The PROMIS®
Autism Battery – Lifespan

An approach to measuring quality of life across individuals and ages

"Quality of Life" can mean different things to different people. While clinical researchers often focus on measuring diagnostic criteria or symptoms, autistic self-advocates, family members, and community organizations have long called for a greater emphasis on measuring specific and practical areas that, if properly addressed, could help people on the autism spectrum achieve a better quality of life.

What is PROMIS®? The Patient Reported Outcomes Measurement Information System is an NIH-funded initiative to develop and validate patient reported outcomes (PROs) for clinical research and practice. PROMIS researchers have created several hundred questionnaires covering a wide range of outcomes across ages, diseases or conditions, and areas of life. PROMIS measures are copyrighted, but free to use for non-profit purposes. They are available in multiple formats (e.g., pdfs, REDCap, EPIC, PROMIS iPad app). Complete information about PROMIS is available at www.nihpromis.org.

The PROMIS Autism Battery – Lifespan (PAB-L) is a collection of PROMIS instruments we curated and validated for autistic youth and adults. We validated PAB-L with input from 912 participants (adolescents and adults with autism, and parents of children and adolescents with autism). You can find our published article for a limited time here: https://onlinelibrary.wiley.com/doi/abs/10.1002/aur.2275; or through your library's subscription (see the full reference on the next page).

The PROMIS PAB-L focuses on 5 domains: Subjective Well-being, Relationships, Emotional Distress, Health, and Adulthood. To make it easier for researchers and clinicians to use the PAB-L, this document provides the list of measures we used and instructions on how to access them through the REDCap shared library or as pdfs.

Children's Hospital of Philadelphia
Center for Autism Research

The PROMIS Autism Battery – Lifespan Instruments

	Parent proxy (5-17 years)	Youth self-report (14-17 years)*	Adult self-report
All PROMIS titles in REDCap begin with:	PROMIS Parent Proxy SF…	PROMIS Ped SF…	PROMIS SF… (or PROMIS Short Form)…
Subjective Well-Being			
Life Satisfaction	v1.0 – Life Satisfaction 8a	v1.0 – Life Satisfaction 8a	v1.0 – Life Satisfaction 5a
Positive Affect	v1.0 – Positive Affect 8a	v1.0 – Positive Affect 8a	v1.0 – Positive Affect 15a
Meaning and Purpose	v1.0 – Meaning & Purpose 8a	v1.0 – Meaning & Purpose 8a	v1.0 – Meaning & Purpose 8a
Relationships			
Family Relationships	v1.0 – Fam Relationships 8a	v1.0 – Fam Relationships 8a	n/a
Peer Relationships	v2.0 – Peer Relationships 7a	v2.0 – Peer Relationships 8a	n/a
Companionship	n/a	n/a	v2.0 – Companionship 6a
Social Isolation	n/a	n/a	v2.0 – Social Isolation 8a
Emotional Support	n/a	n/a	v2.0 – Emotional Support 8a
Informational Support	n/a	n/a	v2.0 – Informational Support 8a
Instrumental Support	n/a	n/a	v2.0 – Instrumental Support 8a

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Emotional Distress			
Depressive Symptoms	v2.0 – Depressive Symptoms 6a	v2.0 – Depressive Sx 6a	v1.0 – Depression 8a
Anger	V2.0 - Anger	v2.0 - Anger 5a	v1.1 - Anger 5a
Anxiety	v2.0 – Anxiety 8a	v2.0 – Anxiety 8a	v1.0 – Anxiety 8a
Psychology Stress Experiences	v1.0 – Psych Stress Exp 8a	v1.0 – Psych Stress Exp 8a	n/a
Health			
Sleep Disturbances	v1.0 – Sleep Disturbance 8a	v1.0 – Sleep Disturbance 8a	v1.0 – Sleep Disturbance 8a
Sleep Impairment	v1.0 – Sleep-Related Impairment 8a	v1.0 – Sleep-Related Impairment 8a	v1.0 – Sleep-Related Impairment 8a
Physical Activity	v1.0 – Physical Activity 8a	v1.0 – Physical Activity 8a	n/a
Cognitive Function	V1 – Cog Function 7a	V1 – Cog Function 7a	V2 – Cog Function 8a
Global Mental Health	n/a	n/a	V1.2, 2a – Global Mental Health
Global Health	v1.0 – Global Health 7+2	Pediatric Scale v1.0 – Global Health 7+2	V1.2 – Global Health**

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Adulthood			
General Self-Efficacy	n/a	n/a	v1.0 – General Self-Efficacy 4a***
Satisfaction with Social Roles	n/a	n/a	v2.0 – Satisfaction Roles Activities 8a

*Younger youth may self-report; the PAB-L began with older youth to assess feasibility and acceptability in this group before extending downwards to include children.

**The Global Health measure requires accessing scores from www.assessmentcenter.net.

***This measure says "Adaptive" in REDCap but likely functions like an AutoScoring

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To create a REDCap survey that will automatically score the measures:

REDCap (Research Electronic Data CAPture) is a secure, free web application for building and managing online surveys for research. If you need help learning how to use REDCap in general, visit www.project-redcap.org. These instructions assume you already have a basic understanding of how to use REDCap. It should take about 30 minutes to create a PAB-L survey in REDCap.

While in your REDCap project, follow these steps:

- **Online Designer** —> **Import** a new instrument from the official REDCap Shared Library
- **Keyword search:** [type the name of the PROMIS instrument here]
- Select the right PROMIS instrument —> **Import** into my REDCap project —> **Agree** to terms —> **Add** the imported instrument.

Once all the PROMIS measures have been added to your project, if you would like the user to automatically do one after the other:

- For each instrument that you would like to send to the participant as a survey, go to "Enabled as Survey" —> **Enable** —> **Save Changes**
- **Survey settings** —> scroll down to "Survey Termination Options"—> Click **(Optional) Auto-continue to next survey** (you will have to do this for each survey).

To access PDFs of each individual PROMIS measure:

- Go to the "Search & View Measures" page of HealthMeasures.net (http://www.healthmeasures.net/search-view-measures)
- Search for each measure name —> click the link next to "View Measure"—> a pdf will be downloaded
- Note that for adults the Global Health pdf includes the Physical and Mental health items.

To learn more, log on to the PROMIS public forum http://www.healthmeasures.net/resource-center/

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