

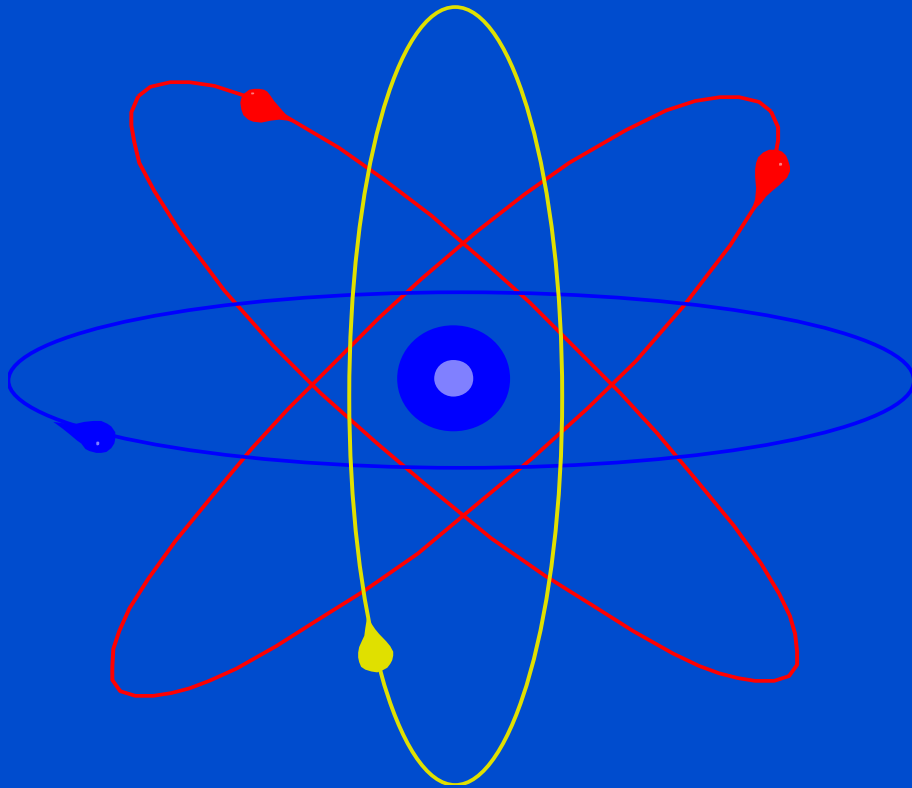
Measurement of Health-Related Quality of Life Outcomes

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October 17, 2002 (3:00-5:00 pm)

Gonda first floor conference room

Health Care System Concerns



Access

Affordability

Accountability

**With better technology, we are able
to detect more “sickness”**

**CT scans can detect hepatic lesions of 2mm.
In 1982, only 20mm lesions could be detected.**

MRI can:

**detect abnormalities of the knee in 25% of
“healthy young men.”**

**find lumbar disc bulge in 50% of adults,
many who have no back pain.**

Outcomes should improve with investment of resources

Health costs increasing despite managed care

Despite much greater growth in costs of health care in the US, no evidence that health has improved more than other G7 countries

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 ☐

What is Effective Care?

- **Maximizes desired outcomes**
- **Outcomes serve as markers of effective care**



“Outcomes”

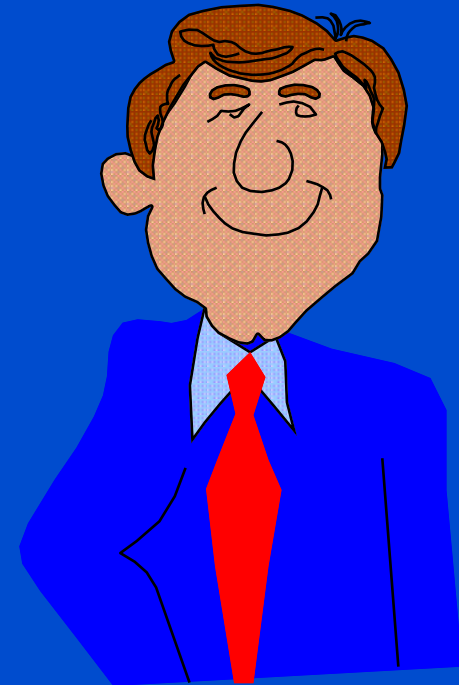
How is the Patient Doing

Biological indicators

- Hematocrit
- Albumin

Self-report indicators

- Functioning
- Well-being (including symptoms)



Health-Related Quality of Life is:

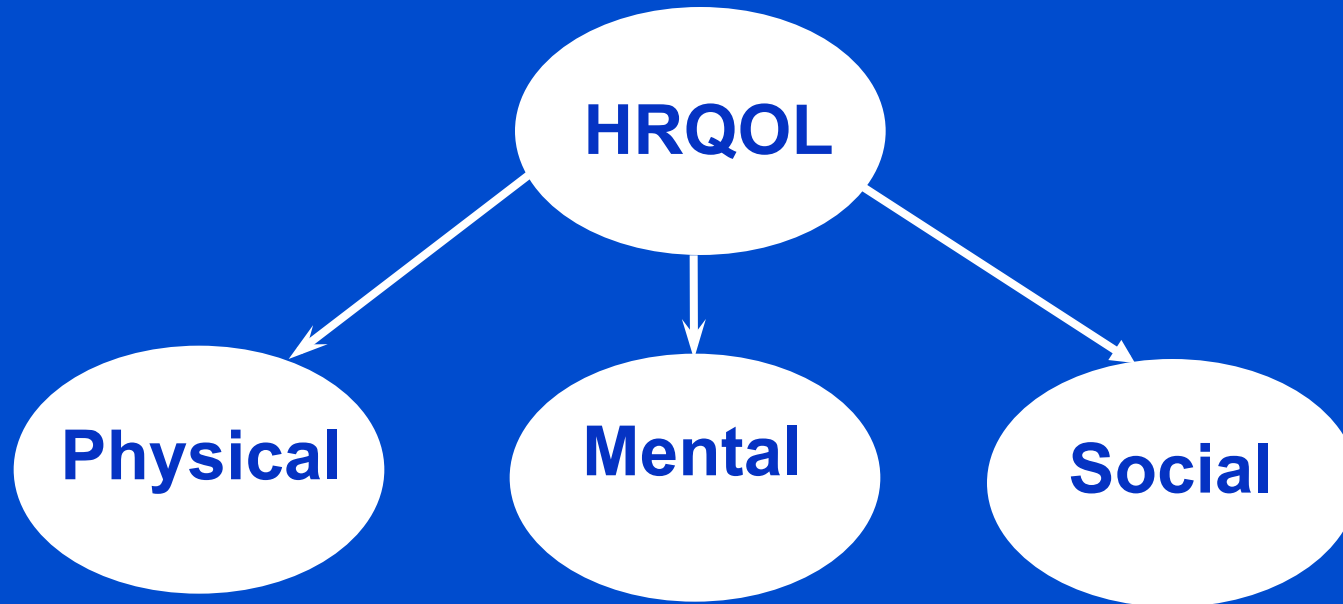
What the person can DO (functioning)

- Self-care
- Role
- Social

How the person FEELS (well-being)

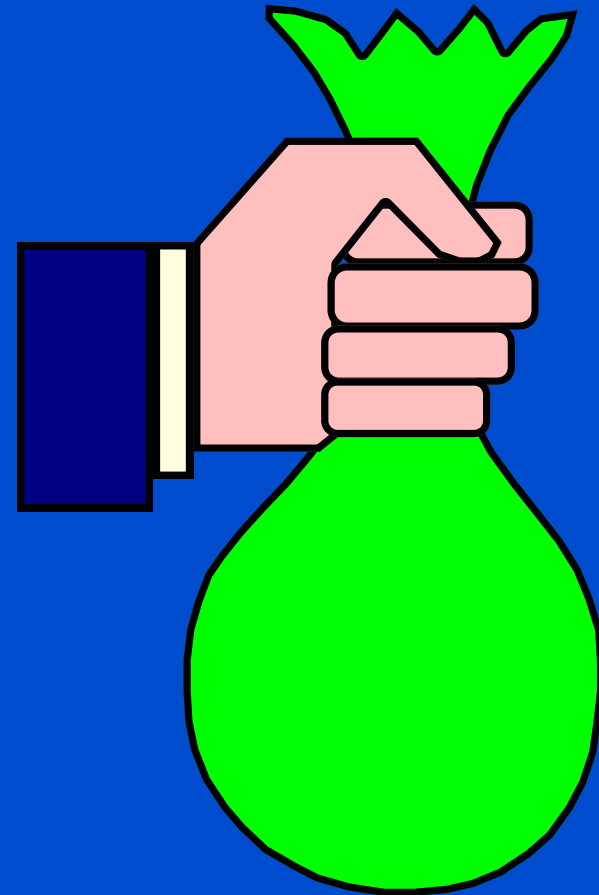
- Emotional well-being
- Pain
- Energy

HRQOL is Multi-Dimensional



HRQOL is Not

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



HRQOL Outcomes

Matter more to patients than biological indicators.

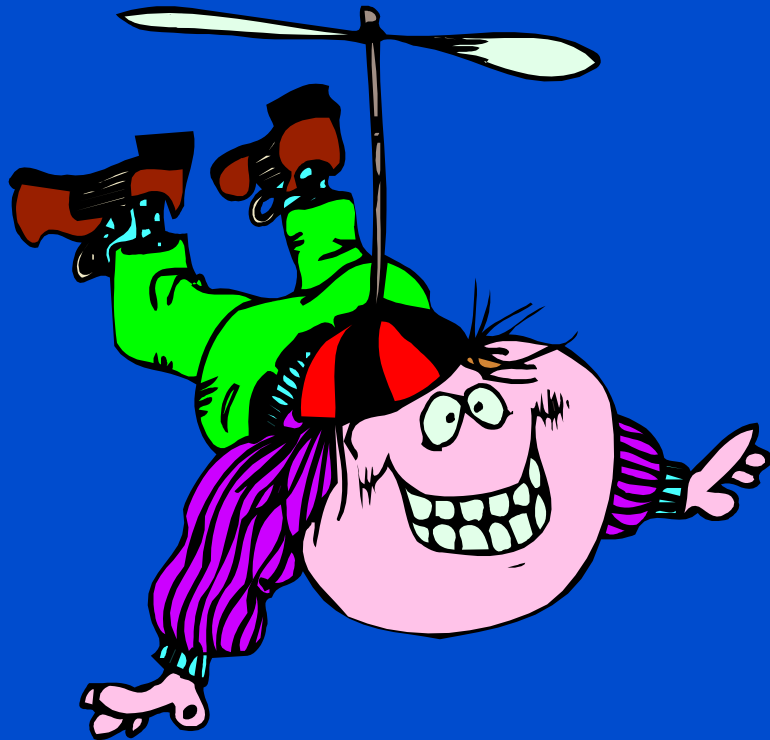
Summarize overall results of health care:

Cost



△ HRQOL

Types of HRQOL Measures



- Profile
 - Generic
 - Targeted
- Preference-based

Example Generic Item

How often has your child
had difficulty running in the
last 30 days?

Never

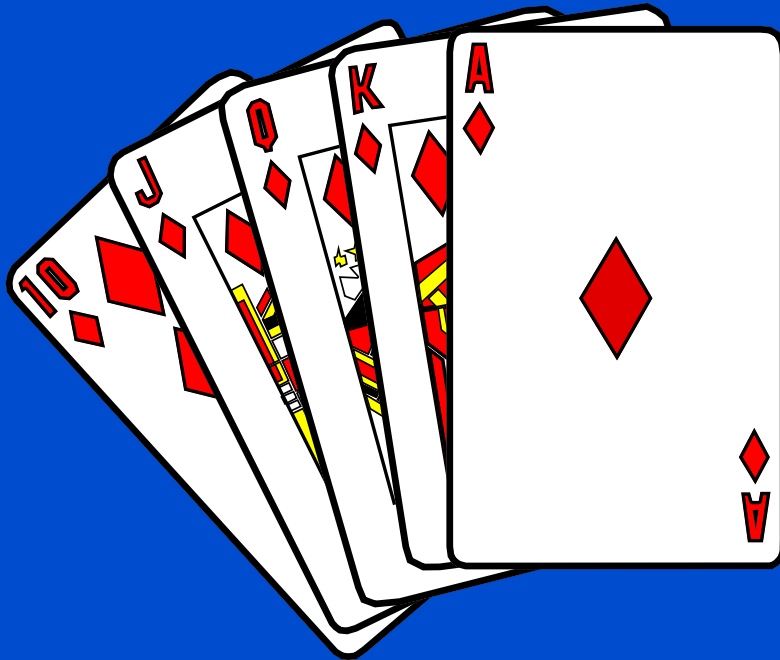
Sometimes

Often



Generic HRQOL Item

In general, would you say
your health is:



Excellent

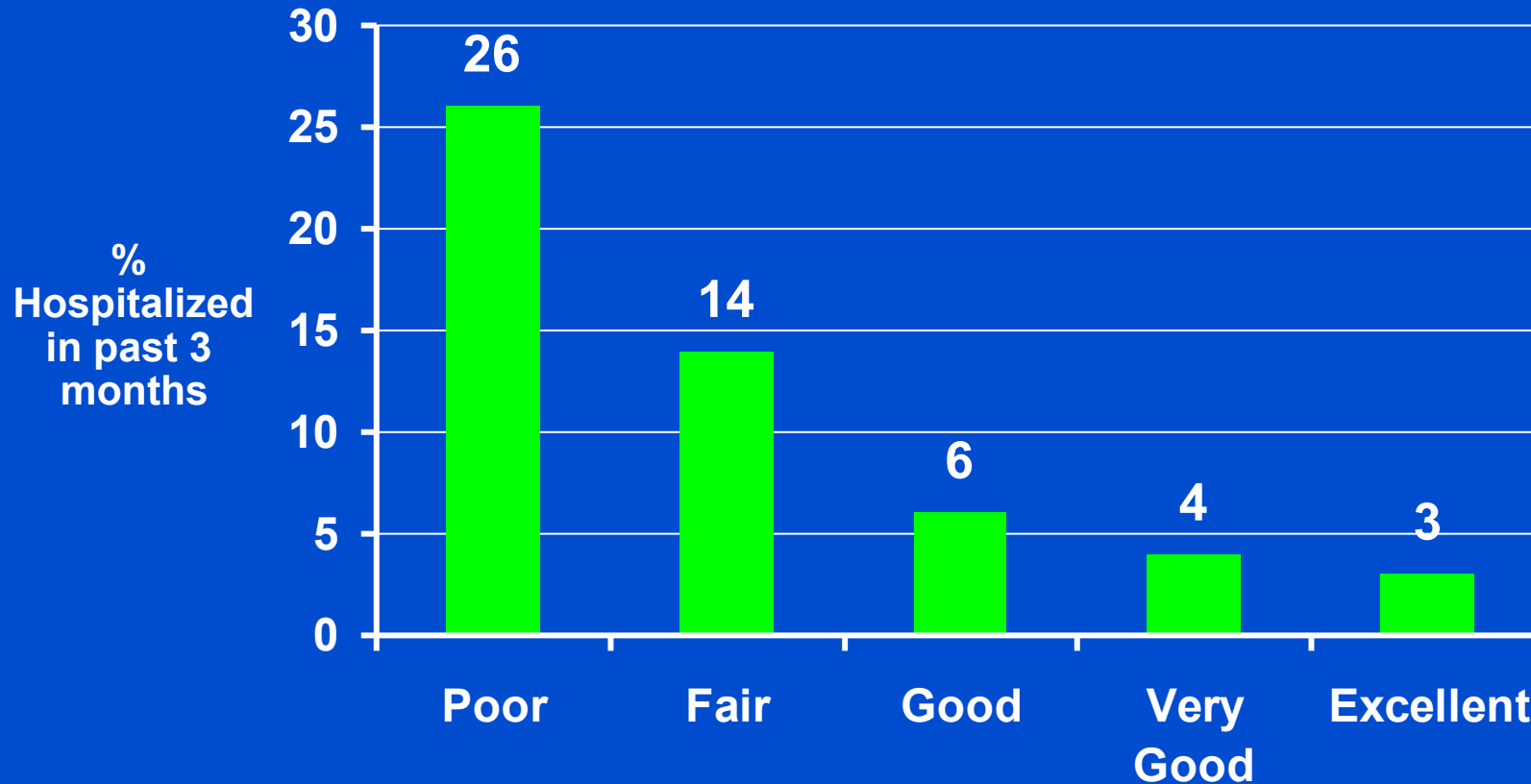
Very Good

Good

Fair

Poor

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.

Health versus Quality of Life

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

→ General health ratings reflect more of physical than mental health

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

→ Global “quality of life” reflects more of mental than physical health

Generic HRQOL Scales (Items)

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

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

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

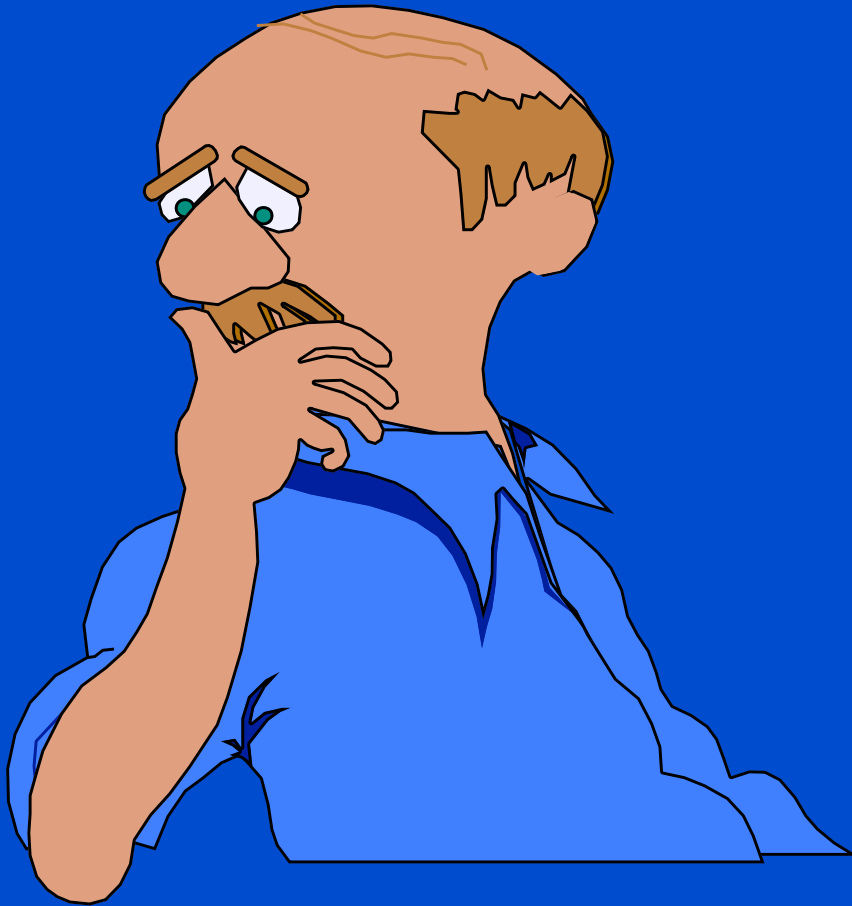
Andresen & Meyers (2000, Archives of Physical Medicine and
Rehabilitation)

Mattson-Prince (1997)

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

Spinal Cord, 35, 326-331

Emotional Well-Being Item



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

None of the time

A little of the time

Some of the time

A Good bit of the time

Most of the time

All of the time

Advantages of Generic Measures

Allow comparisons across different people

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

Can detect unexpected side effects

Scoring Generic HRQOL Scales

Average or sum all items in the same scale.

Transform raw average or sum linearly to

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

Formula for Transforming Scores

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

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

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

URLs

www.rand.org/health/surveys.html

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

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

Common Uses of Generic Measures

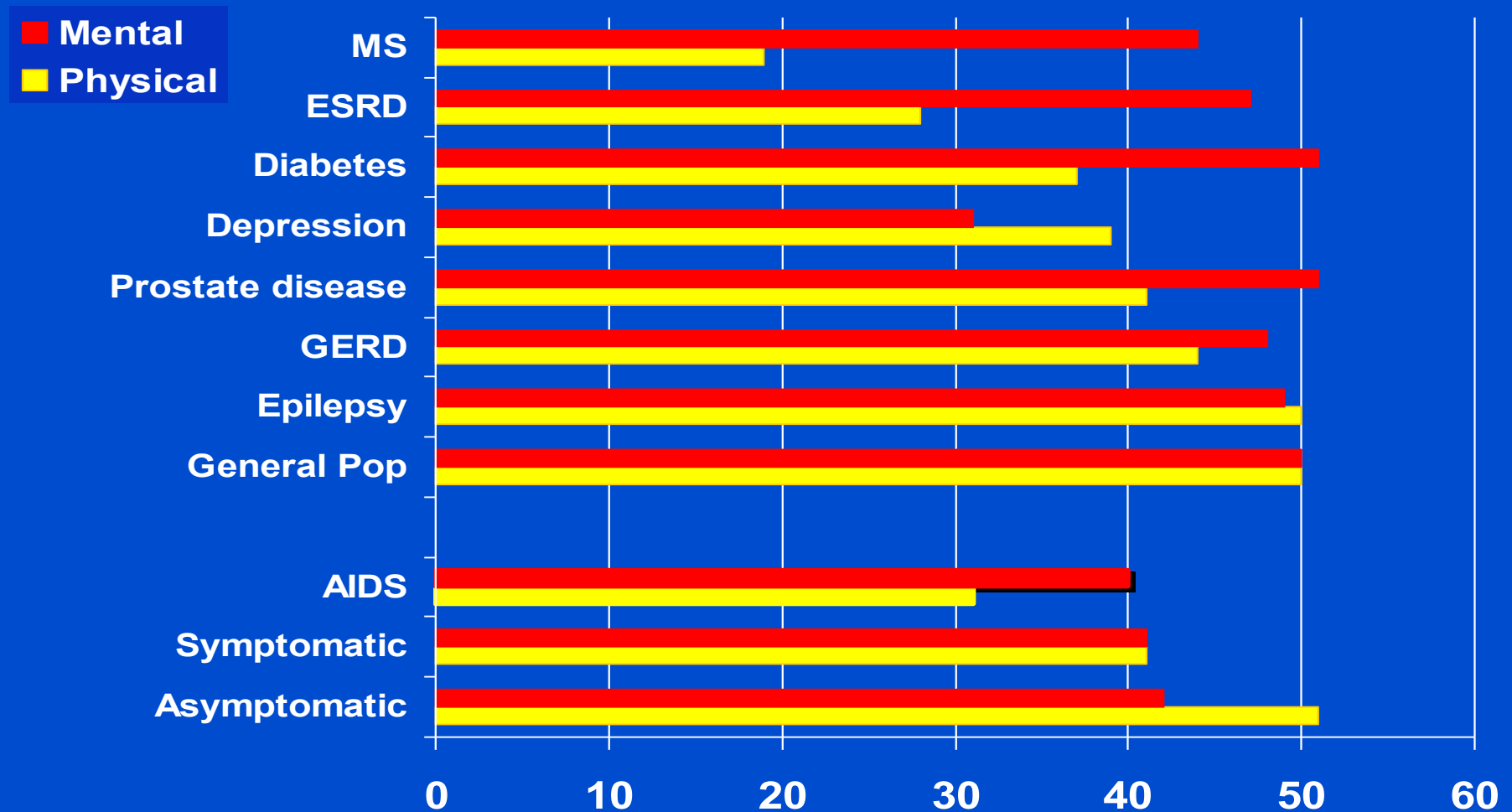
Cross-Sectional

- **Profiles of Different Diseases**
- **Comparison of Different Samples**

Longitudinal

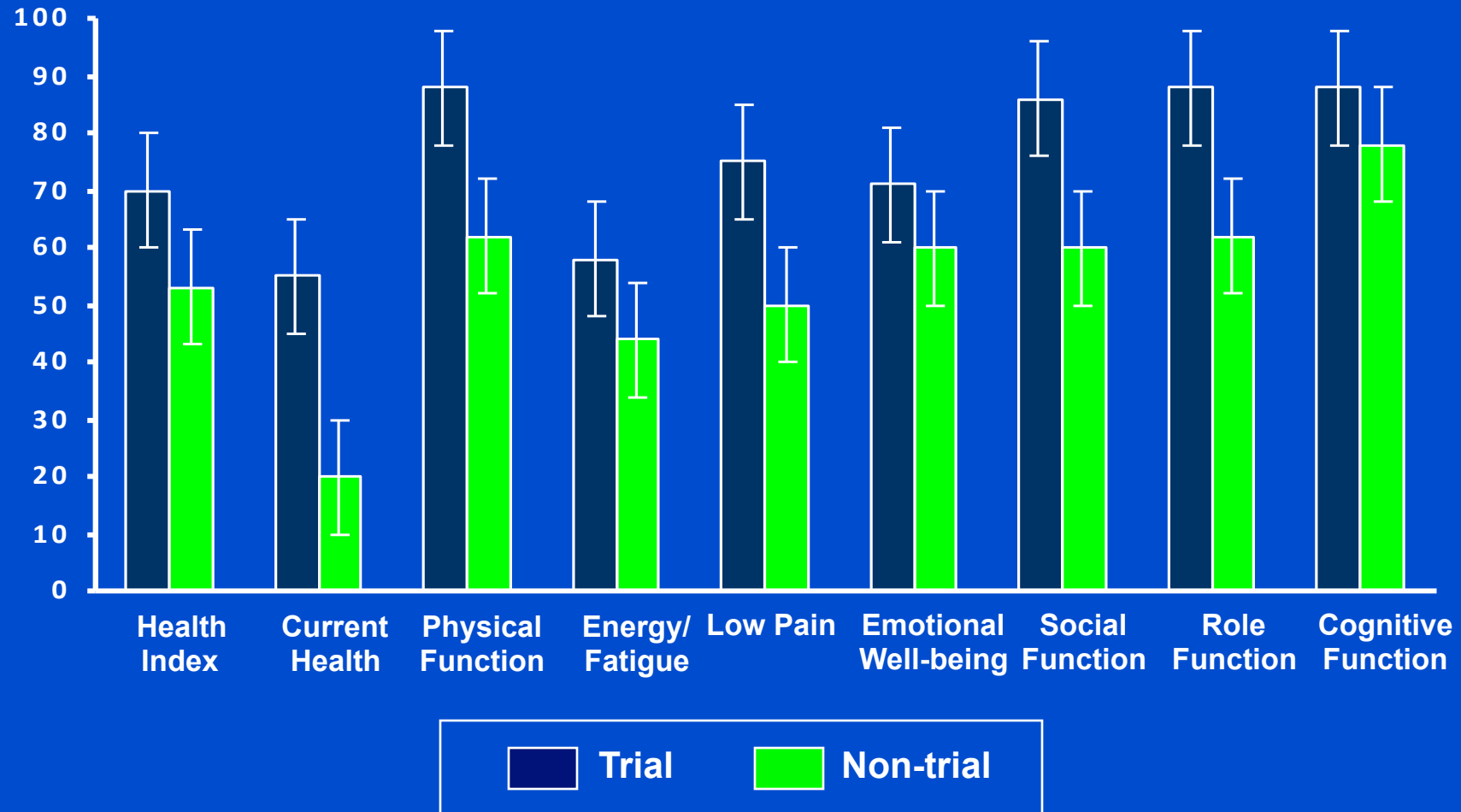
- **Profiles of Different Diseases**
- **Examining Antecedents**

HRQOL of Those with Chronic Illness Compared to General Population

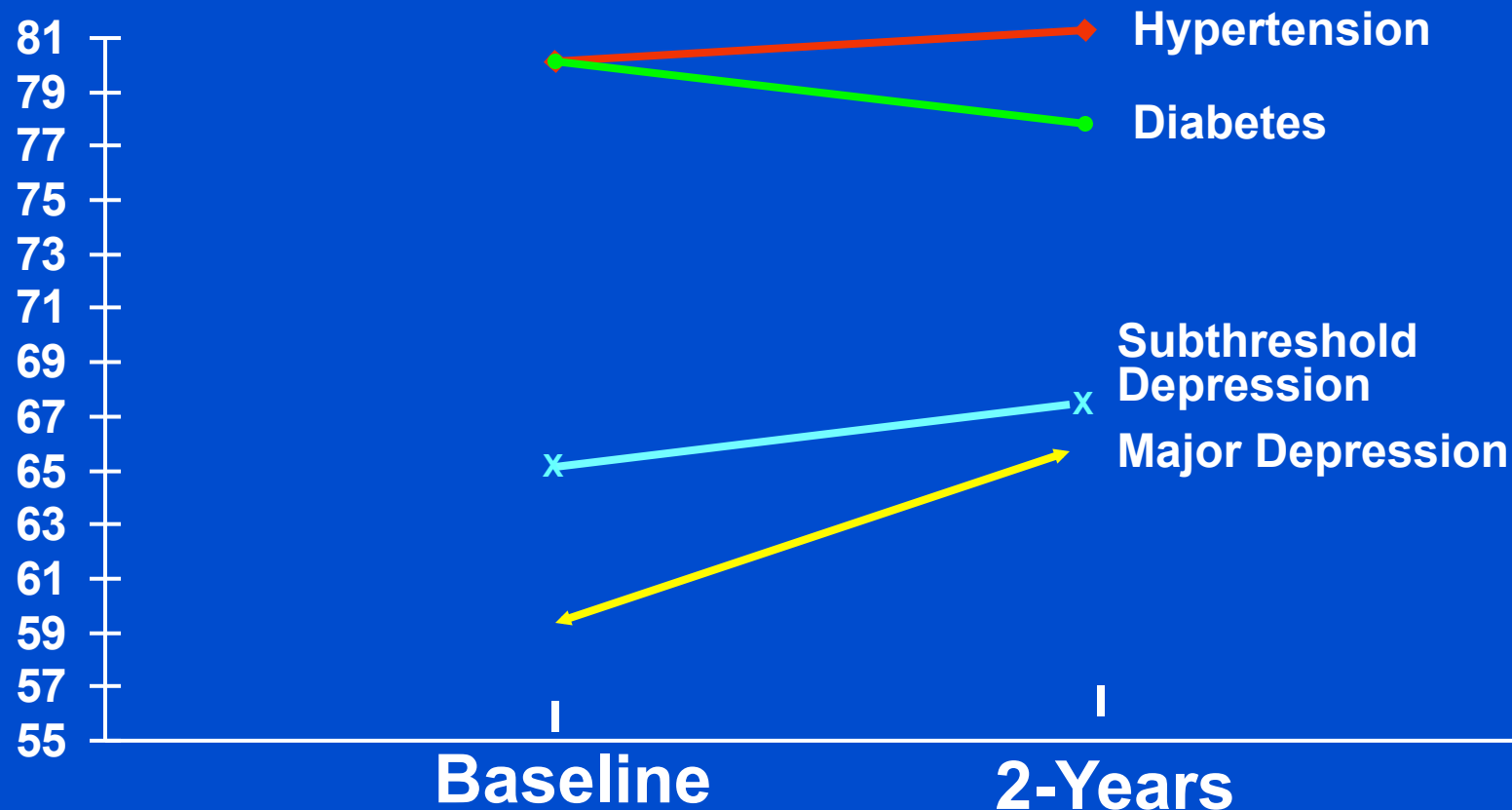


HRQOL Scores of Clinical Trial and Non-Clinical Trial HIV Patients

Cunningham et al. (1995)

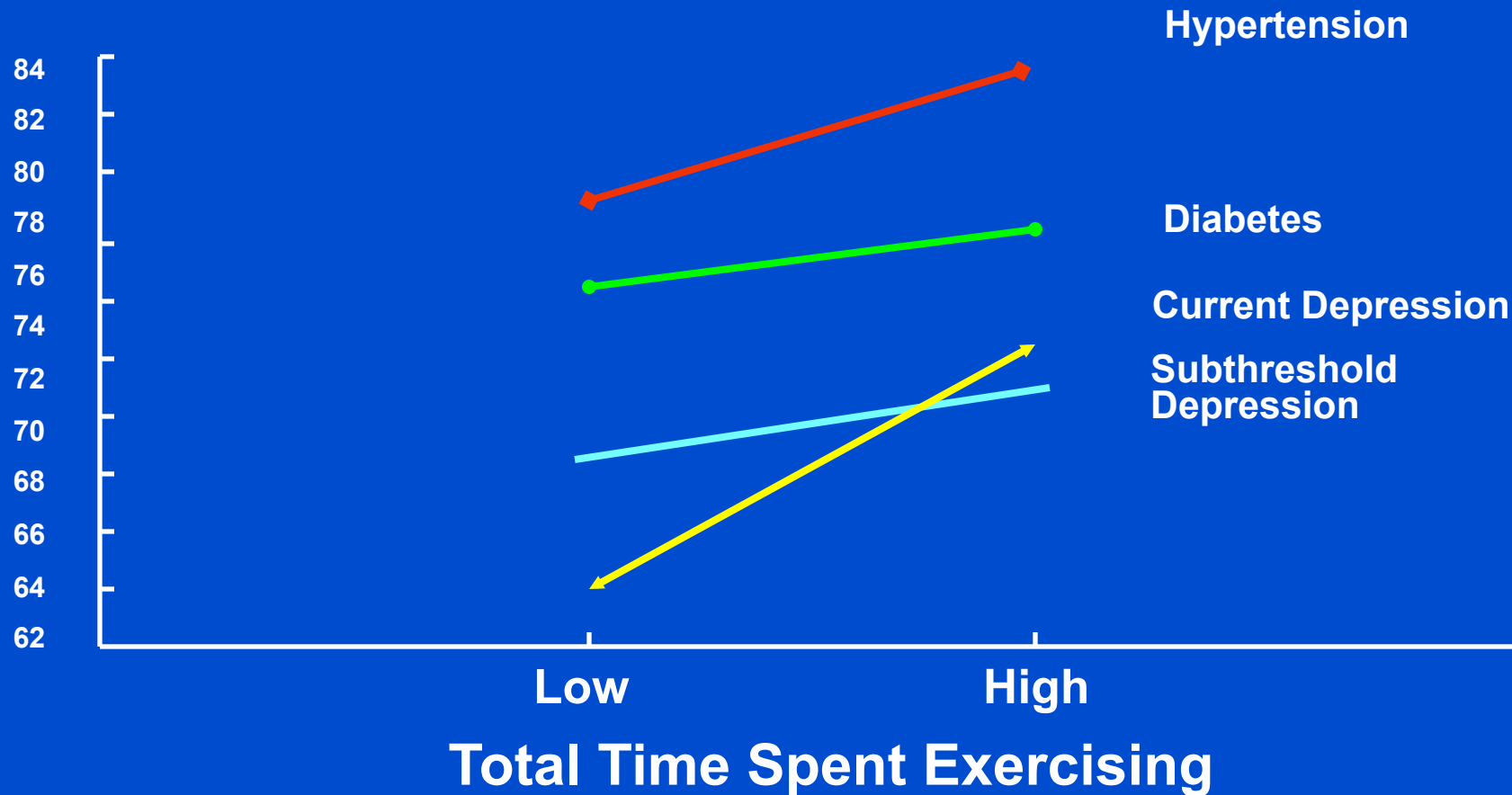


Course of Emotional Well-being Over 2-years for Patients in the MOS General Medical Sector



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.

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 to Extremely)

KDQOL-SF™

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)

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 & sphincter management

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

HRQOL in Men Treated for Localized Prostate Cancer

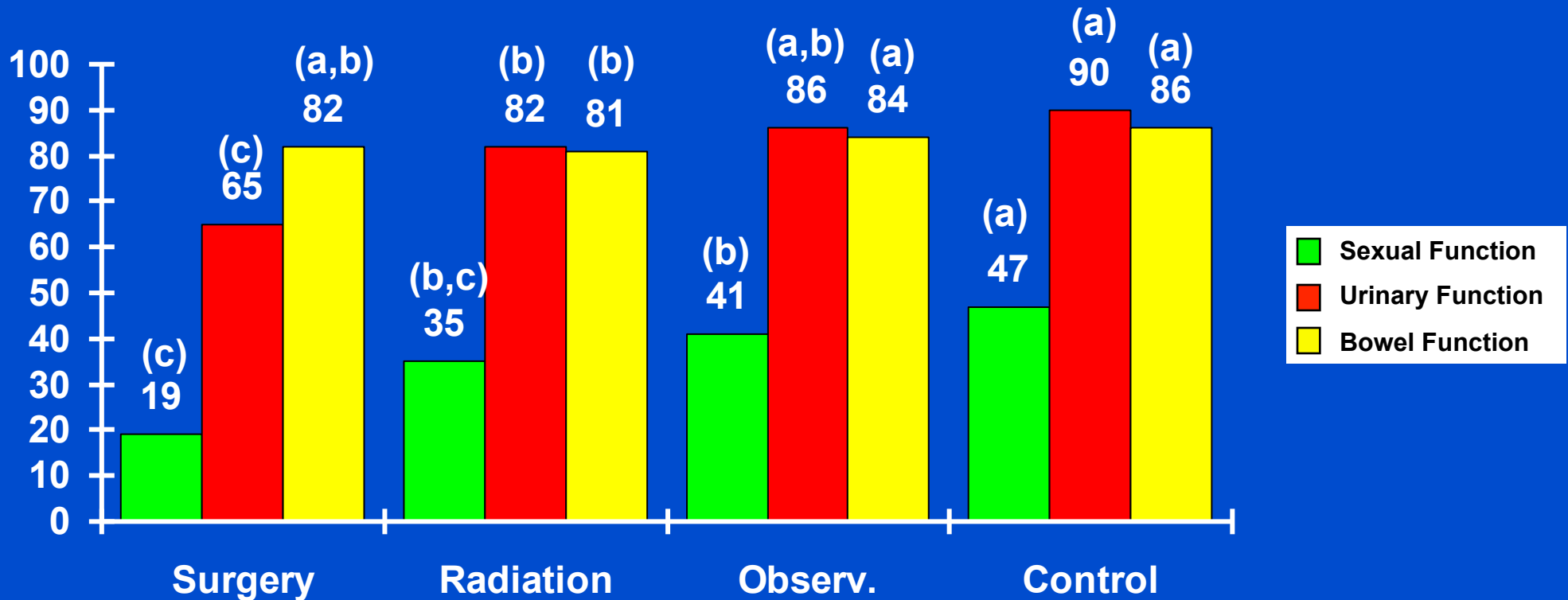
Cross-sectional study of managed care pop.

Sexual, urinary and bowel function and distress

214 men with prostate cancer (98 radical prostatectomy, 56 primary pelvic irradiation, and 60 observation alone)

273 age/zip matched pts. without cancer

Sexual, Urinary, and Bowel Function Outcomes



Litwin, et al. (1995, JAMA)

Check-in Point

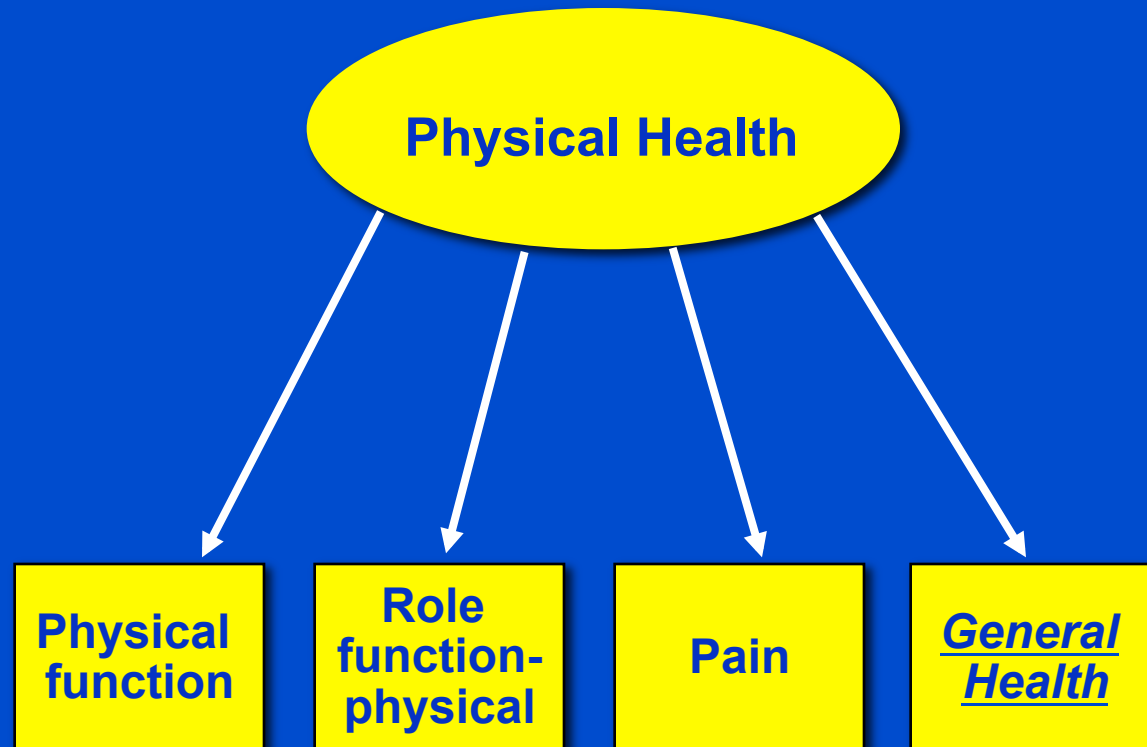
Generic Profile Measures

Targeted Profile Measures

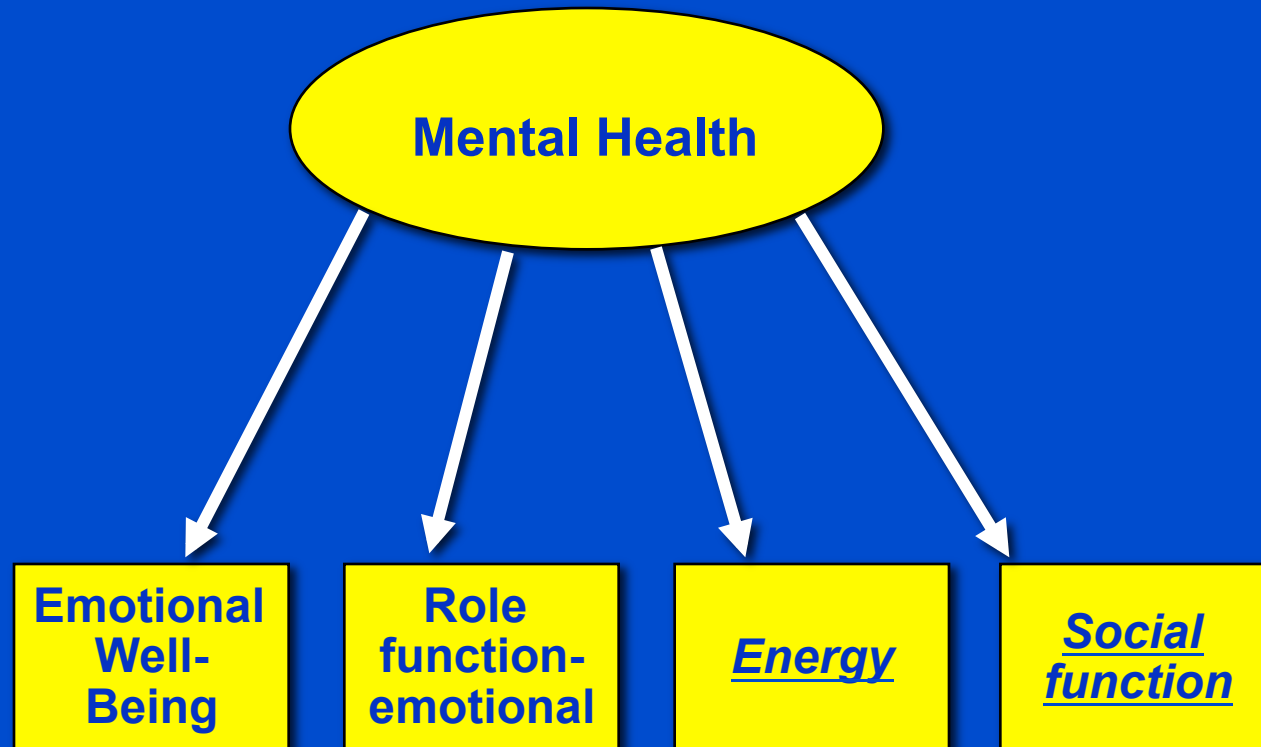
-> Summarizing Profile Information

Preference Measures

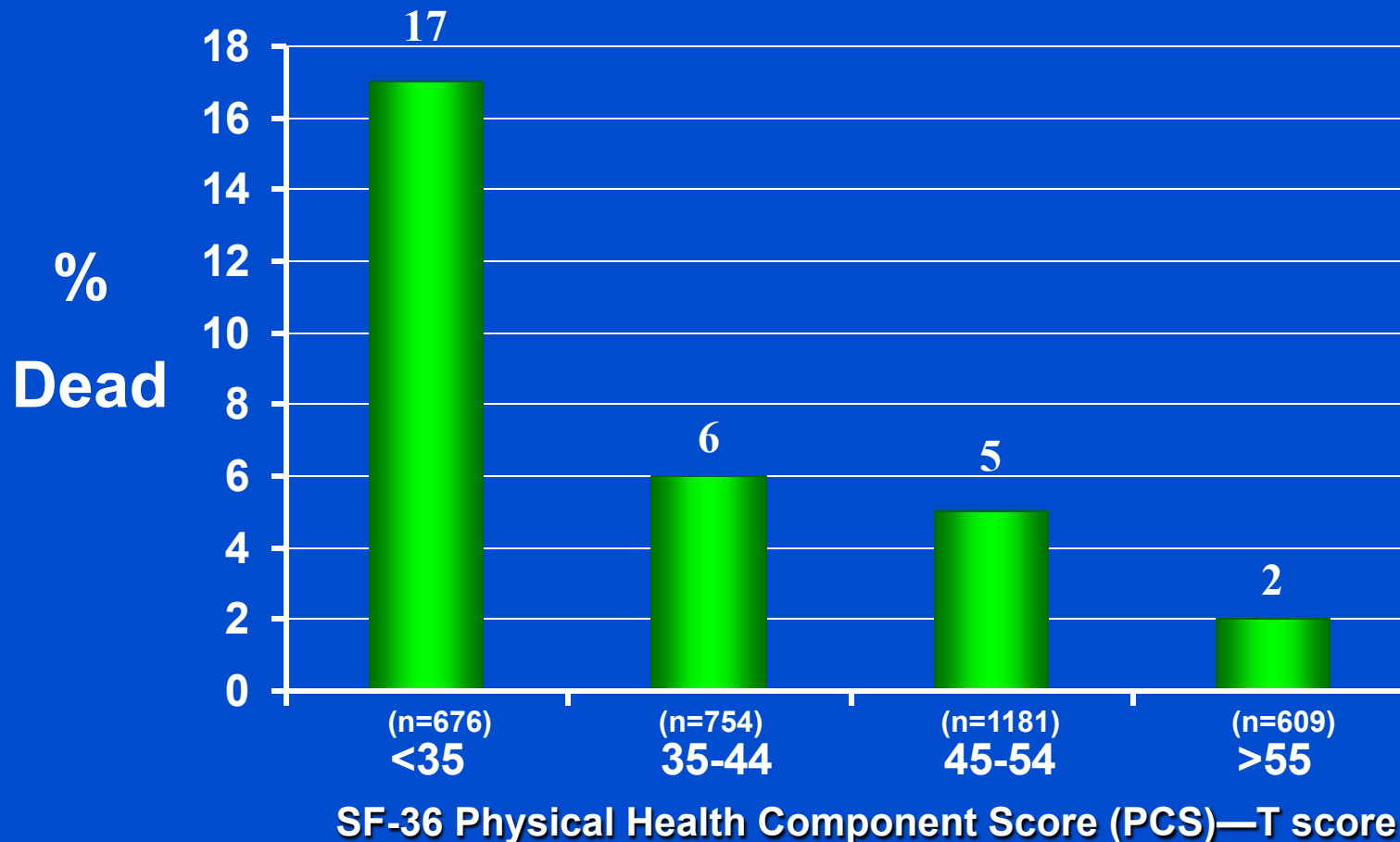
Physical Health



Mental Health

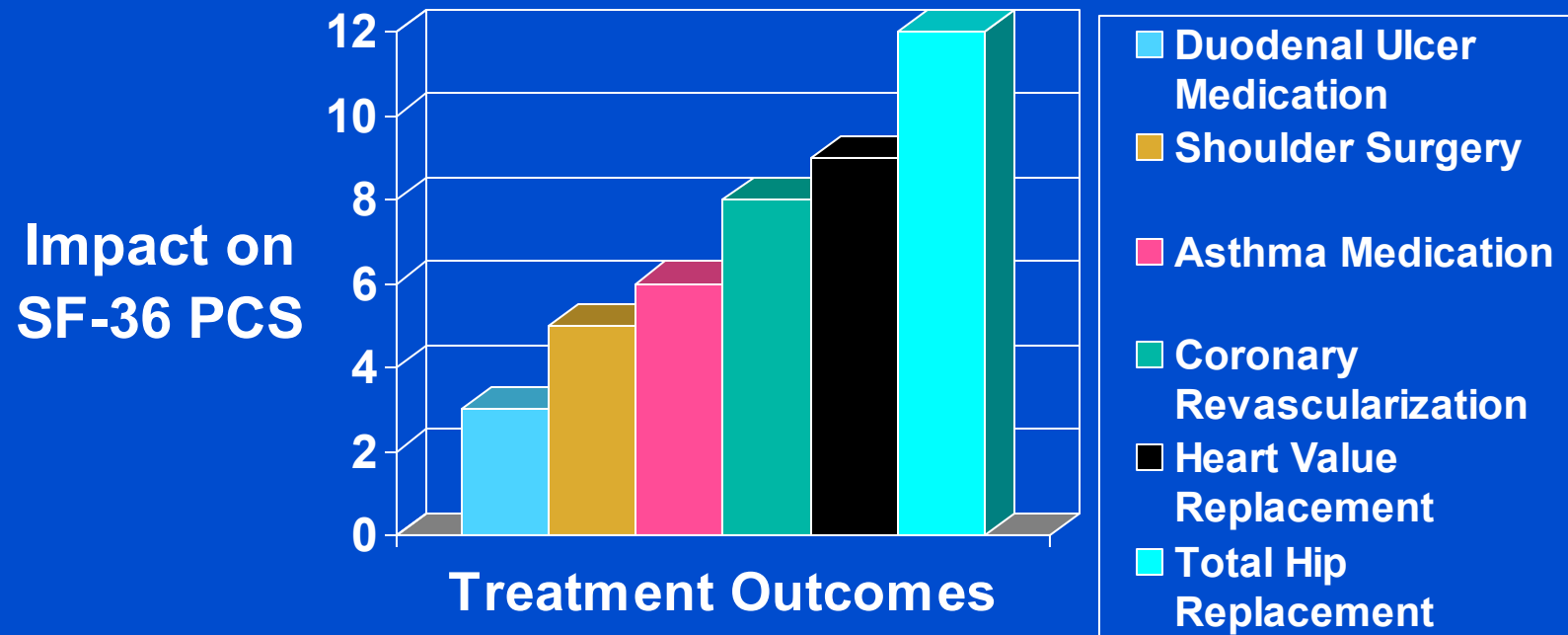


Five-Year Mortality Rates by Levels of Physical Health

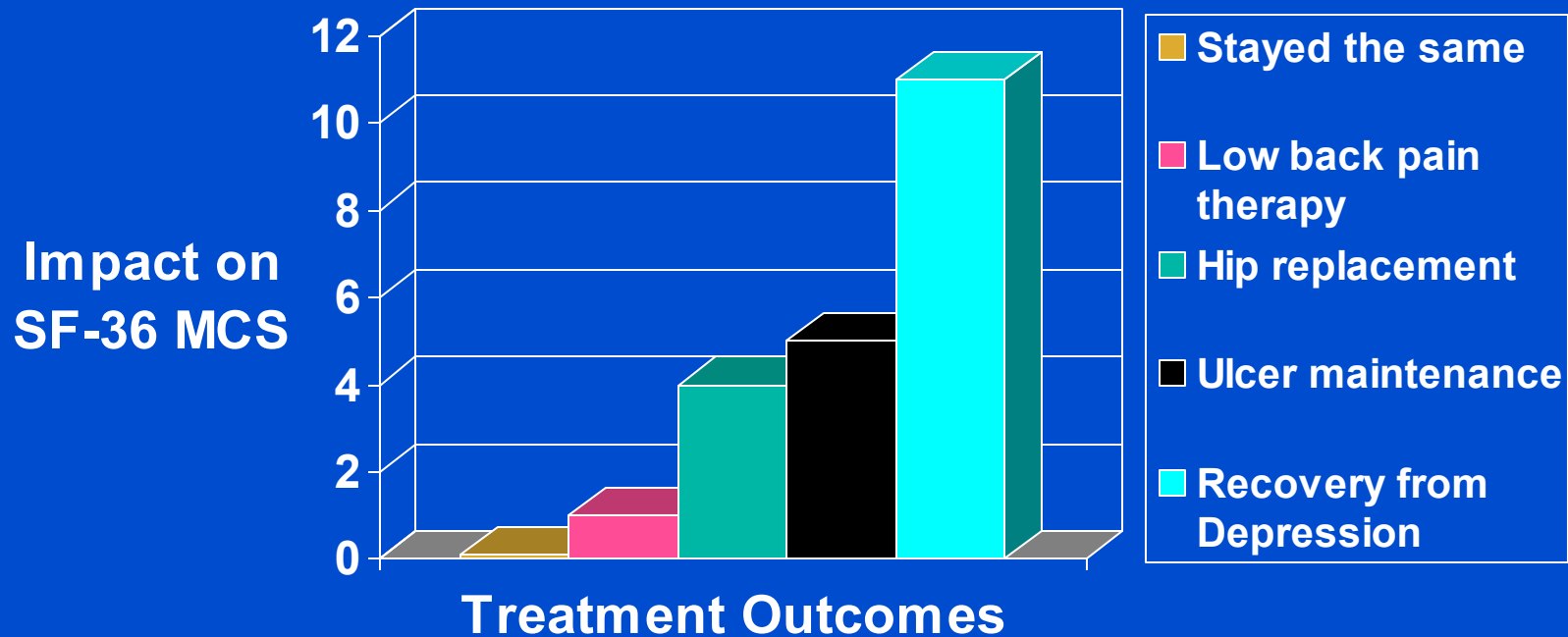


Ware et al. (1994). SF-36 Physical and Mental Health Summary Scales: A User's Manual.

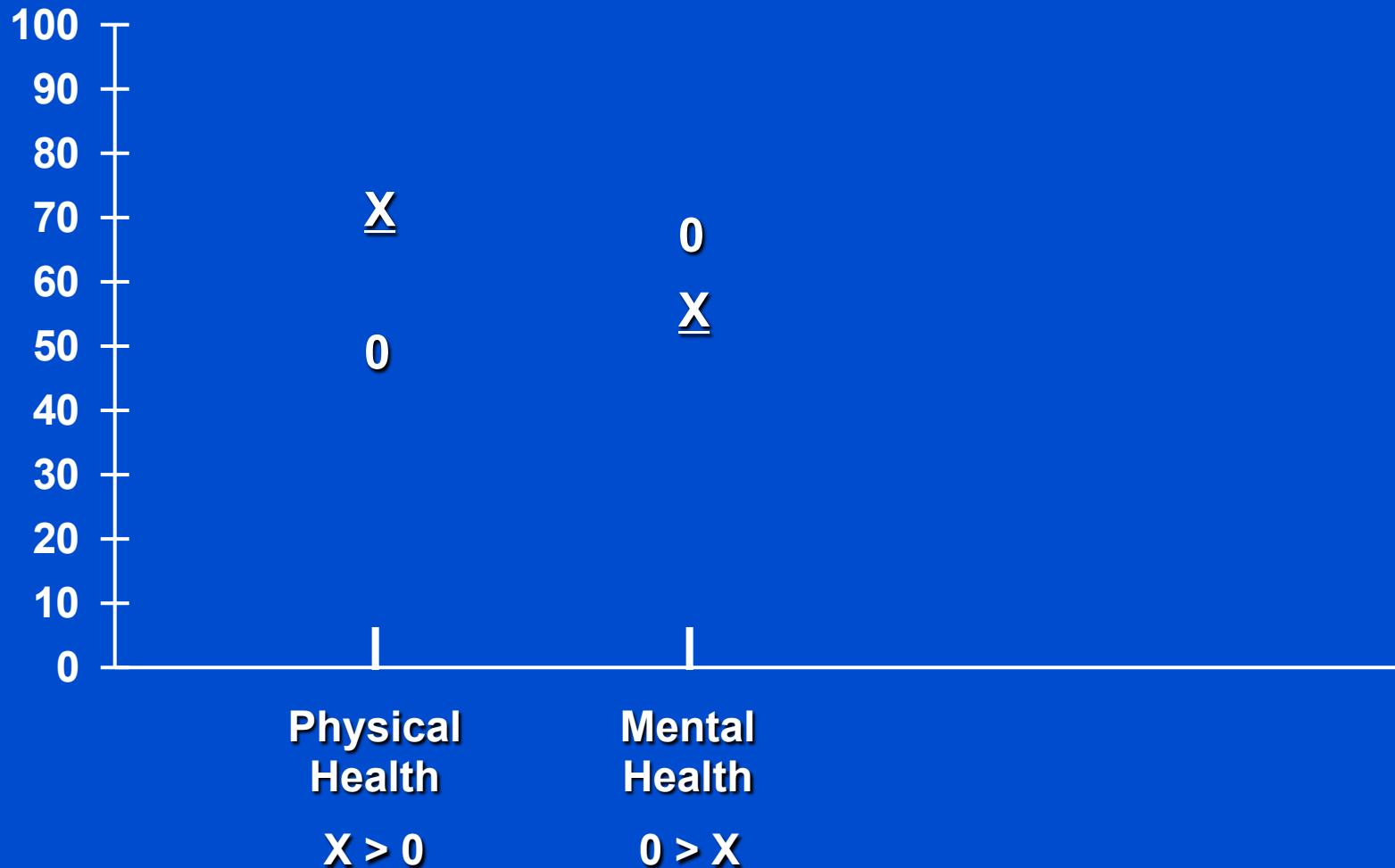
Treatment Impact on Physical Health



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

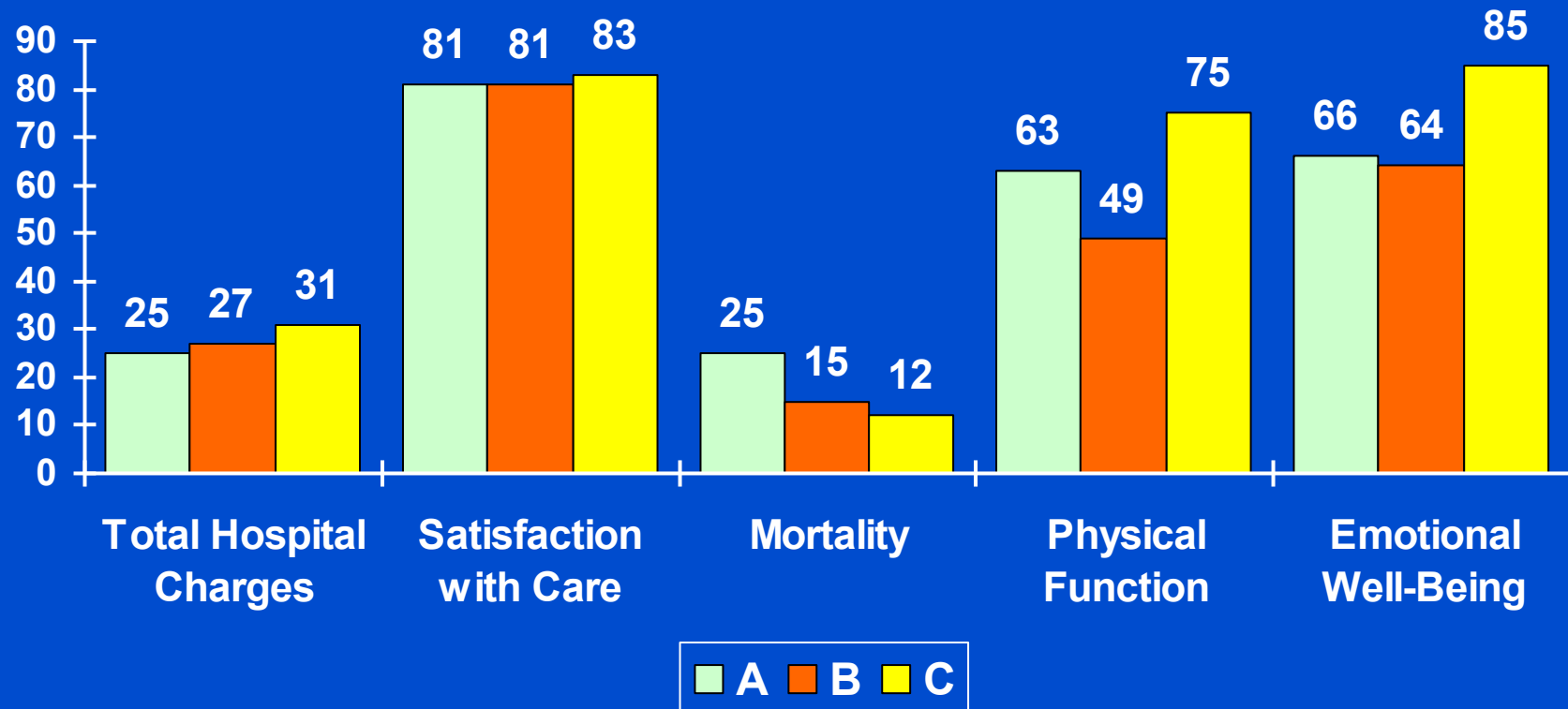
Marathoner 1.0

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

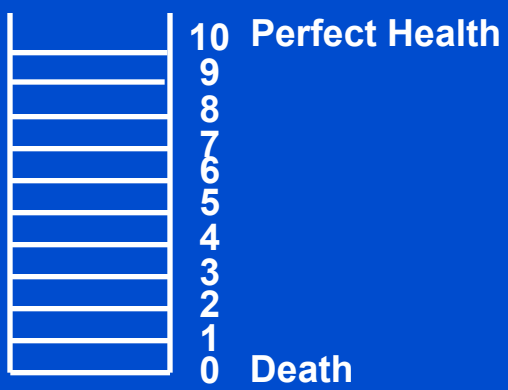
Adult (18-65)

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**

HUI-3

Vision

Hearing

Speech

Ambulation

Dexterity

Cognition

Pain and discomfort

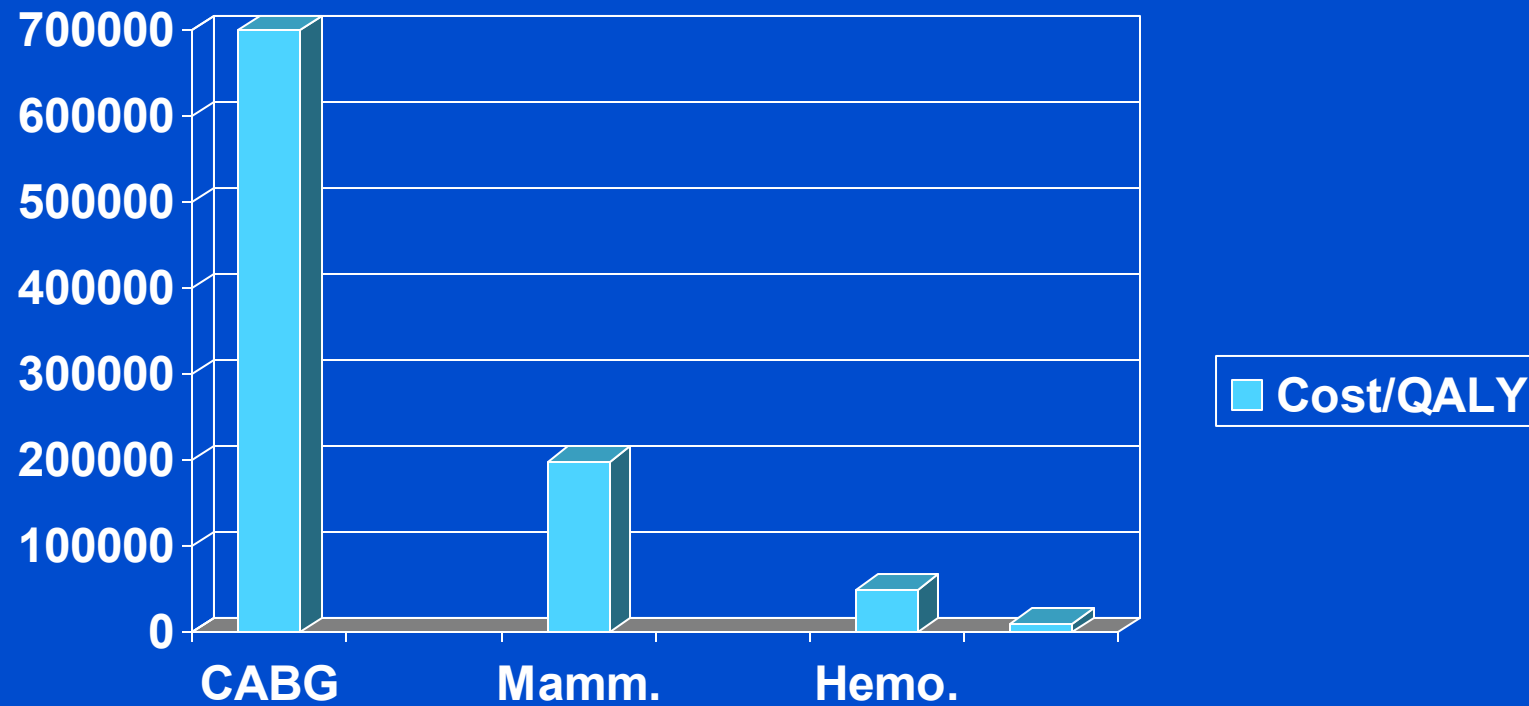
Emotion

- **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

Cost/QALY



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.

Child Measures

- Child Health and Illness Profile (CHIP)
 - Starfield et al., Medical Care, 1995
- COOP Charts
 - Baribeau, P. et al., 1991 (final report)
- Functional Status II-R
 - Stein & Jessop, Medical Care, 1990
- Child Health Questionnaire
 - Landgraf, Abetz, & Ware (2000)

