

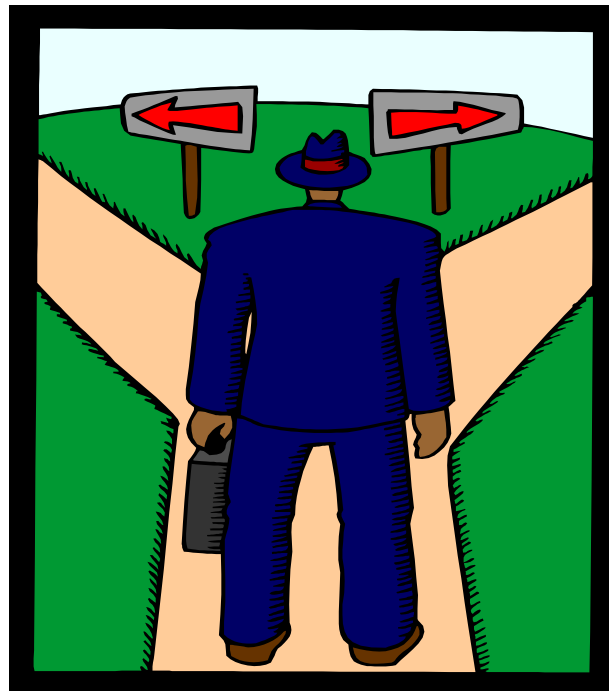
Generic and Targeted HRQOL Measures

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

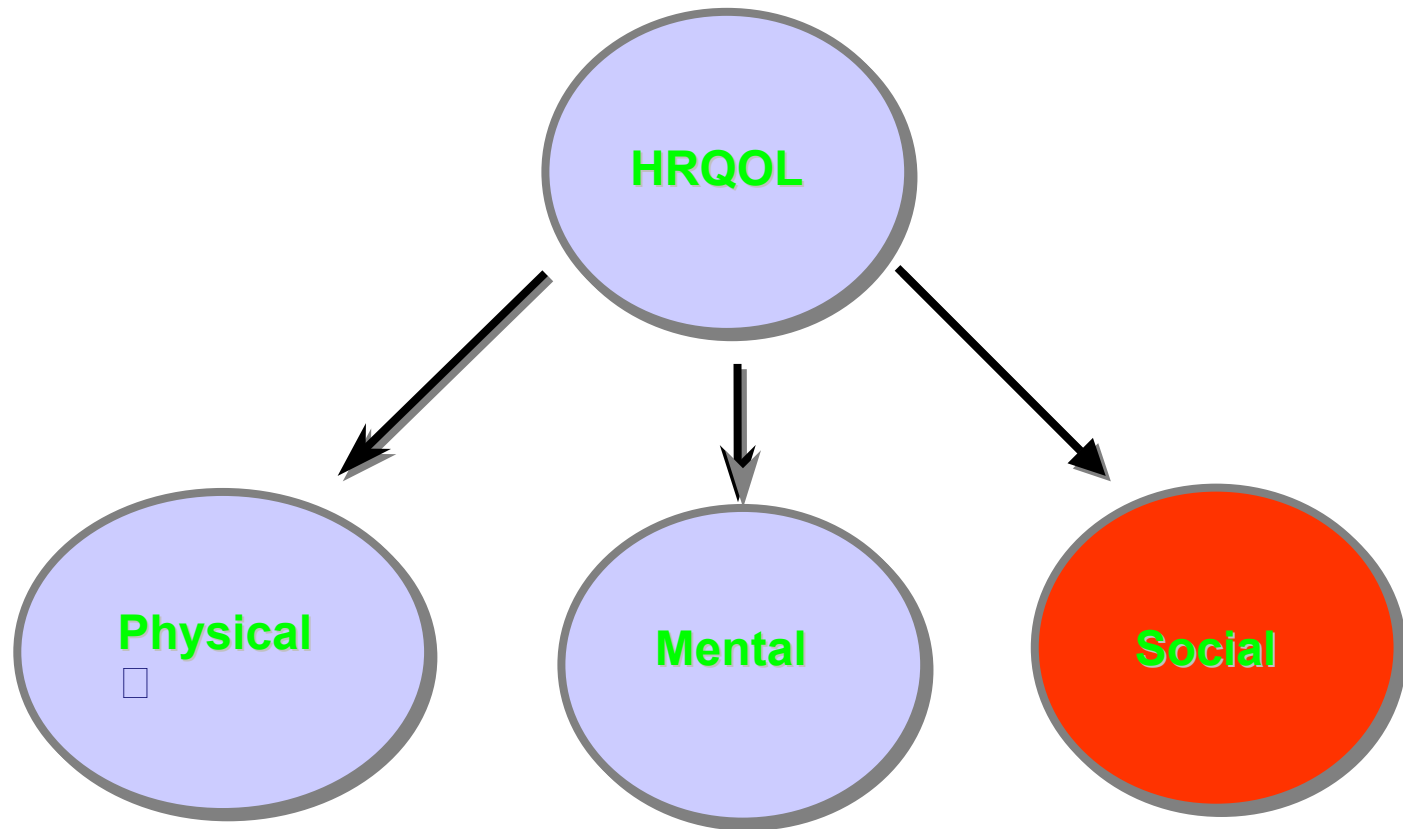


One path leads to despair and utter hopelessness, the other to total extinction. Let us pray that we have the wisdom to choose correctly.

Woody Allen



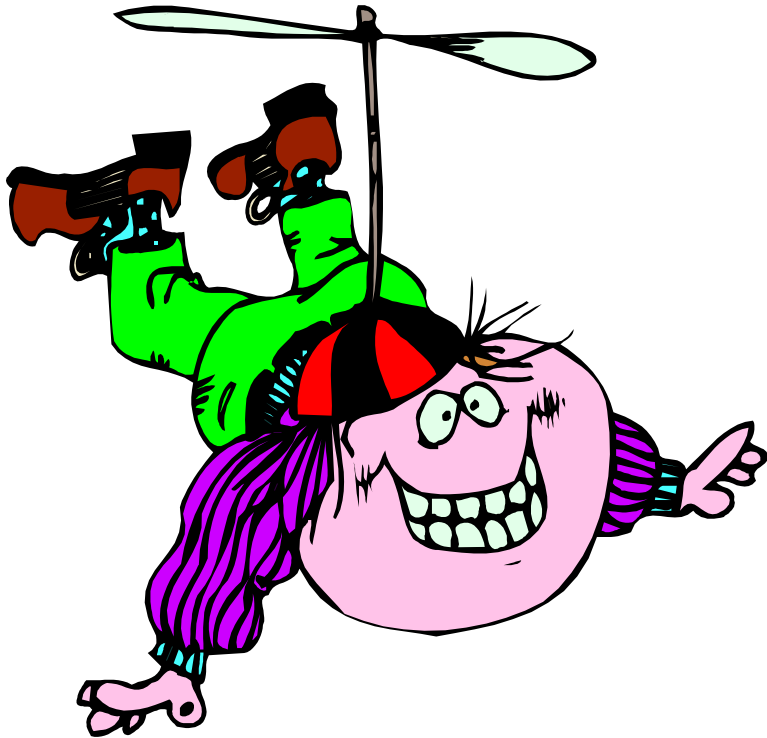
Health-Related Quality of Life



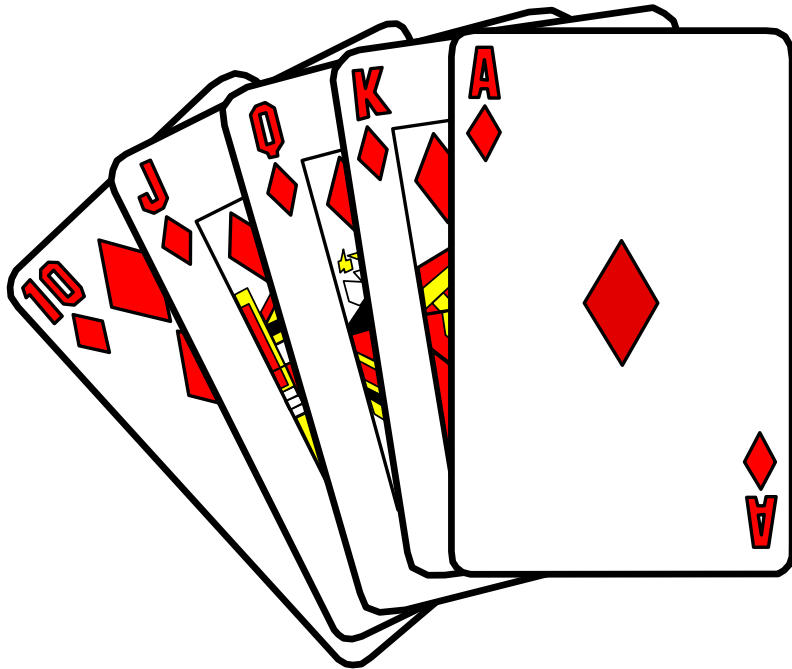
Health-Related Quality of Life

- **What the person can DO (functioning)**
 - Self-care
 - Role
 - Social
- **How the person FEELS (well-being)**
 - Emotional well-being
 - Pain
 - Energy

Types of HRQOL Measures



- Profile
 - Generic
 - Targeted
- Preference-based



**In general, would you
say your health is:**

Excellent

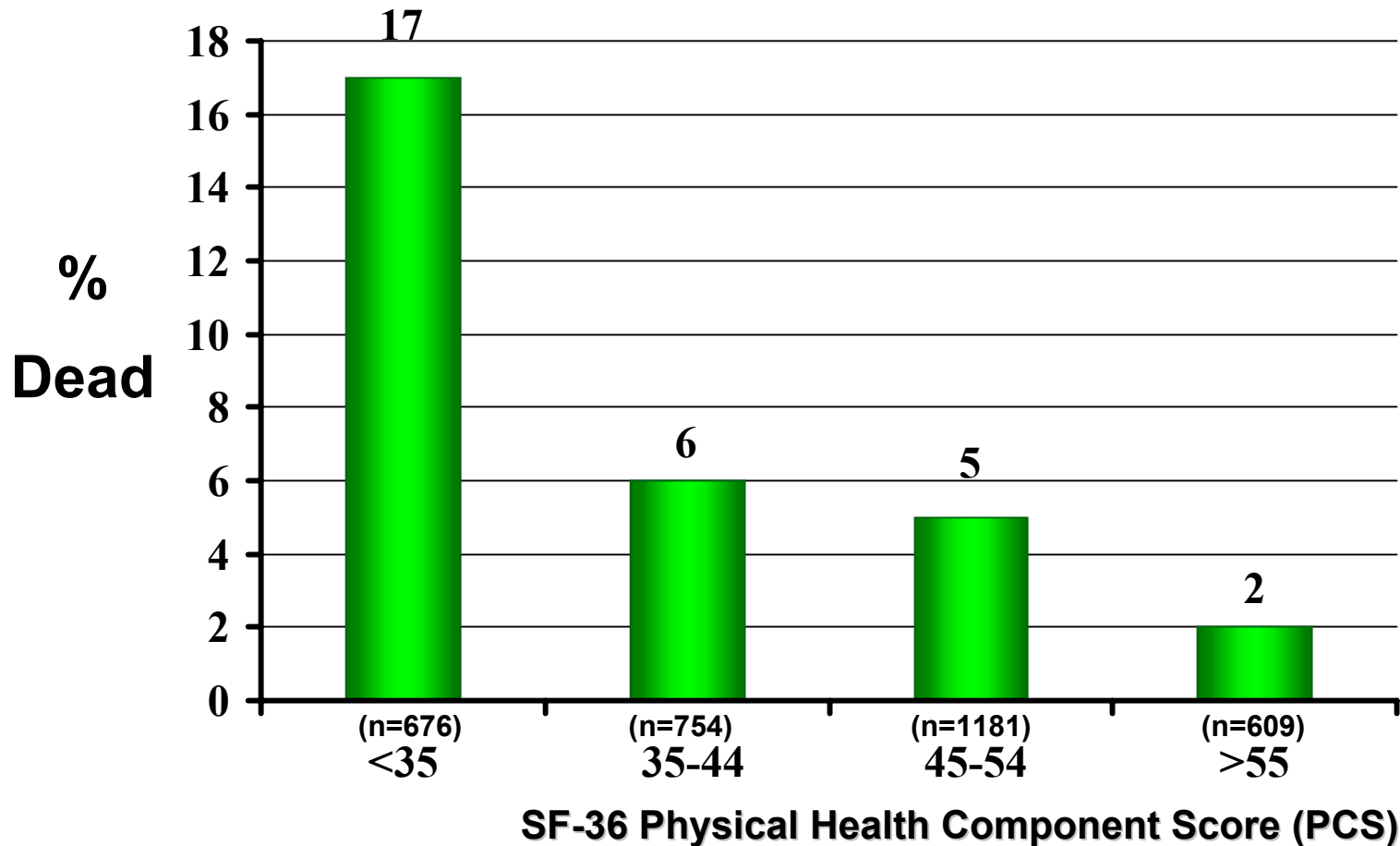
Very Good

Good

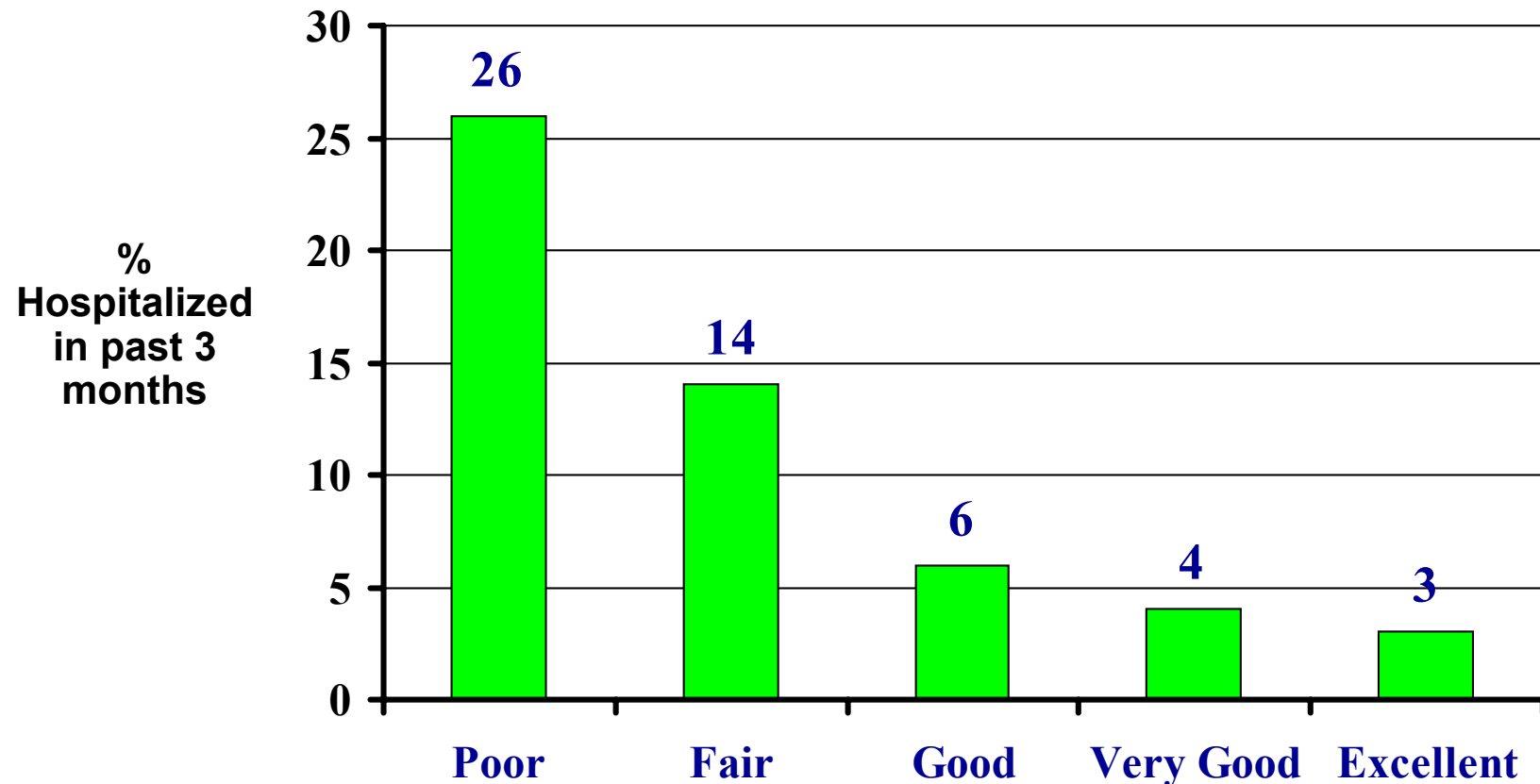
Fair

Poor

Five-Year Mortality Rates by Levels of Physical Health



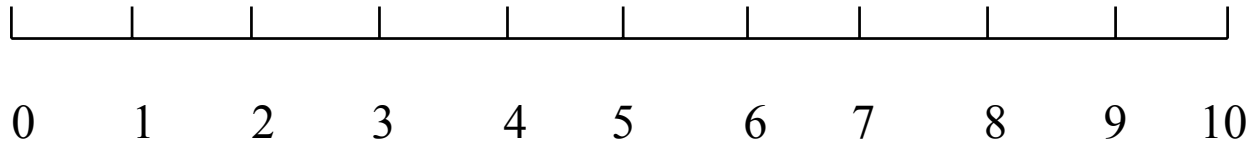
Generic Health Ratings Associated with Hospitalizations (N = 20,158)



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.

Overall Health Rating Item

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



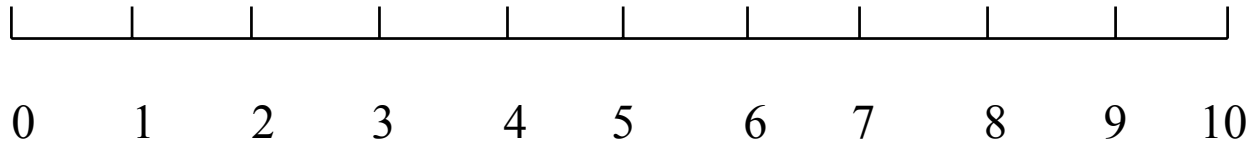
Worst possible
health (as bad or
worse than
being dead)

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

Single-Item Measures (Ladder Scale)

At the bottom of this picture ladder is the worst situation you might reasonably expect to have. At the top is the best you might expect to have. The other rungs are in between. Where on the ladder would you put your quality of life over the past four weeks?

	9
	8
	7
	6
	5
	4
	3
	2
	1

BEST LIFE I COULD EXPECT TO HAVE

WORST LIFE I COULD EXPECT TO HAVE

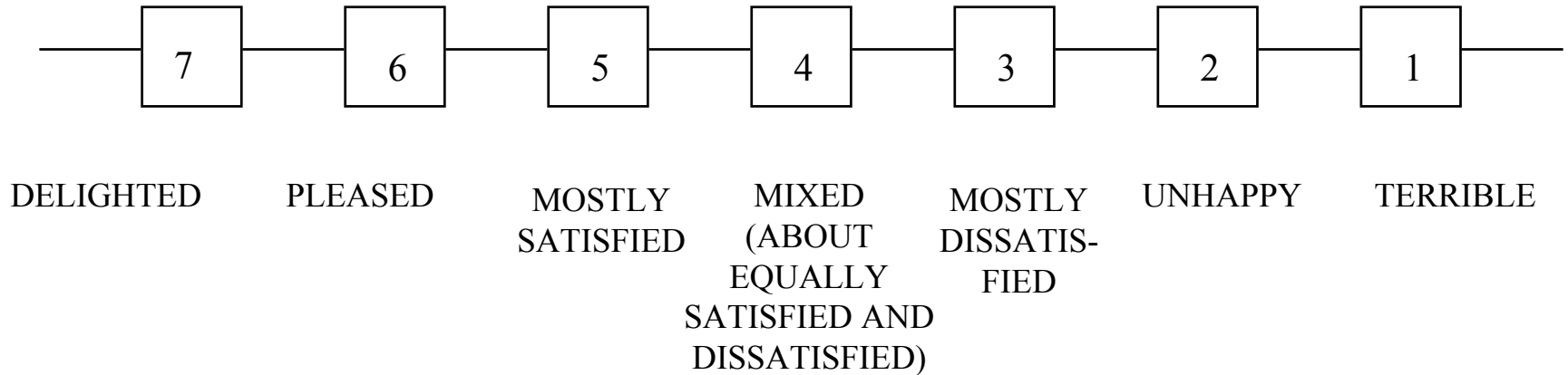
Delighted-Terrible Item

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

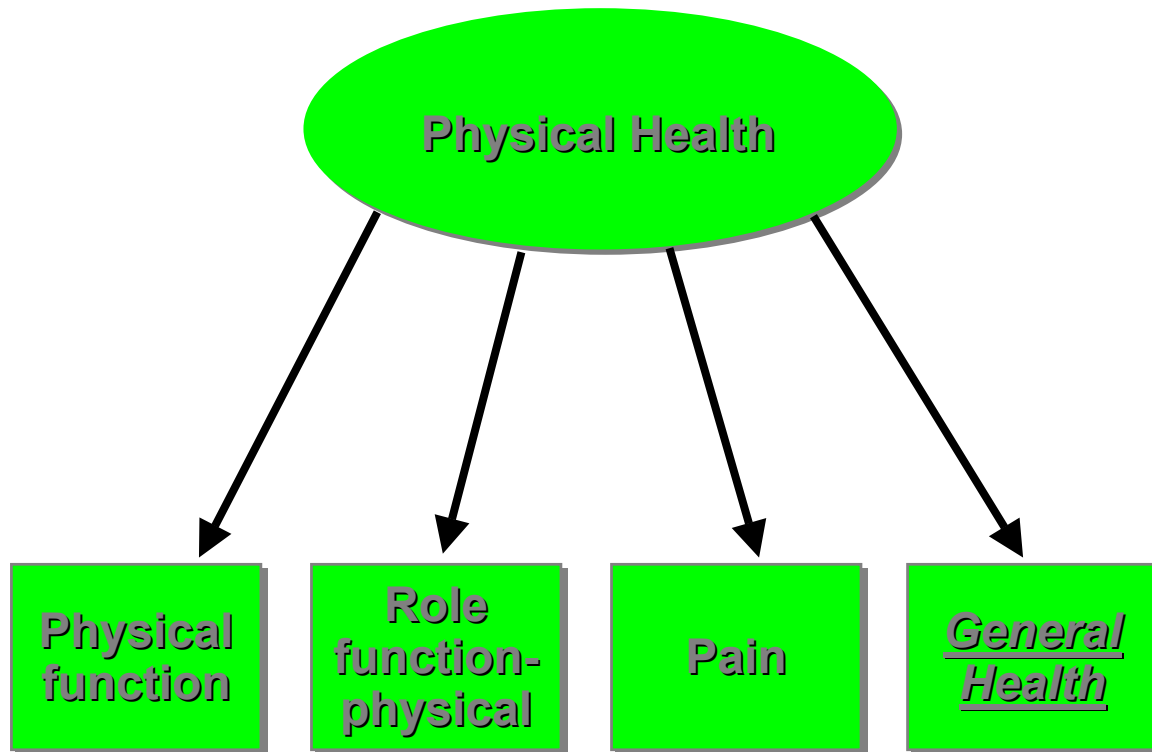
Delighted-Terrible Scale

I FEEL:

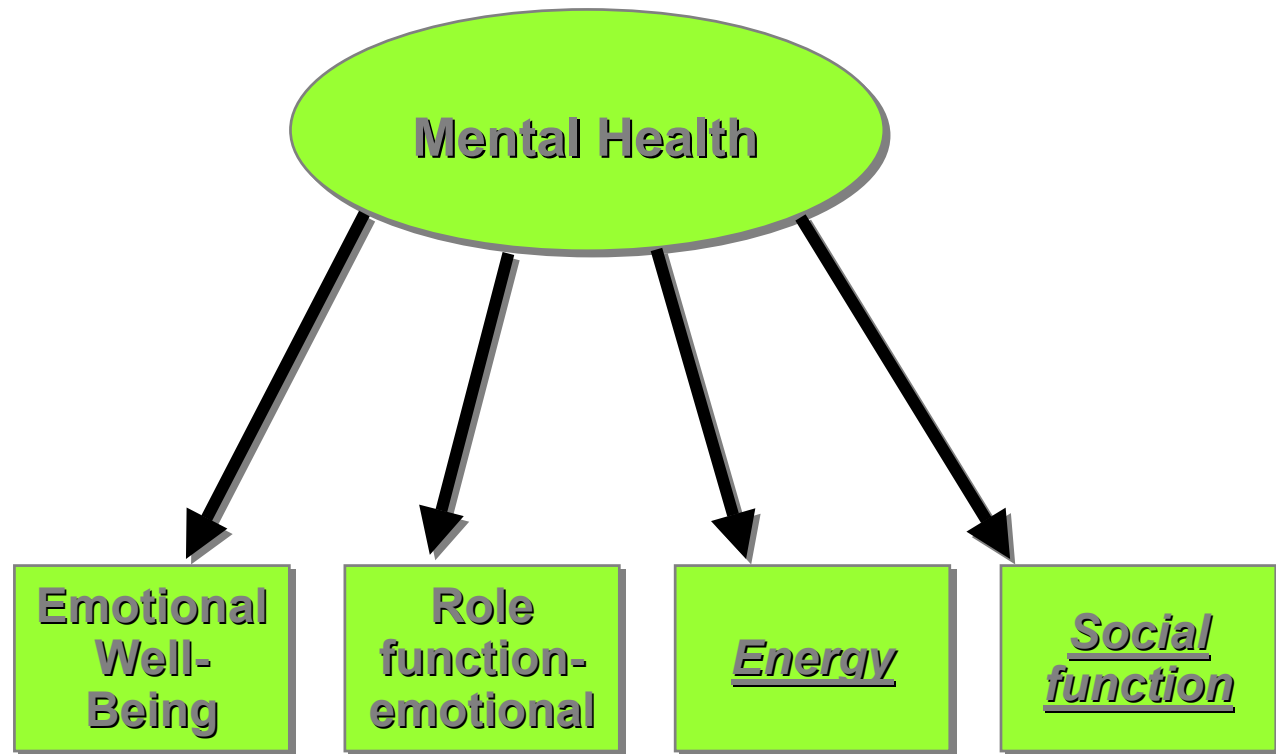


Andrews, F.M., and Withey, S.B. 1976

SF-36 Physical Health



SF-36 Mental Health



Scoring Generic Scales

- **Average or sum all items in the same scale.**
- **Transform raw average or sum to 0-100 possible range (linear transformation)**
– **$(\text{raw score} - \text{minimum}) * 100 / (\text{max} - \text{min})$**
- **Transform to T-score (mean of 50, SD of 10)**

www.sf-36.com (A)

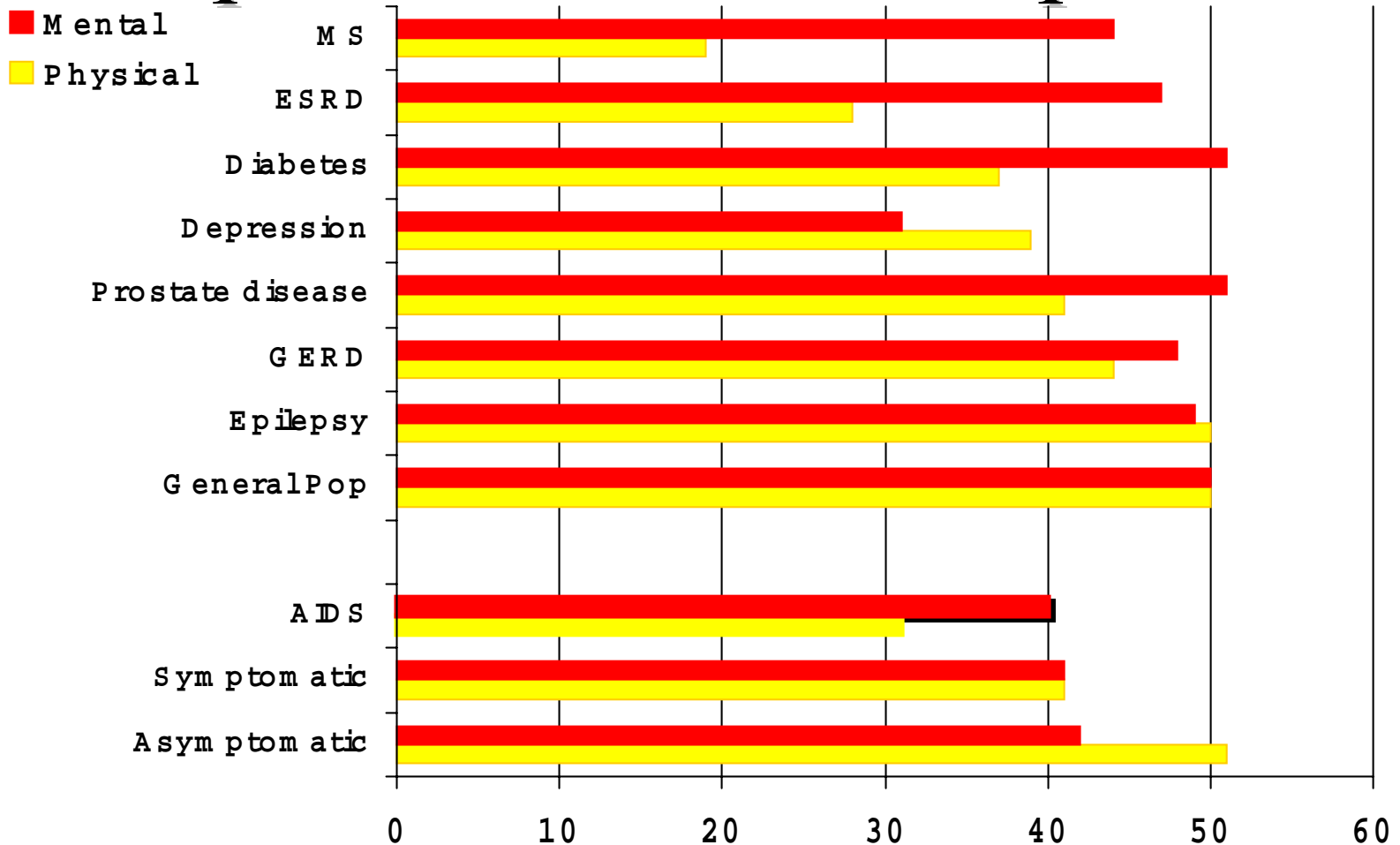


- Version 2
- Norm based scoring

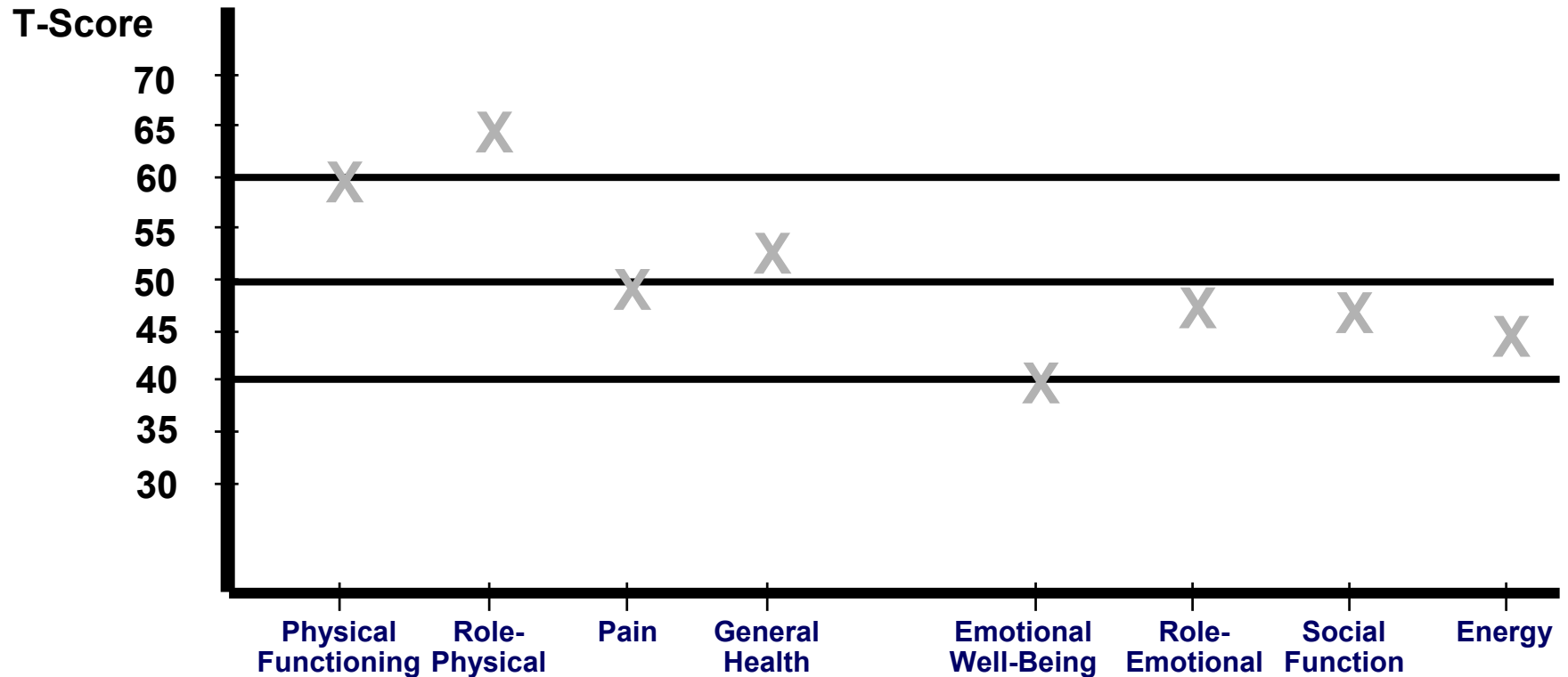
Uses of Generic Measures

- **Cross-Sectional**
 - **Profiles of Different Diseases**
 - **Comparison of Different Samples**
 - **Profiles by Medical Group**
- **Longitudinal**
 - **Profiles of Different Diseases**
 - **Examining Antecedents of HRQOL**

HRQOL of Those with Chronic Illness Compared to General Population

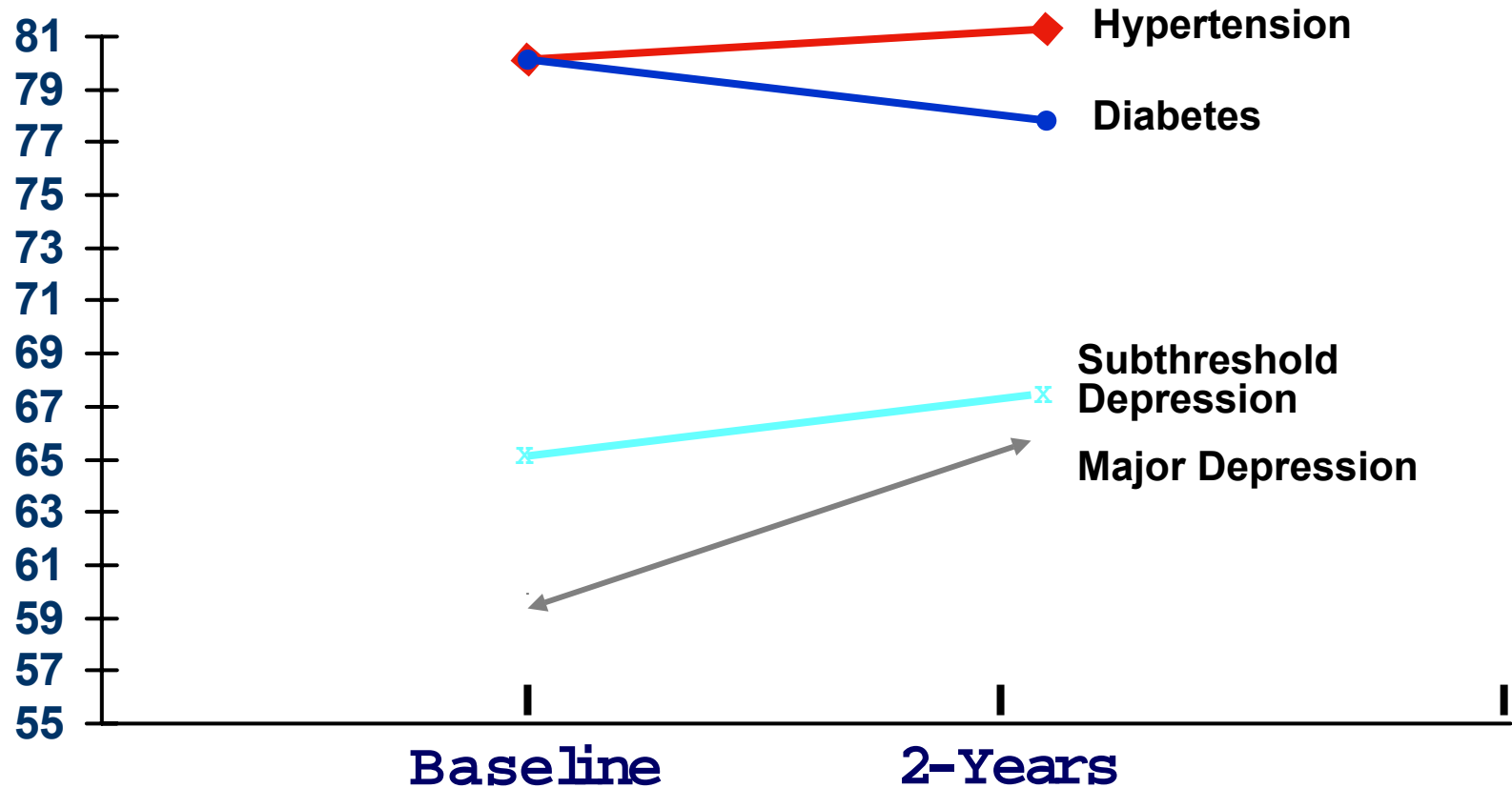


SF-36 Health Profiles for Health Plan or Medical Group



WHAT THIS FIGURE SHOWS: X's denote average SF-36 score for a sample of 200 members from your medical group. Average score across all 48 medical groups is 50 (standard deviation is 10).

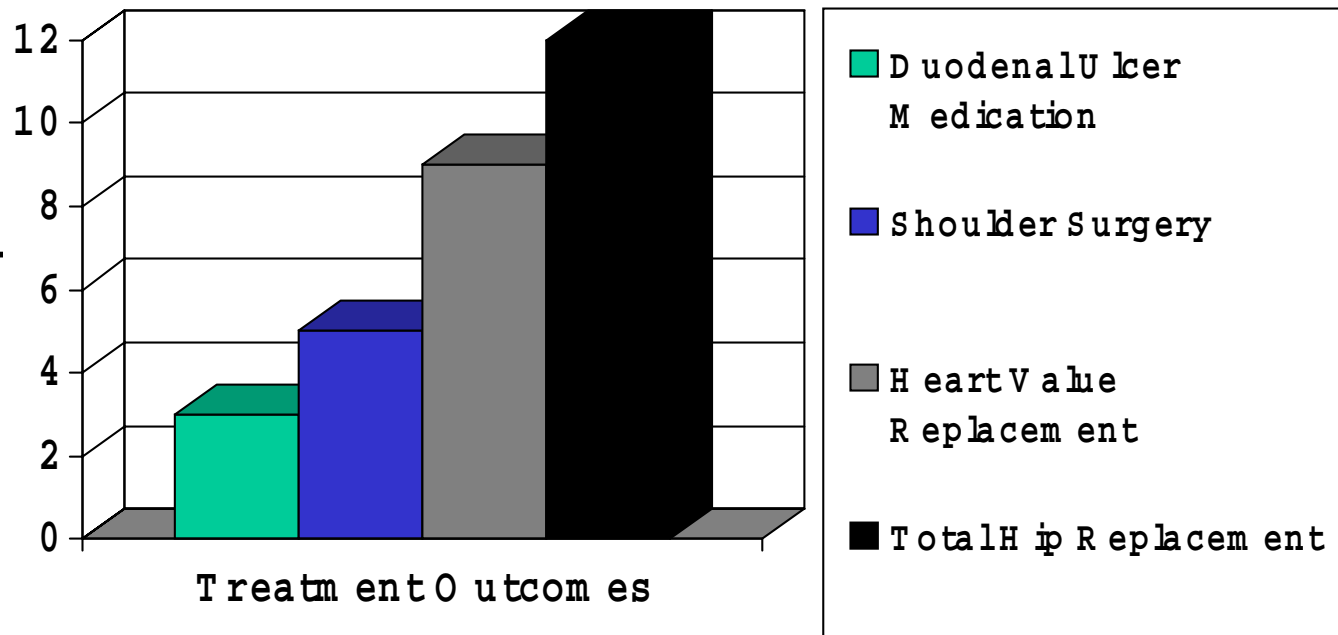
Course of Emotional Well-Being Over Two Years for Patients in the Medical Outcomes Study



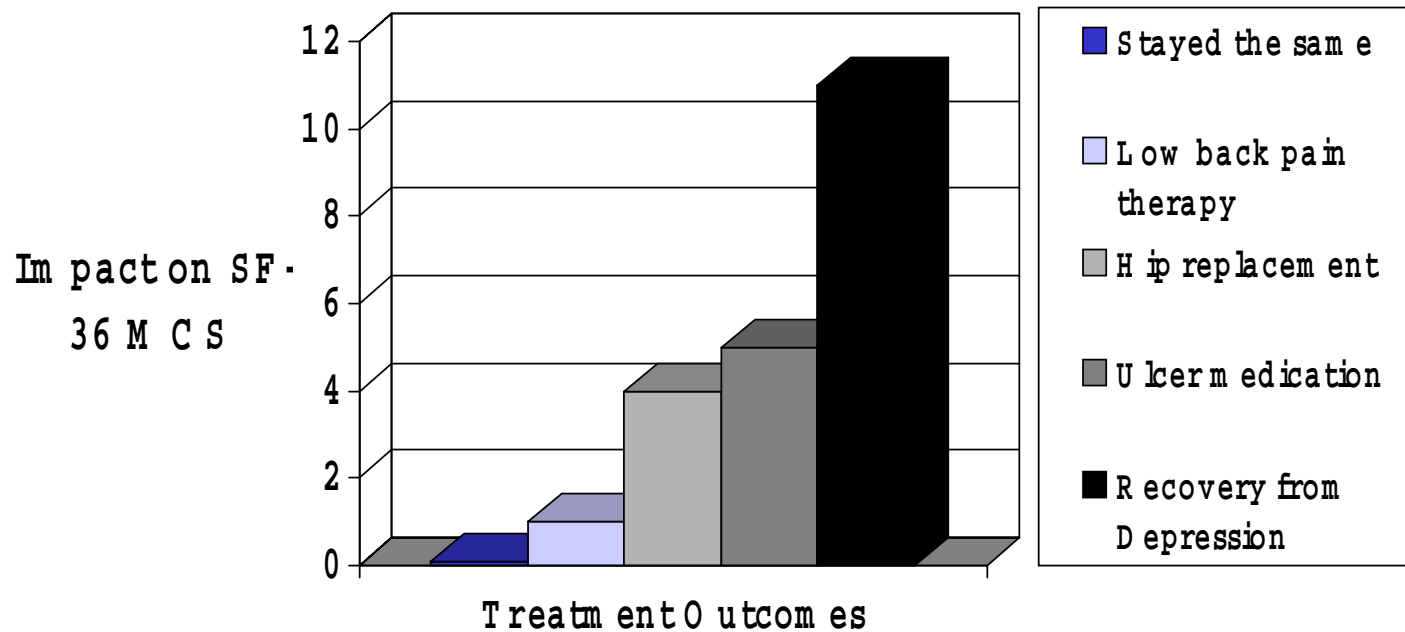
Hays, R. et al. (1995). Functioning and well-being outcomes of patients with depression compared to chronic medical illnesses. Archives of General Psychiatry, **52**, 11-19.

Treatment Impact on PCS

Impact on SF-36 PCS



Treatment Impact on MCS



COOP Charts

- Based on HIE/MOS measures
- Designed to accommodate busy practices
 - 35-40 seconds to administer
- Similar to Snellen Charts
- Patient or nurse/clinician administered

COOP Charts (cont'd)






Each chart has:

- Simple title
- Item stem
- Five response choices
- Past four weeks recall period

Physical Condition COOP Charts

During the past 4 weeks...

What was the most strenuous level of physical activity you could do for at least 2 minutes?

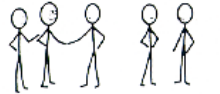




<p>Very heavy, (for example)</p> <ul style="list-style-type: none"> •Run, fast pace •Carry a heavy load upstairs or uphill (25 lbs/10 kgs) 		1
<p>Heavy, (for example)</p> <ul style="list-style-type: none"> •Jog, slow pace •Climb stairs or a hill moderate pace 		2
<p>Moderate, (for example)</p> <ul style="list-style-type: none"> •Walk, medium pace •Carry a heavy load level ground (25 lbs/10 kgs) 		3
<p>Light, (for example)</p> <ul style="list-style-type: none"> •Walk, medium pace •Carry light load on level ground (10 lbs/5kgs) 		4
<p>Very light, (for example)</p> <ul style="list-style-type: none"> •Walk, slow pace •Wash dishes 		5

Nelson, E.C., Landraf, J.M.,
Hays, R.D., et al. 1990

Social Activities COOP Charts

During the past 4 weeks...

To what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

Not at all		1
Slightly		2
Moderately		3
Quite a bit		4
Extremely		5

Nelson, E.C., Landraf, J.M.,
Hays, R.D., et al. 1990

COOP Charts

- Functioning
 - Physical condition
 - Daily work
 - Social activities
- Well-being
 - Emotional condition
 - Pain
 - Overall condition
 - Quality of life

Generic Child Health Measures (B)

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)

Targeted HRQOL Measures (C)

- **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?

(Not at all to Extremely)

- **Cramps during dialysis**
- **Washed out or drained**

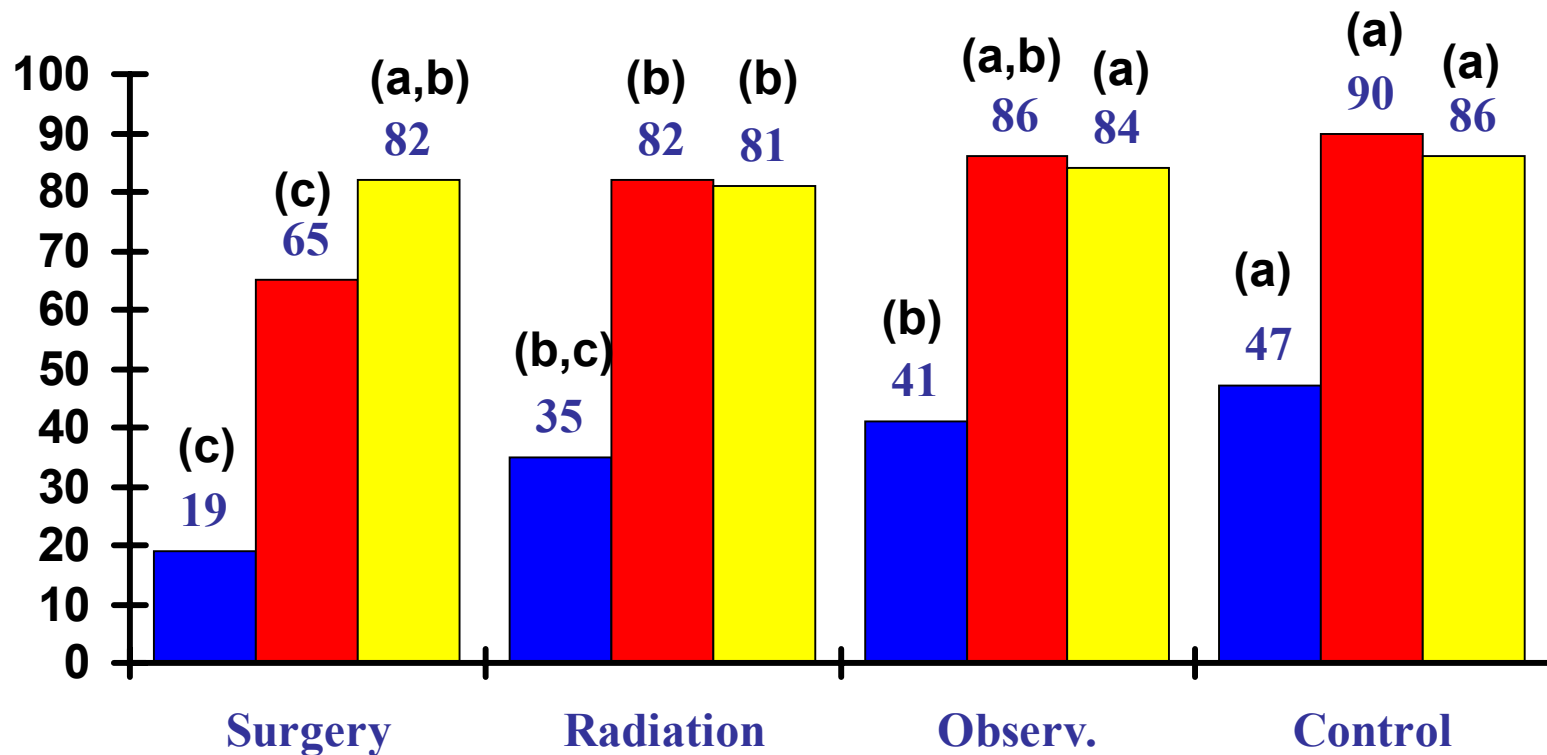
HRQOL in Men Treated for Localized Prostate Cancer

- **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**

HRQOL Measures in Prostate Cancer Study

- **Generic**
 - **36-Item Health Survey**
- **Intermediate**
 - **Cancer Rehabilitation Evaluation System (CARES)**
 - **Functional Assessment of Cancer Therapy (FACT)**
- **Disease-Targeted**
 - **Sexual, Urinary, Bowel Function/Distress**

Sexual, Urinary and Bowel Function by Treatment Group



MS-Targeted HRQOL Measures

- Criterion measures
 - Self-rated symptom severity
 - 34->44%
 - Self-rated overall quality of life
 - 46->51%
 - Expanded Disability Status Scale (EDSS)
 - 51->70%

Questions?

