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The NIH PROMIS: Measuring Health Related Quality of Life in Children and Adults with CP

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PROMIS[®]



Dynamic Tools to Measure Health Outcomes from the Patient Perspective



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Overview

- Brief overview of PROMIS
- Preliminary findings: PROMIS validity in CP
- Ongoing and future studies



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Patient Reported Outcomes Measurement Information System

- *Domain* focused, not *disease* focused
- Goal = to be able to measure a feeling, function, or perception (e.g., anxiety, mobility, self-efficacy) *across* medical conditions and the general population.
- **A universal system**
 - T-Metric: General US Population \underline{M} = 50, \underline{SD} = 10





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Measurement Terminology: Item Bank

- A large collection of items measuring a single domain
- Items cover a wide range
- Item banks make computer adaptive test (“smart test”) administration possible.





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Item Bank Administration

Item Bank

**Computer
Adaptive Test
(CAT)**

Short Form





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Computer Adaptive Test (CAT)

- Selects questions based on person's answers to previous questions
 - administers only the *most informative items*
 - a kinder way to measure
- Iteratively estimates a person's score on a domain
 - Administers items until:
 - Reaches maximum number of items allowed
 - Reaches critical standard error
- High level of precision with minimum number of items



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Computer Adaptive Test (CAT)

- **Assessment Center** – online measure administration and data capture platform

Assessment CenterSM

In the past 7 days

How much did pain interfere with your household chores?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

Previous

Next

Exit



Short Form

- A static set of items from the item bank
- Can use PROMIS pre-set short form or select new customized set of items

PROMIS Parent Proxy Short Form v1.0 - Anger 5

Anger – Short Form 5

Please respond to each question or statement by marking one box per row.

In the past 7 days...		Never	Almost Never	Sometimes	Often	Almost Always
PfAnger1	My child felt mad	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
PfAnger5	My child was so angry he/she felt like yelling at somebody	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
PfAnger3	My child was so angry he/she felt like throwing something	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
PfAnger10	My child felt upset.....	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
PfAnger4	When my child got mad, he/she stayed mad.....	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4



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PROMIS Administration

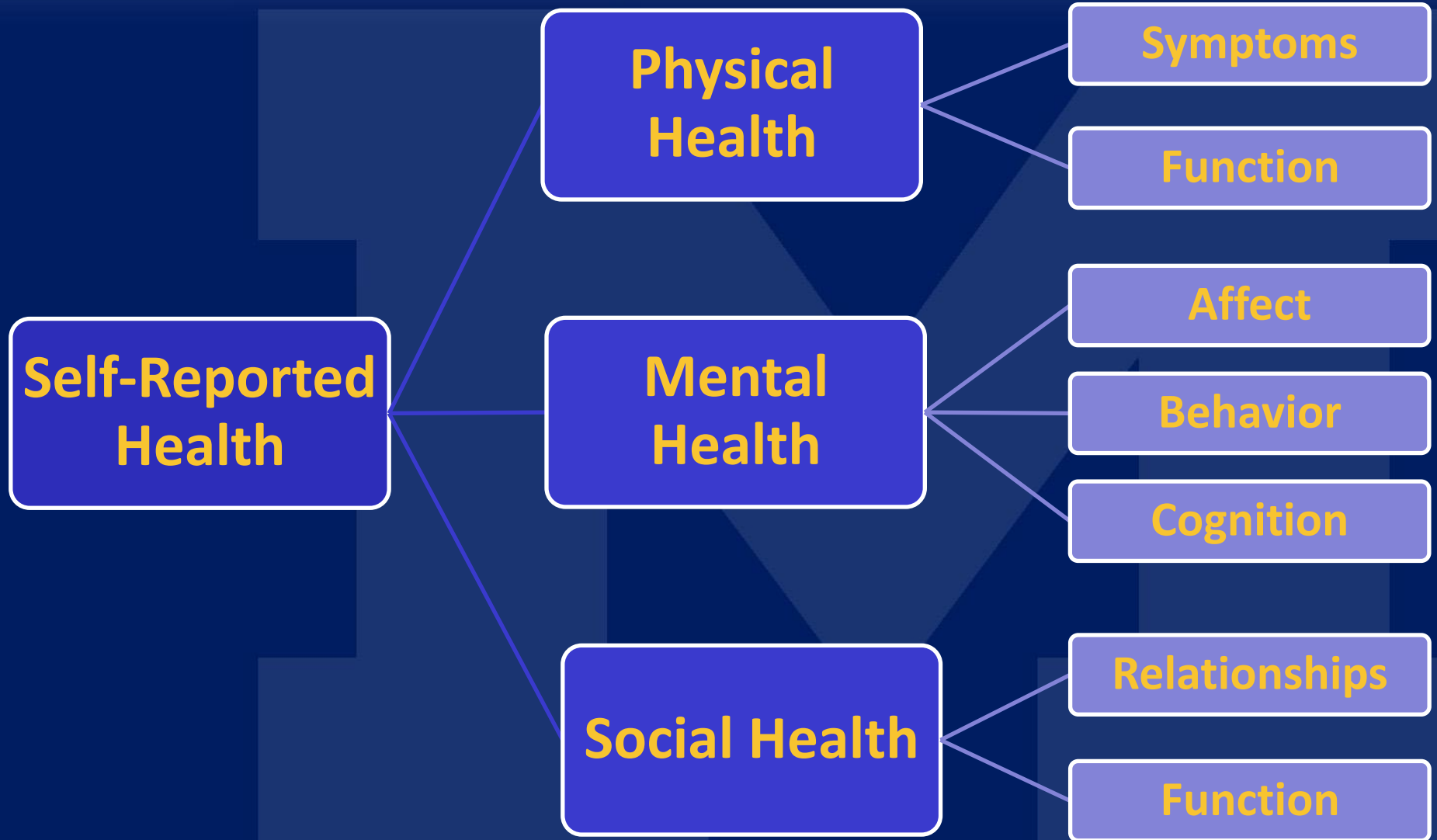
- **Pediatric:** 8-17 years old
 - Self-report
 - Proxy (parent) report
- **Adult:** 18+ years old
 - Self-report
- Languages
 - Available: English, Spanish, German, French
 - Other language development is ongoing.





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PROMIS Domain Framework





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PROMIS Current (2012)

ADULT

Pain Behavior

Pain Interference

Fatigue

Sleep Disturbance

Sleep-related
Impairment

Physical Function

Sexual Function

PEDIATRIC/PARENT PROXY

Pain Interference

Fatigue

Upper Extremity

Mobility

Asthma Impact

Physical
Health



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PROMIS Validation in CP

- There is a need to validate PROMIS measures in clinical populations
- PROMIS Pediatric Mobility Item Bank – 23 items developed in sample of typically developing children
 - **Mobility CAT**
 - administers at least 5 items, up to 12 items
 - Default critical standard error of 0.4
 - **Mobility Short Form**
 - 8 Items
- Kratz, Slavin, Mulcahey, Jette, Tulsy, & Haley (under review) [An Examination of the PROMIS® Pediatric Instruments to Assess Mobility in Children with Cerebral Palsy](#)



PROMIS Validation in CP

- 82 children ages 8-19 (M = 12.70 years); 48% male
- **Concurrent validity** – correlations with (1) self-report, (4) parent-report, and (3) performance-based measures of mobility
- **Known-groups validity** based on GMFCS

GMFCS	Description of Function	Sample
Level I	Walks without limitations	33 (39.8%)
Level II	Walks with limitations	32 (38.6%)
Level III	Walks using a handheld mobility device	14 (16.9%)
Level IV	Self-mobility with limitations; may use power wheelchair	2 (2.4%)
Level V	Transported in a manual wheelchair	1 (1.2%)



PROMIS Validation Efforts in CP

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Pearson Bivariate Correlations	Child Self-Report		Parent-Reported				Performance-Based (Examiner-Administered)		
	2 PROMIS Mobility CAT	3 PedsQL Move	4 PODCI mobility	5 PODCI Sports	6 FAQ	7 CP-CAT LE	8 TUG	9 GMFM Stand	10 GMFM Walk
1. PROMIS Mobility Short Form	.88**	.58**	.52**	.60**	.48**	.54**	-.30**	.39**	.39**
2. PROMIS Mobility CAT	-	.60**	.39**	.49**	.41**	.38**	-.16	.21	.19

Concurrent Validity

- Short Form demonstrated small to moderate correlations with comparison measures.
- CAT correlations with comparison measures were weaker than expected, and no correlation with performance-based measures was found.



PROMIS Validation Efforts in CP

Measure	GMFCS Category Means			ANOVA
	Group I	Group II	Groups III-V	
PROMIS Mobility Short Form (n = 33, 32, 17)	45.06	40.53	36.06	$F(2,81) = 9.55, p < .001$
PROMIS Mobility CAT (n = 31, 31, 17)	45.45	42.56	41.09	$F(2,78) = 2.90, p = .06$

■ Known Groups Validity

- All measures (including the PROMIS Short Form) discriminated between groups of children with CP with different levels of functioning.
- PROMIS Mobility CAT *did not*.



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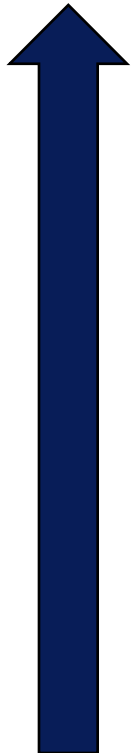
Question:

- The PROMIS Mobility Short Form seems to function well...
- Why doesn't the PROMIS Mobility CAT show good validity in CP?
 - Look at how the CAT administered items



PROMIS Mobility Items

More
Mobile



Less
Mobile

Items, arranged from highest to lowest mobility difficulty

Format*

I could run a mile	CAT Only
**I could do sports and other exercise that kids my age could do	Both CAT/SF
I have been physically able to do the activities I enjoy most	Both CAT/SF
I could ride a bike	CAT Only
I could keep up when I played with other kids	Both CAT/SF
I could walk more than one block	CAT Only
I could walk up stairs without holding on to anything	Both CAT/SF
I could stand on my tiptoes	Both CAT/SF
I could stand up by myself	Both CAT/SF
I could get up from the floor	Both CAT/SF
I could walk across the room	CAT Only
I could move my legs	Both CAT/SF
I could carry my books in a backpack	CAT Only
I could get down on my hands and knees without holding on to something	CAT Only
I could get in and out of a car	Not Administered
I could get into bed by myself	Not Administered
I could bend over to pick something up	CAT Only
I used a wheelchair to get around	Not Administered
I used a walker, cane, or crutches to get around	Not Administered
I could go up one step	Not Administered
I could get up from a regular toilet	Not Administered
I could turn my head all the way to the side	Not Administered
I could get out of bed by myself	CAT Only



Improving Validity of the PROMIS Mobility CAT in CP

- **Some Possibilities:**
 - Adjust CAT rules
 - Increase number of items administered.
 - Lower standard error stopping rule so additional items are administered.
 - Collect CP-specific data and develop *new* item calibrations.
 - Incorporate strategies to expose children using mobility devices to appropriate items.
 - Screening question
 - Custom Short Form



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Recommendations to Researchers

- Use PROMIS!
 - Consider using thoughtfully-constructed Short Forms.
 - When using CATs, consider adjusting stopping rules.
 - Consider collaborating with someone who understands how PROMIS works.



Ongoing and Future Work

■ Ongoing:

- Replication and extension of validity findings in a larger sample of young adults (ages 14-25 years) with CP.
- Examination of other PROMIS instruments (fatigue, pain interference) in the same validation sample

■ Future:

- Cognitive interviewing of participants with CP when completing PROMIS measures
- Development of a PROMIS parent proxy measure applicable to children age 0-5 years old.



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Thank You

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www.nihpromis.org

www.assessmentcenter.net