

PROMIS[®]



Dynamic Tools to Measure Health Outcomes from the Patient Perspective



Patient-Reported Outcomes Measurement Information System



- Initierad av National Institute of Health (NIH) ' "roadmap" for medical research in the 21st century. ' 2002,
 - Re-engineering clinical research

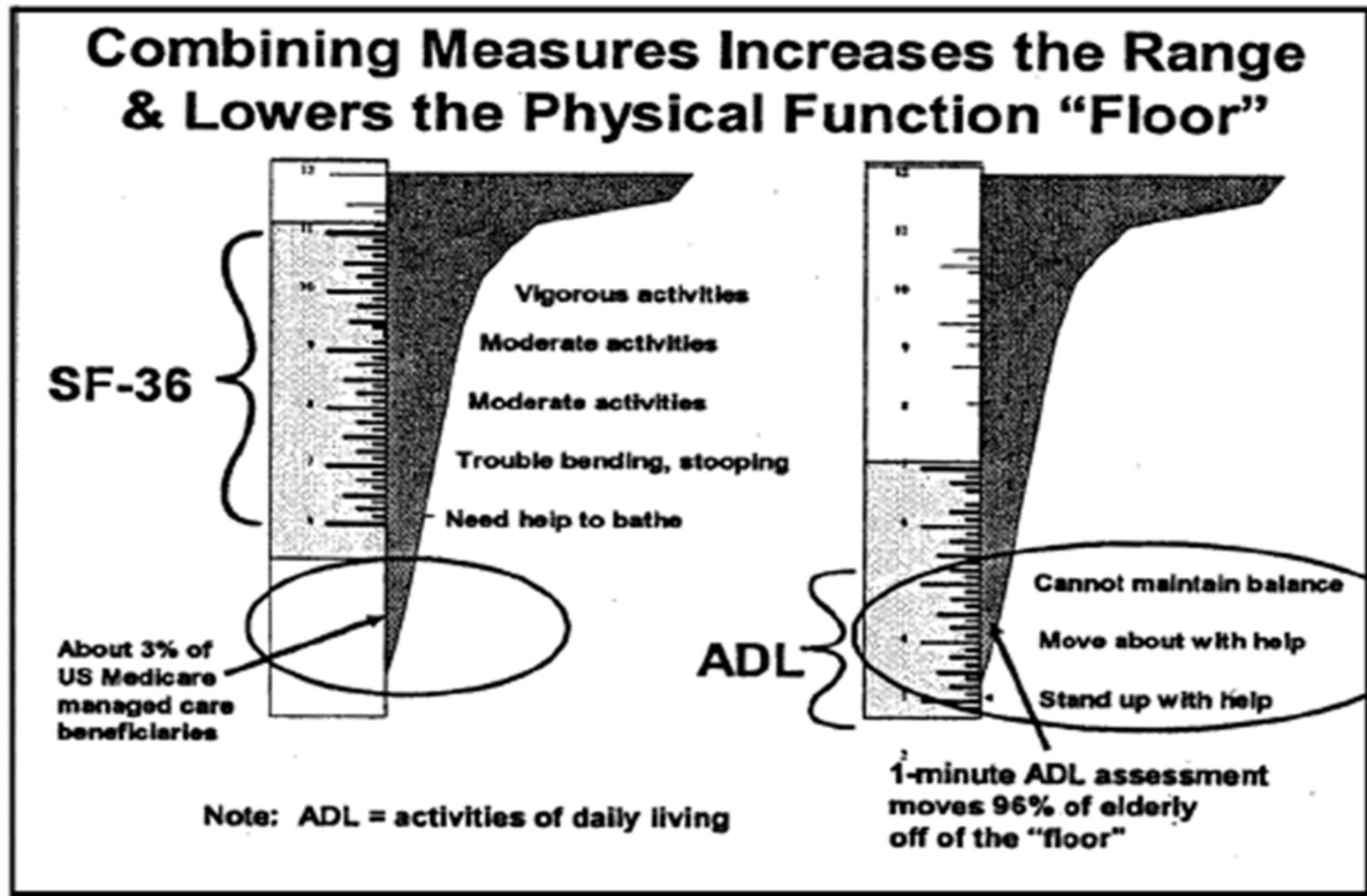
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Rörlighet	
Jag går utan svårigheter	<input type="checkbox"/>
Jag kan gå men med viss svårighet	<input type="checkbox"/>
Jag är sängliggande	<input type="checkbox"/>
Hygien	
Jag behöver ingen hjälp med min dagliga hygien, mat eller påklädnig	<input type="checkbox"/>
Jag har vissa problem att tvätta eller klä mig själv	<input type="checkbox"/>
Jag kan inte tvätta eller klä mig själv	<input type="checkbox"/>
Huvudsakliga aktiviteter (t ex arbete, studier, hushållssysslor, familje- och fritidsaktiviteter)	
Jag klarar av mina huvudsakliga aktiviteter	<input type="checkbox"/>
Jag har vissa problem med att klara av mina huvudsakliga aktiviteter	<input type="checkbox"/>
Jag klarar inte av mina huvudsakliga aktiviteter	<input type="checkbox"/>
Smärtor/besvär	
Jag har varken smärtor eller besvär	<input type="checkbox"/>
Jag har måttliga smärtor eller besvär	<input type="checkbox"/>
Jag har svåra smärtor eller besvär	<input type="checkbox"/>
Oro/nedstämdhet	
Jag är inte orolig eller nedstämd	<input type="checkbox"/>
Jag är orolig eller nedstämd i viss utsträckning	<input type="checkbox"/>
Jag är i högsta grad orolig eller nedstämd	<input type="checkbox"/>

[illegible]

Over the <u>last 2 weeks</u> , how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
<p><i>Add the score for each column</i> <u> </u> + <u> </u> + <u> </u> + <u> </u></p> <p>Total score: <u> </u></p>				

Full range of the concept





- *state-of-the-art* PROM
 - Based on modern psychometric methods (item response theory) which improves measurement precision and responsiveness.
 - Allows for the use of computer adapted testing
 - Item banks not questionnaires
 - Standardised measurement / analysis
 - Adult, child and proxy versions
 - License free



PROMIS Adult Self-Reported Health

Global Health

Physical Health

Physical Function
Pain Intensity
Pain Interference
Fatigue
Sleep Disturbance

PROMIS Profile
Domains

Pain Behavior
Pain Quality
Sleep-related
Impairment
Sexual Function
Gastro-Intestinal
Symptoms
Dyspnea

PROMIS Additional
Domains

Mental Health

Depression
Anxiety

Anger
Cognitive Function
Alcohol Use,
Consequences, &
Expectancies
Smoking
Substance Use
Psychosocial Illness
Impact
Self-efficacy

Social Health

Ability to
Participate in Social
Roles & Activities

Satisfaction with
Social Roles &
Activities
Social Support
Social Isolation
Companionship



PROMIS Pediatric Self- and Proxy-Reported Health

Global Health

Physical Health

Mobility
Upper Extremity
Function
Pain Intensity
Pain Interference
Fatigue

Mental Health

Depressive
Symptoms
Anxiety

Social Health

Peer Relationships

PROMIS Profile
Domains

Asthma Impact
Pain Behavior
Pain Quality
Physical Activity
Physical Stress
Experiences
Strength Impact

Anger
Cognitive Function
Life Satisfaction
Meaning and
Purpose
Positive Affect
Psychological
Stress Experiences

Family
Relationships

PROMIS Additional
Domains

What is an itembank?



1. *Hur skulle du säga att din hälsa är i allmänhet?*

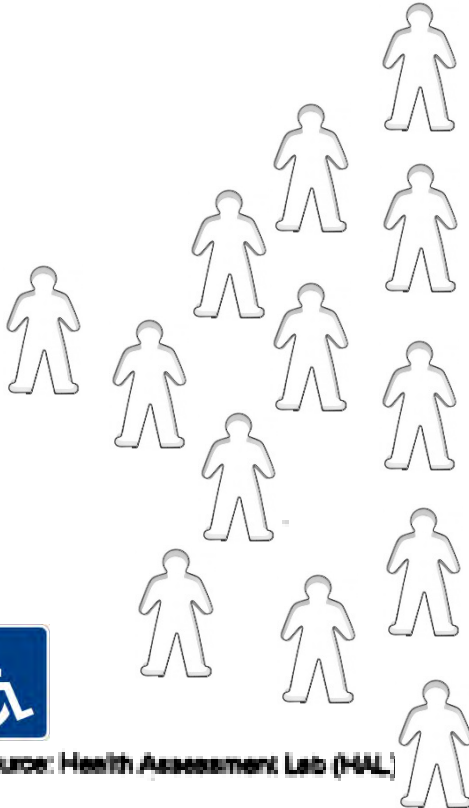
123. *Klarar du att öppna en tung dörr?*

56. *De senaste 7 dagarna:
Hur ofta hindrade smärta dig
umgås med andra människor?*

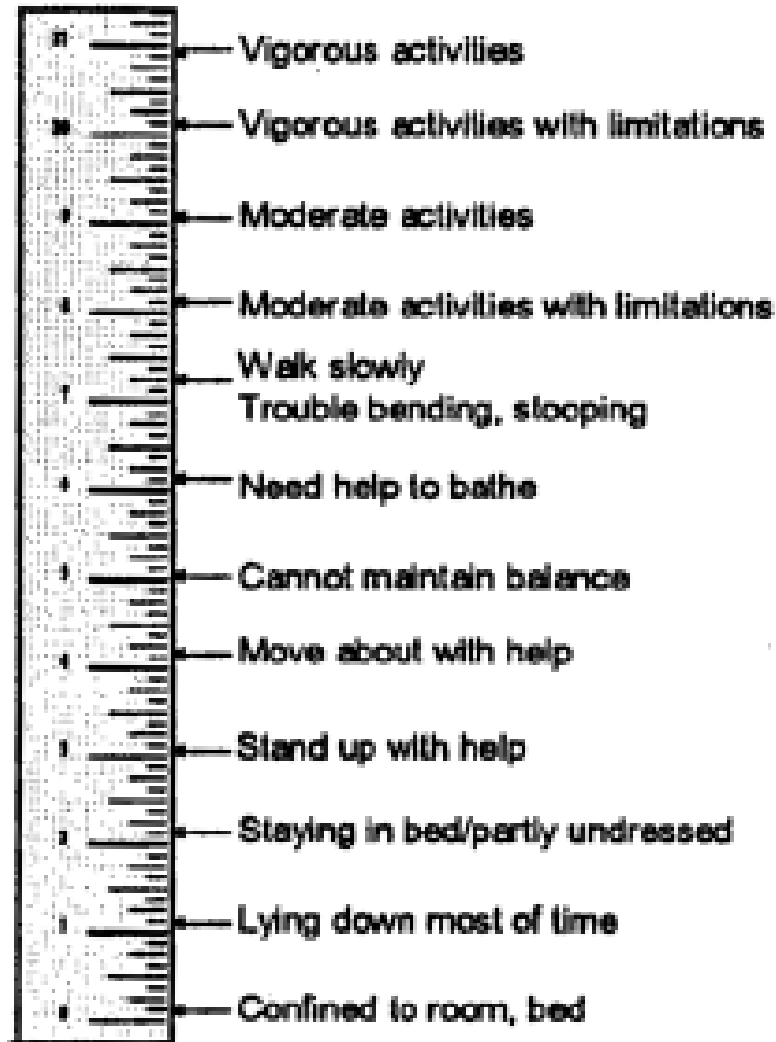
73. *De senaste 7 dagarna har jag inte känt mig behövd.*

14. *De senaste 7 dagarna har jag haft svårt att möta min familjs behov.*

Using item response theory (IRT) it is possible to rank the questions in difficulty



Source: Health Assessment Lab (HAL)



What is a CAT?

Cat /kat/ *noun*

noun: cat; plural noun: cats

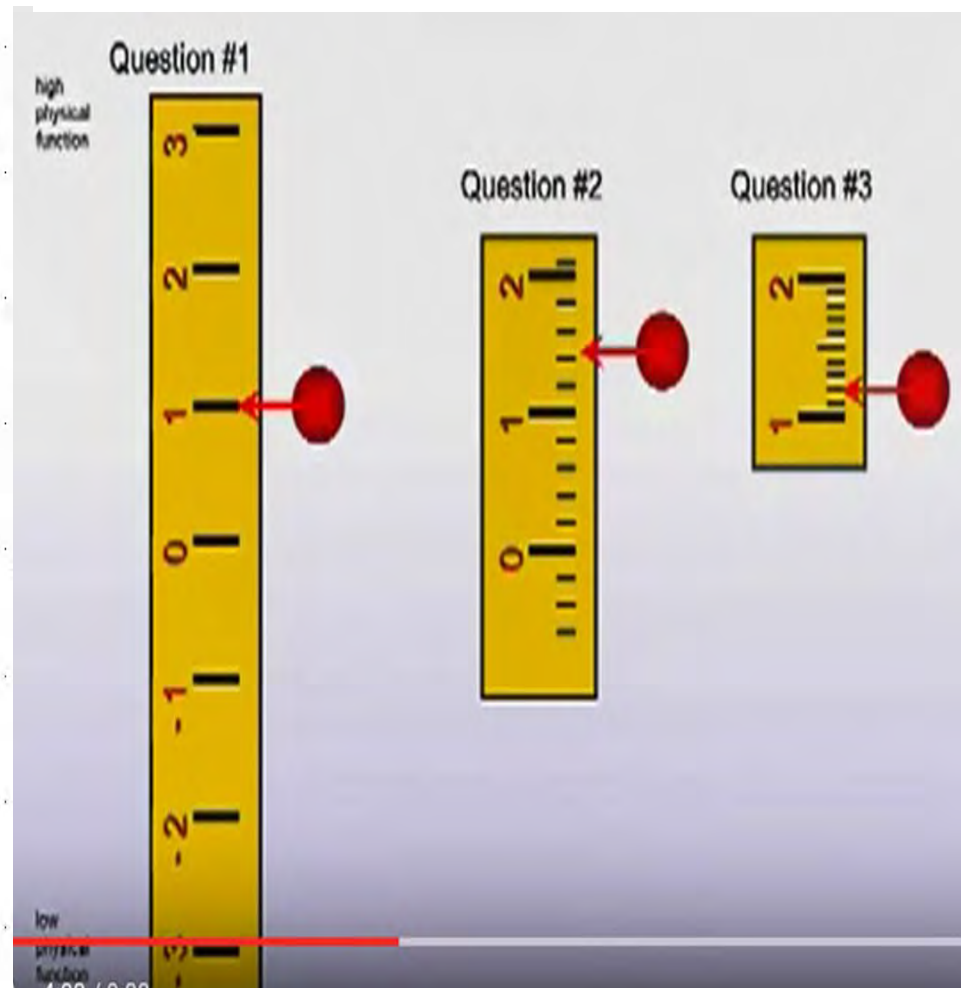
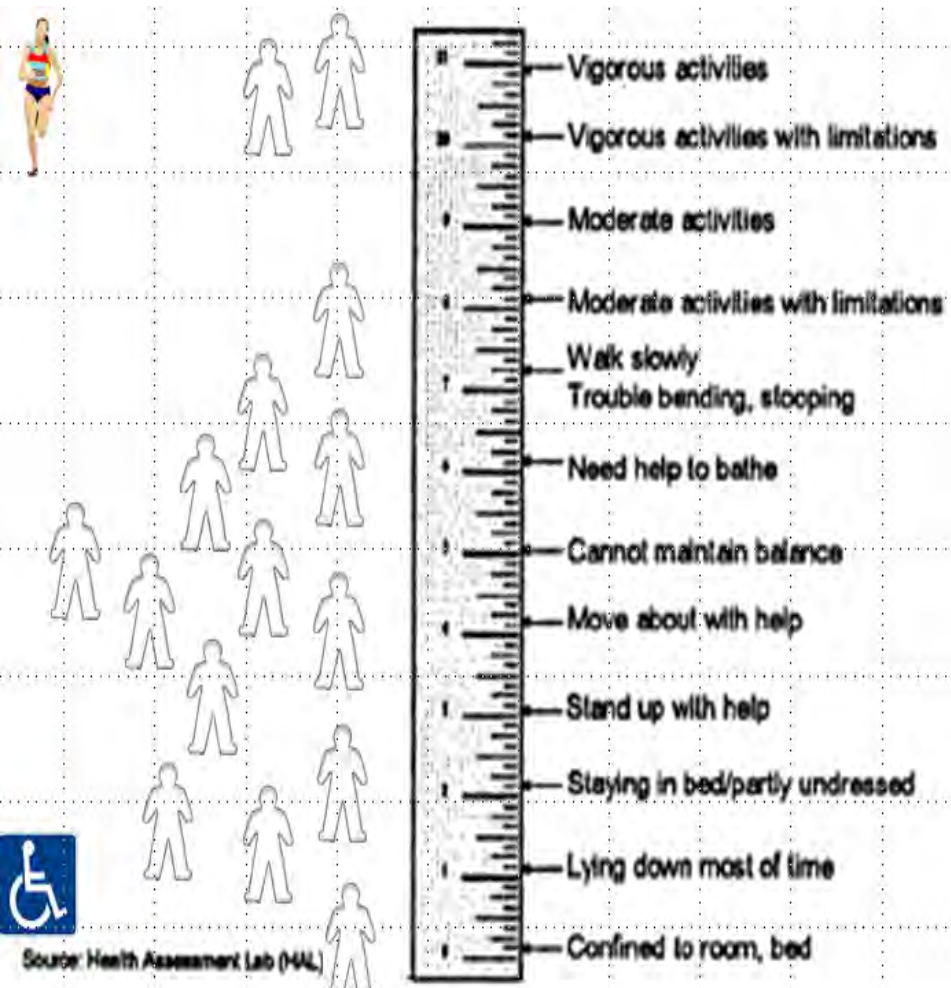
1. a small domesticated carnivorous mammal with soft fur

2. Computerized Adaptive Testing

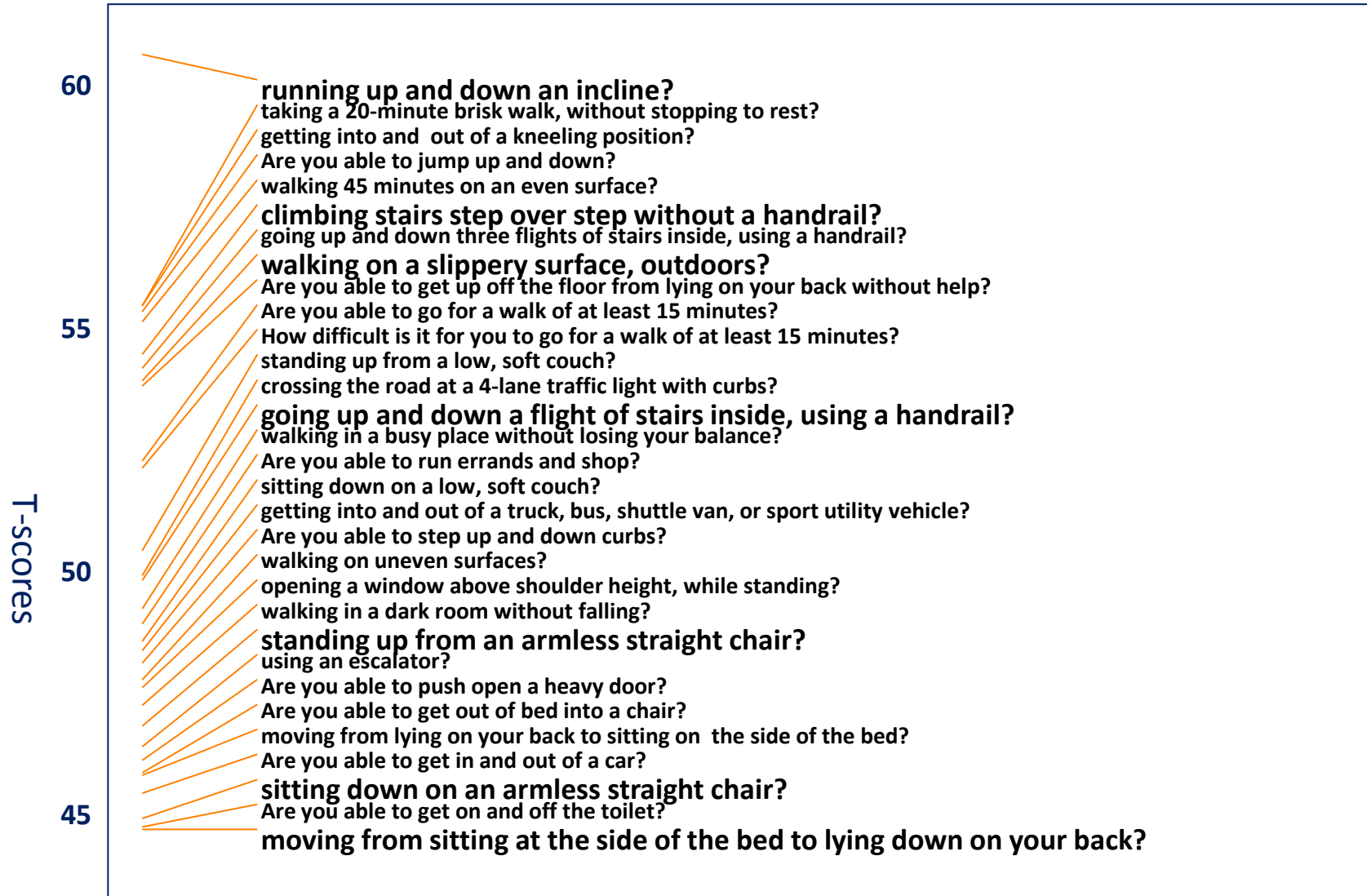


- Flexible administration
 - Test persons are given only questions appropriate for their specific level of the condition.
 - Reduces the number of questions - thus reduced patient burden and increased patient motivation
 - Scores are standardised and comparable across the item bank
- Greater precision of measurement
- Administration and analysis are automated therefore cost saving

How does a CAT work?



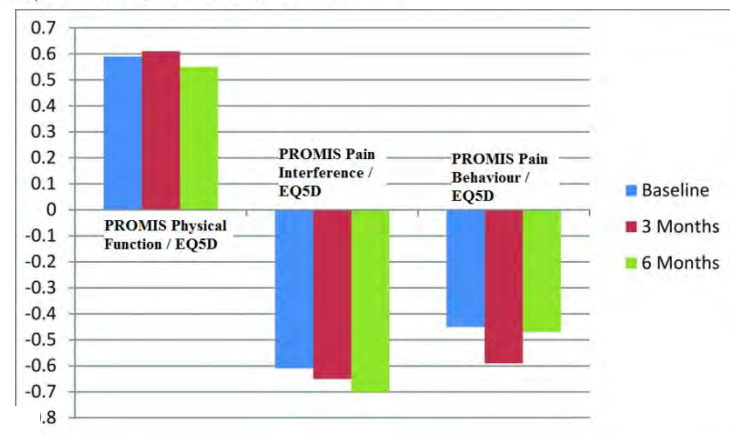
Lower Extremity Function – Mobility



Correlation of the Patient Reported Outcomes Measurement Information System with Legacy Outcomes Measures in Assessment of Response to Lumbar Transforaminal Epidural Steroid Injections

L. Shahgholi, K.J. Yost, R.E. Carter, J.R. Geske, C.E. Hagen, K.K. Amrami, F.E. Diehn, T.J. Kaufmann, J.M. Morris, N.S. Murthy, J.T. Wald, K.R. Thielen, D.F. Kallmes, and T.P. Maus

Spearman correlation coefficients between PROMIS scores and EQ-5D on the first day and from 3- and 6-month evaluations in the Transforaminal Epidural Steroid Injection group.



PMC full text: [Value Health. Author manuscript; available in PMC 2013 Jan 1.](#)

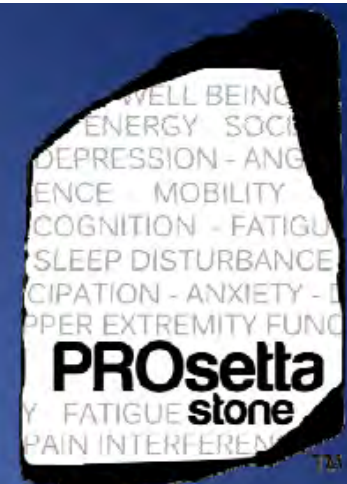
PROMIS CAT	CES-D	FACIT-Fatigue	SF-BP	SF-PF	Sleep index	SF_SF
Depression 1.0	0.67	0.44	0.31	0.20	0.33	0.46
Fatigue 1.0	0.59	0.76	0.59	0.51	0.49	0.59
Pain Behavior 1.0	0.44	0.53	0.66	0.38	0.37	0.47
Phys. Function 1.0	0.46	0.72	0.56	0.82	0.43	0.55
Sleep Disturb 1.0	0.50	0.37	0.23	0.24	0.75	0.28
Social Sat Discretionary 1.0	0.56	0.62	0.48	0.54	0.46	0.61

PMC full text: [Qual Life Res. 2009 Aug; 18\(6\): 783–791.](#)

Mean actual and predicted EQ-5D index scores by gender and age groups in PROMIS general population sample ($n = 2,722$)

Age groups	Males		Females		Total	
	Actual	Predicted	Actual	Predicted	Actual	Predicted
<35	0.89	0.89	0.88	0.86	0.88	0.87
35–44	0.87	0.86	0.85	0.84	0.86	0.85
45–54	0.87	0.86	0.79	0.79	0.82	0.82
55–64	0.84	0.85	0.81	0.82	0.82	0.83
65–74	0.86	0.88	0.84	0.85	0.85	0.86

PROsetta Stone



- Linking tables
 - Legacy instruments to PROMIS metric
- BPI, CES-D, FACIT, HAQ, SF-36, PHQ-9, etc
- www.prosettastone.org

SF-36/PF Score	PROMIS T-score	SE
10	24.5	4.0
11	28.3	2.8
12	30.3	2.5
13	32.0	2.2
14	33.4	2.1
15	34.8	2.0
16	36.0	2.0
17	37.2	2.0
18	38.4	1.9
19	39.5	1.9
20	40.7	1.9
21	41.8	1.9
22	42.9	1.9
23	44.1	2.0
24	45.2	2.0

Alternative Item Banking systems



HealthMeasures consists of four precise, flexible, and comprehensive measurement systems that assess physical, mental, and social health, symptoms, well-being and life satisfaction; along with sensory, motor, and cognitive function.



PROMIS®

Self-reported and parent-reported measures of global, physical, mental, and social health for adults and children in the general population and those living with a chronic condition



Neuro-QoL

Self-reported and proxy-reported measures of physical, mental, and social health for adults and children living with a neurological condition



ASCQ-MeSM

Self-reported measures of physical, mental, and social health for adults living with sickle cell disease



NIH Toolbox®

Performance tests of cognitive, motor, and sensory function and self-reported measures of emotional function for adults and children in the general population and those living with a chronic condition

- **Item Bank Properties**
 - psychometric characteristics based on a representative sample of respondents
- **Item Pool Construction**
 - provide measurement across the target construct.
- **Testing and Instrument Formats**
 - comparable scale properties across models (self, proxy) and methods (CATs, short forms) for children and adults
- **Interpretability**
 - Standardised approach. T score Mean = 50 SD = 10 Referenced to the General Population
- **Language Translation and Cultural Adaptation**
 - A universal approach to translation

Advantages over older questionnaires

- *Higher measurement precision*
 - An item bank covers the whole range of the concept
- *Questions used have greater relevance*
 - CAT process selects relevant questions
- *Minimises the burden on the patient*
 - Often as few as 4 questions provide sufficient precision
- *Comparable results despite being individualised*
 - A total score is based on any combination of questions
- *Sustainable over time*
 - Questions can be removed or added – therefore never out-of-date



- 3rd stage of the PROMIS project
= Internationalisation