NIH initiatives to improve measurement: PROMIS and Toolbox

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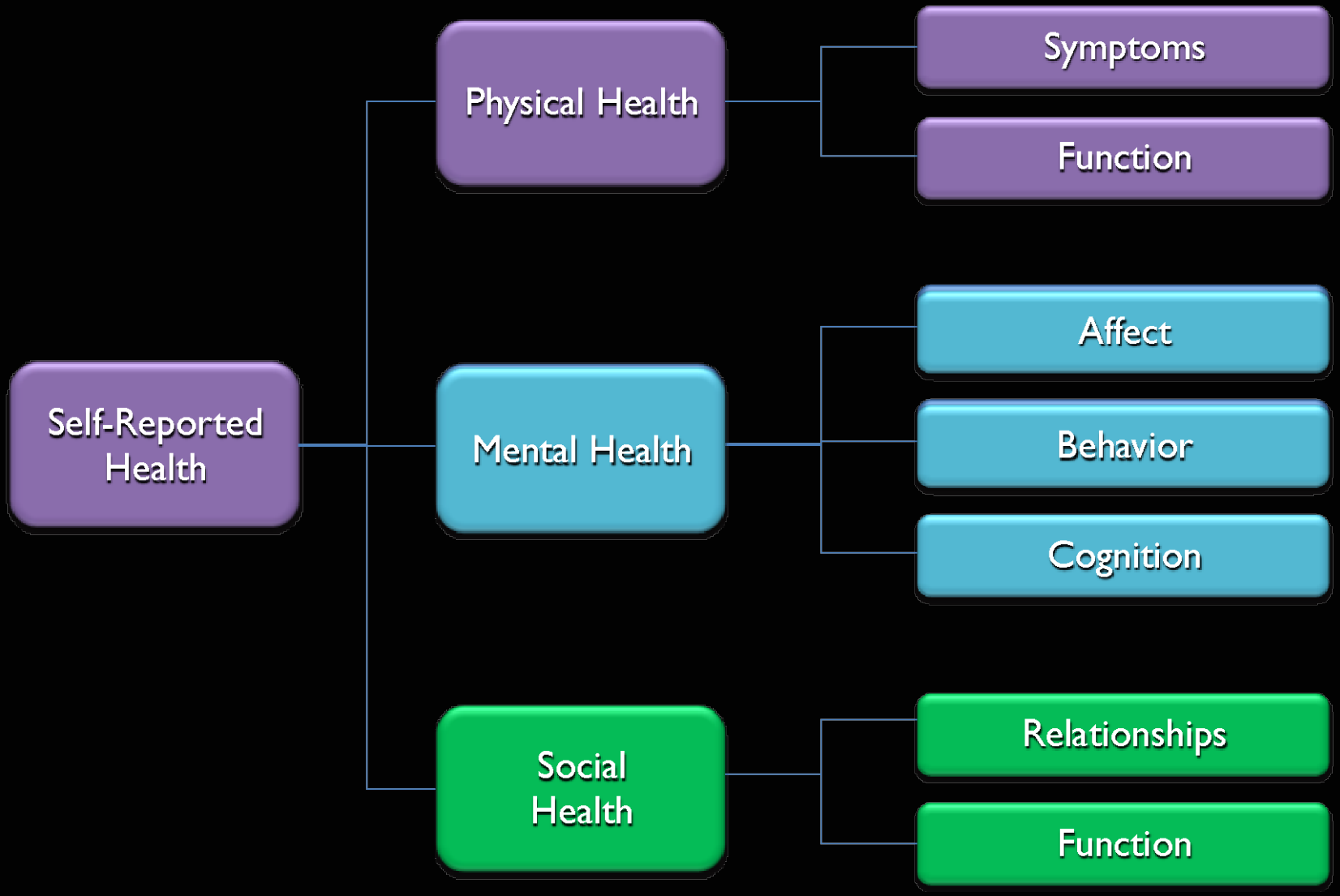
Karon F. Cook, PhD
Department of Medical Social Sciences
Feinberg School of Medicine
Northwestern University, Chicago, IL

PROMIS®
Dynamic Tools to Measure Health Outcomes from the Patient Perspective

Goals of PROMIS

- Develop system of measures of patient–reported health status for physical, mental, and social well–being.
- Measure outcomes across chronic diseases and conditions

Domain Framework



PROMIS Current (2012) Physical Health Banks

Physical Health

Adult	Pediatric
Pain Behavior	Pain Interference
Pain Interference	Fatigue
Fatigue	Upper Extremity
Sleep Disturbance	Mobility
Sleep-related Impairment	Asthma Impact
Physical Function	
Sexual Function	

PROMIS Current (2012) Mental Health Banks

Mental Health

Adult	Pediatric
Anxiety	Anxiety
Depression	Depression
Anger	Anger
Illness Impact Neg, Pos	
Applied Cog – Concerns, Abilities	
Alcohol Use, Consequences, Expectancies	

Measuring with Item Banks

- An item bank is a large collection of items measuring a single domain.
  - "Calibrated" on a common metric (arranged by difficulty)

- Any and all items can be used to provide a score for the domain that is being measured.

Qualities of High Quality Item Banks

- Questions are easy to understand
- Shared understanding across individuals
- Measure what you think it should measure
- To get there, utilize rigorous qualitative and quantitative methods

Qualitative Methods

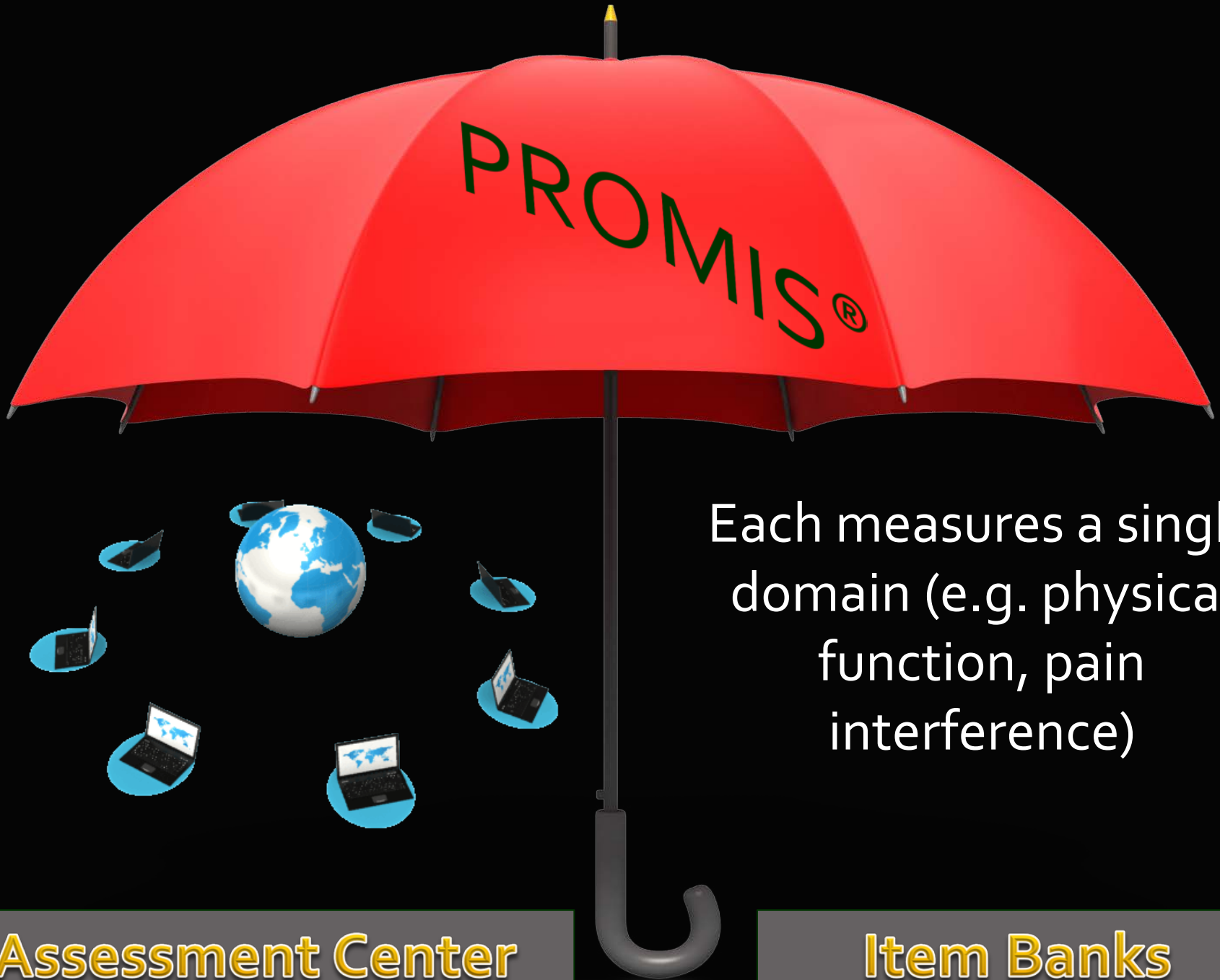
- Definition of construct
- Identification of existing measures
- Patient focus groups
- Expert review/consensus/revision
- Cognitive interviews
- Cultural sensitivity and translatability
- Repeat as necessary

Quantitative Methods

- Large scale testing (500/item)
- Statistical analysis
  - Dimensionality
  - Differential Item Function
  - Fit to item response theory model (IRT)
- Final decisions about inclusion/exclusion

Many formats, one metric

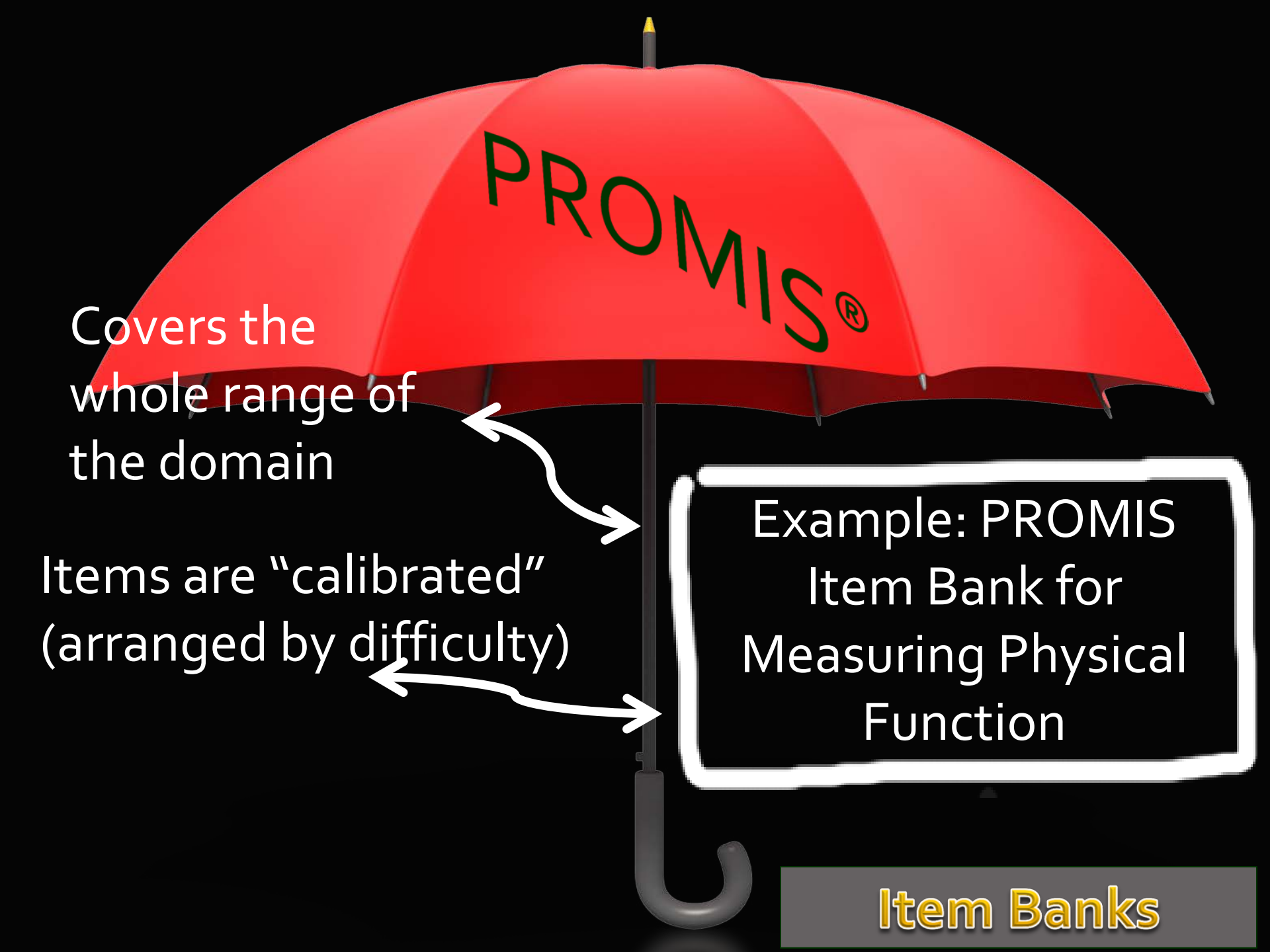
- Short Forms
- Long Forms
- Computer Adaptive testing



Each measures a single domain (e.g. physical function, pain interference)

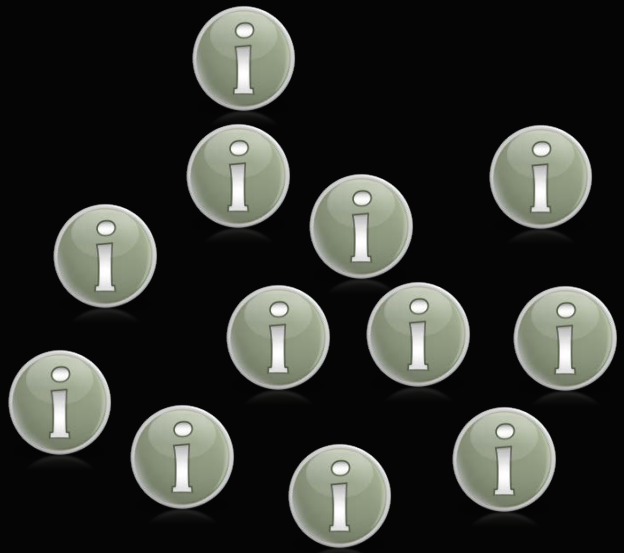
Assessment Center

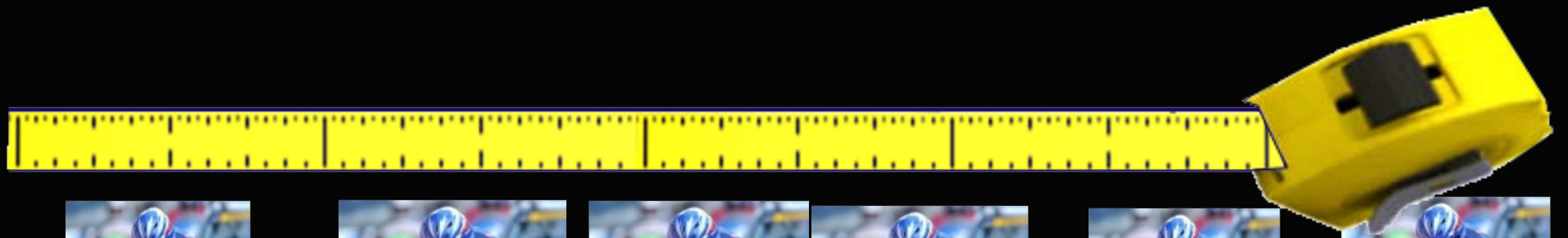
Item Banks


PROMIS®
Covers the whole range of the domain
Items are "calibrated" (arranged by difficulty)
Example: PROMIS Item Bank for Measuring Physical Function
Item Banks

An Example Item Bank

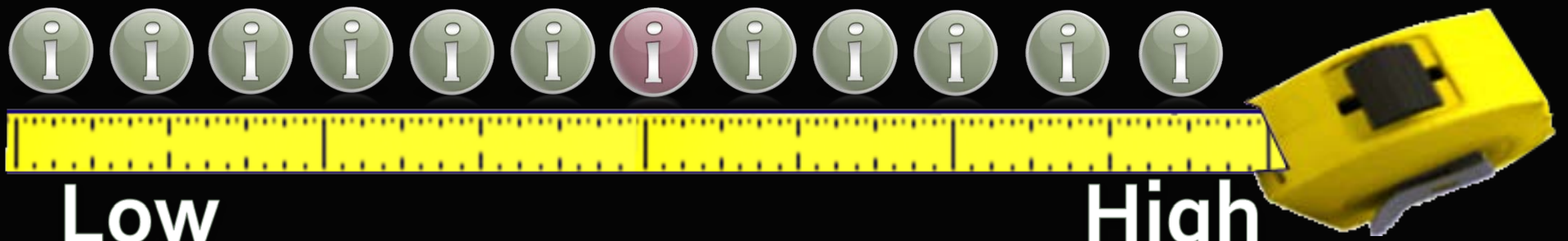
Physical Function





Computer adaptive testing

An Example Item Bank



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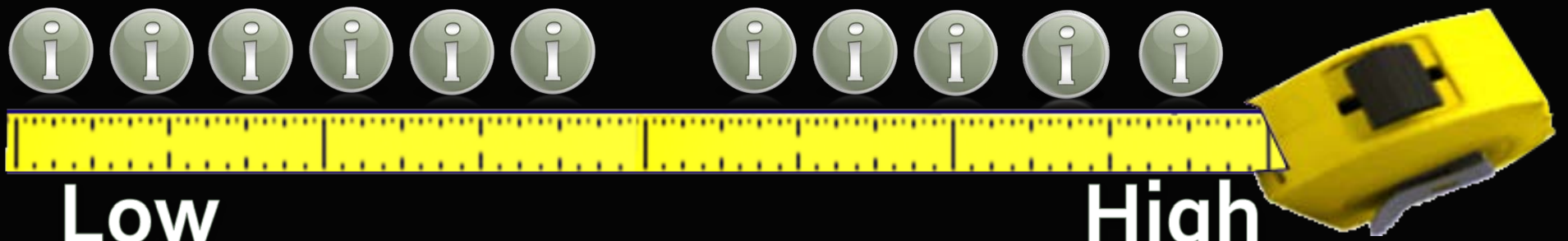

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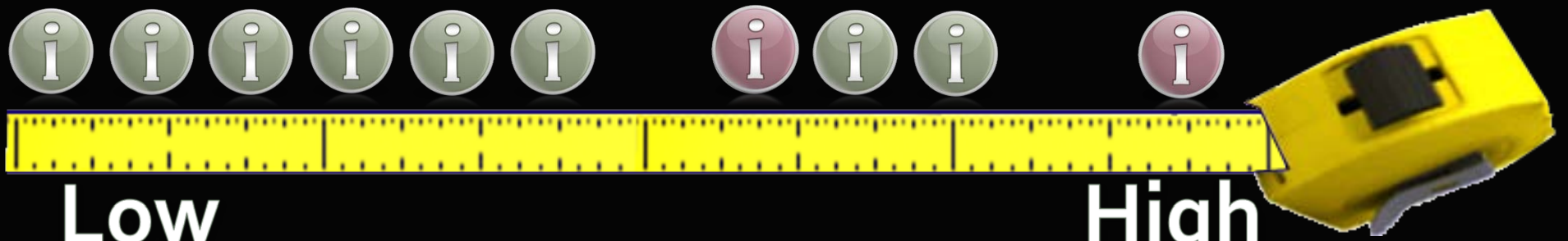

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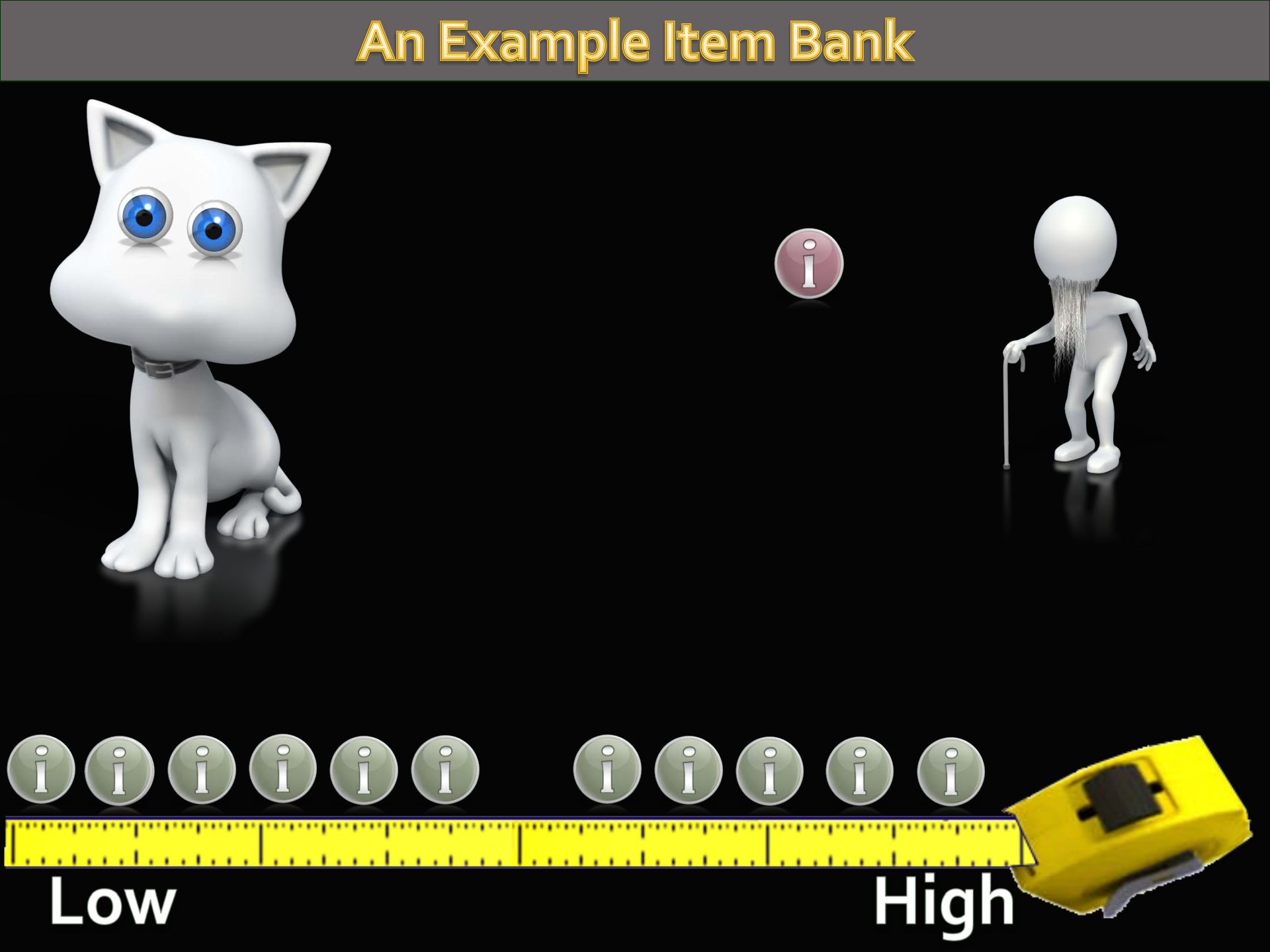

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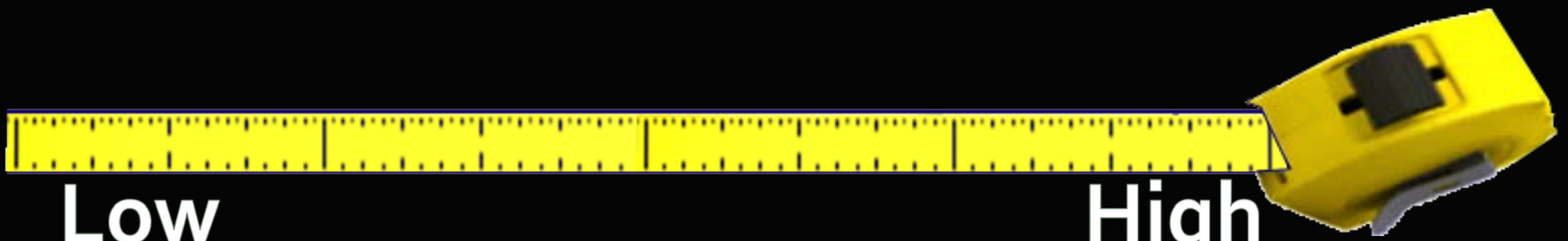

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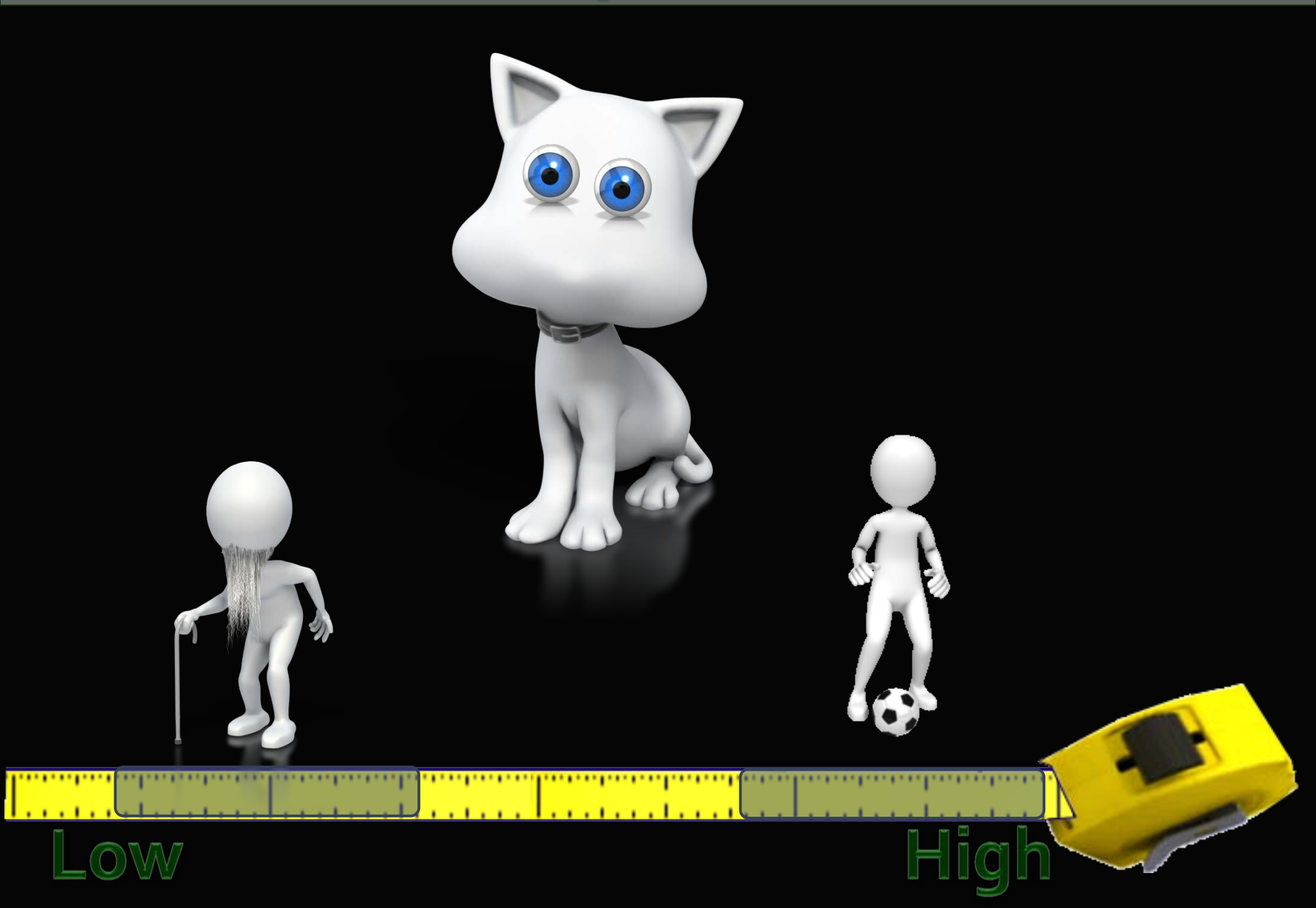

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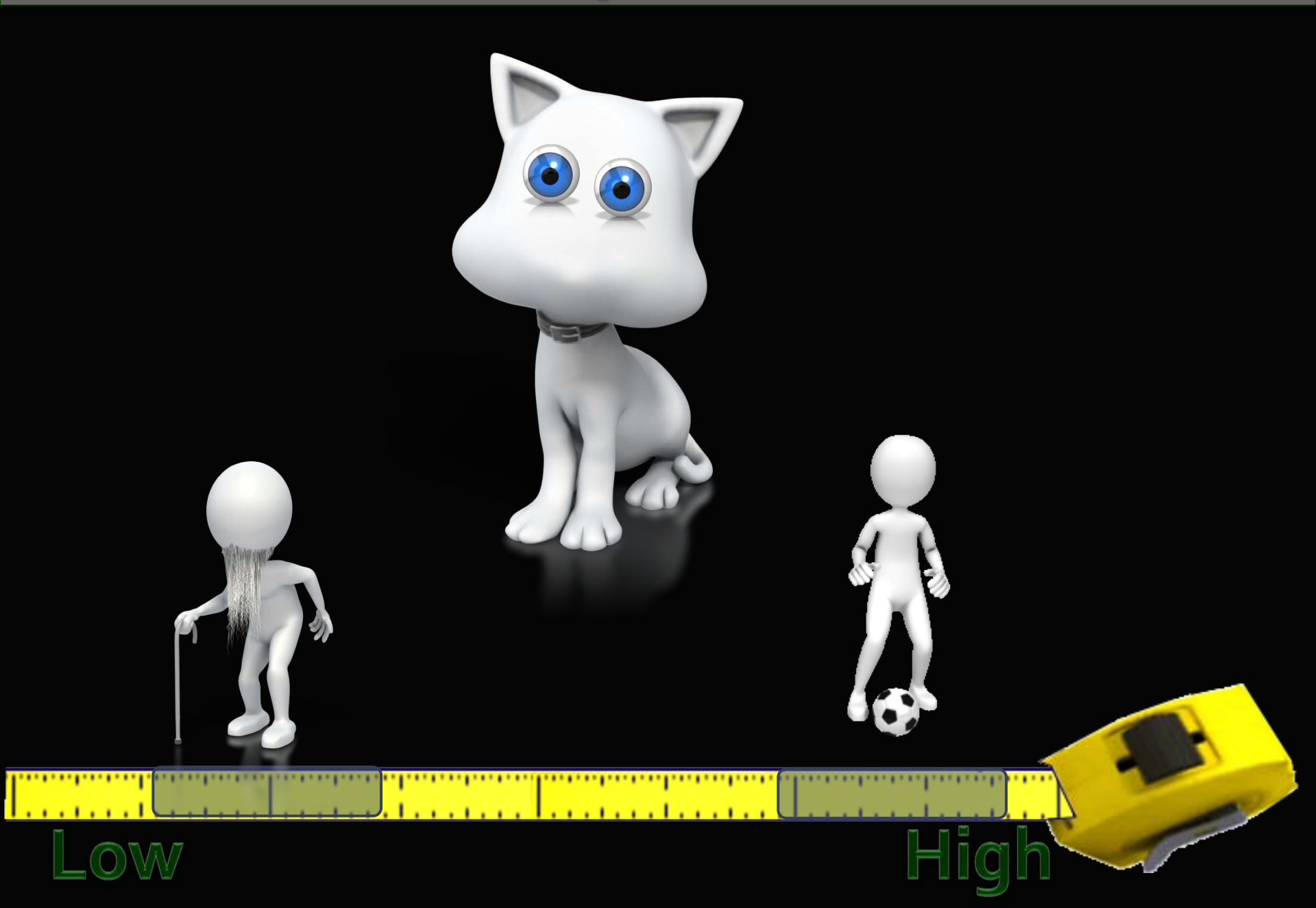

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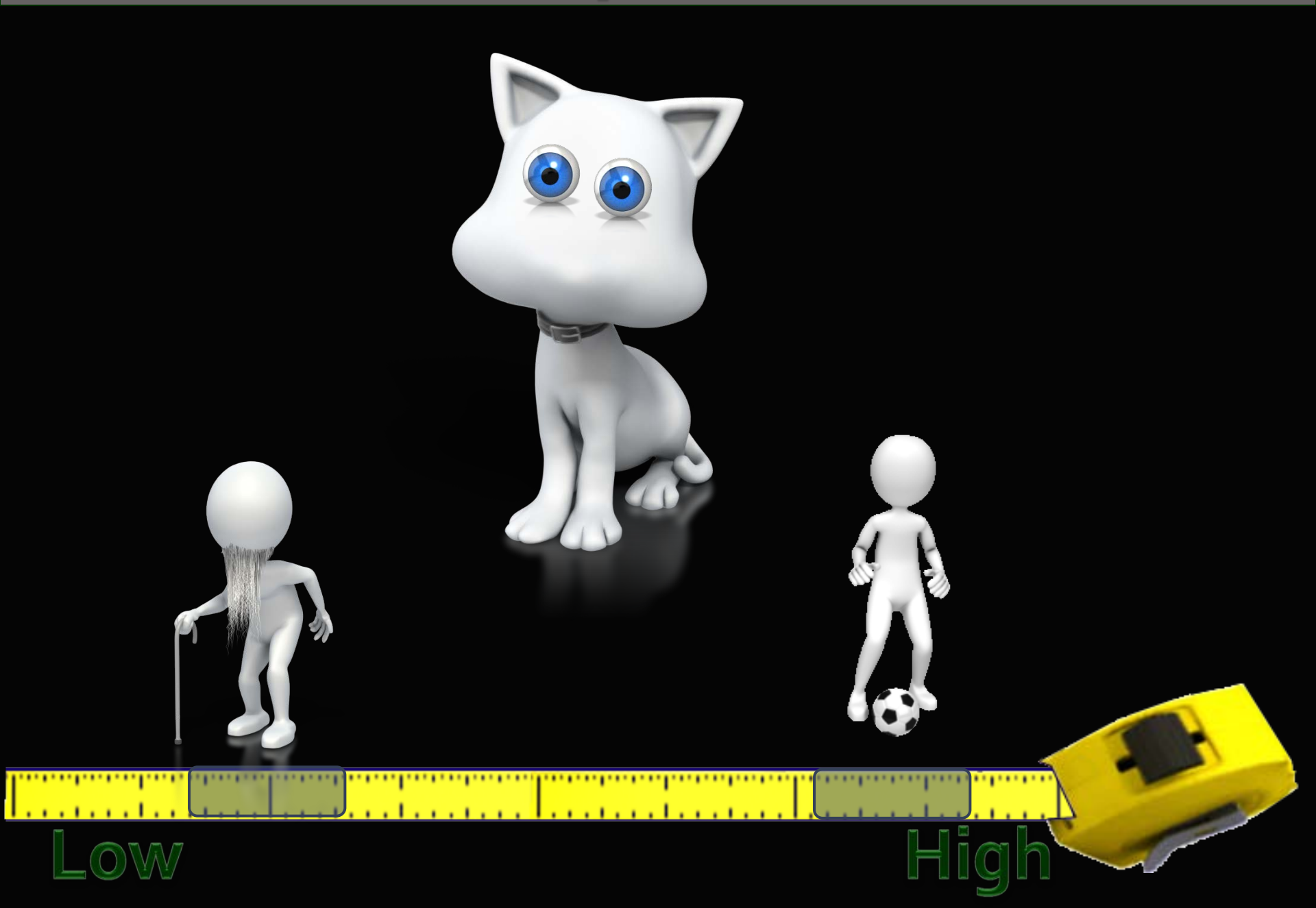

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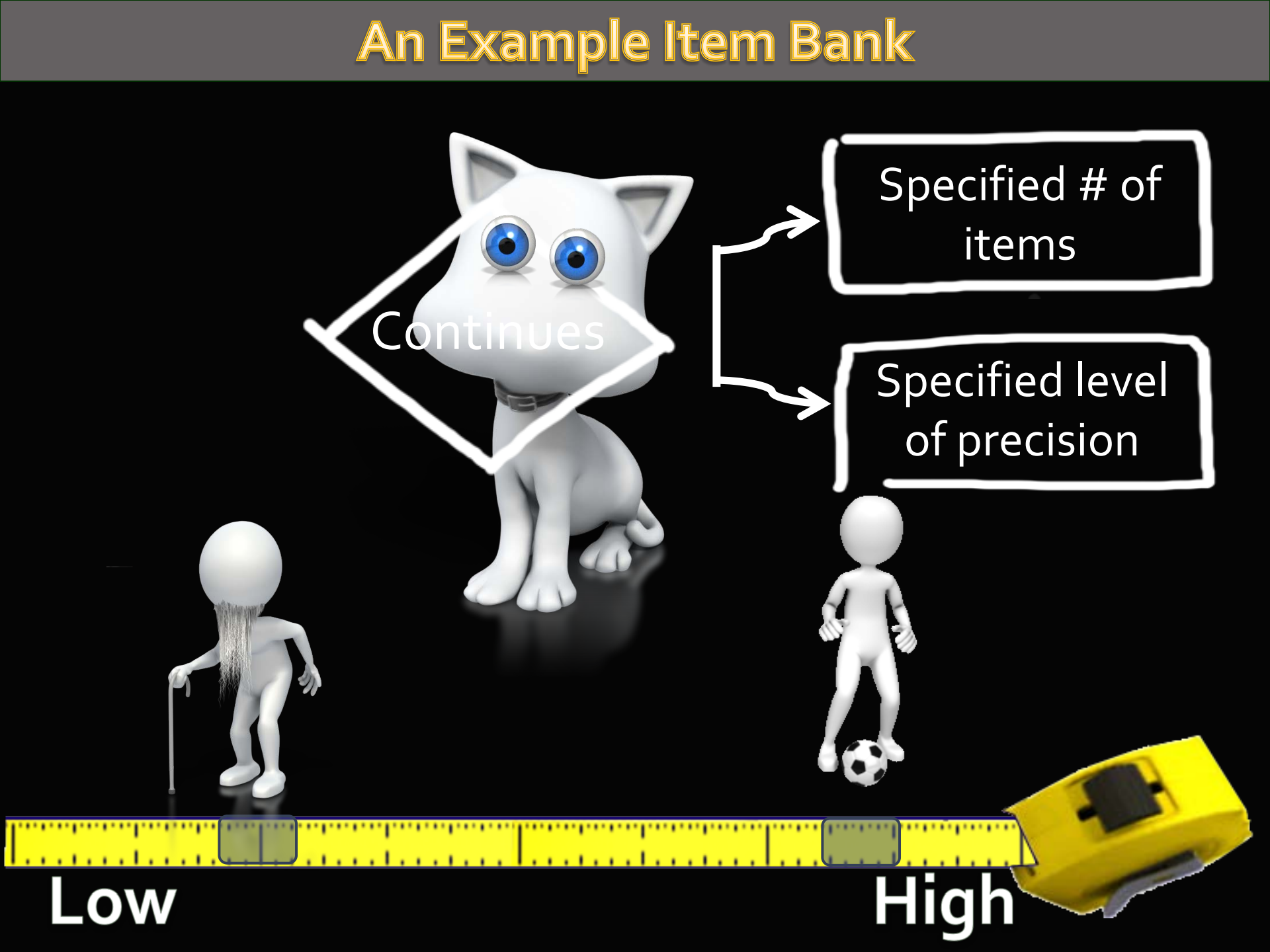


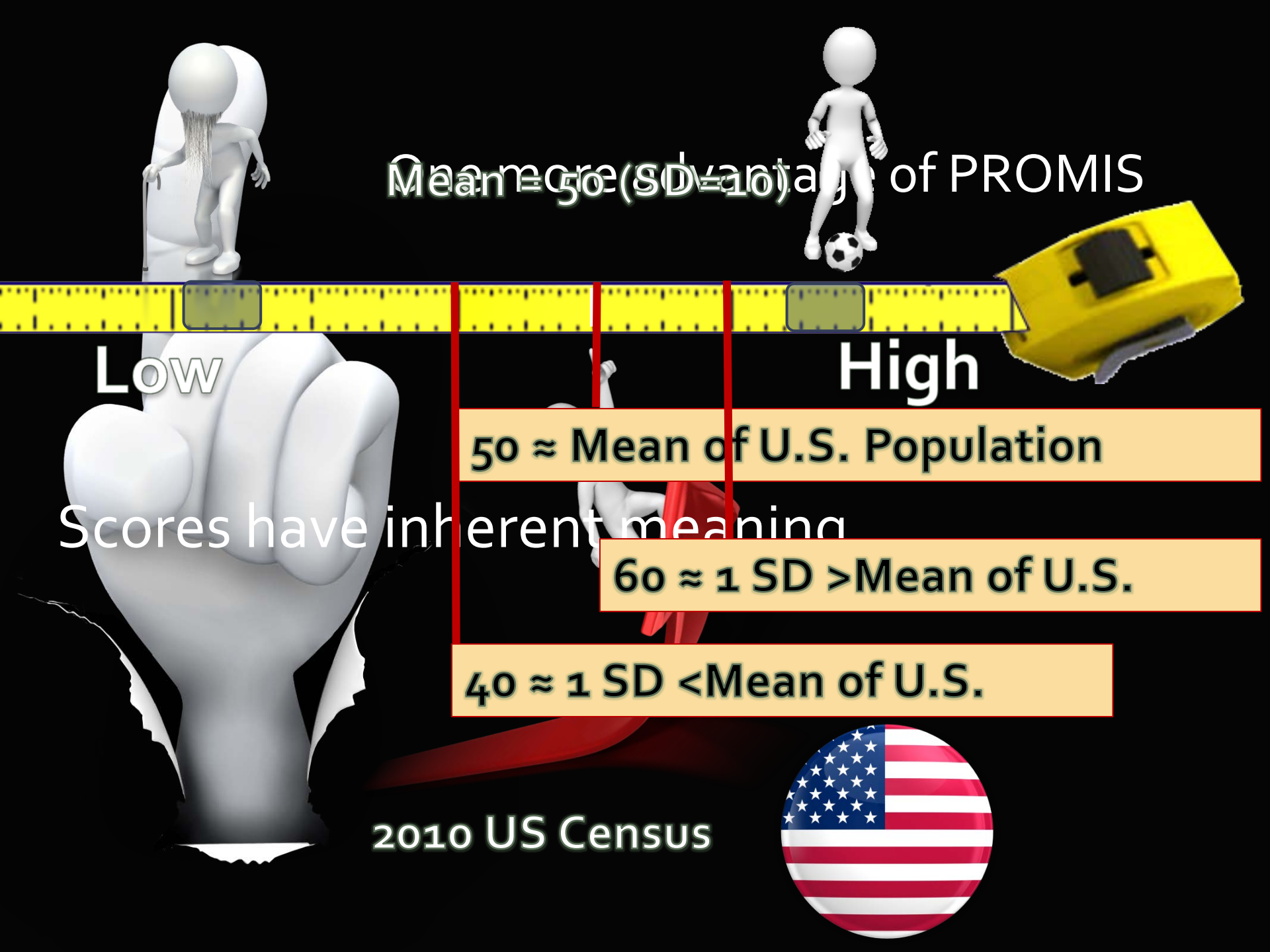
- Reduce burden of responding
- Make room for measuring more domains

$$\text{Max (Efficiency)} \quad \frac{\text{precision}}{\text{\# of items}}$$

Why bother?

One more advantage of PROMIS

Mean = 50 (SD = 10)



50 ≈ Mean of U.S. Population

Scores have inherent meaning

60 ≈ 1 SD >Mean of U.S.

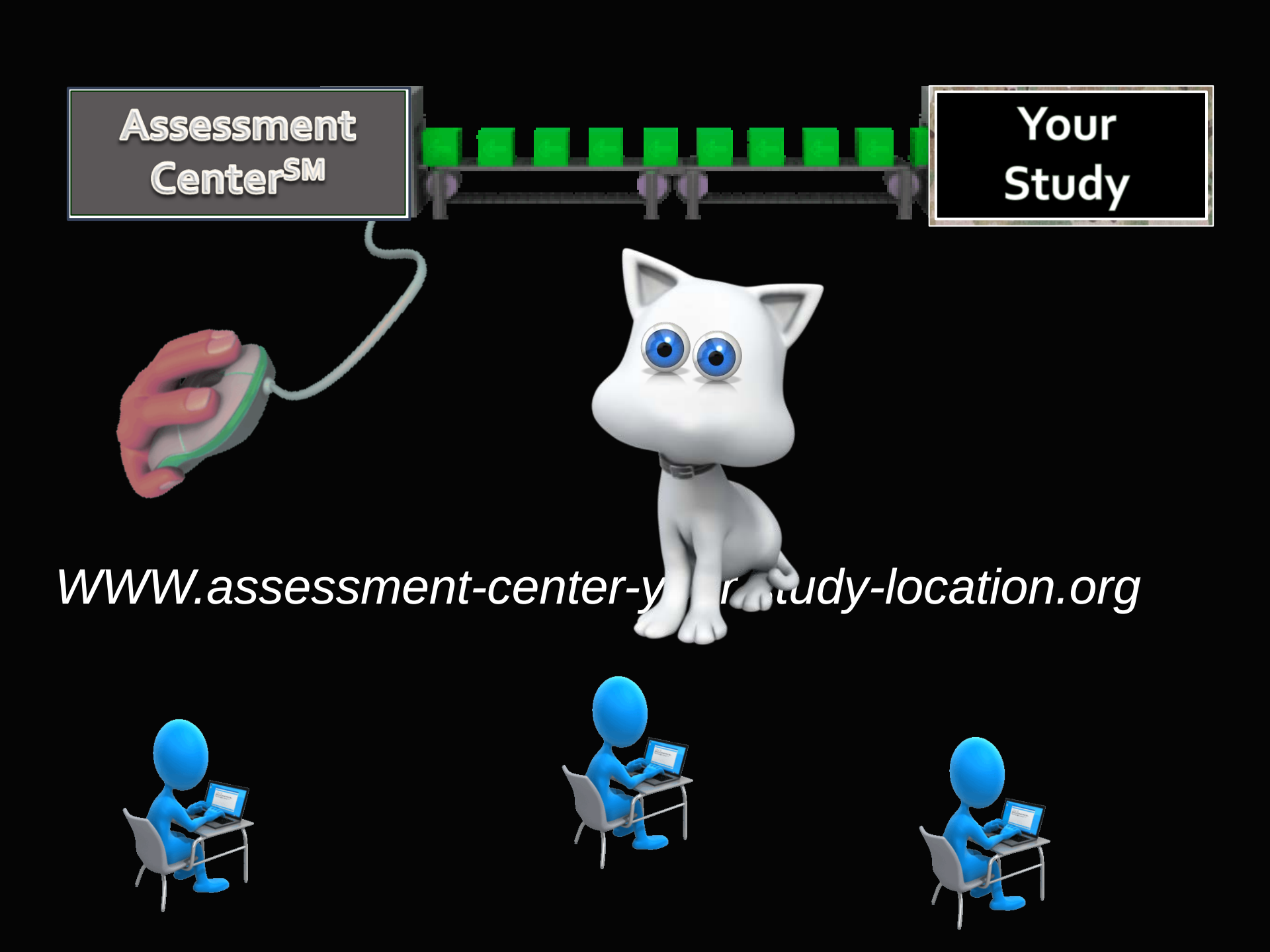
40 ≈ 1 SD <Mean of U.S.

2010 US Census

PROMIS®
Assessment Center
Item Banks

Assessment Center

- Free, online data collection tool
- Creates secure, study-specific websites for capturing participant data


Assessment Center℠
Your Study
WWW.assessment-center-y r study-location.org

NIH Toolbox

Assessment of Neurological and Behavioral Function

http://www.nihtoolbox.org

Toolbox Scope

- Multidimensional set of brief measures
  - assess cognitive, emotional, motor and sensory function
  - ages 3-85

- NIH Toolbox monitors neurological and behavioral function
  - over time
  - across developmental stages

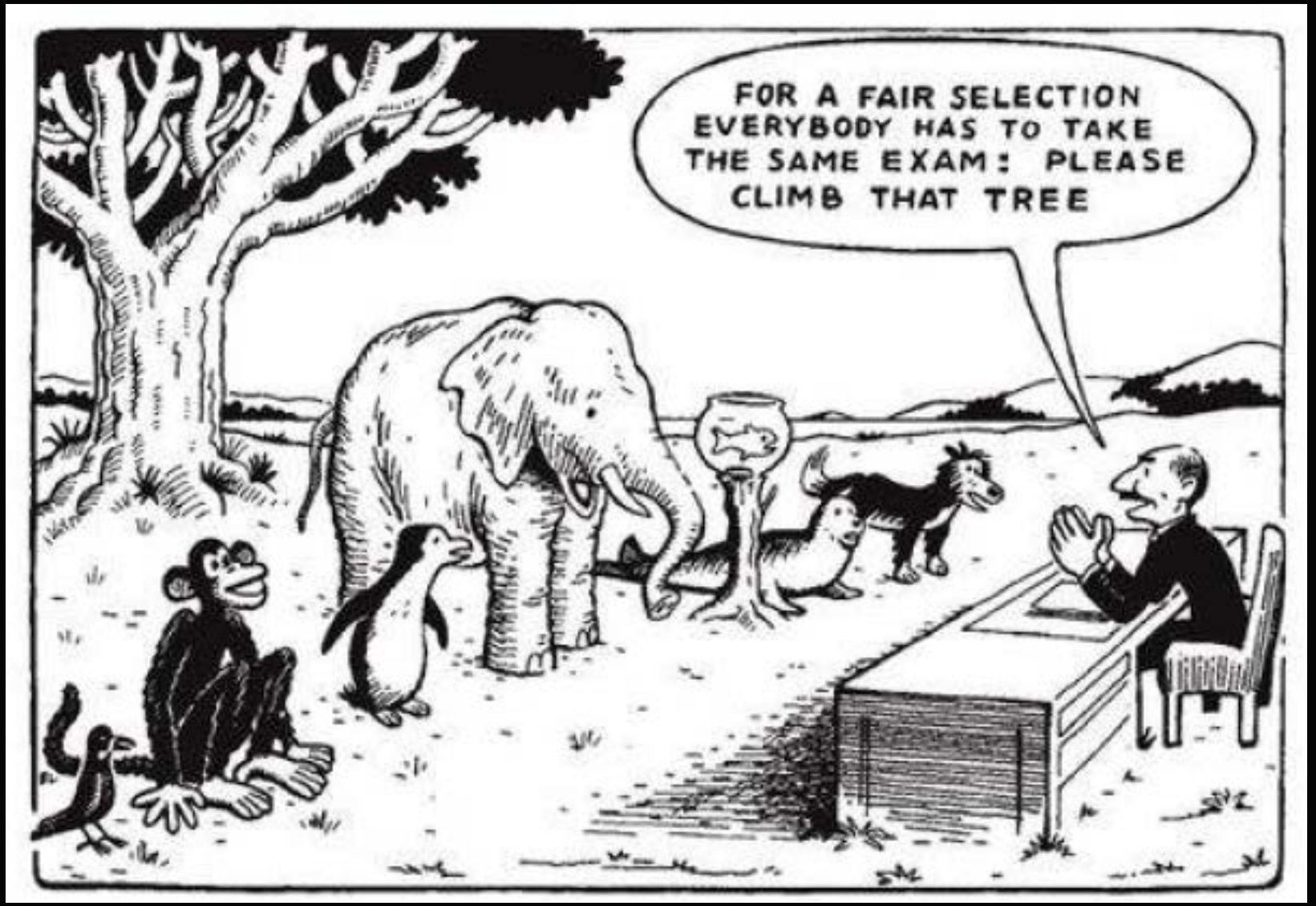
Toolbox Strategy

- Uses existing measures where possible
  - Familiarity to research community
  - Avoid duplication of effort

- Develop novel measures where needed

Toolbox Methods

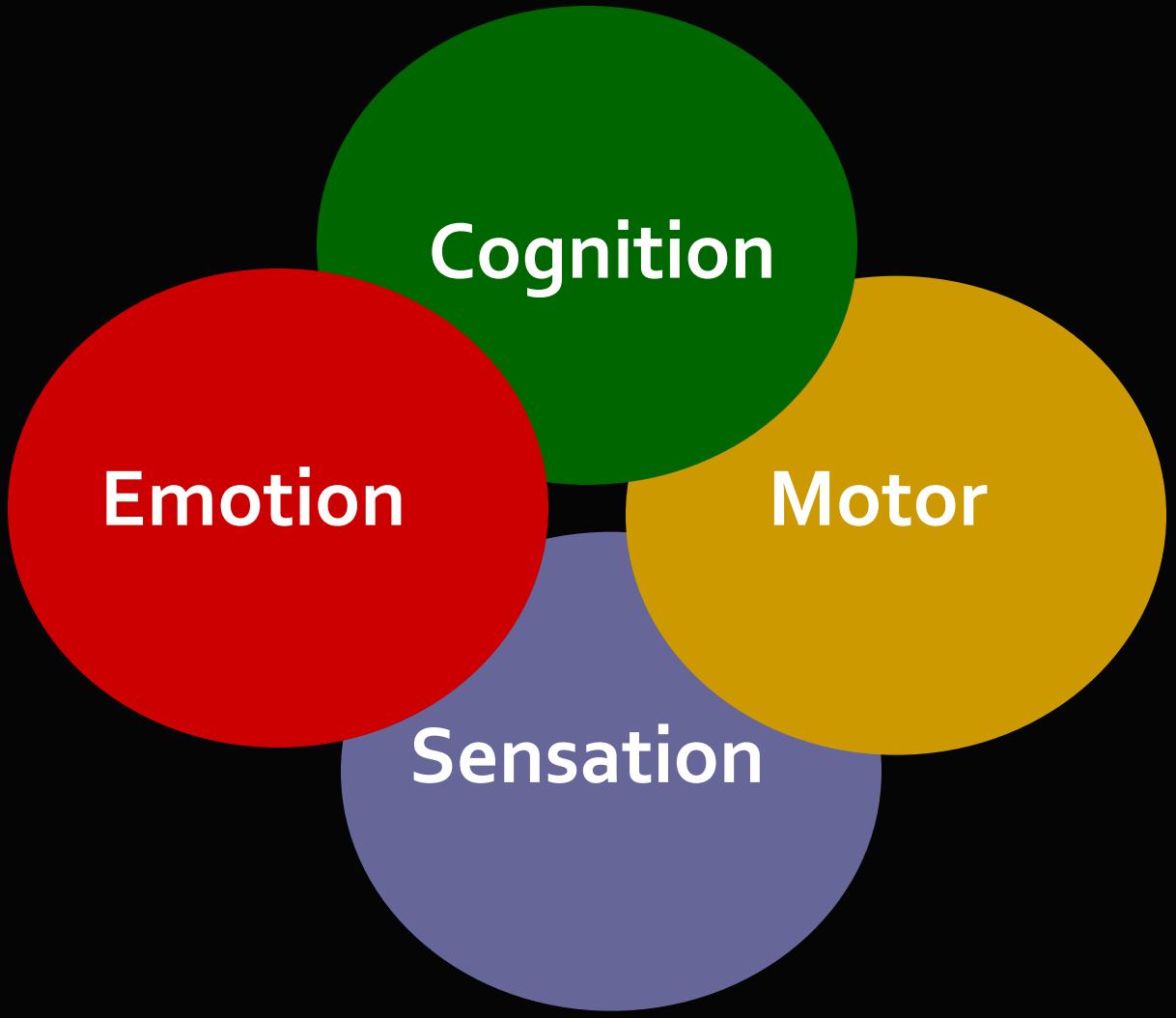
- Employs modern psychometric approaches and methods
  - Item Banking
  - CAT; Fixed-Forms


FOR A FAIR SELECTION EVERYBODY HAS TO TAKE THE SAME EXAM: PLEASE CLIMB THAT TREE

Across the lifespan

- Battery Approach: Self or Parent Report
- Age - Appropriate Versions
  - Adult (over 18)
  - 13-17
  - 8-12
  - 3-7

Toolbox Domains



Toolbox Measures

- Four 30-minute domain-level batteries
- English and Spanish versions
- Fully normed for ages 3-85
- 108 instruments in total

Qualitative Standards

- Expert Survey of selection criteria (152 responses)
- Focus group interviews with patients
- Expert Interviews (44 interviews)
- Surveys to nominate and rank sub-domains and constructs

Cognition Domain Framework

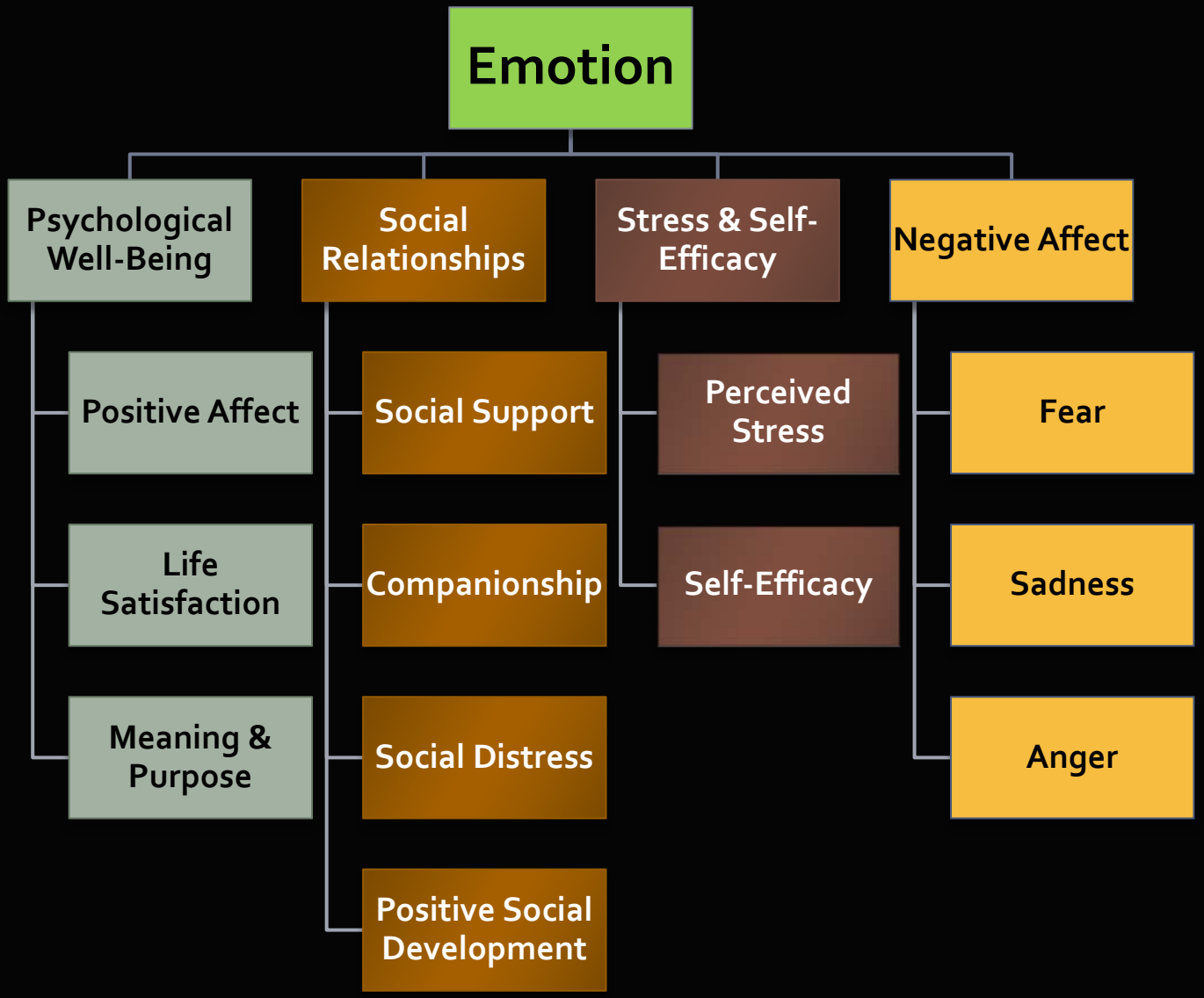
Subdomain	NIH Toolbox Tests	Validation Instruments
Executive Function (Set Shifting)	NIHTB Dimensional Change Card Sort Test (DCCS)	DKEFS Measures, WCST
Executive Function/Attention (Visual, inhibitory)	NIHTB Flanker Inhibitory Control and Attention Test	NINDS EXAMINER Dot Count, WCST, Children's Behavior Questionnaire
Working Memory	NIHTB List Sorting Working Memory Test	Wechsler Letter-Number Sequencing, PASAT
Episodic Memory	NIHTB Picture Sequence Memory Test	RAVLT Word List Brief Visuospatial Memory Test-Revised NEPSY Sentence Repetition
Language	NIHTB Picture Vocabulary Test NIHTB Oral Reading Recognition Test	Peabody Picture Vocabulary Test-4 Wide Range Achievement Test-4
Processing Speed	NIHTB Pattern Comparison Test	Wechsler Processing Speed Index

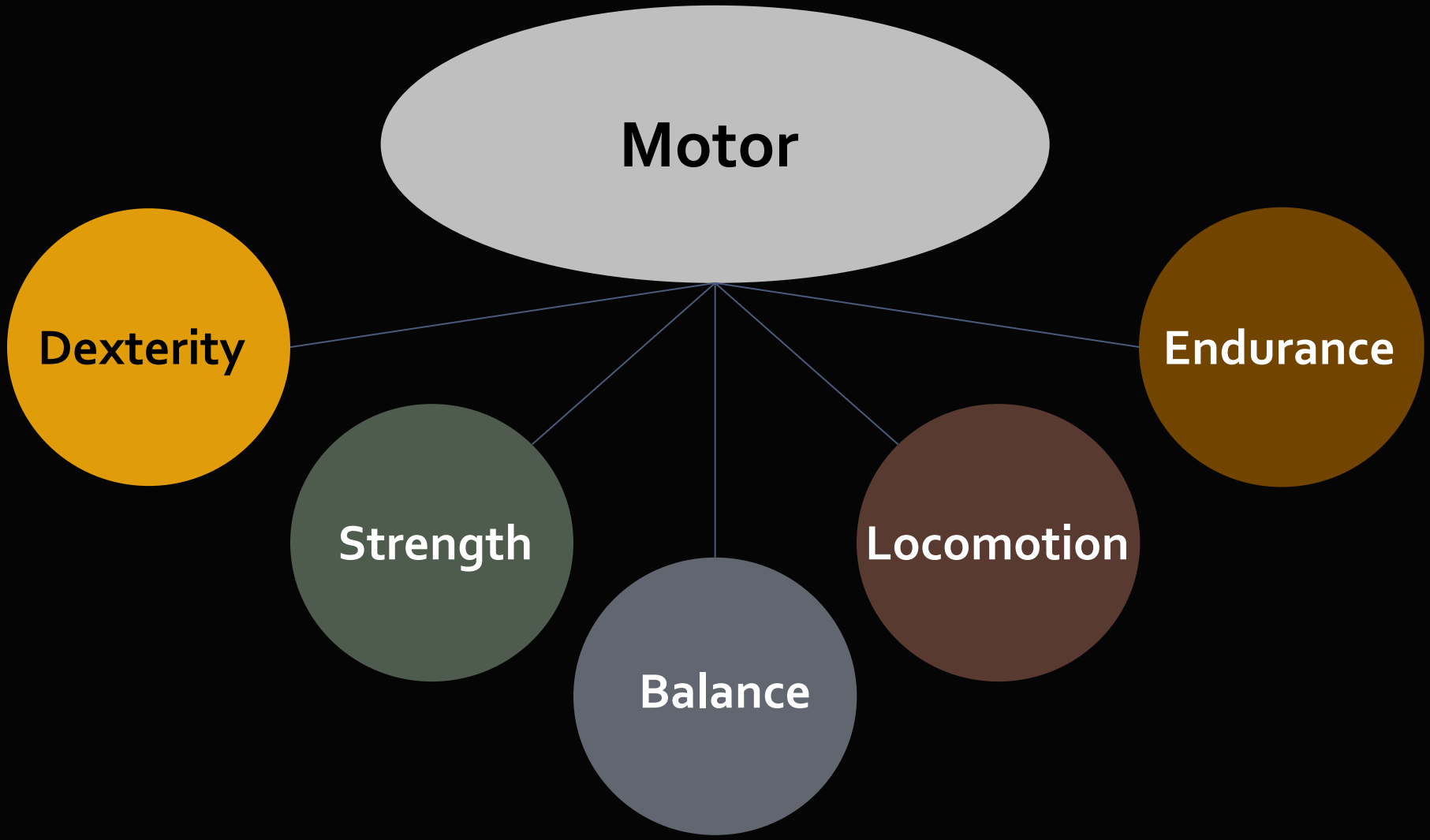
Language Subdomain: NIHTB Picture Vocabulary Test

- Task: Point to/click on picture that shows meaning of the word (picture-word matching)
- Total trials: CAT-administered (~25-30 items)
- Total time: 4 minutes

"BABY"

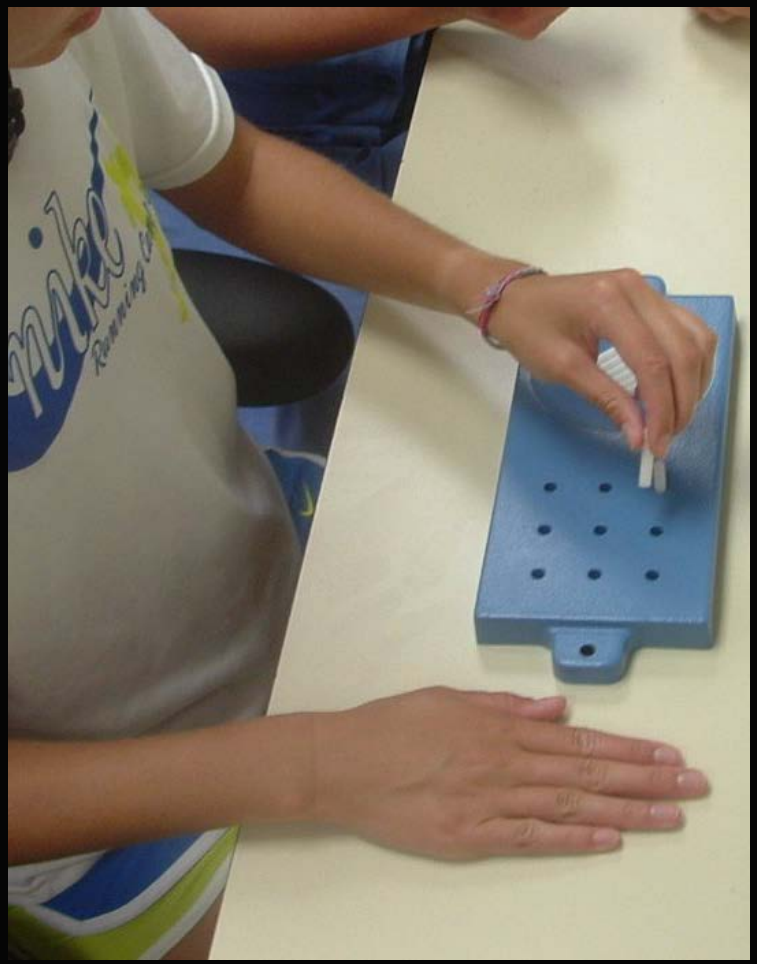
Emotion Domain Framework



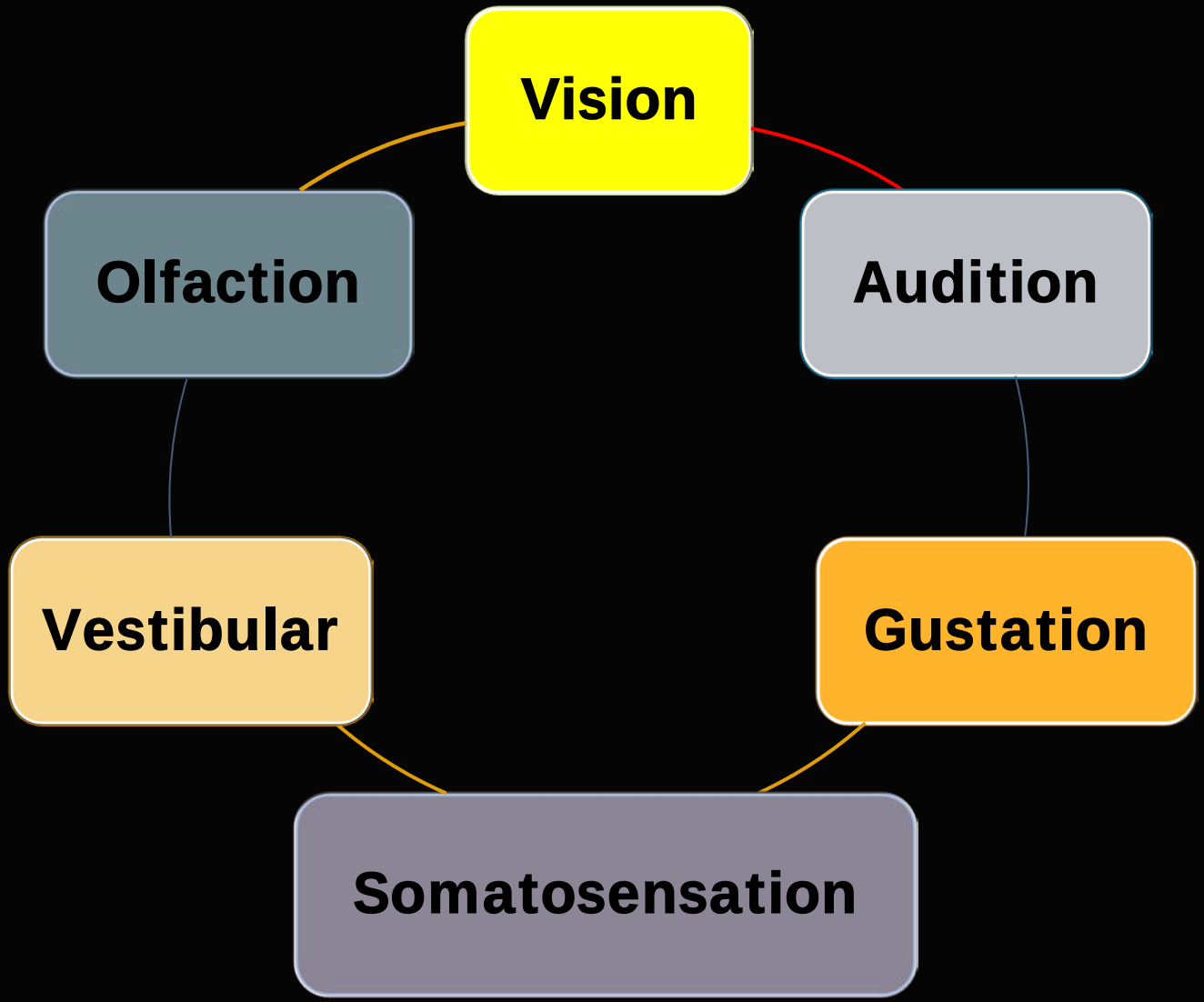

Motor
Dexterity
Endurance
Strength
Locomotion
Balance

Dexterity

- NIH Toolbox 9-Hole Pegboard Dexterity Measure
- 1 practice and 1 test trial per hand.
- Raw Score: Time in seconds to complete 1 trial



Sensation Domain



Audition (Hearing)

- Toolbox Measures
  - Words-In-Noise (WIN): English version *(Wilson, 2003)* and Spanish version *(McArdle et al, 2009)*
  - Monosyllabic, high-frequency words (e.g., red, mouse)
  - 7 signal-to-babble ratios (multi-talker)
  - Hearing tested separately in each ear, randomized order

Toolbox Particulars

- The measures do not have any licensing fees
- Some have equipment and supply costs.
- More information on the website http://www.nihtoolbox.org/WhatAndWhy/Materials/Pages/default.aspx

Publications

- Neurology Special Issue
  - highlights development and Validation Results for all Toolbox Domains Society for
- Research in Child Development Monograph
  - highlights pediatric use of the cognition battery
- Journal of the International Neuropsychological Society – 2013
  - Issue highlights adult use of the cognition battery

PROMIS