HealthMeasures Fees: NIH Toolbox®, PROMIS®, Neuro-QoL, and ASCQ-Me^{SM}

Executive Summary

- HealthMeasures is the official information and distribution center for NIH Toolbox®, PROMIS®, Neuro-QoL, and ASCQ-Me^{SM}
- Most HealthMeasures are freely available
- Use of assessment delivery systems, and some content, carries fees
- Other measure-related services (e.g., consultation, training, analysis) are available, with pricing information provided upon request

This document provides more information about HealthMeasures and the costs for specific services and resources.

What are the HealthMeasures?

HealthMeasures is a global resource and serves as the official information and distribution center for four measurement systems developed and evaluated with National Institutes of Health (NIH) funding between 2004 and 2014. These measurement systems are:

- **NIH Toolbox (NIH Toolbox for Assessment of Neurological and Behavioral Function):** Performance, self-report, and proxy measures of cognitive, motor, sensory, and emotional functioning from ages 3-85

- **PROMIS (Patient Reported Outcomes Measurement Information System):** Self and proxy reports of multiple domains of physical, mental and social health for children ages 5-17 and adults of all ages

- **Neuro-QoL (Quality of Life in Neurological Disorders Measurement System):** PROMIS-compatible self-report measures of health domains relevant across neurological conditions for children ages 8-17 and adults of all ages

- **ASCQ-Me (Adult Sickle Cell Quality of Life Measurement Information System):** PROMIS-compatible self-report measures of health domains relevant to adults with sickle cell disease

This family of measures provides state-of-the-art assessment of physical, mental, and social health, as well as performance-based measures of cognition, motor and sensory function, for use across a range of chronic diseases as well as the general population. These measures provide clinicians, researchers, healthcare administrators and policy-makers with efficient, precise, valid and responsive measures of functional abilities, symptoms, and general health perceptions surrounding life quality and life satisfaction.

The HealthMeasures mission is to elevate the quality and impact of person-centered assessment in clinical research, clinical practice, and health policy. We accomplish this by:

- Providing assessment tools of the highest quality and value.
- Meeting the diverse needs of a wide array of end-users.
- Educating end-users to contribute to advancing human health with the these tools.

Who is using HealthMeasures?

HealthMeasures can be used in research, clinical, and educational settings. Numerous grants have furthered understanding of how these measures perform, how they can inform clinical care, and refined score interpretation. Although HealthMeasures were developed and initially evaluated within the United States (in English and Spanish languages), they are increasingly being used around the world. Some HealthMeasures have been translated into more than 40 languages and are being deployed in over 50 different countries. Globalization of HealthMeasures has been an incremental process of collaboration that is expanding rapidly.

What is the cost?

Since 2014 the infrastructure that makes HealthMeasures available to the public has been supported by an NIH grant awarded to Northwestern University and five performance sites. Effective in late 2016, NIH funding was reduced with the expectation that Northwestern University will lead the transition to a new business model that can sustain and distribute these measures. The NIH remains committed to the success of these measures and strives for future sustainability that includes public and private partners.

The HealthMeasures.net website delivers free access to hundreds of self- and proxy-report measures from the four measurement systems, along with information to help users select, administer, score, and interpret measures. Utilization of Assessment Center^{SM} and other assessment delivery services will carry fees associated with maintaining and updating these technologies. HealthMeasures will also provide consultation, training, custom software development, and translation services, with pricing available by quote.

All services will be performed under a cost-recovery business model with no profit motivation.

What are the reasons behind the pricing changes?

The HealthMeasures public/private sustainability model is a partnership that includes Northwestern University, the participation of investigators from several institutions that received prior funding, and the PROMIS Health Organization, a 501(C)(3) charitable foundation dedicated to promoting research and education on the use of PROMIS. The NIH will partner with us through investigator-initiated research and other projects that rely upon these tools.

The HealthMeasures partnership has a strong commitment to deliver services to end users at the lowest possible cost. Indeed, most of the content (copies and/or demonstration videos for all HealthMeasures), as well as information on assessment delivery systems that include the measures, is freely available at www.healthmeasures.net.

Naturally, not all user needs can be met by a website. Users have questions and special requirements and often need our help and advice, which takes time. In addition, there are costs associated with maintaining a high quality web-based information-sharing system, including developing new content where there are gaps or changes with time and incorporating new content into the measurement system. HealthMeasures software and staff are available to fill these needs. Since 2004, the NIH has covered the cost of meeting these needs. Although the NIH is committed to continuing to support new developments and innovative applications of these tools under its investigator-initiated research funding program, NIH support for maintaining the HealthMeasures infrastructure, and distributing these high quality assessments, is declining and will end in 2018.

Assessment Center^{SM} (www.assessmentcenter.net) is the original technology cornerstone of HealthMeasures. Assessment Center carries significant costs to be maintained properly. These costs include a help desk, operating system upgrades, new measure loading, troubleshooting of technical issues, quality assurance activity, and server costs. Assessment Center, long subsidized by the NIH, can no longer be freely available to all users. Fortunately, with options such as REDCap, application programming interfaces (APIs), local electronic health record installations with data warehousing options, and mobile applications, there are several excellent alternatives to Assessment Center for both administration and data storage. Those wishing to continue to use Assessment Center from January 2017 forward will be expected to pay an annual fee that contributes to its sustainability.

> **Consistent with the charitable and educational mission of Northwestern University, all activity will be done under a cost-recovery business model with no profit motivation. Charges will support personnel time and basic infrastructure costs.**

HealthMeasures Current and Projected Charges for Instruments, Technologies and Services

Following is a list of HealthMeasures instruments, technologies and services, accompanied by information regarding current or projected future charges.

Instrument Availability

1. **Static Forms**
   PDFs of most self- and proxy-report instruments for all measurement systems are available at www.healthmeasures.net in "Search & View Measures." The instruments may be used in paper form or embedded in electronic systems without further permission as long as the text is not changed.

   Measure PDF Download ....**FREE**

2. **Assessment Center**
   Until recently, most HealthMeasures instruments were available only at www.assessmentcenter.net. Assessment Center functionality and most HealthMeasures instruments are now available at over 1,600 institutions, often at little or no charge to individual investigators or clinicians *(See Section 6 - Other Platforms for Access, below)*.

   a) **The Assessment Center Computer Adaptive Test (CAT) Demonstration Page** can be used to view a demonstration of how the popular PROMIS computer adaptive tests (CATs) are administered and scored in real time, but it is not practical for data collection. To try the CAT demo, cut and paste the following URL in your browser window (https://www.assessmentcenter.net/ac1/Default.aspx?SID=6A465ED7-6A02-4764-B83F-38F6A9595D56) or go to http://www.assessmentcenter.net/ and click on the CAT demo icon in the upper right corner.

      Assessment Center CAT Demo..**FREE**

   b) **Web-Based Administration and Study Management:** www.AssessmentCenter.net provides access for all PROMIS and Neuro-QoL instruments for web-based administration and study management.

      New studies initiated after December 31, 2016, will be charged an annual fee. Continuing studies that go beyond December 31, 2016 will be charged a reduced fee.

      New studies administered in Assessment Center: **$5,000 for Calendar Yr. 2017**
      Continuing studies administered in Assessment Center: **$2,500 for Calendar Yr. 2017**

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For more information about PROMIS, Neuro-QoL, NIH Toolbox and ASCQ-Me, please visit www.HealthMeasures.net.
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i. **New Studies using www.AssessmentCenter.net (data collection starting on or after January 1, 2017)**
New studies will be charged an annual fee of $5,000 per study for Calendar Yr. 17 beginning January 1, 2017, to offset the cost of operating the website. Costs for study administration in Assessment Center in 2018 have not been set. Please contact help@assessmentcenter.net for additional information.

ii. **Continuing (PRE-EXISTING) studies using www.AssessmentCenter.net (launched prior to January 1, 2017)**
Continuing studies may use www.AssessmentCenter.net at a pre-paid charge of $2,500 for Calendar Yr. 17. Costs for study administration in Assessment Center in 2018 have not been set. Users will be charged *per study* created in Assessment Center, not per grant. This fee will be waived for studies that complete data collection prior to April 1, 2017 and for students or K-awardees who are scheduled to complete data collection prior to July 1, 2017.

NIH Toolbox users should not plan on using www.AssessmentCenter.net beyond December 31, 2017, after which time this functionality will be removed. NIH Toolbox users are encouraged to transition to the NIH Toolbox iPad App. Please contact help@assessmentcenter.net for additional information and help in migrating to the iPad version of the NIH Toolbox.

3. Assessment Center Application Programming Interface (AC API)
The AC API easily integrates with existing patient portals, survey systems, and mobile apps to administer and score PROMIS and Neuro-QoL computer adaptive tests (CATs) and short forms. The AC API is used to operationalize access to HealthMeasures instruments for most of the implementations listed in Section 6 below. An annual license fee is required. For additional information, please contact api@assessmentcenter.net.

Annual API license .... **By Quote**

4. NIH Toolbox iPad App
This App includes the NIH Toolbox instruments in an easy-to-use format suitable for in-clinic and office-based use, with significantly lower long-term costs. It also includes select PROMIS, Neuro-QoL, SCI-QOL, SCI-FI and TBI-QOL measures. Search "NIH Toolbox" in the iTunes App store for details.

NIH Toolbox English iPad App (annual subscription per iTunes account) **$499**
NIH Toolbox Spanish iPad App (annual subscription per iTunes account) **$499**

[Each subscription includes support for installation on up to 10 iPads. Studies administering instruments in both English and Spanish will need to purchase two subscriptions.]

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5. PROMIS iPad App

This App includes a library of PROMIS instruments in an easy-to use-format suitable for in-clinic and office-based use. It also includes select NIH Toolbox, Neuro-QoL, SCI-QOL, SCI-FI and TBI-QOL measures. (Search "PROMIS" in the iTunes App store for details).

PROMIS English iPad App (annual subscription per iTunes account) **$499**

6. Other Platforms for Access

Numerous organizations make PROMIS and Neuro-QoL CATs and short forms available to their researchers and clinicians. Please contact the organizations below for additional information, including which instruments are offered.

a) **REDCap Sites.** Over 1,500 institutions use REDCap to make most PROMIS and Neuro-QoL instruments available for their researchers and clinicians, generally at little or no charge for local researchers and clinicians. See http://www.project-redcap.org/consortium.php for the complete list of REDCap organizations and their contact information. The Library at www.project-redcap.org provides a search tool to view available PROMIS and Neuro-QoL instruments.

b) **Epic Electronic Health Record (Epic Systems Corporation)**. Clinicians at most institutions that license Epic electronic medical record products are able to include selected PROMIS short forms in their clinical workflows at no additional charge. PROMIS and Neuro-QoL Computer Adaptive Tests (CATs) and item response theory (IRT) scored short-forms are scheduled to be available in Epic by the end of the first quarter of 2017 (as part of the Epic November, 2016 release). Epic will assess an annual license fee based upon institution size. Additional information will be available closer to final release.

c) **Department of Defense (DoD).** Limited PROMIS instruments are available for clinical use within the Health and Readiness Medical Survey System (HERMES) at no additional cost to DoD-based clinicians. Please contact Rick Barnhill (richard.l.barnhill.civ@mail.mil) for additional information. Clinical researchers have access to most PROMIS and Neuro-QoL instruments through a copy of REDCap hosted by the Uniformed Services University of the Health Sciences. Please contact Joshua Suen (jsuen@dvcipm.org) for additional information.

d) **Outcomes Based Electronic Research Database (OBERD).** OBERD optimizes patient compliance for outcomes data capture and provides access to most PROMIS and Neuro-QoL instruments at no additional charge to their licensees. There is also no charge for student or other non-commercial research projects. Please contact Brian McCuiston (sales@oberd.com) for additional information.

e) **AO Patient Outcomes Center (AOPOC)**. Designed for use in orthopedic clinical care, AOPOC includes selected PROMIS CATs and short forms. See http://www.aopatientoutcomescenter.com/ for additional information.

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f) **Custom Solutions.** The following organizations have also developed custom solutions to make many PROMIS and Neuro-QoL instruments available for clinical and research use. Contact help@healthmeasures.net to learn more about these custom solutions.

> **NIH Clinical Center**
> **Bring Life Sciences Consulting, Inc.**
> **Cleveland Clinic**
> **Intermountain Healthcare**
> **Northwestern Medicine**
> **Partners (Harvard) Health System**
> **University of Alabama**
> **University of Iowa Healthcare**
> **University of Rochester Medical Center**
> **University of Utah**
> **Washington University**

Other Services

1. **Scoring Instructions.** Two methods for calculating scores for most HealthMeasures are available for free. The first option is the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoringservice), a web-based tool that calculates scores for most PROMIS and Neuro-QoL original and customized short forms. An end-user uploads a file with responses and receives a scored file. The second free option is for users to calculate scores by hand using instructions in PDF Scoring Manuals available at http://www.healthmeasures.net/score-and-interpret/calculate-scores.

   HealthMeasures Scoring Service ....**FREE**
   HealthMeasures Scoring Manuals (PDFs) ....**FREE**

2. **Measurement Consulting and Analysis**. We offer training and consulting on all aspects of measurement, from instrument development to quantitative analysis of data, and planning for clinical research and clinical care. For advice beyond the initial consultation (e.g., on an ongoing basis during a funded grant period), HealthMeasures experts can be included as co-investigators on grant/contract submissions for a specified percent effort. Our consultants are trained in methods applied to the development of HealthMeasures tools, including qualitative and quantitative methods. This includes item response theory (IRT) methods and their many applications, such as custom short form development and computer adaptive testing (CAT). Our team also has expertise in clinical trial planning, including research design, psychometrics and regulatory strategy. For further information, please contact help@healthmeasures.net.

   Consultation and Analysis ....**Hourly Fee or Funded Percent Effort**
   Clinical Trial Planning... **By Quote**

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3. **Measurement Workshops and Training.** We periodically offer workshops and training opportunities through HealthMeasures (www.healthmeasures.net) and the PROMIS Health Organization (www.promishealth.com). These include instruction for the administration of NIH Toolbox, education on measurement topics (e.g., hands-on training to link the scores from different measures), and application of HealthMeasures (e.g., use of patient-reported outcomes in clinical practice). For custom workshops, including private training, please contact training@healthmeasures.net.

   Training session or workshop..**Priced per Event**
   Custom Workshop.. **By Quote**

4. **Custom Software Development.** Our information technology team has over a decade of experience developing solutions for a wide range of assessment and intervention projects in research, education, and clinical settings. Please contact help@healthmeasures.net for additional information.

   Custom Software.. **By Quote**

5. **CAT Algorithms, IRT Parameters, and Test Cases** are available as part of the Assessment Center API license (see Section 3 above). We do not directly provide CAT algorithms or CAT algorithm code. The algorithms and some of the parameters used in various HealthMeasures instrument systems are available in the literature.

6. **Translation Services and Distribution:** HealthMeasures does not directly translate its measures into other languages. However, we do manage all of the translation efforts to ensure quality and consistency. Referral to approved translation vendors can be made by HealthMeasures staff. In addition, we can provide information about what measures have translations available and in what languages, and we can provide information about the required translation methodology. For more information, please contact translations@healthmeasures.net.

   Our translation-related services include:

   Distribution of non-English versions of HealthMeasures with certification. **By Quote**
   Consultation on translation methodology .... **By Quote**
   Quality review and cross-cultural harmonization of translations................ **By Quote**
   Item translatability review (cost based on # of items and languages) .... **By Quote**

   For more information, contact us at help@healthmeasures.net.

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