

HealthMeasures Fees: NIH Toolbox[®], PROMIS[®], Neuro-QoL, and ASCQ-Me[®]

Executive Summary

- HealthMeasures is the official information and distribution center for NIH Toolbox[®], PROMIS[®], Neuro-QoL, and ASCQ-Me[®]
- 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 on costs for specific services and resources.

Why are there fees?

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](http://www.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 CenterSM, the NIH Toolbox iPad apps, the PROMIS iPad app, the Assessment Center API, and other assessment delivery services carry fees associated with maintaining and updating these technologies.

HealthMeasures scientists 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.

HealthMeasures Charges for Measures, Technologies and Services

Following is a list of HealthMeasures measures, technologies and services accompanied by information regarding current charges.

Measure Availability

1. Static Paper Forms

Respondent-ready PDFs of most English self- and proxy-report instruments for all measurement systems are available at www.HealthMeasures.net in “Search & View Measures.” These measures may be used in paper or electronic form for single use (i.e., solely for the user’s own individual clinical trial, academic research study, healthcare or clinical application, community-based or educational program, or other discrete application with a defined timeline, area of focused health measurement, and deliverables or research products) without permission or fees as long as the text is not changed. Options for scoring static fixed length measures are listed below.

English measure for single use..... **Free**

Respondent-ready PDFs of selected Spanish self- and proxy-report HealthMeasures instruments are available at www.HealthMeasures.net in “Search & View Measures.” Non-commercial users (i.e., any institution, organization, or other incorporated entity which is defined as a Tax-Exempt Organization under the regulations of the United States’ Internal Revenue Service; for users outside the United States, all not-for-profit entities including national health services and their affiliate providers and academic institutions) may use these measures in paper or electronic form for single use without permission or fees as long as the text is not changed. Commercial users (i.e., any company, organization, or other incorporated limited liability entity which does not fit the definition of a Tax-exempt Organization under the regulations of the United States’ Internal Revenue Service or which otherwise operates under the rubric of financial profit) must seek license to use any non-English translation of a HealthMeasure instrument. For more information, please contact translations@HealthMeasures.net.

Non-commercial user: Spanish measure downloaded from HealthMeasures.net for single use..... **Free**
Commercial user: all non-English translated measures..... **By Quote**

The HealthMeasures static, fixed length short forms, computer adaptive tests, profiles, and performance tests of cognition, motor, and sensory function are available for administration within numerous data collection platforms. Different software applications have varying fees.

2. Assessment Center

- a) **The Assessment Center Computer Adaptive Test (CAT) Demonstration Page** can be used to view a demonstration of how several 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/assessments/catdemo>).

Assessment Center CAT Demo **Free**

- b) **Web-Based Administration and Study Management:**

www.AssessmentCenter.net provides access for all PROMIS, Neuro-QoL, and ASCQ-Me instruments as well as NIH Toolbox Emotion instruments for web-based administration and study management. All measures are automatically scored.

- i. **New Studies using www.AssessmentCenter.net starting after January 1, 2017**

Assessment Center Study **\$5,000 per study per calendar year**

- ii. **Continuing (pre-existing) studies using www.AssessmentCenter.net launched for data collection prior to January 1, 2017**

Pre-existing Assessment Center Study **\$2,500 per study per calendar year**

Note: no new studies utilizing NIH Toolbox Cognition, Sensation, or Motor tests may be launched in Assessment Center. NIH Toolbox users should not plan on using www.AssessmentCenter.net beyond December 31, 2018 after which time Microsoft has announced that they will no longer support some of the functionality required to run the web-based version of the NIH Toolbox Cognition, Sensation, and Motor tests. NIH Toolbox users are encouraged to transition to the NIH Toolbox iPad App.

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, Neuro-QoL, and ASCQ-Me computer adaptive tests (CATs), profiles, and short forms as well as NIH Toolbox Emotion measures. The AC API is used to operationalize access to HealthMeasures measures for most of the implementations listed in Section 6 below. An annual license fee is required. The fee is dependent upon the several factors including purpose for use (e.g., single use versus distribution, as well as number of instances/servers), and language of measures (English and Spanish versus other translations). For additional information, please contact api@assessmentcenter.net.

Annual API license **By Quote**

Version 1.6, Oct 16, 2018

For more information about PROMIS, Neuro-QoL, NIH Toolbox and ASCQ-Me, please visit www.HealthMeasures.net. ASCQ-Me, the Adult Sickle Cell Quality of Life Measurement Information System, PROMIS, Patient-Reported Outcomes Measurement Information System, NIH Toolbox for the Assessment of Neurological and Behavioral Function, and their logos are marks owned by the U. S. Department of Health and Human Services.

4. NIH Toolbox iPad App

This App includes the NIH Toolbox instruments in an easy-to-use format allowing for examiner-based administration in a variety of settings. There are no additional fees; after the purchase of an annual subscription, the examiner receives unlimited administration and scoring as well as free updates (e.g., additional tests). The subscription also includes select PROMIS, Neuro-QoL, SCI-QOL, SCI-FI and TBI-QOL measures. All measures are scored in real-time on the app. One subscription can be installed on up to 10 iPads. Studies administering instruments in both English and Spanish must purchase 2 subscriptions.

A free Trial Mode is available to help users explore the app and access emotion, sensation, and motor tests. However to ensure the integrity of the cognition tests, the examiner must submit for a credential review and an access code will be provided to qualified users (Level C qualifications). If permission is granted, these tests can also be seen in the free trial. Please note this Trial Mode has no time constraints, but does not score or store data. More details are available in the [iTunes App store](#).

NIH Toolbox English iPad App (annual subscription per iTunes account)	\$499.99
NIH Toolbox Spanish iPad App (annual subscription per iTunes account)	\$499.99
NIH Toolbox Ceubona iPad App (annual subscription per iTunes account)	\$499.99

**Note: the exact price of NIH Toolbox iPad app subscriptions purchased outside of the United States may vary. Any variance in this price is controlled by Apple.*

5. PROMIS iPad App

This App includes a limited library of PROMIS instruments in an easy-to use-format suitable for on demand administration in a clinic or office setting. It also includes the NIH Toolbox, and select Neuro-QoL, SCI-QOL, SCI-FI and TBI-QOL measures. All measures are scored in real-time. A free Trial Mode is available to help users explore the app and access the instruments with no time constraint. Please note this Trial Mode does not save data or allow access to reports and data exports. More details are available in the [iTunes App store](#).

PROMIS English iPad App (annual subscription per iTunes account)	\$499.99
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**Note: the exact price of PROMIS iPad app subscriptions purchased outside of the United States may vary. Any variance in this price is controlled by Apple.*

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. Instruments with the label “auto-scored” will be automatically scored.
- b) **Epic Electronic Health Record (Epic Systems Corporation).** Clinicians at most institutions that license Epic electronic medical record products (Epic 2017 and later) are able to utilize the Epic PROMIS App that provides access to PROMIS CATs in modules including Hyperspace, MyChart, and Epic Welcome. Epic charges an annual license fee based upon institution size. For comprehensive information regarding all the measures your organization has made available, consult with your local Epic IT team.
- c) **Outcomes Based Electronic Research Database (OBERD).** OBERD optimizes patient compliance for outcomes data capture and scoring 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.
- d) **Custom Solutions.** Several university and healthcare systems have 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.

Integration of a HealthMeasure into an Electronic Data Collection System

Users integrating downloadable static paper forms of HealthMeasures outside of the scope described in Section 1 and users integrating HealthMeasures through the Assessment Center API into an electronic data collection system should contact [Help@HealthMeasures](mailto:Help@HealthMeasures.net) for information on permission for use, review of respondent interface, and score certification.

Other Services

1. **Scoring Instructions.** For instances when the administration platform does not automatically calculate a score, two scoring methods for most HealthMeasures are available for free. The first option is the HealthMeasures Scoring Service (https://www.assessmentcenter.net/ac_scoring-service), a web-based tool that

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calculates scores for most PROMIS, Neuro-QoL, ASCQ-Me, and NIH Toolbox Emotion original and customized short forms. A user uploads a file with response scores and receives a scored file by email. 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..... **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**

- 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). A list of upcoming workshops can be found at <http://www.healthmeasures.net/resource-center/user-community/workshops-and-events>. 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 published 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. Information about required translation methodology and referral to approved translation vendors can be made by HealthMeasures staff. For more information, please contact translations@HealthMeasures.net.
In addition, we can provide information about what measures have translations available and in what languages. Selected Spanish language PDFs of PROMIS and Neuro-QoL, for example, are available at www.HealthMeasures.net in “Search & View Measures.”

Please note that translation of many of the NIH Toolbox tests, including all of the cognition tests, require the creation of a new app to support these translations.

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**