



**HealthMeasures**  
TRANSFORMING HOW HEALTH IS MEASURED

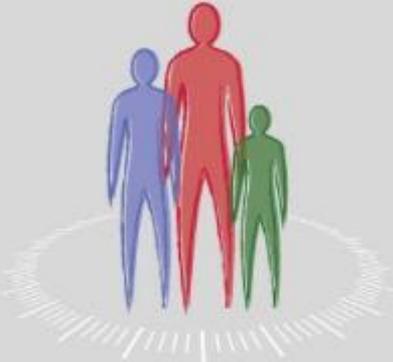
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For more information, please visit  
[www.healthmeasures.net](http://www.healthmeasures.net)

The NIH Toolbox App can be found in the iTunes Store  
<https://itunes.apple.com/us/app/nih-toolbox/id1002228307?mt=8>

# The Same, but different.



## HealthMeasures

TRANSFORMING HOW HEALTH IS MEASURED



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# HealthMeasures are hosted by

The National Person-Centered Assessment Resource  
(PCAR – PI: David Cella)

A trans-NIH cooperative agreement (U2CCA186878)  
funded by 12 NIH Institutes

And led by  
Ashley Wilder Smith  
Here, at the NCI!

The NIH seeks proposals for innovative approaches to measuring patient-reported outcomes (PROs) that will meet the needs of clinical researchers across a wide variety of chronic disorders and diseases.

- ◆ Develop and test a large bank of items measuring PROs
- ◆ Create a computerized adaptive testing system that will allow for efficient, psychometrically robust assessment of PROs in clinical research involving a wide range of chronic diseases
- ◆ Create a publicly-available system that will allow clinical researchers to access a common repository of items and CAT.

PROMIS was funded originally out of the NIH Roadmap (and later NIH Common Fund) Initiative. Thus, it was developed over 10 years

# Resources



## Tools

>200 Adult & Pediatric Measures

## Diseases

Non-Disease Specific

## Translations

Most item banks

→ Spanish

Individual Banks and  
Instruments in many  
Languages



## Cooperative Group

12 Research Sites

3 Centers

150+ Scientists

## Informatics

Assessment Center

Firestar

Scoring Service

## Advancing Knowledge

>200 Peer-Reviewed  
Publications

# NIH Toolbox

Assessment of Neurological and Behavioral Function



- Develop unified/integrated of multiple indicators (cognitive, emotional, motor, sensory) of neural and behavioral health functioning for use in large cohort studies and clinical trials
- Could be used as a form of “common currency” across diverse study designs and populations
- Would maximize yield from large, expensive studies with minimal increment in subject burden and cost

**NIH Neuroscience Blueprint, 2006**

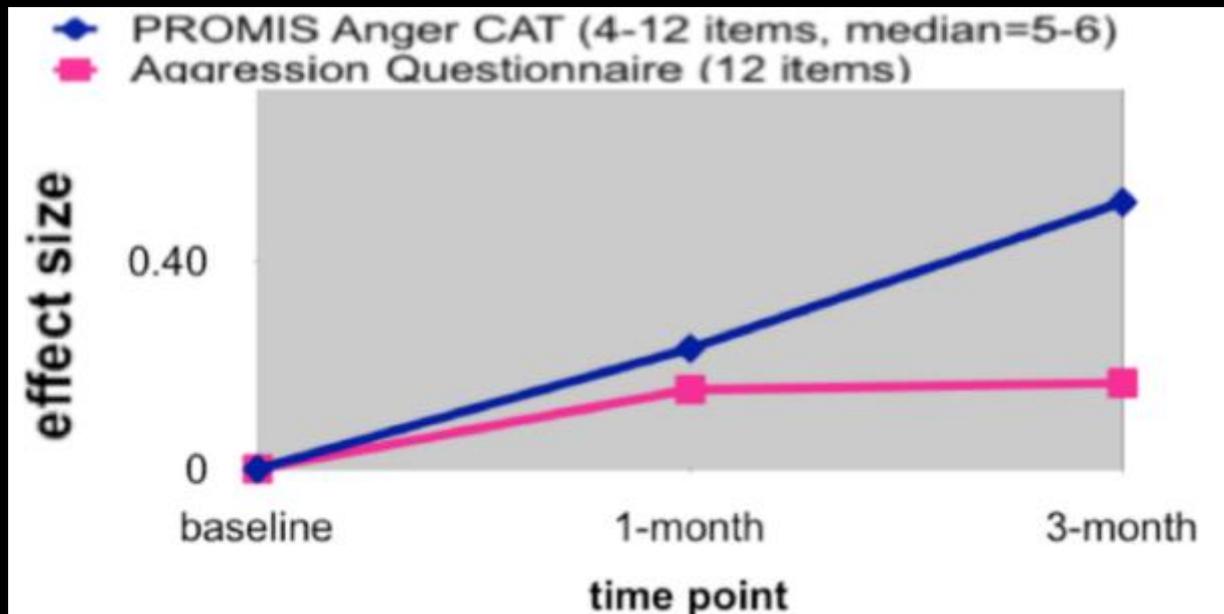
# Selection Criteria



- ◆ Applicable across the age span
- ◆ No intellectual property concerns
- ◆ Psychometrically sound
- ◆ Brief, easy to use
- ◆ Cover the full range of a trait
  - ◆ No Floor Effect
  - ◆ No Ceiling Effect
- ◆ Available for use across the age span

# More on the issue

- ◆ Legacy measures can fail to identify treatment success, nor do they typically accurately assess anyone above the mean!



# NIH Toolbox

Assessment of Neurological and Behavioral Function



## Tools

Four 30-minute domain level batteries  
Normed for ages 3-85  
34 supplemental instruments  
108 total instruments

## Diseases

Non-disease specific

## Translations

All instruments  
→ Spanish



## Developed via Contract

80 Institutions  
256 Scientists and Staff  
20,000 Participants

## Advancing Knowledge

54 Peer-Reviewed  
Publications  
>850 citations

## Informatics

Assessment Center  
>500 studies launched  
iPad App > 300 users

# Public, but private

- ◆ Free access/use of content: ROYALTY FREE!!!!
- ◆ But, revenue-neutral fees for technology
- ◆ “Open Access” for research, clinical use and education
- ◆ But, restricted where exposure would negate the value of the instruments (e.g. NIH Toolbox Cognition Battery)

# Computer Adaptive Testing

*... or "CAT" is based on Item Response Theory*

- ◆ For Dichotomous Items
  - ◆ Vocabulary
  - ◆ Reading
- ◆ For Rating Scale Items
  - ◆ Most of the health measures

# Who uses CAT?

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- ◆ Shorter
- ◆ Targeting
- ◆ Computerized Algorithm

# What is CAT?



Financial Industry Regulatory Authority

Low

Pass

High



Low

Pass

High

Rating Scale 2



Low

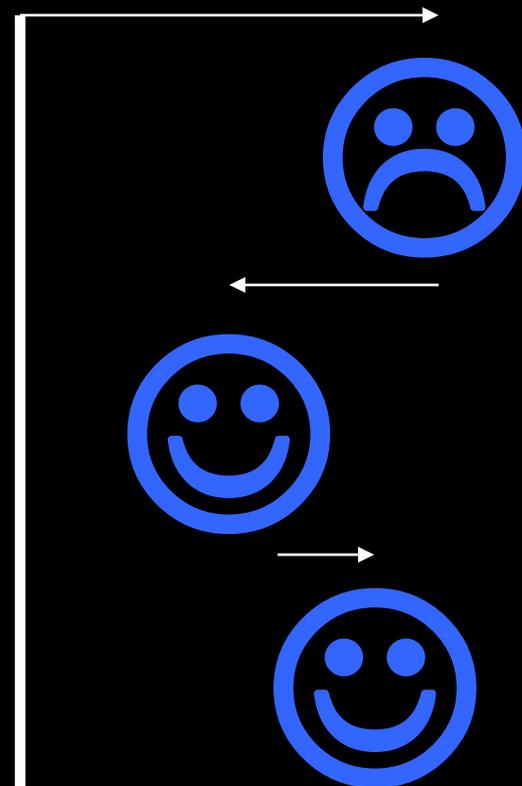
Pass

High

Rating Scale 3



**PASS!**



Low

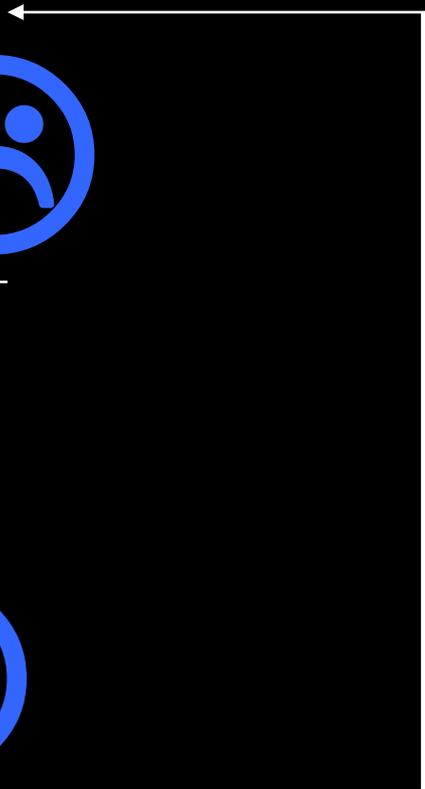
Pass

High

Rating Scale 4



**FAIL**



|    |    |    |    |    |    |    |    |    |     |
|----|----|----|----|----|----|----|----|----|-----|
| 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  | 10  |
| 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20  |
| 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30  |
| 31 | 32 | 33 | 34 | 35 | 36 | 37 | 38 | 39 | 40  |
| 41 | 42 | 43 | 44 | 45 | 46 | 47 | 48 | 49 | 50  |
| 51 | 52 | 53 | 54 | 55 | 56 | 57 | 58 | 59 | 60  |
| 61 | 62 | 63 | 64 | 65 | 66 | 67 | 68 | 69 | 70  |
| 71 | 72 | 73 | 74 | 75 | 76 | 77 | 78 | 79 | 80  |
| 81 | 82 | 83 | 84 | 85 | 86 | 87 | 88 | 89 | 90  |
| 91 | 92 | 93 | 94 | 95 | 96 | 97 | 98 | 99 | 100 |

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**1**

**100**

**1**

**100**



**1**

**100**

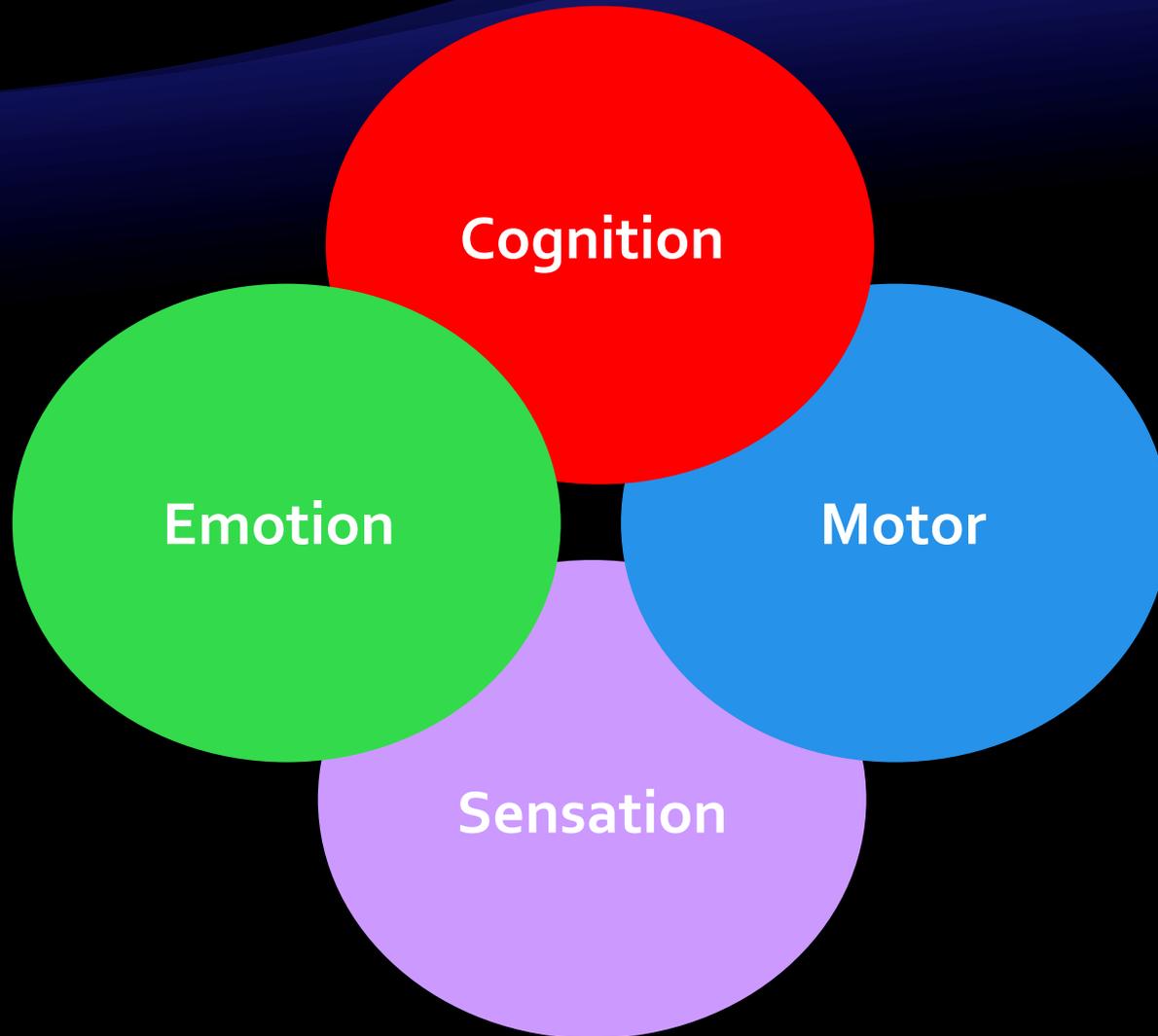


**1**

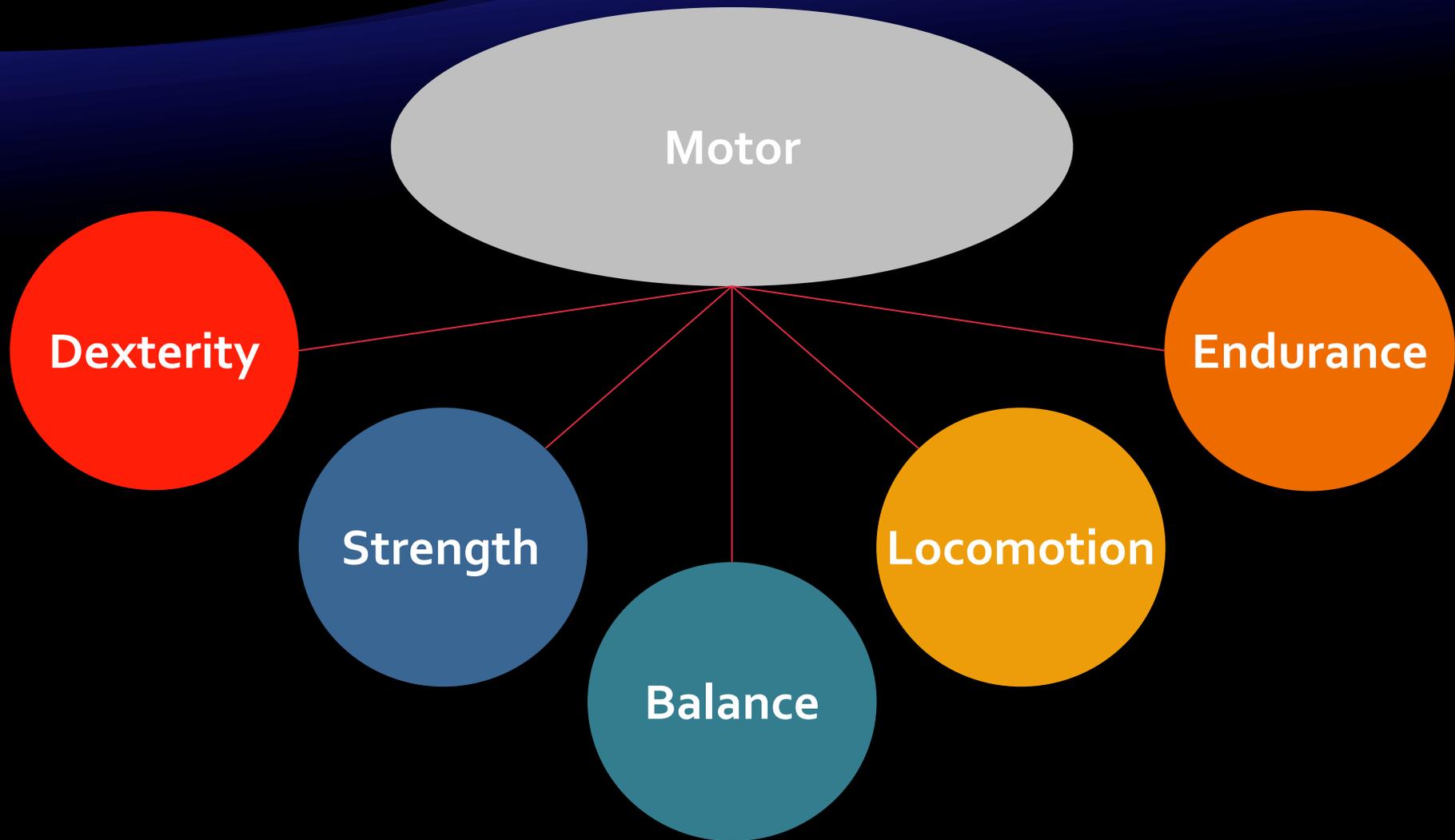
**100**



# Toolbox Domains



# Motor Domain Framework



# Balance

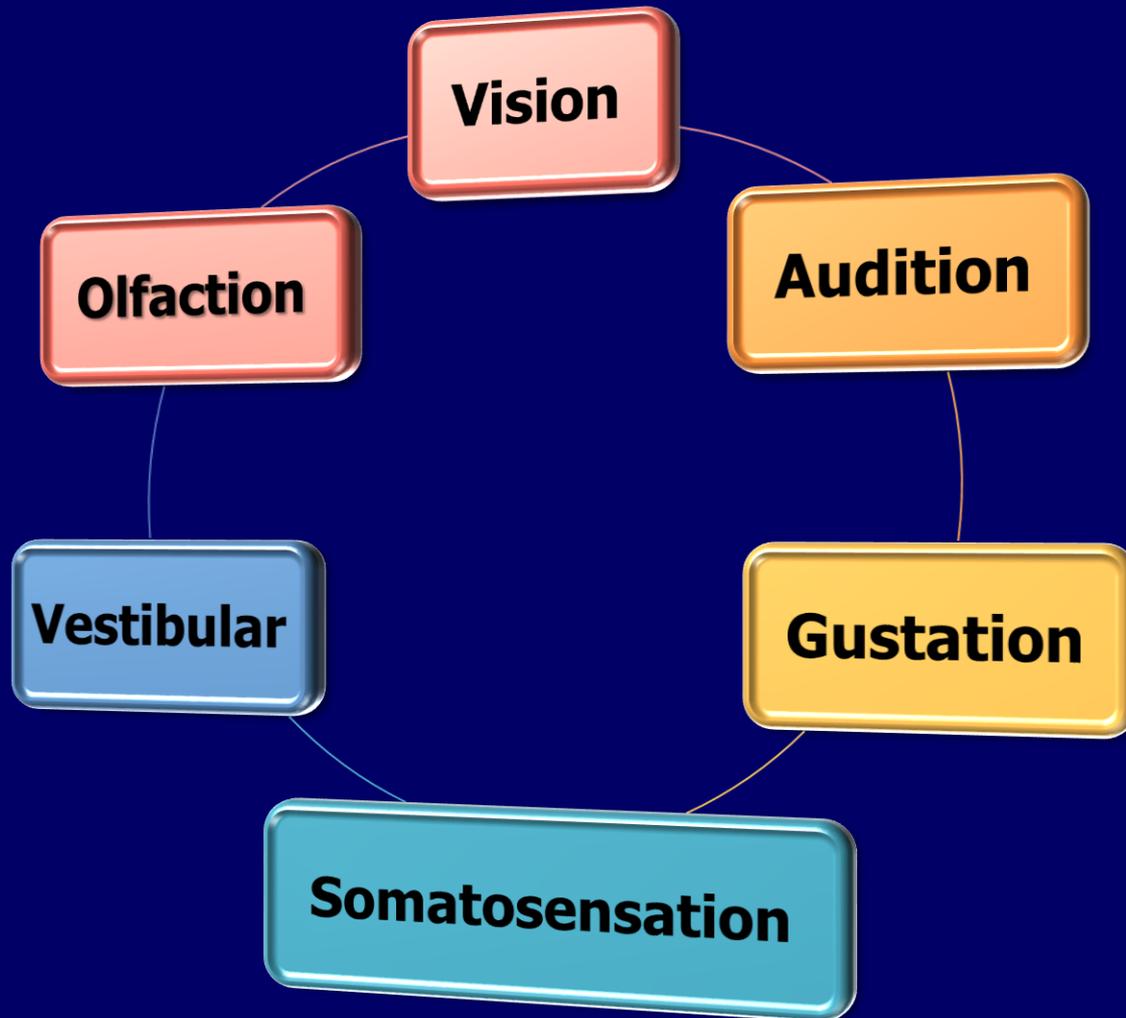
## NIH Toolbox Standing Balance Measure



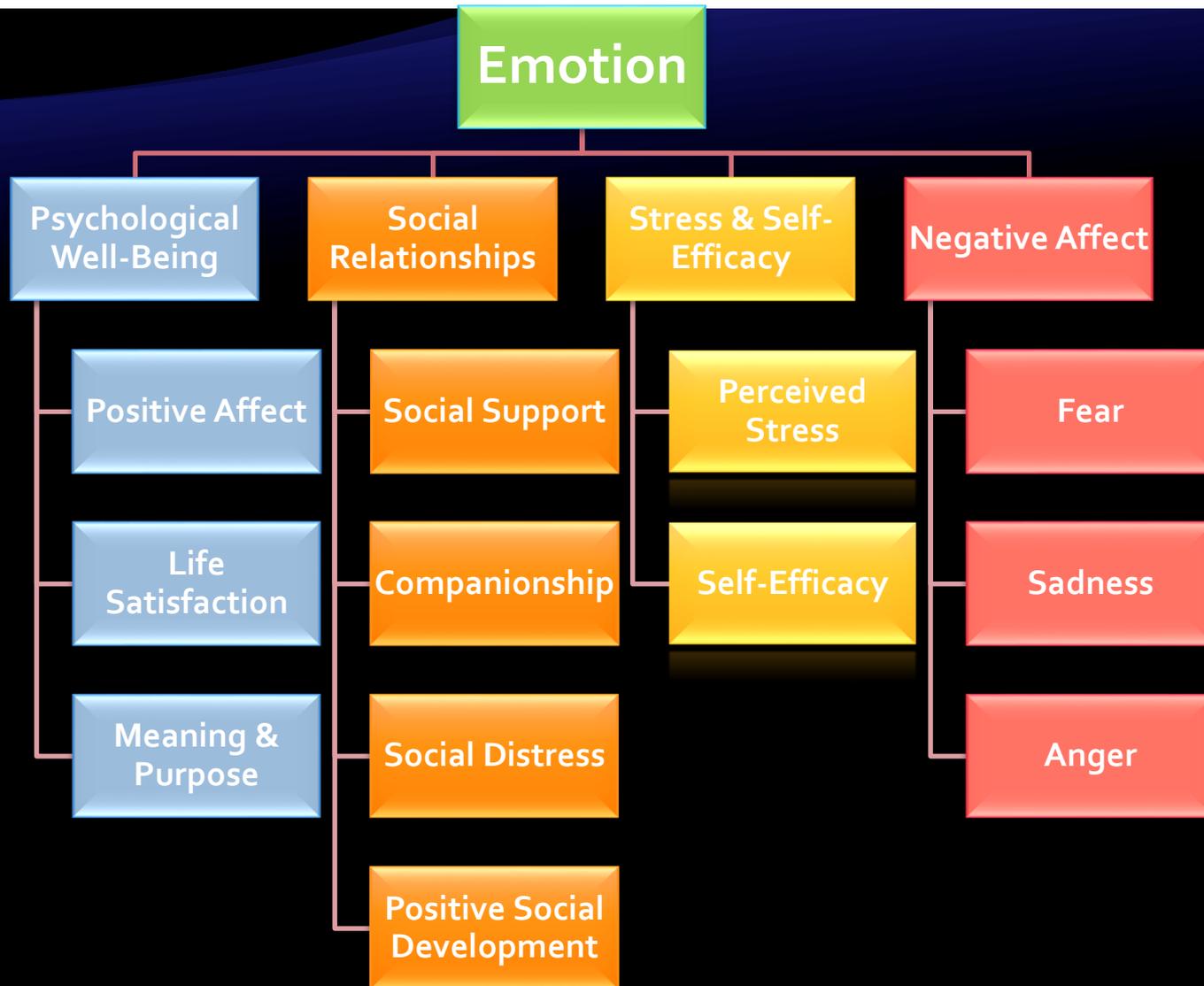
Balance allows people to orient their body in space and maintain an upright posture under a variety of conditions.



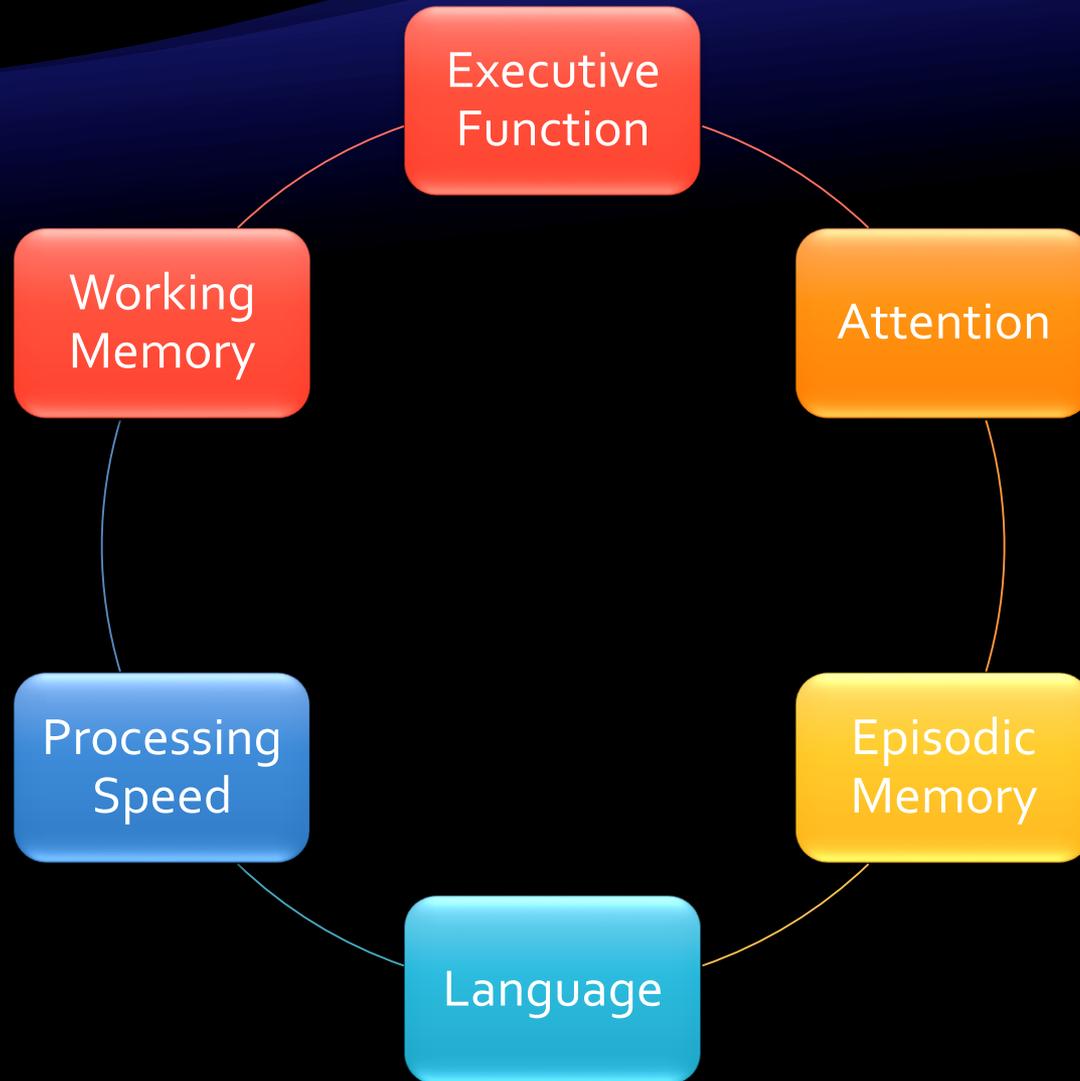
# Sensation Domains



# Emotion Domain Framework



# Cognition Domain Framework



# Executive Function – Attention

## NIHTB Flanker Inhibitory Control & Attention Test

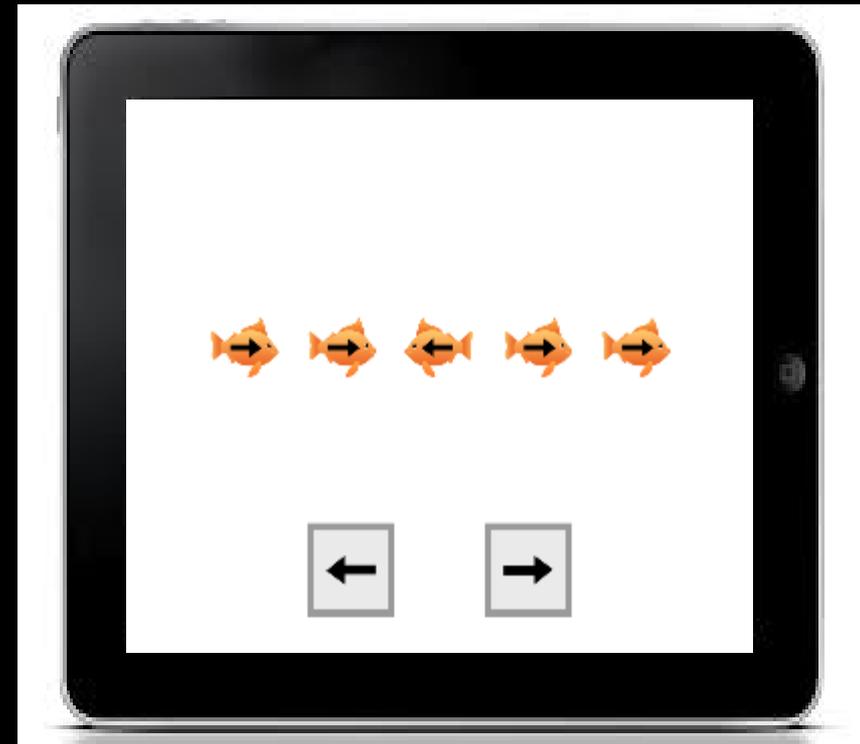


Task: Indicate the direction of a central target flanked by foils in the same (congruent) and opposite (incongruent) orientations

Scoring: Algorithm weighting accuracy and reaction time

Total time: 4 minutes

Validation Measure:  
D-KEFS Inhibition



# Language

## NIHTB Picture Vocabulary Test



Task: Touch picture that shows meaning of the verbally presented word (picture-word matching)

Total time: 4 minutes

Spanish: Separate but parallel test was developed

Validation Measure:  
Peapody Picture Vocabulary (PPVT)



# Executive Function-Set Shifting

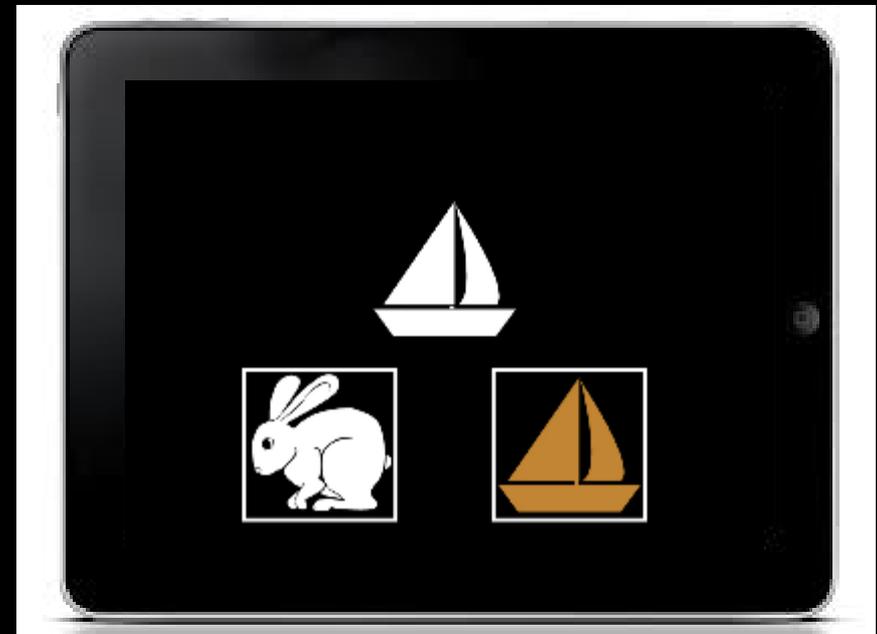
## NIHTB Dimensional Change Card Sort Test (DCCS)



Task: Sort by color; sort by shape; shift according to instructions; 3 sets of trials – shape, color, mixed

Total time: 4 minutes

Validation Measures:  
DKEFS Measures  
WCST



# Working Memory

## NIHTB List Sorting Working Memory Test



Task: List sequentially presented test items in order of size (and within categories); establishes working memory span

Total time: 7 minutes

Validation Measures:  
Wechsler Letter-  
Number Sequencing  
PASAT



# Episodic Memory

## NIHTB Picture Sequence Memory Test



Task: Replicate spatial placement of a previously demonstrated sequence of pictures

Total time: 7 minutes

Validation Measures:

RAVLT Word List

Brief Visuospatial Memory  
Test

NEPSY Sentence Repetition

# Episodic Memory

## NIHTB Picture Sequence Memory Test



# Language

## NIHTB Oral Reading Recognition Test



Task: The participant is asked to read words (or letters) as accurately as possible.

Total time: 3 minutes

Spanish: Separate but parallel test was developed

Validation Measure: Wide Range Achievement Test

# Processing Speed

## NIHTB Pattern Comparison Processing Speed Test



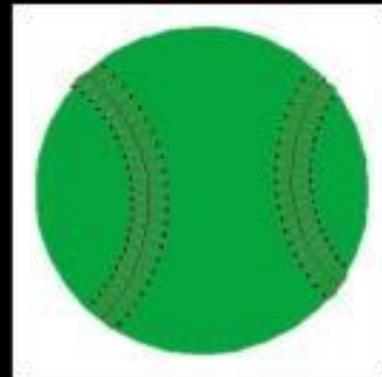
Task: Decide as quickly as possible if two items are the same or not

Total trials: Single

Scoring: Total number of items correctly responded to in 90 seconds

Total time: 90 seconds

Validation Measure:  
Wechsler Processing Speed Index



# Norming



- ◆ 4,859 subjects English and Spanish, ages 3-85
- ◆ 1-week retest (N=500)
- ◆ Stratified random sampling from recruitment lists maintained at ten geographically diverse market research firms
  - ◆ Single year age bands 3-17, 7 adult bands through 85
  - ◆ Census balanced by age, race, ethnicity and education
  - ◆ Separate English and Spanish samples

# NIH Toolbox App

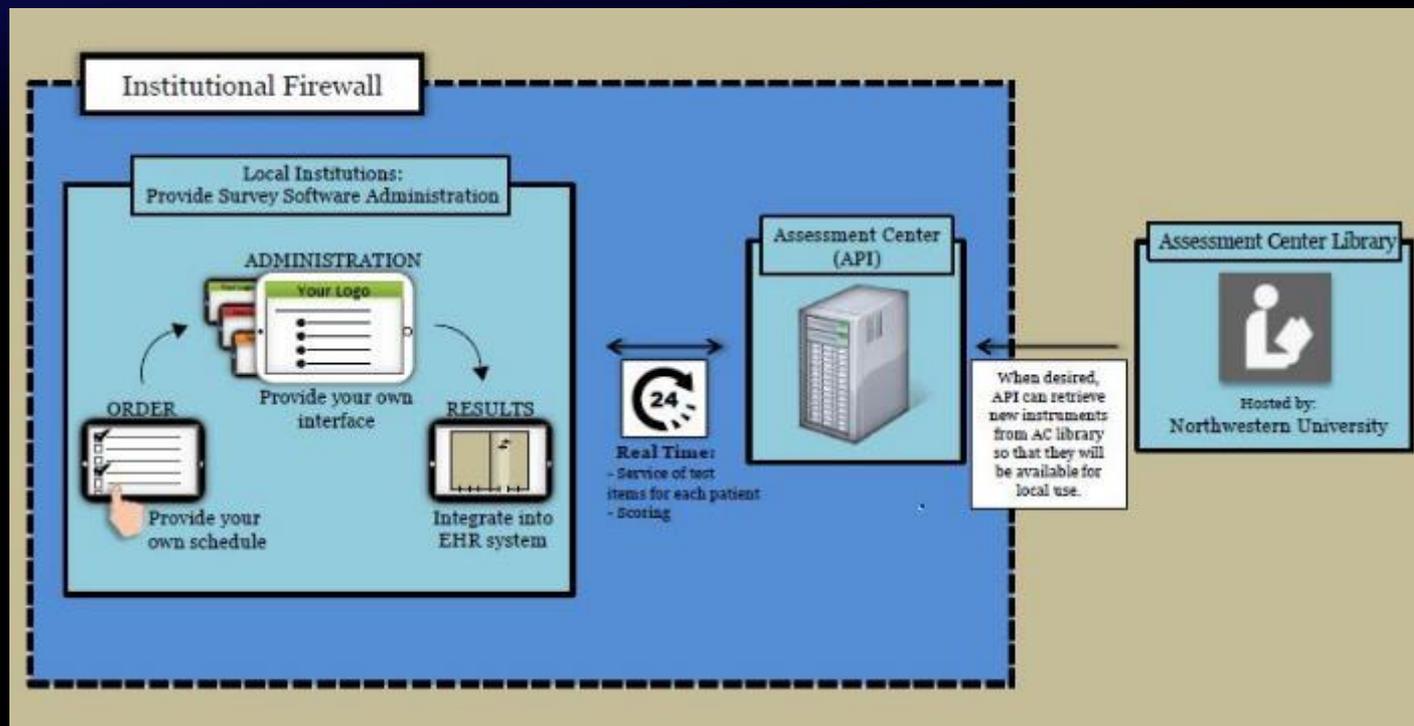


- ◆ For use in-clinic and other data collections sites
  - ◆ (not a “take-home” tool)
- ◆ Tailored for the iPad
- ◆ Also Features selected PROMIS CATs, Global, PROMIS-29
- ◆ Released July 1, 2015
- ◆ (in the iTunes store search for “NIH Toolbox”)
- ◆ Annual license fee for use on up to 10 iPads

# Assessment CENTER API



# Assessment Center API



# Research Electronic Data Capture (REDCap)



- ◆ Incorporates Assessment Center API
- ◆ Available as Cloud-hosted API
- ◆ Local API hosting also enabled (used by the DoD)
- ◆ @ 1,600 institutions (351 are already using the Assessment Center API)

# Research Electronic Data Capture (REDCap)



**Epic**

- ◆ Native Epic 2012 and later
  - ◆ Selected PROMIS short forms
  - ◆ Patient utilization of MyChart



- ◆ Select PROMIS instruments
  - ◆ Available "in clinic" and online "at home"

# Other Formats for Outcome Measures



- ◆ For use in-clinic and other data collections sites
  - ◆ (not a “take-home” tool)
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A common problem when using a variety of patient-reported outcome measures is the comparability of scales on which the outcomes are reported. Linking establishes relationships between scores on two different measures.

The PRO Rosetta Stone (PROsetta Stone®) developed and applied methods to PROMIS and other PCORR instruments with other related instruments (e.g., SF-36, Brief Pain Inventory, CES-D, MASQ, FACIT-Fatigue) to expand the range of PRO assessment options within a common, standardized metric. It provides equivalent scores for different scales that measure the same health outcome.



## PROMIS Anger

|      |   |   |
|------|---|---|
| BPAQ | <a href="#">PROMIS Anger and BPAQ Linking Table</a> | <a href="#">PROMIS Anger and BPAQ Full Report</a> |
|------|---|---|

## PROMIS Anxiety

|                     |  |  |
|---------------------|--|--|
| MASQ                | <a href="#">PROMIS Anxiety and MASQ Linking Table</a>                | <a href="#">PROMIS Anxiety and MASQ Full Report</a>                |
| SF-36/Mental Health | <a href="#">PROMIS Anxiety and SF-36/Mental Health Linking Table</a> | <a href="#">PROMIS Anxiety and SF-36/Mental Health Full Report</a> |
| GAD-7               | <a href="#">PROMIS Anxiety and GAD-7 Linking Table</a>               | <a href="#">PROMIS Anxiety and GAD-7 Full Report</a>               |
| K6                  | <a href="#">PROMIS Anxiety and K6 Linking Table</a>                  | <a href="#">PROMIS Anxiety and K6 Full Report</a>                  |
| Neuro-QOL Anxiety   | <a href="#">PROMIS Anxiety and Neuro-QOL Anxiety Linking Table</a>   | <a href="#">PROMIS Anxiety and Neuro-QOL Anxiety Full Report</a>   |

## PROMIS Depression

|                      |  |  |
|----------------------|--|--|
| CES-D                | <a href="#">PROMIS Depression and CES-D Linking Table</a>                | <a href="#">PROMIS Depression and CES-D Full Report</a>                |
| SF-36/Mental Health  | <a href="#">PROMIS Depression and SF-36/Mental Health Linking Table</a>  | <a href="#">PROMIS Depression and SF-36/Mental Health Full Report</a>  |
| PHQ-9                | <a href="#">PROMIS Depression and PHQ-9 Linking Table</a>                | <a href="#">PROMIS Depression and PHQ-9 Full Report</a>                |
| Neuro-QOL Depression | <a href="#">PROMIS Depression and Neuro-QOL Depression Linking Table</a> | <a href="#">PROMIS Depression and Neuro-QOL Depression Full Report</a> |

## PROMIS Fatigue

|                |   |   |
|----------------|---|---|
| FACIT-Fatigue  | <a href="#">PROMIS Fatigue and FACIT-Fatigue Linking Table</a>  | <a href="#">PROMIS Fatigue and FACIT-Fatigue Full Report</a>  |
| SF-36/Vitality | <a href="#">PROMIS Fatigue and SF-36/Vitality Linking Table</a> | <a href="#">PROMIS Fatigue and SF-36/Vitality Full Report</a> |

## PROMIS Pain

|                  |  |  |
|------------------|--|--|
| BPI Severity     | <a href="#">PROMIS Pain and BPI Severity Linking Table</a>     | <a href="#">PROMIS Pain and BPI Severity Full Report</a>     |
| BPI Interference | <a href="#">PROMIS Pain and BPI Interference Linking Table</a> | <a href="#">PROMIS Pain and BPI Interference Full Report</a> |



Appendix Table 7: Raw Score to T-Score Conversion Table (IRT Fixed Parameter Calibration Linking) for CES-D to PROMIS Depression (PROMIS Study). RECOMMENDED

| <b>CES-D Score</b> | <b>PROMIS T-score</b> | <b>SE</b> | <b>CES-D Score</b> | <b>PROMIS T-score</b> | <b>SE</b> |
|--------------------|-----------------------|-----------|--------------------|-----------------------|-----------|
| 0                  | 34.5                  | 6.0       | 40                 | 69.2                  | 2.3       |
| 1                  | 38.6                  | 5.1       | 41                 | 69.8                  | 2.3       |
| 2                  | 41.1                  | 4.7       | 42                 | 70.4                  | 2.3       |
| 3                  | 42.9                  | 4.6       | 43                 | 71.0                  | 2.4       |
| 4                  | 44.7                  | 4.1       | 44                 | 71.7                  | 2.4       |
| 5                  | 46.2                  | 3.8       | 45                 | 72.3                  | 2.5       |
| 6                  | 47.5                  | 3.6       | 46                 | 73.0                  | 2.5       |
| 7                  | 48.7                  | 3.4       | 47                 | 73.7                  | 2.6       |
| 8                  | 49.8                  | 3.2       | 48                 | 74.4                  | 2.7       |
| 9                  | 50.8                  | 3.0       | 49                 | 75.2                  | 2.7       |
| 10                 | 51.7                  | 2.9       | 50                 | 76.0                  | 2.8       |
| 11                 | 52.6                  | 2.8       | 51                 | 76.8                  | 2.9       |
| 12                 | 53.4                  | 2.7       | 52                 | 77.7                  | 3.0       |



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