

Health-Related Quality of Life

November 14, 2011: 9-10:30am

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- UCLA School of Public Health: Department of Health Services
- RAND, Santa Monica

Health-Related Quality of Life is ...

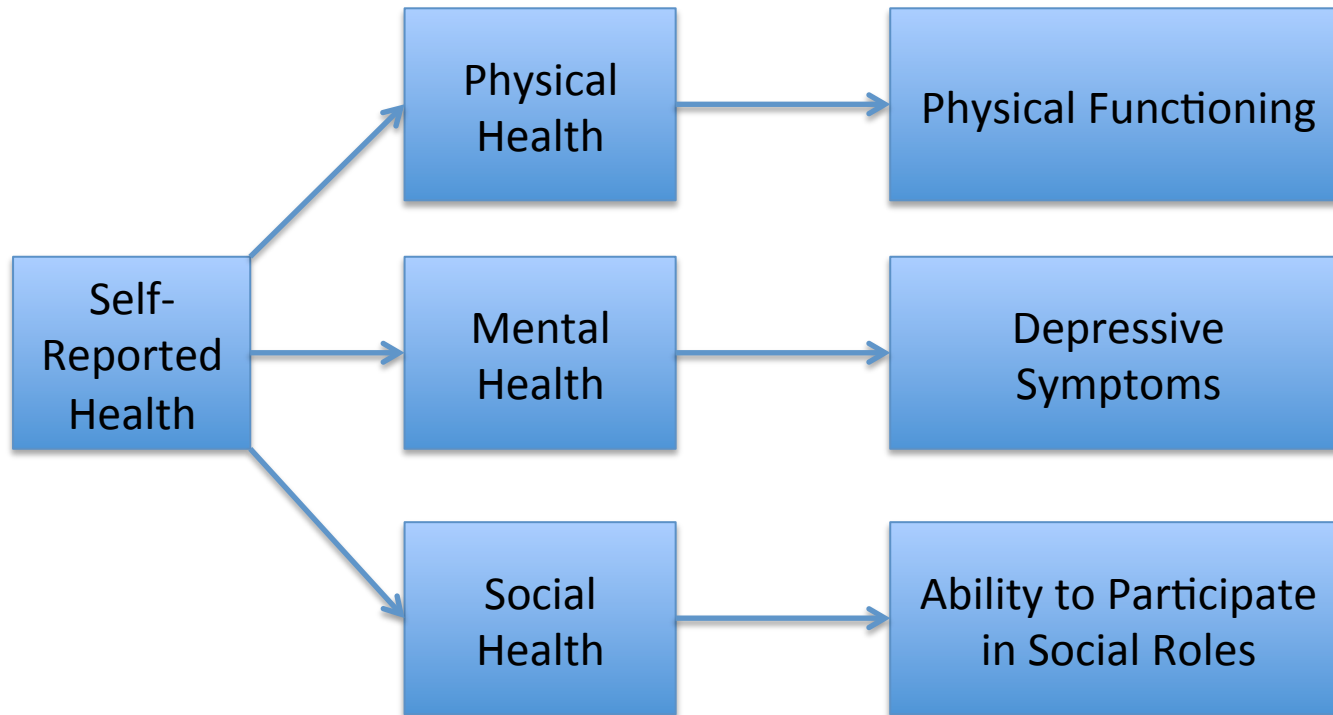
What you can do.

- Functioning
 - Self-care
 - Role
 - Social

How you feel about your life.

- Well-being
 - Emotional well-being
 - Pain
 - Energy

HRQOL Framework



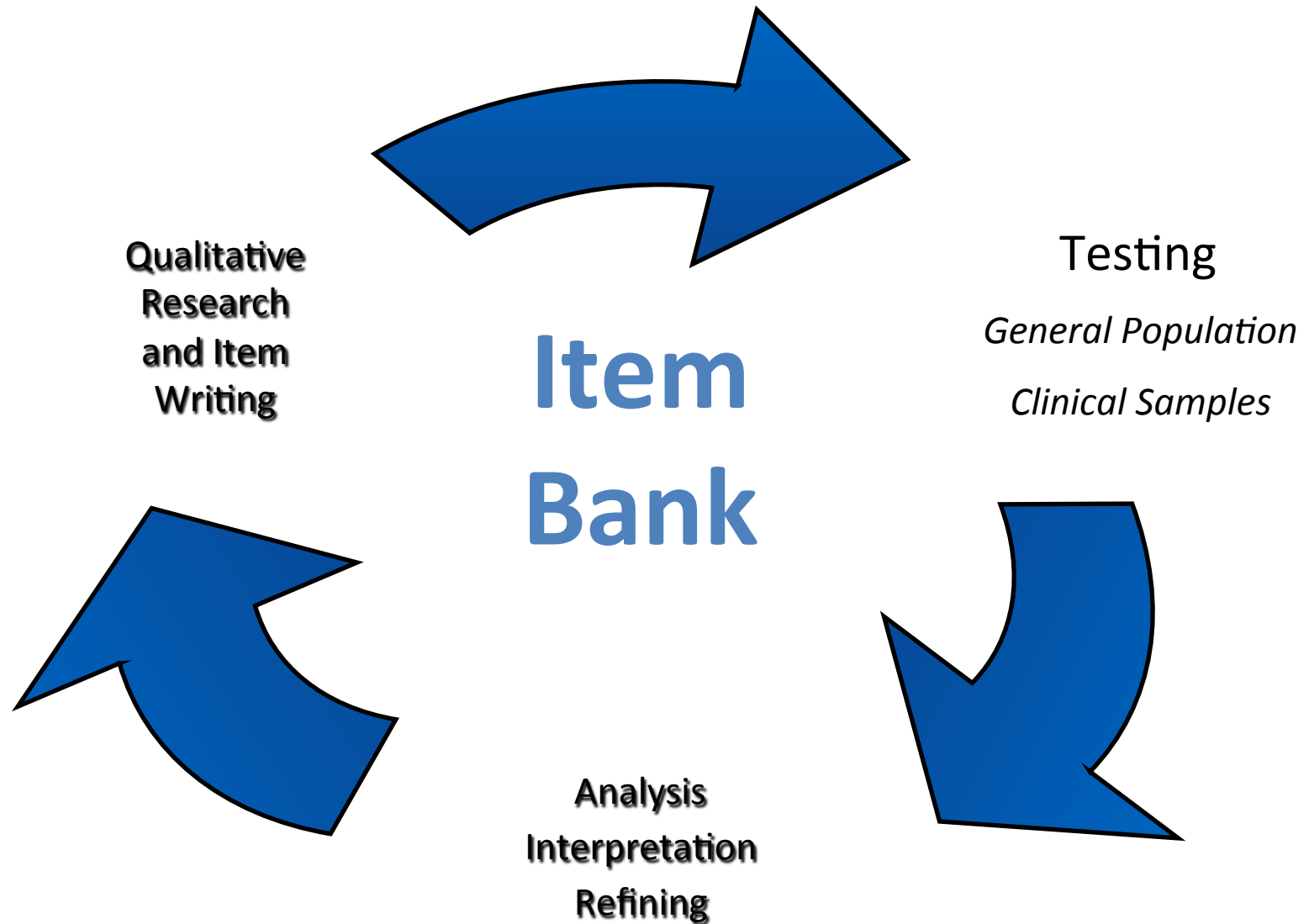
SF-36®

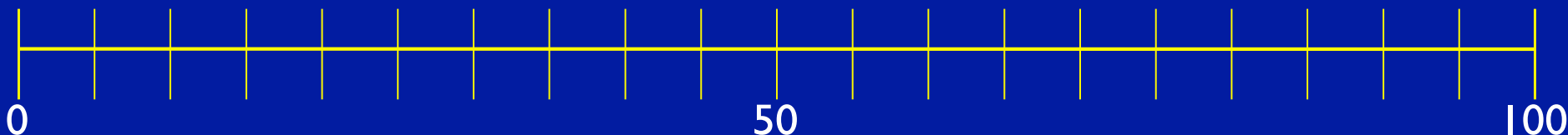
- Functioning
 - Physical functioning (10 items)
 - Role limitations/physical (4 items)
 - Role limitations/emotional (3 items)
 - Social functioning (2 items)
- Well-Being
 - Emotional well-being (5 items)
 - Energy/fatigue (4 items)
 - Pain (2 items)
 - General health perceptions (5 items)

*An **item bank** is a large collection of items measuring a single domain.*

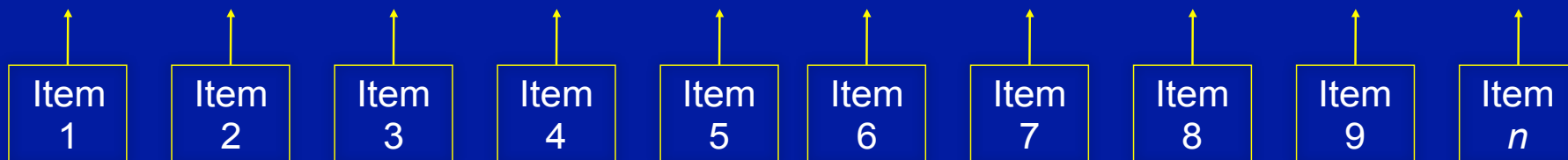
Any and all items can be used to provide a score for that domain.

Item Development Cycle





Physical Functioning Item Bank



Are you able to get in and out of bed?

Are you able to stand without losing your balance for 1 minute?

Are you able to walk from one room to another?

Are you able to walk a block on flat ground?

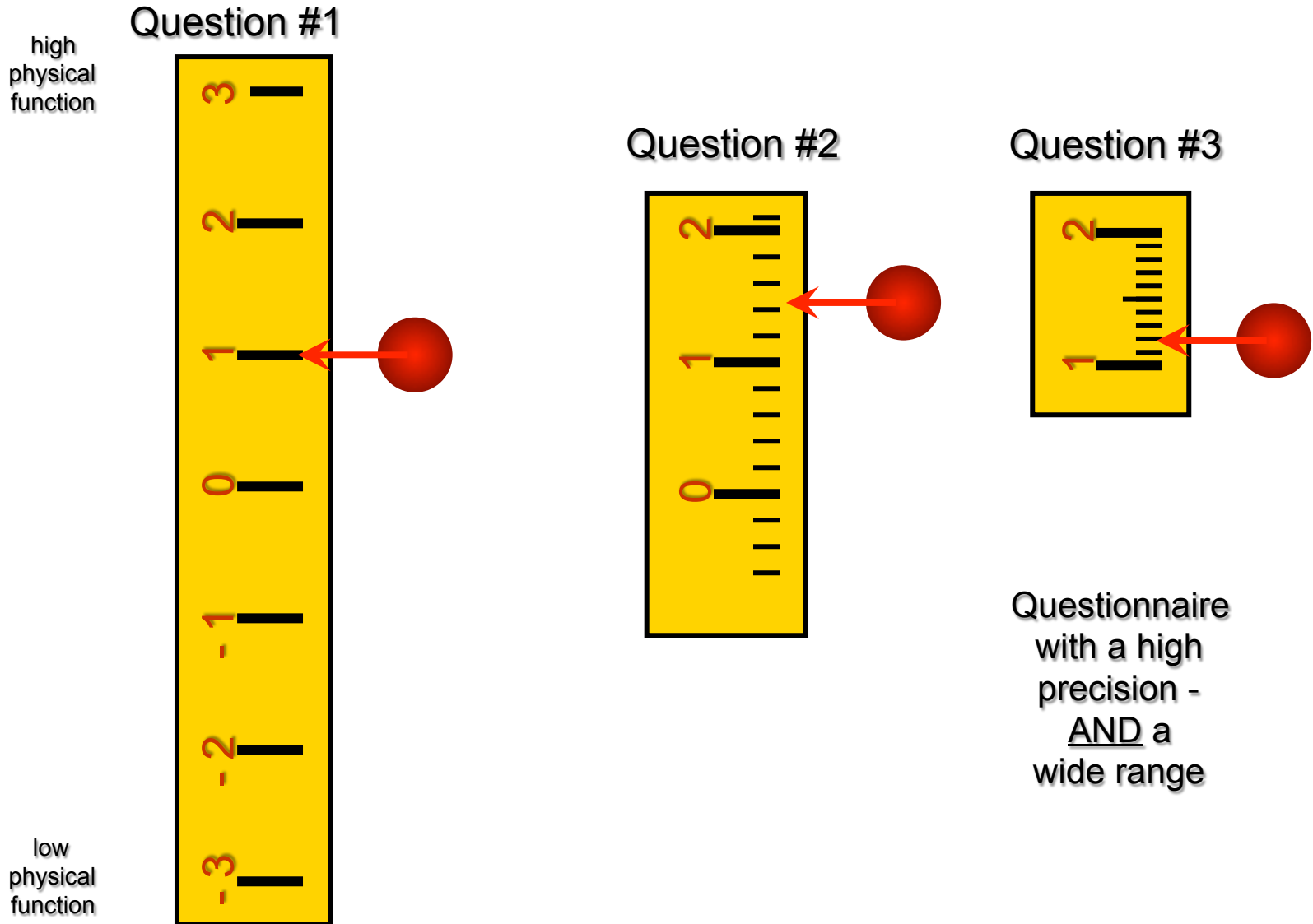
Are you able to run or jog for two miles?

Are you able to run five miles?

Computerized Adaptive Testing (CAT)

- Select questions based on responses to previously administered questions.
 - Pick most “informative” items
- Iteratively estimate “location” on the domain (e.g., anger)
- Stop administering items when desired level of precision is reached.

Computerized Adaptive Tests



Reliability and SEM

- z-score (mean = 0 and SD = 1)
 - Reliability = $1 - \text{SEM}^2$ (for z-scores)
 - = 0.91 (when SEM = 0.30)
 - = 0.90 (when SEM = 0.32)
- With 0.90 reliability
 - 95% Confidence Interval for score at mean
 - z-score: - 0.62 → 0.62
- T-score = (z-score * 10) + 50
 - T-score: 44 → 56

In the past 7 days

I was grouchy

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Previous

Next

Exit

Google Search dr.ron...

McAfee SiteAdvisor

Search the Web

hp Yahoo!

Favorites Google Calendar (2) Google Calendar iGoogle (5) iGoogle (4) iGoogle (3) iGoogle (2) iGoogle Redirect (2) iGoogle Redirect

Response	Theta	Score	SE
EDANG30=3	0.61	56.1	0.57

In the past 7 days

I felt like I was ready to explode

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

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Favorites Google Calendar (2) Google Calendar iGoogle (5) iGoogle (4) iGoogle (3) iGoogle (2) iGoogle Redirect (2) iGoogle Redirect

Response	Theta	Score	SE
EDANG30=3	0.61	56.1	0.57
EDANG15=1	0.19	51.9	0.48

In the past 7 days

I felt angry

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

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Response	Theta	Score	SE
EDANG30=3	0.61	56.1	0.57
EDANG15=1	0.19	51.9	0.48
EDANG09=2	0.05	50.5	0.39

In the past 7 days

I felt angrier than I thought I should

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

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Favorites Google Calendar (2) Google Calendar iGoogle (5) iGoogle (4) iGoogle (3) iGoogle (2) iGoogle Redirect (2) iGoogle Redirect

Page Safety Tools

Response	Theta	Score	SE
EDANG30=3	0.61	56.1	0.57
EDANG15=1	0.19	51.9	0.48
EDANG09=2	0.05	50.5	0.39
EDANG28=1	-0.12	48.8	0.36

In the past 7 days

I felt annoyed

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Google Search

McAfee SiteAdvisor

Search the Web

AIM 1 New AIM Express New IM IM This Page Set Status

hp Yahoo! Web Search Bookmarks Settings HP Access HP Solutions HP Create HP Smart Deals

Favorites Google Calendar (2) Google Calendar iGoogle (5) iGoogle (4) iGoogle (3) iGoogle (2) iGoogle Redirect (2) iGoogle Redirect

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EDANG09=2	0.05	50.5	0.39
EDANG28=1	-0.12	48.8	0.36
EDANG35=3	0.01	50.1	0.32

In the past 7 days

I made myself angry about something just by thinking about it

- ☐ Never
- ☒ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Google Search dr.ron...

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Search the Web

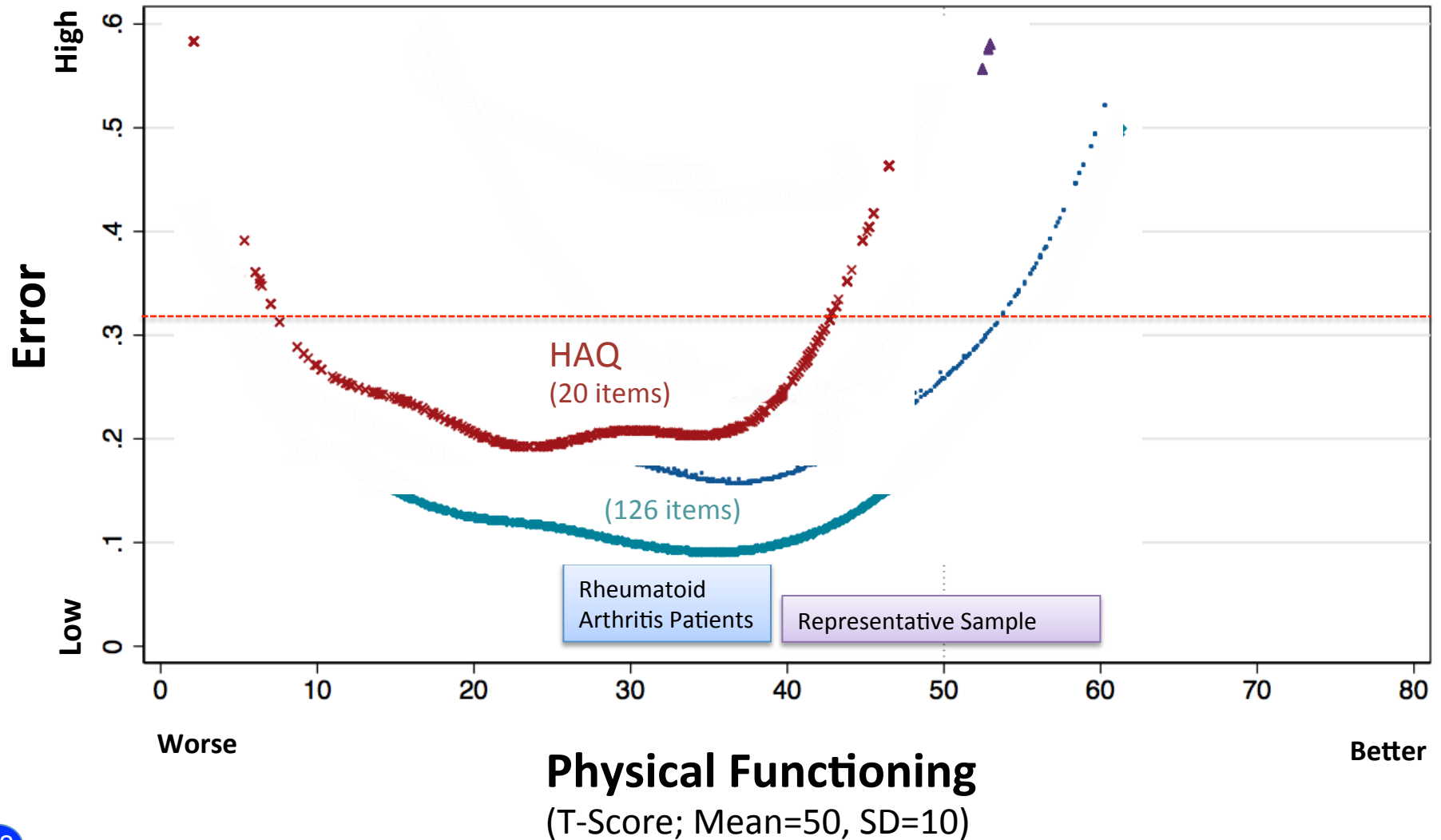
hp Yahoo!

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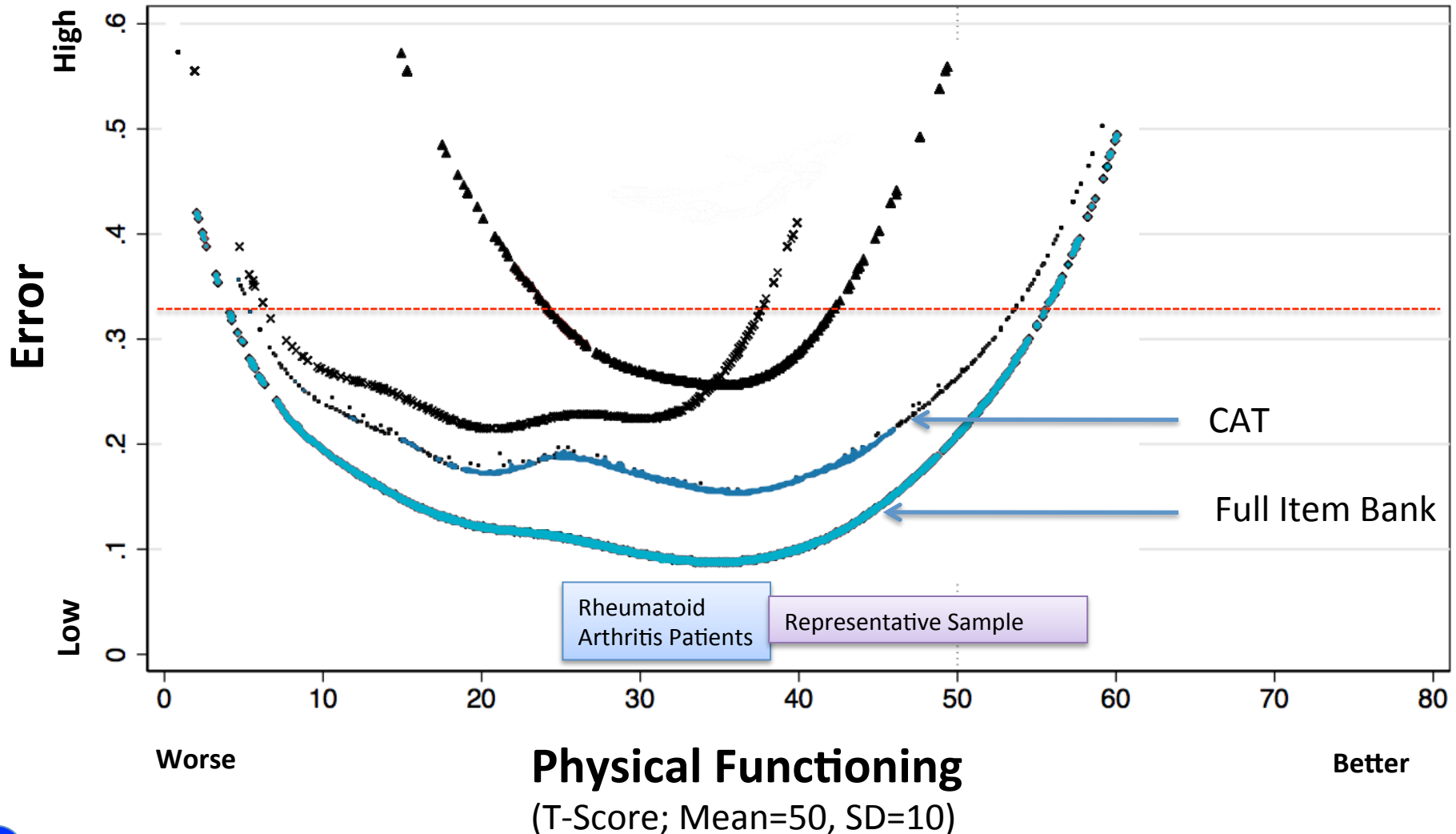
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EDANG28=1	-0.12	48.8	0.36
EDANG35=3	0.01	50.1	0.32
EDANG06=2	0.02	50.2	0.28

End of Form

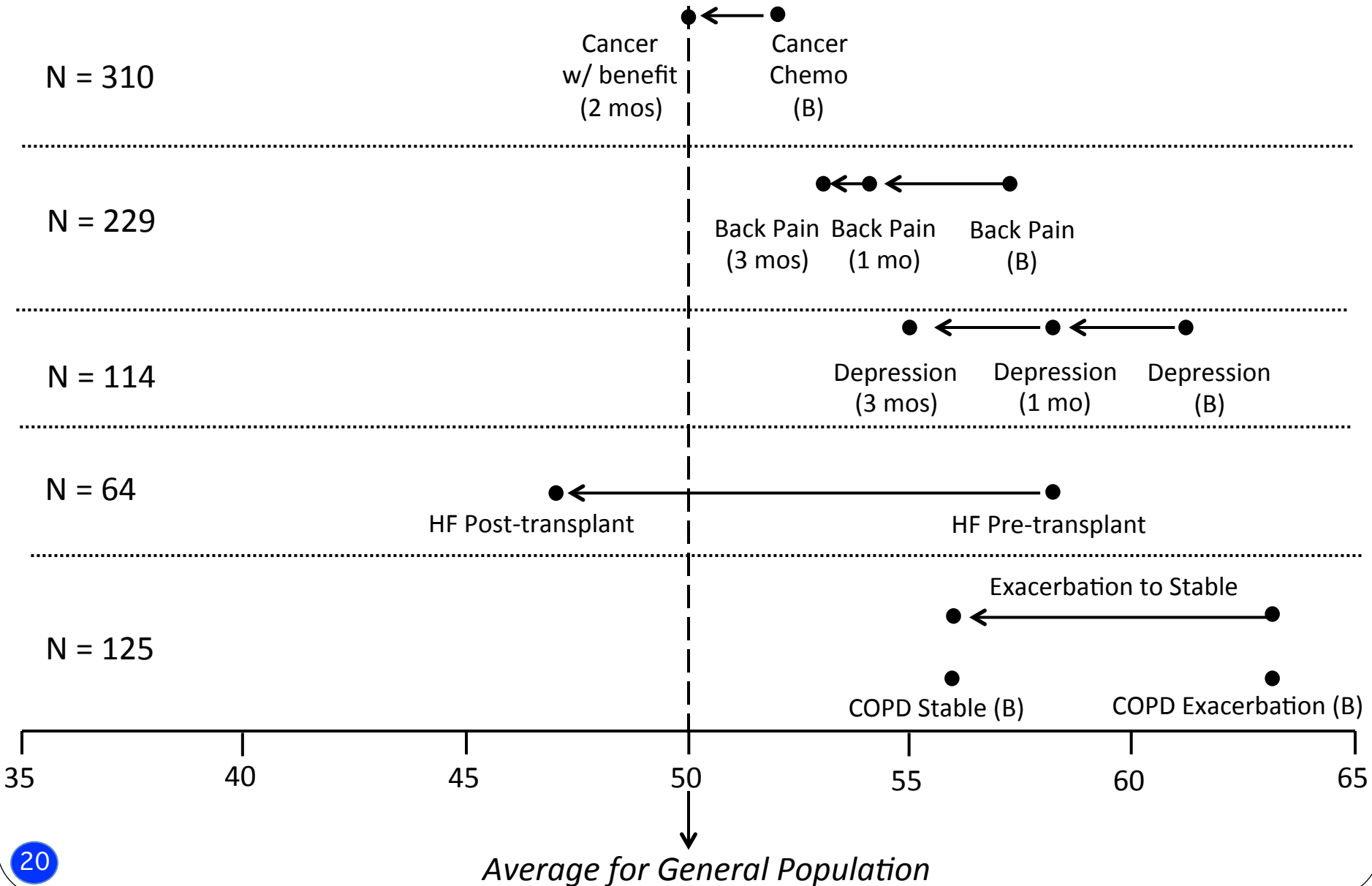
Relative Precision of Measures



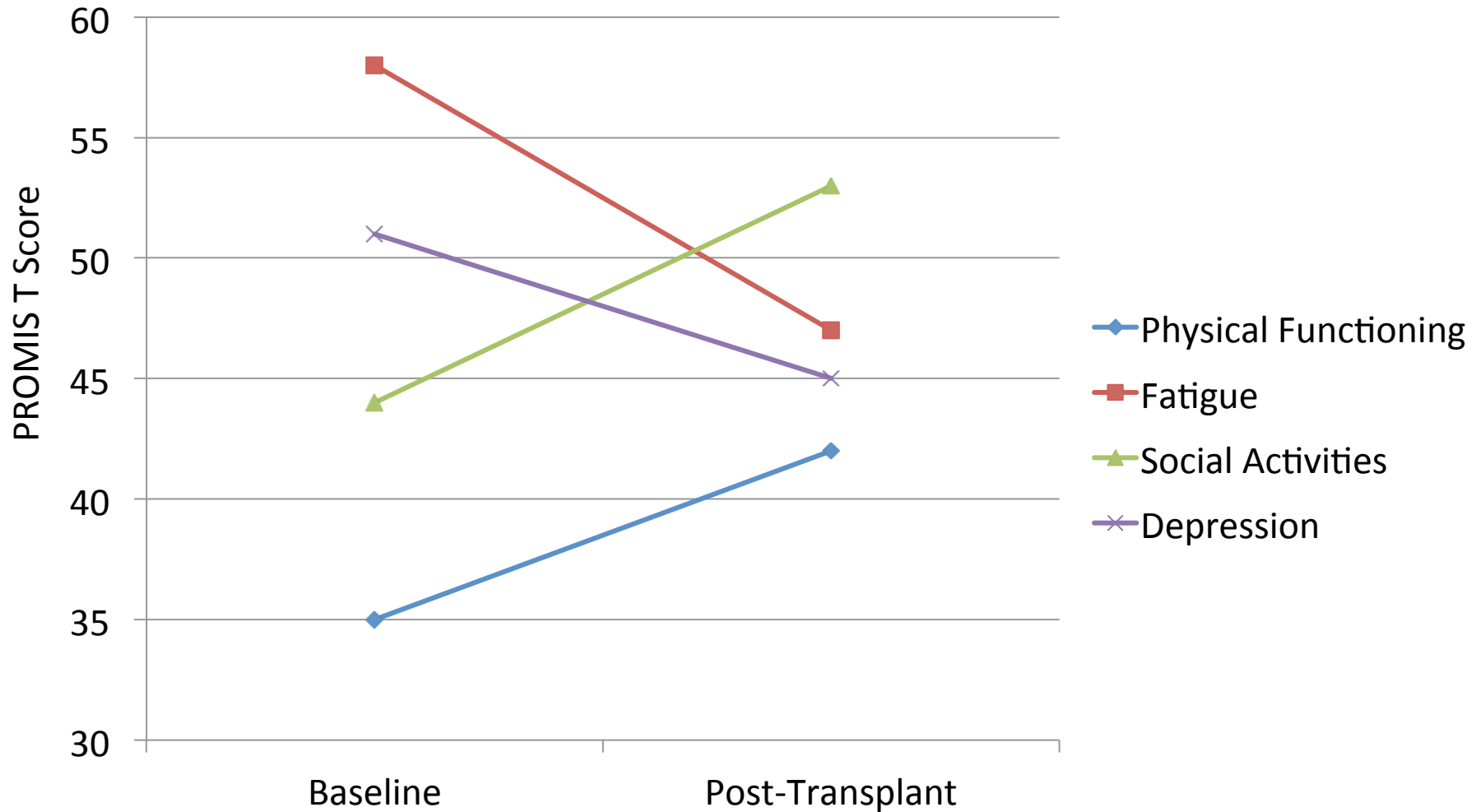
Relative Precision of Measures



PROMIS Fatigue in Five Clinical Conditions



Multi-Domain Results from Heart Transplant Trial



Assessment Center

www.nihpromis.org

- PROMIS surveys
- CAT software
- Study-specific URL
- Non-PROMIS items
- eConsent
- NIH inclusion enrollment report



Welcome to Assessment CenterSM!

Assessment CenterSM is a dynamic application that will allow researchers to centralize all research activities. Assessment CenterSM includes features that promote instrument development, study administration, data management, and storage of statistical analysis results.

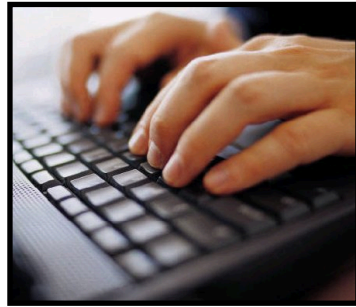
If this is your first visit to our site, please click on the Register New User link below.

Once you have completed your registration, you will be able to download PDFs of all the PROMIS instruments so that they may be administered via paper & pencil. You will also be able to immediately log into Assessment CenterSM to begin work. An email will be sent to you with your username and password for your records.

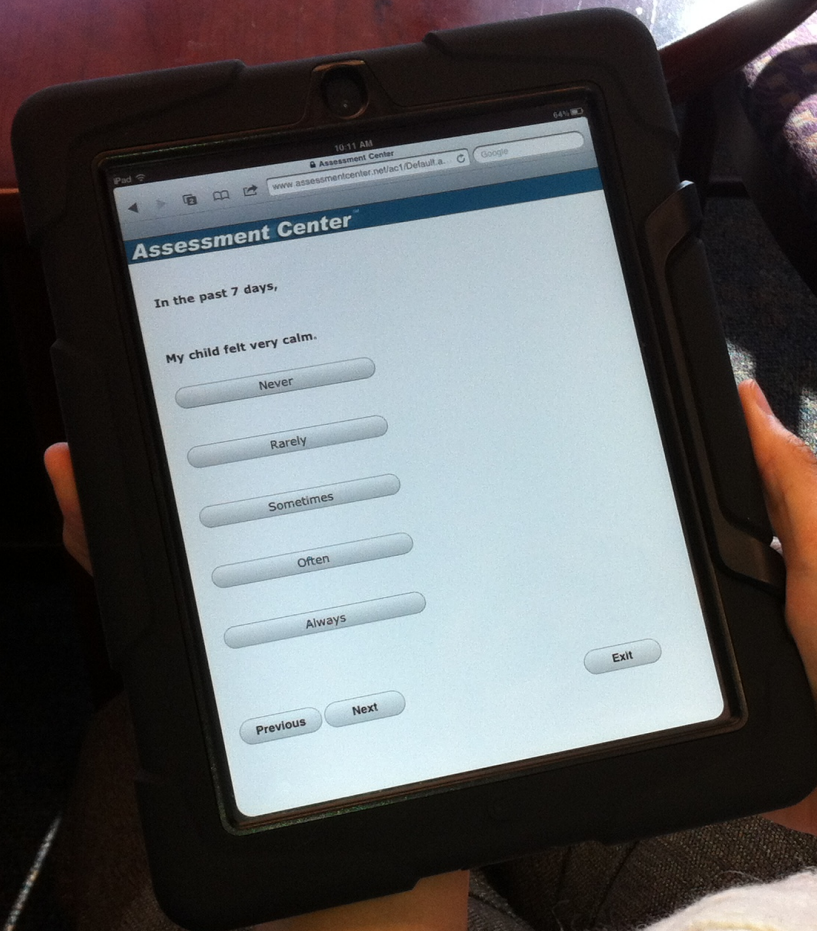
If you have already registered and would like to work in Assessment CenterSM, please click on the Login link below.

If you will be working in Assessment CenterSM and have not downloaded a copy of the User Manual, please do so now by clicking on the User Manual link below. It provides comprehensive information about using Assessment CenterSM and PROMIS instruments.

- [Register New User](#)
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*Assessment Center
supports different modes
of administration*

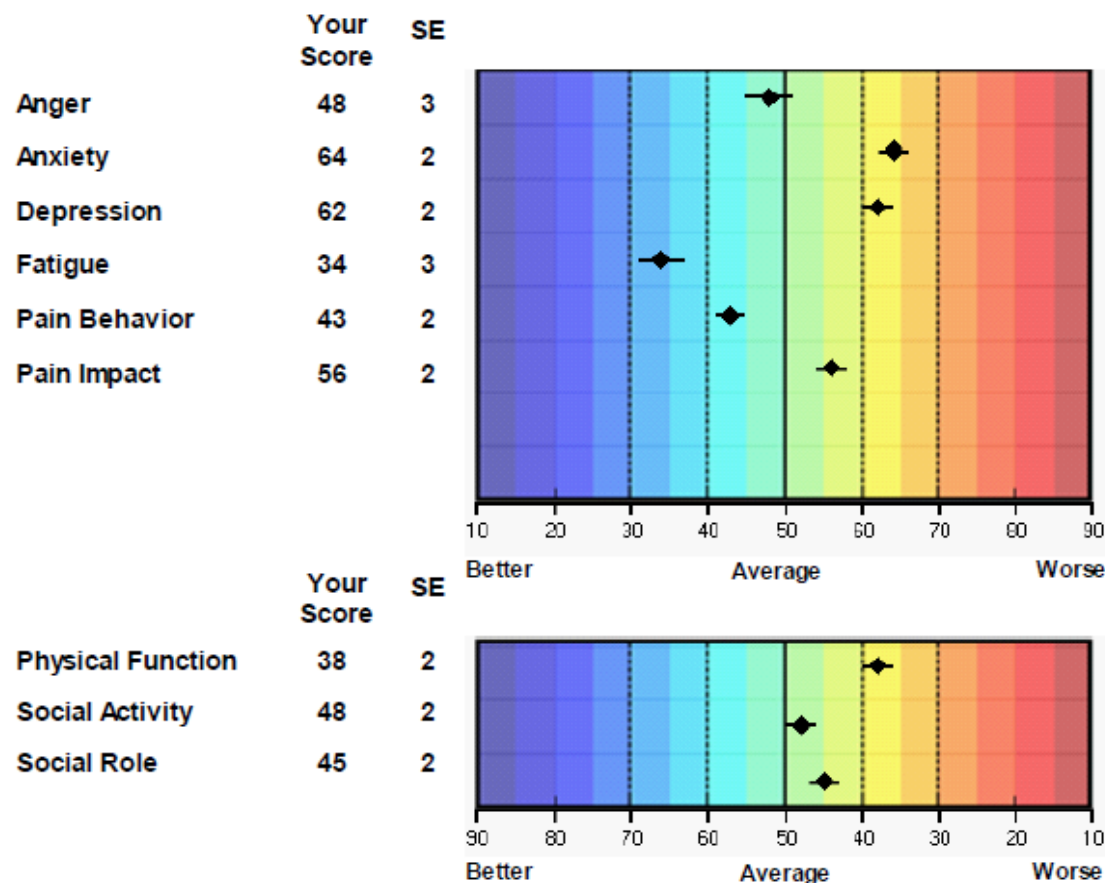


CAT Graph

Your scores for the CATs you completed are shown below.

The diamond ♦ is placed where we think your score lies. This diamond is placed on your T-Score, which is a standardized score that is based on an average score of 50, based on responses to the same questions in the United States general population. The T-score also has a standard deviation of 10 points, so a score of 40 or 60 represents a score that is one standard deviation away from the average score of the general US population.

The Standard Error (SE) is a statistical measure of variance and represents the possible range of your score. The lines on either side of the diamond in your profile report show the possible range of your actual score around this estimated score. It is very likely that your score is in the range of these lines.



Significant Improvement in all but 1 of SF-36 Scales (Change is in T-score metric)

	Change	t-test	prob.
PF-10	1.7	2.38	.0208
RP-4	4.1	3.81	.0004
BP-2	3.6	2.59	.0125
GH-5	2.4	2.86	.0061
EN-4	5.1	4.33	.0001
SF-2	4.7	3.51	.0009
RE-3	1.5	0.96	.3400 ←
EWB-5	4.3	3.20	.0023
PCS	2.8	3.23	.0021
MCS	3.9	2.82	.0067

Defining a Responder: Reliable Change Index (RCI)

$$\frac{X_2 - X_1}{(\sqrt{2})(SEM)}$$

$$SEM = SD_{bl} \times \sqrt{1 - r_{xx}}$$

Note: SD_{bl} = standard deviation at baseline
 r_{xx} = reliability

Amount of Change in Observed Score Needed for Significant Individual Change

Scale	Change	Effect size	Reliability
PF-10	8	0.7	0.94
RP-4	8	0.7	0.93
BP-2	10	1.0	0.87
GH-5	13	1.1	0.83
EN-4	13	1.3	0.77
SF-2	14	1.1	0.85
RE-3	10	0.7	0.94
EWB-5	13	1.3	0.79
PCS	7	0.6	0.94
MCS	10	0.7	0.93

7-31% of People in Sample Improve Significantly

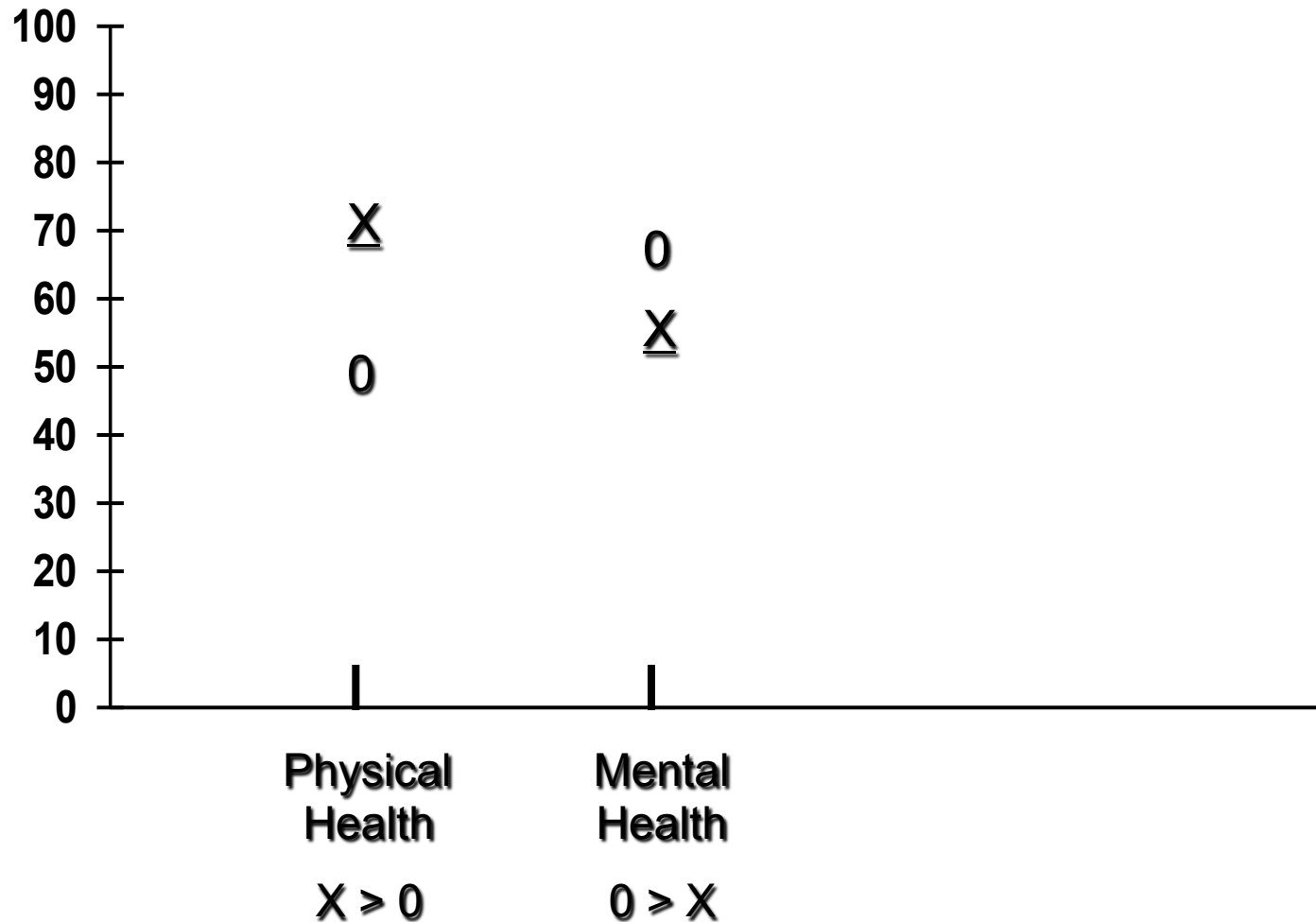
	% Improving	% Declining	Difference
PF-10	13%	2%	+ 11%
RP-4	<u>31%</u>	2%	+ 29%
BP-2	22%	7%	+ 15%
GH-5	<u>7%</u>	0%	+ 7%
EN-4	9%	2%	+ 7%
SF-2	17%	4%	+ 13%
RE-3	15%	15%	0%
EWB-5	19%	4%	+ 15%
PCS	24%	7%	+ 17%
MCS	22%	11%	+ 11%

Ultimate Use of HRQOL Measures-- Helping to Ensure Access to Cost-Effective Care

Cost ↓

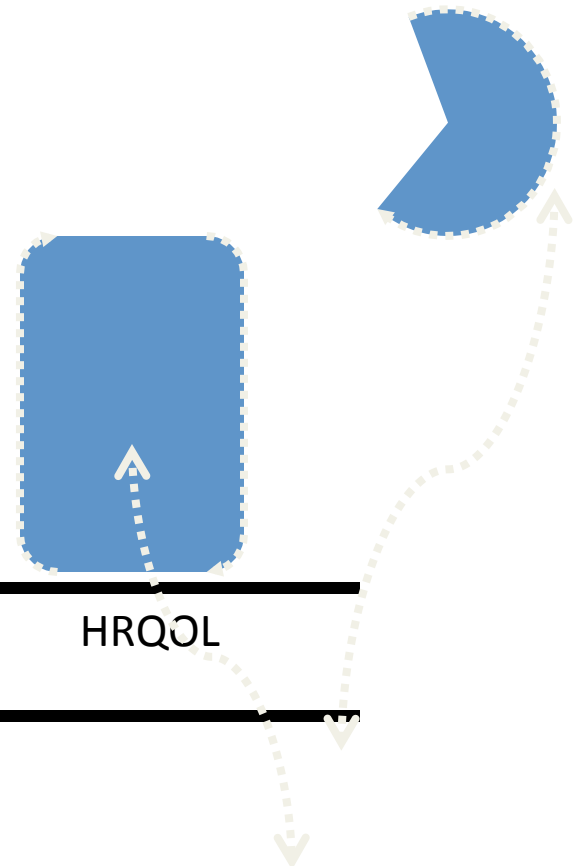
Effectiveness ↑

Is New Treatment (X) Better Than Standard Care (O)?



Is Medicine Related to Worse HRQOL?

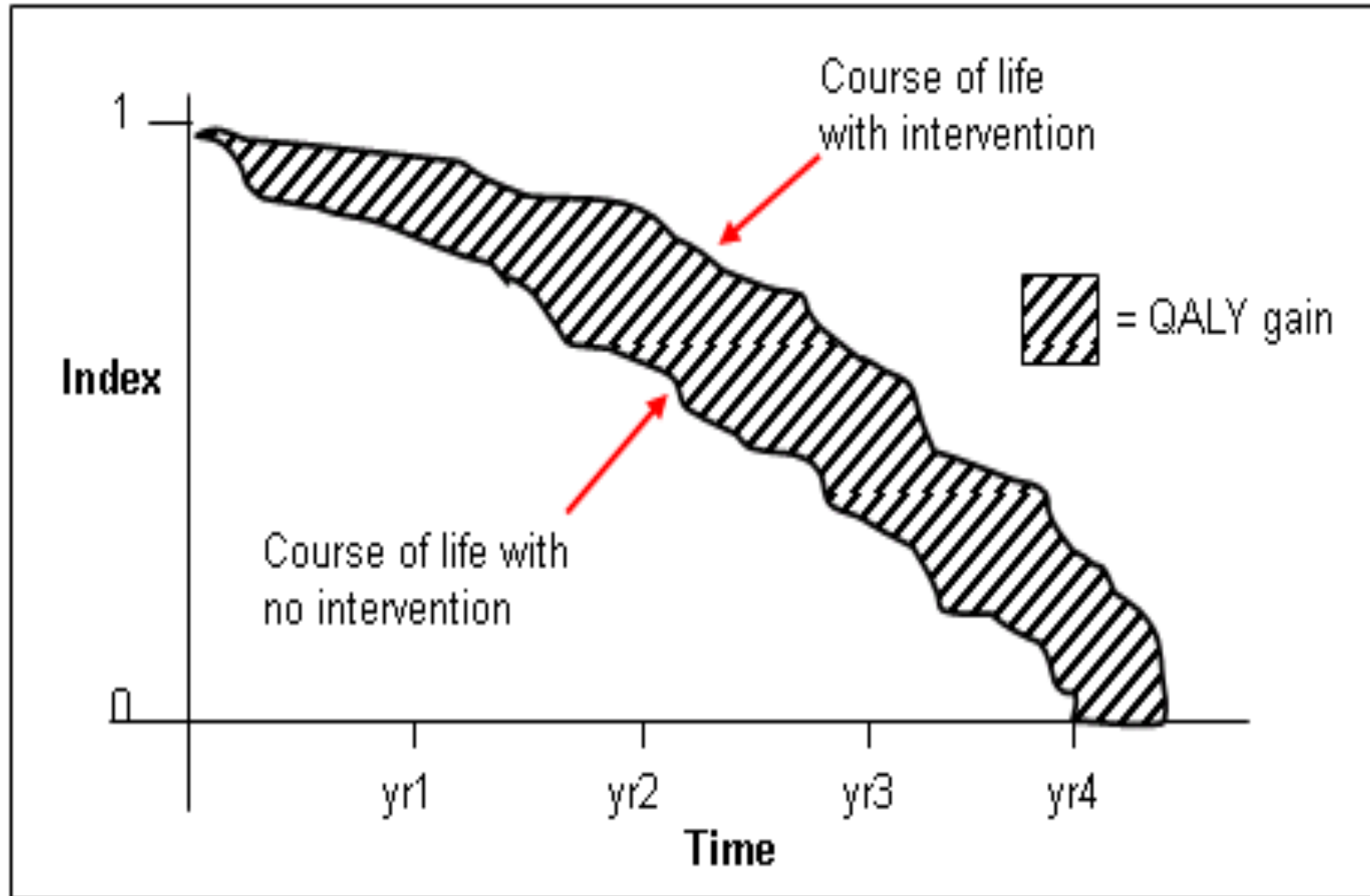
Person	Use	Medication	HRQOL (0-100)
1	No	dead	
2	No	dead	
3	No	50	
4	No	75	
5	No	100	
6	Yes	0	
7	Yes	25	
8	Yes	50	
9	Yes	75	
10	Yes	100	
Group	n	HRQOL	
No Medicine		3	75
Yes Medicine		5	50



Indirect Preference Measures

- Attributes known and used to estimate societal preferences
 - Quality of Well-Being (QWB) Scale
 - EQ-5D
 - HUI2 and HUI3
 - SF-6D

QALY with and without Intervention

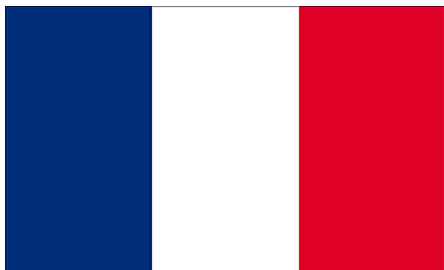
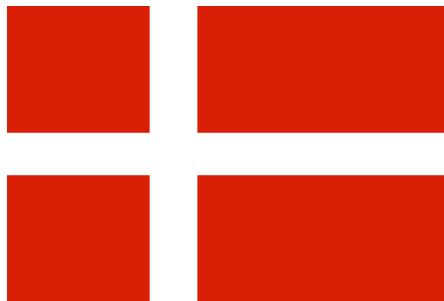
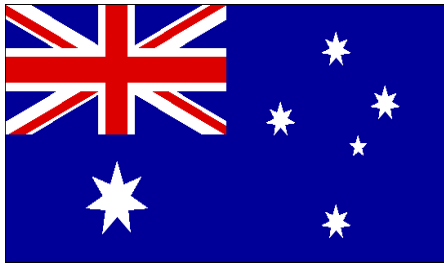


Use of PROMIS

- 44 NIH grants
 - R01; R21; P01; P60; U01; K; SBIR
- 111 studies collecting data on AC
- 20 NIH-sponsored clinical trials
 - ECOG; GOG; RTOG; SWOG; NCCTG; COG
- 8 Industry-sponsored clinical trials
- 12 Foundation-sponsored registries
 - Surgery; cardiology; oncology; nephrology; pediatrics



PROMIS International Users' Group



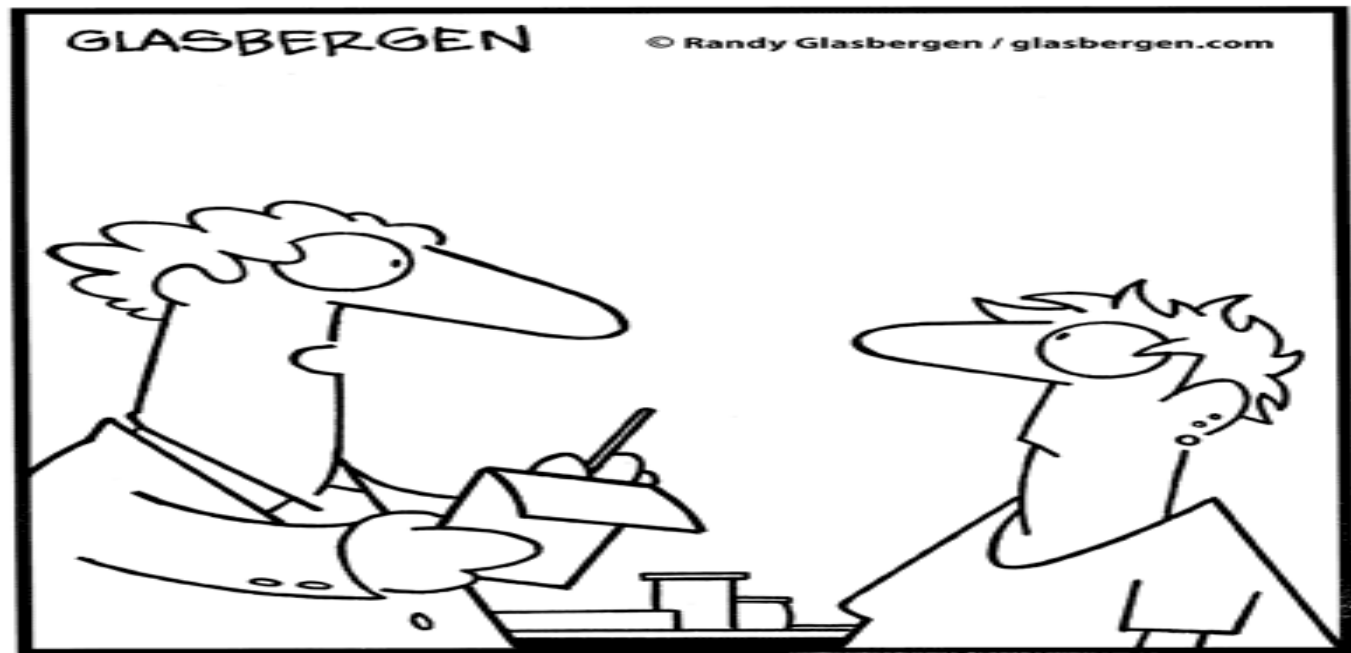
...and more

Questions?

<http://gim.med.ucla.edu/FacultyPages/Hays/>

<http://twitter.com/RonDHays>

www.nihpromis.org



**"I'm prescribing a diet patch to
repair the leak in your willpower."**