Measuring Health-Related Quality of Life

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May 13, 2015, 8-9:50am (M218, 41-268)

Students

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- Nancy Guerrero-Llamas, Comm. Health Sci.
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- Melissa Johnson, Nursing
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- Leslie Thomas, Community Health Sciences
- Lumo Tserling, Visiting student from Tibet

U.S. Health Care Issues

- **A**ccess to care
  - ~ 50 million people without health insurance
- **C**osts of care
  - Expenditures ~ $ 2.7 Trillion
- **E**ffectiveness (quality) of care

How Do We Know If Care Is Effective?

- Effective care maximizes probability of desired health outcomes
  - Health outcome measures indicate whether care is effective

Cost ↓

Effectiveness ↑

Indicators of Health

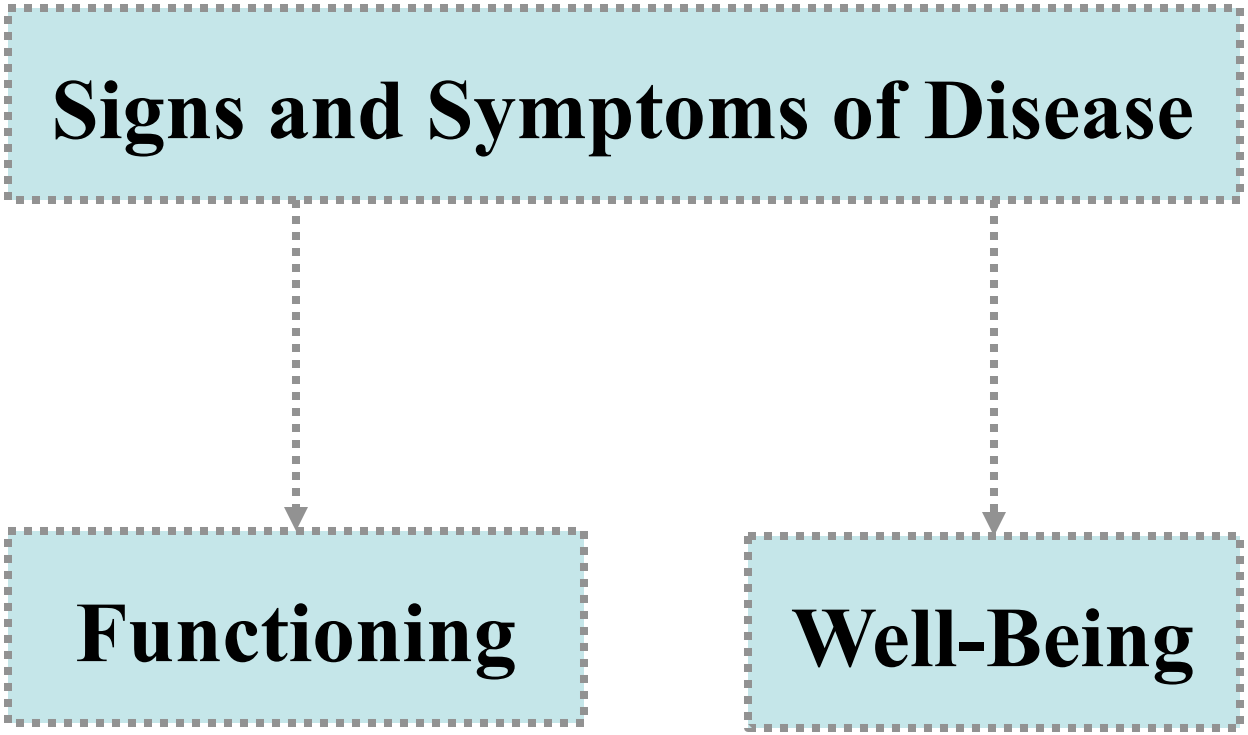
Signs and Symptoms of Disease

Vital Signs – e.g. bp

Hematocrit

SOB

Indicators of Health



Health-Related Quality of Life (HRQOL)

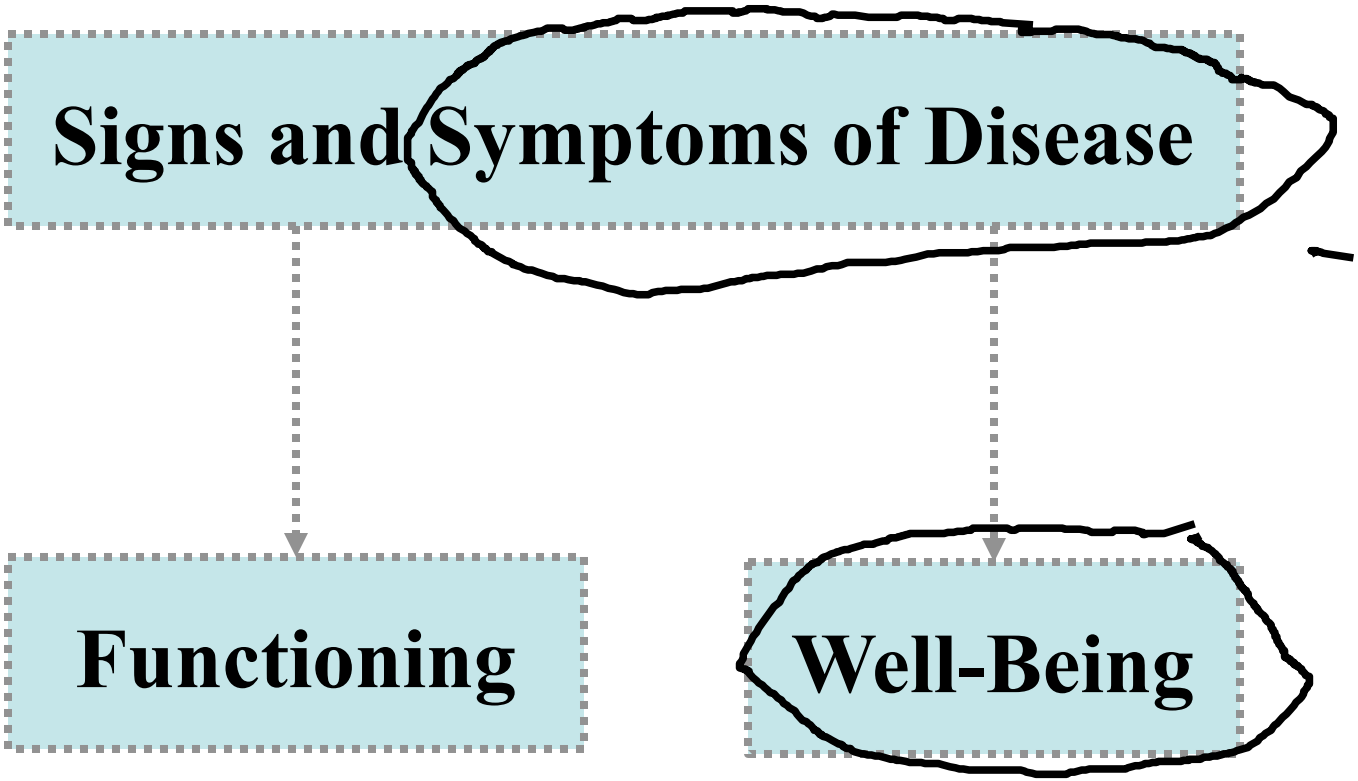
<u>How the person FEELs (well-being)</u>

- Emotional well-being
- Pain
- Energy

<u>What the person can DO (functioning)</u>

- Self-care
- Role
- Social

Indicators of Health



KDQOL Symptoms/Problems

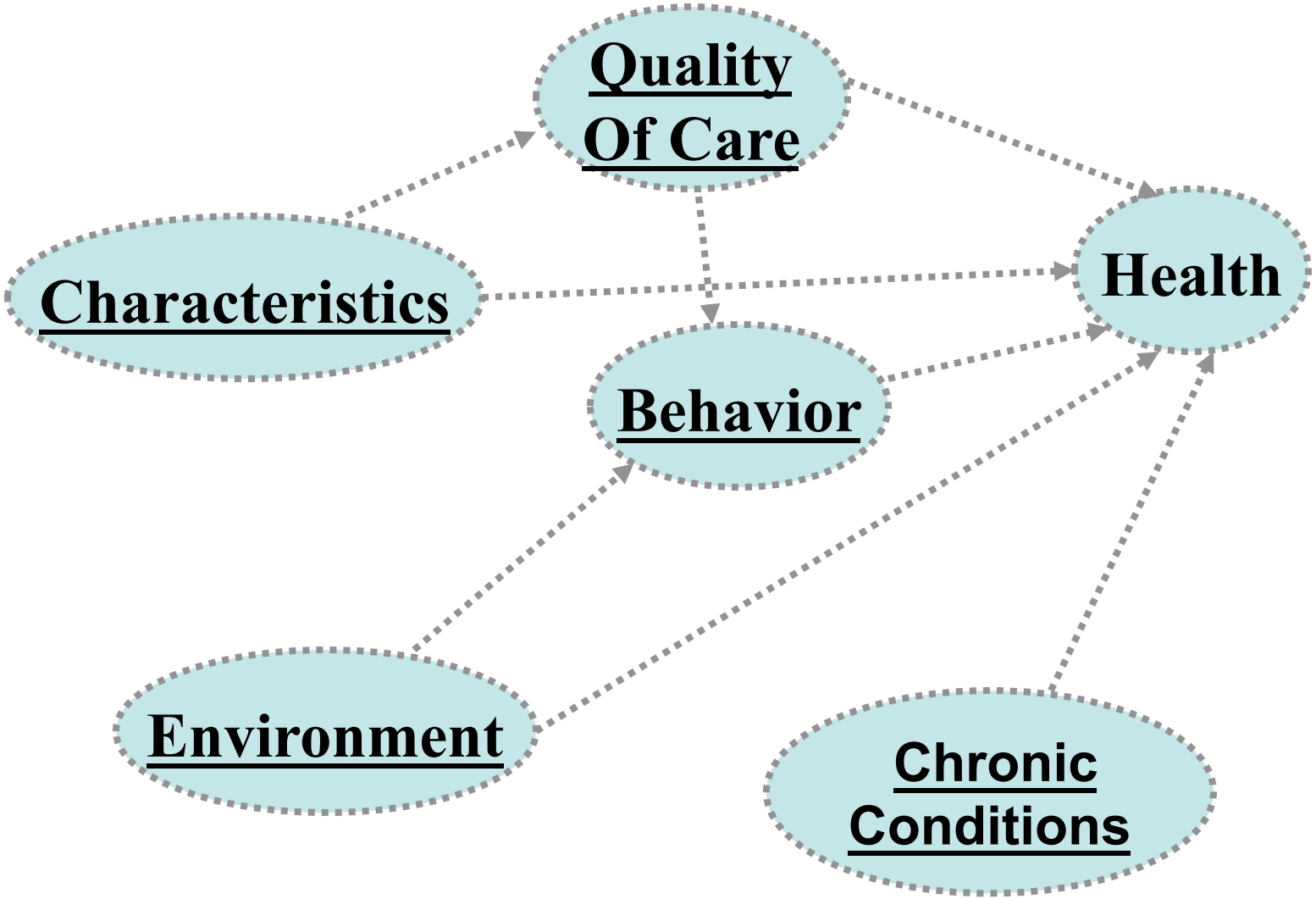
During the past 4 weeks, to what extent were you bothered by each of the following?

- Soreness in your muscles?
- Chest pain?
- Itchy skin?
- Shortness of breath?
- Faintness or dizziness?

Health-Related Quality of Life (HRQOL)

~~Quality of environment~~
~~Type of housing~~
~~Level of income~~
~~Social Support~~

Determinants of Health



Patient-Reported Measures (PRMs)

- Mediators
  - Health behaviors (adherence)
- Health Care Process
  - Reports about care (e.g., communication)
- Outcomes (PROs)
  - Patient satisfaction with care
  - Health-Related Quality of Life (HRQOL)

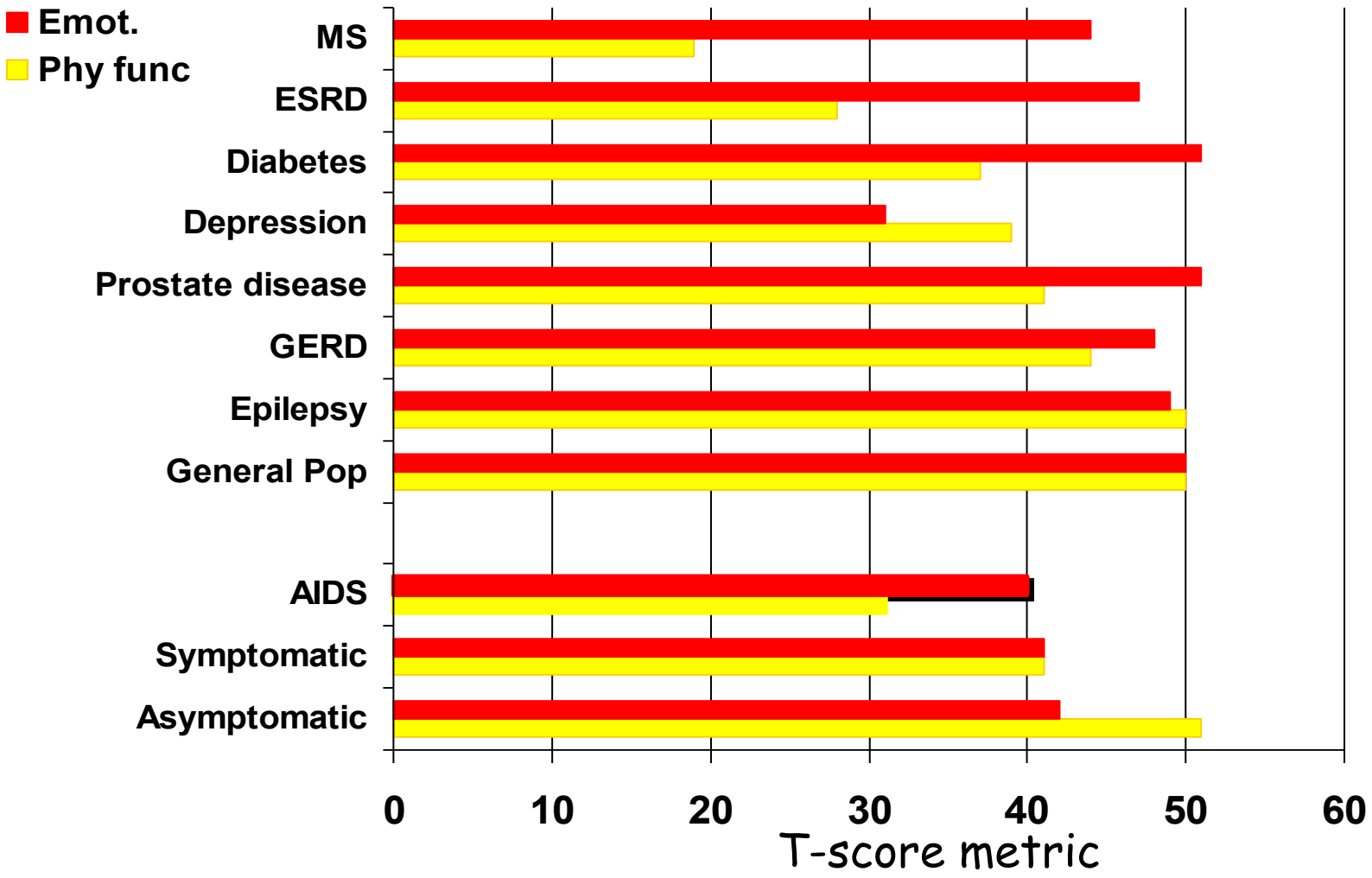
Type of HRQOL Scores

- Multiple Scores (Profile)
  - Generic (SF-36)
    - How much of the time during the past 4 weeks have you been happy? (*None of the* time → *All of the time*)
  - Targeted ("Disease specific")
    - KDQOL-36
      - My kidney disease interferes too much with my life.
- Single Score
  - Preference-based (EQ-5D, HUI, SF-6D)
- Combinations of above

HRQOL Scoring Options

- 0-100 possible range
- T-scores (mean = 50, SD = 10)
  - (10 * z-score) + 50
    - z-score = (score – mean)/SD
- 0 (dead) to 1 (perfect health)

HRQOL in HIV Compared to other Chronic Illnesses and General Population



Hays et al. (2000), American Journal of Medicine

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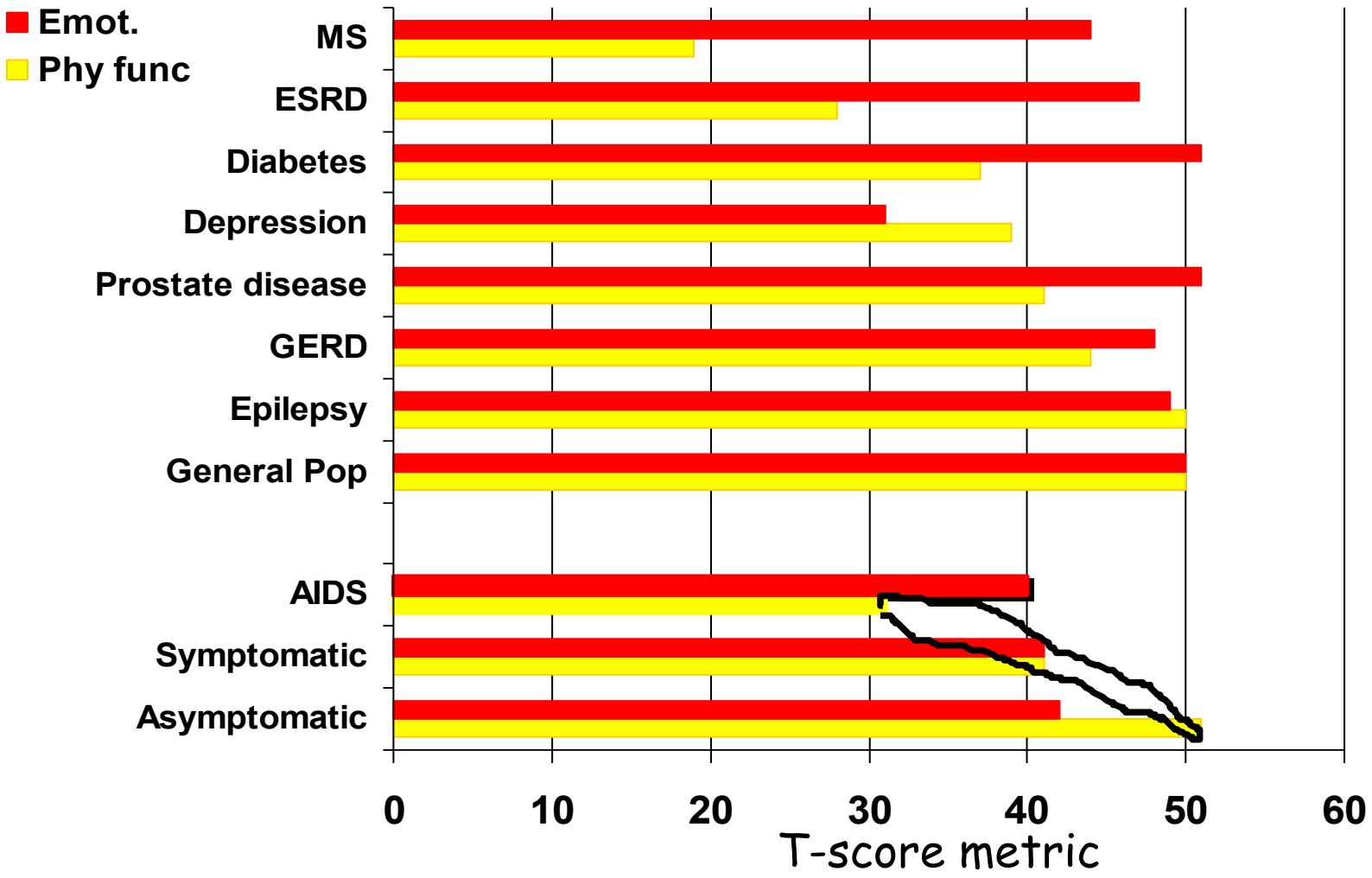

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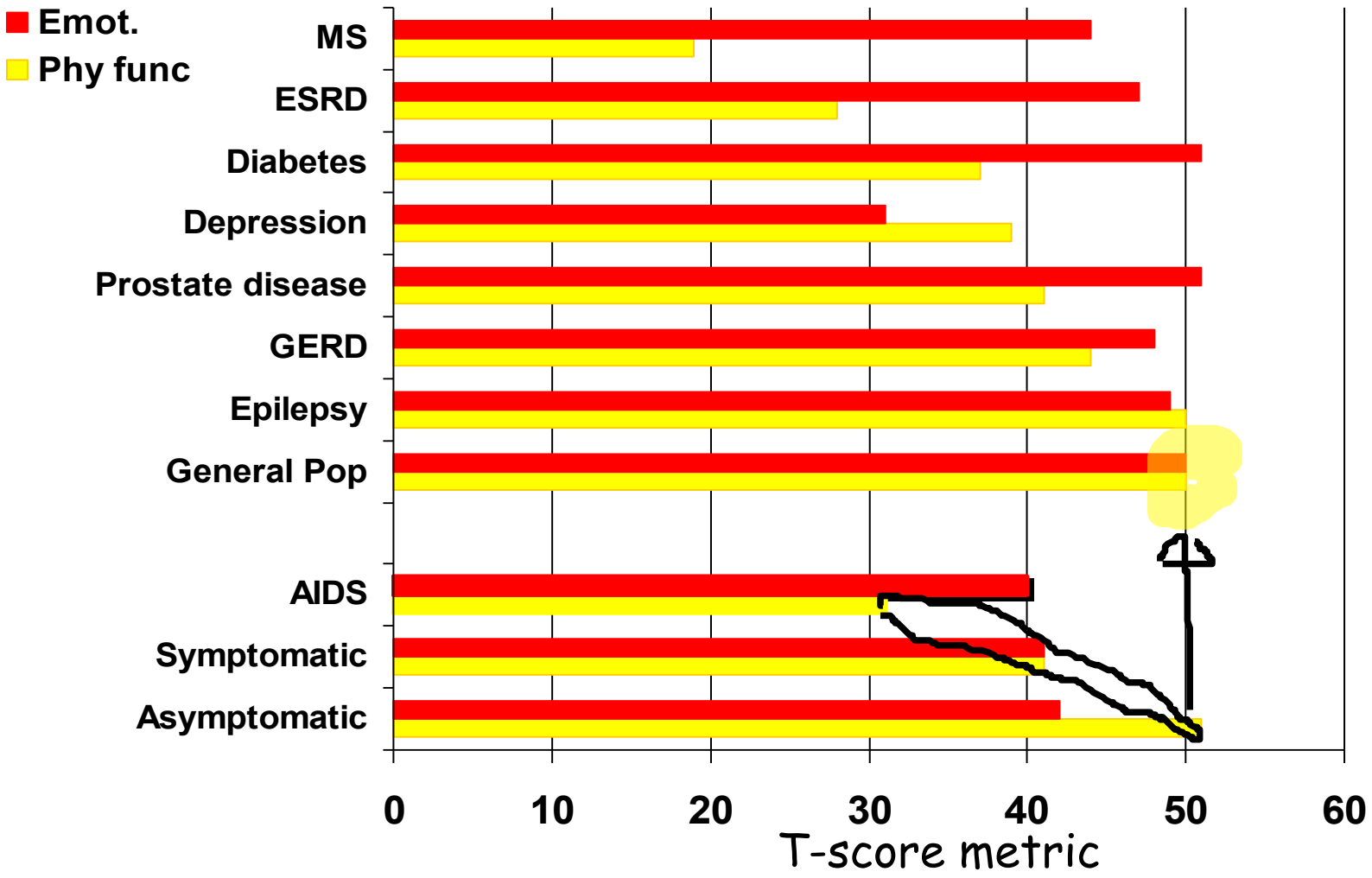

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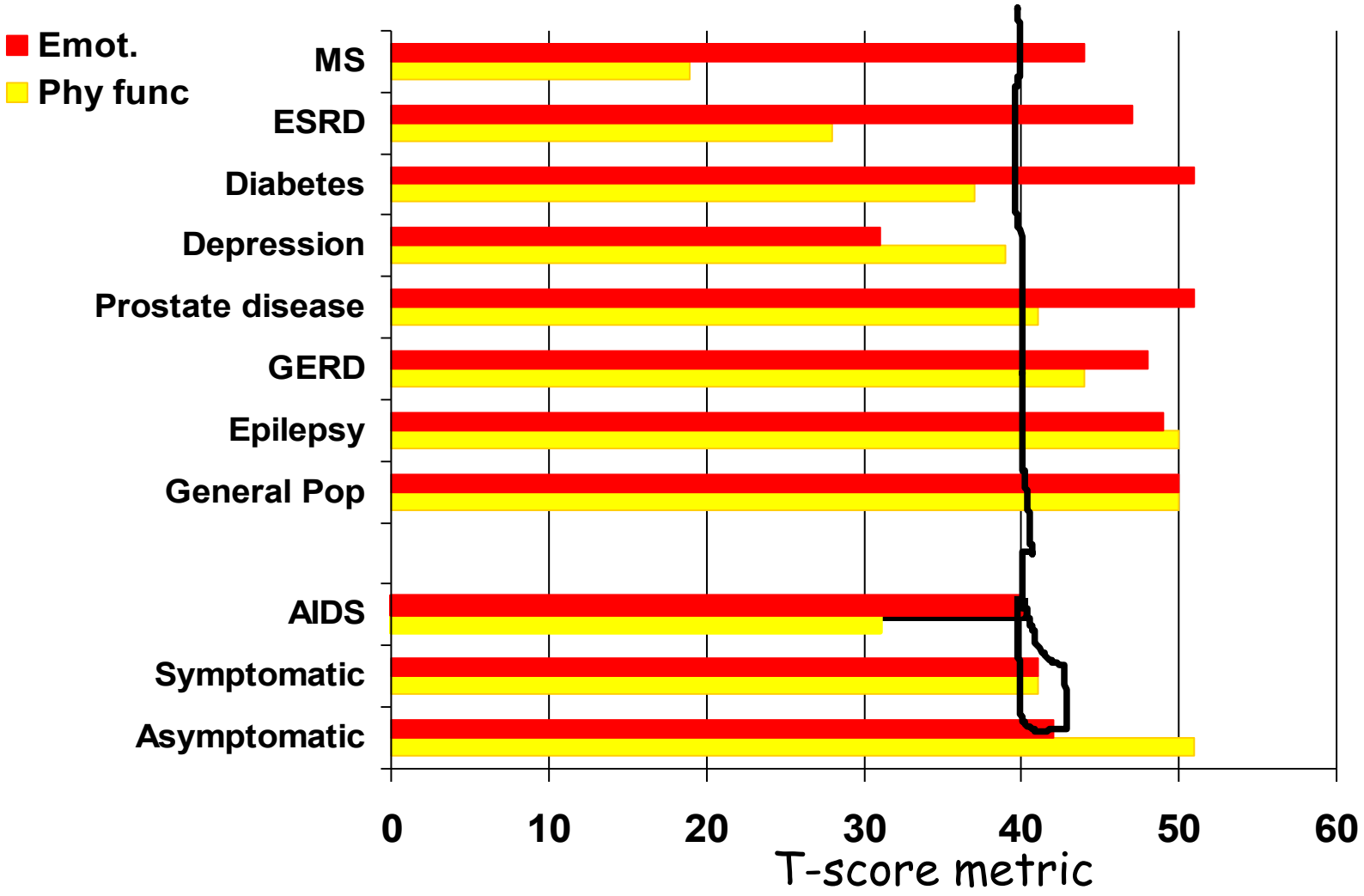

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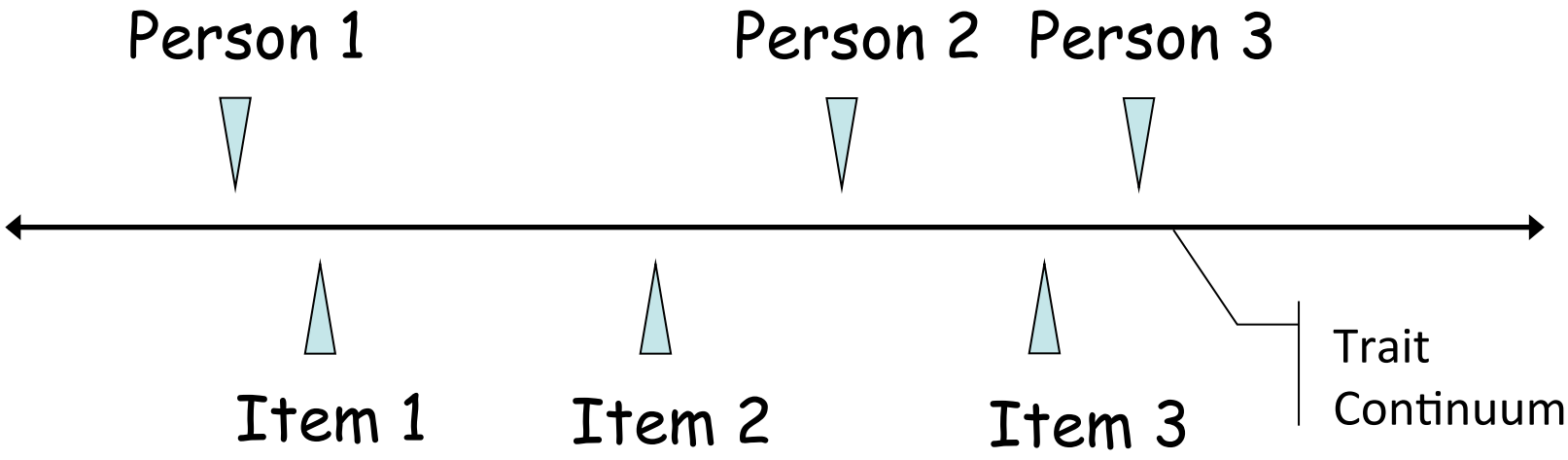
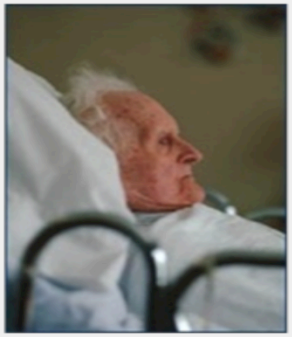
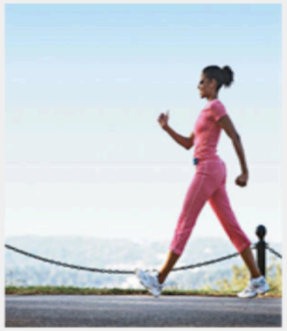
Item Responses and Trait Levels



www.nihpromis.org




0 50 100

Physical Functioning Item Bank

Item 1 | Item 2 | Item 3 | Item 4 | Item 5 | Item 6 | Item 7 | Item 8 | Item 9 | Item *n*

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?

In general, how would you rate your health?

Excellent

Very Good

Good

Fair

Poor

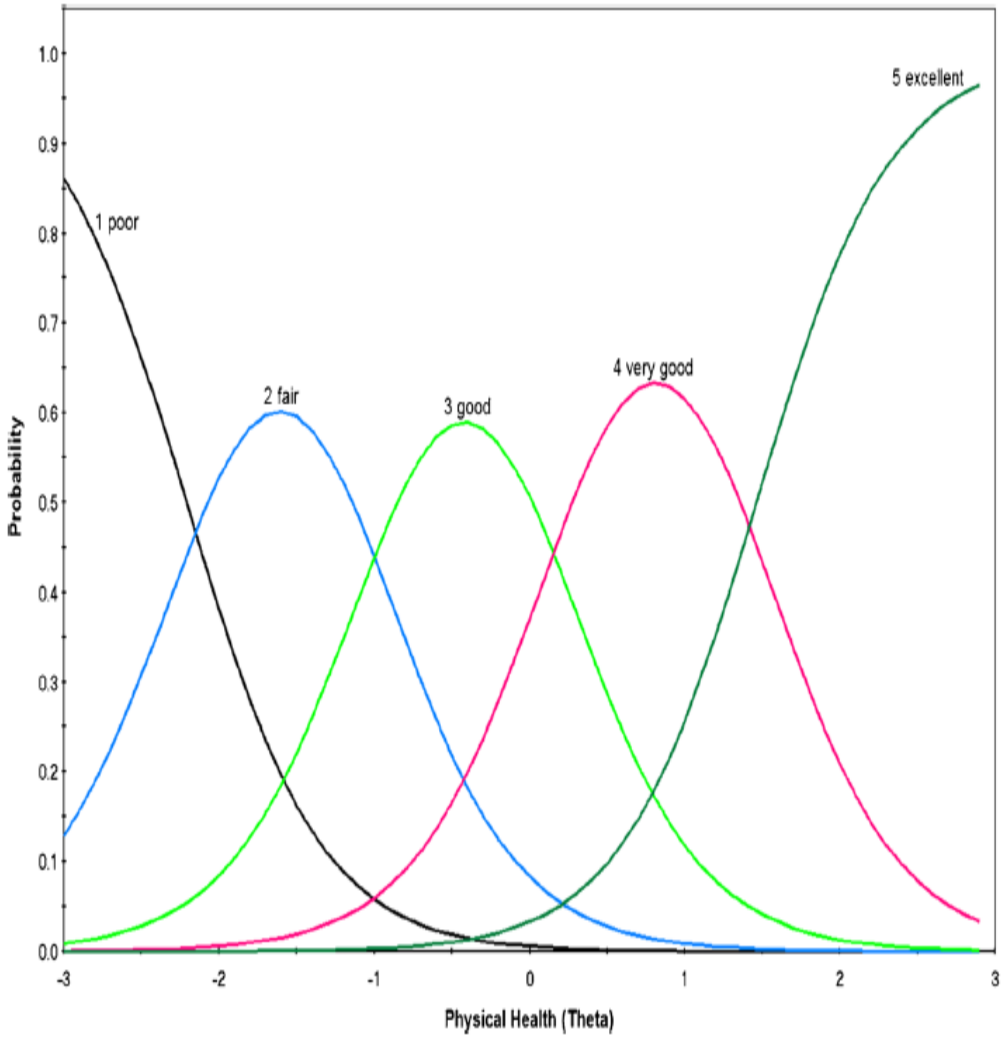


Fig. 1 Category Response Curves for PROMIS Global Health Item (global01) (Image file: Figure 1.tif).

In general, how would you rate your health?

62 = Excellent

54 = Very Good

47 = Good

38 = Fair

29 = Poor

Reliability = 0.52 (compared to 0.81 for 4-item scale).

Reliability Target for Use of Measures with Individuals

- Reliability ranges from 0-1
  - 0.90 or above is goal
- $SE = SD\ (1 - \text{reliability})^{1/2}$
- $\text{Reliability} = 1 - (SE/10)^2$
  - Reliability = 0.90 when SE = 3.2
  - 95% CI = true score +/- 1.96 x SE

In the past 7 days …

I was grouchy [1st question]

- Never [39]
- Rarely [48]
- Sometimes [56]
- Often [64]
- Always [72]

Estimated Anger = 56.1

SE = 5.7 (rel. = 0.68)

In the past 7 days …

I felt like I was ready to explode

[2nd question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 51.9

SE = 4.8 (rel. = 0.77)

In the past 7 days …

I felt angry [3rd question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.5

SE = 3.9 (rel. = 0.85)

In the past 7 days …

I felt angrier than I thought I should
[4th question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 48.8

SE = 3.6 (rel. = 0.87)

In the past 7 days …

I felt annoyed [5th question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.1

SE = 3.2 (rel. = 0.90)

In the past 7 days …

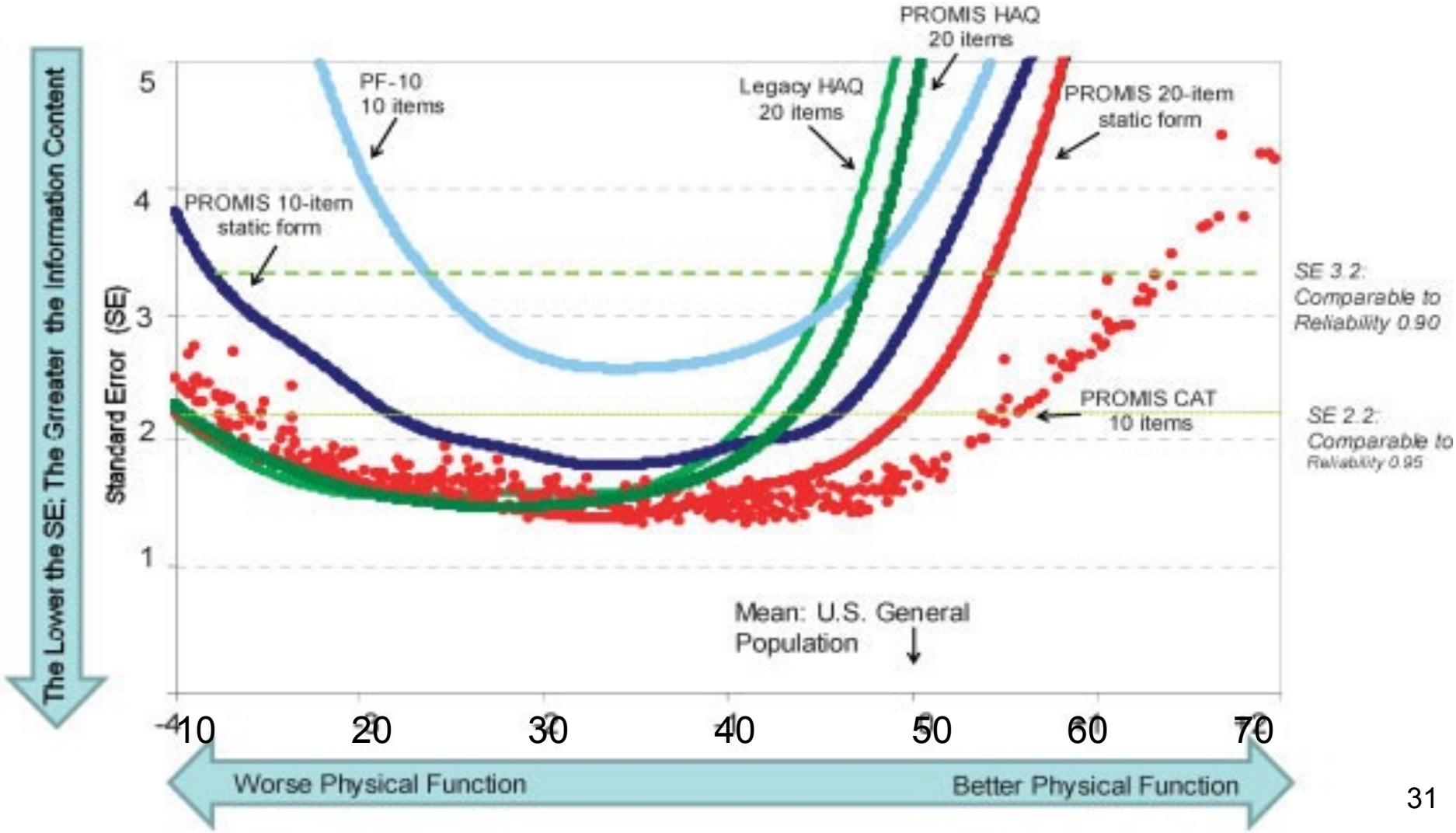
I made myself angry about something just by thinking about it. [6th question]

- Never
- Rarely
- Sometimes
- Often
- Always

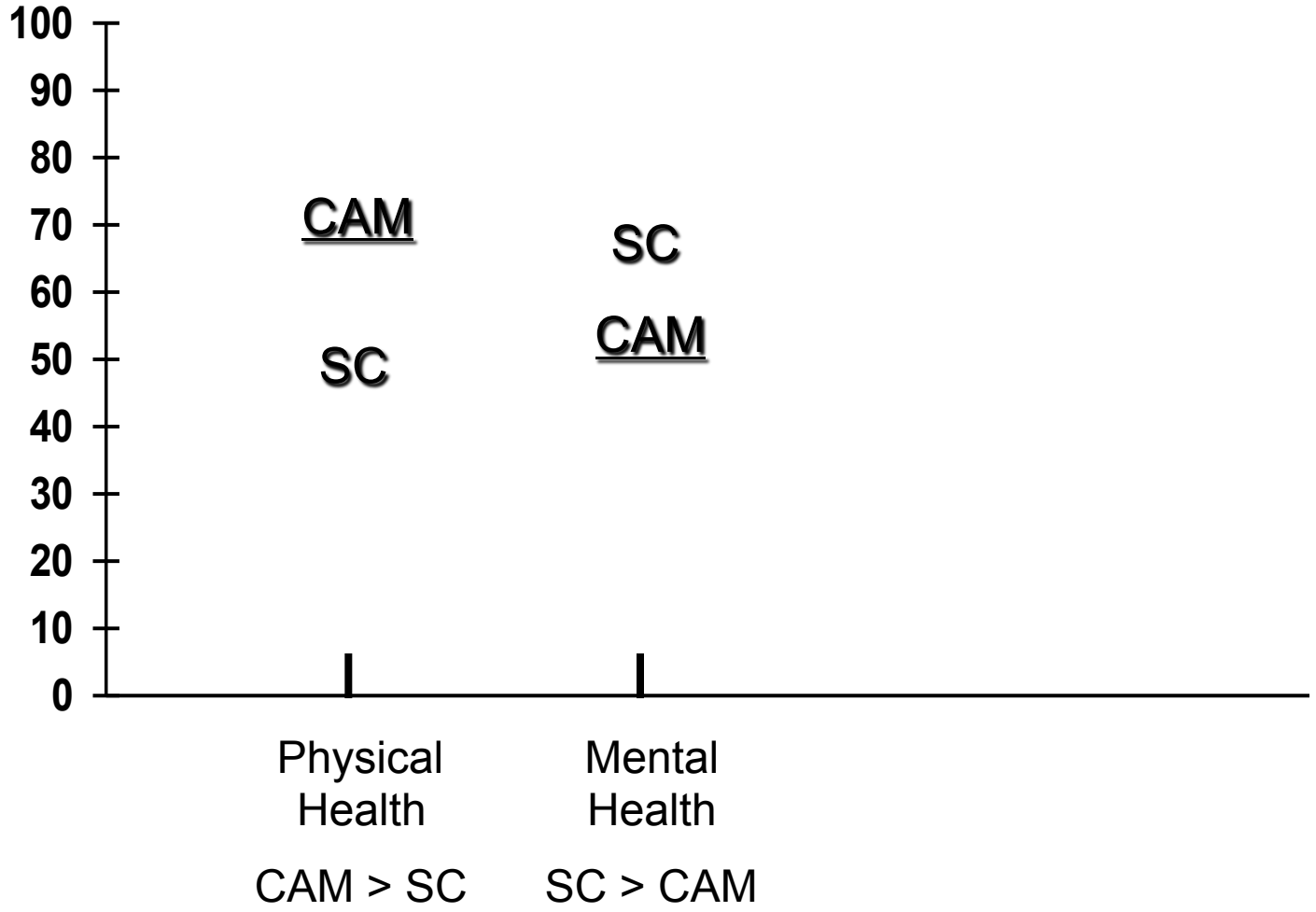
Estimated Anger = 50.2

SE = 2.8 (rel = 0.92)

PROMIS Physical Functioning vs. "Legacy" Measures



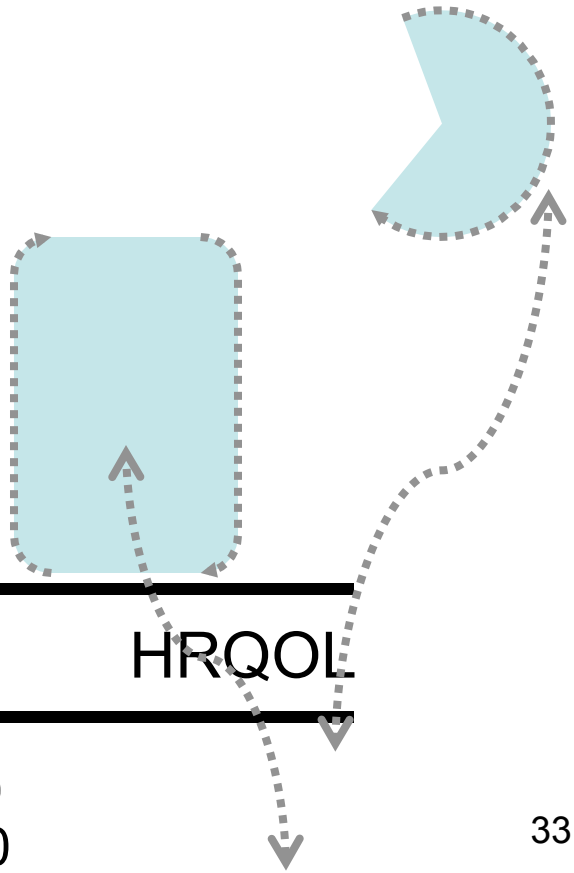
Is CAM Better than Standard Care (SC)?



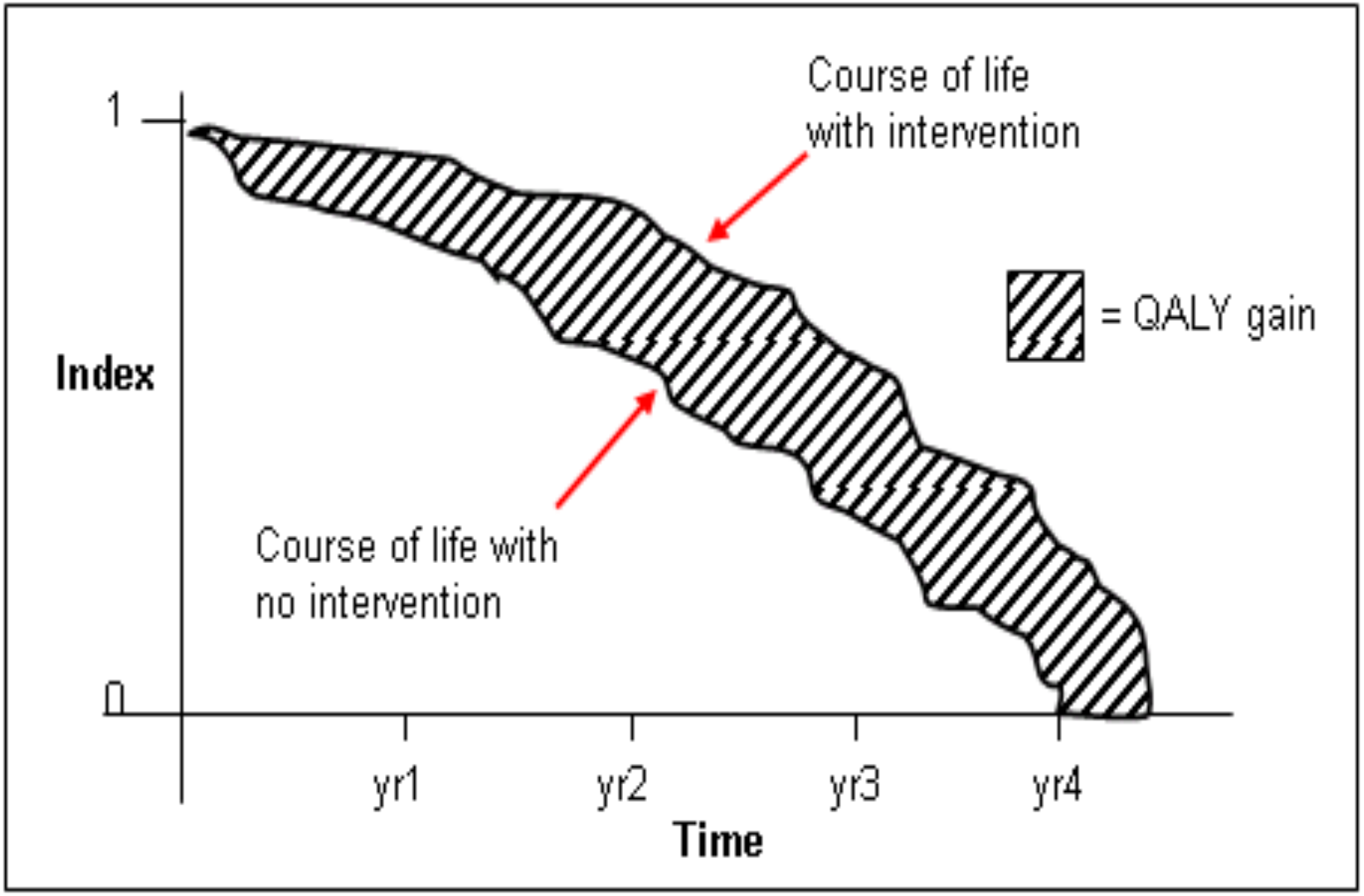
Is Acupuncture Related to Worse HRQOL?

Subject	Acupuncture	General Health
1	No	dead
2	No	dead
3	No	50
4	No	60
5	No	70
6	Yes	40
7	Yes	50
8	Yes	50
9	Yes	55
10	Yes	

Group	n	HRQOL
No Acupuncture	360	
Yes Acupuncture	550	

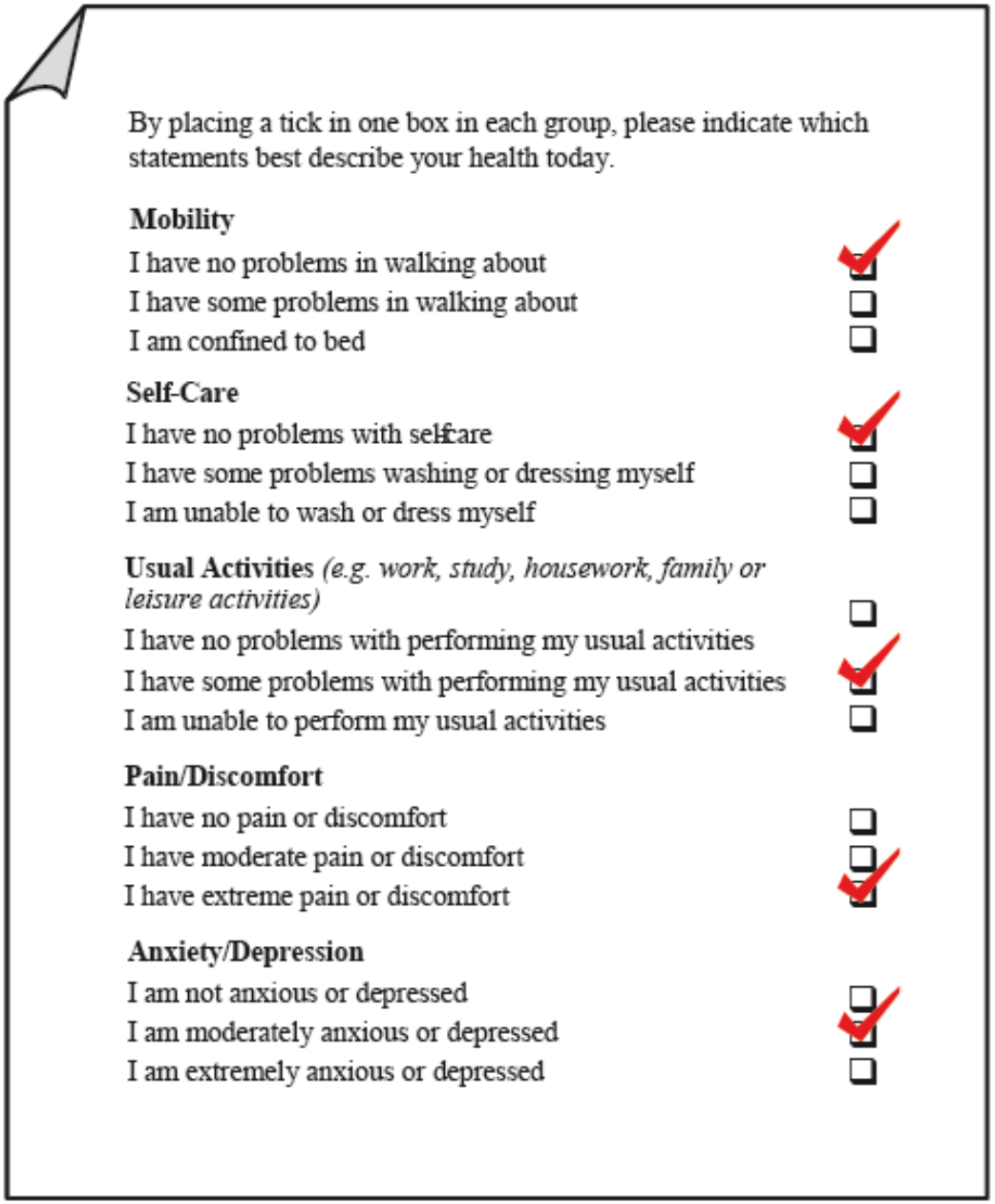


http://www.ukmi.nhs.uk/Research/pharma_res.asp



The EQ-5D-3L descriptive system should be scored as follows:

0.435



By placing a tick in one box in each group, please indicate which statements best describe your health today.

Mobility
- I have no problems in walking about ☑
- I have some problems in walking about ☐
- I am confined to bed ☐

Self-Care
- I have no problems with self-care ☑
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

Usual Activities *(e.g. work, study, housework, family or leisure activities)*
- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☑
- I am unable to perform my usual activities ☐

Pain/Discomfort
- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☑

Anxiety/Depression
- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☑
- I am extremely anxious or depressed ☐

Levels of perceived problems are coded as follows:

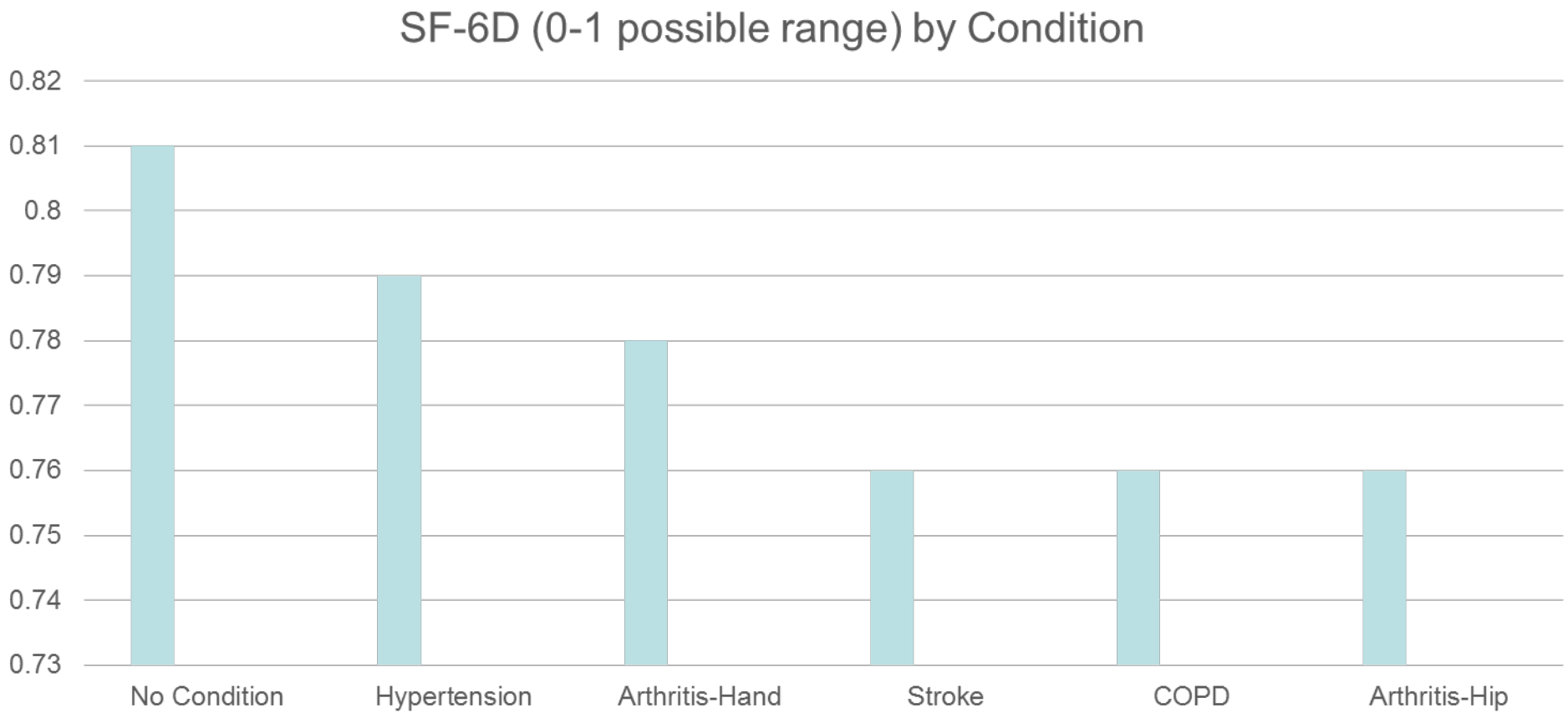
☑ ☐ ☐ Level 1 is coded as a '1'

☐ ☑ ☐ Level 2 is coded as a '2'

☐ ☐ ☑ Level 3 is coded as a '3'

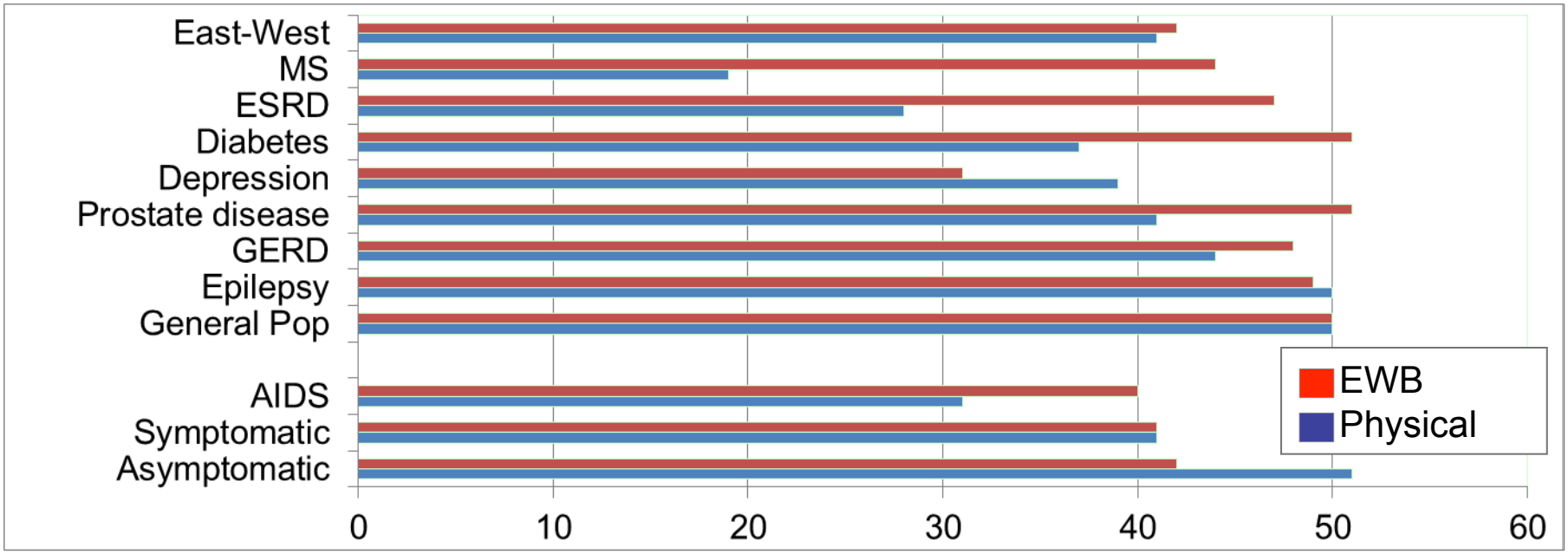
NB: There should be only <u>one</u> response for each dimension.

HRQOL in SEER-Medicare Health Outcomes Study (n = 126,366)



Controlling for age, gender, race/ethnicity, education, income, and marital status.

Physical Functioning and Emotional Well-Being at Baseline for 54 Patients at UCLA-Center for East West Medicine



MS = multiple sclerois; ESRD = end-stage renal disease; GERD = gastroesophageal reflux disease.

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

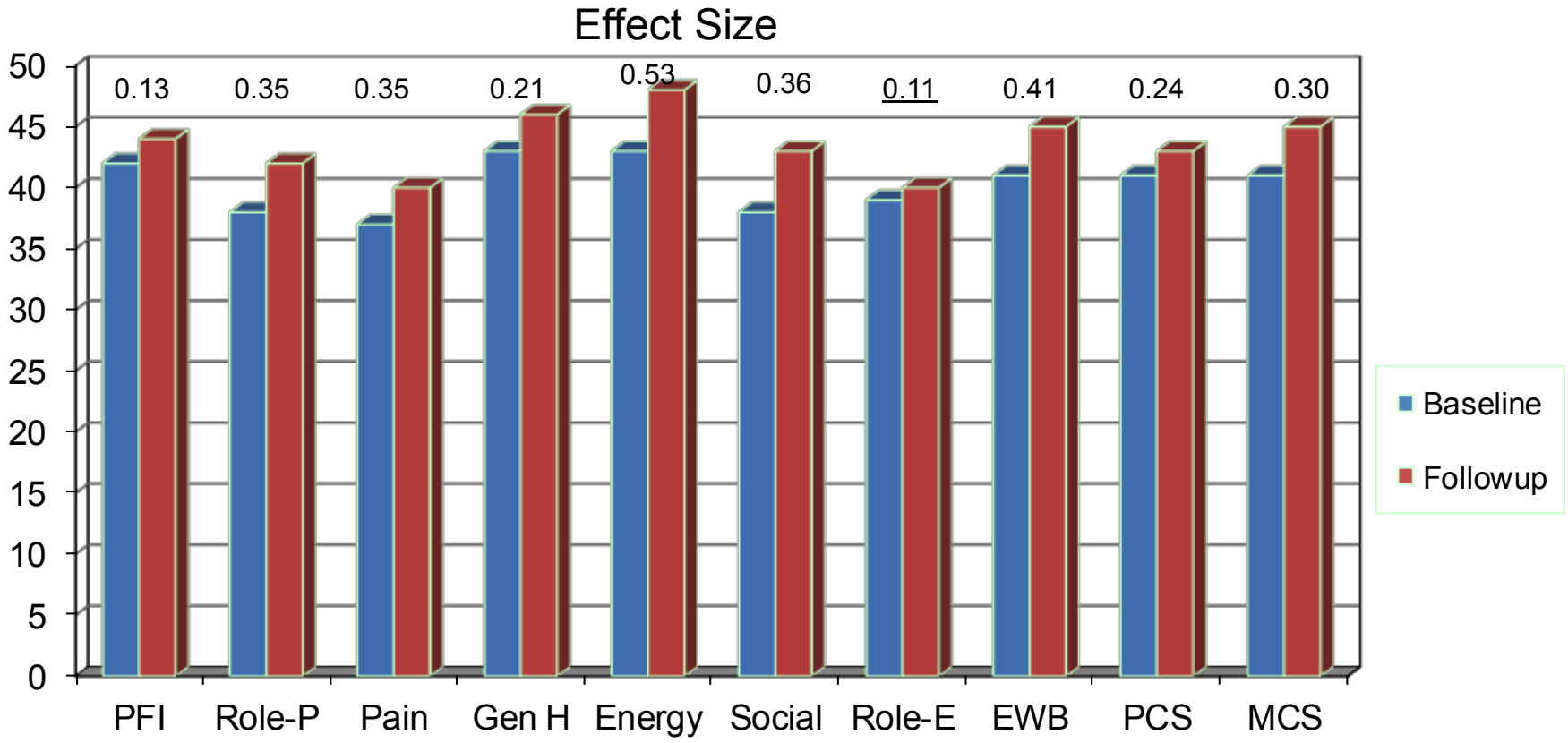
Effect Size

(Follow-up – Baseline)/ $SD_{baseline}$

Cohen's Rule of Thumb:

- ✓ ES = 0.20 Small
- ✓ ES = 0.50 Medium
- ✓ ES = 0.80 Large

Effect Sizes for Changes in SF-36 Scores



PFI = Physical Functioning; Role-P = Role-Physical; Pain = Bodily Pain; Gen H=General Health; Energy = Energy/Fatigue; Social = Social Functioning; Role-E = Role-Emotional; EWB = Emotional Well-being; PCS = Physical Component Summary; MCS =Mental Component Summary.

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 To be Statistically Significant

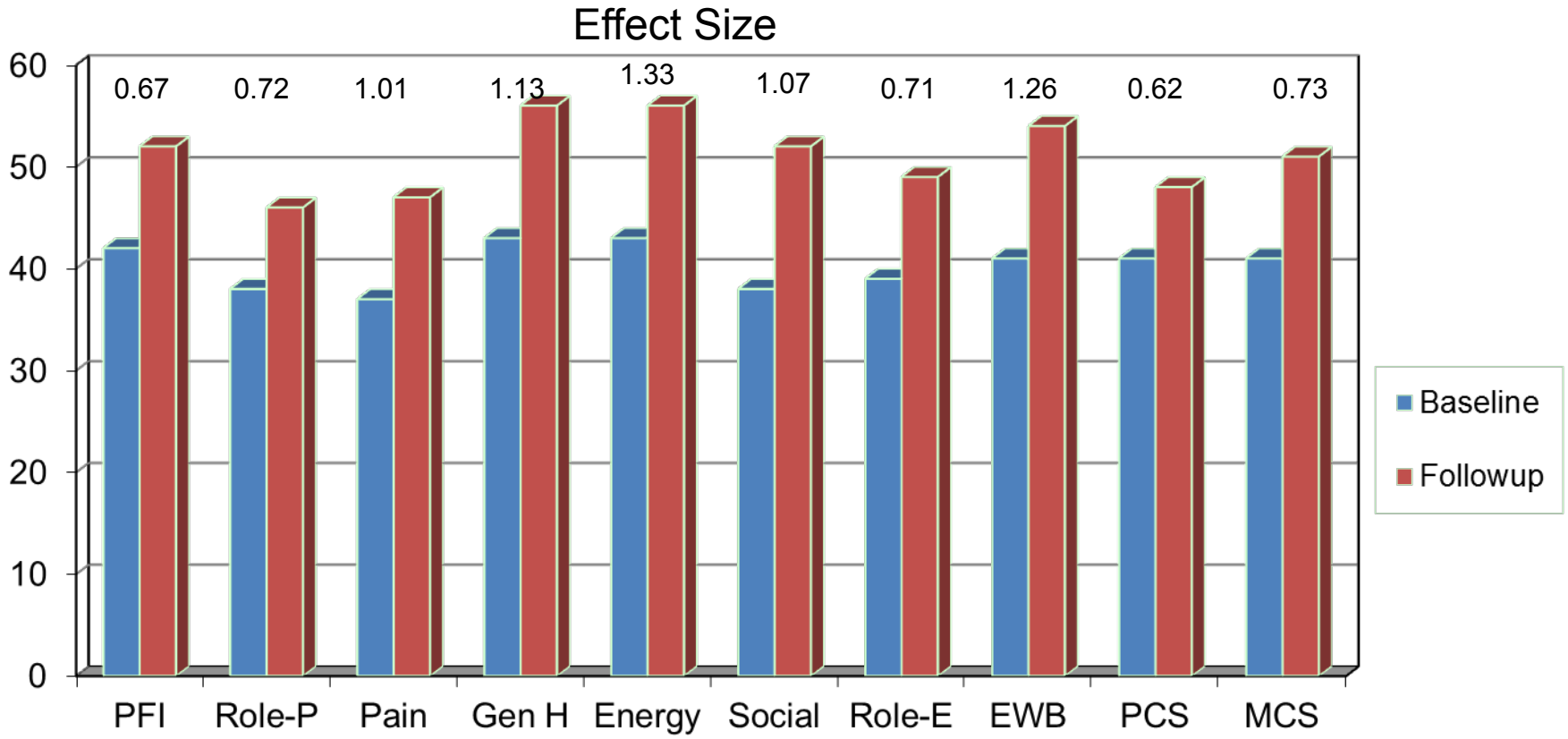
$$(\sqrt{2})\,(SD_{bl})\sqrt{(1 - r_{xx})}\,(1.96)$$

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

Amount of Change in Observed Score Needed for Significant Individual Change

Scale	RCI	Effect size	Cronbach's alpha
PF-10	8.4	0.67	0.94
RP-4	8.4	0.72	0.93
BP-2	10.4	1.01	0.87
GH-5	13.0	1.13	0.83
EN-4	12.8	1.33	0.77
SF-2	13.8	1.07	0.85
RE-3	9.7	0.71	0.94
EWB-5	13.4	1.26	0.79
PCS	7.1	0.62	0.94
MCS	9.7	0.73	0.93

Amount of Change Needed for Significant Individual Change



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7-31% of People in Sample Improve Significantly

	% Improving	% Declining	Difference
PF-10	13%	2%	+ 11%
RP-4	31%	2%	+ 29%
BP-2	22%	7%	+ 15%
GH-5	7%	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%

Thank you.

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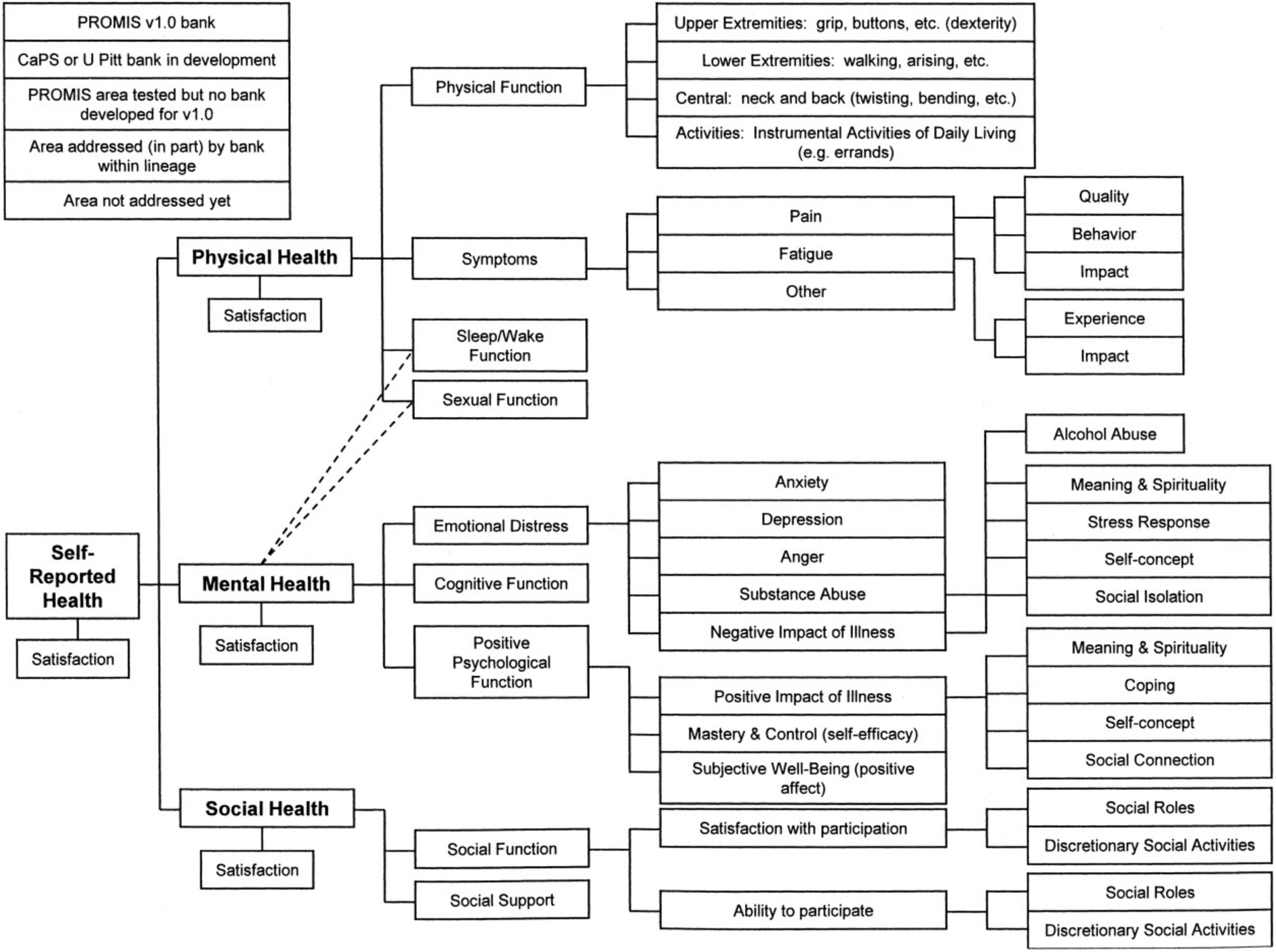
Powerpoint file at:

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


PROMIS v1.0 bank
CaPS or U Pitt bank in development
PROMIS area tested but no bank developed for v1.0
Area addressed (in part) by bank within lineage
Area not addressed yet
Self-Reported Health
Satisfaction
Physical Health
Satisfaction
Mental Health
Satisfaction
Social Health
Satisfaction
Physical Function
Upper Extremities: grip, buttons, etc. (dexterity)
Lower Extremities: walking, arising, etc.
Central: neck and back (twisting, bending, etc.)
Activities: Instrumental Activities of Daily Living (e.g. errands)
Symptoms
Pain
Fatigue
Other
Quality
Behavior
Impact
Experience
Impact
Sleep/Wake Function
Sexual Function
Emotional Distress
Cognitive Function
Positive Psychological Function
Anxiety
Depression
Anger
Substance Abuse
Negative Impact of Illness
Alcohol Abuse
Meaning & Spirituality
Stress Response
Self-concept
Social Isolation
Positive Impact of Illness
Mastery & Control (self-efficacy)
Subjective Well-Being (positive affect)
Meaning & Spirituality
Coping
Self-concept
Social Connection
Social Function
Social Support
Satisfaction with participation
Ability to participate
Social Roles
Discretionary Social Activities
Social Roles
Discretionary Social Activities