

# Measuring Health-Related Quality of Life

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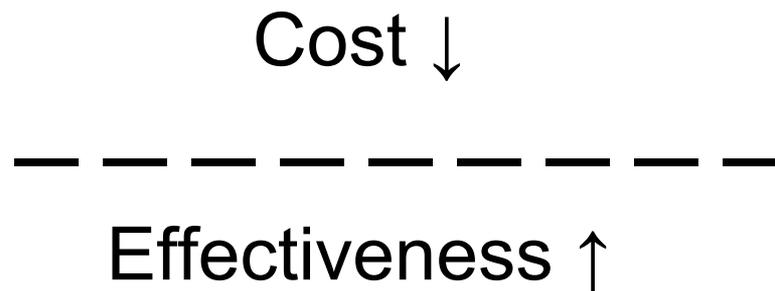
# U.S. Health Care Issues



- **Access to care**
  - ~ 50 million people without health insurance
- **Costs of care**
  - Expenditures ~ \$ 2.7 Trillion
- **Effectiveness (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



# Indicators of Health

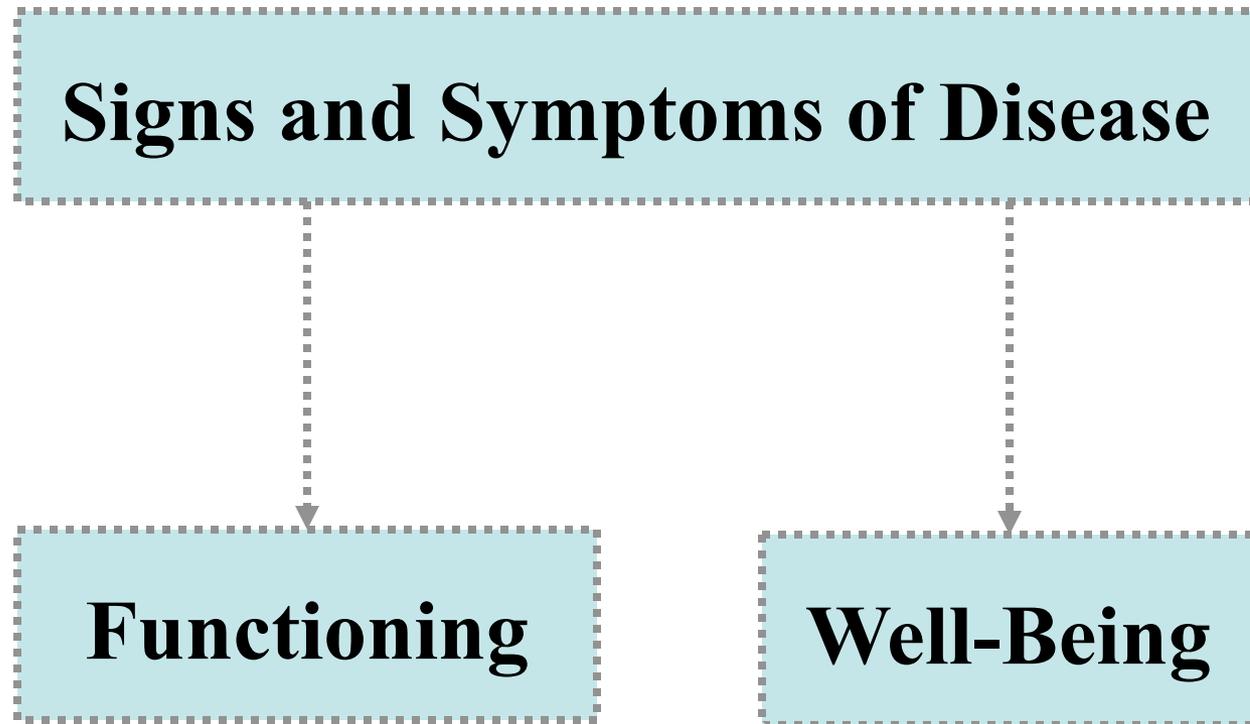
## Signs and Symptoms of Disease

Vital signs — e.g. bp

Hematocrit

SOB

# Indicators of Health



# Health-Related Quality of Life (HRQOL)

## How the person FEELS (well-being)

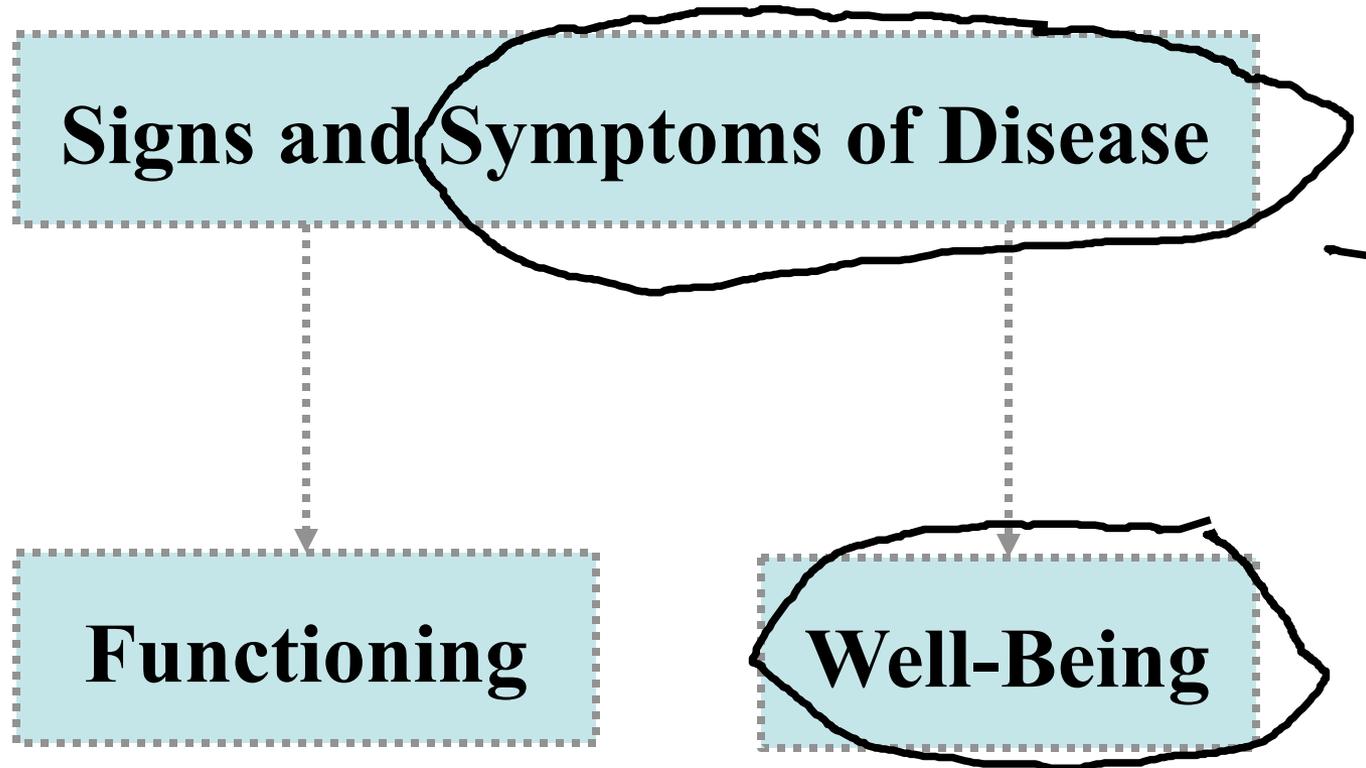
- Emotional well-being
- Pain
- Energy

## What the person can DO (functioning)

- 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?

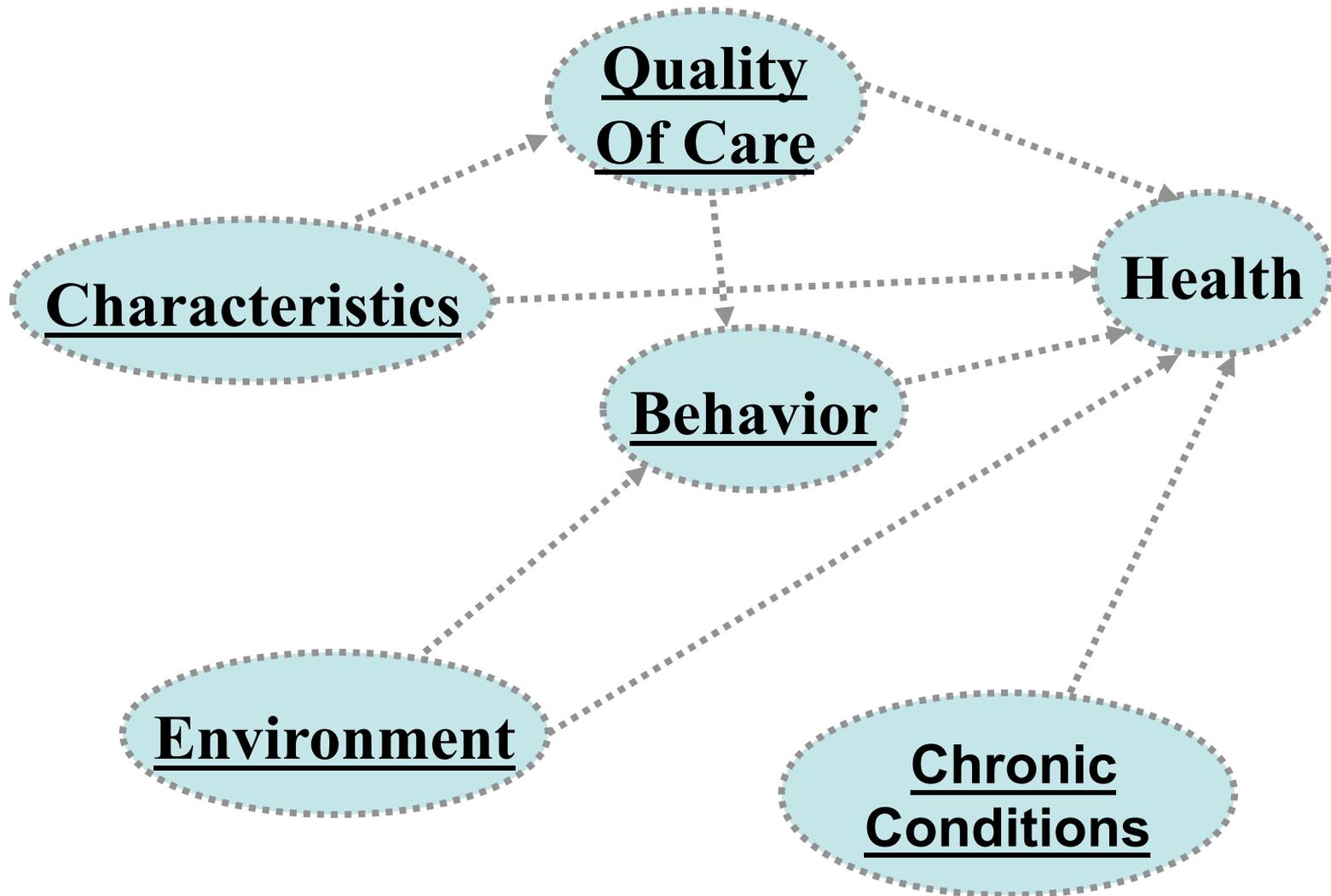
- ❖ Soreness in your muscles?
- ❖ Chest pain?
- ❖ Itchy skin?
- ❖ Shortness of breath?
- ❖ Faintness or dizziness?

# Health-Related Quality of Life (HRQOL)



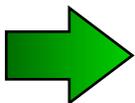
Quality of environment  
Type of housing  
Level of income  
Social Support

# 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)



# Types of HRQOL Measures

- Single item
  - In general, how would you rate your health?
- 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)

# HRQOL Scoring Options

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

# In general, how would you rate your health?

Hays, Spritzer, Thompson, & Cella (2015, JGIM)

62 = Excellent

54 = Very Good

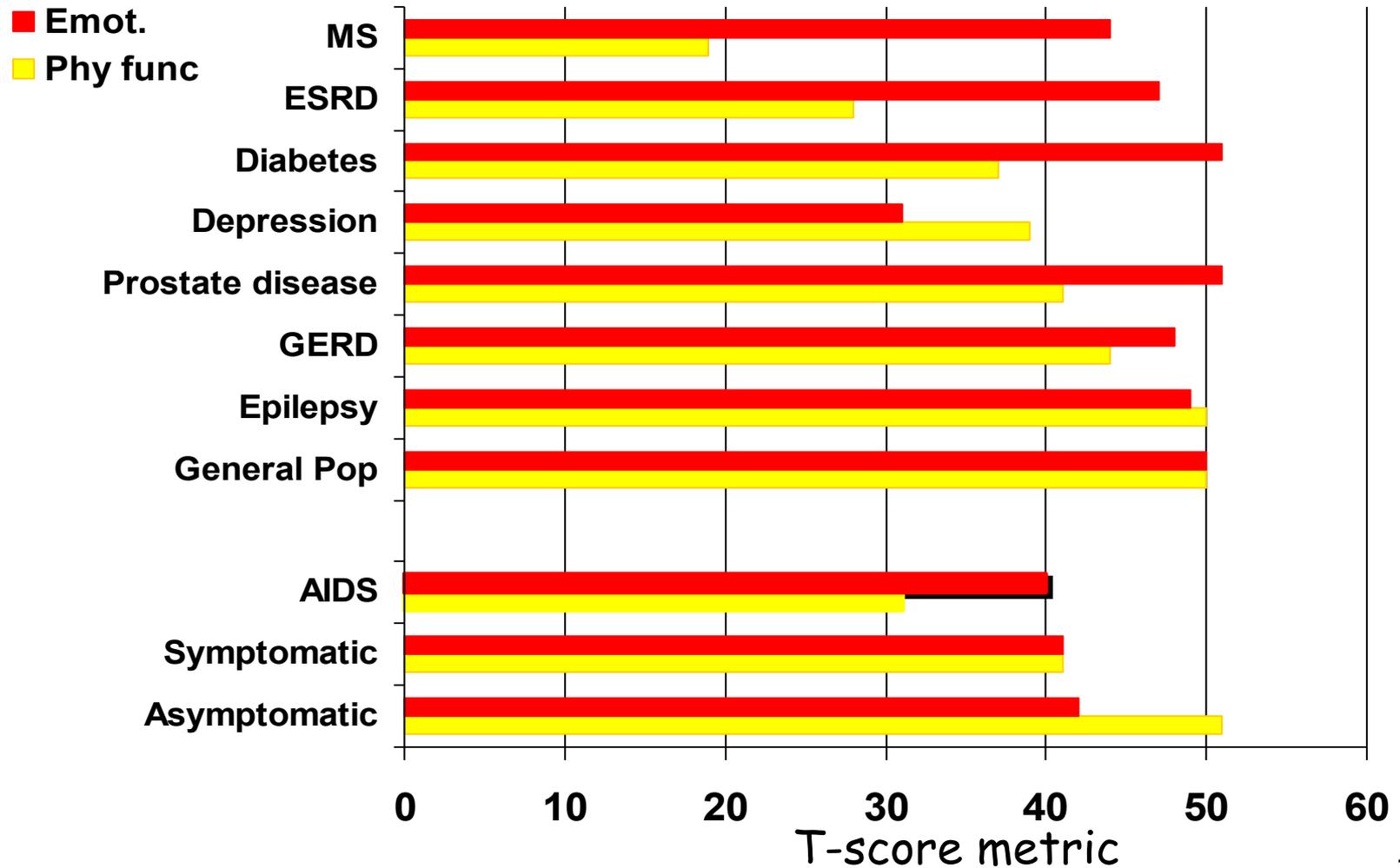
47 = Good

38 = Fair

29 = Poor

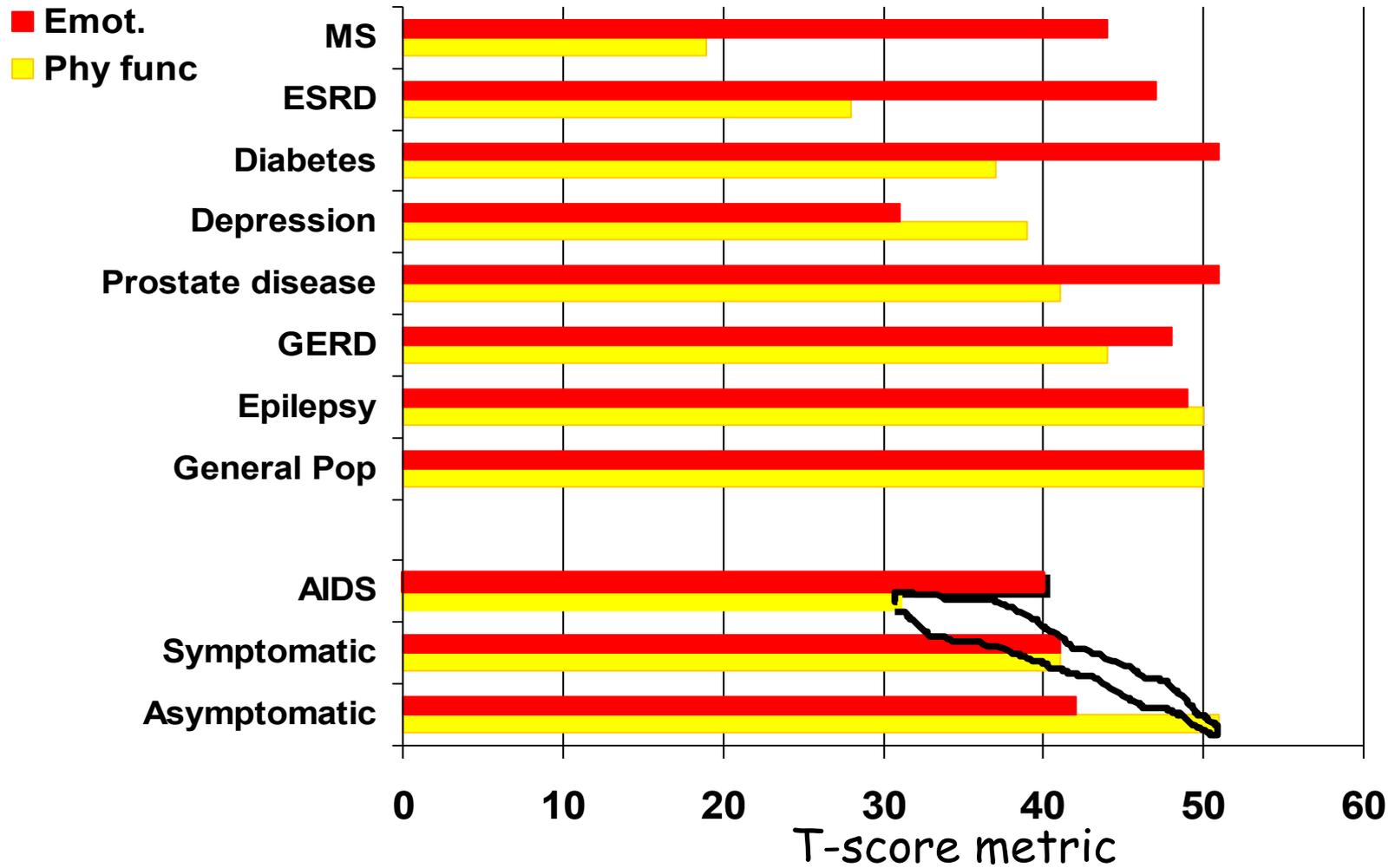
Reliability = 0.52 (compared to 0.81 for 4-item scale).

# HRQOL in HIV Compared to other Chronic Illnesses and General Population



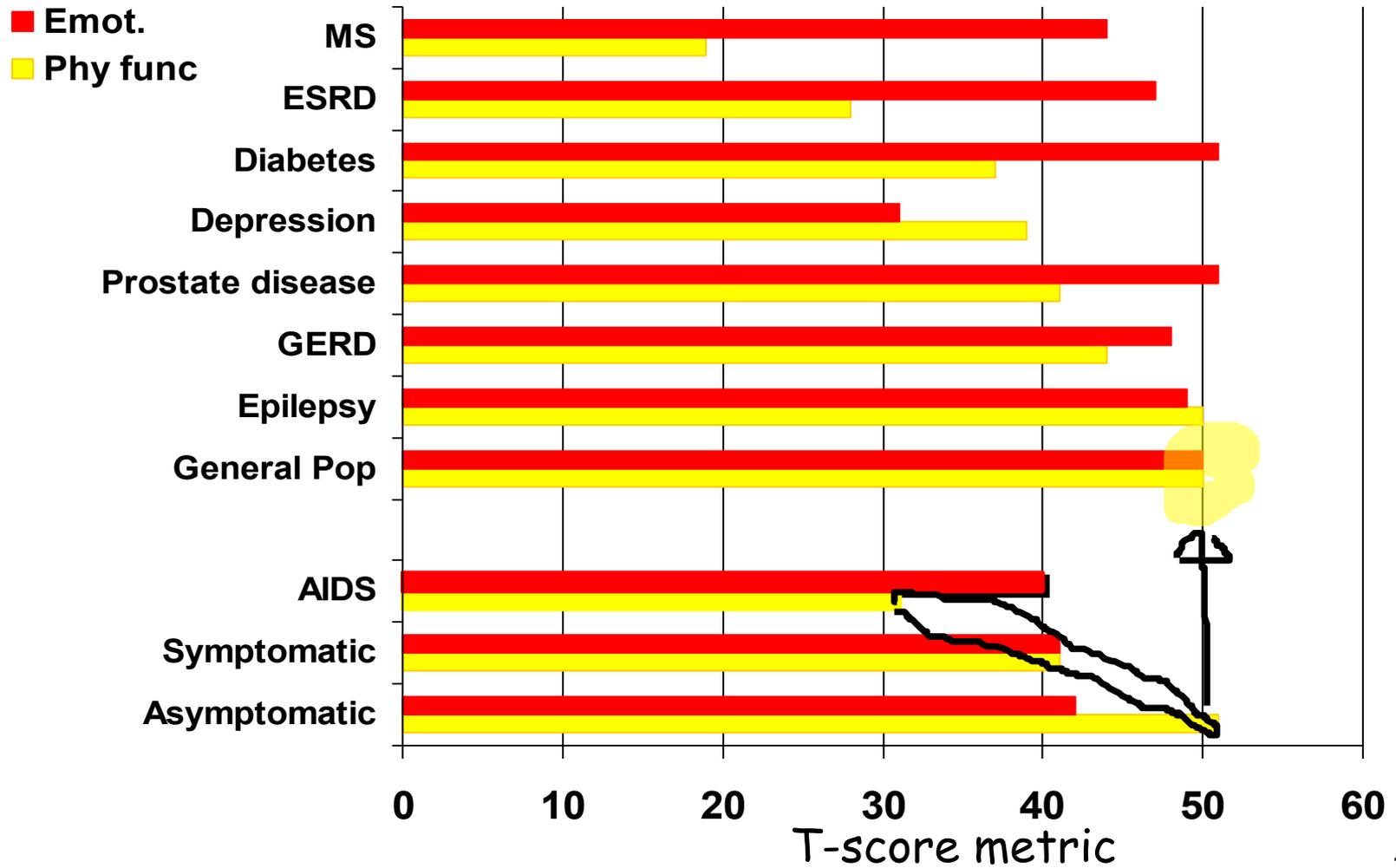
Hays et al. (2000), *American Journal of Medicine*

# HRQOL in HIV Compared to other Chronic Illnesses and General Population



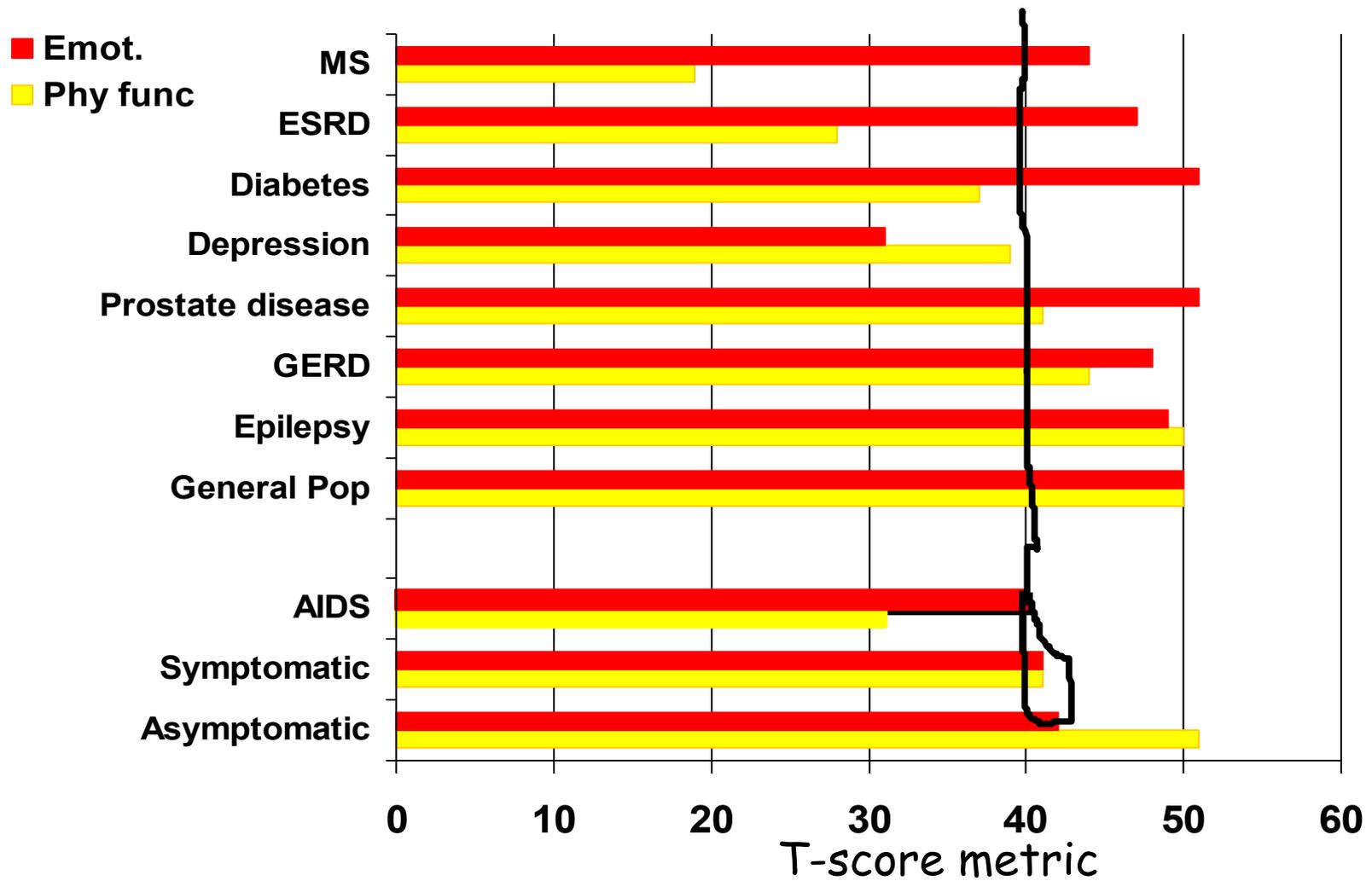
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# HRQOL in HIV Compared to other Chronic Illnesses and General Population



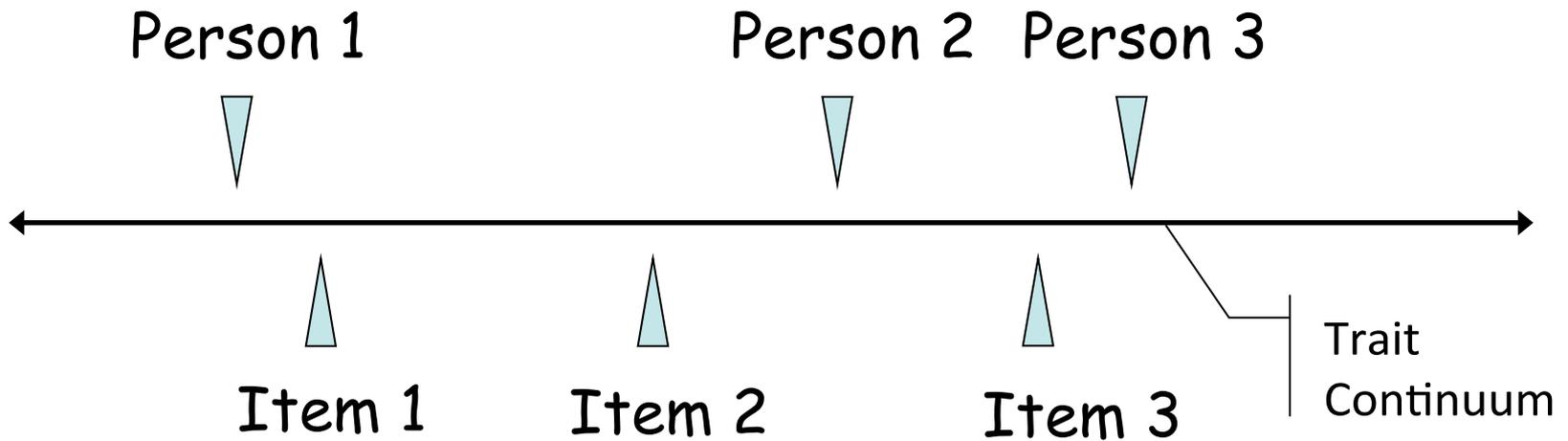
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# HRQOL in HIV Compared to other Chronic Illnesses and General Population

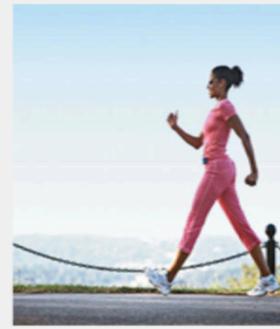


Hays et al. (2000), *American Journal of Medicine*

# Item Responses and Trait Levels



[www.nihpromis.org](http://www.nihpromis.org)



20

30

40

50

60

70

80

## 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?

# 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 [1<sup>st</sup> 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

[2<sup>nd</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 51.9

SE = 4.8 (rel. = 0.77)

# In the past 7 days ...

I felt angry [3<sup>rd</sup> 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

[4<sup>th</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 48.8

SE = 3.6 (rel. = 0.87)

# In the past 7 days ...

I felt annoyed [5<sup>th</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.1

SE = 3.2 (rel. = 0.90)

# In the past 7 days ...

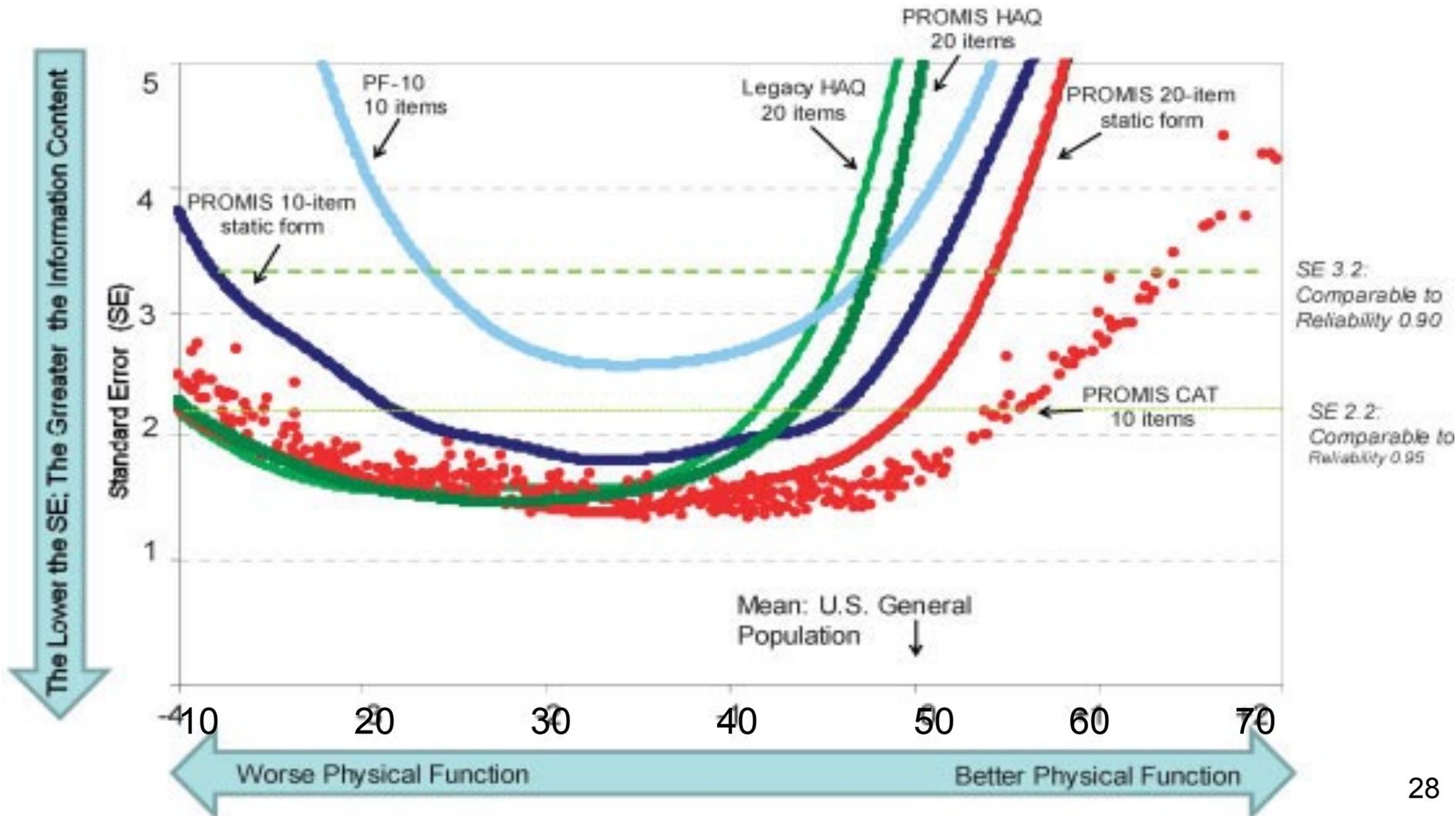
I made myself angry about something just by thinking about it. [6<sup>th</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.2

SE = 2.8 (rel = 0.92) (95% CI: 44.7-55.7)

# PROMIS Physical Functioning vs. "Legacy" Measures



**In general, how would you  
rate your health?**

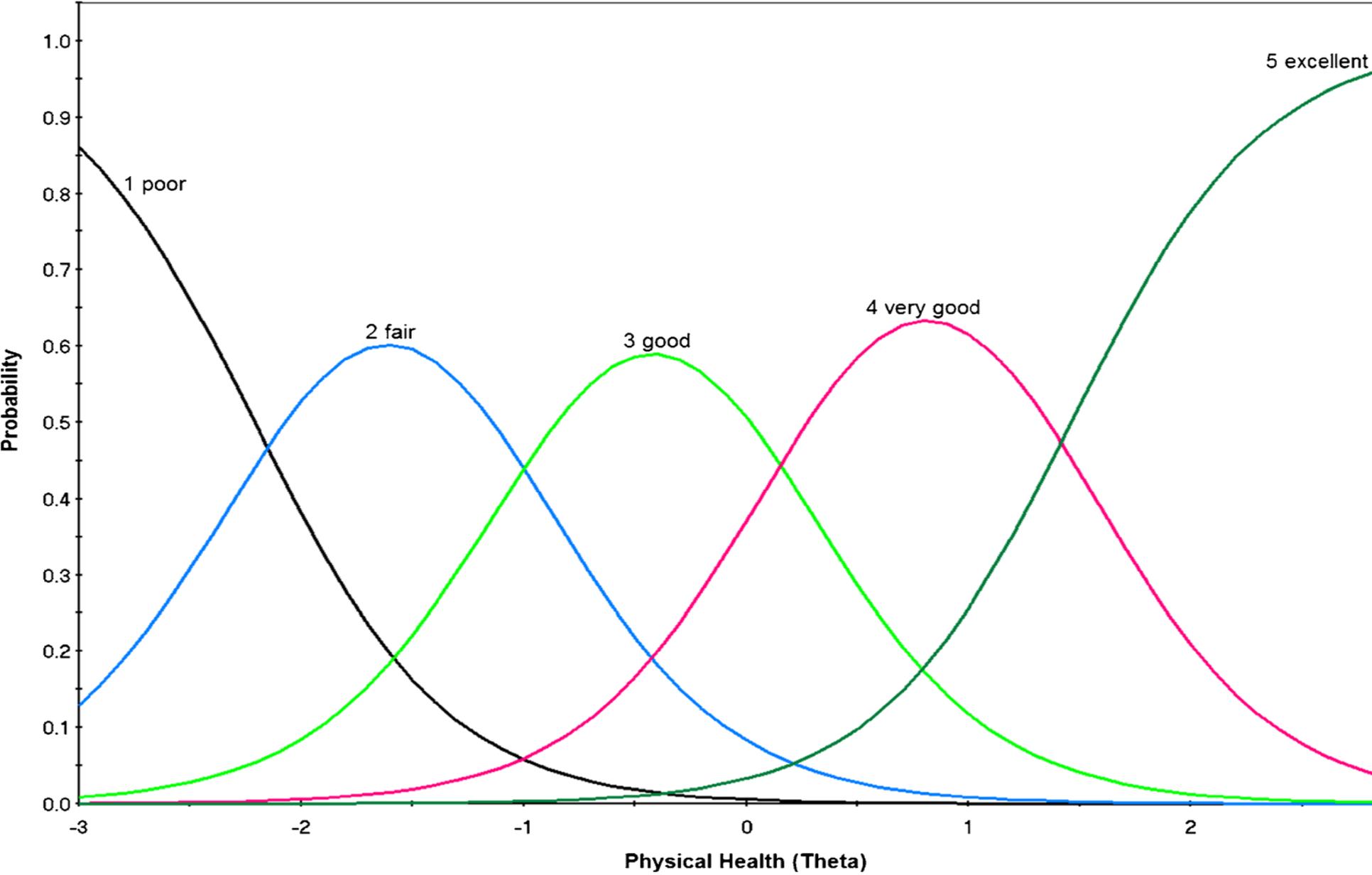
Excellent

Very Good

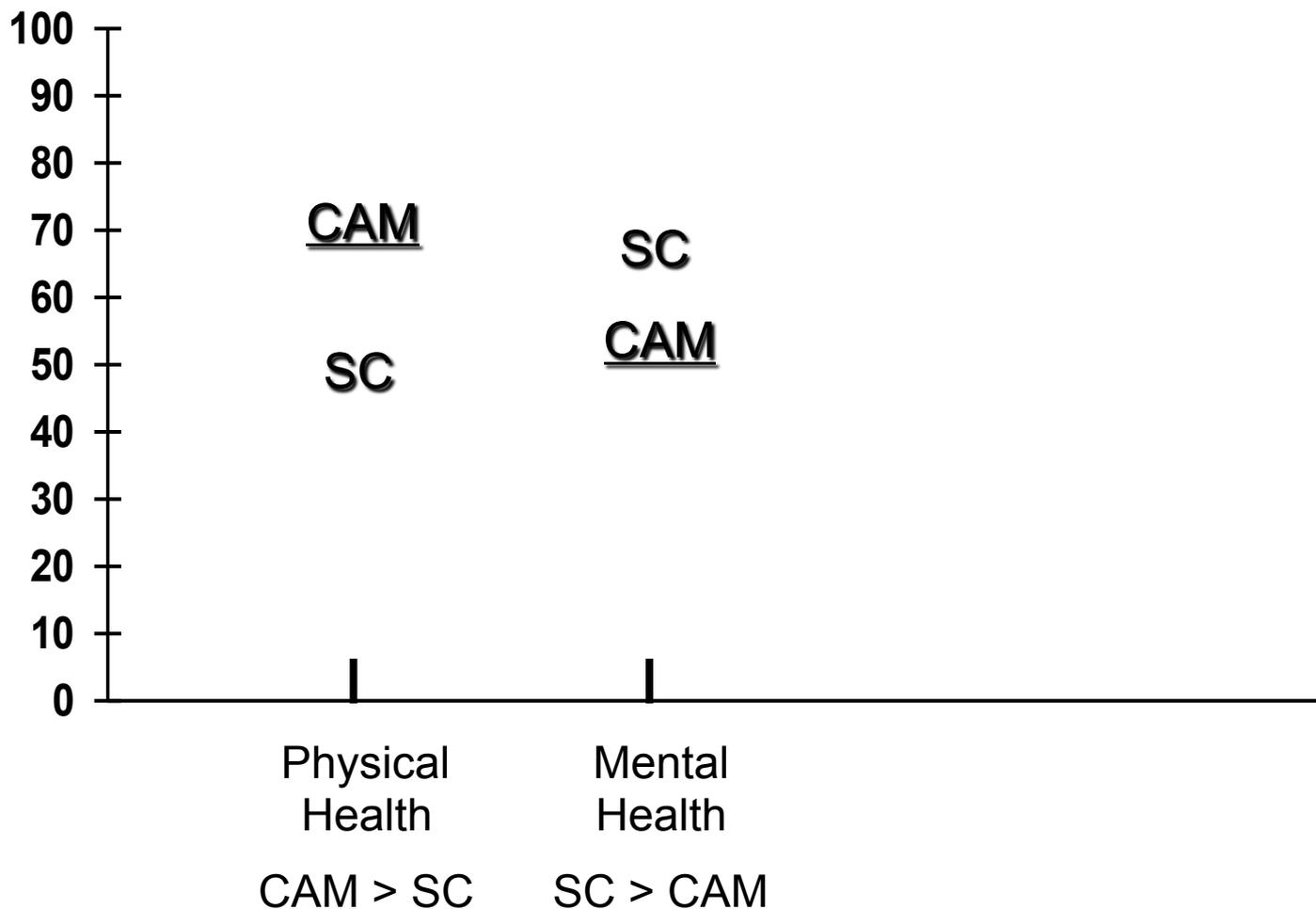
Good

Fair

Poor



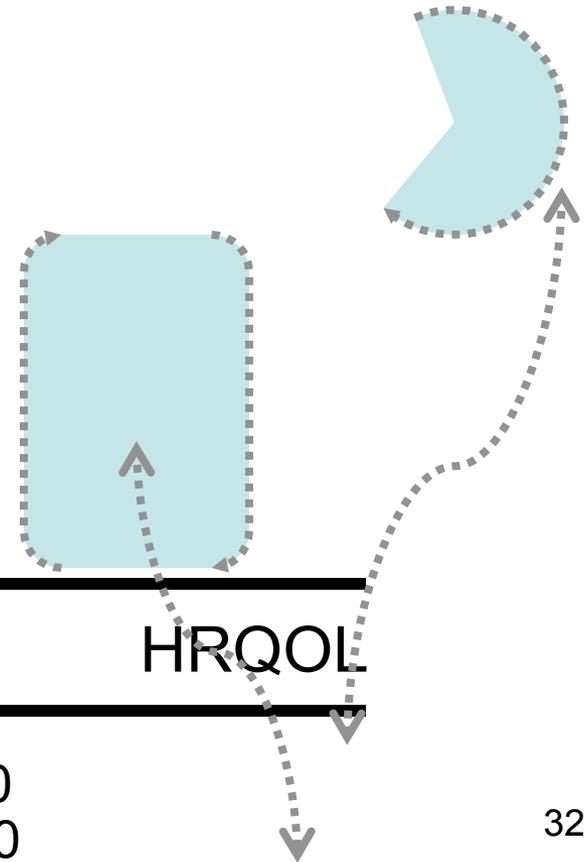
# Is CAM Better than Standard Care (SC)?



# Is Acupuncture Related to Worse HRQOL?

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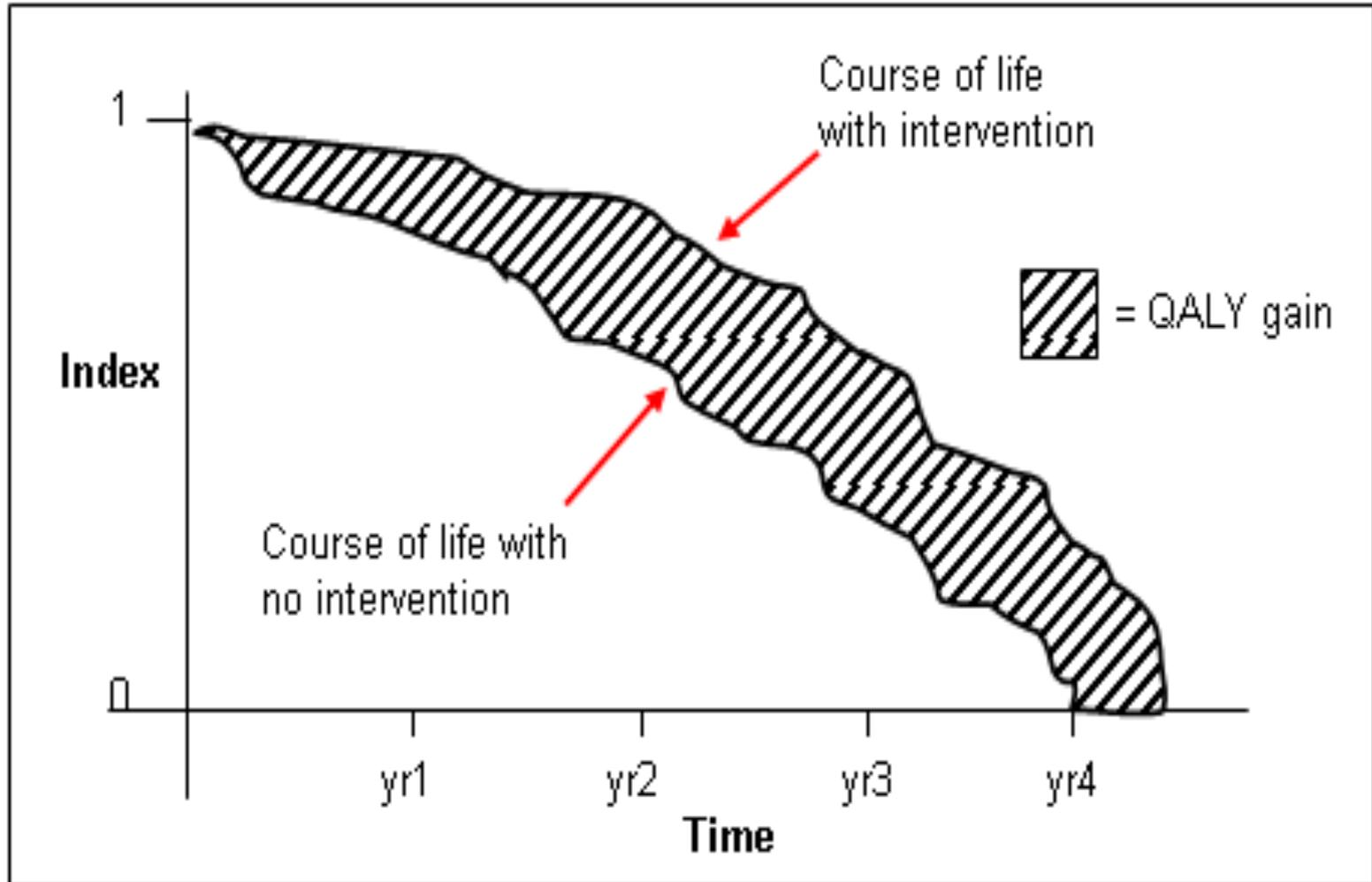
		1	No	dead
		2	No	dead
		3	No	50
		4	No	60
		5	No	70
		6	Yes	40
		7	Yes	50
		8	Yes	50
9	Yes	55	10	Yes



Group	n	HRQOL
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No Acupuncture	360
Yes Acupuncture	55

[http://www.ukmi.nhs.uk/Research/pharma\\_res.asp](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

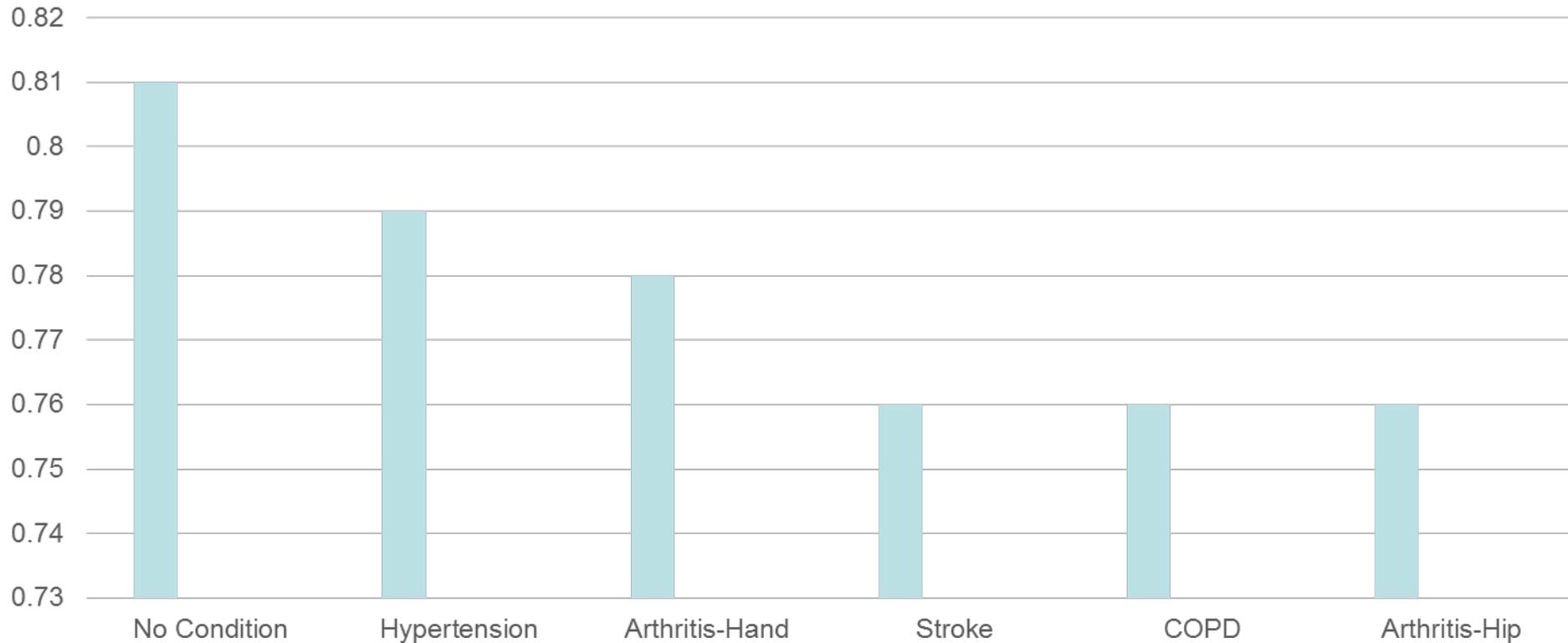
Levels of perceived problems are coded as follows:

- 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 one response for each dimension.*

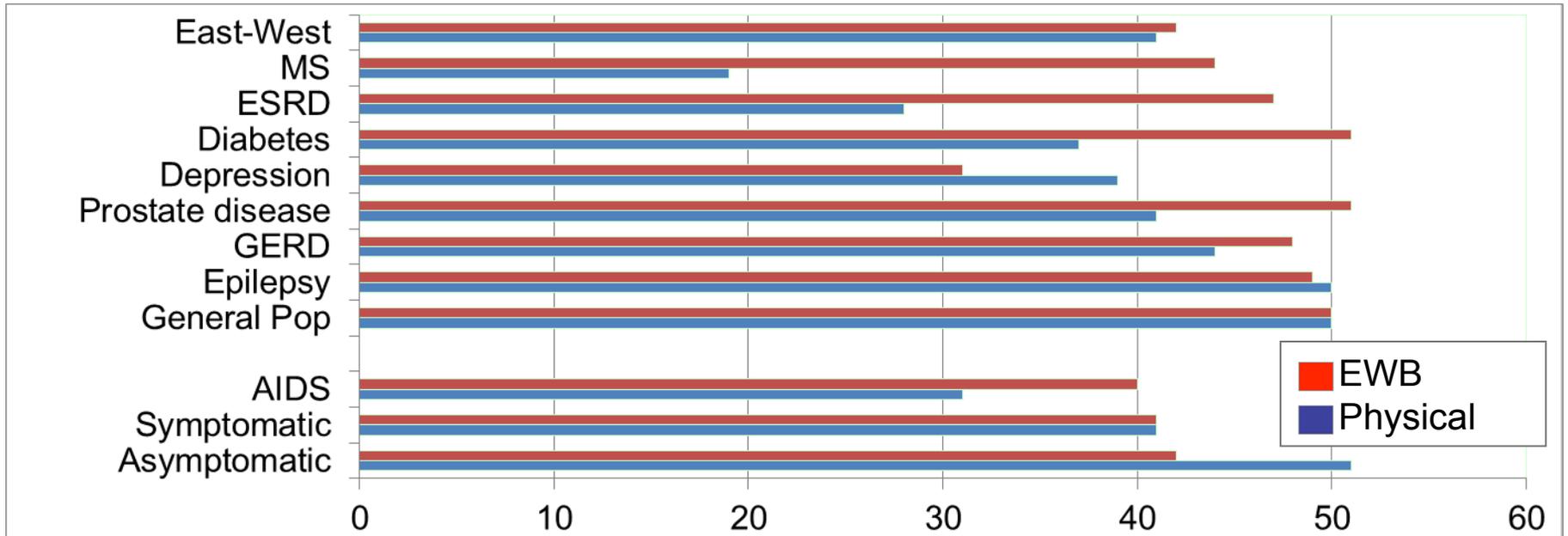
# HRQOL in SEER-Medicare Health Outcomes Study (n=126,366)

SF-6D (0-1 possible range) by Condition



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 sclerosis; 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

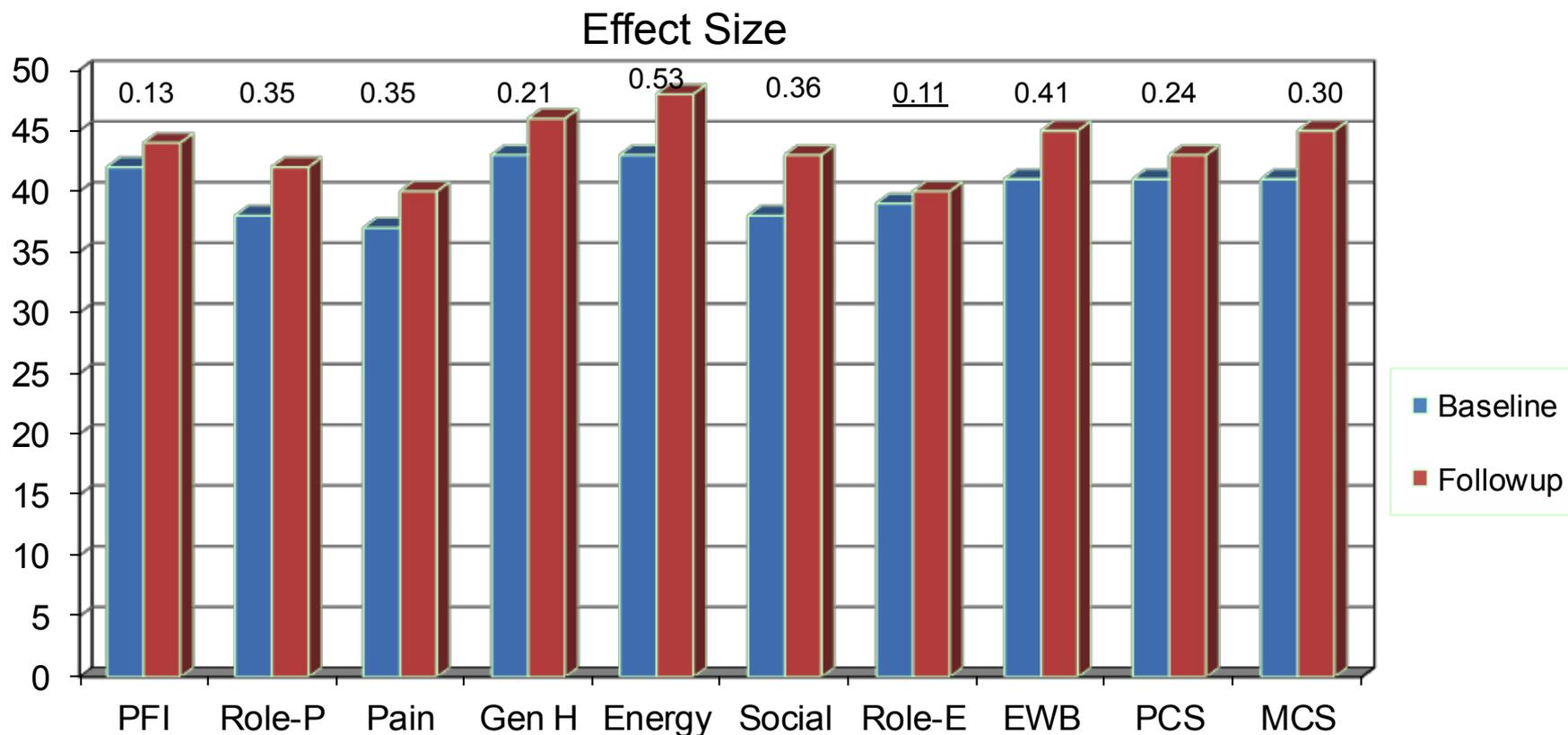
# Effect Size

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

*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

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

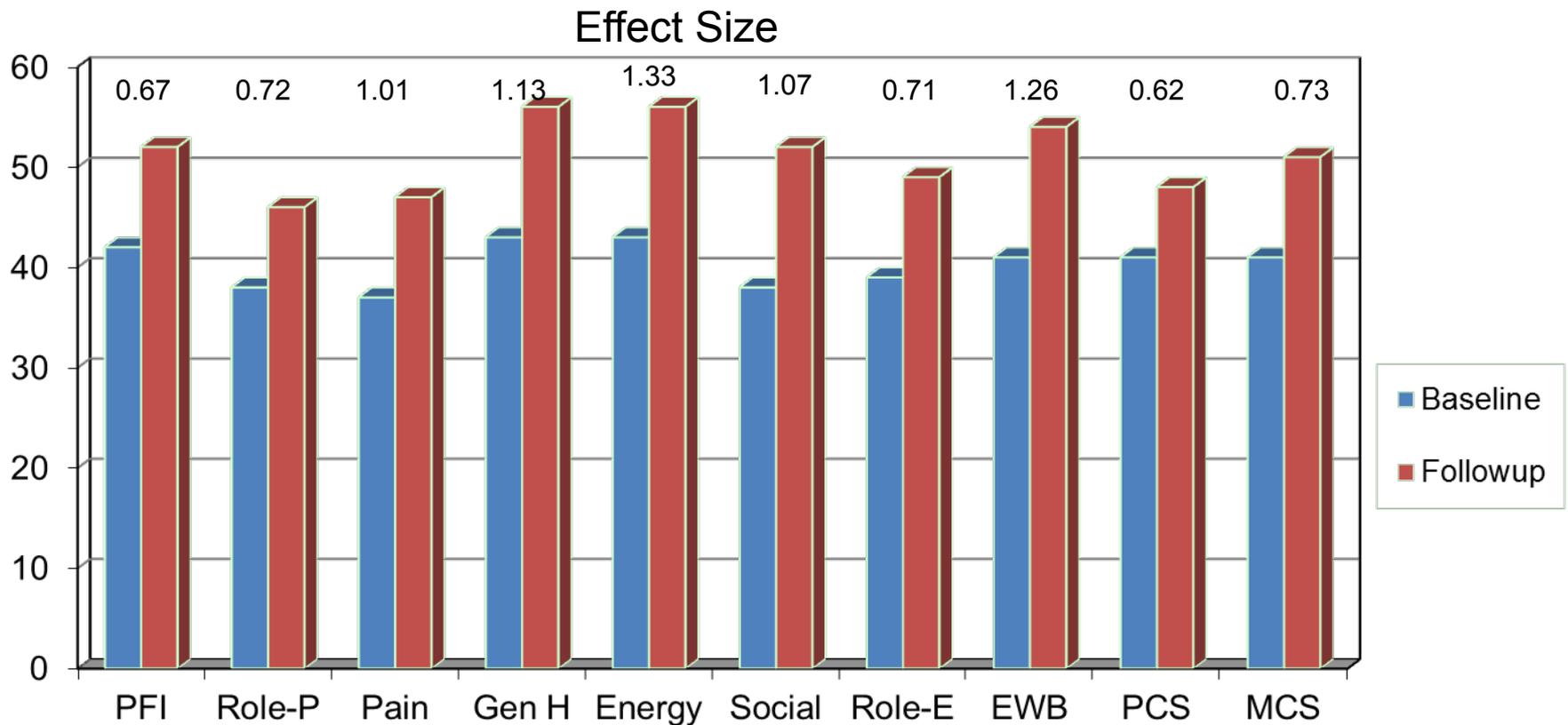

*Note:*  $SD_{bl}$  = standard deviation at baseline and  $r_{xx}$  = reliability

# 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*

\* Mosier's formula (not coefficient alpha).

# Amount of Change Needed for Significant Individual Change



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.

# 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%

# HRQOL vs SWB

## HRQOL

- International Society of Quality of Life Research (ISOQOL)
- Founded 1994
- Quality of Life Research
  - Springer

## SWB

- International Society of Quality of Life Studies (ISQOLS)
- Founded around 1994
- Applied Research in Quality of Life
  - Springer

**ISOQOL**

23<sup>rd</sup> Annual Conference

**19-22 October 2016**

**COPENHAGEN**

**DENMARK**



*Save the date:*

**14th ISQOLS Conference**

*August 25-27, 2016*

*Seoul, Korea*

# Experienced Well-Being

- Emotional states or mood over short periods of time.

“Did you experience anger during a lot of the day yesterday?”

- Yes
- No



# Eudemonic Well-Being

- Perceived purpose and fulfillment

“Overall, to what extent do you feel that the things you do in your life are worthwhile?”

- Not at all (0) - 10 (Completely)



# Evaluative Well-Being

- Overall appraisal of one's life

"How satisfied are you with your life in general?"

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied



# Thank you.



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Powerpoint file at:

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