Measuring Health-Related Quality of Life

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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 ↓

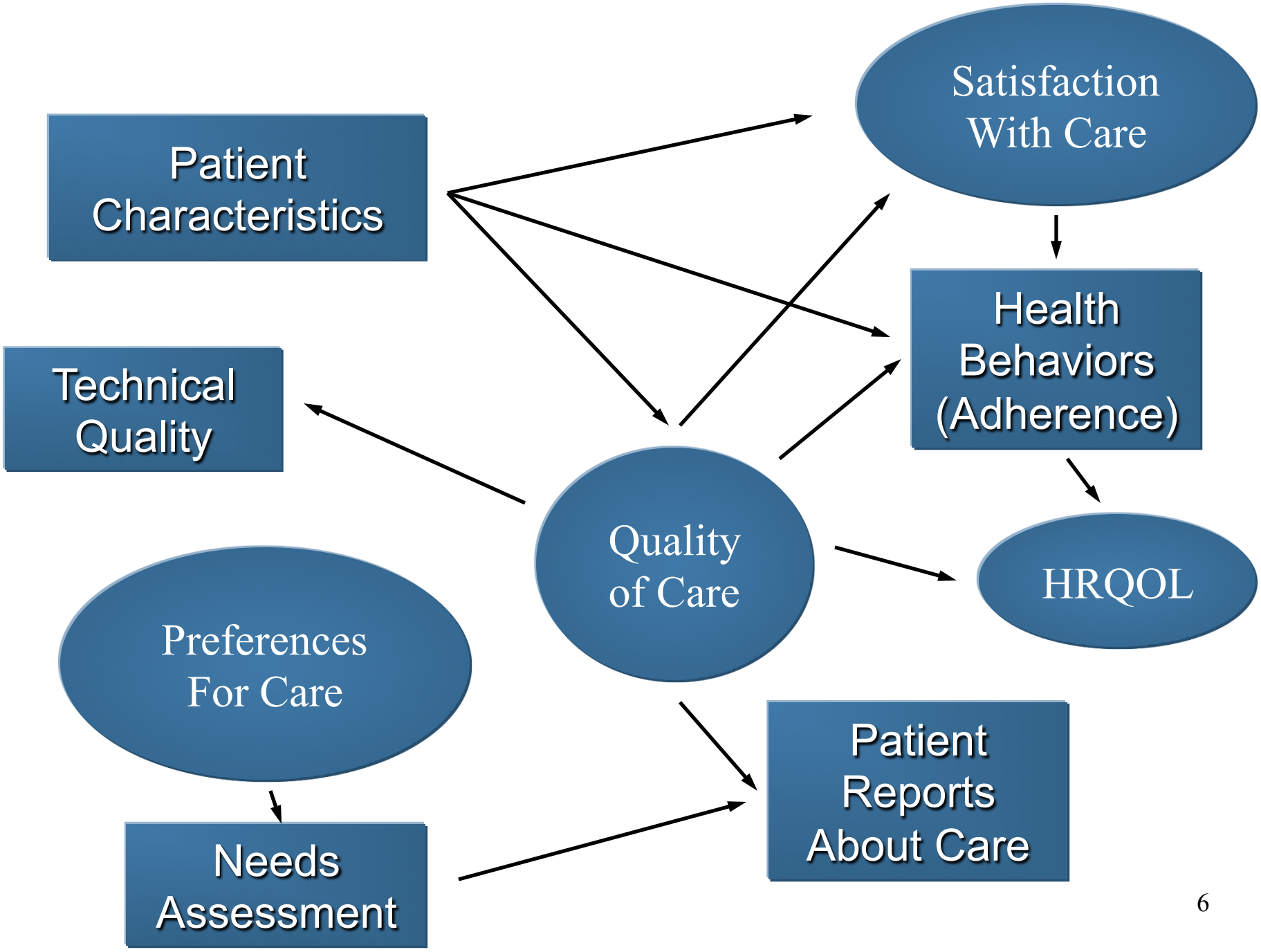
Effectiveness ↑

Health Outcomes Measures

- Traditional clinical endpoints
  - Survival
  - Clinical/biological indicators
    - Rheumatoid factor
    - Blood pressure
    - 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)


Satisfaction With Care
Patient Characteristics
Health Behaviors (Adherence)
Technical Quality
Quality of Care
HRQOL
Preferences For Care
Patient Reports About Care
Needs Assessment

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, but clinically-important changes.
- More familiar and actionable for clinicians.
- Enhance respondent cooperation.

IBS-Targeted Item

"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

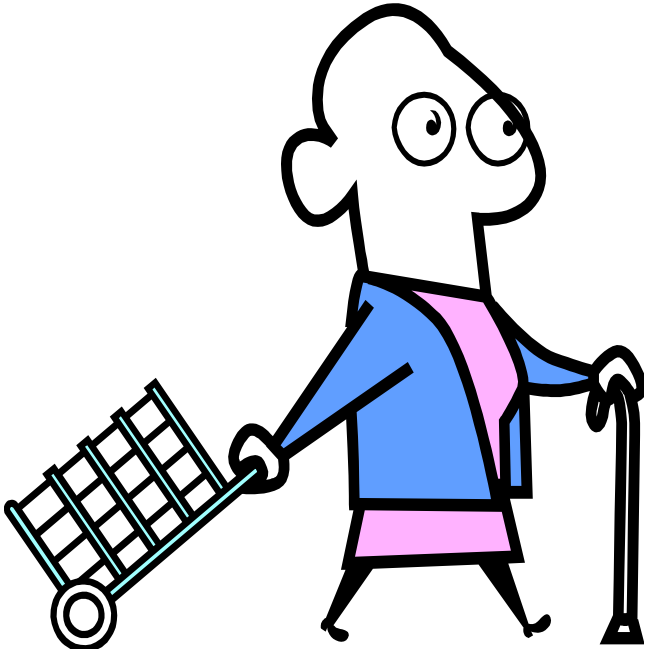
Does your health now limit you in walking more than a mile?

(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

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

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

$$Z_X = \frac{(X - \bar{X})}{SD_X}$$

SF-36 PCS and MCS

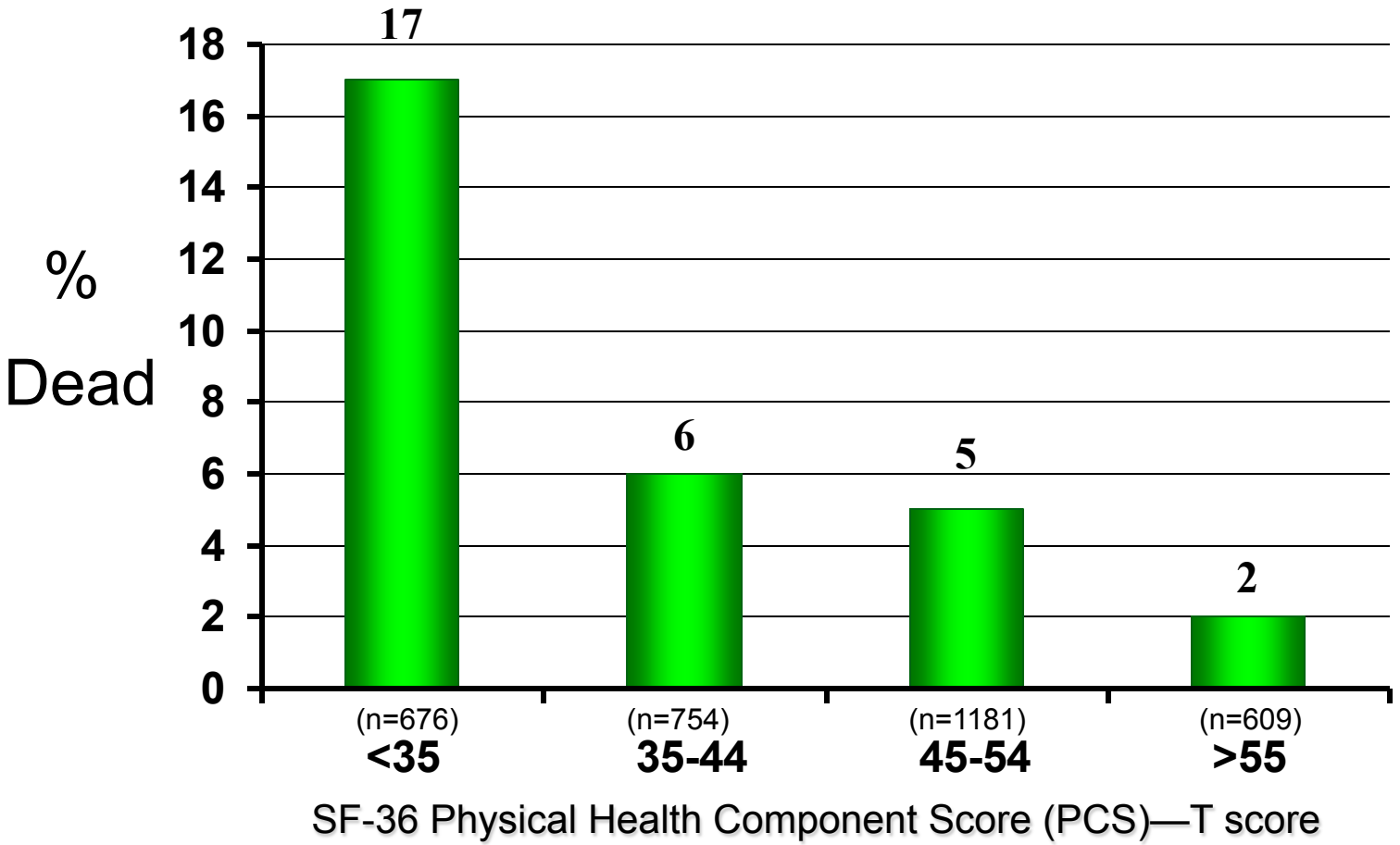
PCS_z = (PF_Z * 0.42) + (RP_Z * 0.35) +
(BP_Z * 0.32) + (GH_Z * 0.25) +
(EF_Z * 0.03) + (SF_Z * -.01) +
(RE_Z * -.19) + (EW_Z * -.22)

MCS_z = (PF_Z * -.23) + (RP_Z * -.12) +
(BP_Z * -.10) + (GH_Z * -.02) +
(EF_Z * 0.24) + (SF_Z * 0.27) +
(RE_Z * 0.43) + (EW_Z * 0.49)

PCS = (PCS_z*10) + 50

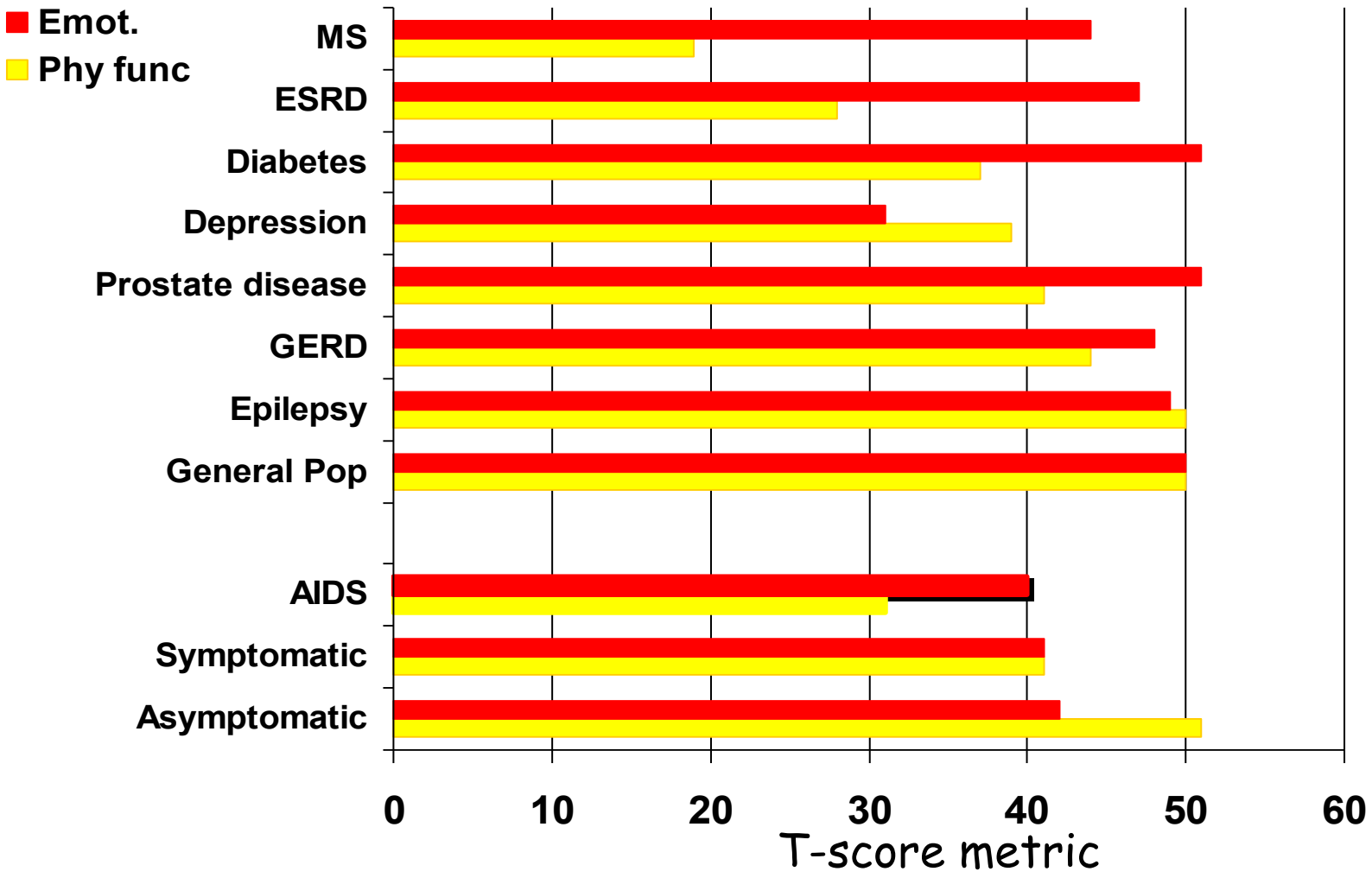
MCS = (MCS_z*10) + 50

HRQOL is Predictive of Mortality (5 years later)



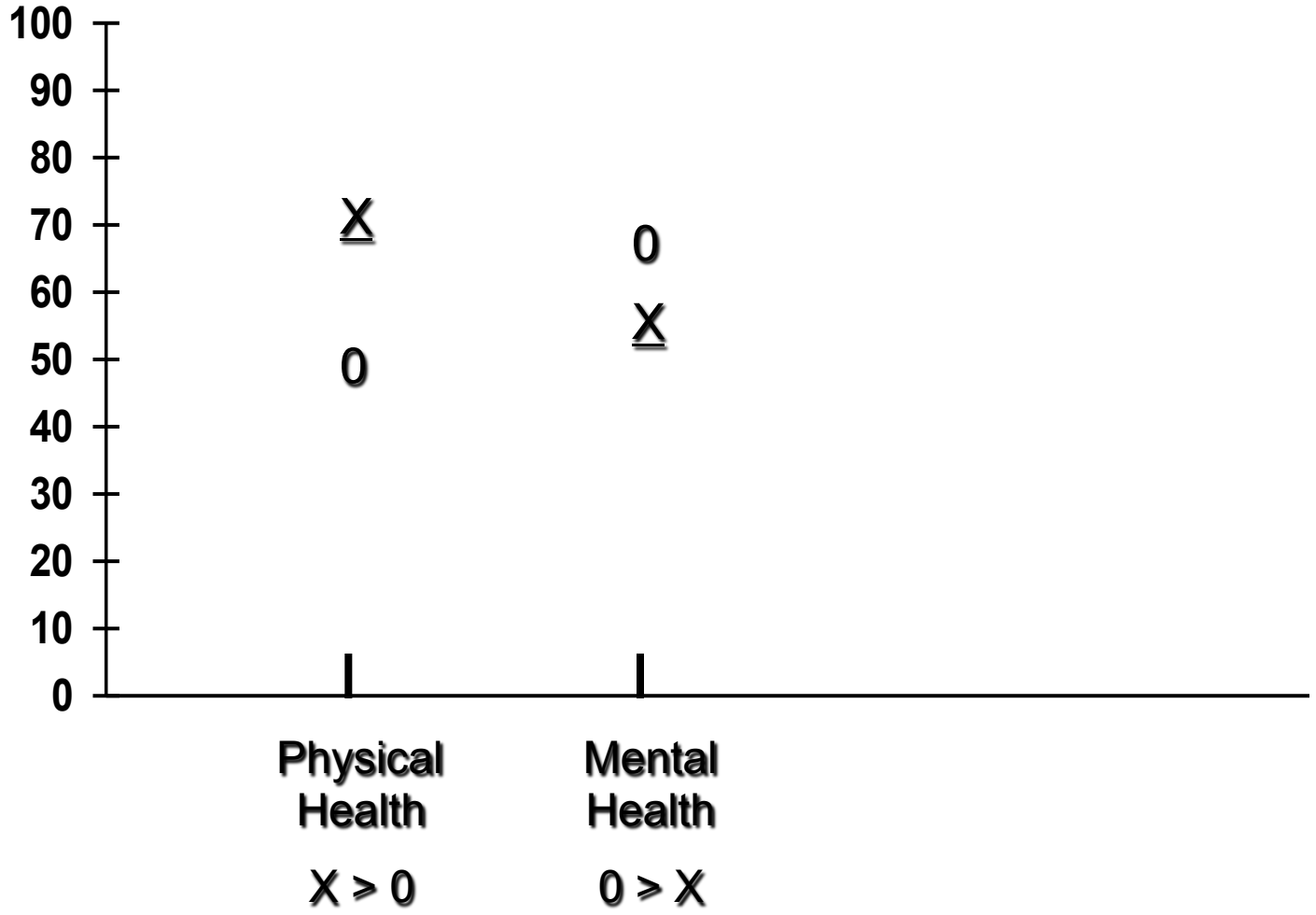
Ware et al. (1994). SF-36 Physical and Mental Health Summary Scales: A User's Manual.

HRQOL in HIV Compared to other Chronic Illnesses and General Population



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

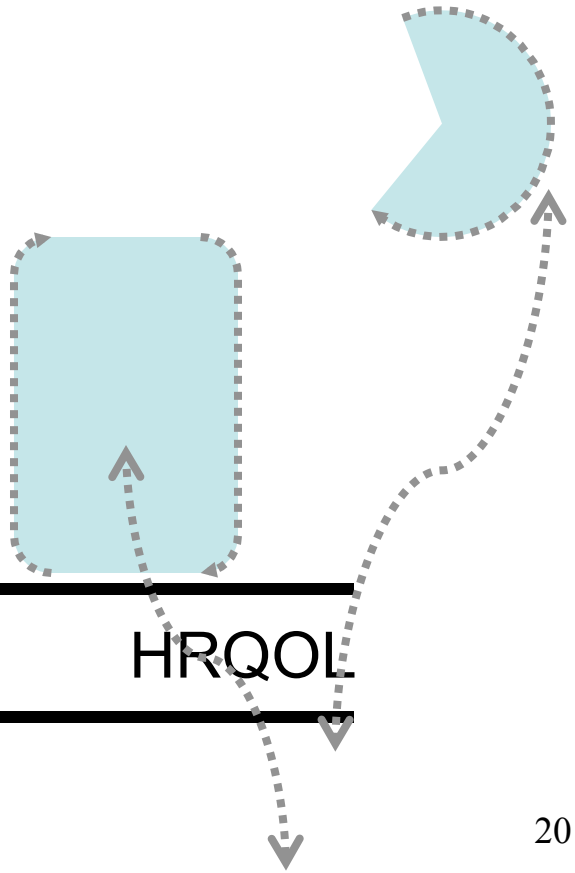
Is New Treatment (X) Better Than Standard Care (O)?



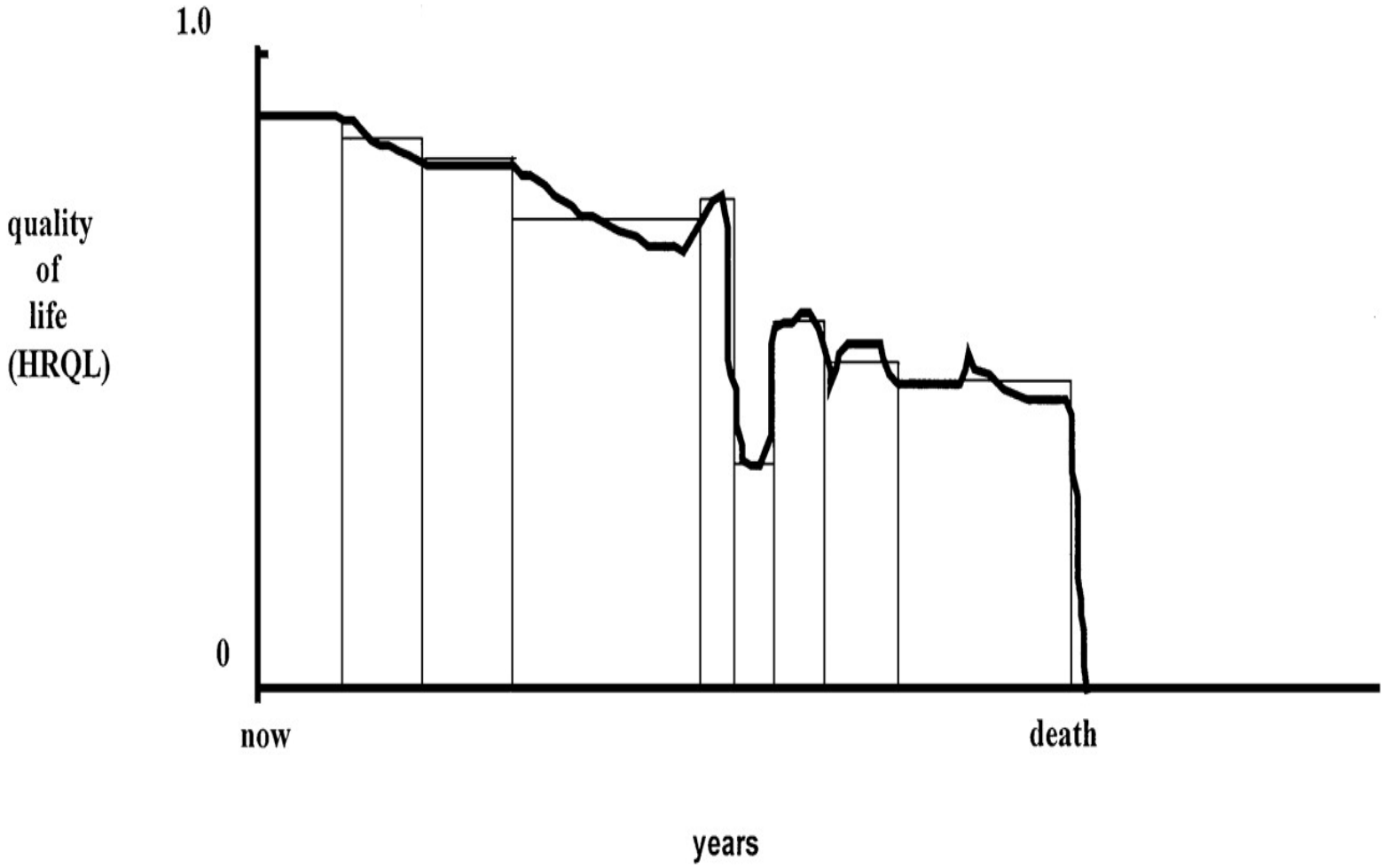
Is Medicine Related to Worse HRQOL?

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

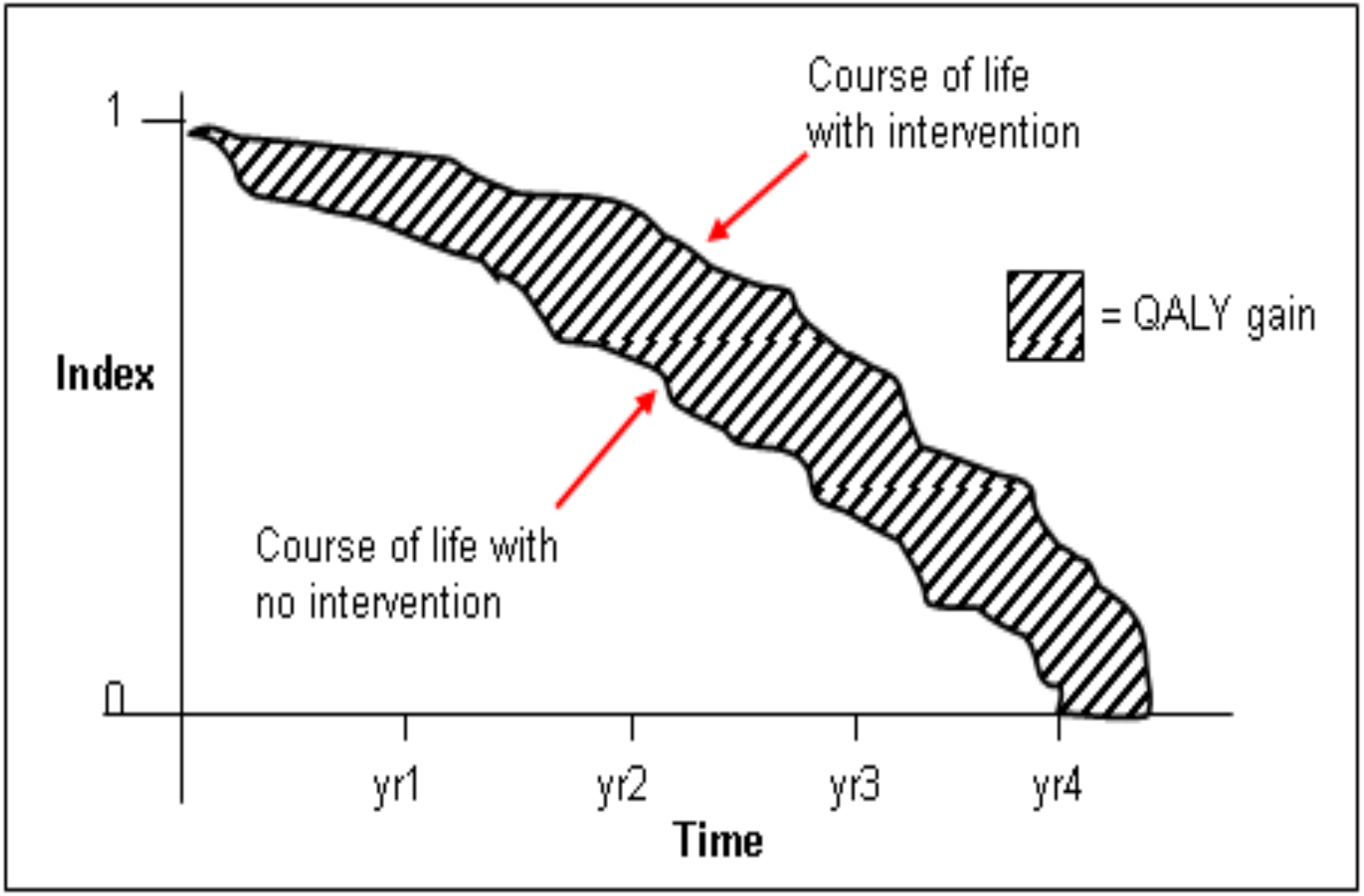
Group	n	HRQOL
No Medicine	3	75
Yes Medicine	5	50



Quality of Life for Individual Over Time



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



SF-6D

Brazier et al. (1998, 2002)

— 6-dimensional classification (collapsed role scales, dropped general health)

— Uses 11 SF-36 items (8 SF-12 and 3 additional physical functioning items)

--- 18,000 possible states

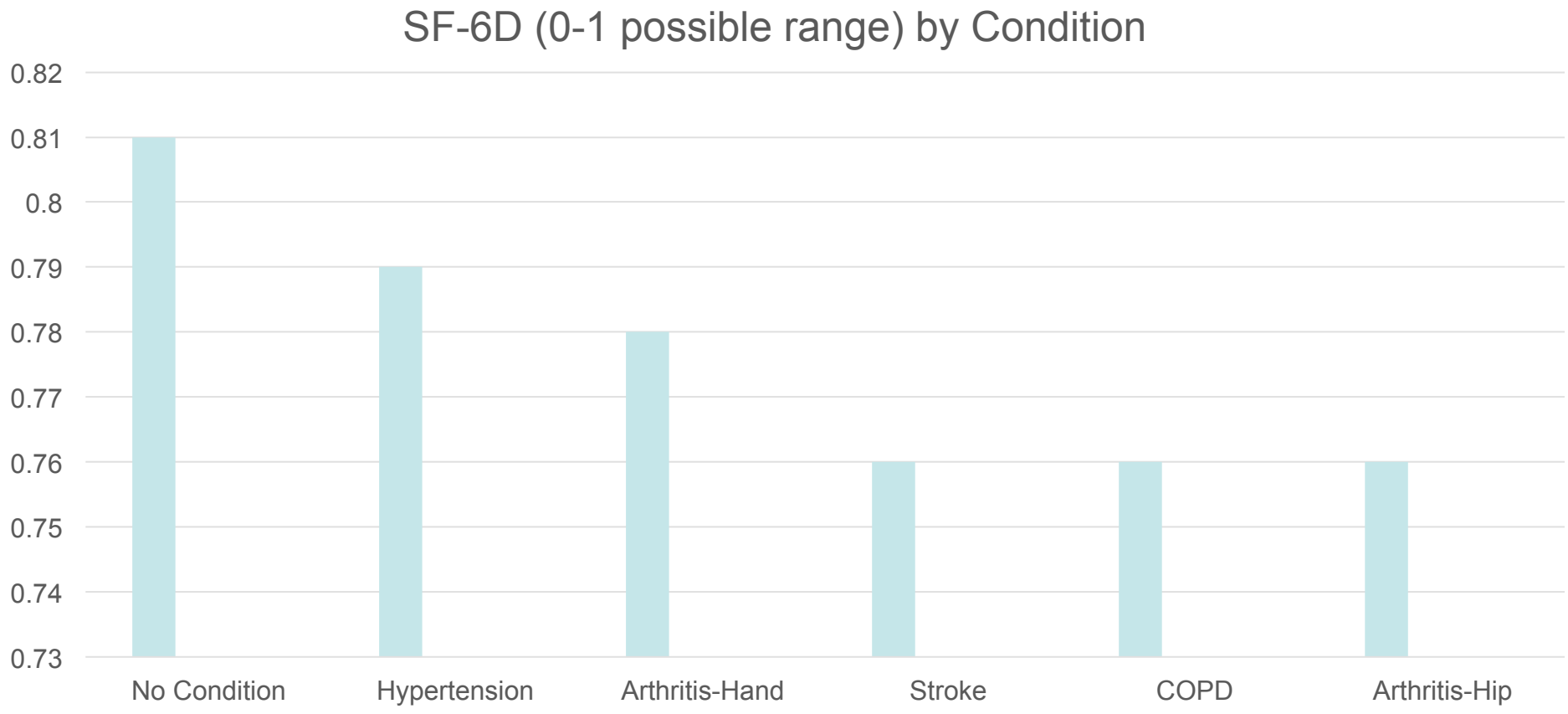
-— 249 states rated by sample of 836 from UK general population

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)



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

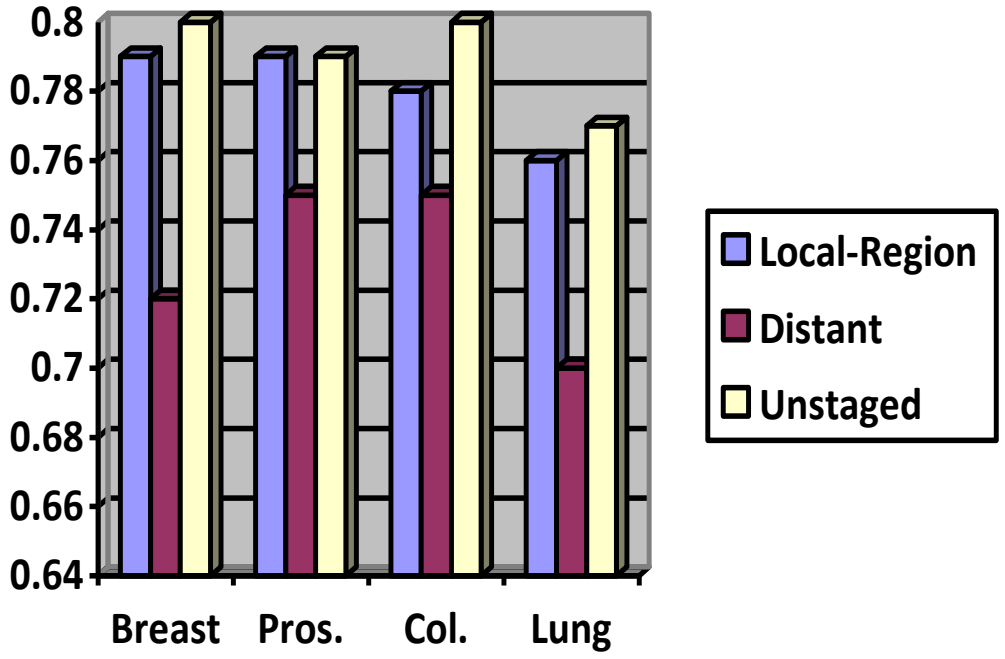
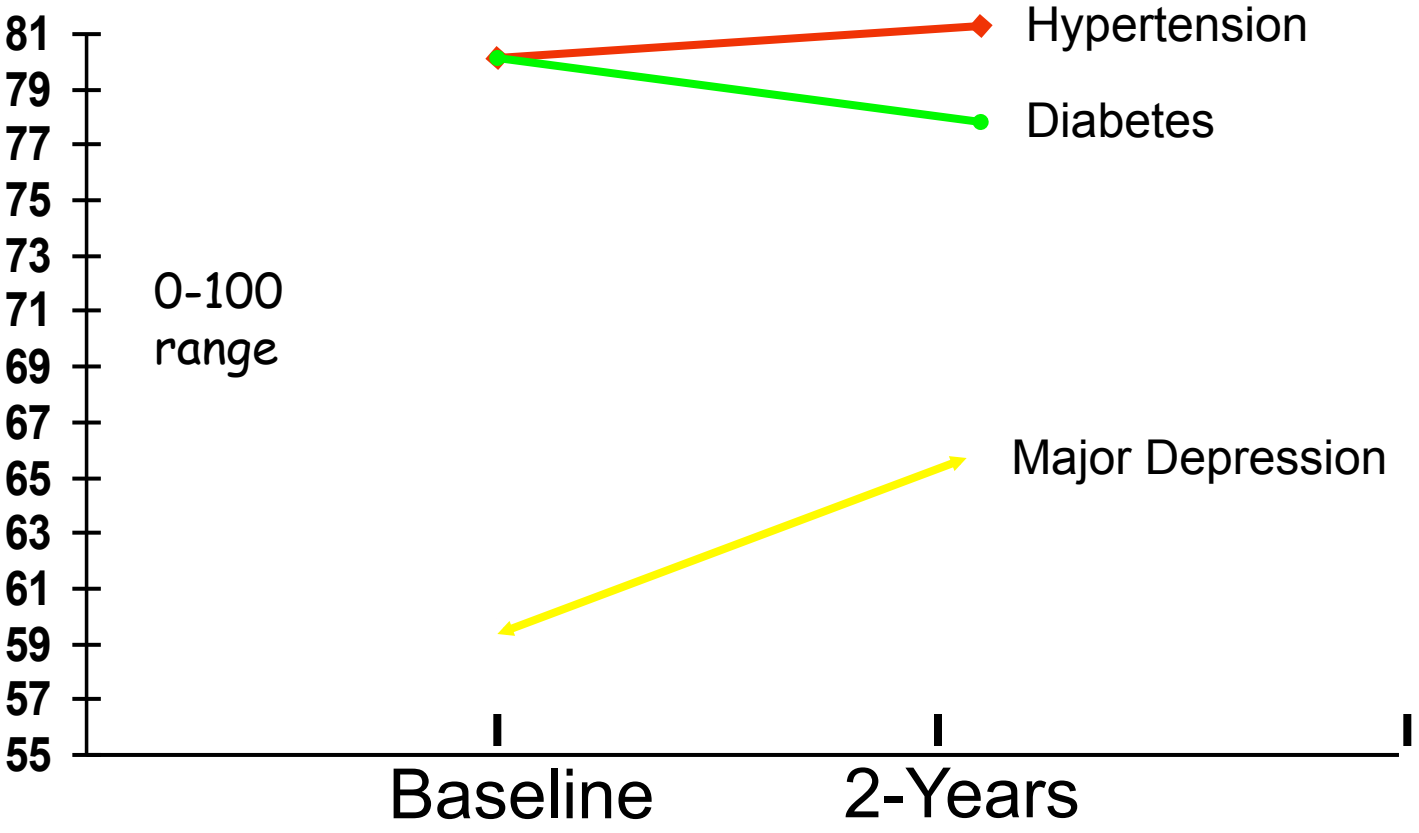


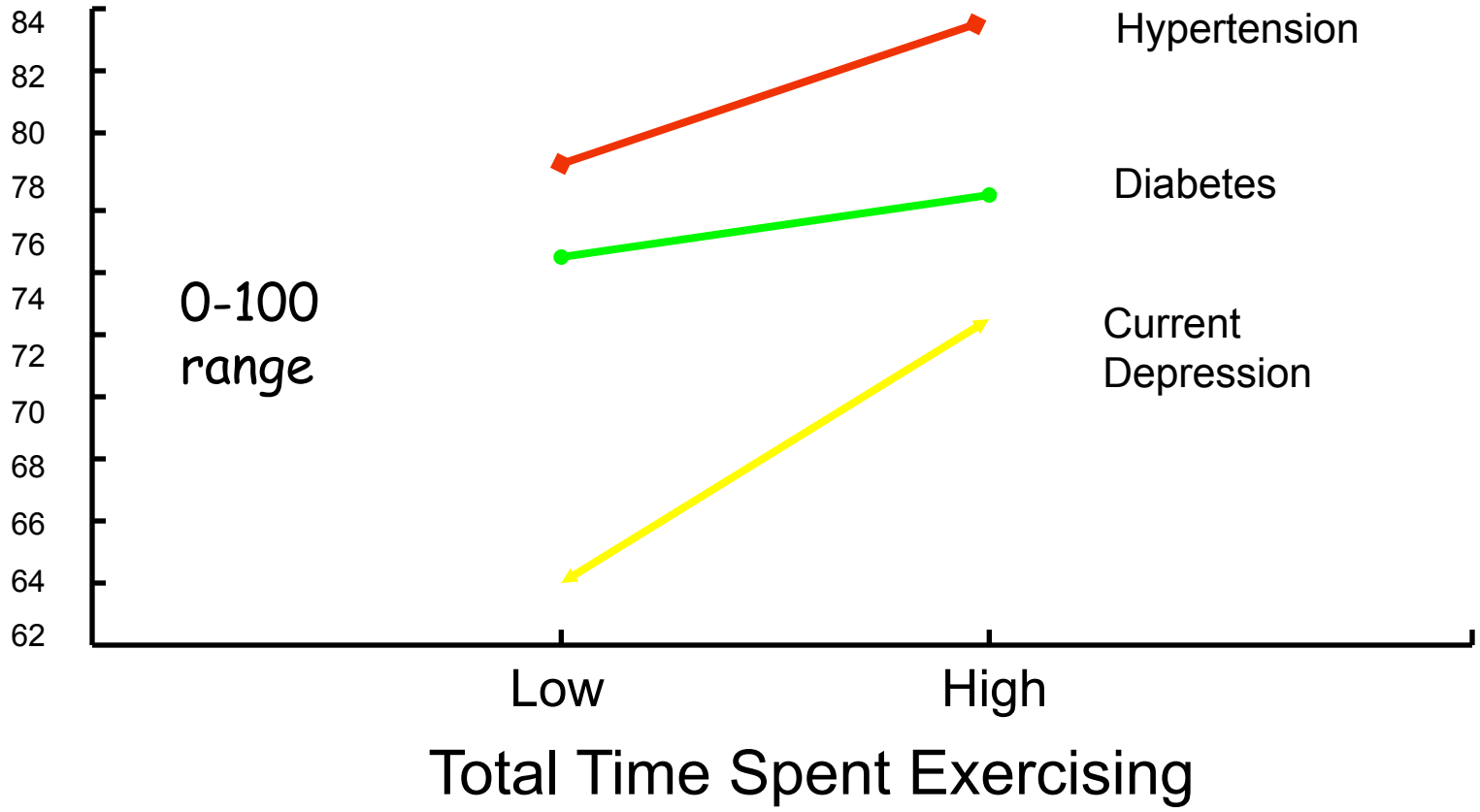
Figure 1. Distant Stage of Disease Associated with Worse SF-6D Scores (Sample sizes for local/regional, distant, and unstaged: Breast (2045,26, 347); Prostate (2652, 61 and 633), Colorectal (1481, 48 and 203), and Lung (466, 47 and 65).

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



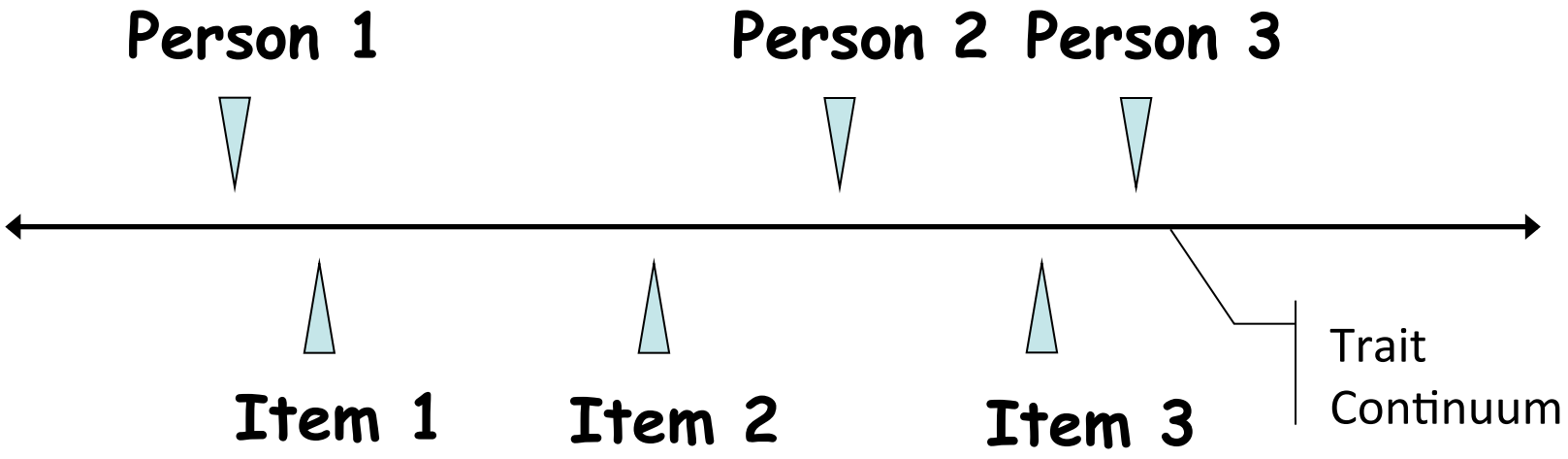
Hays, R.D., Wells, K.B., Sherbourne, C.D., Rogers, W., & Spritzer, K. (1995). Functioning and well-being outcomes of patients with depression compared to chronic medical illnesses. Archives of General Psychiatry, 52, 11-19.

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.

Item Responses and Trait Levels



www.nihpromis.org

Computer Adaptive Testing (CAT)

Response Burden Reduced

- Paper and pencil rules of thumb
  - 3-5 items per minute
- PROMIS computer administration to general population
  - 8-12 items per minute
- Scleroderma patients at UCLA
  - 6 items per minute

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 [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 …

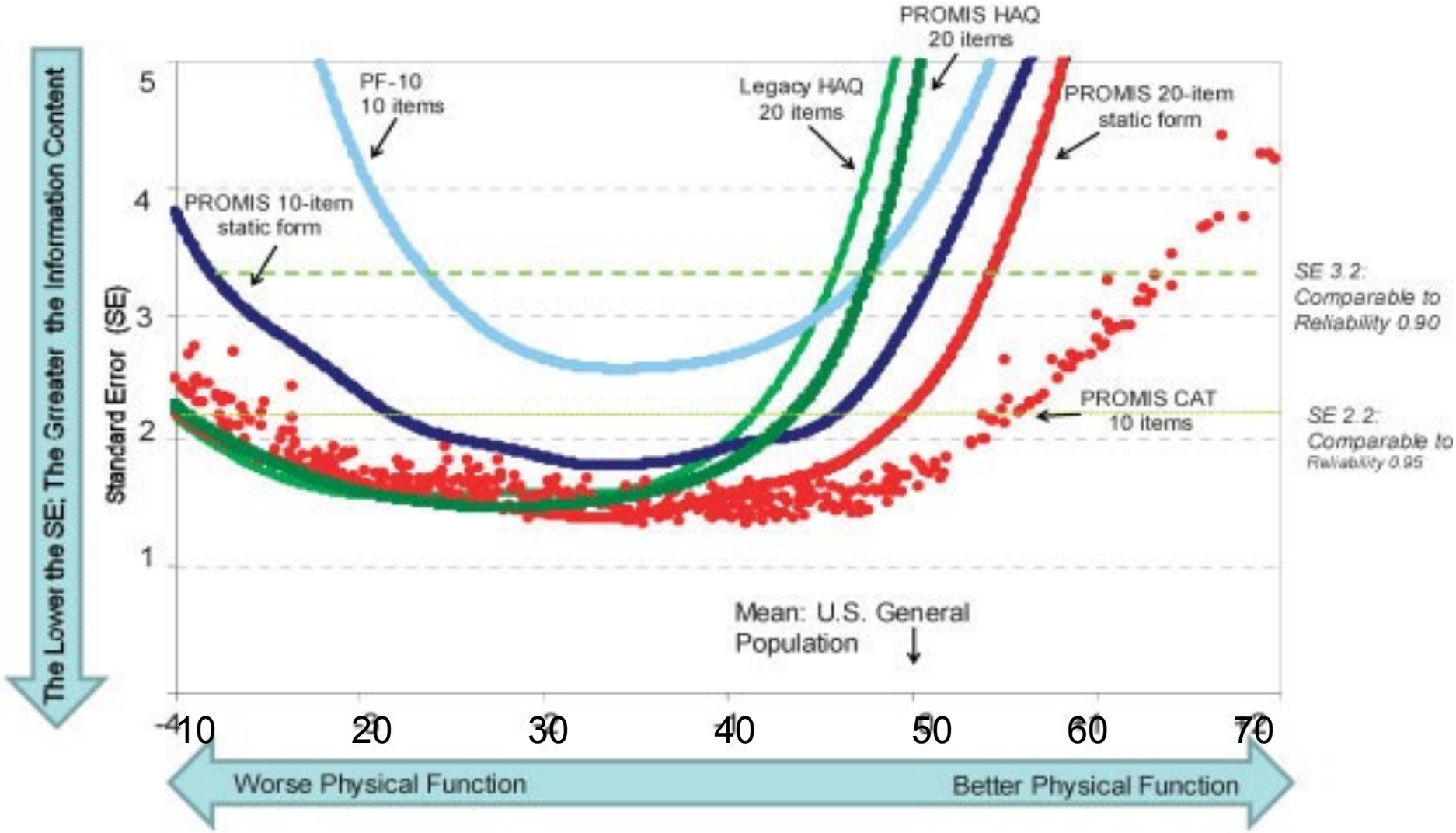
I made myself angry about something just by thinking about it. [6th question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.2

SE = 2.8 (rel = 0.92)

PROMIS Physical Functioning vs. “Legacy” Measures

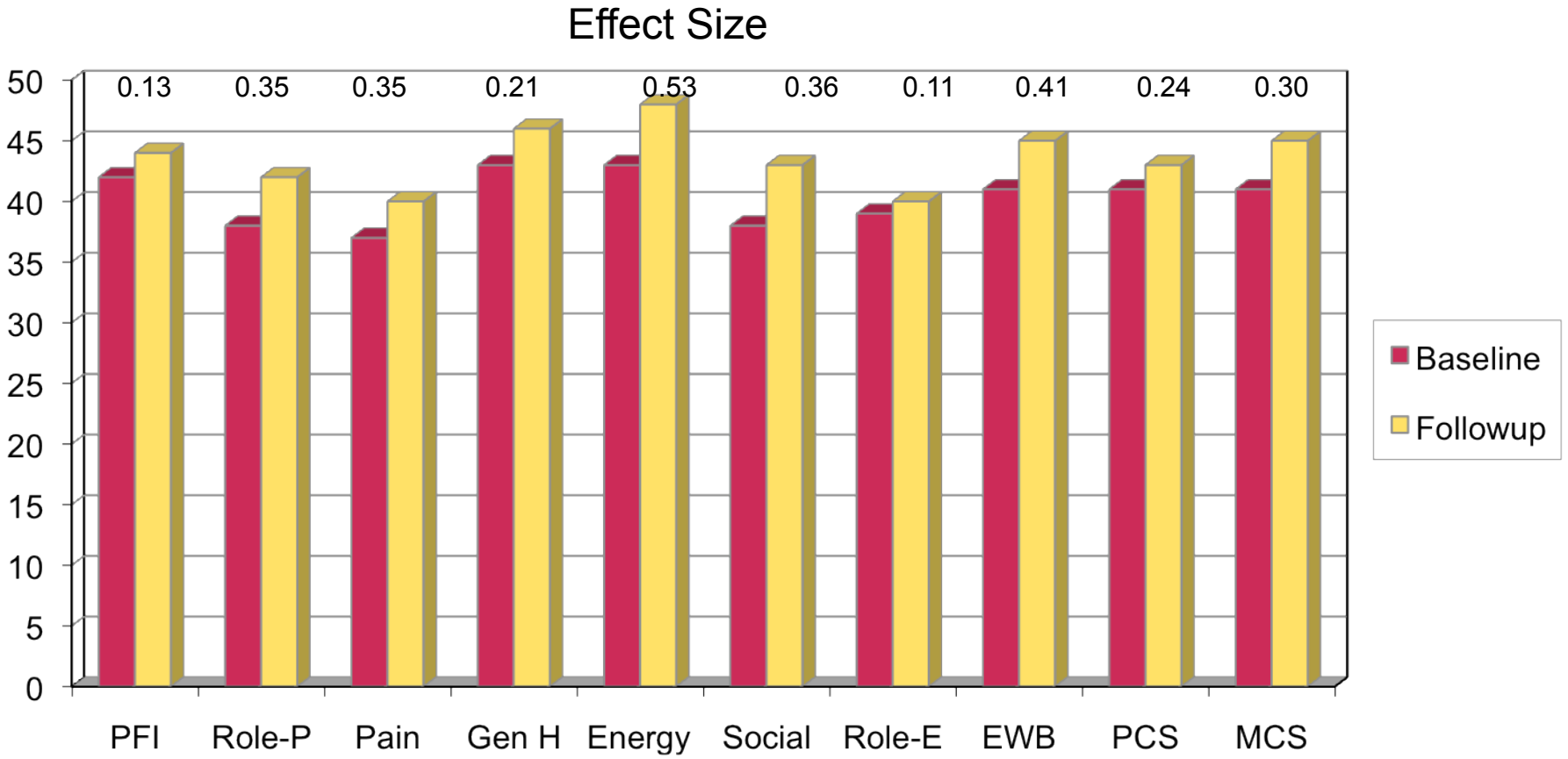


Defining a Responder: Reliable Change Index (RCI)

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

RCI >=1.96 is statistically significant individual change..

Effect Sizes for Changes in SF-36 Scores



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

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

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?

Contact Information:
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Powerpoint file available for downloading at:
http://gim.med.ucla.edu/FacultyPages/Hays/

Recommended Readings

Cella, D., et al. (2010). Initial item banks and first wave testing of the Patient-Reported Outcomes Measurement Information System (PROMIS) network: 2005-2008. Journal of Clinical Epidemiology, 63 (11), 1179-1194.

Hahn, E. A., et al. (2007). Precision of health-related quality-of-life data compared with other clinical measures. Mayo Clin Proceedings, 82 (10), 1244-1254.

Hambleton, R. K., & Swaminathan, H. (1985). Item response theory: Principles and applications. Boston: Kluwer-Nijhoff.

Hays, R. D., Morales, L. S., & Reise, S. P. (2000). Item response theory and health outcomes measurement in the 21st Century. Medical Care, 38, II-28-42.

Hays, R. D., Reeve, B. B., Smith, A. W., & Clauser, S. B. (2013, epub). Associations of cancer and other chronic medical conditions with SF-6D preference-based scores in Medicare beneficiaries. Quality of Life Research.