

# Health-Related Quality of Life Assessment as an Indicator of Quality of Care

**Ron D. Hays, Ph.D.**  
**HS249F**

January 31, 2007 (3:30-6:30 pm)

RAND Conference Room, 5312

# Questions

- **What is the difference between symptoms and health-related quality of life?**
- **How does one estimate the minimally important difference in health-related quality of life measures?**
- **How do you know if a measure is responsive to change?**

# Contact Information

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# How do you know how the patient is doing?

Temperature

Respiration

Pulse

Weight

Blood pressure



**Also, by talking to her or him about ...**

## **Symptoms**

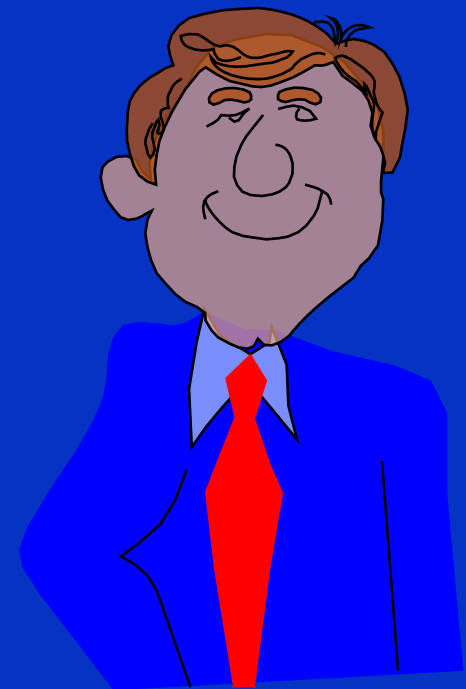
**- Have you had a fever in the last 7 days?**

**No**

**Yes**

**What they are able to do**

**And how they feel about their life**



# First RCT of Treatment for Newly Diagnosed Prostate Cancer (NEJM, 2002)

## Radical prostatectomy vs. watchful waiting

- Trend to reduction in all-cause mortality

(18% versus 15%; RR 0.83, 0.57 to 1.2,  $p = 0.31$ )

# Impact on Symptoms

+ Urinary obstruction (weak stream)

-> 44% waiting, 28% prostatectomy (+)

- Sexual dysfunction

-> 80% prostatectomy (-) vs. 45% waiting

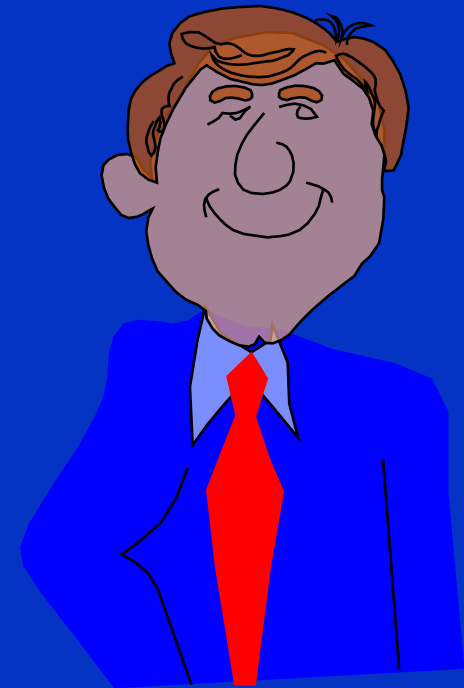
- Urinary leakage

-> 49% prostatectomy (-) vs. 21% waiting

# "Outcomes" -- How is the Patient Doing?

## Physiological

- Vital signs (pulse, BP, temperature, respiration)
- Hematocrit
- Albumin



## Physician observation

- Physical performance

## Self-report indicators

- Functioning and well-being



# Health-Related Quality of Life (HRQOL) is:

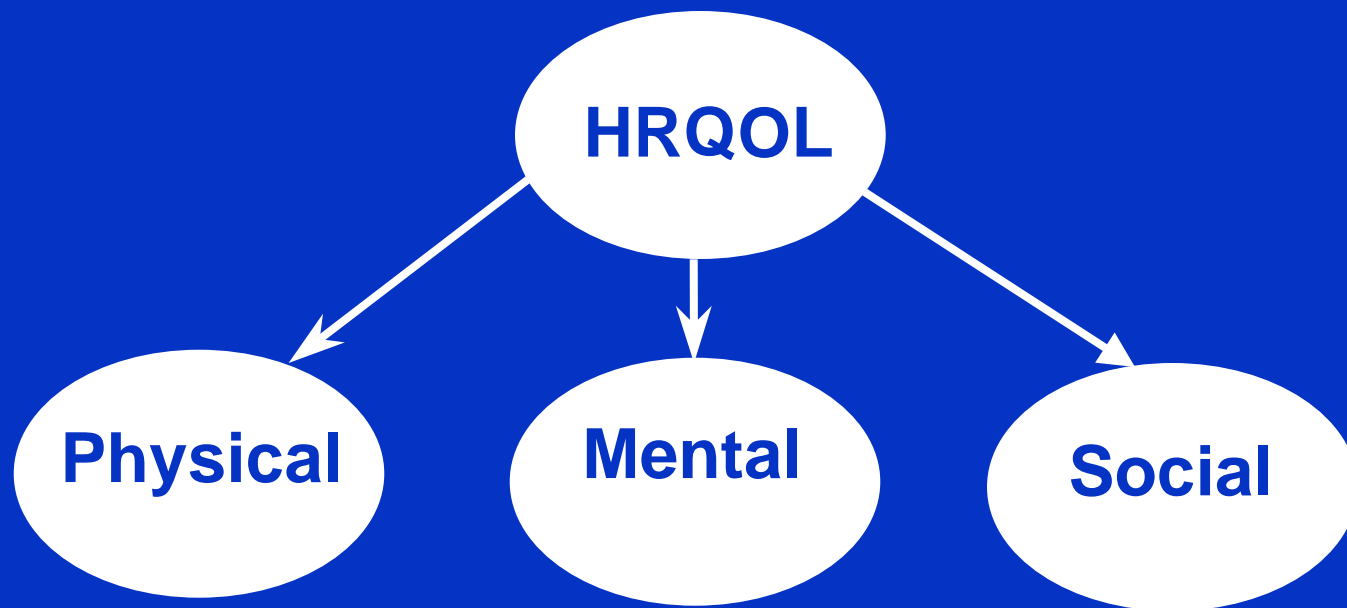
## What the person can DO (functioning)

- Self-care
- Role
- Social

## How the person FEELS (well-being)

- Emotional well-being
- Pain
- Energy

# HRQOL is Multi-Dimensional



**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***

How much of the time during the past  
4 weeks have you been happy?

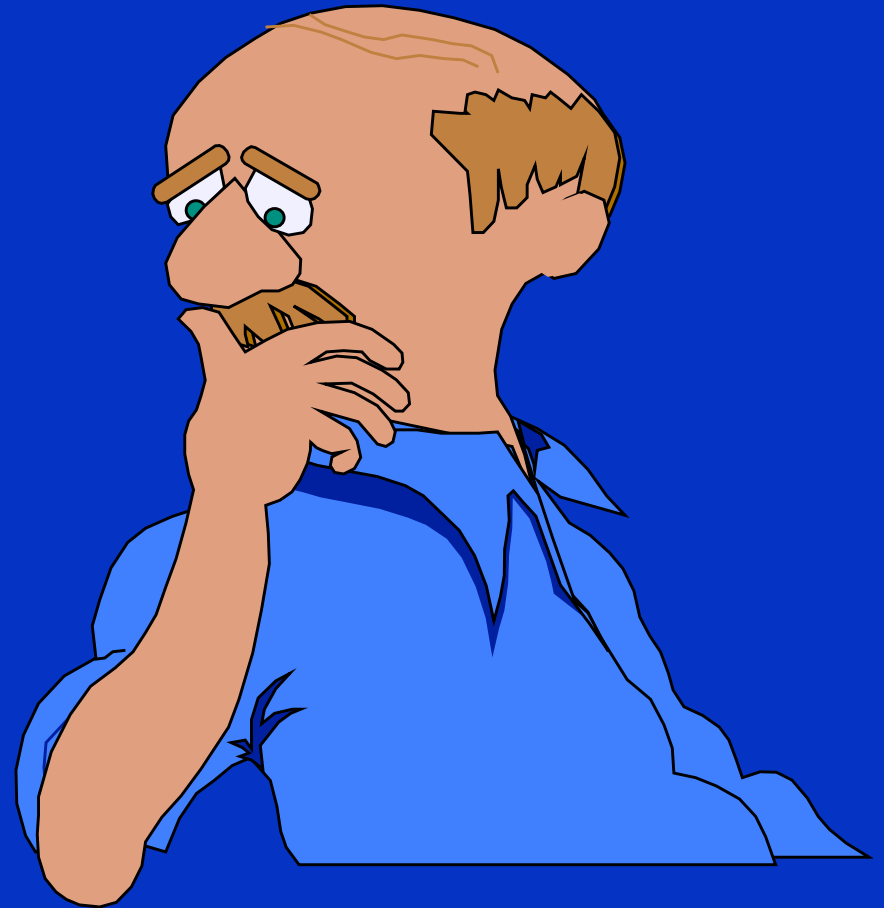
*None of the time*

*A little of the time*

*Some of the time*

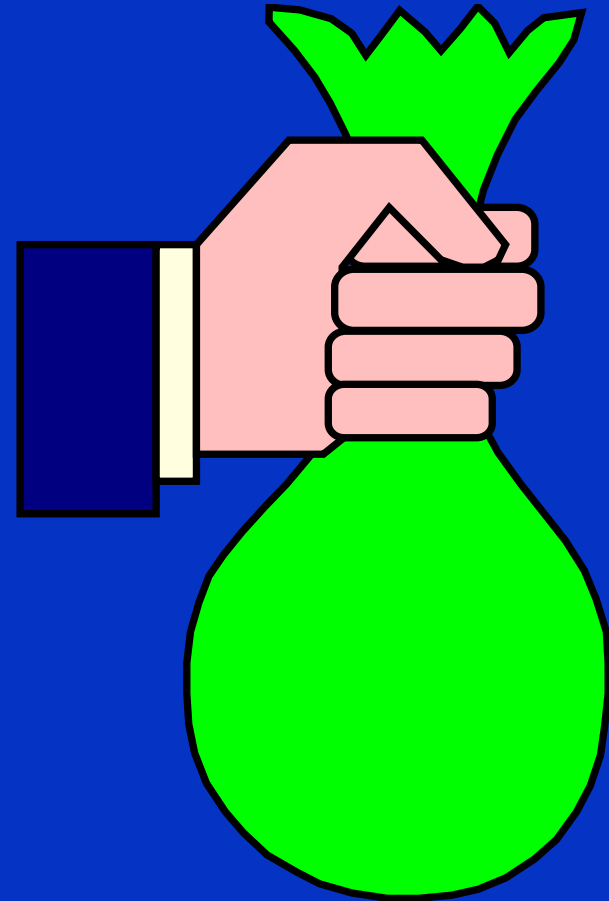
*Most of the time*

*All of the time*



# HRQOL is Not

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



# Are self-reports reliable?

**Reliability—extent to which you get the same score on repeated assessments**

# Reliability is an issue in blood pressure measurement

- Do not place the blood pressure cuff over clothing or roll a tight fitting sleeve above the biceps when determining blood pressure as either can cause elevated readings.
- If you have a chance, obtain measurements on the same patient with both a large and small cuff.
- If the reading is surprisingly high or low, repeat the measurement towards the end of your exam.
- These exercises should give you an appreciation for the magnitude of error that can be introduced when improper technique is utilized.



# Range of reliability estimates

**0.80-0.90 for blood pressure**

**0.70-0.90 for multi-item self-report scales**

# Are self-reports about HRQOL valid?

**Validity—score represents what you are trying to measure rather than something else**

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

**Excellent**

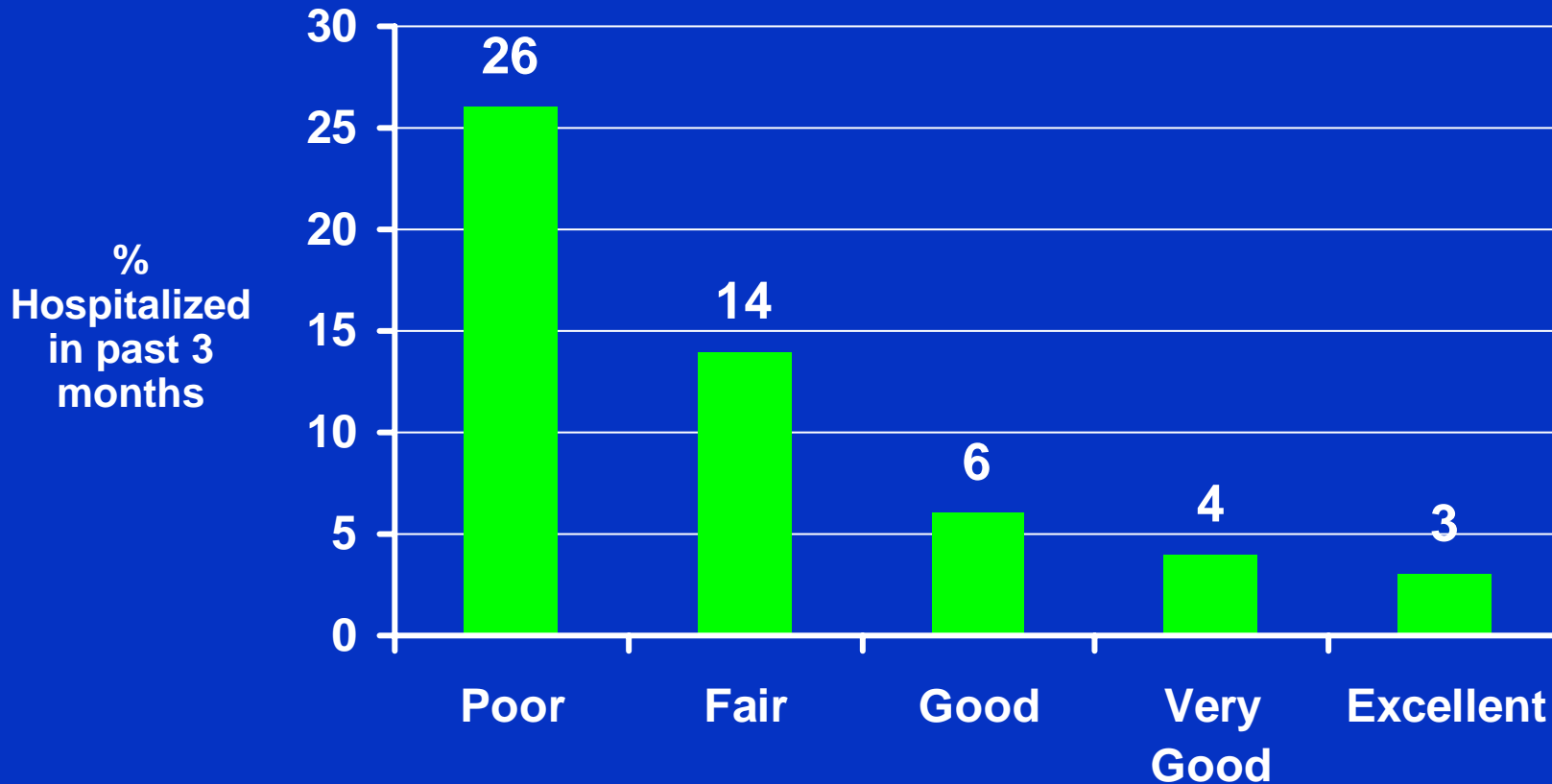
**Very Good**

**Good**

**Fair**

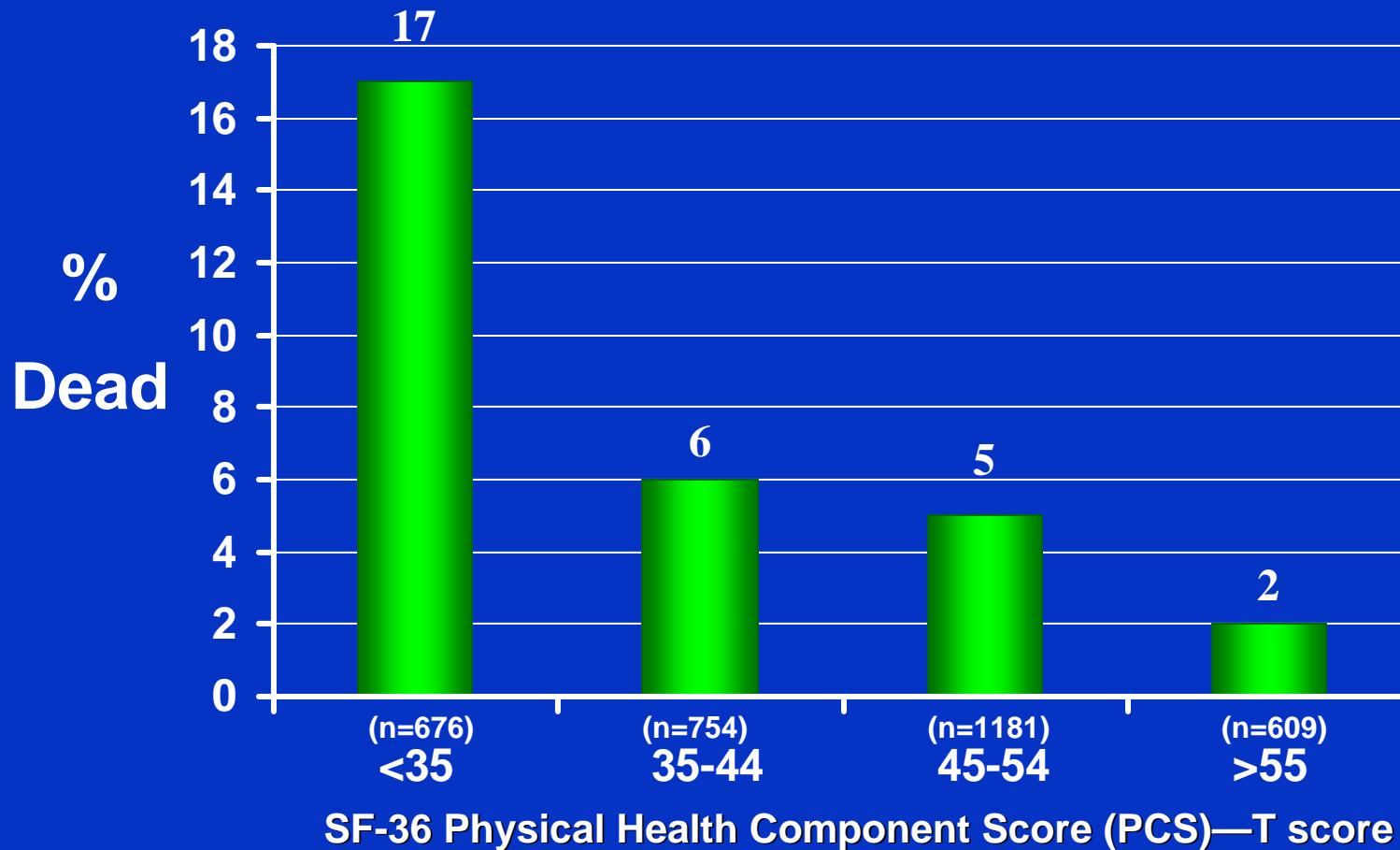
**Poor**

# Hospitalized Patients Report Worse General Health (n = 20,158)



Kravitz, R. et al. (1992). Differences in the mix of patients among medical specialties and systems of care: Results from the Medical Outcomes Study. *JAMA*, *267*, 1617-1623.

# Self-Reports of Physical Health Predictive of Five-Year Mortality Rates



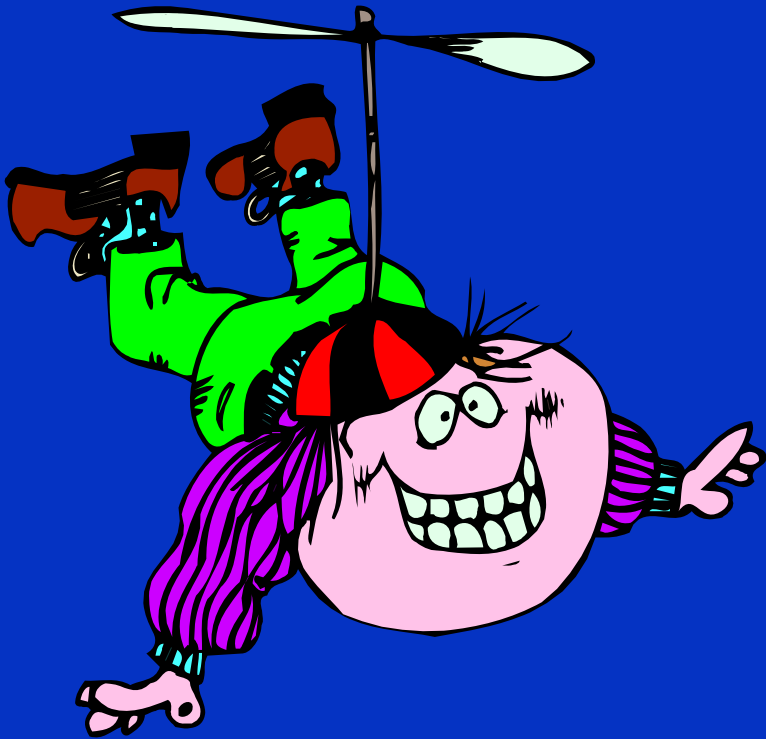
Ware et al. (1994). SF-36 Physical and Mental Health Summary Scales: A User's Manual.

# Mark D. Sprenke et al. (Chest, 2004)

“The Veterans Short Form 36 Questionnaire is predictive of mortality and health-care utilization in a population of veterans with a self-reported diagnosis of asthma or COPD”



# Types of HRQOL Measures



**Profile: Generic vs. Targeted**  
**Preference Measure**

# **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)**

# Persons with mobility impairments object to SF-36 physical functioning items:

Does your health now limit you in (if so, how much) ...

climbing several flights of stairs

climbing one flight of stairs

walking more than a mile

walking several hundred yards

walking one hundred yards

Andresen & Meyers (2000, Archives of Physical Medicine and  
Rehabilitation)



# Scoring Generic HRQOL 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)

# Formula for Transforming Scores

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

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

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

Microsoft Excel - transforming-scores.xls



File Edit View Insert Format Tools Data Window Help

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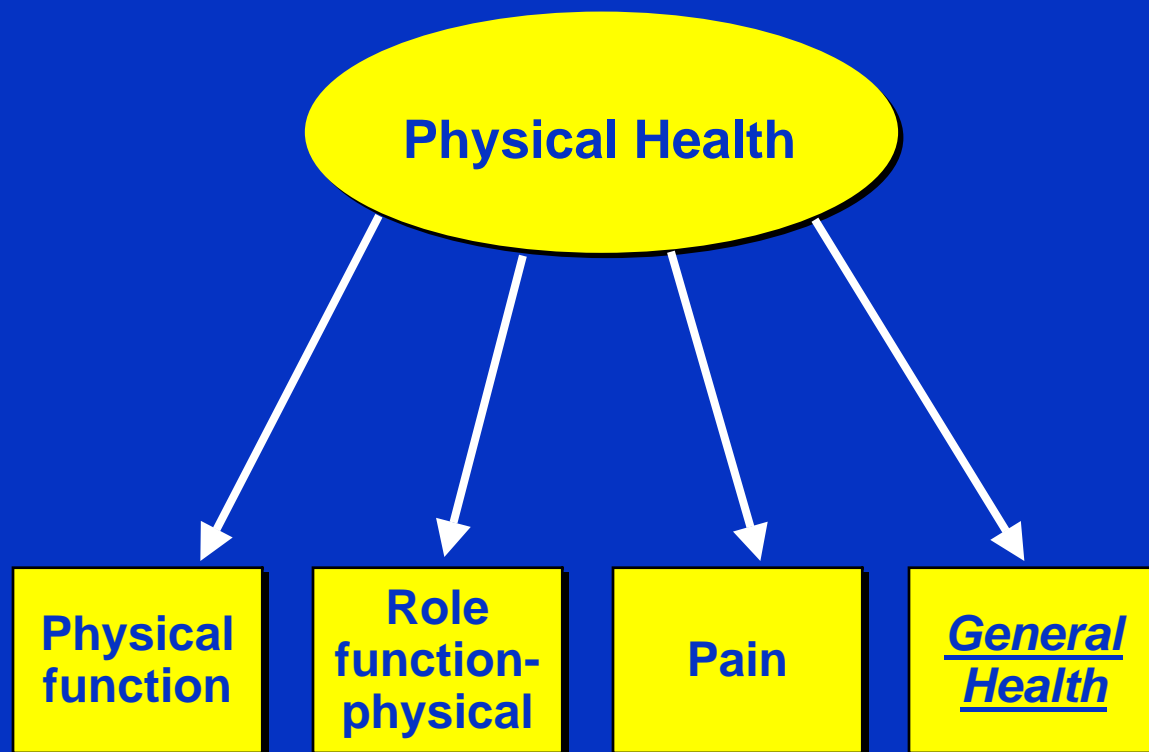
	A	B	C	D	E	F	G
1	1	0	39.5285	-1.26491	37.3509		
2	2	25	39.5285	-0.63246	43.6754		
3	3	50	39.5285	0	50		
4	4	75	39.5285	0.63246	56.3246		
5	5	100	39.5285	1.26491	62.6491		
6	raw	x	SDx	Zx	T-score		
7							
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Sheet1 Sheet2 Sheet3

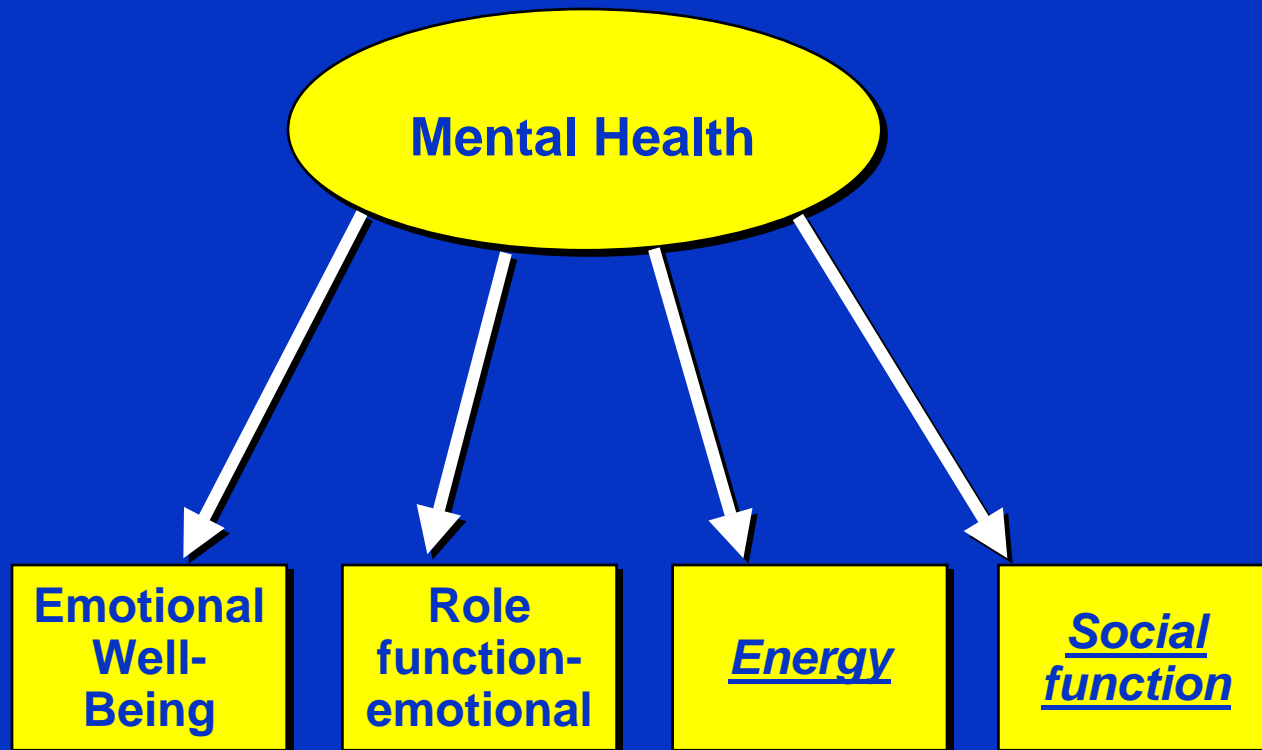
Ready



# Physical Health



# Mental Health



## SF-36 PCS and MCS

$$\begin{aligned} \text{PCS} = & (\text{PF\_Z} * .42402) + (\text{RP\_Z} * .35119) + \\ & (\text{BP\_Z} * .31754) + (\text{GH\_Z} * .24954) + \\ & (\text{EF\_Z} * .02877) + (\text{SF\_Z} * -.00753) + \\ & (\text{RE\_Z} * -.19206) + (\text{EW\_Z} * -.22069) \end{aligned}$$

$$\begin{aligned} \text{MCS} = & (\text{PF\_Z} * -.22999) + (\text{RP\_Z} * -.12329) + \\ & (\text{BP\_Z} * -.09731) + (\text{GH\_Z} * -.01571) + \\ & (\text{EF\_Z} * .23534) + (\text{SF\_Z} * .26876) + \\ & (\text{RE\_Z} * .43407) + (\text{EW\_Z} * .48581) \end{aligned}$$

# T-score Transformation

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

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

# SF-36 Survey Version 1

<http://www.sf-36.org/demos/SF-36.html>

<http://www.sf-36.org/demos/SF-36v2.html>



# Example Uses of Generic HRQOL Measures

## Cross-Sectional

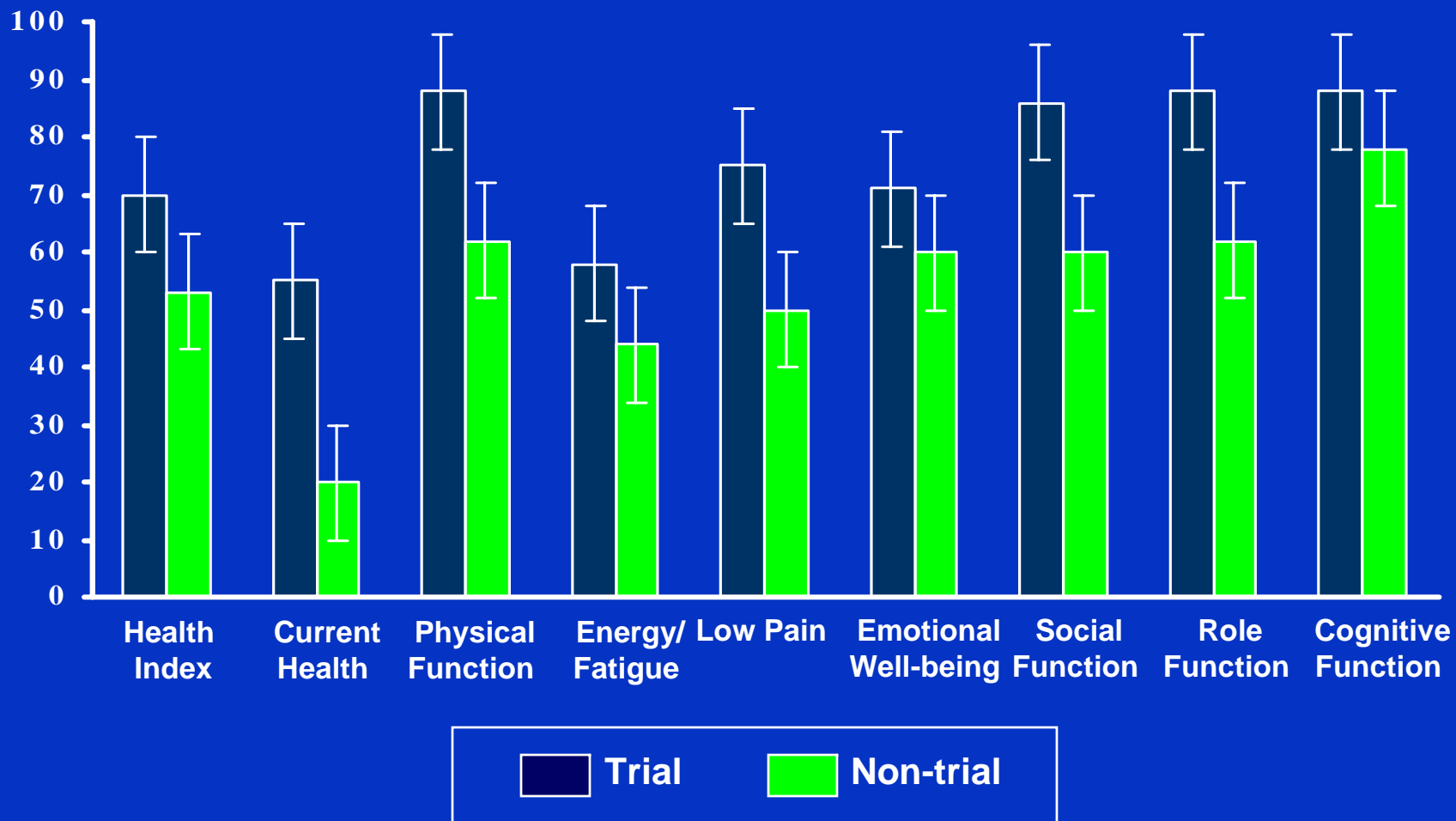
- Comparison of Same Disease in Different Samples
- Profiles of Different Diseases

## Longitudinal

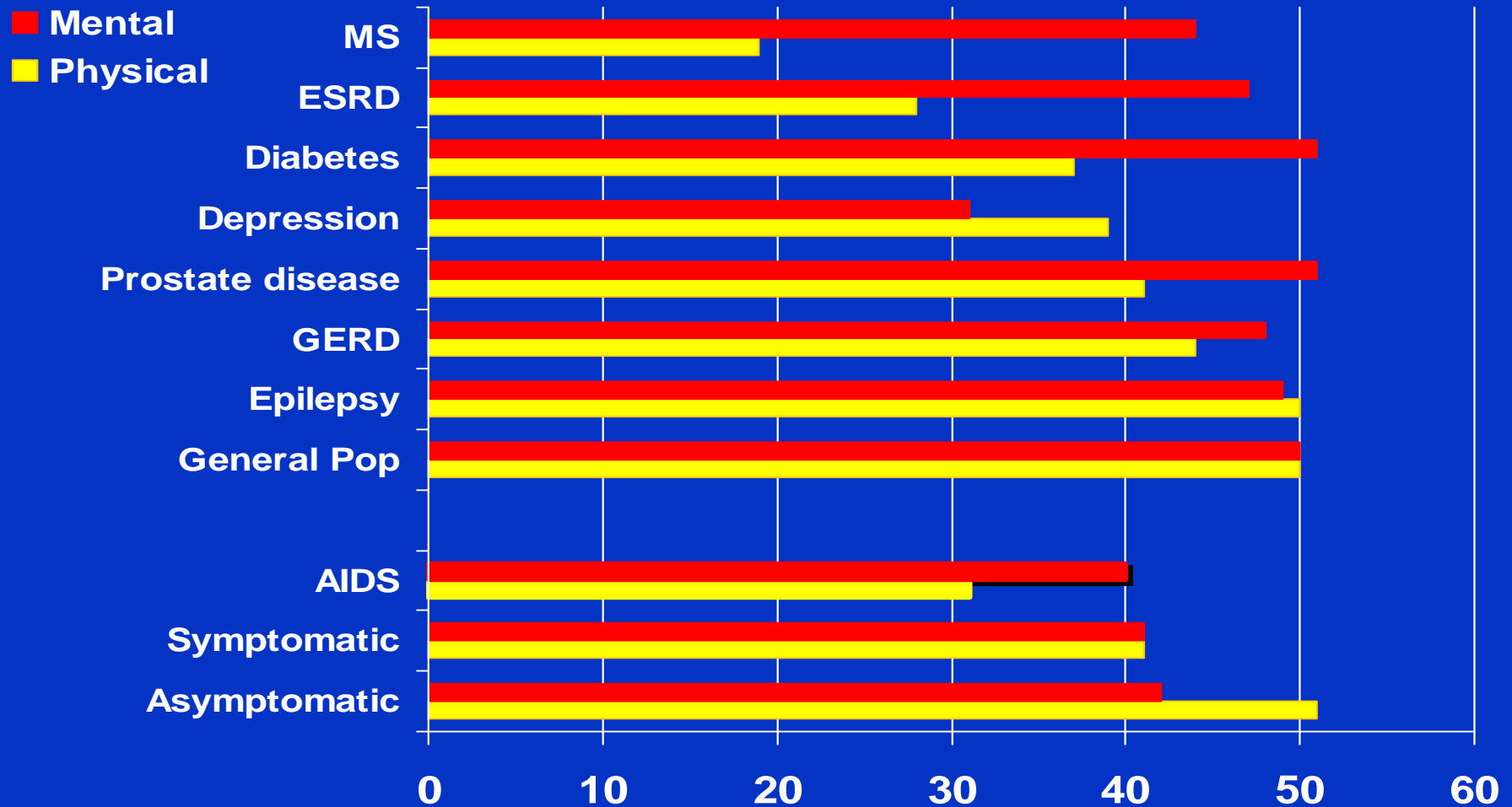
- Profiles of Different Disease
- Identifying Antecedents/Causes of HRQOL

# HRQOL of Patients in ACTG versus Public Hospital Samples

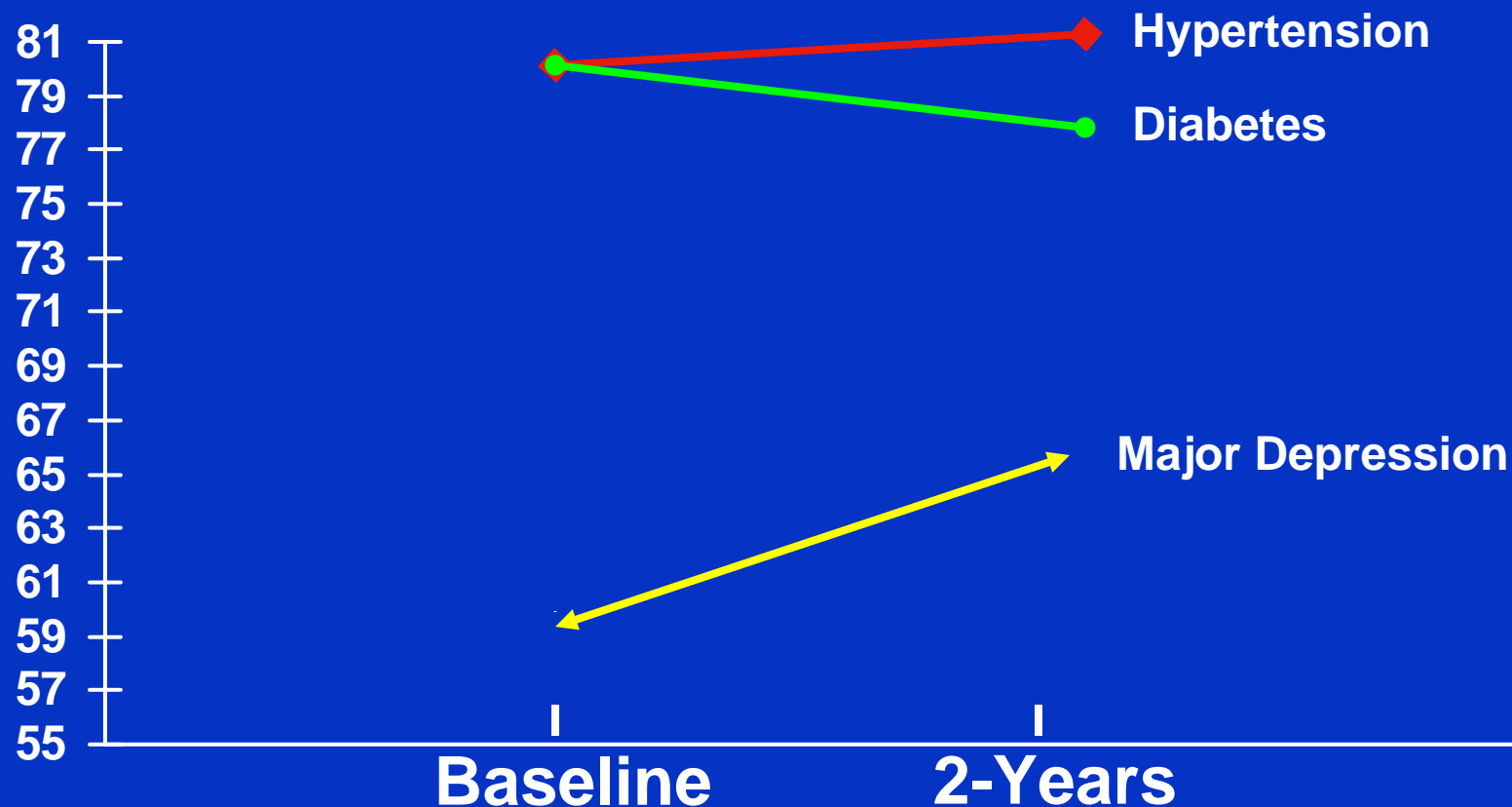
Adjusted Scale Scores (Cunningham et al., 1995)



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

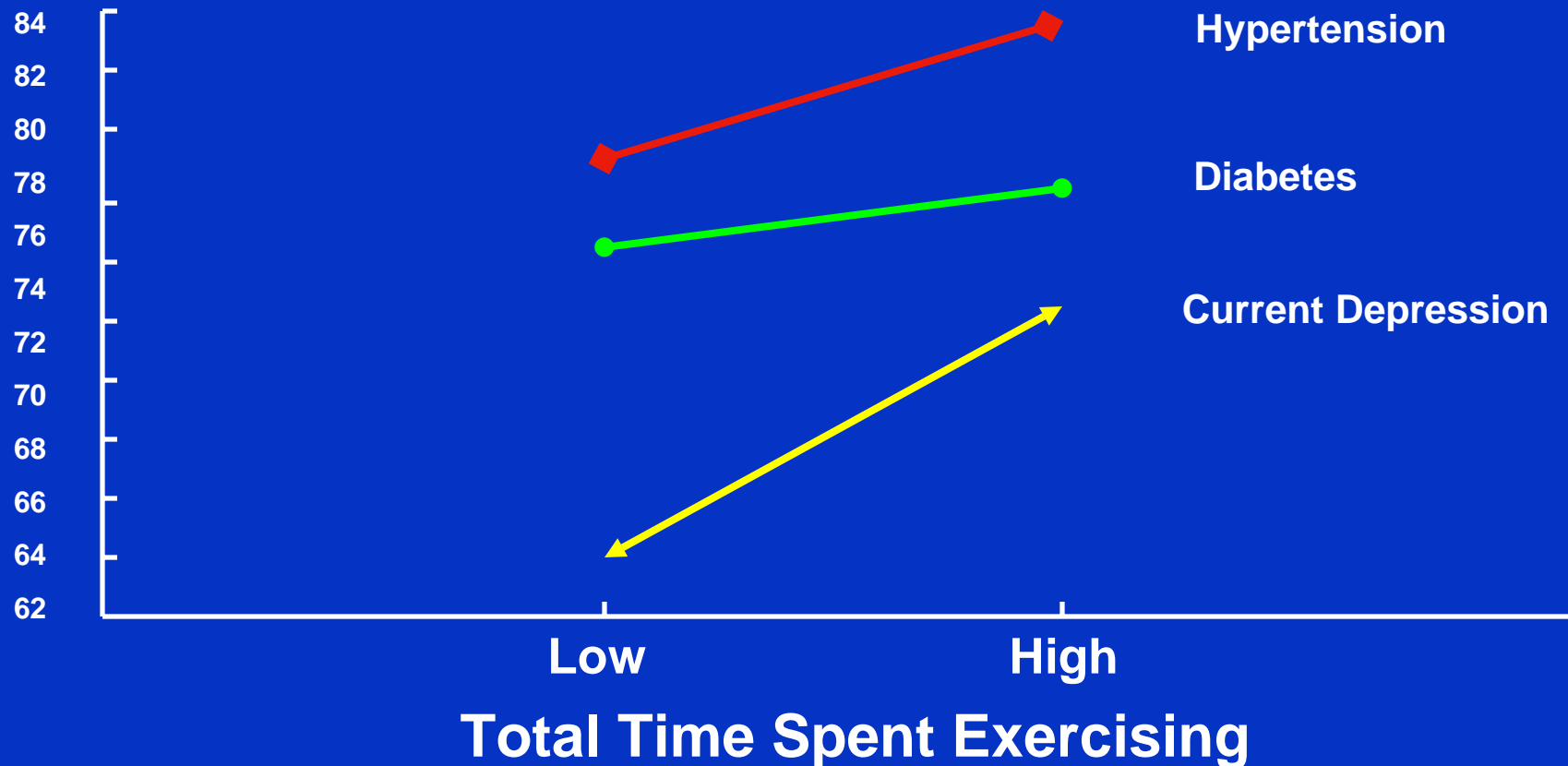


# Course of Emotional Well-being Over 2-years for Patients in the MOS General Medical Sector



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.

# Targeted HRQOL Measures

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

# Kidney-Disease Targeted Items

During the last 30 days, to what extent were you bothered by each of the following?

- Cramps during dialysis
- Washed out or drained

*Not at all bothered*

*Somewhat bothered*

*Moderately bothered*

*Very much bothered*

*Extremely bothered*

# IBS-Targeted Item

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*



# HRQOL in Men Treated for Localized Prostate Cancer

Cross-sectional study of managed care pop.

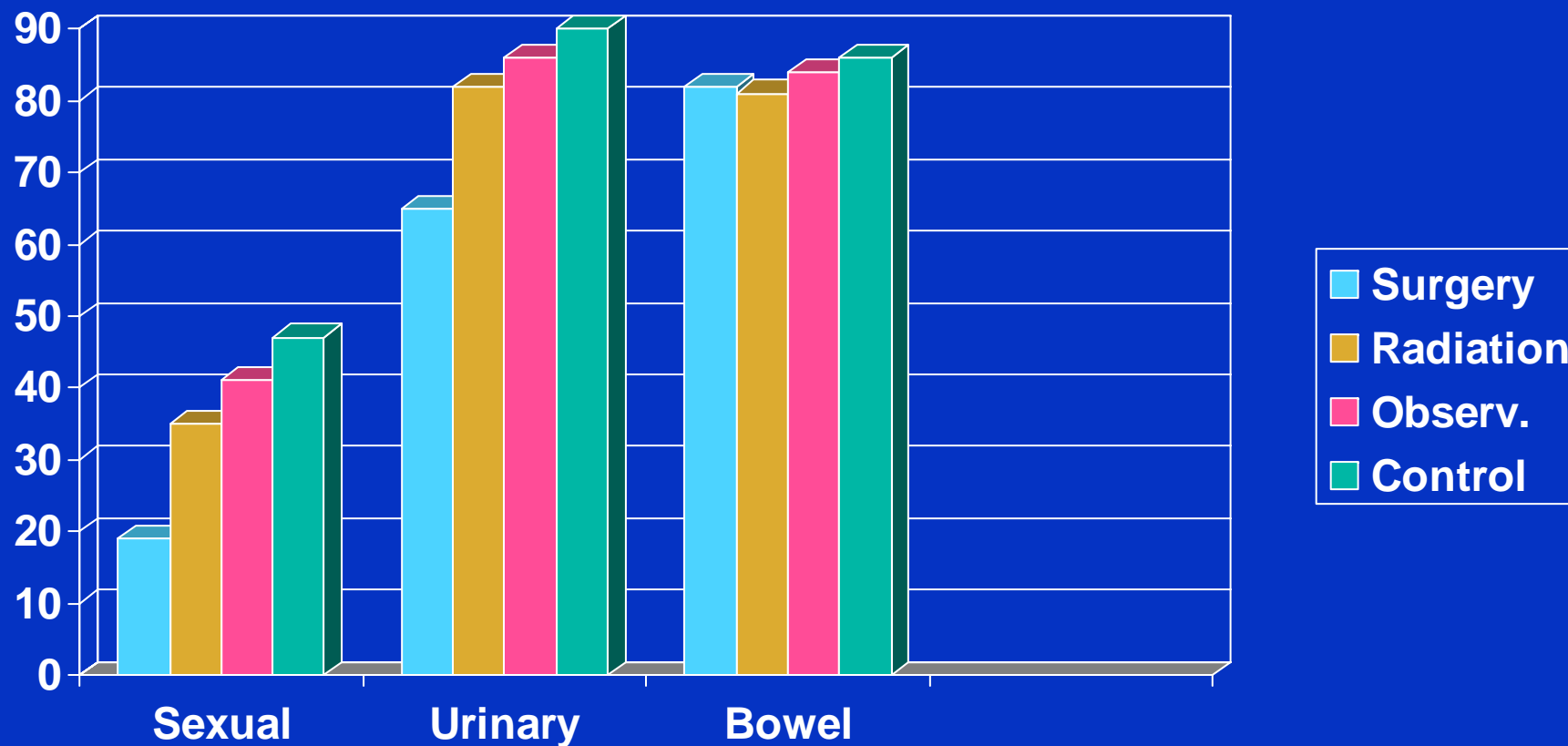
214 men with prostate cancer

- 98 radical prostatectomy
- 56 primary pelvic irradiation
- 60 observation alone

273 age/zip matched pts. without cancer

*Litwin et al. (1995, JAMA)*

# Sexual, Urinary and Bowel Function



# HRQOL Measures Helpful in Ensuring Access to Cost-Effective Care

Cost ↓



Effectiveness ↑

# HRQOL Outcomes

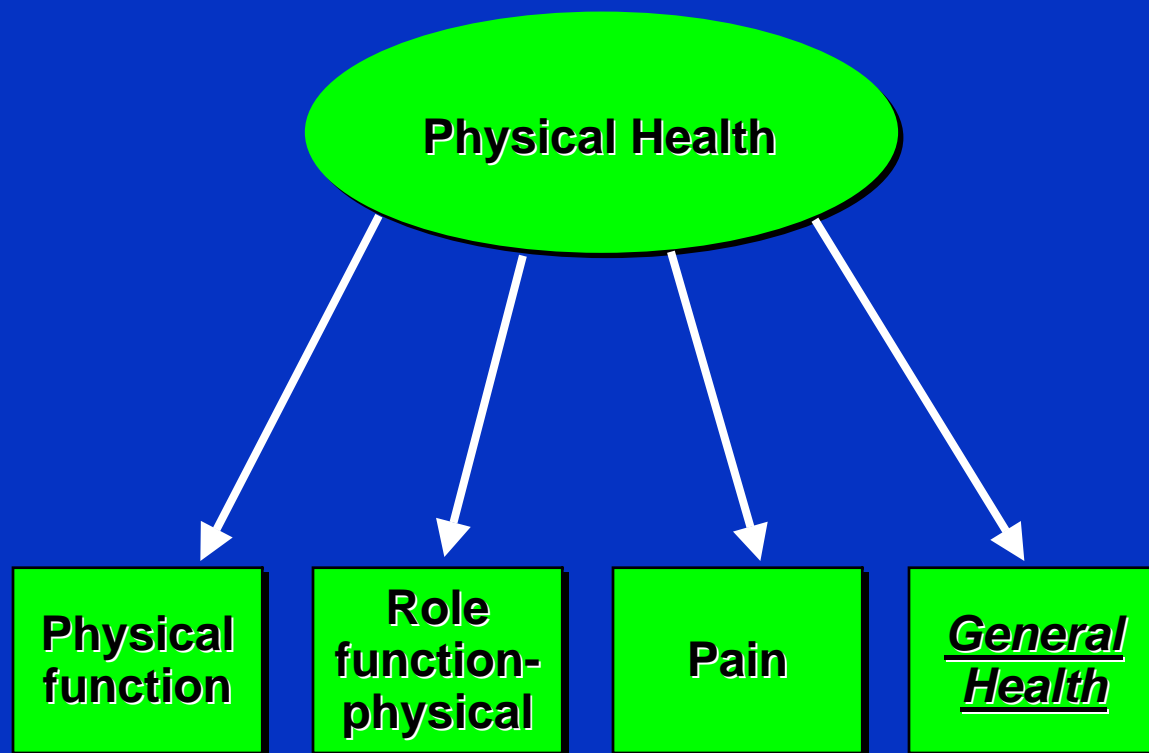
Summarize overall results of health care:

Cost

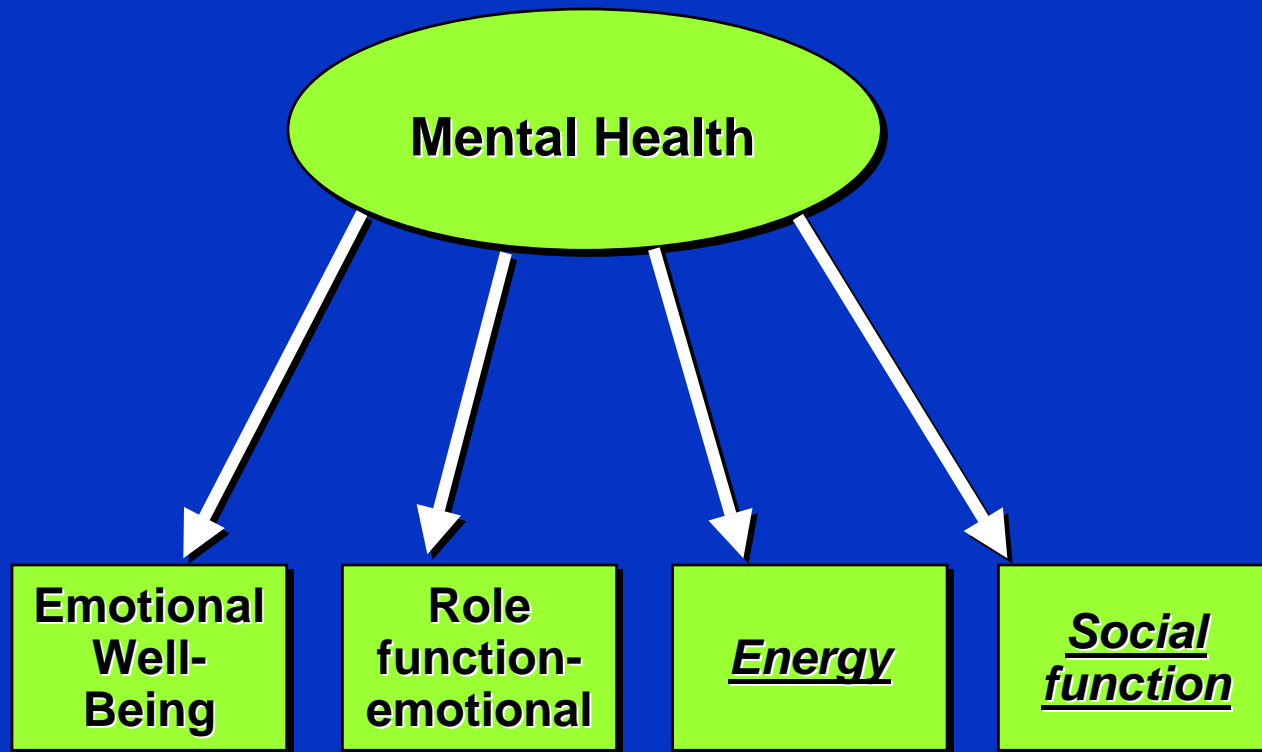


$\rho$  HRQOL

# SF-36 Physical Health

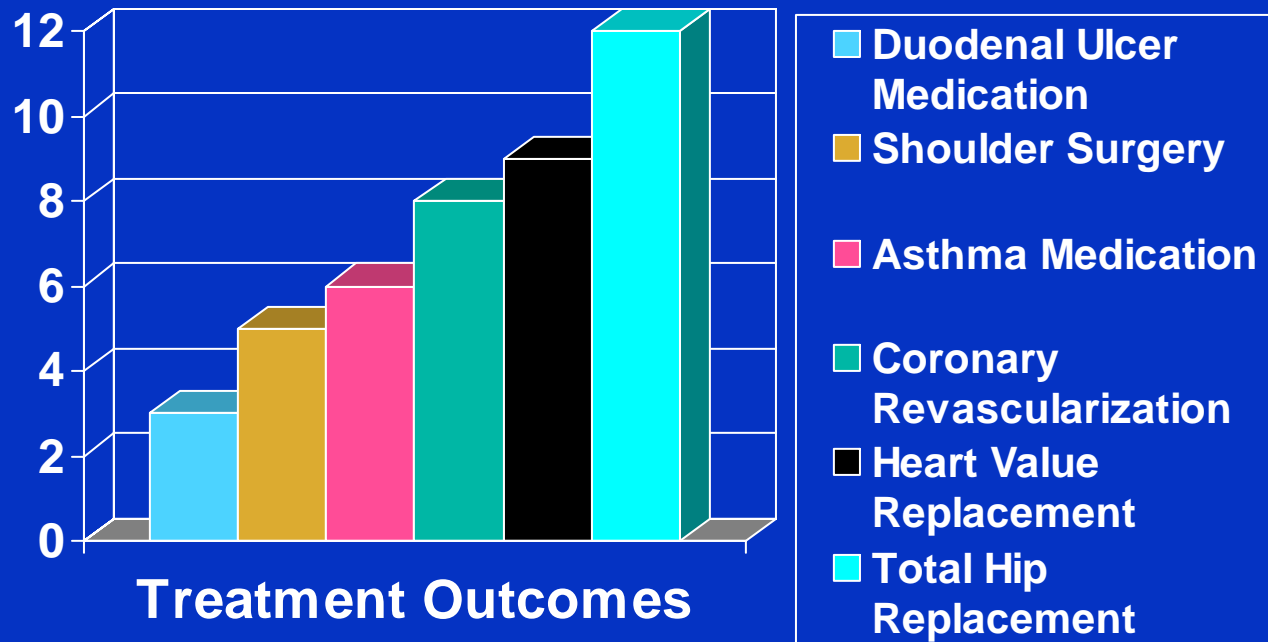


# SF-36 Mental Health

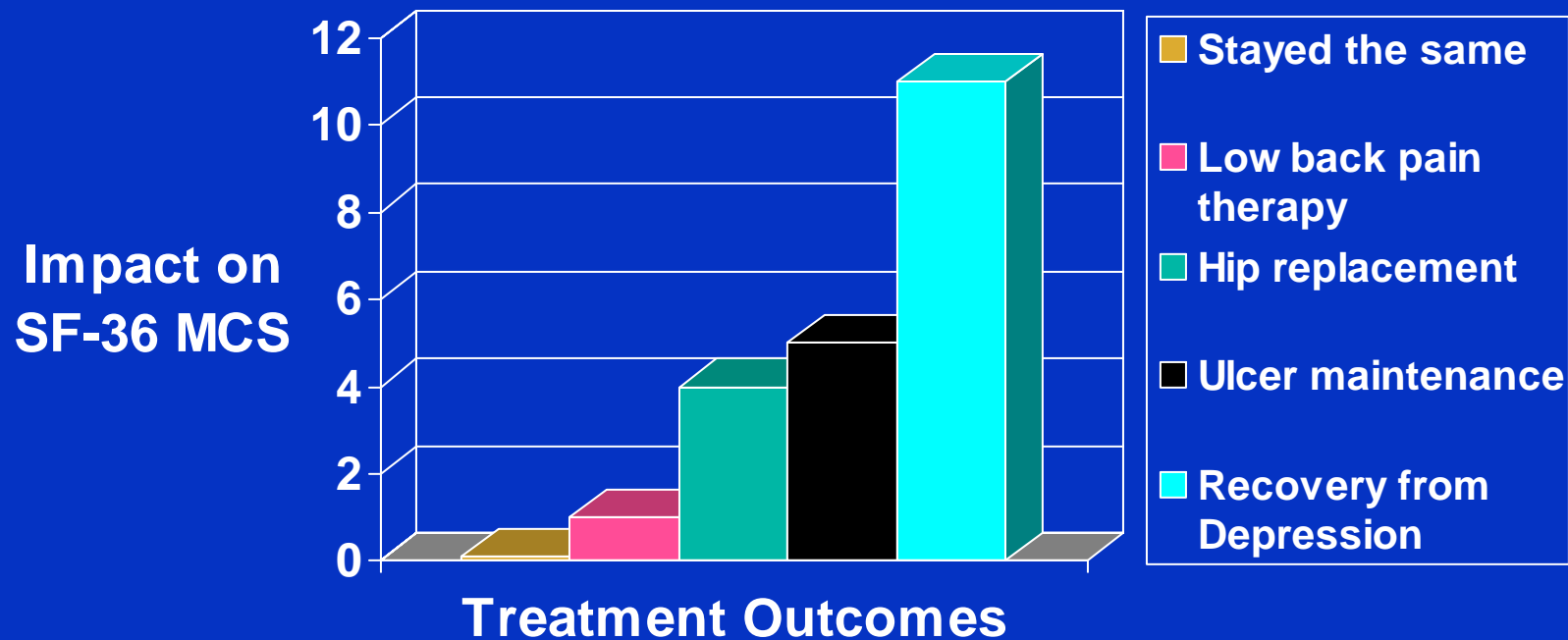


# Treatment Impact on Physical Health

Impact on  
SF-36 PCS



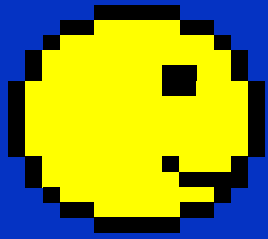
# Treatment Impact on Mental Health





# Debate About Summary Scores

- Taft, C., Karlsson, J., & Sullivan, M. (2001). Do SF-36 component score accurately summarize subscale scores? Quality of Life Research, 10, 395-404.
- Ware, J. E., & Kosinski, M. (2001). Interpreting SF-36 summary health measures: A response. Quality of Life Research, 10, 405-413.
- Taft, C., Karlsson, J., & Sullivan, M. (2001). Reply to Drs Ware and Kosinski. Quality of Life Research, 10, 415-420.



# Weights

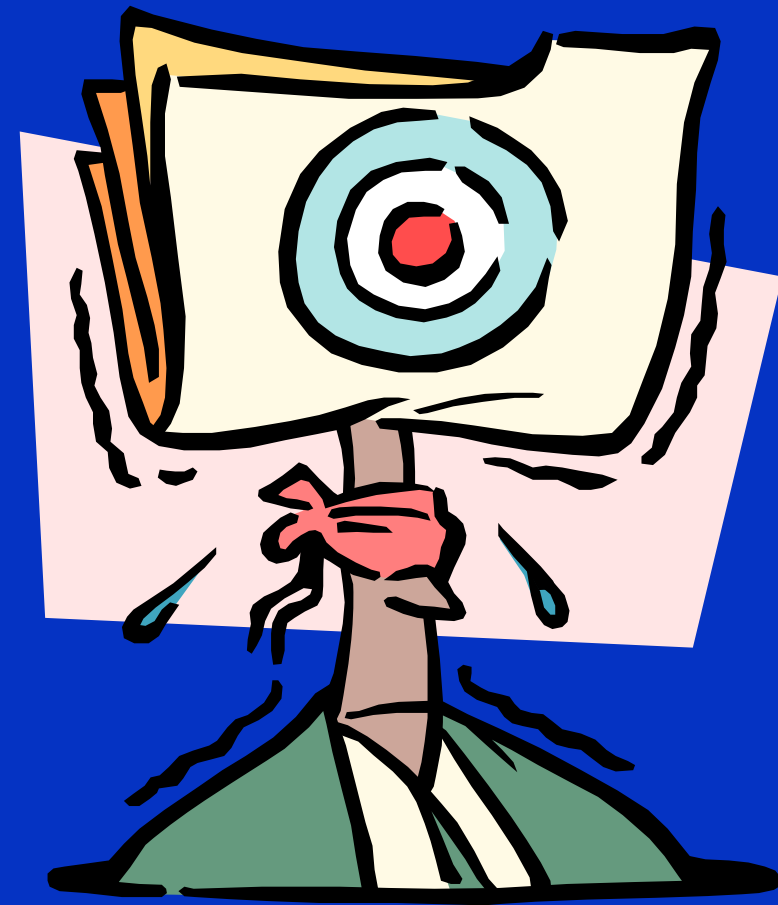
Summary scores for SF-36 derived from uncorrelated (orthogonal) two factor (physical and mental health) solution introduces – and + weights into scoring algorithm

$$\text{PCS-z} = (\text{PF-z}^*.42) + (\text{RP-z}^*.35) + (\text{BP-z}^*.32) + (\text{GH-z}^*.25) \\ + (\text{EN-z}^*.03) + (\text{SF-z}^*-.01) + (\text{RE-z}^*-.19) + (\text{MH-z}^*-.22)$$

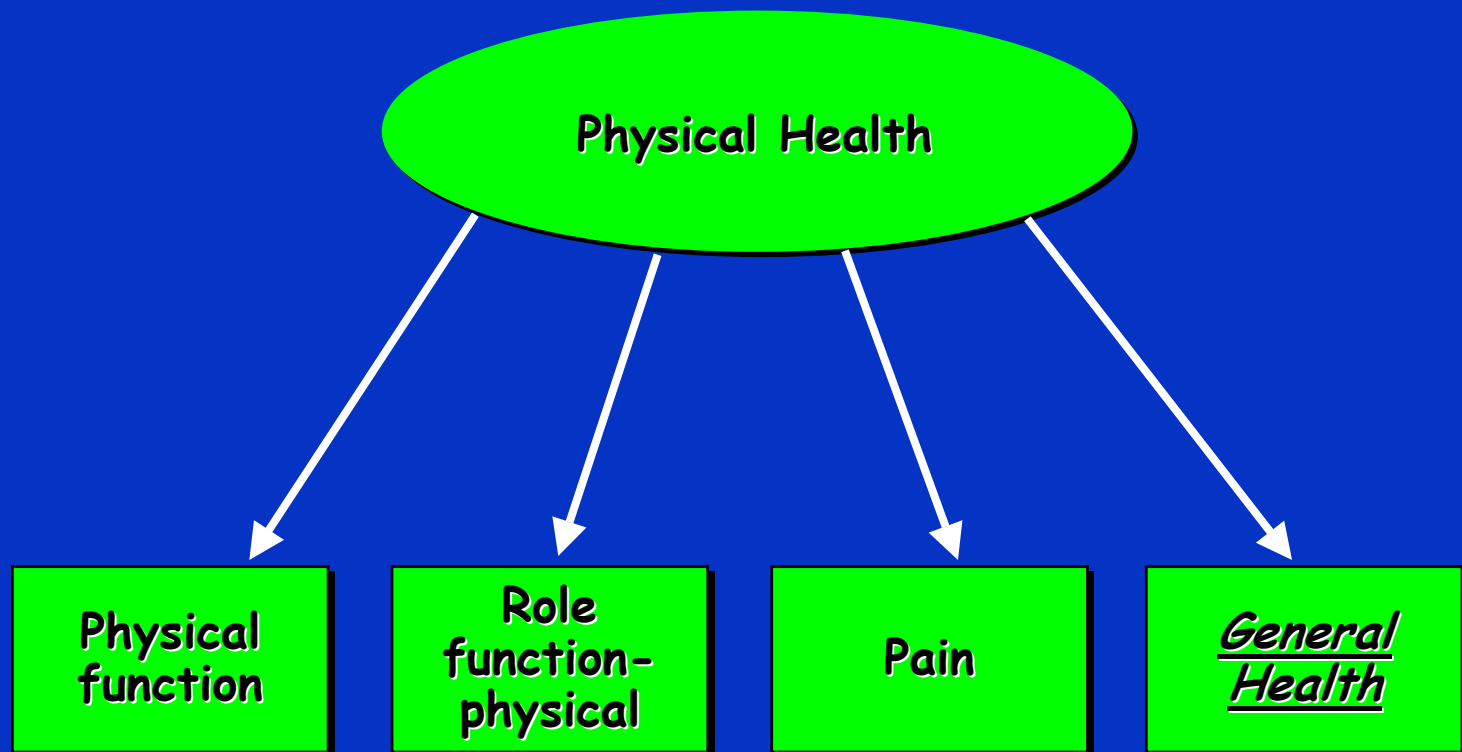
$$\text{MCS-z} = (\text{PF-z}^*-.23) + (\text{RP-z}^*-.12) + (\text{BP-z}^*-.10) + \\ (\text{GH-z}^*-.12) + (\text{EN-z}^*.24) + (\text{SF-z}^*.27) + (\text{RE-z}^*.43) + \\ (\text{MH-z}^*.48)$$

# 536 Primary Care Patients Initiating Antidepressant Tx

- ≥3-month improvements in physical functioning, role—physical, pain, and general health perceptions ranging from 0.28 to 0.49 SDs.
- ≥Yet SF-36 PCS did not improve.
- ≥*Simon et al. (Med Care, 1998)*



Four scales improve 0.28-0.49 SD, but physical health summary score doesn't change

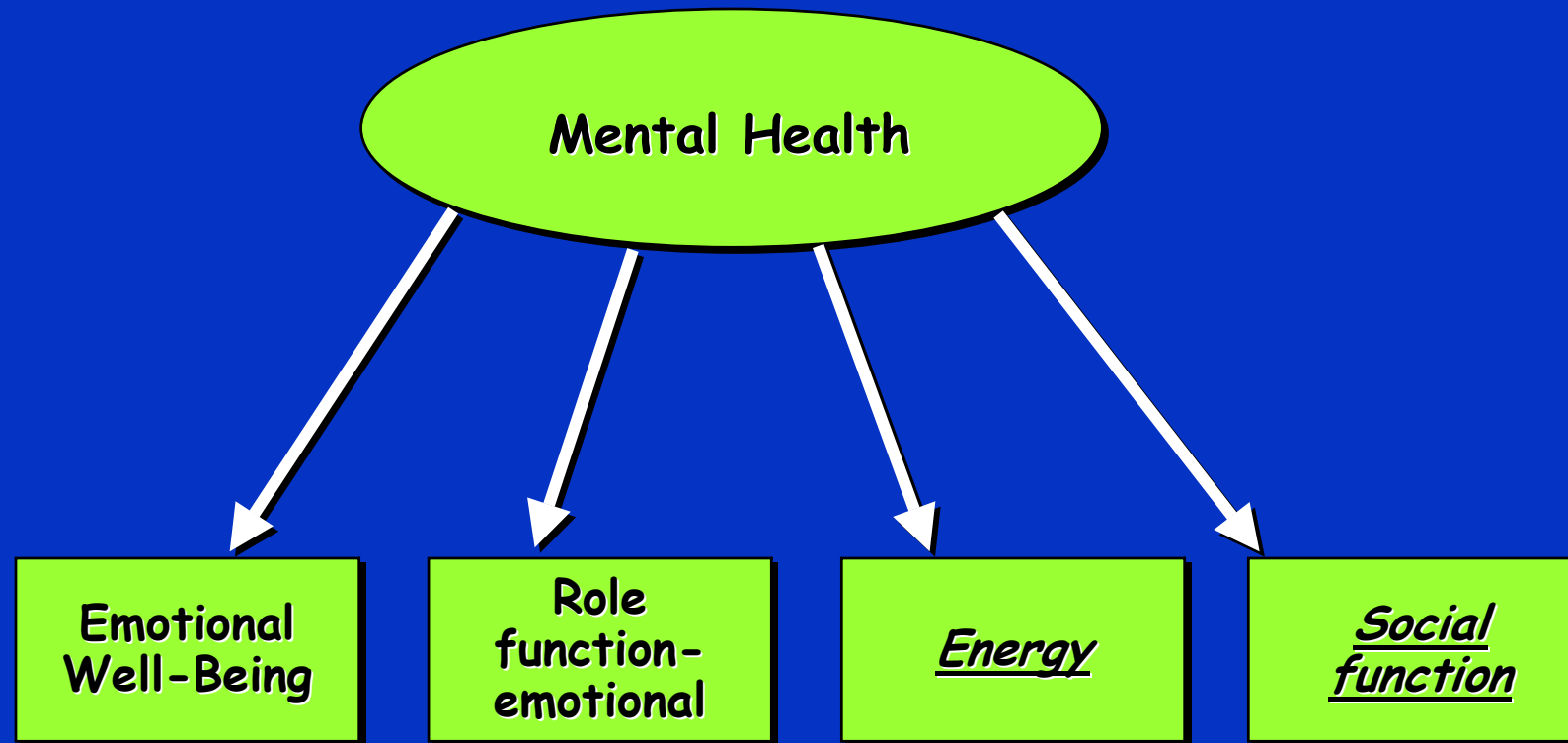


# n = 194 with Multiple Sclerosis

- ≥ Lower scores than general population on
  - " Emotional well-being (↓ 0.3 SD)
  - " Role—emotional (↓ 0.7 SD)
  - " Energy (↓1.0 SD)
  - " Social functioning (↓1.0 SD)
- ≥ Yet SF-36 MCS was only 0.2 SD lower.
- ≥ RAND-36 mental health was 0.9 SD lower.

*Nortvedt et al. (Med Care, 2000)*

Four scales 0.3-1.0 SD lower, but  
mental health summary score  
only 0.2 SD lower

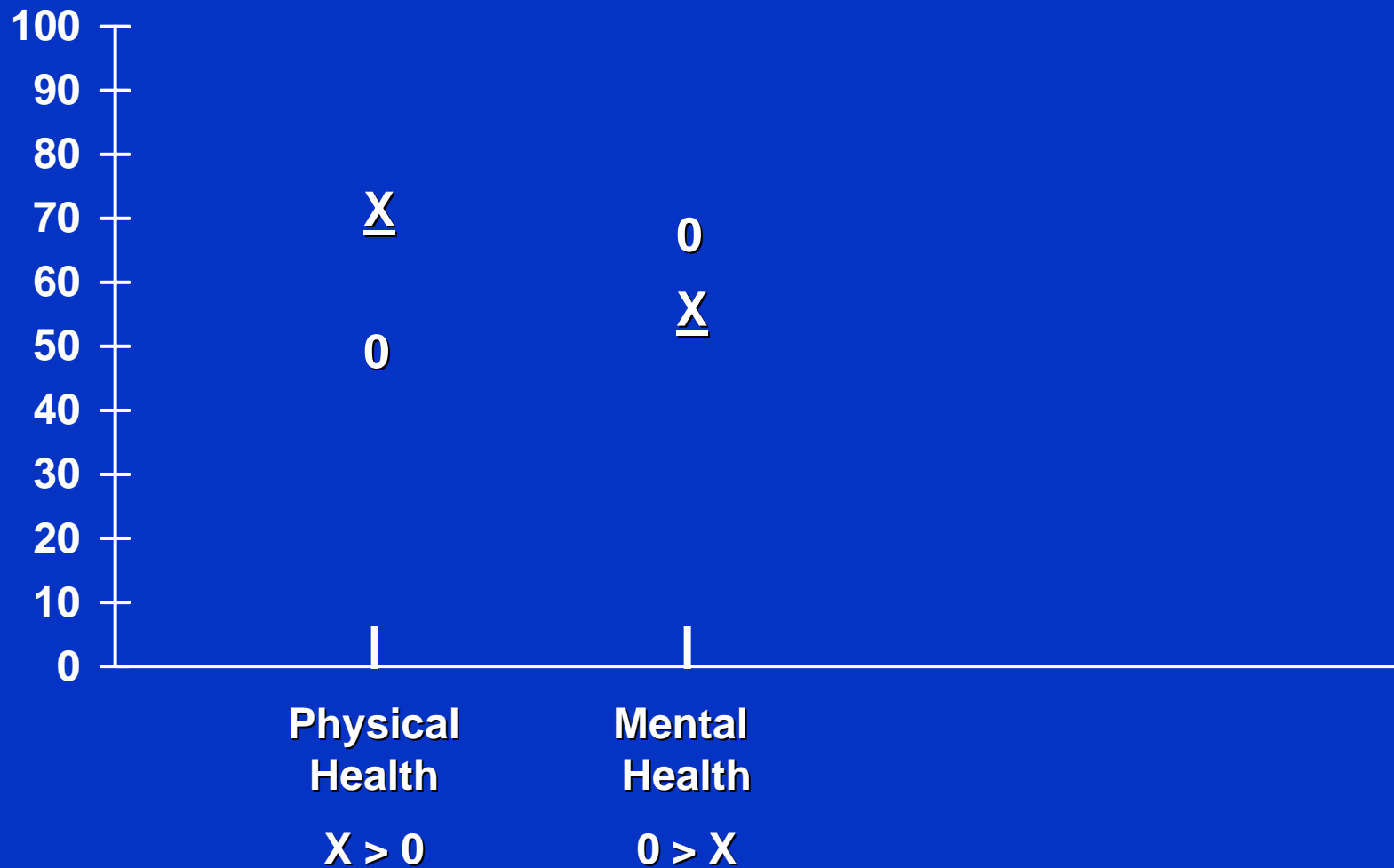


# Farivar et al. alternative weights

$$\text{PCS}_z = (\text{PF}_z * .20) + (\text{RP}_z * .31) + (\text{BP}_z * .23) + (\text{GH}_z * .20) + (\text{EF}_z * .13) + (\text{SF}_z * .11) + (\text{RE}_z * .03) + (\text{EW}_z * -.03)$$

$$\text{MCS}_z = (\text{PF}_z * -.02) + (\text{RP}_z * .03) + (\text{BP}_z * .04) + (\text{GH}_z * .10) + (\text{EF}_z * .29) + (\text{SF}_z * .14) + (\text{RE}_z * .20) + (\text{EW}_z * .35)$$

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





# Single Weighted Combination of Scores

Perceived Health Index (n = 1,862; reliability = 0.94)

Highest      Lowest      Quartile on Index

---

35%      84%      at least 1 moderate symptom

7%      70%      at least 1 disability day

1%      11%      hospital admission

2%      14%      performance of invasive  
diagnostic procedure

---

Perceived Health Index = 0.20 Physical functioning + 0.15 Pain + 0.41 Energy +  
0.10 Emotional well-being + 0.05 Social functioning + 0.09 Role functioning.

Bozzette, S.A., Hays, R.D., Berry, S.H., & Kanouse, D.E. (1994). A perceived health index for use in persons with advanced HIV disease: Derivation, reliability, and validity. Medical Care, 32, 716-731.

# Is Use of Medicine Related to Worse HRQOL?

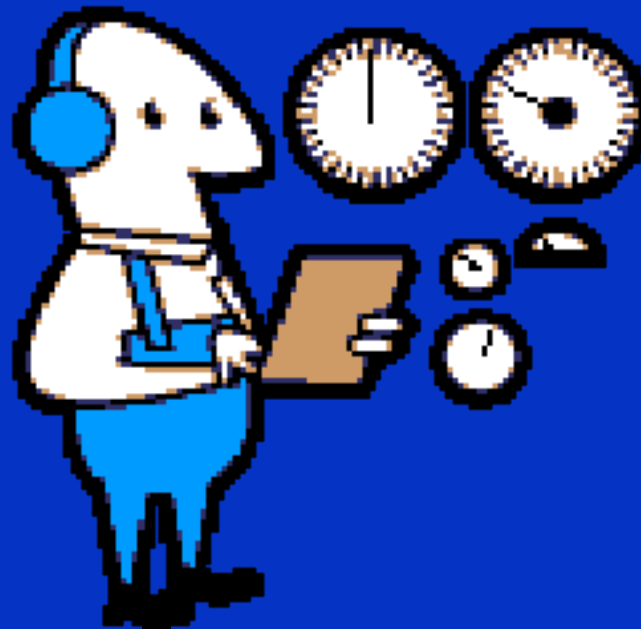
Person	Medication Use	HRQOL (0-100 scale)
1	No	dead
2	No	dead
3	No	50
4	No	75
5	No	100
6	Yes	0
7	Yes	25
8	Yes	50
9	Yes	75
10	Yes	100

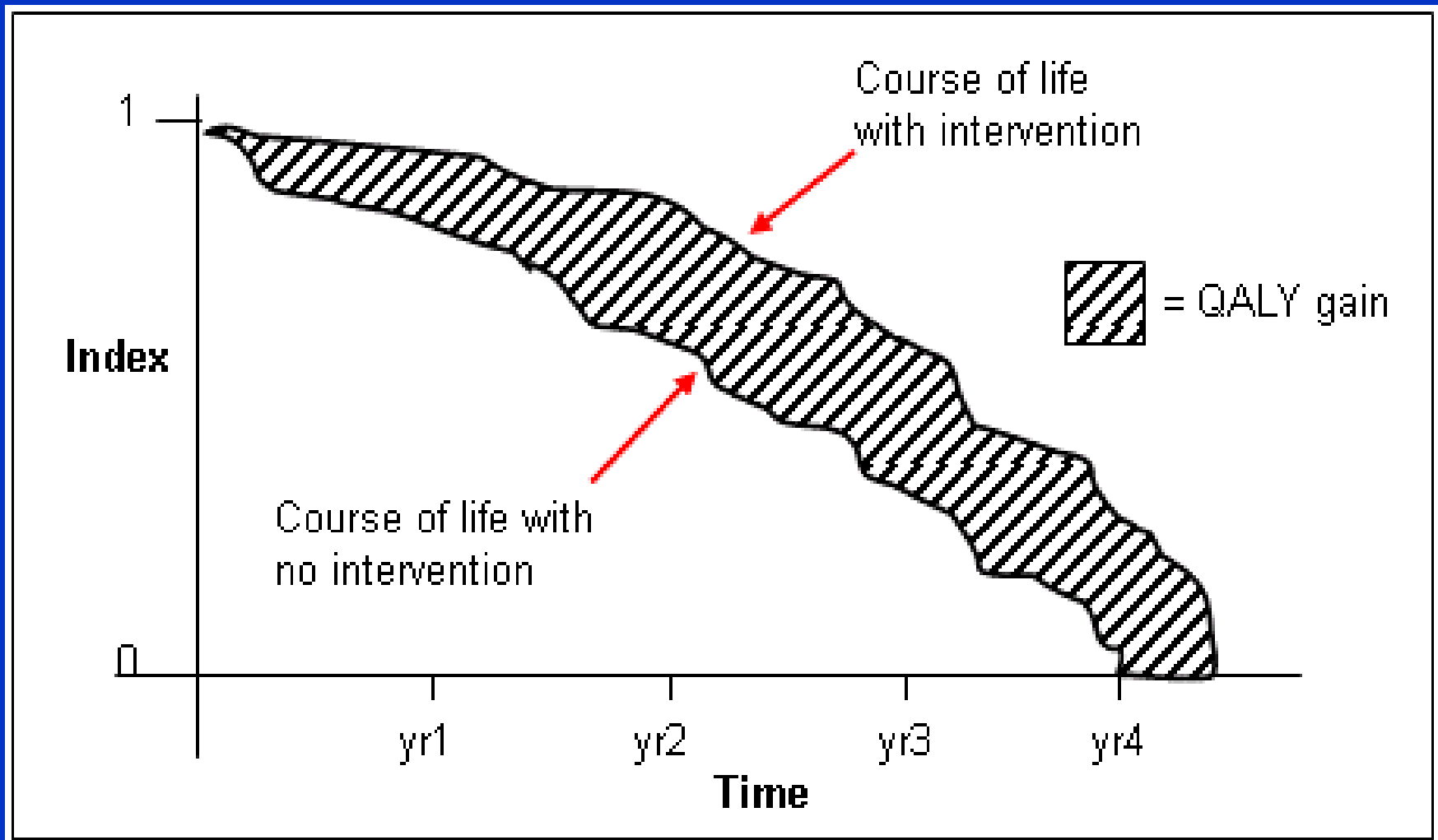
  

Group	n	HRQOL
No Medicine	3	75
Yes Medicine	5	50

# Do a Survival Analysis?

Marathoner and person in coma = 1.0





# Overall Health Rating Item

Overall, how would you rate your current health?  
(Circle One Number)



Worst possible  
health (as bad or  
worse than  
being dead)

Half-way  
between worst  
and best

Best  
possible  
health

# Overall Quality of Life Item

Overall, how would you rate your quality of life?



Worst possible  
quality of life  
(as bad or worse  
than being dead)

Half-way  
between worst  
and best

Best possible  
quality of life

# Brazier et al. 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

# Health State 111111

## **Health state 111111**

Your health does not limit you in **vigorous activities** (e.g. running, lifting heavy objects, participating in strenuous sports).

You have no problems with your work or other regular daily activities as a result of your **physical health or any emotional problems**.

Your health limits your **social activities** (like visiting friends or close relatives) a little or none of the time

You have no pain

You feel **tense or downhearted and low** a little or none of the time.

You have a lot of **energy** all of the time



# 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

# Indirect Preference Measures-- Quality of Well-Being Scale

- Summarize HRQOL in QALYs
  - Physical activity (PAC)
  - Mobility (MOB)
  - Social activity (SAC)
  - Symptom/problem complexes (SPC)



- Well-Being Formula  $w = 1 + PAC + MOB + SAC + SPC$

# Quality of Well-Being Weighting Procedure

Each page in this booklet tells how an imaginary person is affected by a health problem on one day of his or her life. I want you to look at each health situation and rate it on a ladder with steps numbered from zero to ten. The information on each page tells 1) the person's age group, 2) whether the person could drive or use public transportation, 3) how well the person could walk, 4) how well the person could perform the activities usual for his or her age, and 5) what symptom or problem was bothering the person.

## Example Case #1

### Adult (18-65)

Drove car or used public transportation without help

Walked without physical problems

Limited in amount or kind of work, school, or housework

Problem with being overweight or underweight



# Quality of Well-Being States and Weights

Component	Measures	States	Weights
Physical activity	Physical function	In bed, chair, couch, or wheelchair*	<u>-.077</u>
		In wheelchair* or had difficulty lifting, stooping, using stairs, walking, etc.	-.060
Mobility	Ability to get around or transport oneself	In hospital, nursing home, or hospice.	<u>-.090</u>
		Did not drive car or use public transportation	-.062
Social activity	Role function and self-care	Did not feed, bath, dress, or toilet	<u>-.106</u>
		Limited or did not perform role	-.061
Symptom/problem	Physical symptoms and complex problems	Worst symptom from loss of consciousness to breathing smog or unpleasant air	<u>-.407</u>
			-.101

\* moved vs. did not move oneself in wheelchair

## Your own health state today

By placing a tick in one box in each group below, please indicate which statement best describes your own health state today.

Do not tick more than one box in each group.

### 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 and dressing myself
- I am unable to wash or dress myself

### Usual Activities (eg. 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

On each dimension, respondent gets three choices of level.

# EQ-5D

**Mobility**

**Self-care**

**Usual activities**

**Pain/discomfort**

**Anxiety/depression**

- **243 states, 3 levels per attribute**

# HUI-3

Vision

Hearing

Speech

Ambulation

Dexterity

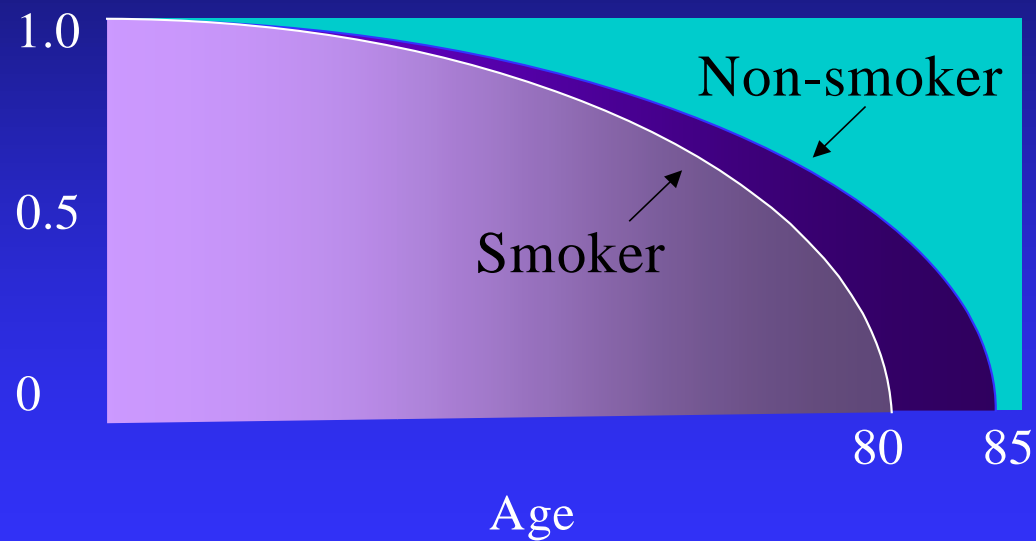
Cognition

Pain and discomfort

Emotion

- **972,000 states, 5-6 levels per attribute**

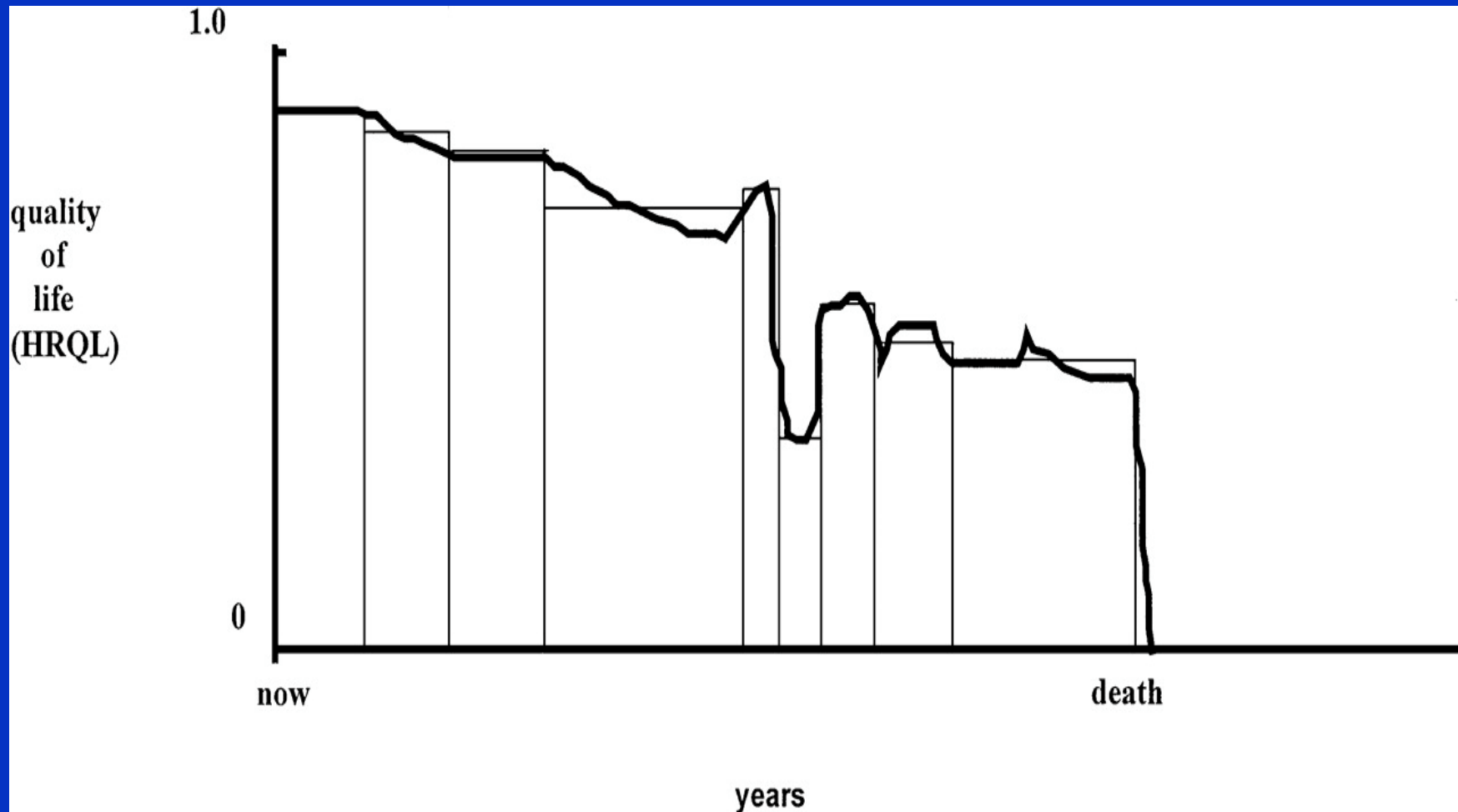
# Quality-adjusted life-years (QALYs)



Tengs, T. Presented at Health Services Research Seminar,  
VA Hospital, San Diego, July, 2000



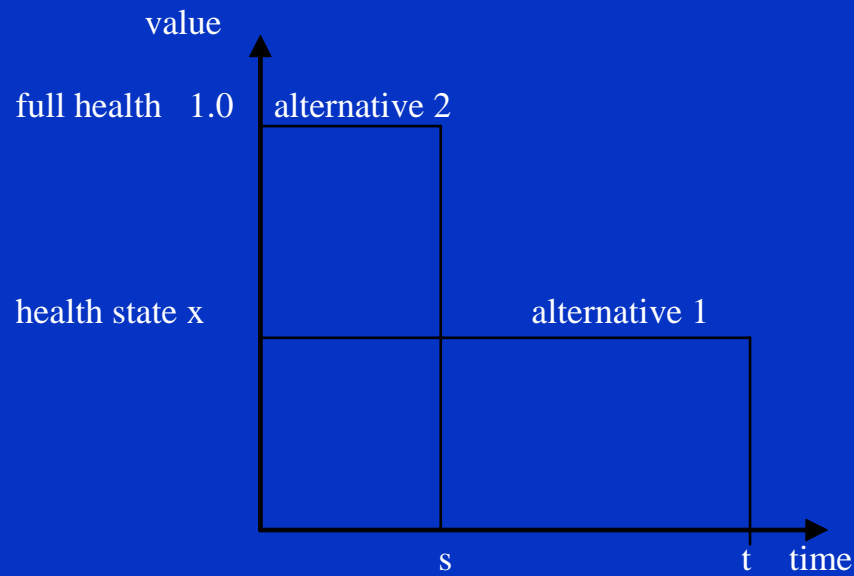
# Quality of Life for Individual Over Time



# Direct Preference Measures Time Tradeoff (TTO)

- Choice between two certain outcomes
- Years of life traded for quality of life
- Simple to administer alternative to SG

### Time Trade-off approach:



Alternative 1: intermediate health state  $x$ , for time  $t$ , followed by death.

Alternative 2: full health for time  $s$  where  $s < t$ , followed by death.

Time  $t$  is given and the individual is asked to state  $s$ . The preference score is then worked out as  $s/t$ .

# Time Tradeoff

Choice #1: Your present state (e.g., paralysis)

Life Expectancy: 10 years

Choice #2: Complete mobility

How many years (x) would you give up in your current state to be able to have complete mobility?

$$\left[ 1 - \frac{x}{10} = \text{QALY} \right]$$

# Time Tradeoff

How many years (x) would you give up in your current state to be able to have complete mobility?

$$X = 0 \rightarrow QALY = 1$$

$$X = 1 \rightarrow QALY = 0.9$$

$$X = 5 \rightarrow QALY = 0.5$$

$$X = 10 \rightarrow QALY = 0$$

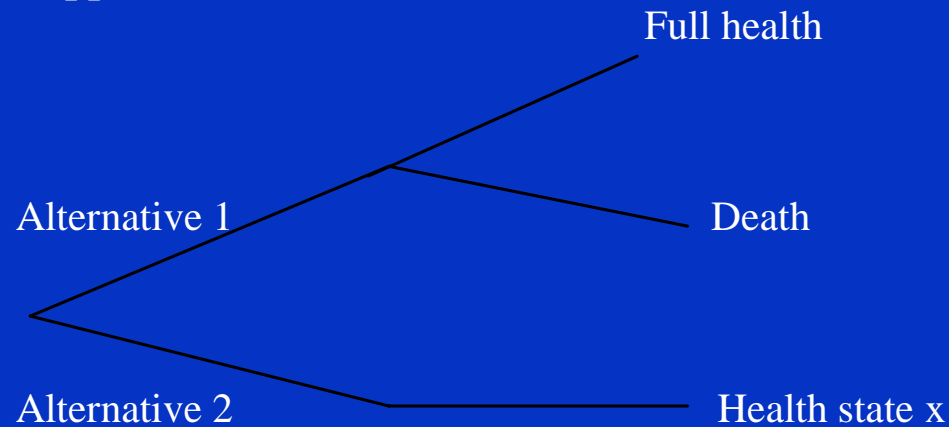
$$\left[ 1 - \frac{X}{10} = QALY \right]$$

# Standard Gamble

## Classical method of assessing preferences

- Choose between certain outcome and a gamble
- Conformity to axioms of expected utility theory
- Incorporates uncertainty (thus, more reflective of treatment decisions).

## Standard Gamble approach



Alternative 1: probability ( $p$ ) of living full health for individual's remaining life expectancy otherwise immediate death.

Alternative 2 is the certainty of living in a given intermediate health state  $x$ .

# Standard Gamble (SG)

Choice #1: Your present state (e.g., paralysis)

Choice #2: X probability of complete mobility  
1-X probability of death

Preference Value: Point at which indifferent  
between choices, varying X

[  $X = QALY$  ]



# Standard Gamble (SG)

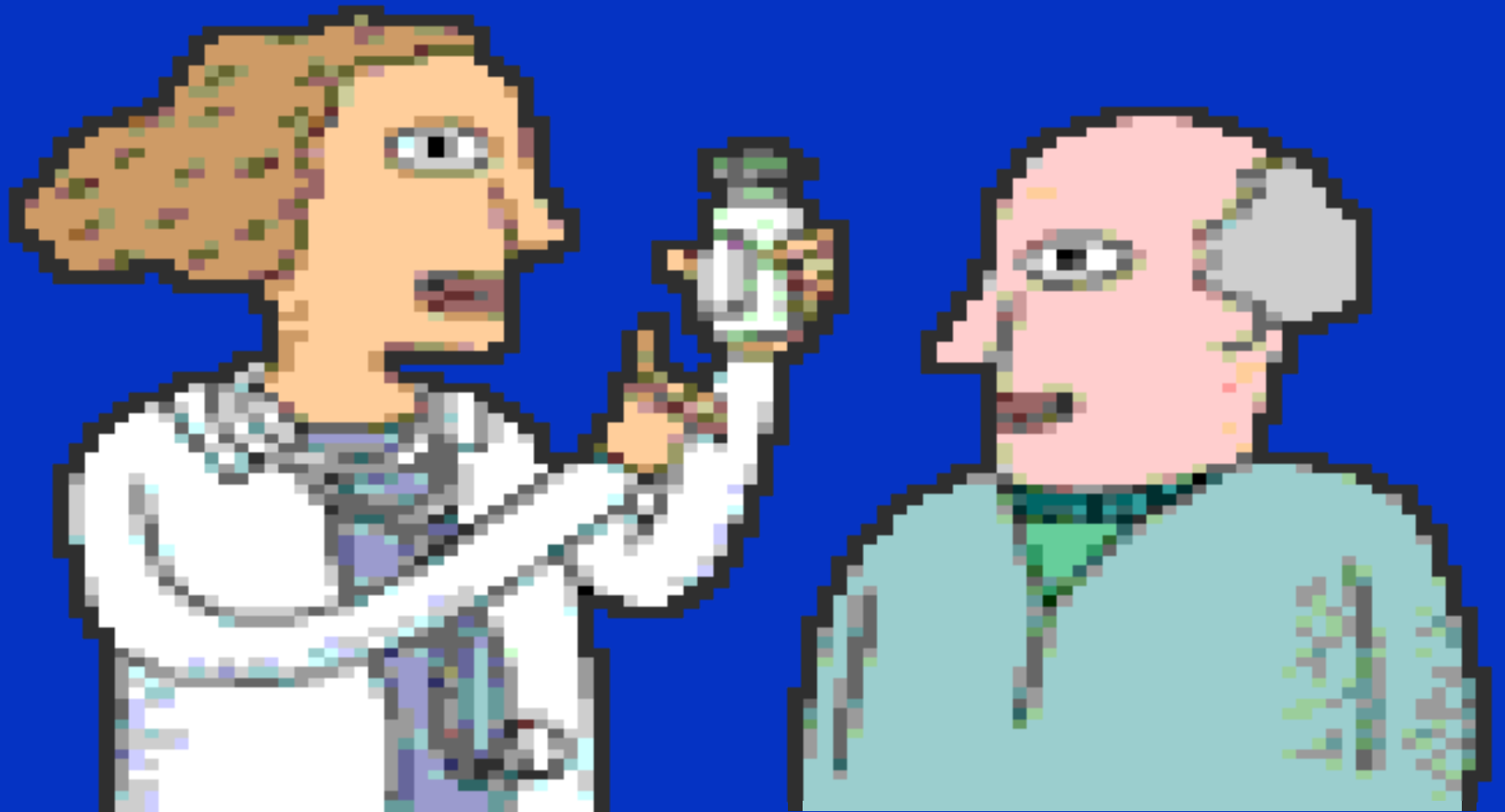
**X probability of complete mobility**

$$X = 1.00 \rightarrow QALY = 1.00$$

$$X = 0.50 \rightarrow QALY = 0.50$$

$$X = 0.00 \rightarrow QALY = 0.00$$

# Questions?



# For further information

<http://hs214.med.ucla.edu/modules/news/>

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

<http://www.rand.org/health/surveys.html>

<http://www.qolid.org/>

[www.sf-36.com](http://www.sf-36.com)

<http://www.nihpromis.org/>

<https://www.editorialmanager.com/quire/>

<http://www.chime.ucla.edu/measurement/measurement.htm>

[http://www.dartmouth.edu/~coopproj/more\\_charts.html](http://www.dartmouth.edu/~coopproj/more_charts.html)

<http://medicine.ucsd.edu/fpm/hoap/index.html>

<http://www.mapivalues.com/>

<http://healthmeasurement.org/>

<http://www.facit.org/>

<http://www.eortc.be/>

[http://www.uclaurology.com/site\\_uo/pdf/PCI\\_short\\_scoring.pdf](http://www.uclaurology.com/site_uo/pdf/PCI_short_scoring.pdf)

# Appendix: *Generic Child Health Measures*

Landgraf, J. M., & Abetz, L. N. (1996). Measuring health outcomes in pediatric populations: Issues in psychometrics and application. In B. Spilker (ed.), Quality of life and pharmacoeconomics in clinical trials, Second edition. Lippincott-Raven Publishers.

# Ad Hoc Preference Score Estimates

**Comprehensive Geriatric Assessment (n = 363 community-dwelling older persons) lead to improvements in SF-36 energy, social functioning, and**

- " Physical functioning (4.69 points) in 64 weeks**
- " Cost of \$746 over 5 years beyond control group**

**Keeler, E. B., et al. Cost-effectiveness of outpatient geriatric assessment with an intervention to increase adherence. Med Care, 1999, 37 (12), 1199-1206.**

# Is CGA worth paying for?

Change in QALYs associated with 4.69 change in SF-36 physical functioning

- "  $r = 0.69 \rightarrow b = .003$
- "  $\rho\text{QWB} = 4.69 \times .003 = .014$
- "  $.014 \times 5 \text{ yrs.} = \underline{0.07 \text{ QALYs}}$
- " Cost/QALY: \$10,600+

<\$20,000 per QALY worthwhile

# Limitations of Preference Measures

**Complexity of task**

**Coarseness of health states**

**Sensitivity to method of elicitation**

# Hypothetical Health States

## Physical Health

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P3	0.00	High
P2	-0.20	Medium
P1	-0.50	Low

## Mental Health

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M3	0.00	High
M2	-0.30	Medium
M1	-0.40	Low



# Mapping Health States into Quality of Life

