

# Measuring Health-Related Quality of Life



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November 26, 2014, 8-9:50am (M218)

# SPORTS

## BRUINS OWN L.A.



er Mater Dei player and UCLA wide receiver Thomas Duarte, left, celebrates with fans and teammates during the game.

### Hundley, Bruins make yet another statement

**SADENA** - He has been historically good against USC, which, of course, is the shortest distance to the part of anything UCLA.

Brett Hundley is now 3-0 when paired opposite what is the personification of evil around here, the Trojans, who used to run L.A.'s college football scene.

But these days - thanks in large part to the Bruins' quarterback and, on Saturday, a defensive front that relented about as willingly and often as the tide does - the Trojans today are more on the run.

"I already said it - 'UCLA runs L.A.'," Hundley said, repeating the statement he made after last season's USC game, and why not say it again after a 38-20 triumph Saturday? "If you guys don't hear it last year, this year sort of made it stomp."

He remained perfect, but the way Hundley reached his third win was made even more impressive because



UCLA defensive lineman Ellis McCarthy sacks USC quarterback Cody Kessler in the second half.

#### MORE ON RIVALRY

**REID:** A rough night for Seven Win Steve. Sports 8  
**UCLA:** Bruins record six sacks of Kessler. Sports 9  
**USC:** Shaw can't save Trojans secondary. Sports 9  
**NOTES:** Duarte, Bruins win on balance. Sports 10

#### LOOKING AHEAD

Stanford at UCLA, Friday, 12:30 p.m., Ch. 7  
Notre Dame at USC, Saturday, 12:30 p.m., Ch. 11

### UCLA's triumph over USC

The Bruins' victory over the Trojans was a statement win for the Bruins.

UCLA's victory over USC was a statement win for the Bruins. The Bruins' defense was the key to the win, with six sacks of USC quarterback Cody Kessler.

The Bruins' offense was also strong, with Brett Hundley leading the way. Hundley's performance was a key factor in the Bruins' victory.

The Bruins' win over USC was a statement win for the Bruins. The Bruins' defense was the key to the win, with six sacks of USC quarterback Cody Kessler.

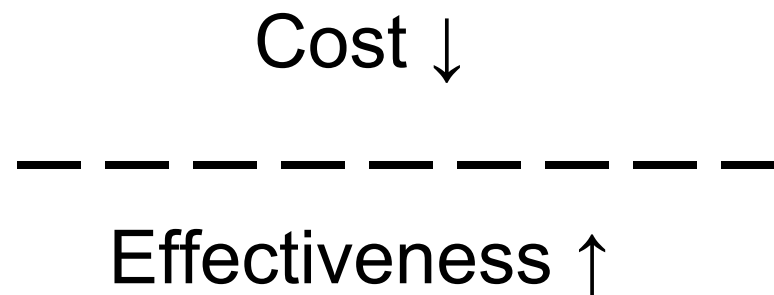
# U.S. Health Care Issues



- **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



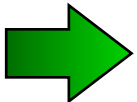
# Health Outcomes Measures

- Traditional clinical endpoints
  - Survival
  - Clinical/biological indicators
    - Vital signs (e.g., blood pressure)
    - Rheumatoid factor
    - Hematocrit

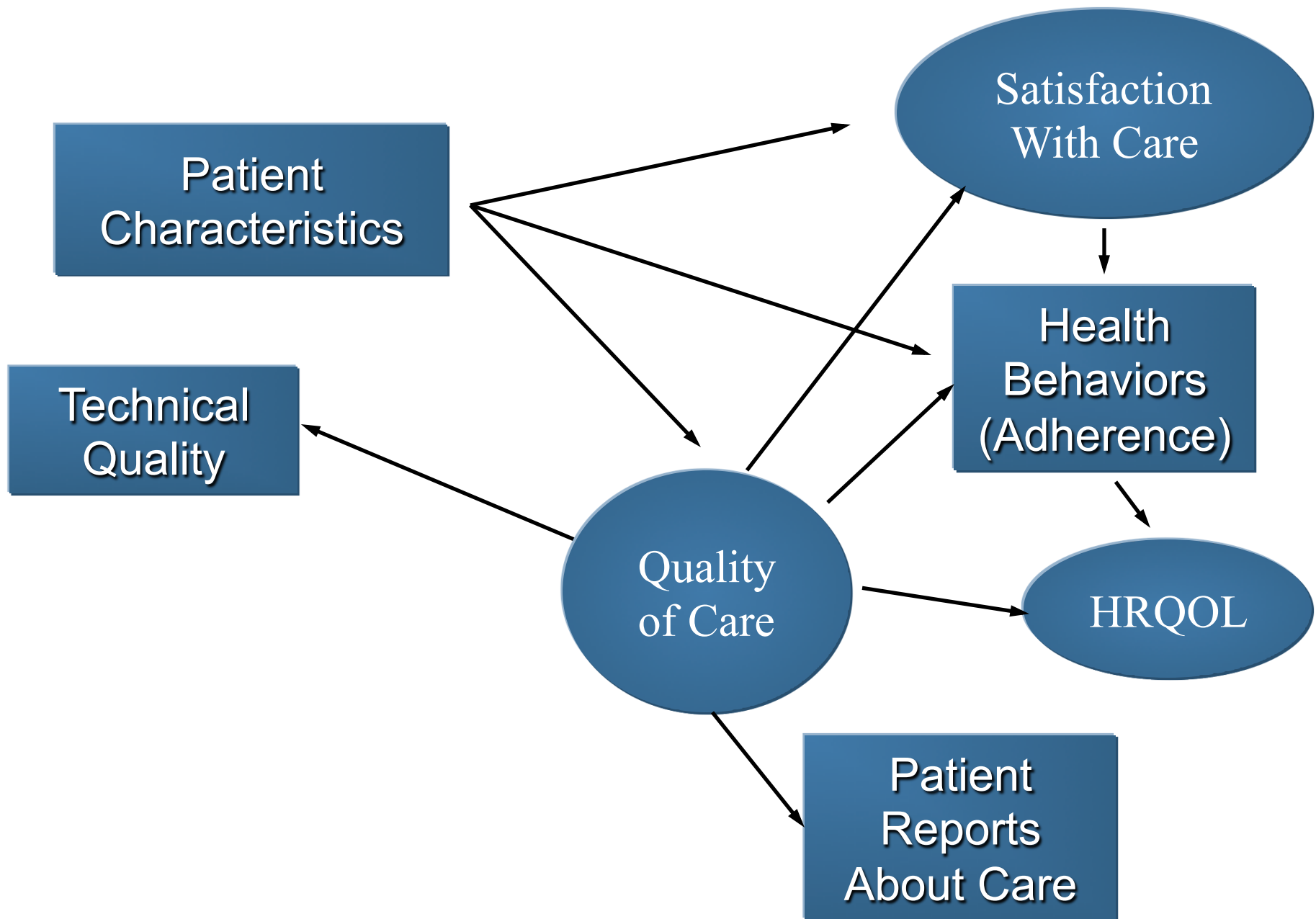
- • Patient-Reported Outcomes

# 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)







# 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





# HRQOL is Not

Quality of environment

Type of housing

Level of income

Social Support



# Targeted HRQOL Measures

- Designed to be relevant to particular group.
- Sensitive to small, clinically-important change.
- More familiar and actionable for clinicians.
- Enhance respondent cooperation.

# IBS-Targeted Item

Snapshots at [jasonlove.com](http://jasonlove.com)



"I'm afraid that your irritable bowel syndrome has progressed. You now have furious and vindictive bowel syndrome."

During the last 4 weeks, how often were you angry about your irritable bowel syndrome?

***None of the time***

***A little of the time***

***Some of the time***

***Most of the time***

***All of the time***

# In general, how would you rate your health?

Excellent

Very Good

Good

Fair

Poor

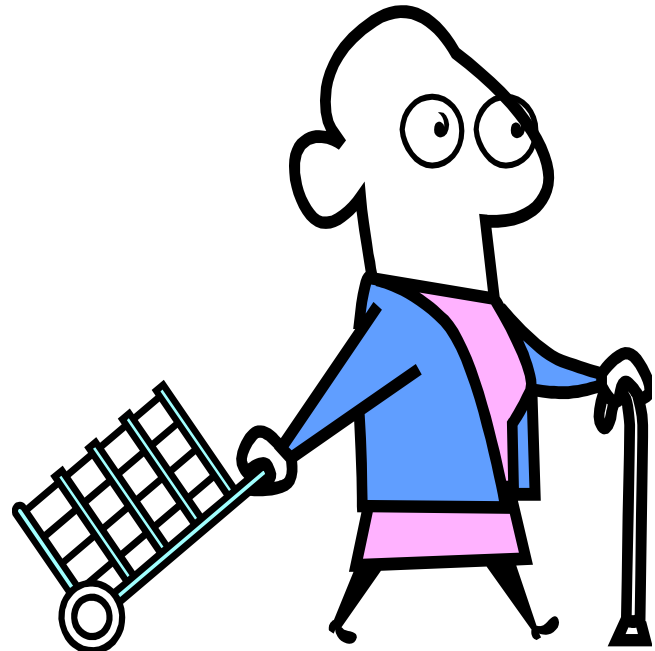
# Does your health now limit you in walking more than a mile?

(If so, how much?)

*Yes, limited a lot*

*Yes, limited a little*

*No, not limited at all*



# SF-36 *Generic Profile Measure*

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



# Scoring HRQOL Profile Scales

- Average or sum all items in the same scale.
- Transform average or sum to
  - 0 (worse) to 100 (best) possible range
  - z-score (mean = 0, SD = 1)
  - T-score (mean = 50, SD = 10)

# Linear Transformations

$$X = \frac{(\text{original score} - \text{minimum}) * 100}{(\text{maximum} - \text{minimum})}$$

$$Y = \text{target mean} + (\text{target SD} * Z_x)$$

$$Z_x = \frac{(X - \bar{X})}{SD_x}$$

# SF-36 PCS and MCS

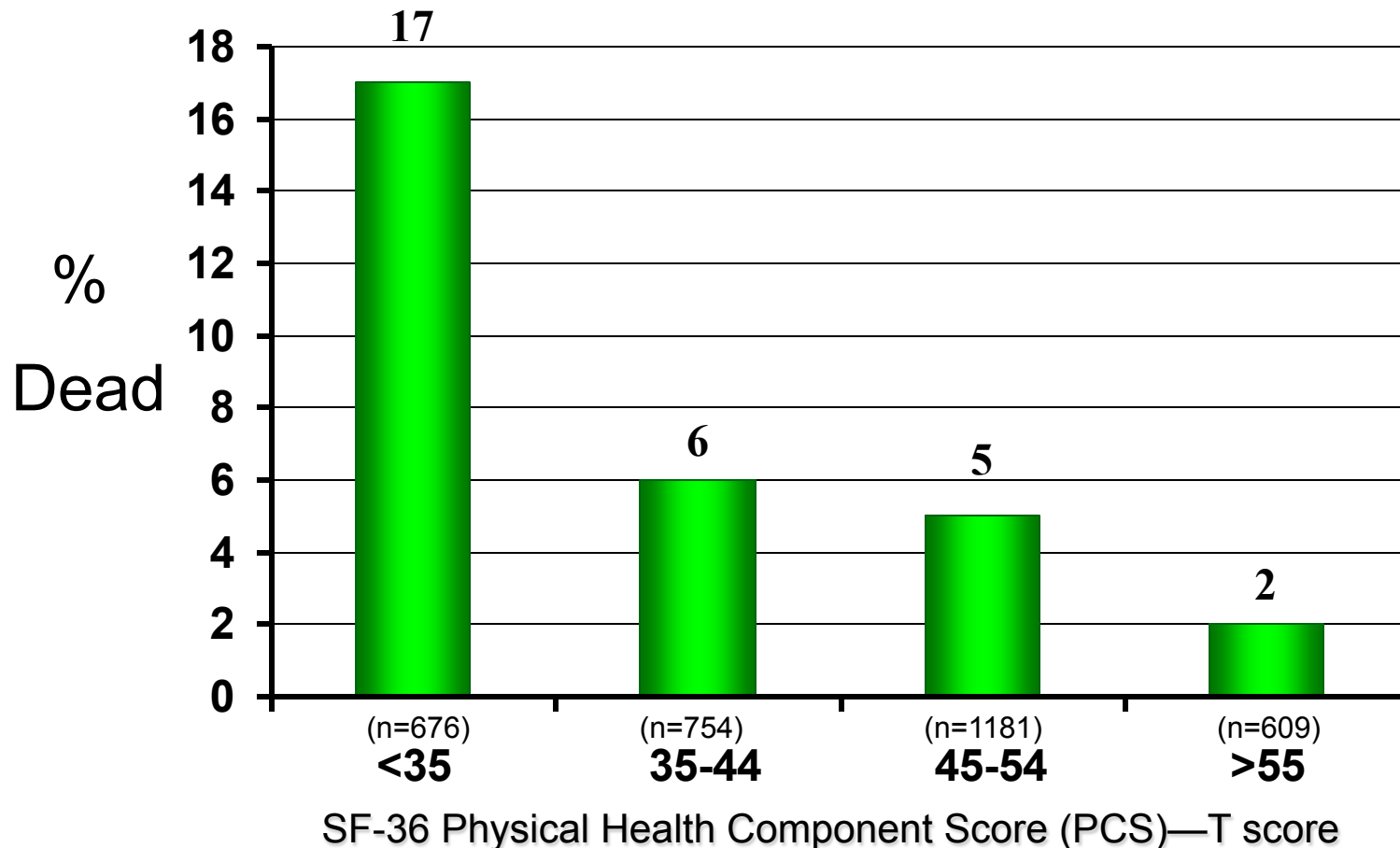
$$\begin{aligned} \text{PCS\_z} = & (\text{PF\_Z} * 0.42) + (\text{RP\_Z} * 0.35) + \\ & (\text{BP\_Z} * 0.32) + (\text{GH\_Z} * 0.25) + \\ & (\text{EF\_Z} * 0.03) + (\text{SF\_Z} * \underline{-0.01}) + \\ & (\text{RE\_Z} * \underline{-0.19}) + (\text{EW\_Z} * \underline{-0.22}) \end{aligned}$$

$$\begin{aligned} \text{MCS\_z} = & (\text{PF\_Z} * \underline{-0.23}) + (\text{RP\_Z} * \underline{-0.12}) + \\ & (\text{BP\_Z} * \underline{-0.10}) + (\text{GH\_Z} * \underline{-0.02}) + \\ & (\text{EF\_Z} * 0.24) + (\text{SF\_Z} * 0.27) + \\ & (\text{RE\_Z} * 0.43) + (\text{EW\_Z} * 0.49) \end{aligned}$$

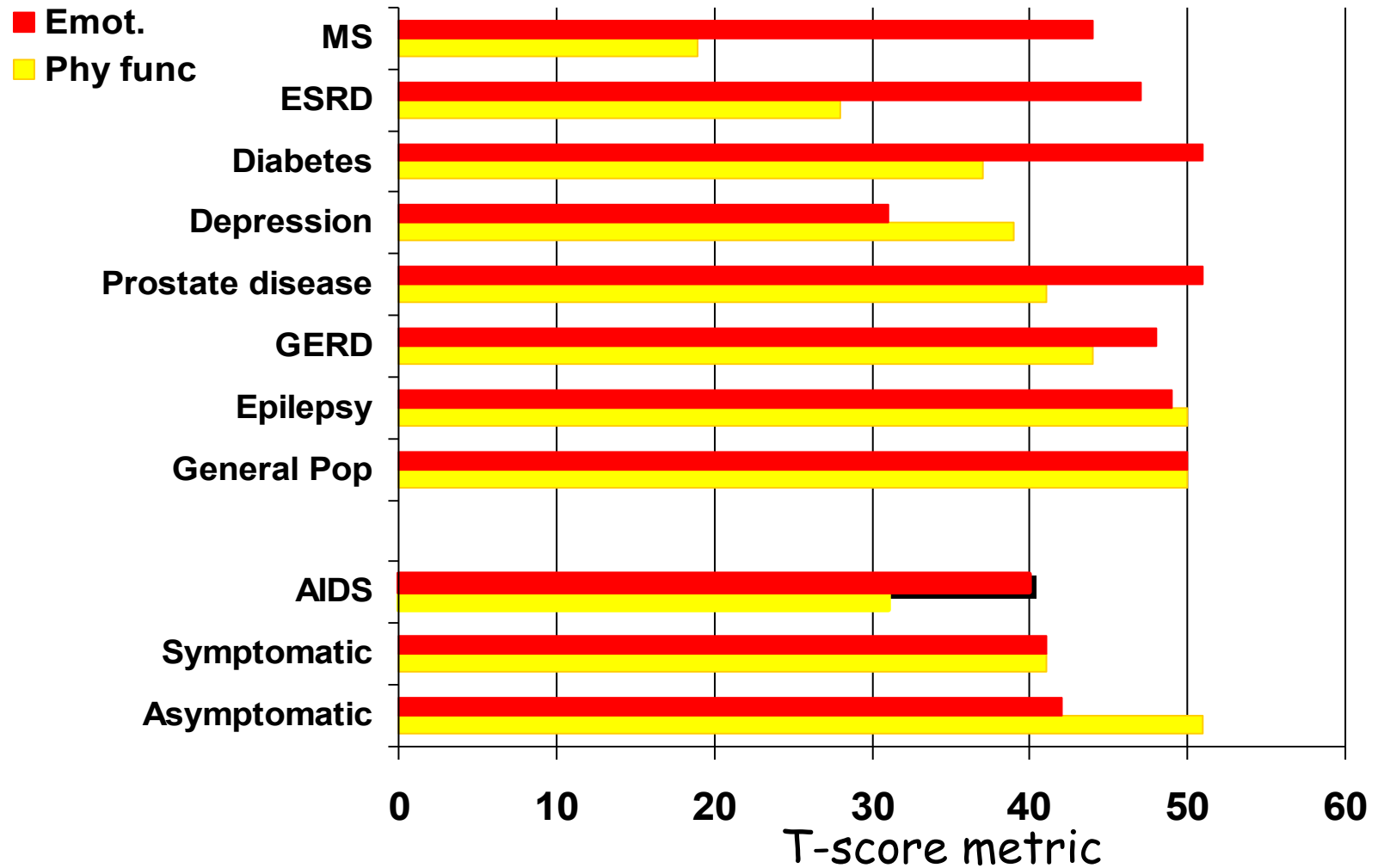
$$\text{PCS} = (\text{PCS\_z} * 10) + 50$$

$$\text{MCS} = (\text{MCS\_z} * 10) + 50$$

# HRQOL is Predictive of Mortality (5 years later)

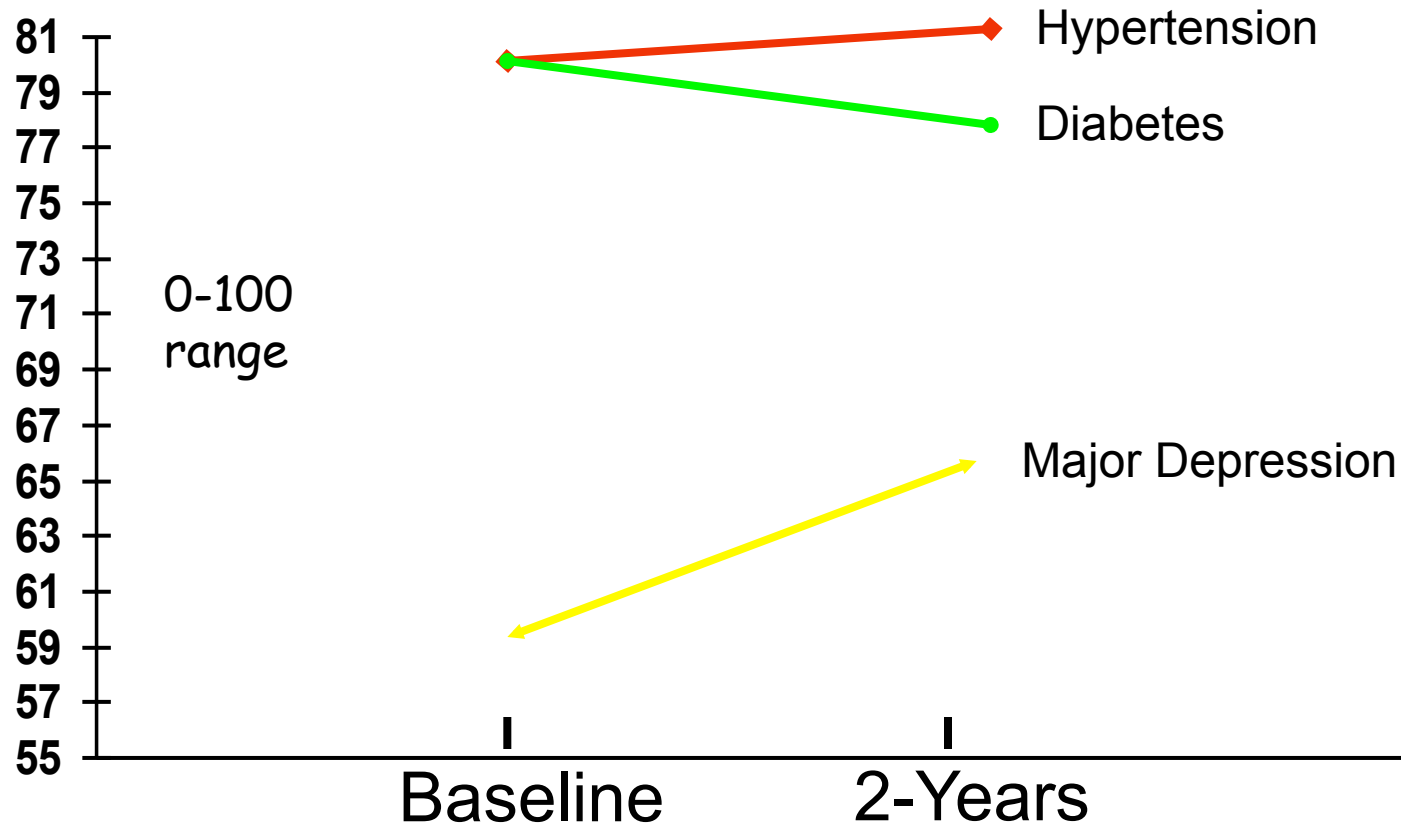


# HRQOL in HIV Compared to other Chronic Illnesses and General Population



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

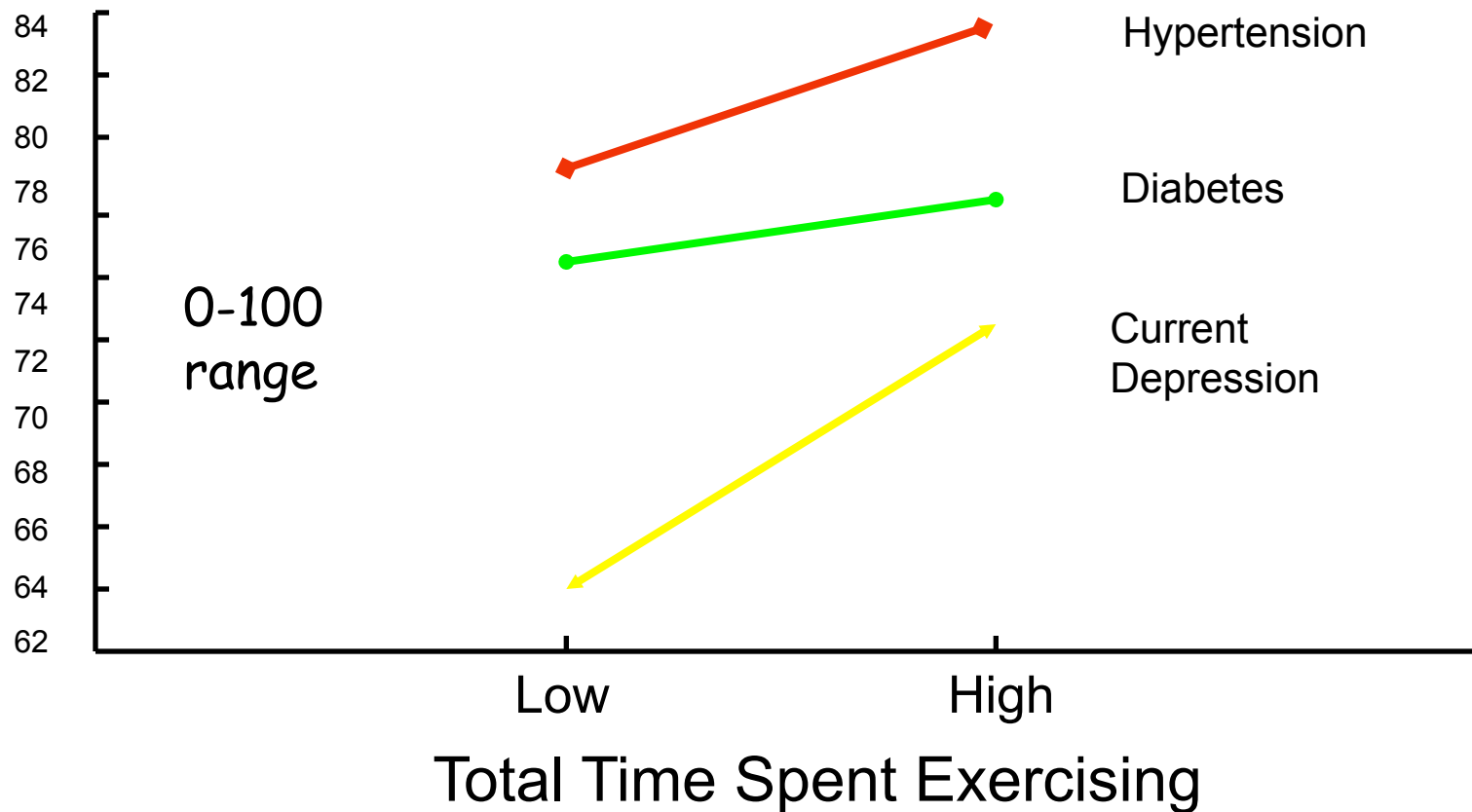
# Course of Emotional Well-being Over 2-years for Patients in the MOS General Medical Sector



Hays, R.D., Wells, K.B., Sherbourne, C.D., Rogers, W., & Spritzer, K. (1995).  
Functioning and well-being outcomes of patients with depression compared  
to chronic medical illnesses. *Archives of General Psychiatry*, 52, 11-19.

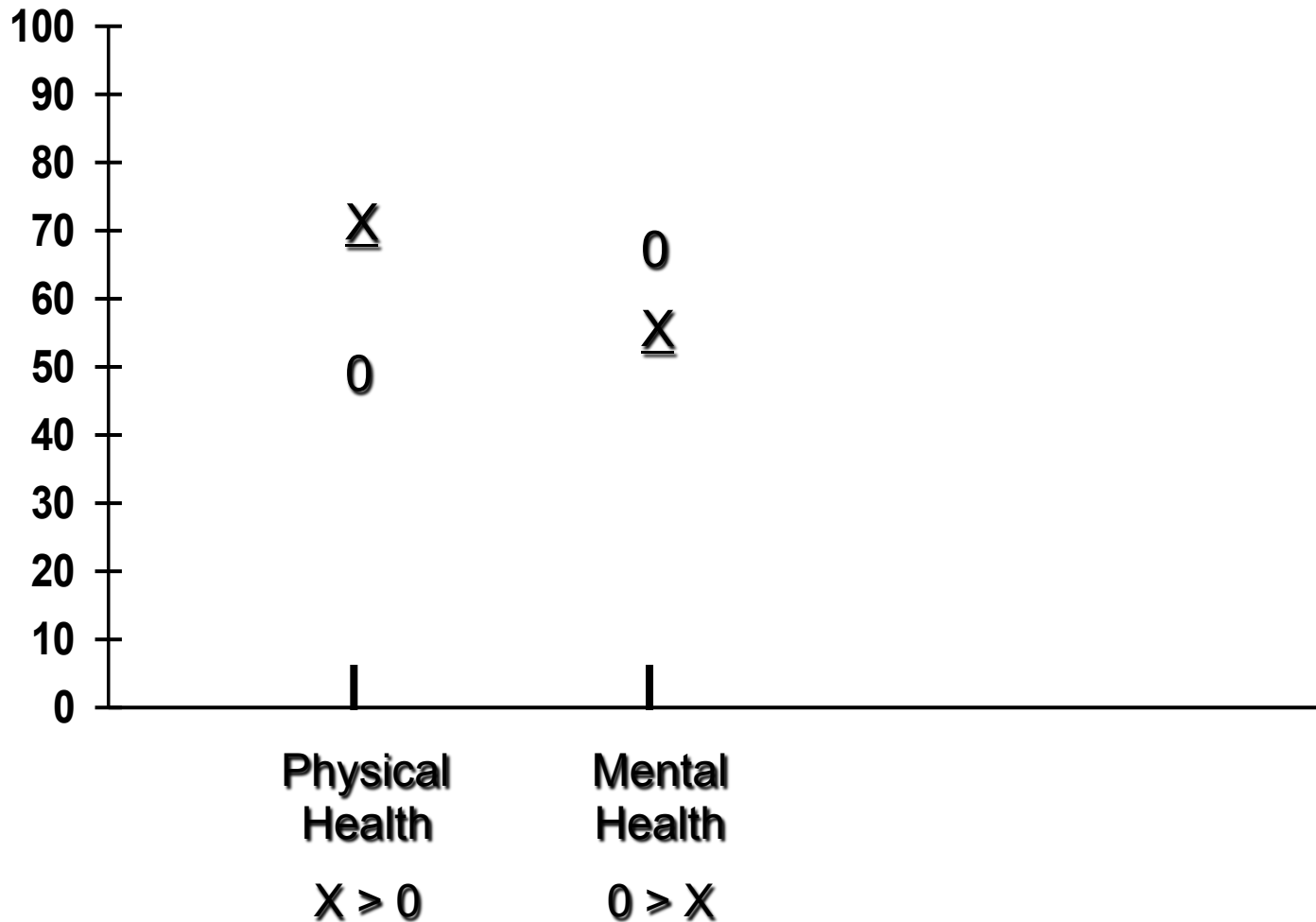


# Physical Functioning in Relation to Time Spent Exercising 2-years Before



Stewart, A.L., Hays, R.D., Wells, K.B., Rogers, W.H., Spritzer, K.L., & Greenfield, S. (1994). Long-term functioning and well-being outcomes associated with physical activity and exercise in patients with chronic conditions in the Medical Outcomes Study. *Journal of Clinical Epidemiology*, 47, 719-730. <sup>21</sup>

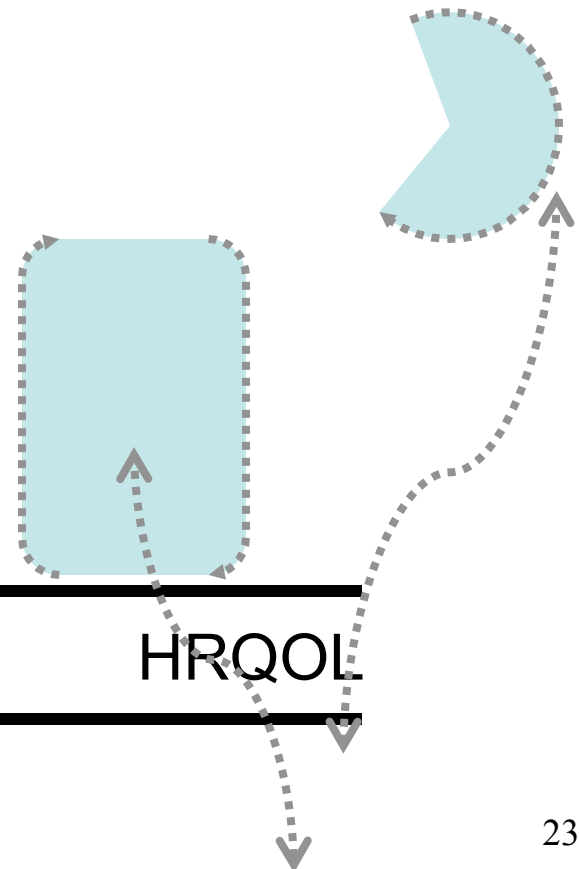
# Is New Treatment (X) Better Than Standard Care (O)?



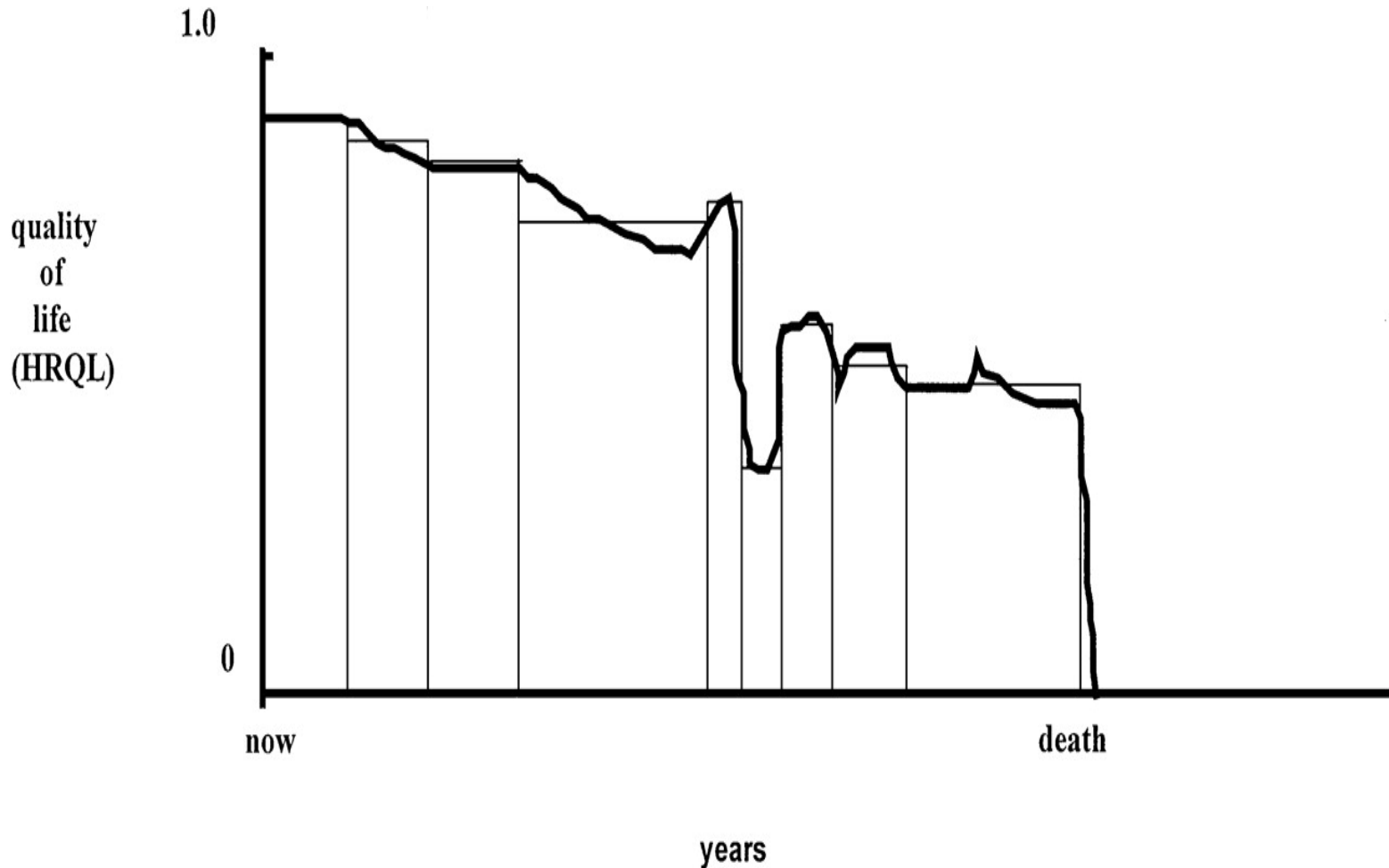
# Is Medicine Related to Worse HRQOL?

Person	Medication Use	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

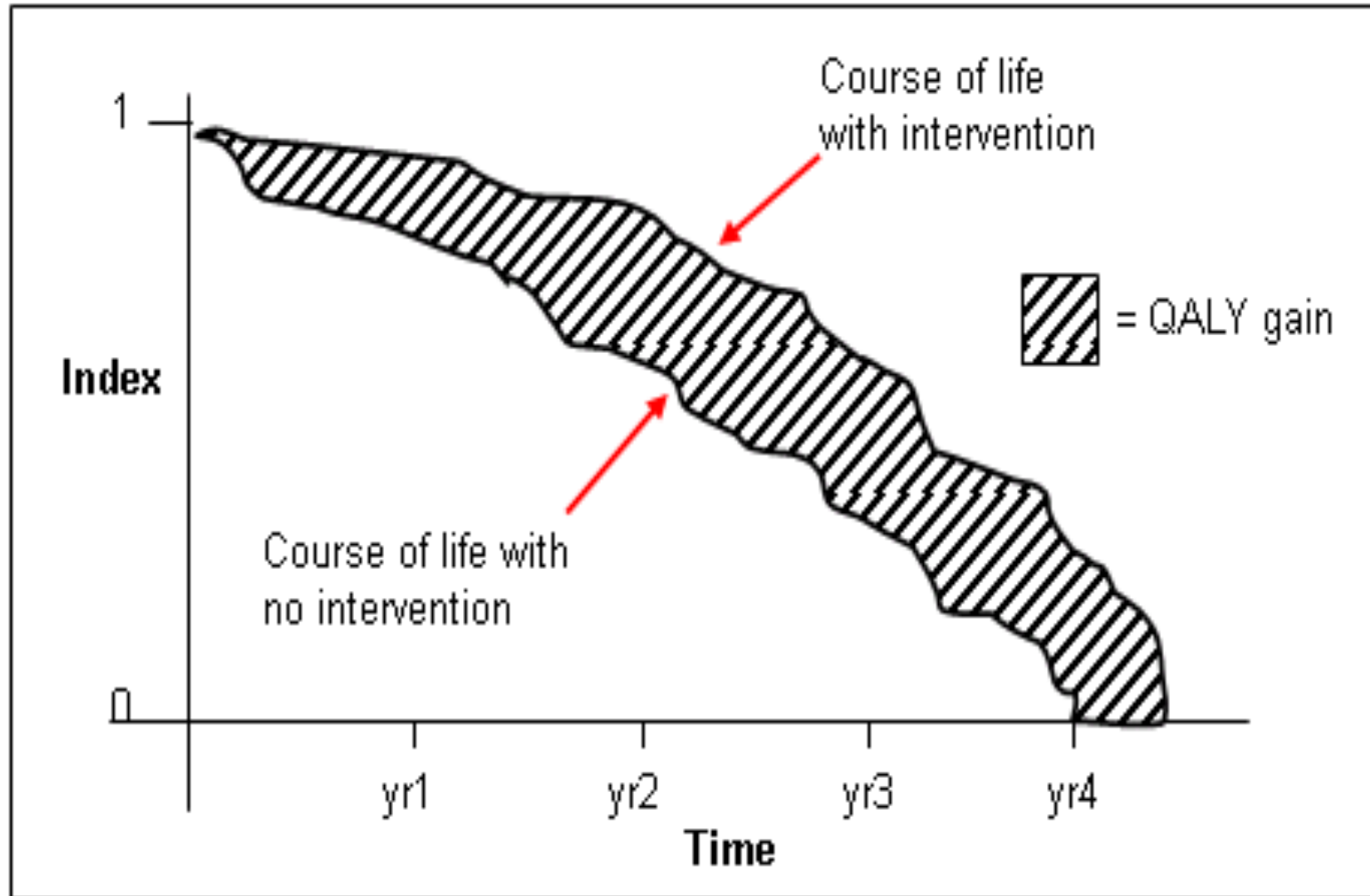
Group	n	HRQOL
No Medicine	3	75
Yes Medicine	5	50



# Quality of Life for Individual Over Time



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



# SF-6D

- 6-dimensional classification  
(collapsed role scales, dropped general health)
- 18,000 possible states
- 249 states rated by sample of 836  
from UK general population

Brazier et al. (1998, 2002)

<http://www.shef.ac.uk/scharr/sections/heds/mvh/sf-6d>

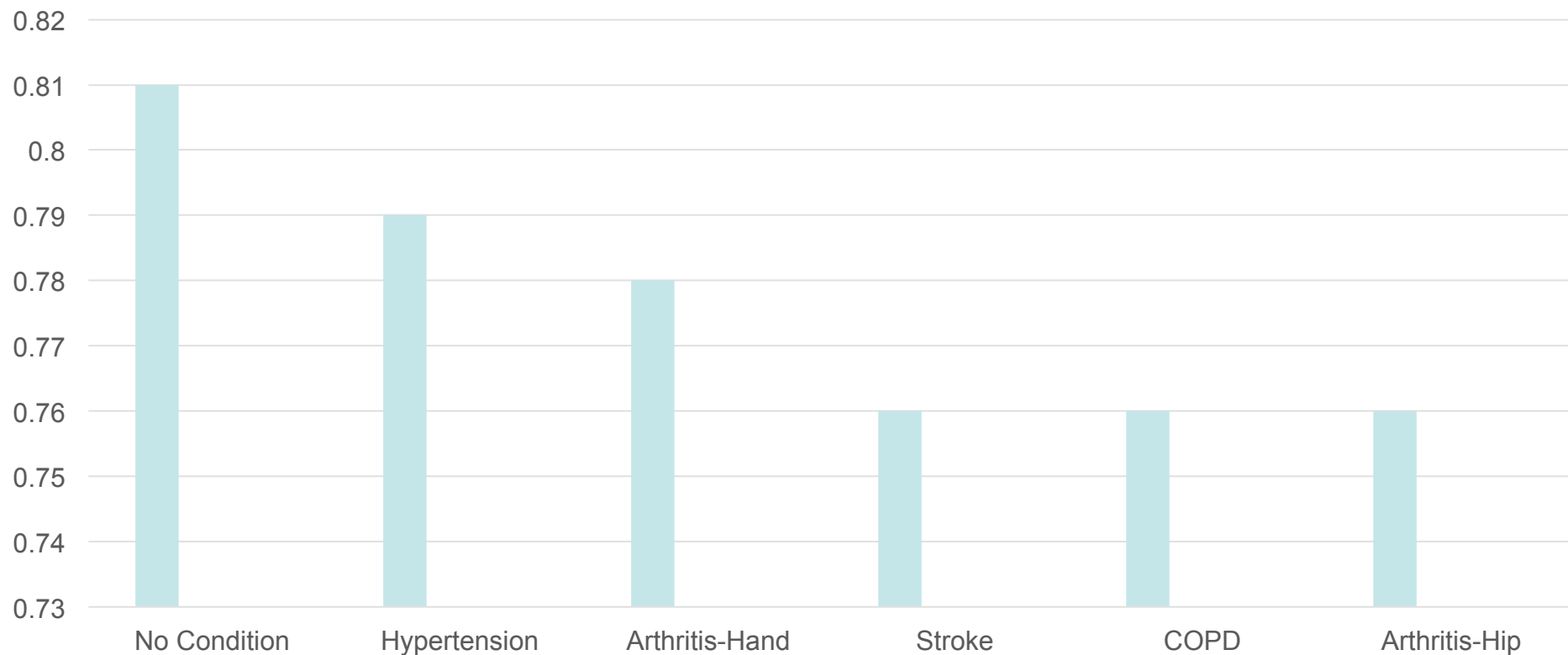


## Health state 424421 (0.59)

- Your health limits you a lot in moderate activities (such as moving a table, pushing a vacuum cleaner, bowling or playing golf)
- You are limited in the kind of work or other activities as a result of your physical health
- Your health limits your social activities (like visiting friends, relatives etc.) most of the time.
- You have pain that interferes with your normal work (both outside the home and housework) moderately
- You feel tense or downhearted and low a little of the time.
- You have a lot of energy all of the time

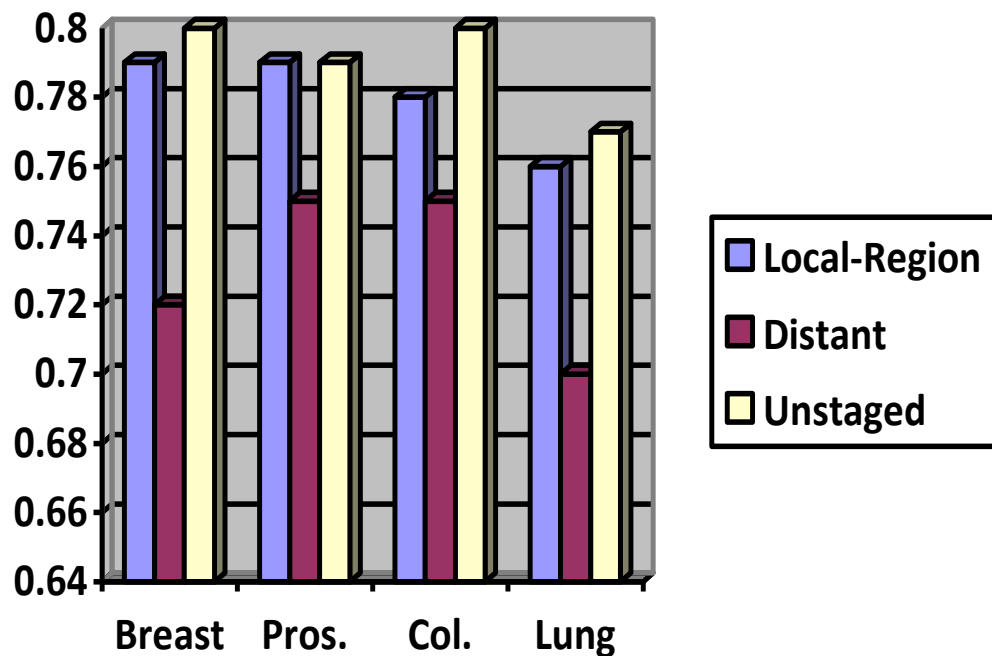
# HRQOL in SEER-Medicare Health Outcomes Study (n = 126,366)

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



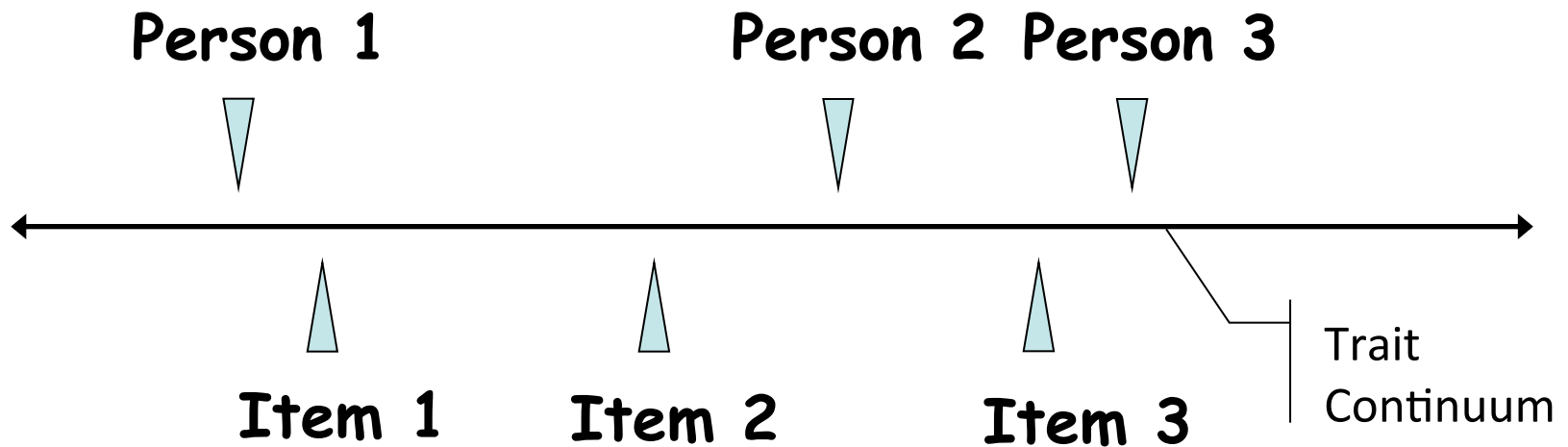
Controlling for age, gender, race/ethnicity, education, income, and marital status.

# Distant stage of cancer associated with 0.05-0.10 lower SF-6D Score



**Figure 1.** Distant Stage of Disease Associated with Worse SF-6D Scores (Sample sizes for local/regional, distant, and unstaged: Breast (2045, 26, 347); Prostate (2652, 61 and 633), Colorectal (1481, 48 and 203), and Lung (466, 47 and 65)).

# Item Responses and Trait Levels



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

# Computer Adaptive Testing (CAT)



**Graduate Record Examinations®**



**National Council  
of State Boards of Nursing, Inc.**



# Reliability Target for Use of Measures with Individuals

- Reliability ranges from 0-1
  - 0.90 or above is goal
- Reliability = 0.90 when SE = 3.2
  - T-scores (mean = 50, SD = 10)
  - Reliability =  $1 - (SE/10)^2$

$$T = 50 + (z * 10)$$



# 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 ...

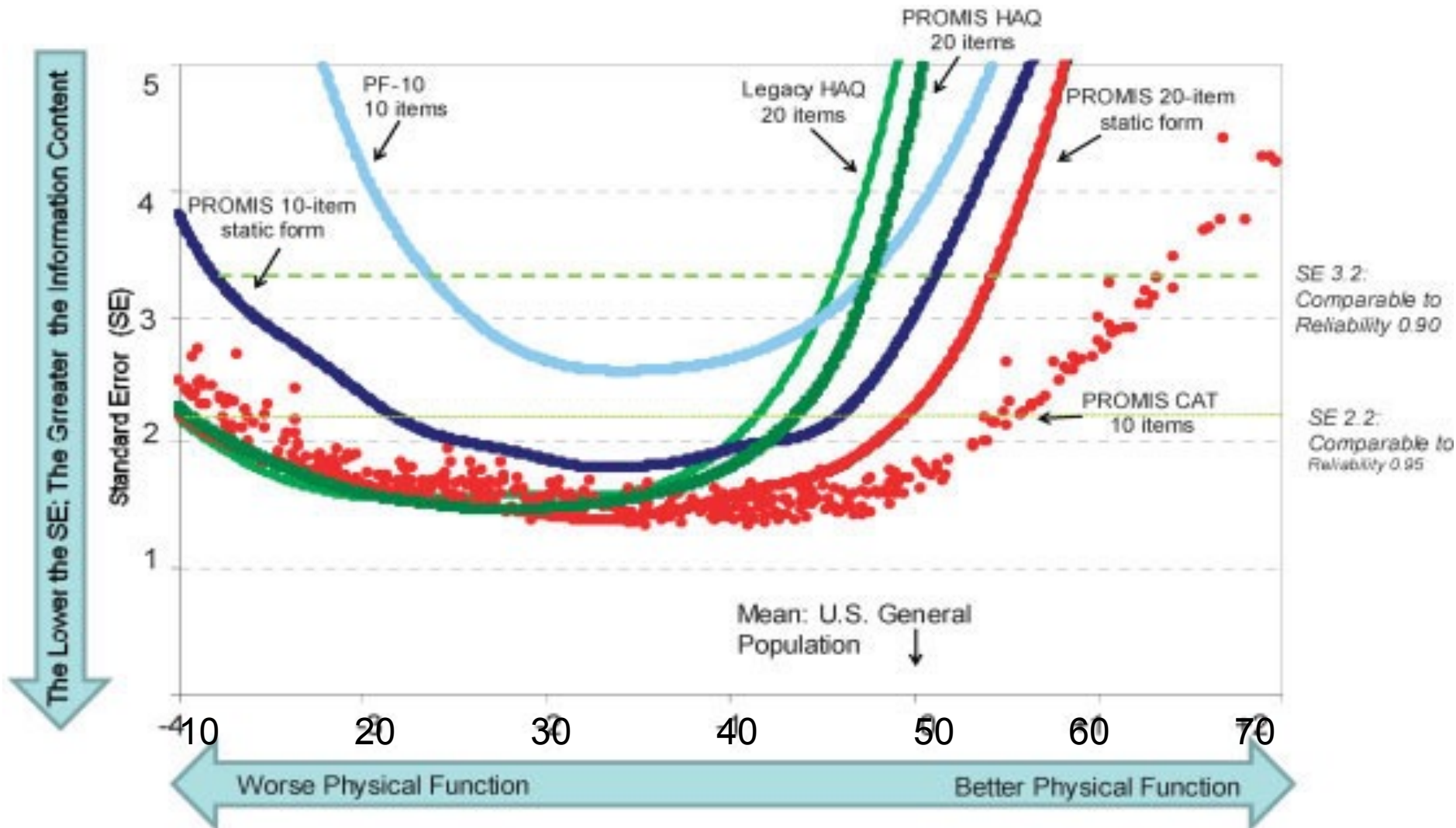
I made myself angry about something just by thinking about it. [6<sup>th</sup> question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.2

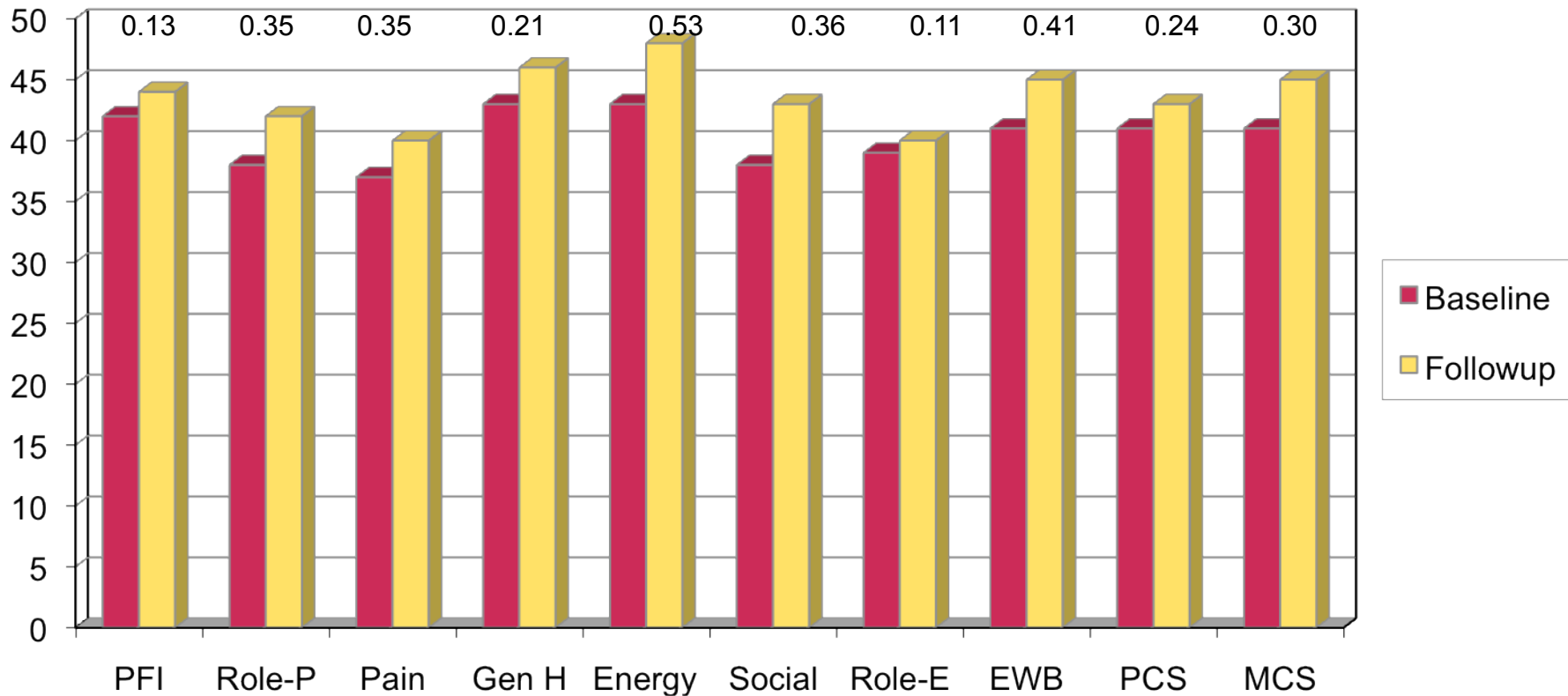
SE = 2.8 (rel = 0.92)

# PROMIS Physical Functioning vs. “Legacy” Measures



# Effect Sizes for Changes in SF-36 Scores

Effect Size



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

PCS = Physical



# 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)

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

RCI  $\geq 1.96$  is statistically significant individual change..

# 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

# 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%

# Questions?



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Powerpoint file available for downloading at:

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