

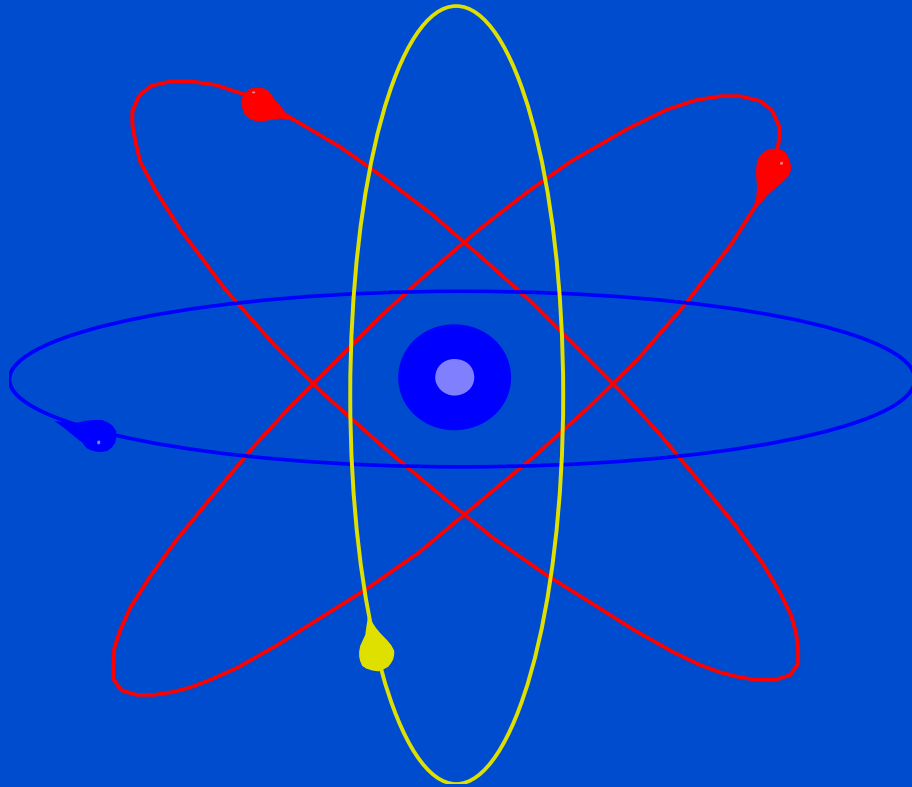
Measurement of Health-Related Quality of Life Outcomes

Ron D. Hays, Ph.D. (hays@rand.org)

January 29, 2002 (3:00-6:00 pm)

Main conference room

Health Care System Concerns



Access

Affordability

Accountability

Resource Allocation Problem

Everyone in health care wants reimbursement for their services

Options range from acute surgery, prevention, to long term care

But there is a limited amount of money

How do we spend limited resources to enhance population health?

Cost Effective Care

Cost ☐

Effectiveness ☐

“Outcomes”

How is the Patient Doing?

Physiological

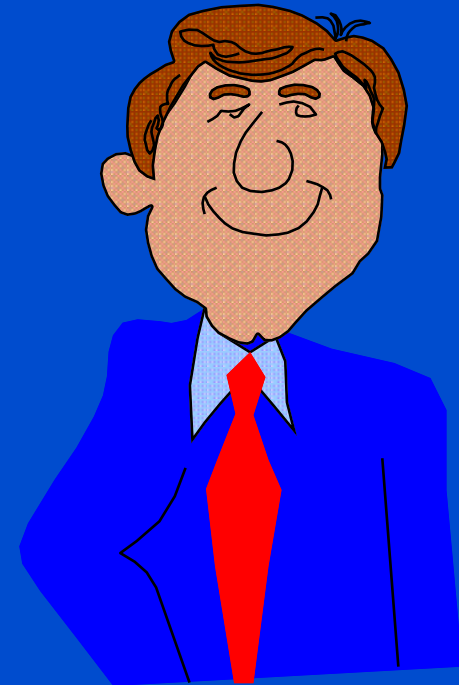
- Hematocrit
- Albumin

Physician observation

- Physical performance

Self-report indicators

- Functioning and well-being



Health-Related Quality of Life is:

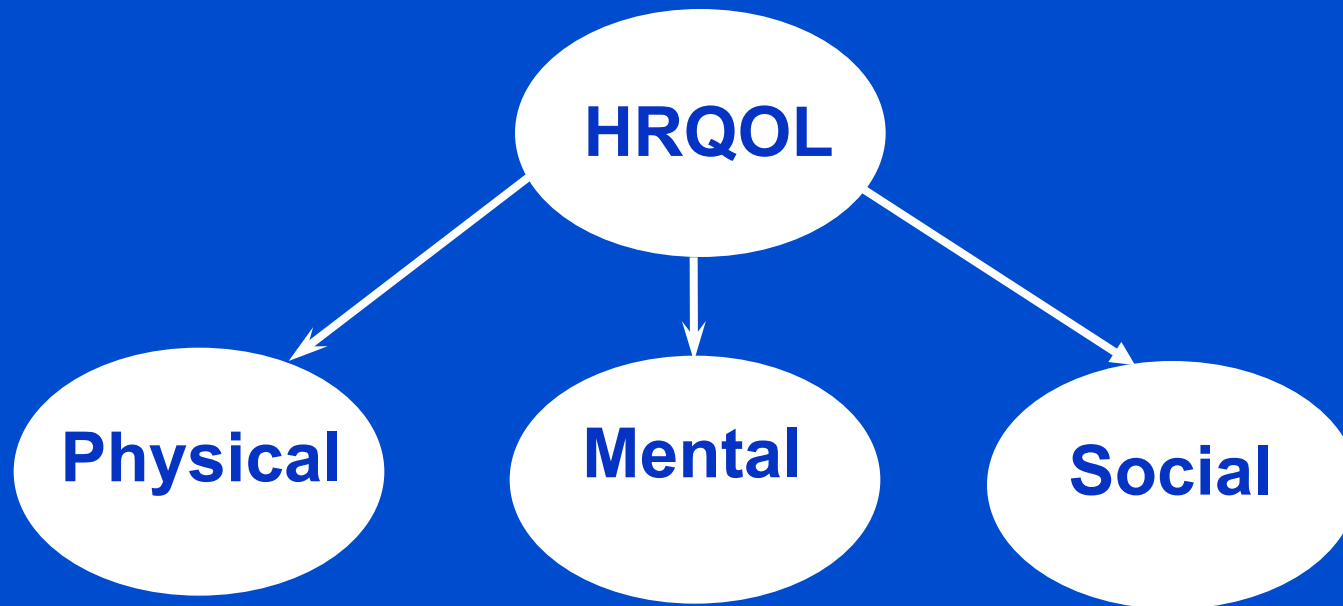
What the person can DO (functioning)

- Self-care
- Role
- Social

How the person FEELS (well-being)

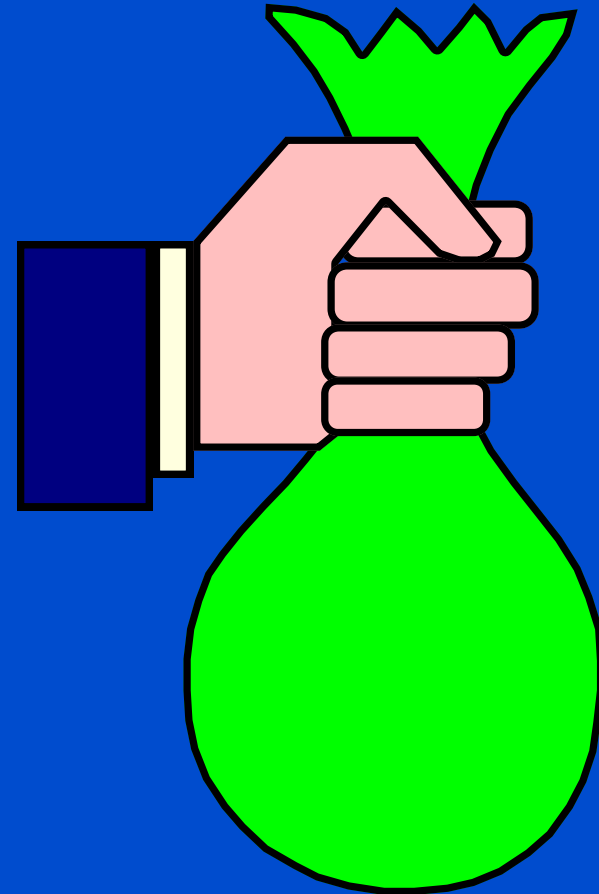
- Emotional well-being
- Pain
- Energy

HRQOL is Multi-Dimensional



HRQOL is Not

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



HRQOL Outcomes

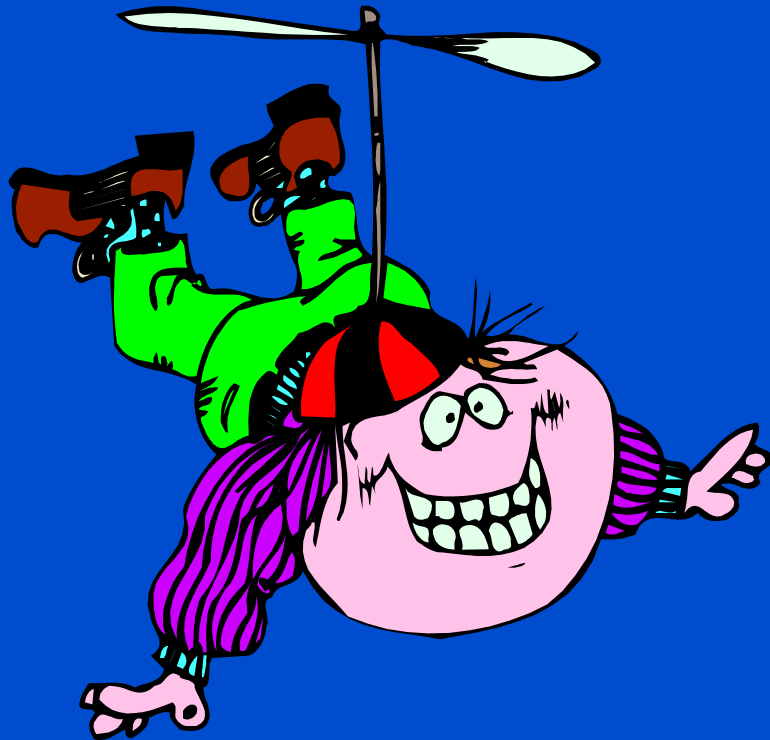
More important to patients than physiological measures or physician observations.

Summarize overall results of health care:

Cost

Δ HRQOL

Types of HRQOL Measures



- Profile
 - Generic
 - Targeted
- Preference-based

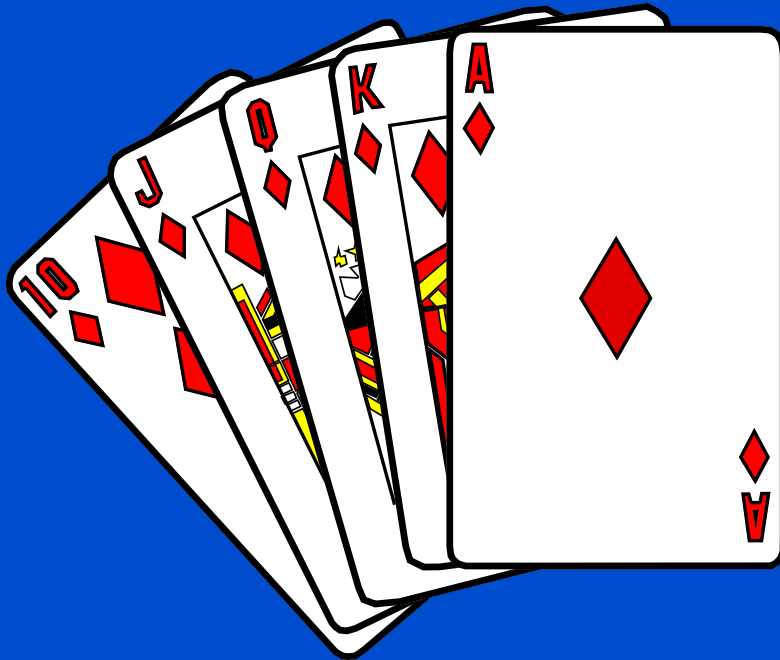
Advantages of Generic Measures

Allow comparisons across different people

- **Across disease groups**
- **Sick versus well**
- **Young versus old**

Can detect unexpected side effects

Generic HRQOL Item



In general, would you say
your health is:

Excellent

Very Good

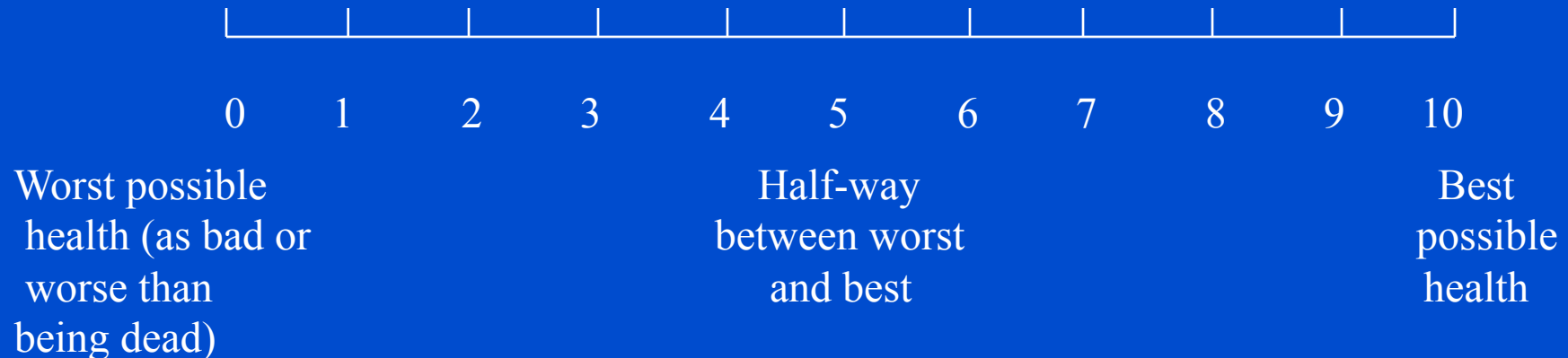
Good

Fair

Poor

Overall Health Rating Item

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



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

Health versus Quality of Life

“In general, how would you rate your health?”

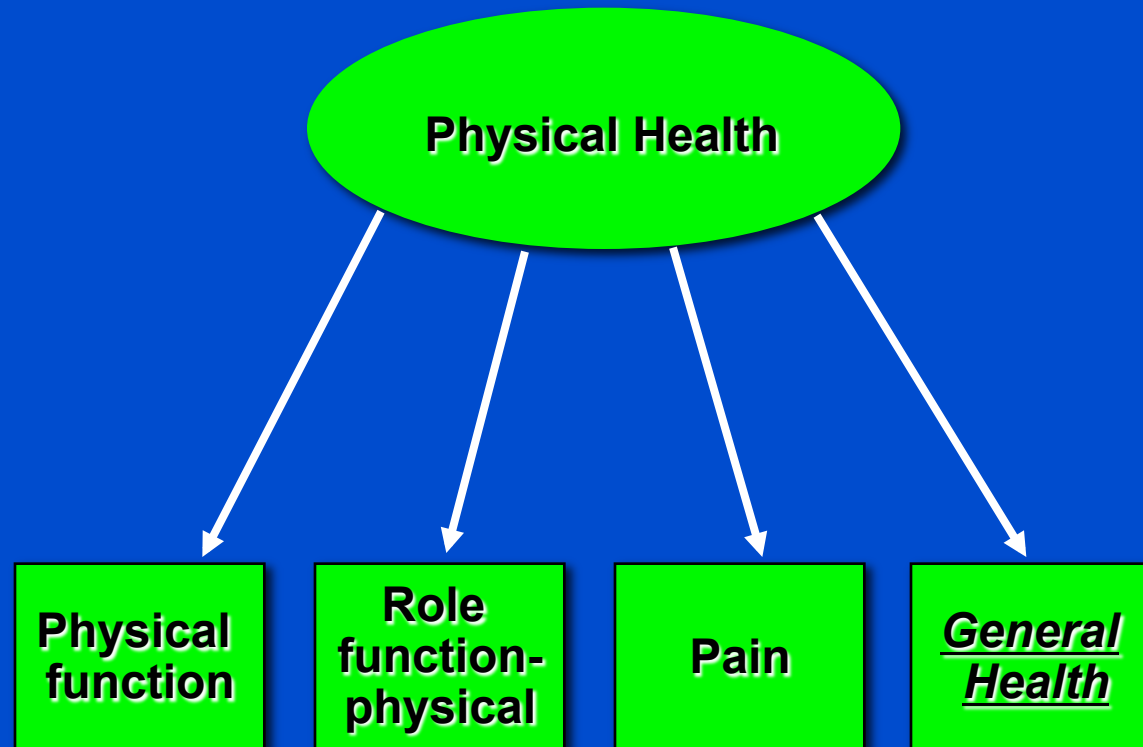
“Overall, how would you rate your quality of life?”

Generic HRQOL: 8 SF-36 Scales

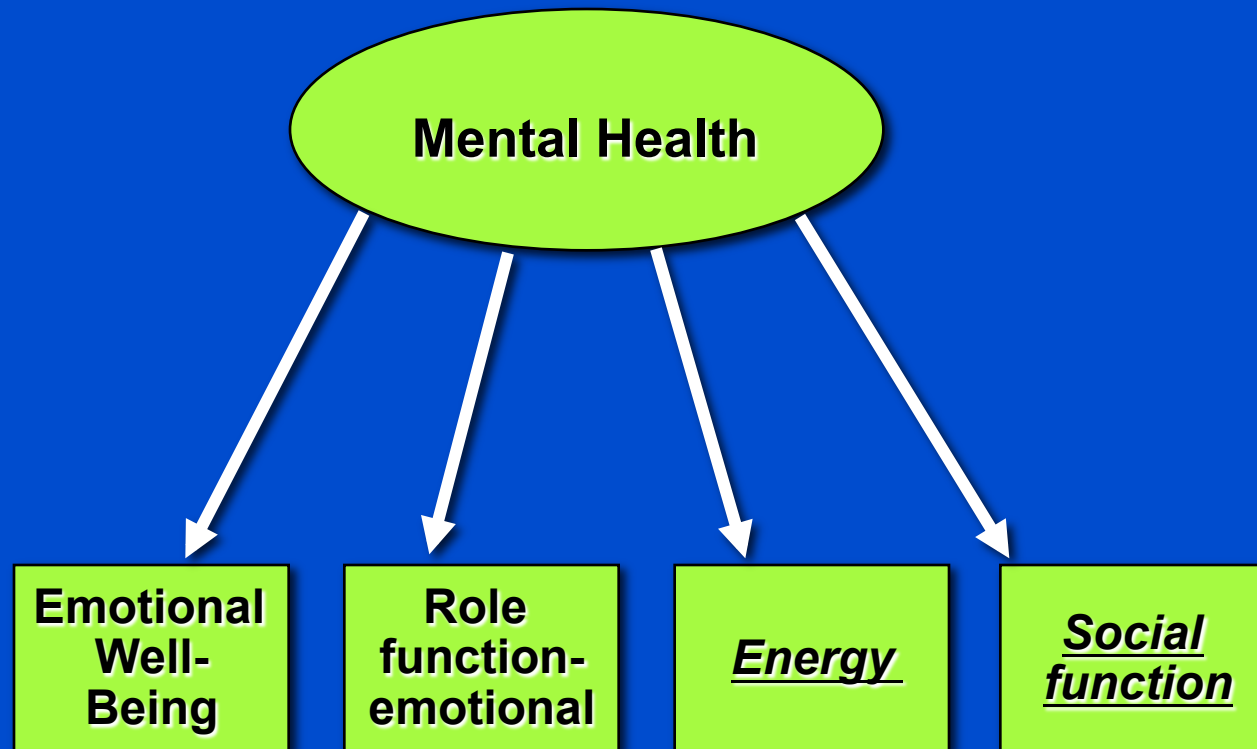


- Physical functioning
- Role limitations/physical
- Pain
- General health perceptions
- Social functioning
- Energy/fatigue
- Role limitations/emotional
- Emotional well-being

SF-36 Physical Health



SF-36 Mental Health



Physical Functioning Item



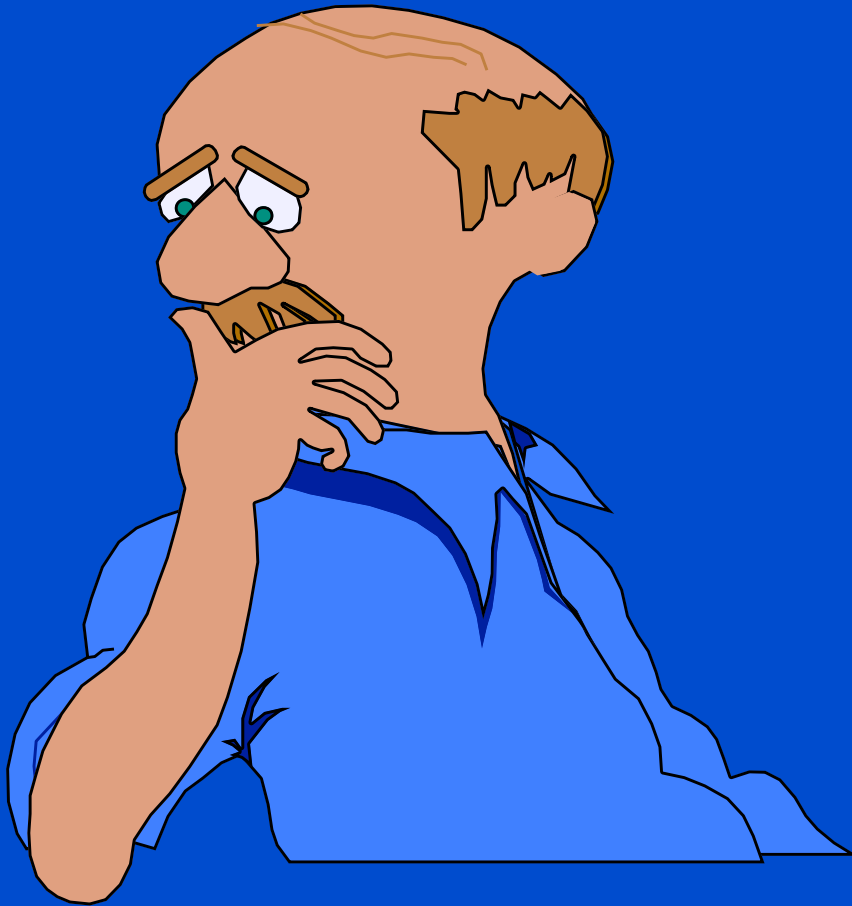
**Does your health now
limit you in bathing or
dressing yourself?**

Yes, limited a lot

Yes, limited a little

No, not limited at all

Emotional Well-Being Item



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


None of the time

A little of the time

Some of the time

Most of the time

All of the time

 **SF-36.com** Search

A community for measuring health outcomes using SF tools

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Threads of Discussion

From: l lie
Date: 10-21-2002
Subject: Stydy only one dimension of the SF 36

Is it possible to administer only some questions of the SF 36 if we want to study only one dimension or should we administer the entire questionnaire ?

Thanks for your help,

L lie

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Message 93 of 100

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Scoring Generic HRQOL Scales

Average or sum all items in the same scale.

Transform average or sum linearly to

- **0-100 possible range**
- **T-score metric**

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

200% Arial 10

A7

	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							
8							
9							
10							
11							
12							
13							
14							
15							
16							
17							

Sheet1 Sheet2 Sheet3

Ready

Uses of Generic Measures

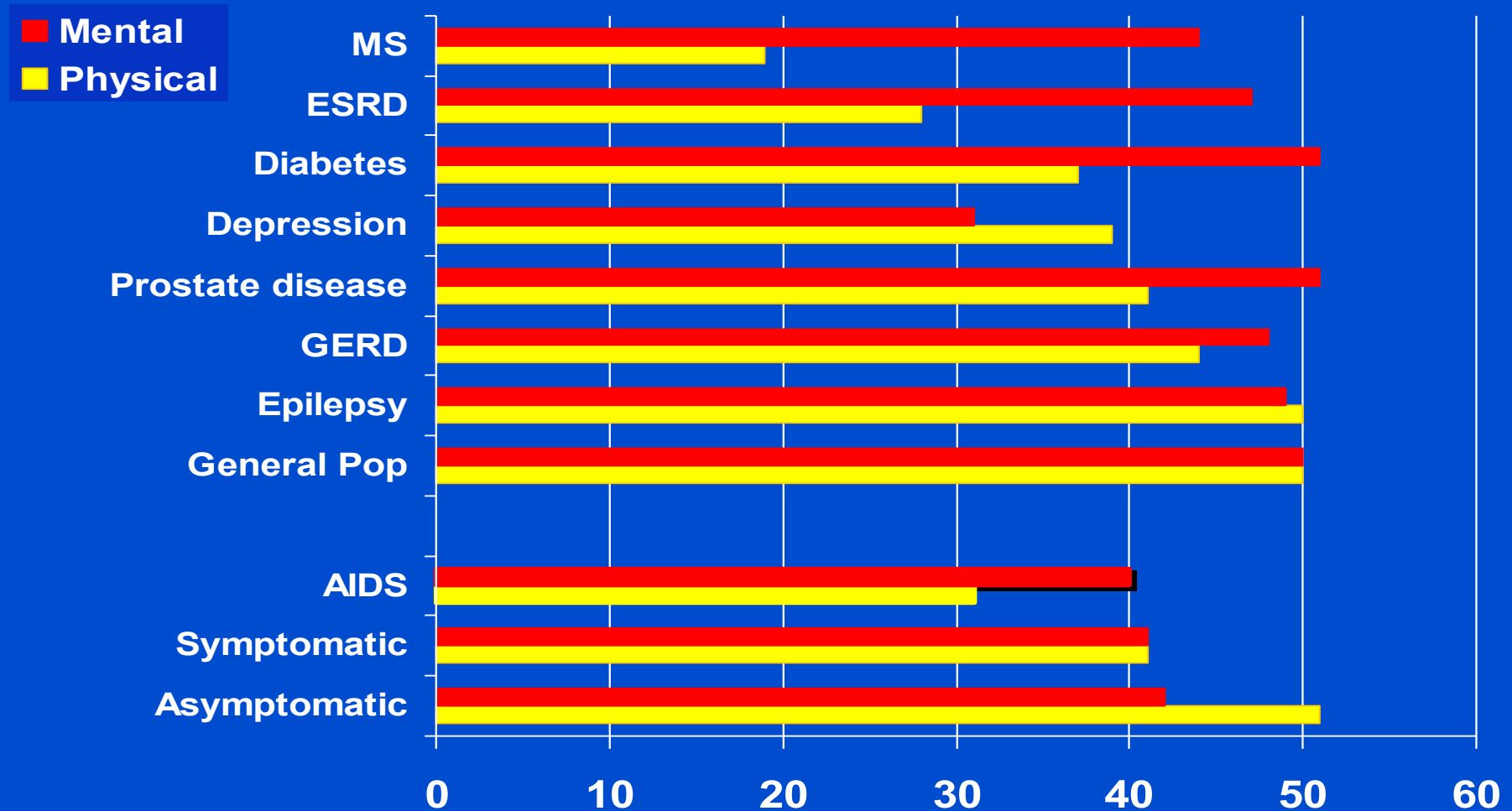
Cross-Sectional

- Profiles of Different Diseases
- Comparison of Different Samples

Longitudinal

- Profiles of Different Diseases
- Examining Antecedents
- Predicting utilization or mortality

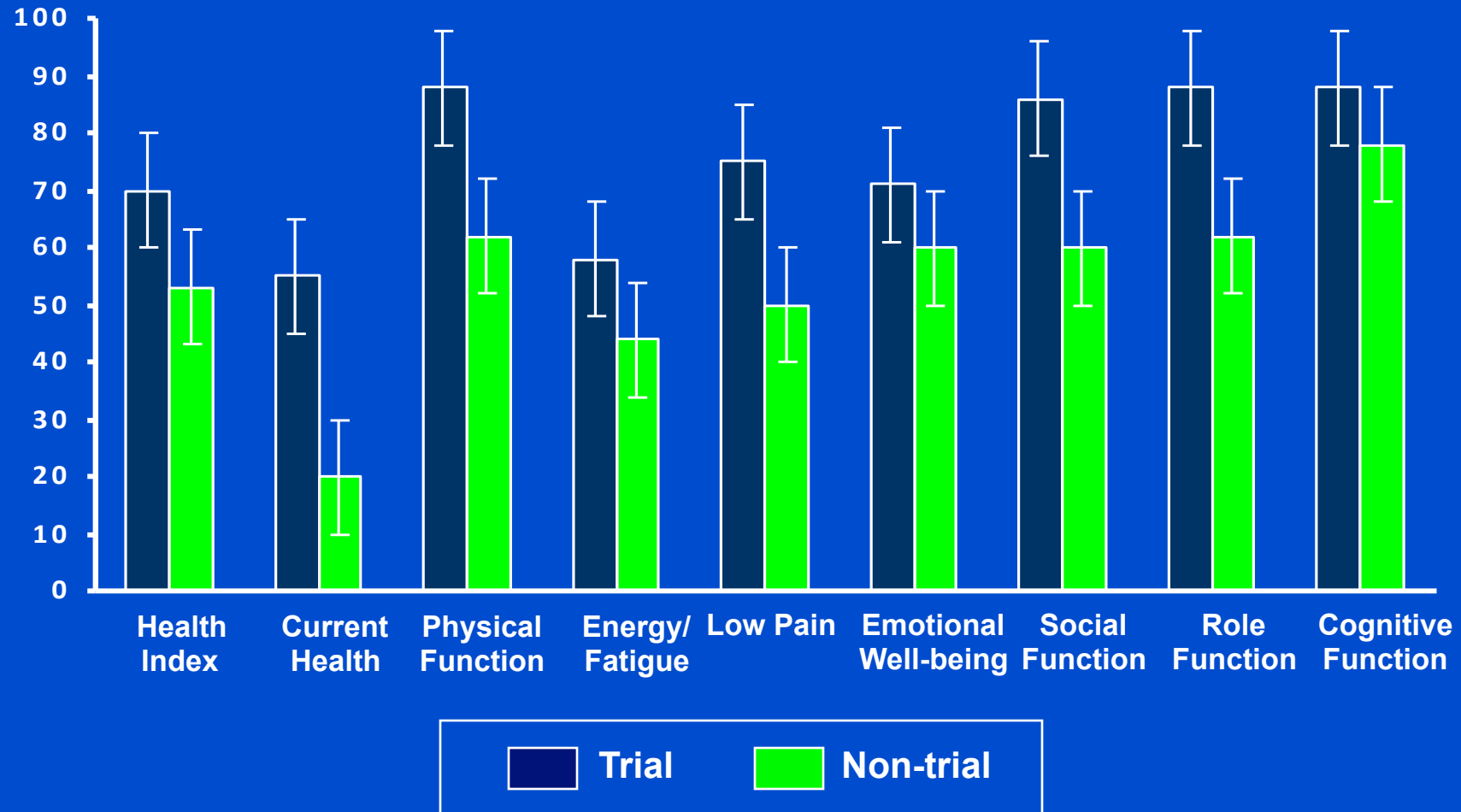
HRQOL of Those with Chronic Illness Compared to General Population



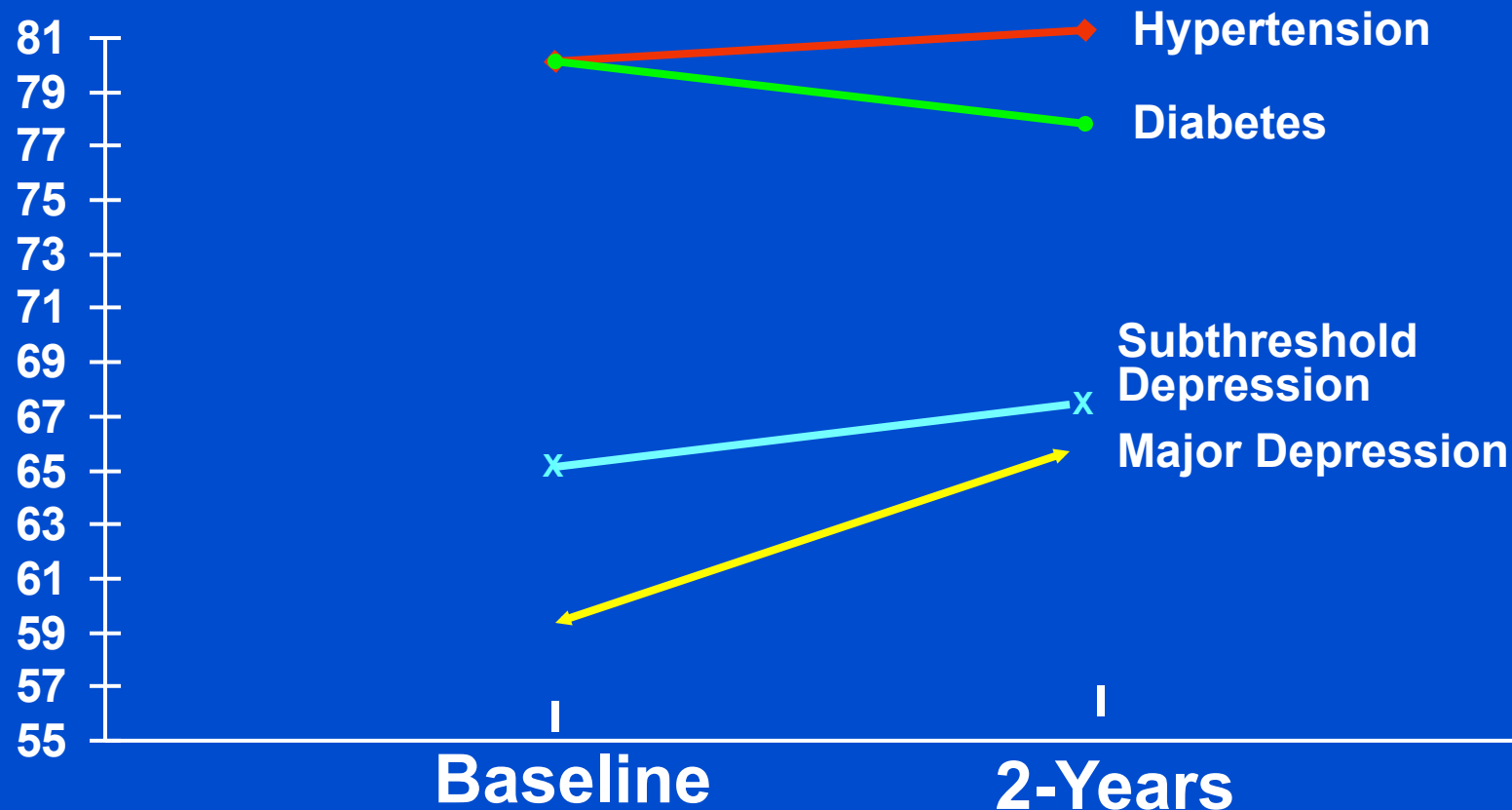
Hays, et al. (2000), American Journal of Medicine

HRQOL Scores of Clinical Trial and Non-Clinical Trial HIV Patients

Cunningham et al. (1995)

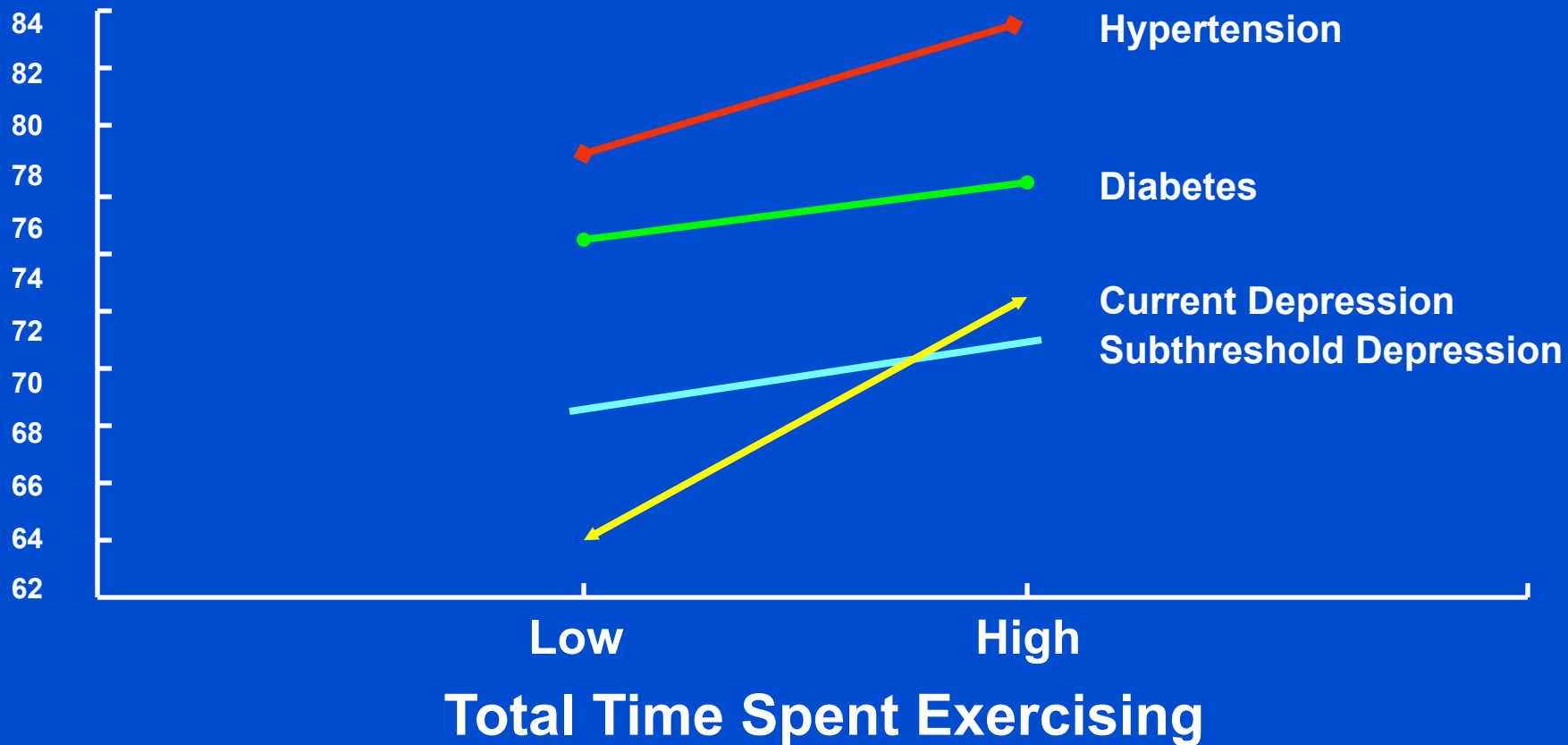


Course of Emotional Well-being Over 2-years for Patients in the MOS General Medical Sector



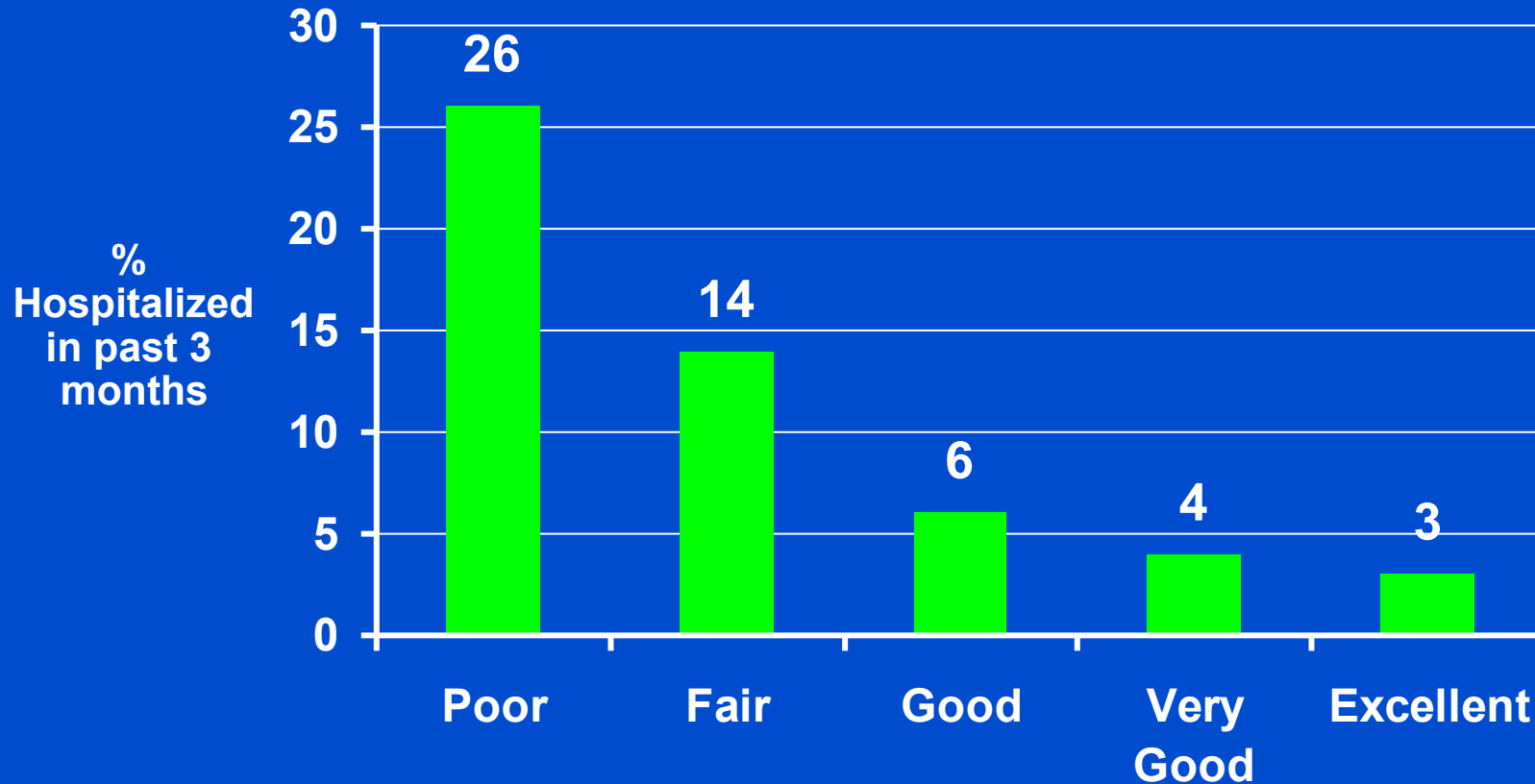
Hays, R.D., Wells, K.B., Sherbourne, C.D., Rogers, W., & Spritzer, K. (1995).
Functioning and well-being outcomes of patients with depression compared
to chronic medical illnesses. *Archives of General Psychiatry*, 52, 11-19.

Association of Exercise with Physical Functioning 2-years After Baseline in the MOS



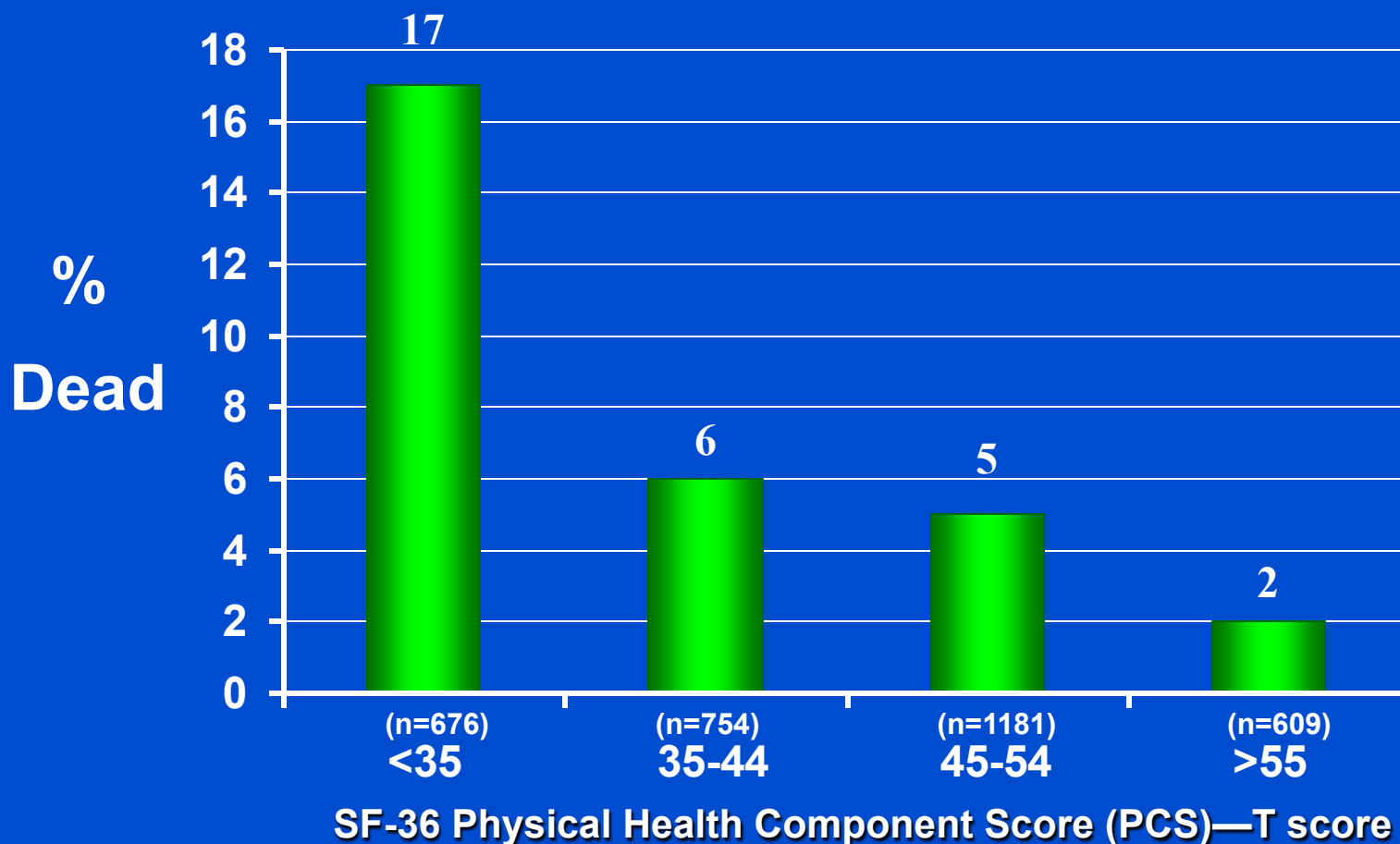
Stewart, A.L., Hays, R.D., Wells, K.B., Rogers, W.H., Spritzer, K.L., & Greenfield, S. (1994). Long-term functioning and well-being outcomes associated with physical activity and exercise in patients with chronic conditions in the Medical Outcomes Study. *Journal of Clinical Epidemiology*, 47, 719-730.

Generic Health Ratings Associated with Hospitalizations (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.

Five-Year Mortality Rates by Levels of Physical Health



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

Targeted HRQOL Measures

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

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)

Mattson-Prince (1997)

**Dropped 10 physical functioning items
because of perception that they were
demeaning to people with SCI**

Spinal Cord, 35, 326-331

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 to Extremely)

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

NEI-RQL-42 Far Vision Item

How much difficulty do you have judging distances, like walking downstairs or parking a car?

No difficulty at all

A little difficulty

Moderate difficulty

A lot of difficulty

Spinal Cord Independence Measure

Self care (feeding, bathing, dressing, grooming)

Respiration and sphincter management

Mobility (in bed and preventing pressure ulcers, bed-wheel chair, wheelchair-toilet-tub transfers)

Kidney Disease-Targeted Scales

- Symptoms/problems (12 items)
- Effects of kidney disease (8 items)
- Burden of kidney disease (4 items)
- Work status (2 items)
- Cognitive function (3 items)
- Quality of social interaction (3 items)
- Sexual function (2 items)
- Sleep (4 items)

HRQOL in Men Treated for Localized Prostate Cancer

Cross-sectional study of managed care pop.

Sexual, urinary and bowel function and distress

214 men with prostate cancer

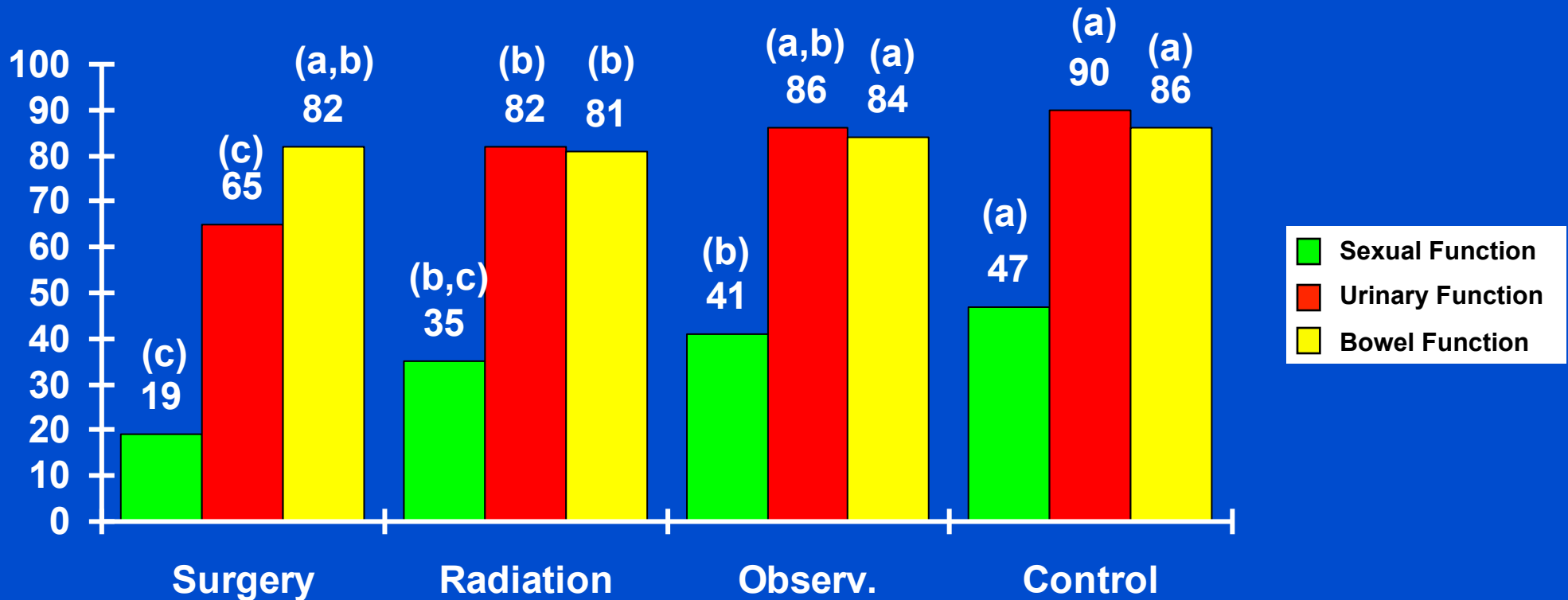
98 radical prostatectomy

56 primary pelvic irradiation

60 observation alone

273 age/zip matched pts. without cancer

Sexual, Urinary, and Bowel Function Outcomes



Litwin, et al. (1995, JAMA)

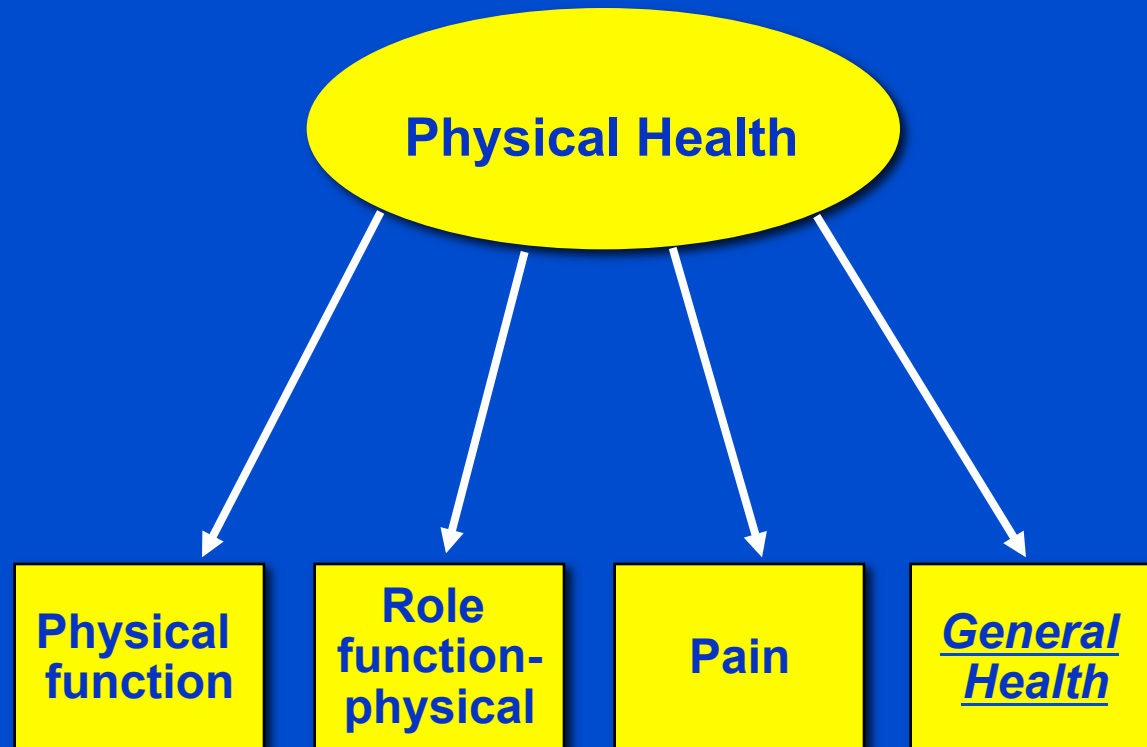
Check-in Point

Generic Profile Measures

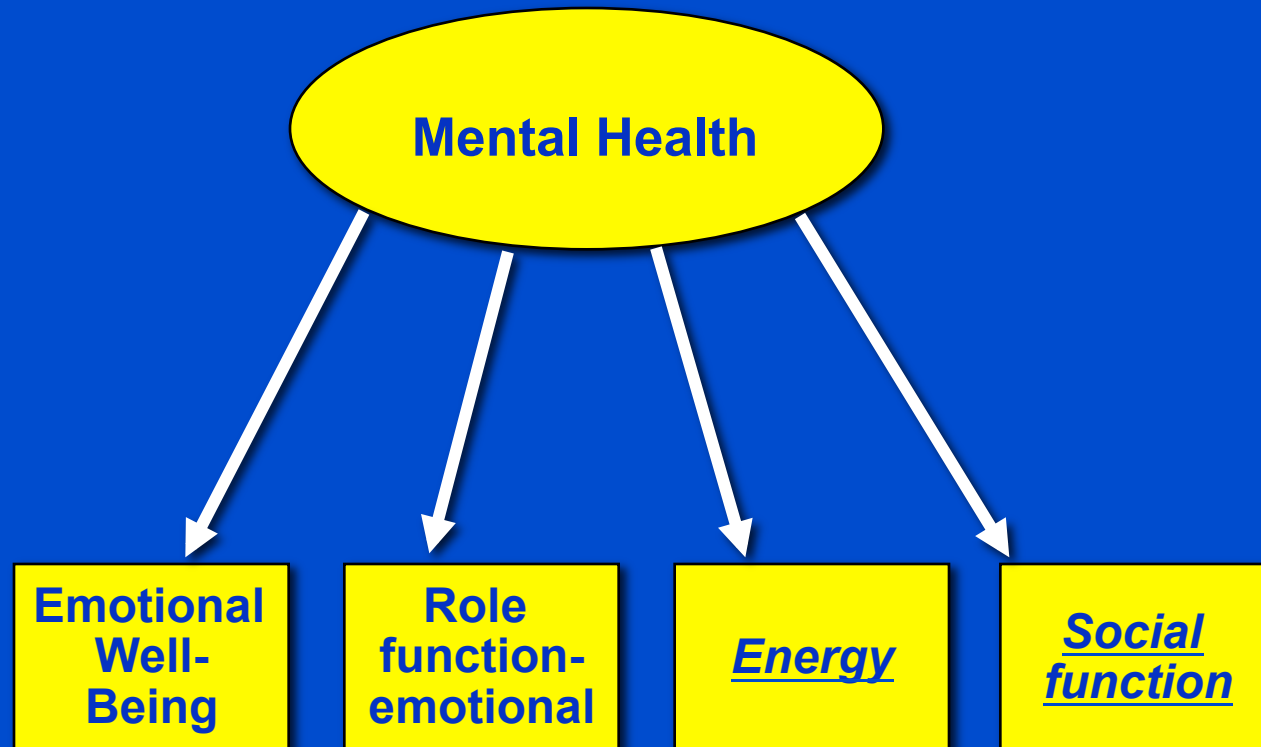
Targeted Profile Measures

-> Summarizing Profile Information

Physical Health



Mental Health

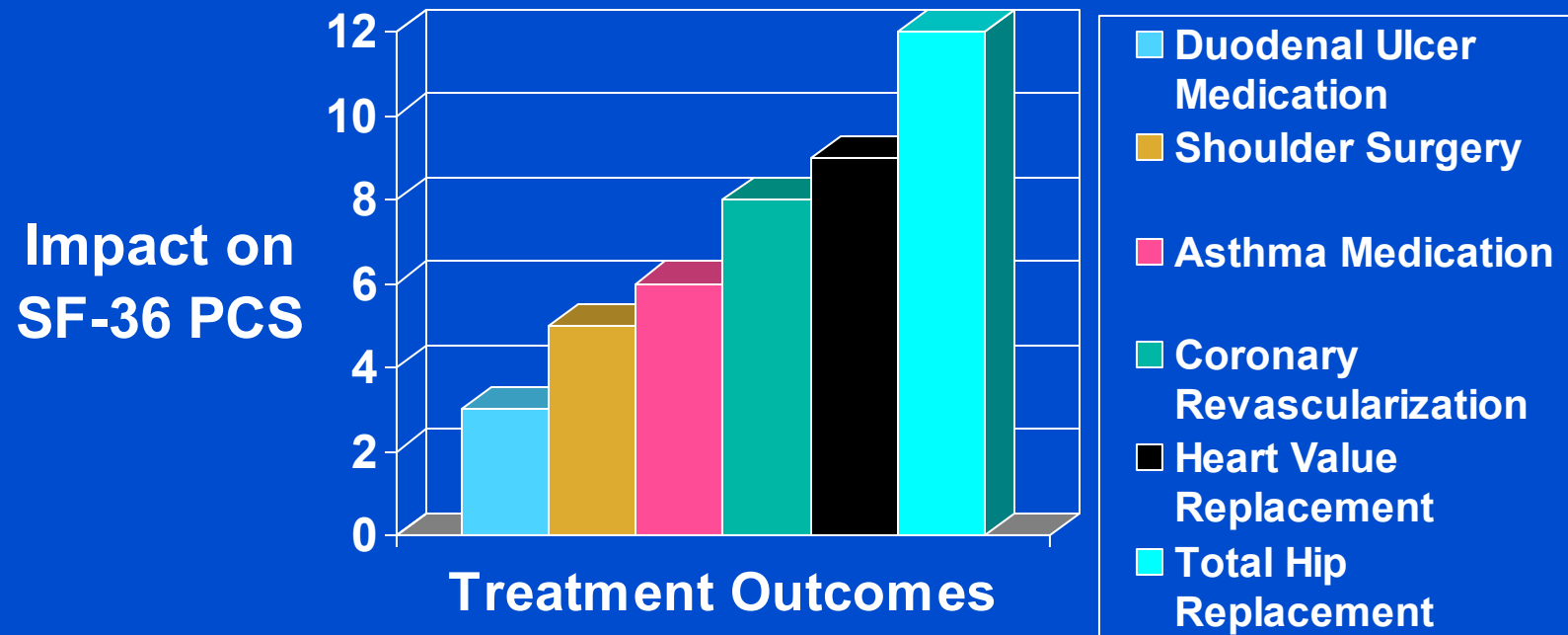


SF-36 PCS and MCS

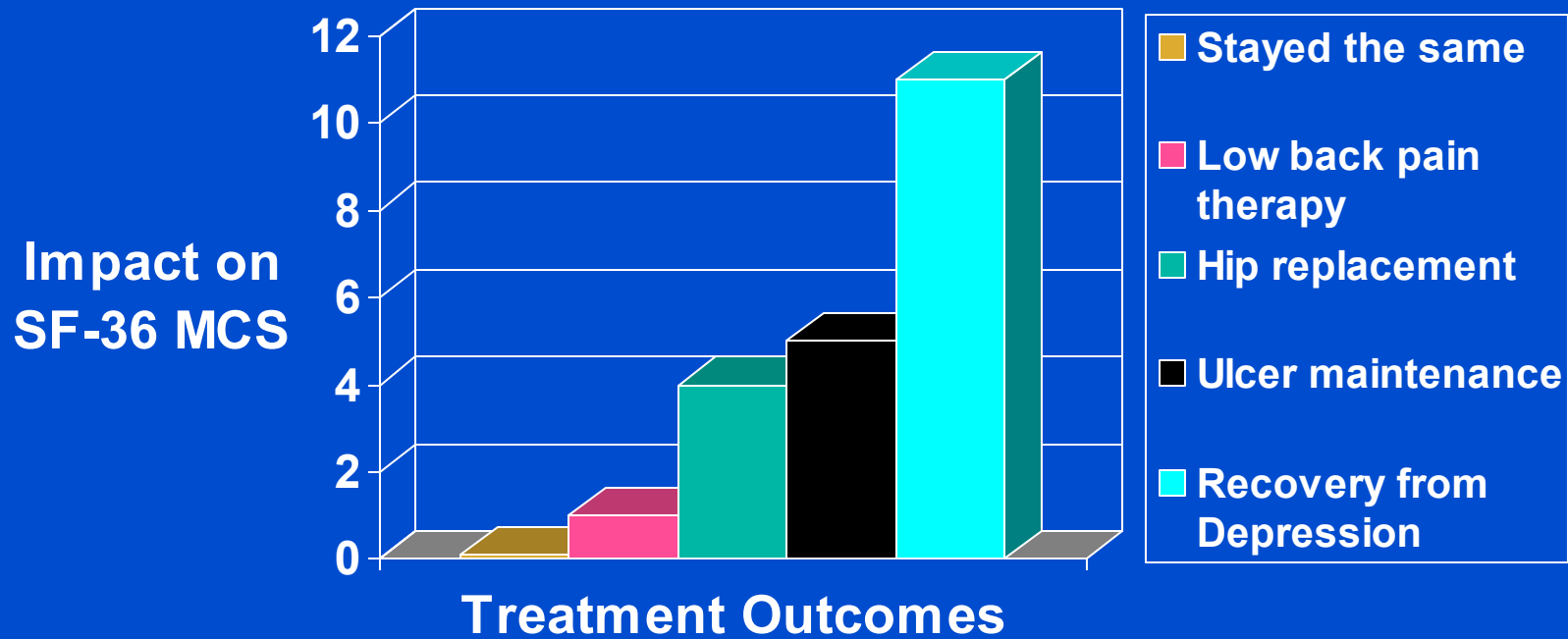
$$\begin{aligned} \text{PCS} = & (\text{PF_Z} * .42402) + (\text{RP_Z} * .35119) + \\ & (\text{BP_Z} * .31754) + (\text{GH_Z} * .24954) + \\ & (\text{EF_Z} * .02877) + (\text{SF_Z} * -.00753) + \\ & (\text{RE_Z} * -.19206) + (\text{EW_Z} * -.22069) \end{aligned}$$

$$\begin{aligned} \text{MCS} = & (\text{PF_Z} * -.22999) + (\text{RP_Z} * -.12329) + \\ & (\text{BP_Z} * -.09731) + (\text{GH_Z} * -.01571) + \\ & (\text{EF_Z} * .23534) + (\text{SF_Z} * .26876) + \\ & (\text{RE_Z} * .43407) + (\text{EW_Z} * .48581) \end{aligned}$$

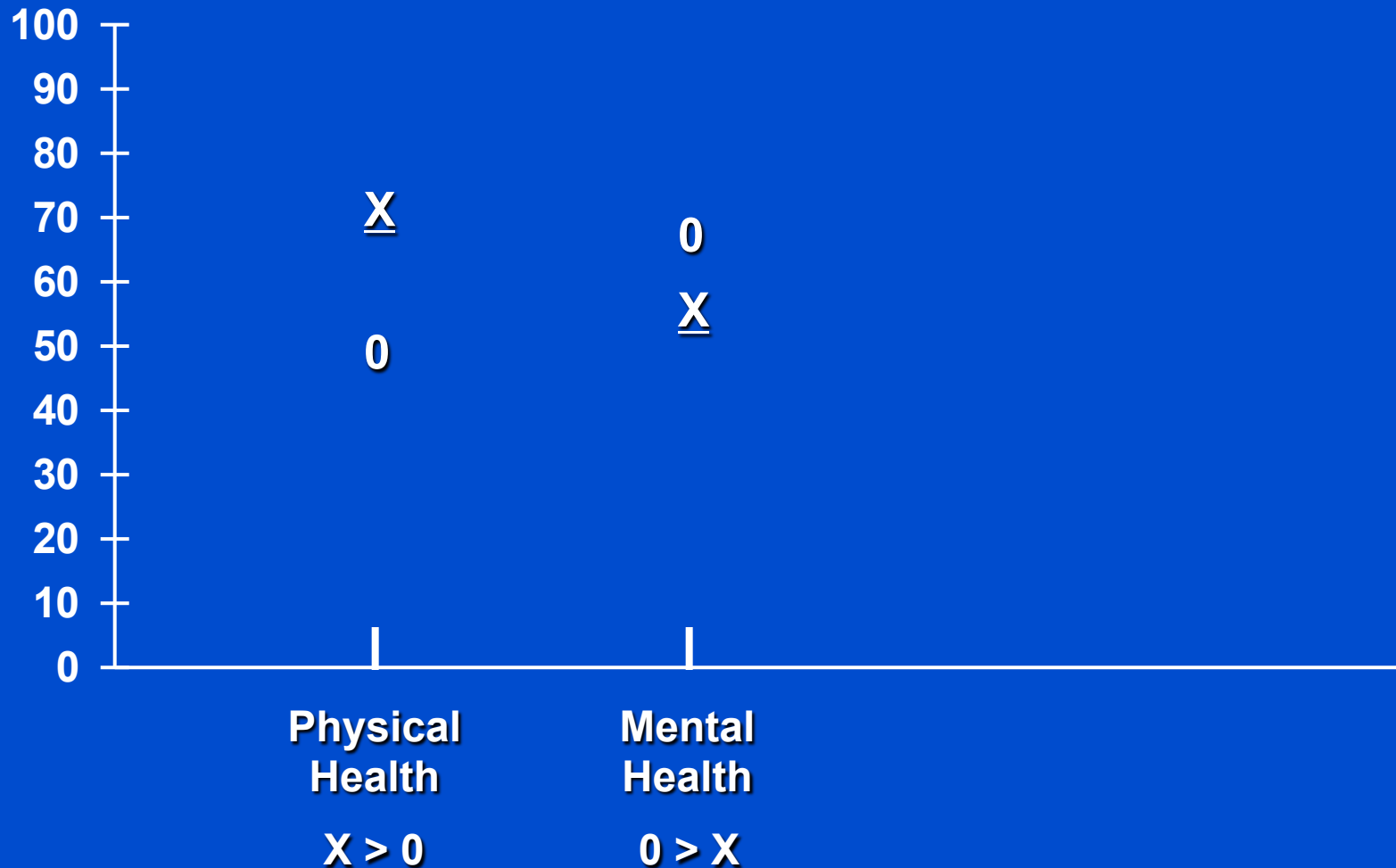
Treatment Impact on Physical Health



Treatment Impact on Mental Health



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

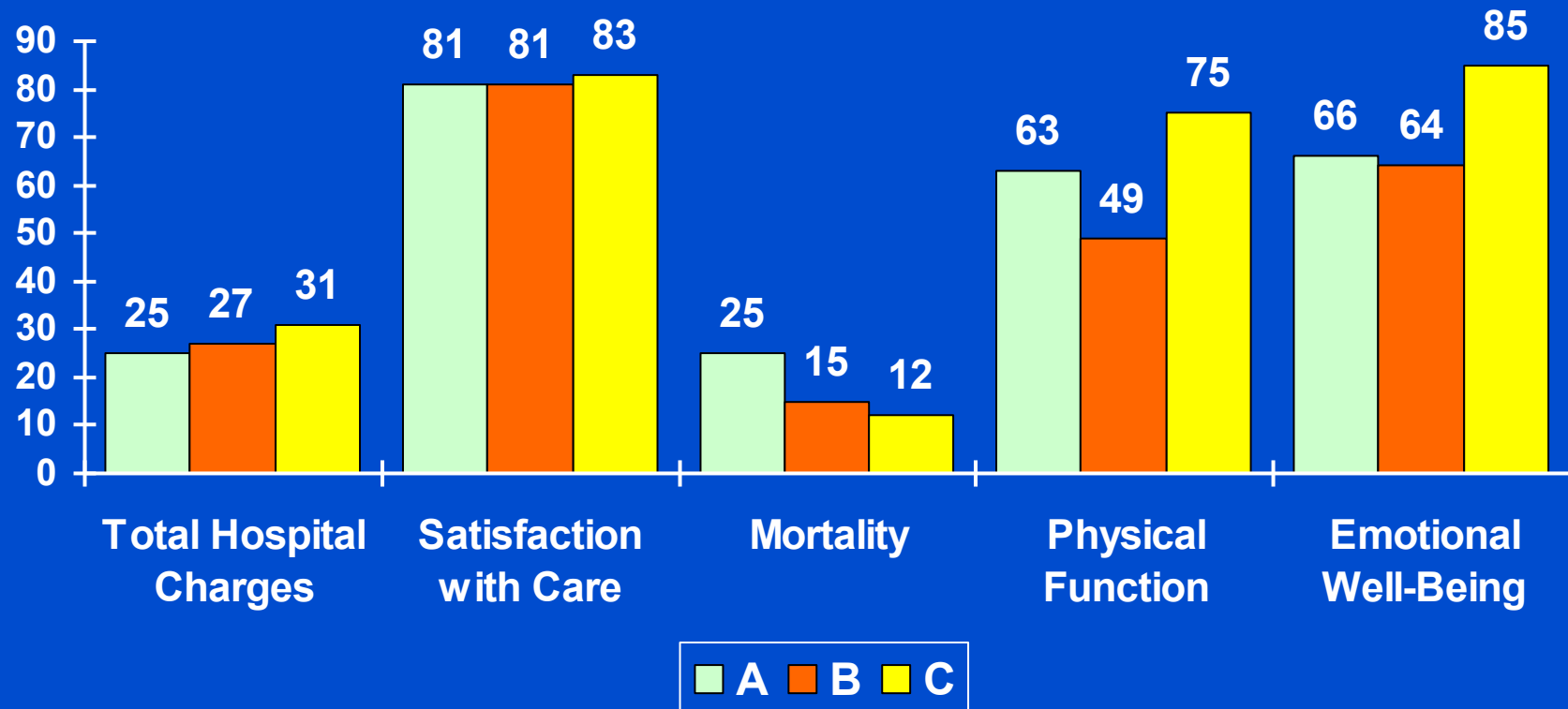
Survival Analysis

Marathoner 1.0

Person in coma 1.0

Profile + Mortality

Outcomes for Acute MI (n = 133)



Preference-Based Measure-- 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



EQ-5D

Mobility

Self-care

Usual activities

Pain/discomfort

Anxiety/depression

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

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 | <input type="checkbox"/> |
| I have some problems in walking about | <input type="checkbox"/> |
| I am confined to bed | <input type="checkbox"/> |

Self-Care

- | | |
|--------------------------------------------------|--------------------------|
| I have no problems with self-care | <input type="checkbox"/> |
| I have some problems washing and dressing myself | <input type="checkbox"/> |
| I am unable to wash or dress myself | <input type="checkbox"/> |

Usual Activities (eg. work, study, housework, family or leisure activities)

- | | |
|----------------------------------------------------------|--------------------------|
| I have no problems with performing my usual activities | <input type="checkbox"/> |
| I have some problems with performing my usual activities | <input type="checkbox"/> |
| I am unable to perform my usual activities | <input type="checkbox"/> |

Pain/Discomfort

- | | |
|------------------------------------|--------------------------|
| I have no pain or discomfort | <input type="checkbox"/> |
| I have moderate pain or discomfort | <input type="checkbox"/> |
| I have extreme pain or discomfort | <input type="checkbox"/> |

Anxiety/Depression

- | | |
|--------------------------------------|--------------------------|
| I am not anxious or depressed | <input type="checkbox"/> |
| I am moderately anxious or depressed | <input type="checkbox"/> |
| I am extremely anxious or depressed | <input type="checkbox"/> |

On each dimension, respondent gets three choices of level.

HUI-3

Vision

Hearing

Speech

Ambulation

Dexterity

Cognition

Pain and discomfort

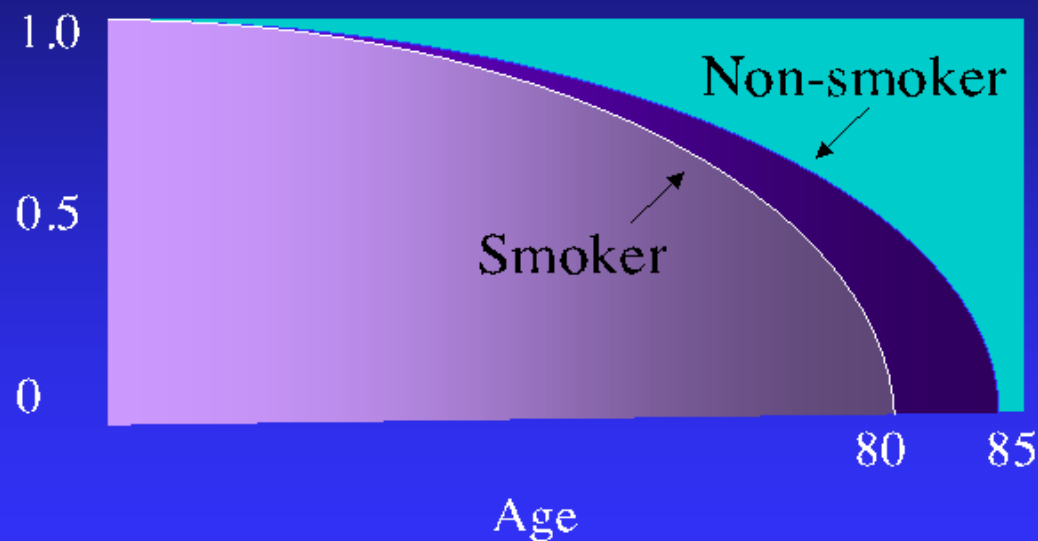
Emotion

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

SF-6D Summary Measure

- 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

Quality-adjusted life-years (QALYs)



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

Cost/QALY (1993 US dollars)

- \$0 Seat belt laws
- \$2k Pneumococcal vaccine
- \$6k Smoking cessation counseling
- \$12k Oral gold for rheumatoid arthritis
- \$40k CABG, 2-vessel disease; hemodialysis
- \$167k Mammography screening
- \$293k Hip replacement
- \$663k CABG, 1-vessel disease

Questions?

www.rand.org/health/surveys.html

<http://gim.med.ucla.edu/kdqol/>

<http://gim.med.ucla.edu/facultypages/hays>

Next Week' s Reading

Hays, R. D., Anderson, R. T., & Revicki, D. (1998). Assessing reliability and validity of measurement in clinical trials. In M. Staquet, R. Hays, & P. Fayers (eds.), Quality of Life Assessment in Clinical Trials: Methods and Practice (pp. 169-182). Oxford: Oxford University Press.