PROMIS: The NIH Patient-Reported Outcomes Measurement System

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Based on a presentation at Retina International's November 2016 Interdisciplinary Workshop addressing the topic "Functional Vision versus Visual Function – Working towards integrating the Patient Perspective."

Ron D. Hays opened his contribution by providing background on the Patient-Reported Outcomes Measurement Information System (PROMIS®). PROMIS is an U.S. National Institutes of Health supported set of patient-reported measures and scoring procedures. PROMIS measures are:

- designed to be relevant across all conditions for the assessment of symptoms and functions.
- intended to enhance communication between clinicians and patients in diverse research and clinical settings.
- available in several languages.
- Evaluated using state-of-the-science methods.

PROMIS includes measures of health for adults and children (<u>www.HealthMeasures.net</u>). The measures can be administered to the general population and to individuals living with chronic conditions.¹

The focus of PROMIS measures is specific domains of Physical Health, Mental Health and Social Health. Some of these include:

- Physical Health: physical function, pain intensity, pain interference, fatigue, sleep disturbance.
- Mental Health: depressive symptoms, anxiety, anger
- Social Health: ability to participate in social roles and activities.

PROMIS also has physical and mental health summary scores²⁻³ and a preference-based single summary score.⁴⁻⁵

PROMIS measures are scored on a T-score metric with a mean of 50 and standard deviation of 10 in the U.S. general population: <u>http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis</u>. The PROMIS scores can be categorized as: within normal limits, mild, moderate and severe. (Figure 1).

There are a range of administrative options for PROMIS measures:

- Paper short forms and profiles
- Computer e.g., Assessment Center (<u>https://www.assessmentcenter.net/</u>)
- Mobile App e.g., PROMIS iPad app

PROMIS includes item banks that can be administered using computer-adaptive testing,⁶ short forms for individual domains,⁷ and profiles that yield information about multiple domains for use in clinical trials, observational studies, and clinical practice.⁸ The PROMIS-29 v2.0 profile measure assesses pain intensity using a single 0–10 numeric rating item and seven health domains (physical function, fatigue, pain interference, depressive symptoms, anxiety, ability to participate in social roles and activities, and sleep disturbance) using four items for each domain. The PROMIS-29 v2.0 profile measure is analogous to the most widely used profile measure to date, the SF-36. But the PROMIS-29 v2.0 profile items were selected from PROMIS item banks calibrated using item response theory (IRT) analyses and all items in a domain are scored on the same underlying metric.⁹

Additional information is available at: <u>http://www.healthmeasures.net/explore-measurement-</u> systems/promis

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Figure 1.



adult, pediatric, and parent proxy Global.

Interpreting PROMIS[®] T-Scores^{*}