## Quality of Life

<table>
<thead>
<tr>
<th>Community</th>
<th>Marriage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>Nation</td>
</tr>
<tr>
<td>Family Life</td>
<td>Neighborhood</td>
</tr>
<tr>
<td>Friendships</td>
<td>Self</td>
</tr>
<tr>
<td>Health</td>
<td>Standard of Living</td>
</tr>
<tr>
<td>Housing</td>
<td>Work</td>
</tr>
</tbody>
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Source: Campbell, 1981
World Health Organization Definition of Health

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”

WHO, 1948
Health is measured in Terms of:

Bodily structure & function
What are you able to do – functioning
How your feel – distress & well-being
What you say it is – personal evaluation

These four points have a circle with the words “Human Function and Well Being” over them.

Sources: Understanding Health Outcomes Educational Series
What Do We Need to Measure Health Outcomes in the 21st Century?

Outcomes that matter to patients
Practical measures
Coverage of a wide range
Greater precision
Comparability of scores
Ease of interpretation

Physical activity limitations
Symptoms of psychological distress
Physical well-being
Life satisfaction
Emotional behavior
Role disability due to physical problems
Psychological well-being
General health perceptions
Physical mobility
Role disability due to emotional problems
Satisfaction with physical condition
Social activities with friends/relatives
Continuum of Disease-specific and Generic Health Measures – CKD
Diagram showing health-related QOL

Adapted from: Wilson and Cleary, JAMS, 1995
            Ware, Annual Rev. Pub. Health, 1996
Chart

Summary of Information about Widely-Used General Health

Diagram: SF-36 Heath Survey Measures
Diagram: There is More to the Continuum

Arrow with the following information in it

Clinical markers -> Specific Symptoms -> Impact of Disease-specific Problems -> Generic Functioning. Well-being and Evaluation
Prediction and Risk Management: HRQOL is one of the Best Predictors

Arrow with Impact of Disease Specific Problems → Generic Functioning. Well-being and Evaluation → Future health
- Inpatient expenditures
- Outpatient expenditures
- Job loss
- Response to treatment
- Return to work
- Work productivity
- Mortality

Health-Related QOL (HR-QOL)
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Problems with Short-Form Surveys

Ruler showing: Measuring Too Low-Ceiling Effect
Some Thermometers Focus on a Very Narrow Range

Photo of a cooking thermometer showing a temperature of 130 – 190 degrees F and 54-88 C
A Promising Solution in 1999: Computerized Adaptive Testing (CAT) Software

Charts showing

Criterion score on the left and Skewed 5-item Headache Pain Measure

Criterion Score on the left and Dynamic 5-Item Headache Pain Measure

Ware, JE, Jr., et. al. *Med Care.* 2000. 38:1173-82.
Improving the Physical Function “Ruler”

Chart with a ruler and bell curve shape
What Do We Need to Measure Health Outcomes in the 21st Century?

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**Greater precision**
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**Original Thermoscope**

Photo 1: Group using the original thermoscope

Photo 2: original thermoscope with the Caption: results were not interpretable, no marks on the “ruler” poor reproducibility, no interpretations guidelines

Photo 3: pain as bad as it could be at the top and no pain at the bottom of the line on the Visual Analogue Scale (VAS)
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Example: Cross-Calibrating Celsius and Fahrenheit

Photo of a thermostat with the caption “Temperature” with three balloons with the wording:

Balloon 1 – Normal Human Blood
Balloon 2 – Shirt Sleeve Weather
Balloon 3 – Water Freezes
Cross-Calibration Makes Scores Comparable and Interpretable

Chart showing Theta (Best Possible Estimate)

Note: Direction of scoring shown with arrows
Source: Ware, Bjorner & Kosinski, *Medical Care*, 2000
What Do We Need to Measure Health Outcomes in the 21st Century?

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**Ease of interpretation**
Standardization

Photos showing different methods of standardization and scoring software on short forms, long forms and dynamic forms

“Improvements in Short Form Measures of Health Status, J. Clinical Epidemiology, 2008
Interpreting Health Measures

Chart on how to interpret health measure

What Do Changes in Health Mean?

Chart showing Physical Component Summary (PCS)
Advances & Solutions

Improved psychometrics
(Item response therapy – IRT)
Computerized adaptive testing (CAT) software
The Internet (and other connectivity)
Chart: Precision Varies for “Static” and Dynamic Forms and Score Levels for Physical Function Measures

2nd Solution:
Assess Health Dynamically

Photo 1: man sitting across from a woman who is recording his responses in a chart

Photo 2: ruler showing patient scores here with the caption on the photo CAT (Computerized Adaptive Testing)
Performance of 5-item CAT Scores Confirmed in NIH-Sponsored Studies

What are the Advantages of Dynamic Assessments?

• More accurate risk screening
• Reliable enough to monitor individual outcomes
• Brevity of a short form – 90% reduction in respondent burden
• Elimination of “ceiling” & “floor” effects
• Can be administered numerous ways
• Markedly reduced data collection costs
• Monitor data quality in real time