

Generic and Targeted HRQOL Measures

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

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

"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:

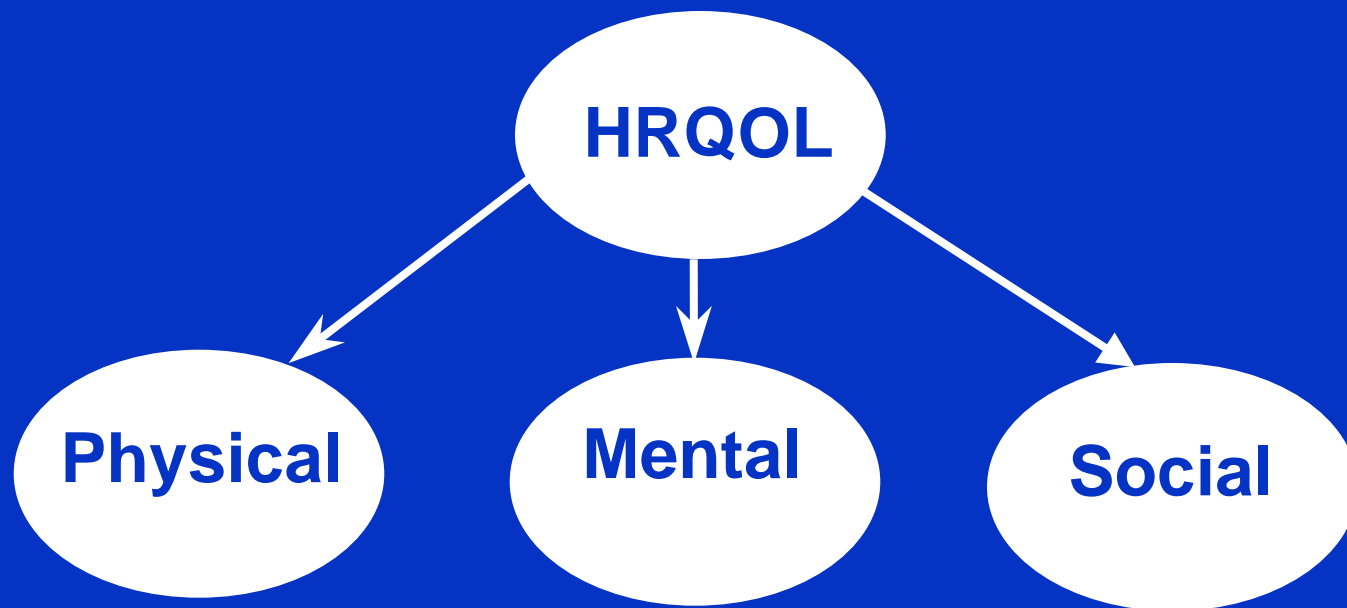
What the person can DO (functioning)

- 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

△ HRQOL

Two Main 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)



0

1

2

3

4

5

6

7

8

9

10

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

Life Satisfaction Item

Which best describes how you feel about **YOUR LIFE AS A WHOLE**?

- | | |
|--------------------------|---|
| <input type="checkbox"/> | 1 = Terrible |
| <input type="checkbox"/> | 2 = Unhappy |
| <input type="checkbox"/> | 3 = Mostly dissatisfied |
| <input type="checkbox"/> | 4 = Mixed -- about equally satisfied and dissatisfied |
| <input type="checkbox"/> | 5 = Mostly satisfied |
| <input type="checkbox"/> | 6 = Pleased |
| <input type="checkbox"/> | 7 = Delighted |

Health versus Quality of Life

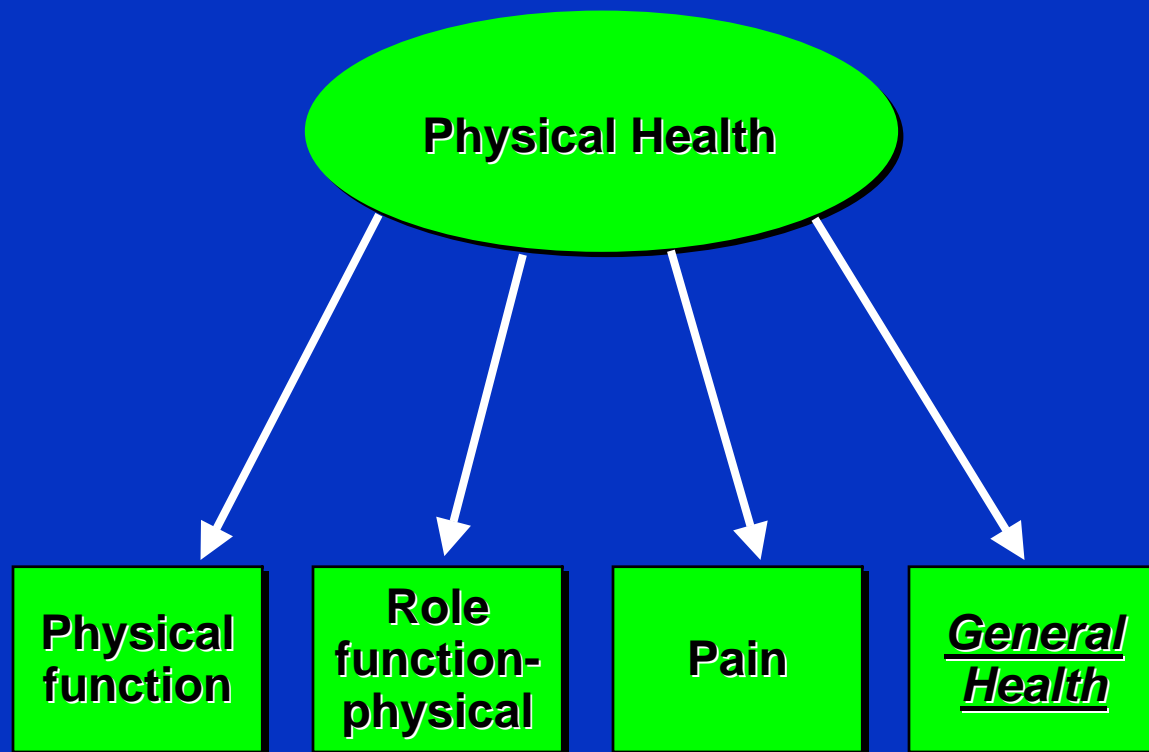
“In general, how would you rate your health?”

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

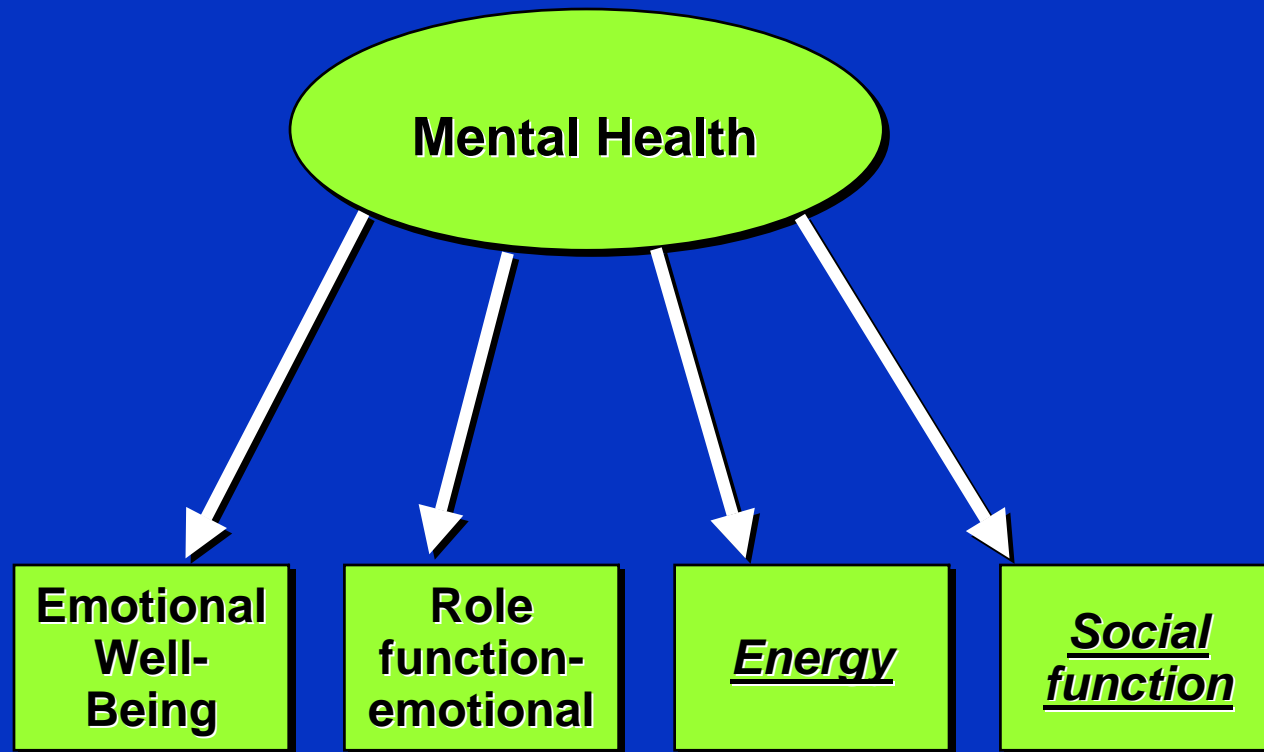
Generic HRQOL: 8 SF-36 Scales

- 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?

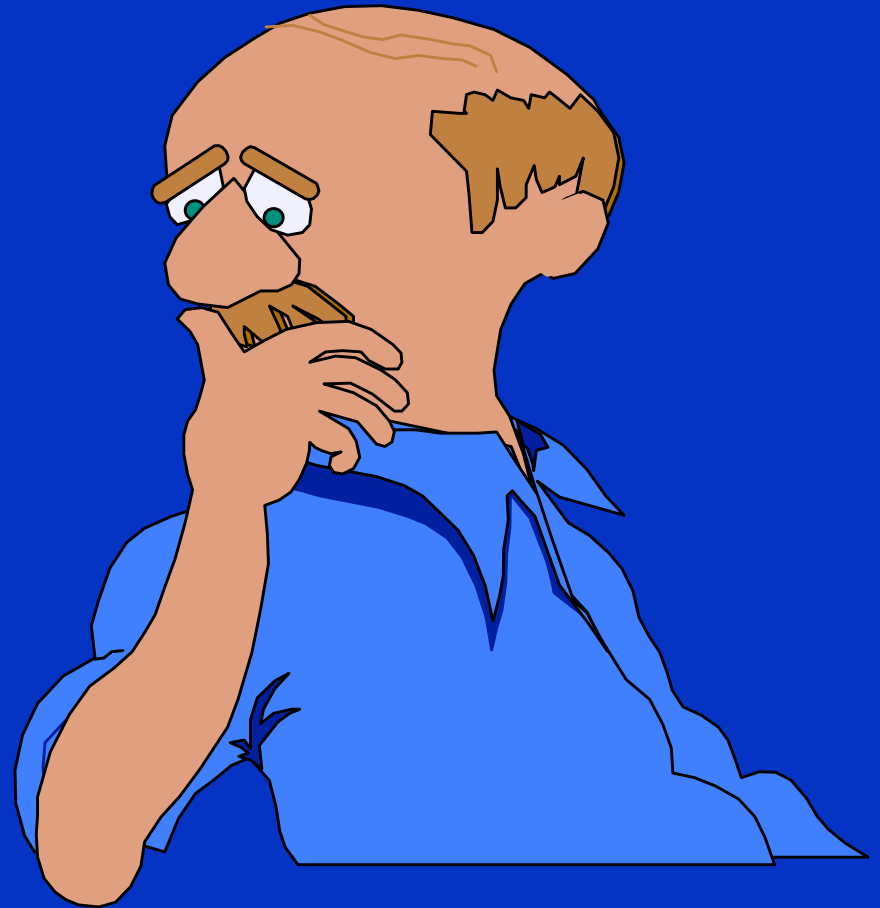
None of the time

A little of the time

Some of the time

Most of the time

All of the time



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

200% Arial 10

	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



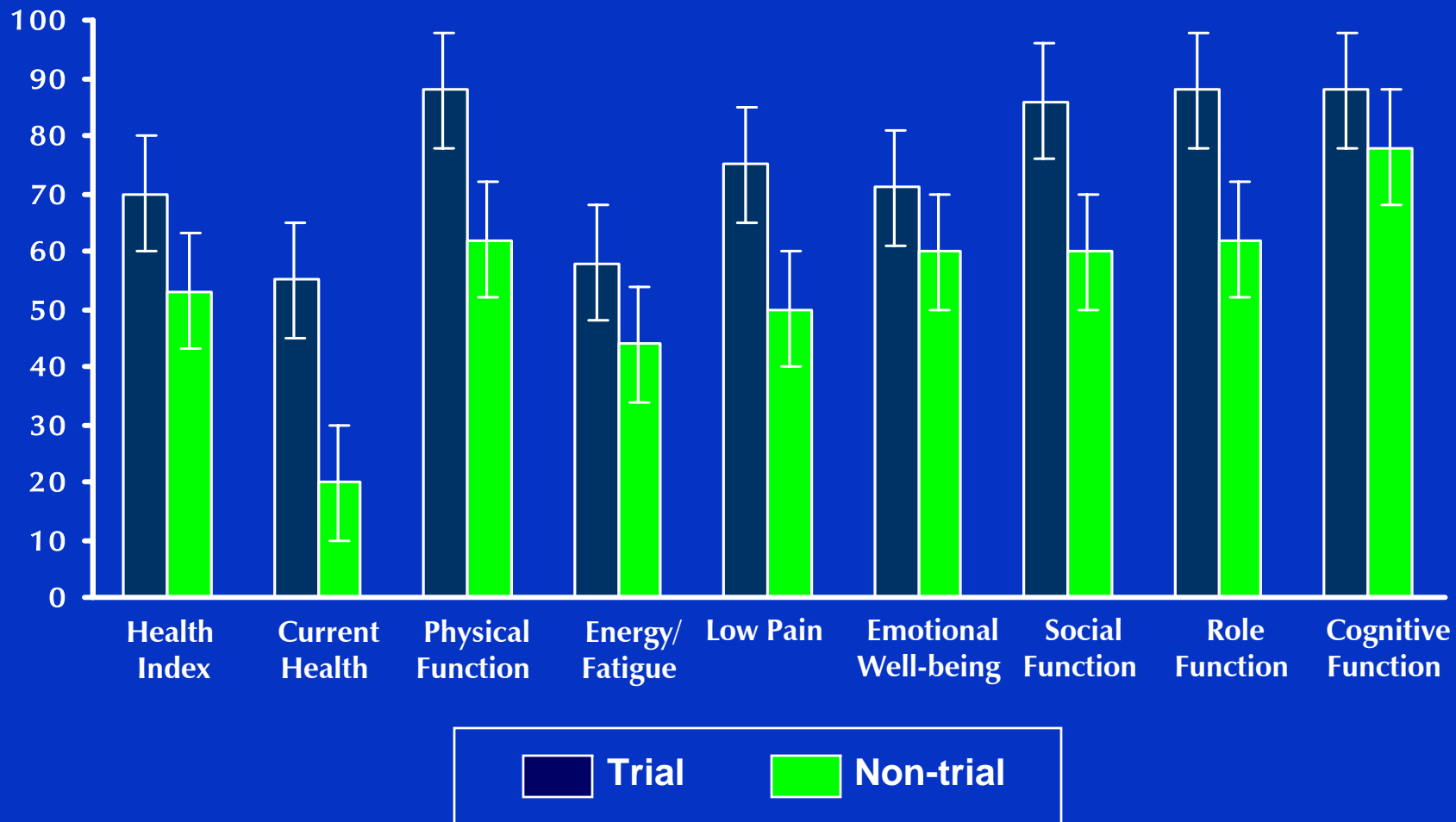
Uses of Generic Measures

Cross-Sectional

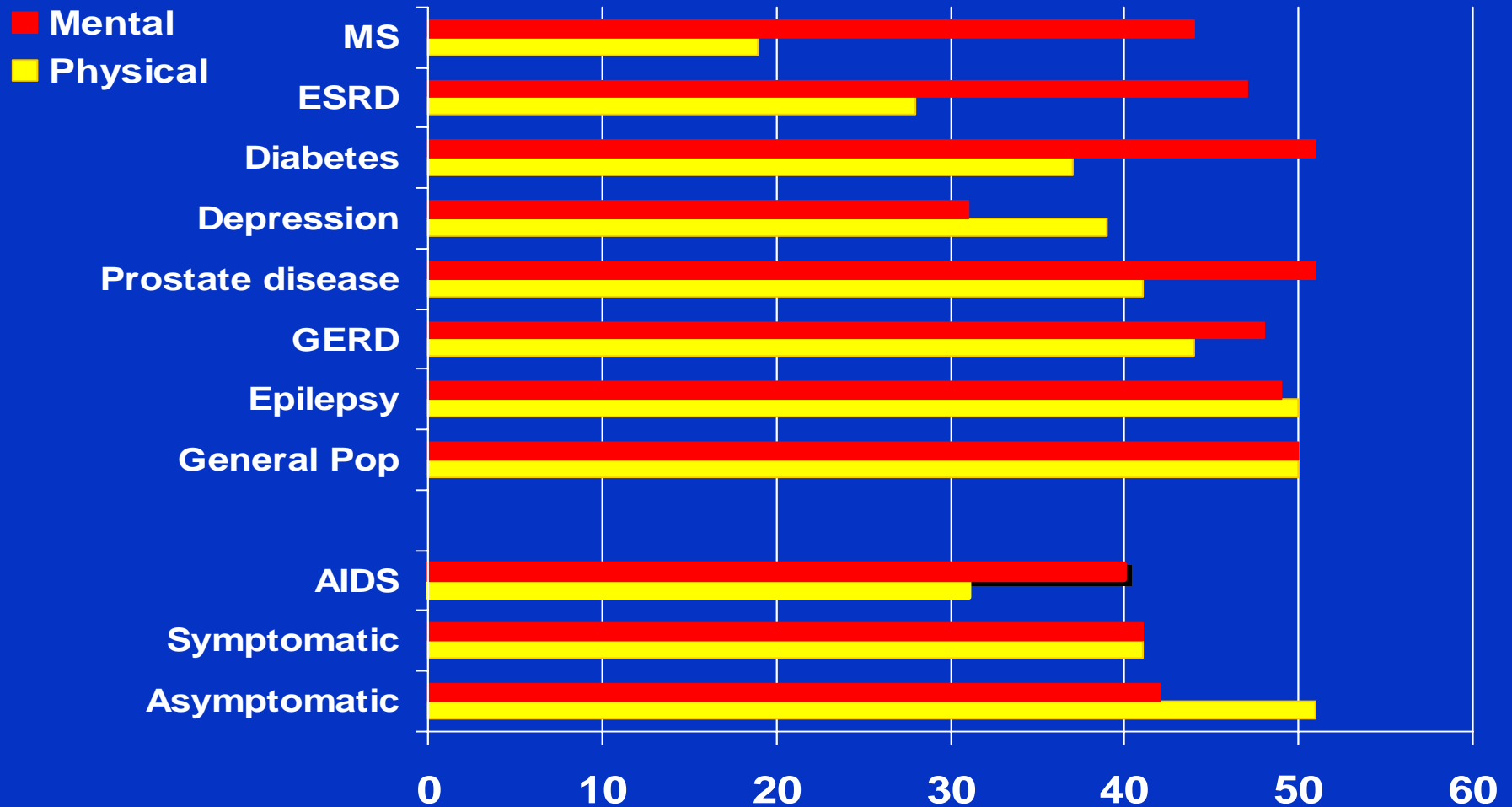
- Comparisons of Different Samples
- Profiles of Different Diseases
- Longitudinal
- Profiles of Different Diseases
- Exploring HRQOL Antecedents
- Predicting future health-related events

HRQOL of Patients in ACTG versus Public Hospital Samples

Adjusted Scale Scores (Cunningham et al., 1995)

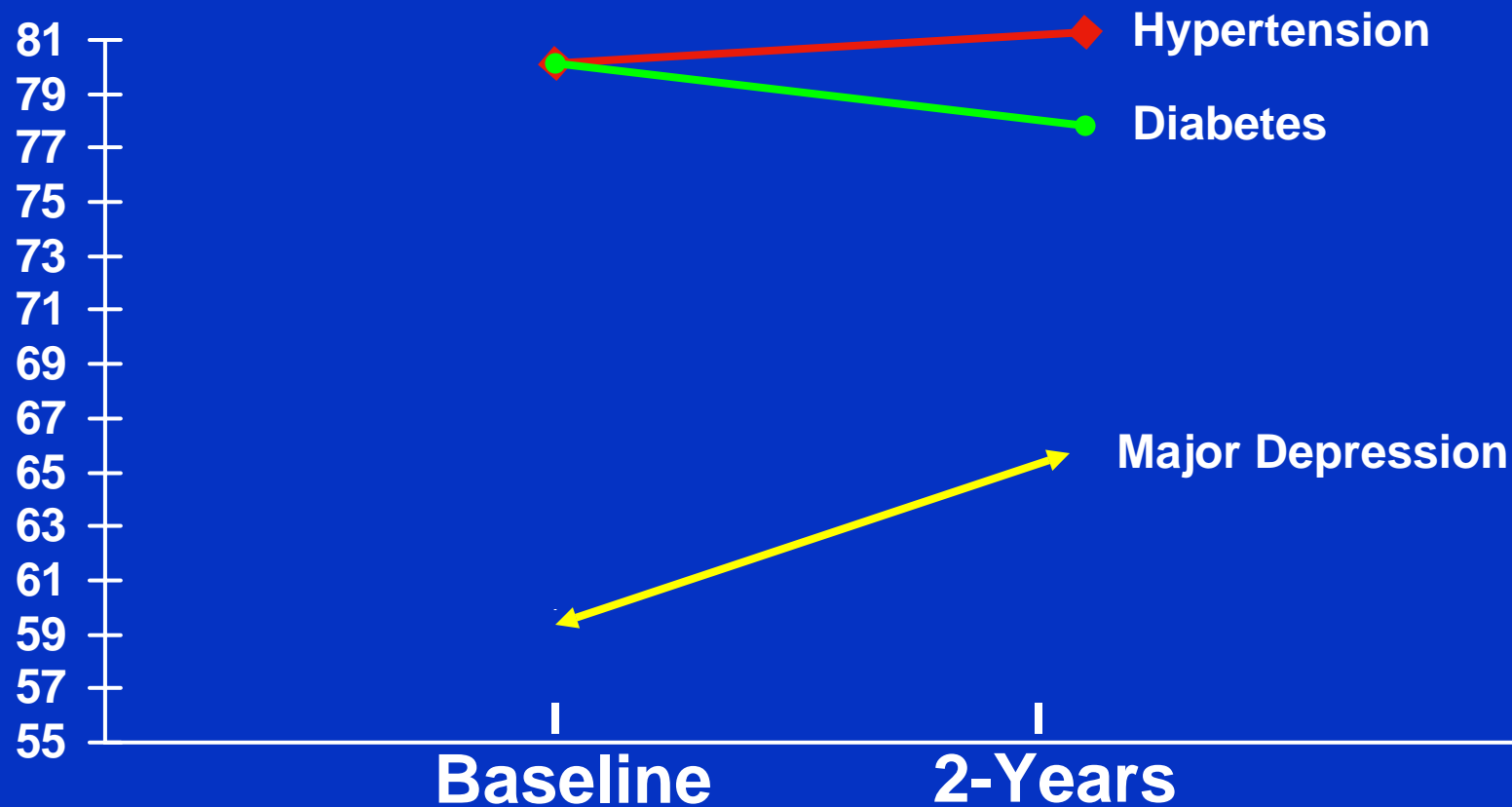


HRQOL for HIV Compared to other Chronic Illnesses and General Population



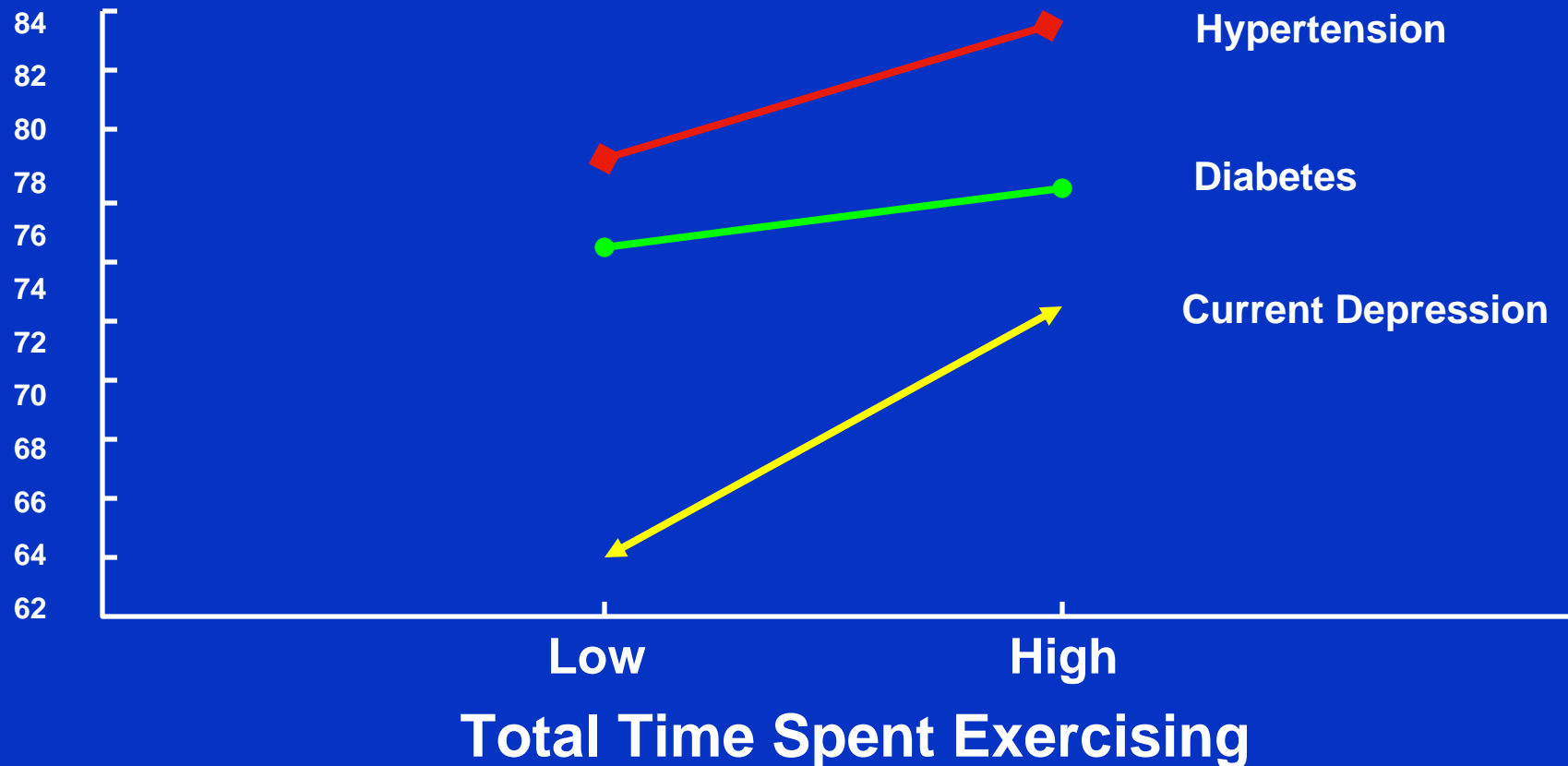
Hays, et al. (2000), American Journal of Medicine

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



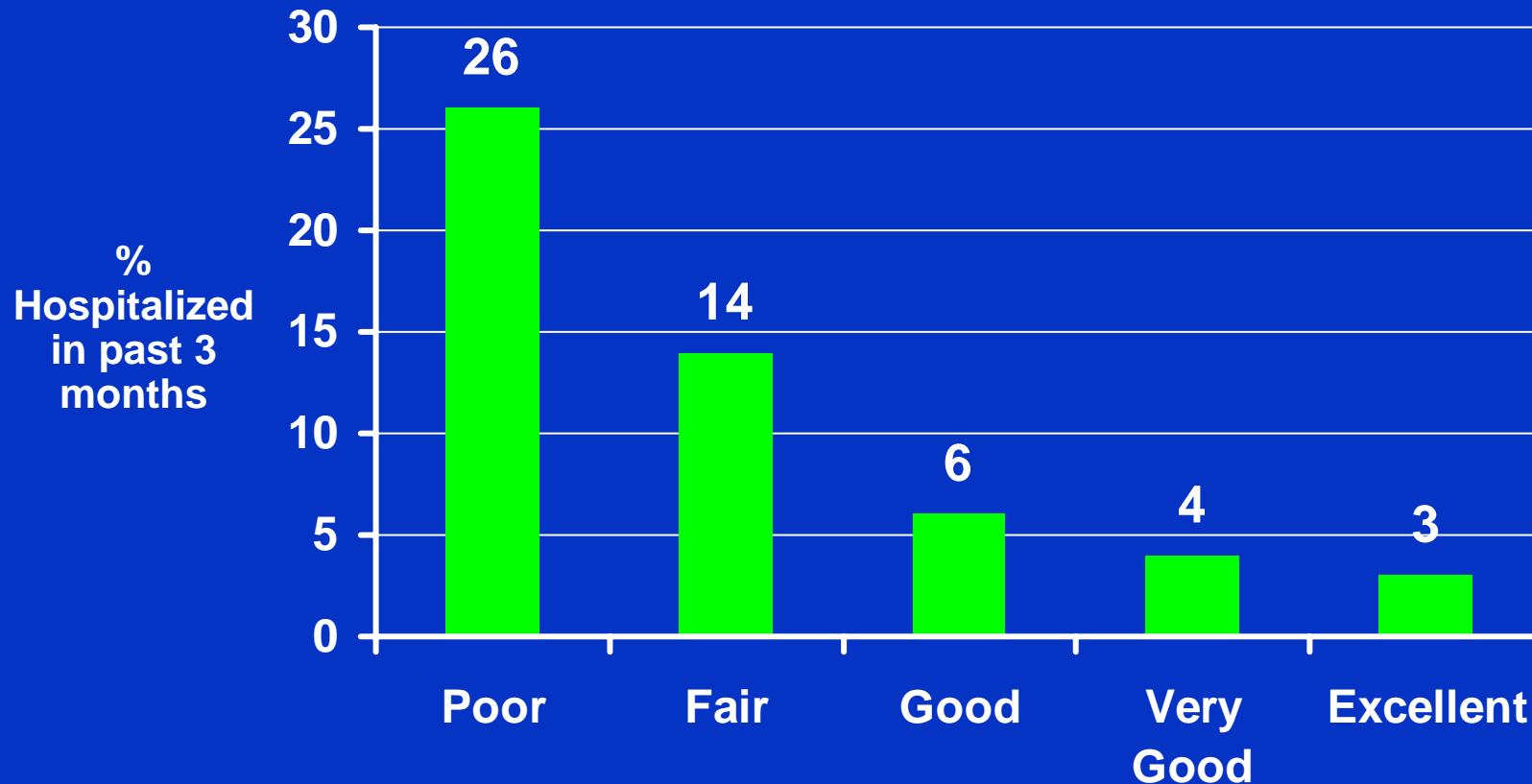
Hays, R.D., Wells, K.B., Sherbourne, C.D., Rogers, W., & Spritzer, K. (1995).
Functioning and well-being outcomes of patients with depression compared
to chronic medical illnesses. *Archives of General Psychiatry*, *52*, 11-19.

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



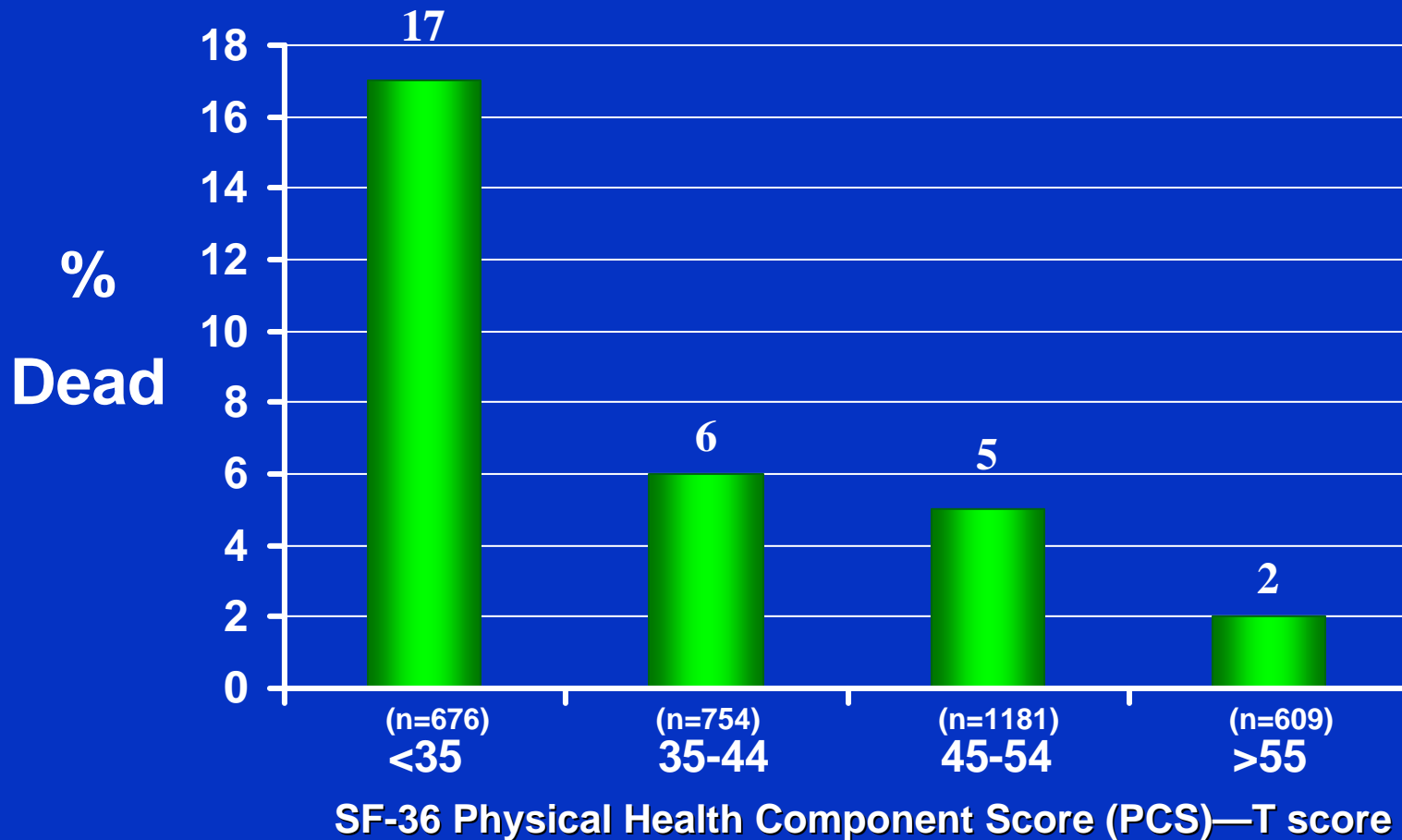
Stewart, A.L., Hays, R.D., Wells, K.B., Rogers, W.H., Spritzer, K.L., & Greenfield, S. (1994). Long-term functioning and well-being outcomes associated with physical activity and exercise in patients with chronic conditions in the Medical Outcomes Study. *Journal of Clinical Epidemiology*, *47*, 719-730.

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.**

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

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

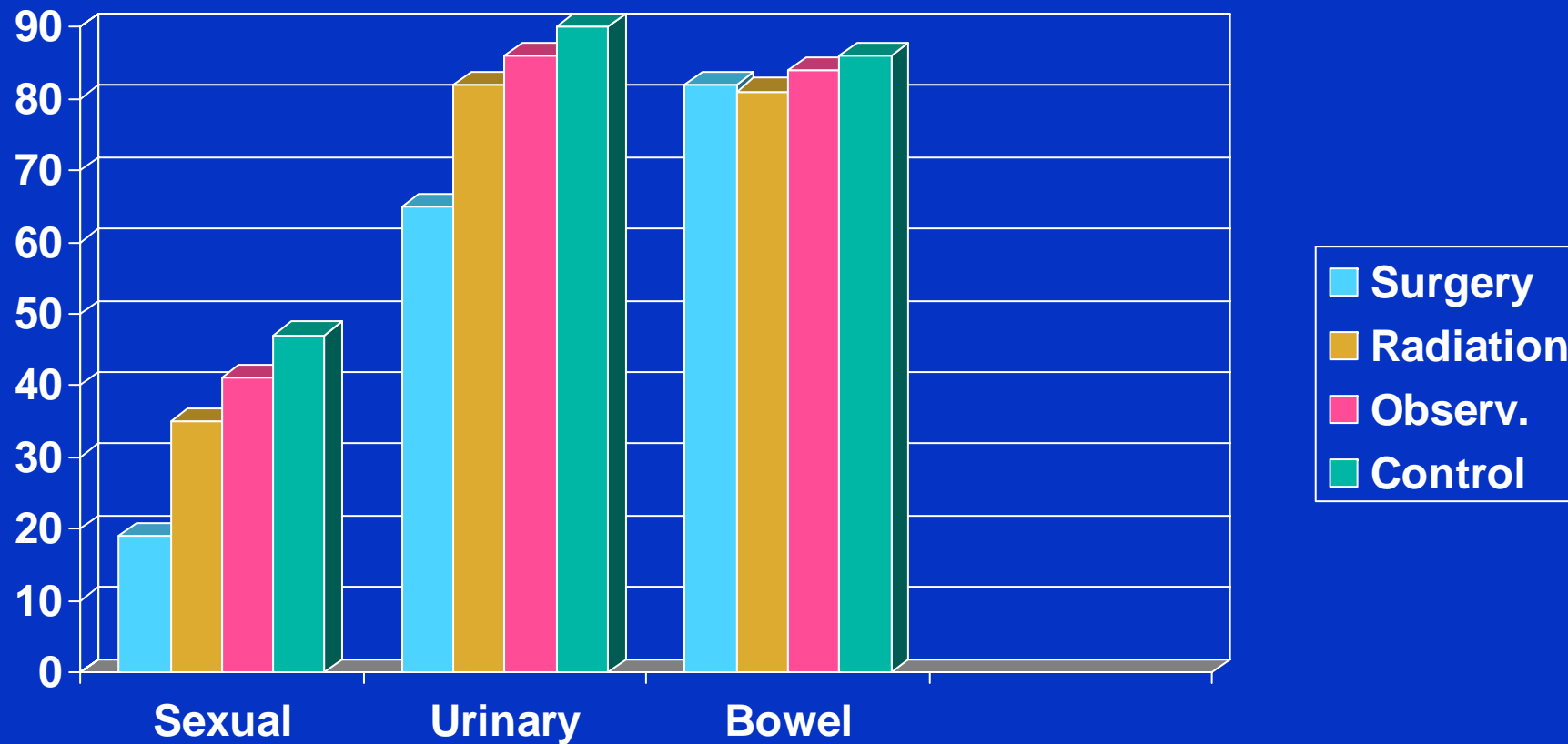
98 radical prostatectomy

56 primary pelvic irradiation

60 observation alone

273 age/zip matched pts. without cancer

Sexual, Urinary and Bowel Function



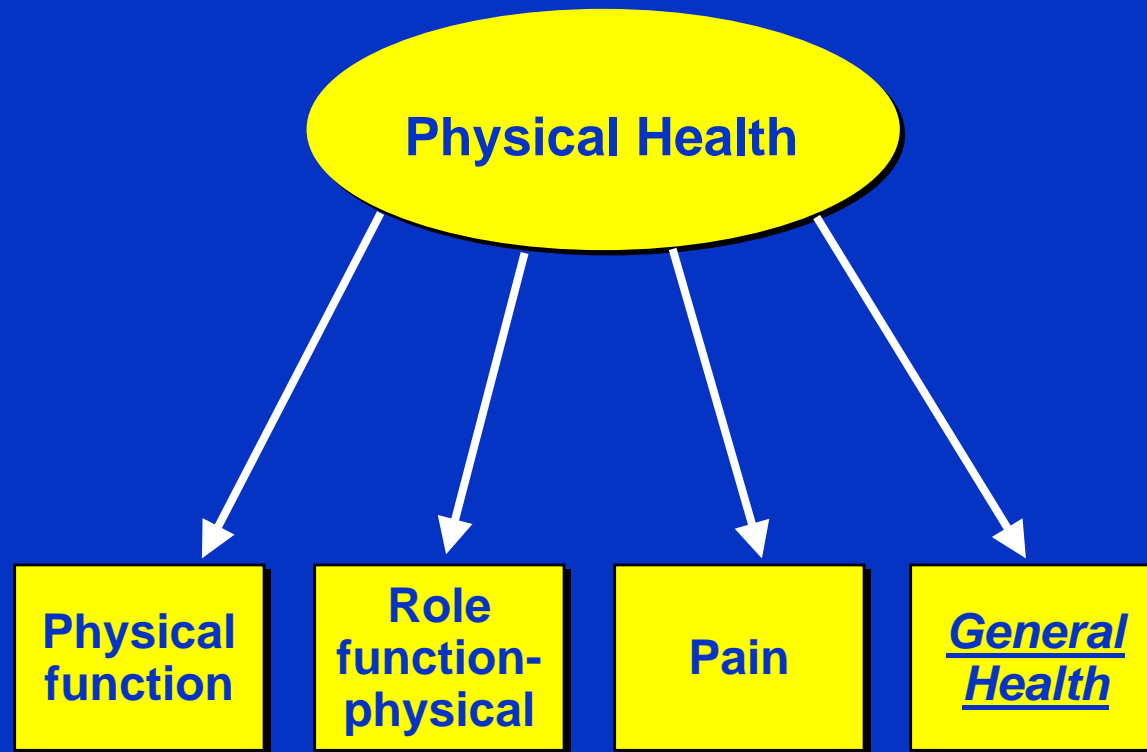
Status Point

Generic Profile Measures

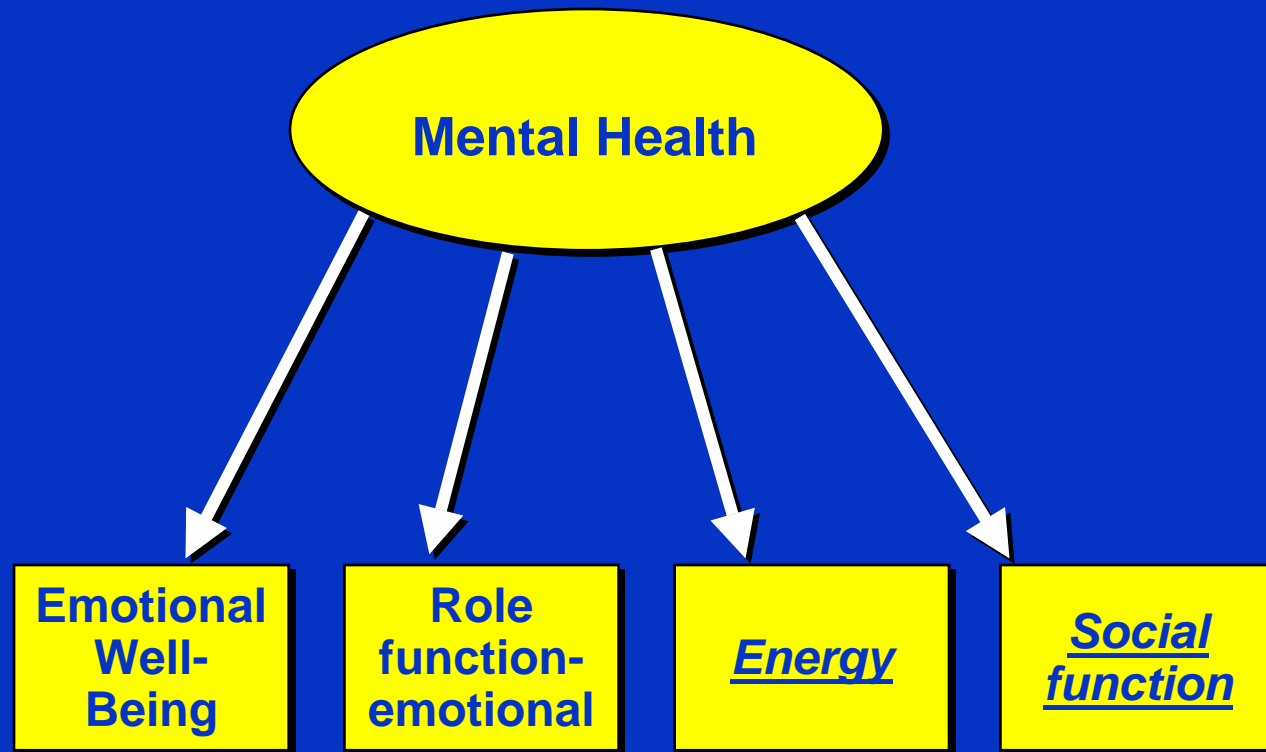
Targeted Profile Measures

-> Summarizing Profile Information

Physical Health



Mental Health



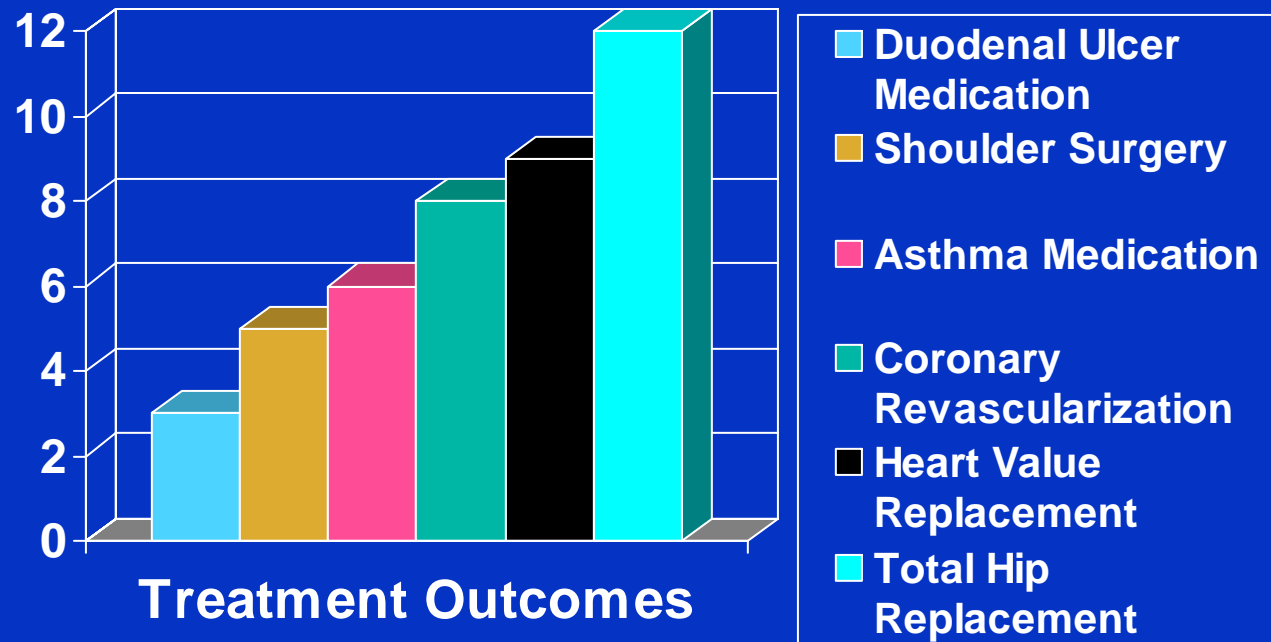
SF-36 PCS and MCS

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

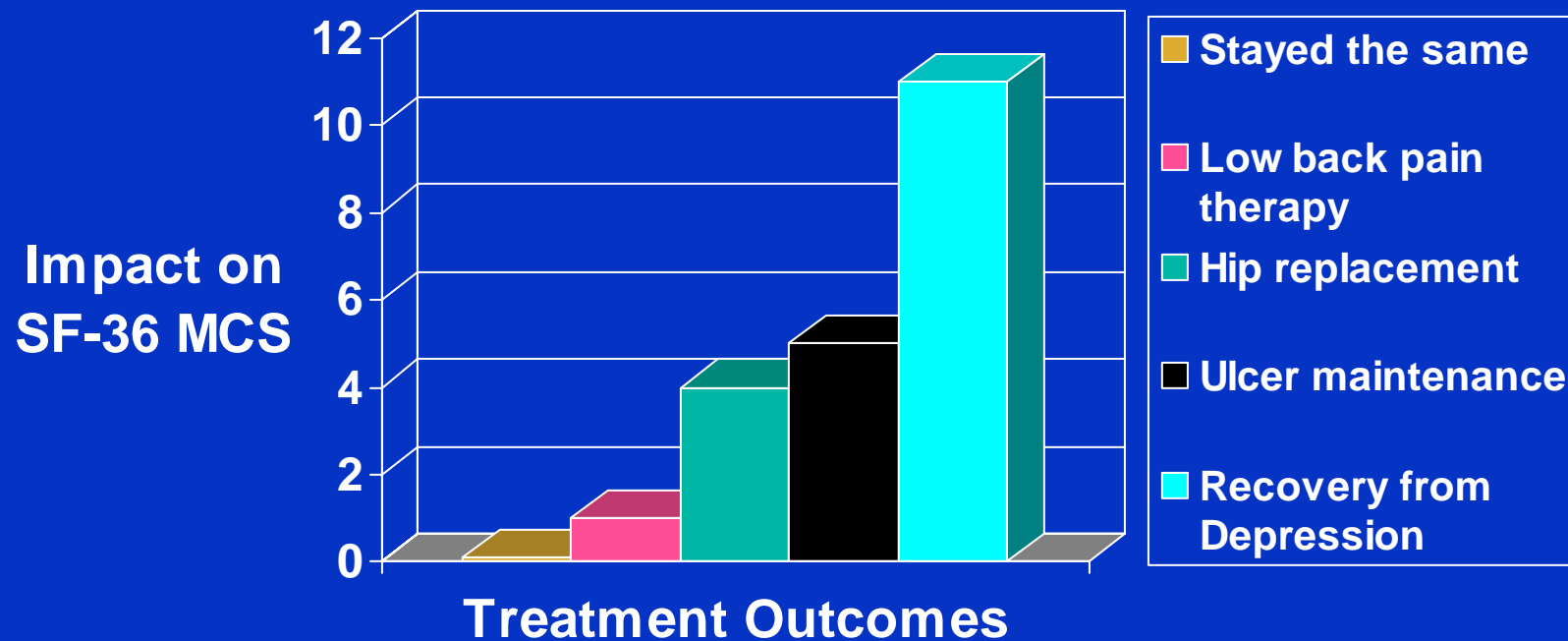
$$\begin{aligned} \text{MCS} = & (\text{PF_Z} * -.22999) + (\text{RP_Z} * -.12329) + \\ & (\text{BP_Z} * -.09731) + (\text{GH_Z} * -.01571) + \\ & (\text{EF_Z} * .23534) + (\text{SF_Z} * .26876) + \\ & (\text{RE_Z} * .43407) + (\text{EW_Z} * .48581) \end{aligned}$$

Treatment Impact on Physical Health

Impact on
SF-36 PCS

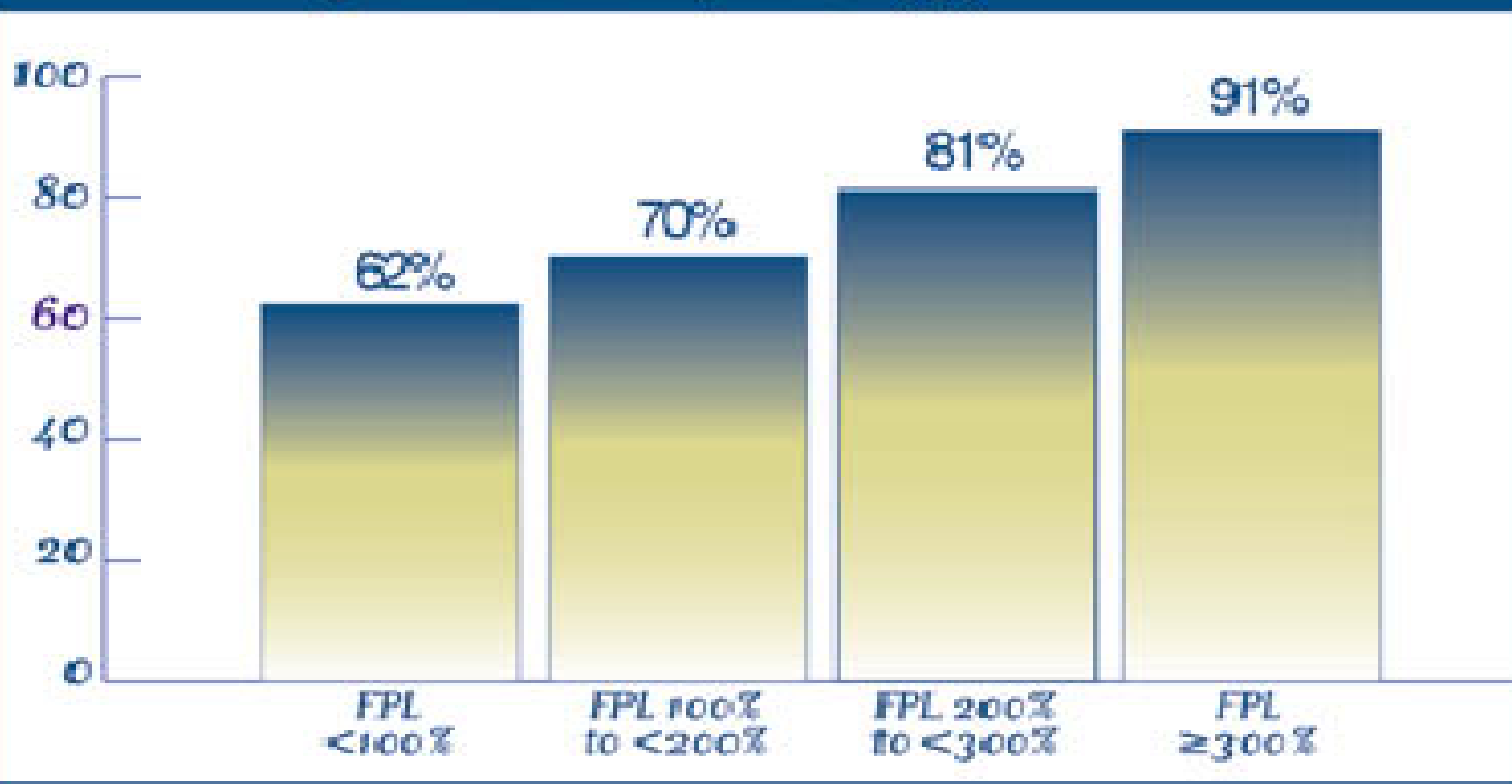


Treatment Impact on Mental Health



Questions?

Figure 1. Percentage of Adults Who Reported Their Health Status as Good to Excellent by Federal Poverty Level, 1999



Source: Los Angeles County Health Survey