someone qualified to use those measures. NIH Toolbox Cognition measures are classified as "C-Level." C-Level tests require a high degree of expertise in test interpretation, and thus can only be requested by a User with state licensure or certification to practice in a field related to the request, or a doctorate degree in psychology, education, or a closely related field, with formal training in the ethical administration, scoring, and interpretation of clinical assessments related to the intended use of the assessment. Any users of C-Level assessments must be supervised by one or more users with C-Level qualifications, which must have been provided in advance to Provider per this process.

## **RULES GOVERNING USE OF THE NIH TOOLBOX BY VARIOUS CATEGORIES OF USERS**

Universities, schools, organizations, businesses, clinics, and hospitals are subject to the guidelines set forth above and must have appropriately qualified individuals on staff in order to use the NIH Toolbox tests.

**PROTECTIVE ORDERS.** User agrees to seek a protective order safeguarding the confidentiality of

test materials classified by Provider as “C-level” assessments if User is required to produce such materials in court or administrative proceedings.

**NO WARRANTY.** Provider makes no warranties, expressed or implied, including warranties of merchantability or fitness for a particular purpose. Provider will not, under any circumstances, be liable for User's expense for delays, for costs of substitute materials, or for possible lost income, grants, profits, or any other special or consequential damages that may result from using the NIH Toolbox.

### **Additional Terms and Conditions of Use for Neuro-QoL**

People using Neuro-QoL should include the following copyright notice.

#### **COPYRIGHT NOTICE**

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**Appendix A**  
**PROMIS Copyright Holders and Their Copyrighted Information and Materials**

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
Smita Bhatia Minneapolis-Manchester Quality of Life Instrument – Adolescent Version
Jill Binkley, PT Lower Extremity Functional Scale
Thomas Borkovec Penn State Worry Questionnaire
Ron Borland Perceived dependence items from International Tobacco Control Policy Evaluation Study (ITC)
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
Amy Copeland Smoking Consequences Questionnaire
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)
Ed Diener Satisfaction with Life Scale
Joe DiFranza Autonomy over smoking scale
Dr. Colleen Dilorio Epilepsy Self-Efficacy Scale
George Domino Assessment of Sleep Sleep Questionnaire
Maxime Dougados, MD Dougados Functional Index (DFI)
Alan B. Douglass Sleep Disorders Questionnaire
David Drobes Questionnaire of Smoking Urges - Long Form
M Tuncay Duruoz, MD Duruoz Hand Index
Jack D. Edinger, Professional Resource Exchange 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
JF Etter The Cigarette Dependence Scale, English-language version
Sydney Ey Youth Life Orientation Test

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
Ross Flett Affectometer-2
James F Fries, MD Health Assessment Questionnaire (HAQ)
Marie Gage Self-Efficacy Gauge (SEG)
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
Todd Heatherton Fagerstrom Test for Nicotine Dependence
Vicki Helgeson Benefit Finding Scale
Philip S Helliwell, MD, PhD Revised Leeds Disability Questionnaire
Sarah Hewlett MD Rheumatoid Arthritis Self-Efficacy Scale (RASE)
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) Student's Life Satisfaction Scale
Paul Jacobsen Fatigue Symptom Inventory
Alan Jette AMPAC

Jeffrey G. Johnson, PhD Patient Health Questionnaire for Adolescents (PHQ-A)
Robert Kerns WHYMOI
Dinesh Khanna UCLA Scleroderma Clinical Trials Consortium Gastrointestinal Tract (SCTC GIT) 2.0
Dr Sunil Kripalani Self-efficacy for Appropriate Medication Adherence Scale (SEAMS)
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)
Anne Lynch-Jordan (S. Kashikar-Zuck, & K. Goldschneider) Adolescent Pain Behavior Questionnaire
Ayala Malach-Pines Burnout Measure
Ralph Marino, MD Capabilities of Upper Extremity (CUE)
Sherry McKee The 39-Item Perceived Risk and Benefits Questionnaire
John Mayer Brief Mood Introspection Scale
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

Olugbenga Ogedegbe Medication Adherence Self-Efficacy Scale
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
Pfizer, Inc. International Index of Erectile Function, Erection Harness Scale
Megan Piper Wisconsin Inventory of Smoking Dependence Motives
Ovide Pomerleau Michigan Nicotine Reinforcement Questionnaire
Arnold L. Potosky Prostate Cancer Outcomes Study
Quentin R. Regestein Hyperarousal Scale
Graham J. Reid (C. Gilbert, & P. McGrath) Pain Coping Questionnaire
Gary T. Reker Life Attitude Profile-Revised (LAP-R)
Dennis Revicki PROMIS Adult Pain Behavior Bank
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
Damaris J. Rohsenow Smoking Effects Questionnaire
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
Michael F. Scheier Life Engagement Test

Raf Schwarzer General Self-Efficacy Scale
Debra Sciabarrasi Barthel Index
William G. Shadel, PhD Smoker Self-concept and Abstainer Self-concept scales
Cathy Sherbourne, Robert Brook, Brent Bradley Rand-36 Index of Vitality
Saul Shiffman Nicotine Dependence Syndrome Scale
Judith Siegel, PhD Multidimensional Anger Inventory
Ann Skinner Sickness Impact Profile (SIP)
C. R. Snyder (by B. Hoza) Children's Hope Scale
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)
Michael Steger Meaning in Life Questionnaire – Expanded Version (MLQ-X)
Kevin Stein Multidimensional Fatigue Symptom Inventory
Mark Sullivan MD Cardiac Self-Efficacy Scale
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)
Wayne Velicer and James Prochaska The Self-Efficacy/Temptations Scale-Long Form Smoking: Decisional Balance Scale Transtheoretical Model Assessment
Johan W. S. Vlaeyen Checklist for Interpersonal Pain Behavior

Lynn S. Walker Pain Response Inventory for Children
John Ware, PhD PIQ-6 SF-36 v2 Medical Outcomes Study Sexual Functioning Scale
David Watson Positive and Negative Affect Scale-Expanded form (PANAS-X)
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
Horng-Shiuann Wu, PhD Cancer-Related Fatigue Instrument