

PMS Workshop

Lebensqualität als Kriterium für Zulassungs-, Therapie- und Erstattungsentscheidungen

Berlin, 6. März 2008

Lebensqualitätsmessung, eine Methodenübersicht

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Definition

„Quality of life (QoL) is an ill-defined term.“

Fayers & Machin 2007

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Fayers & Machin 2007

„Lebensqualität bedeutet hier *[in der Medizin]* die vom Befragten ausgehende Beurteilung von Befinden und Funktionsfähigkeit in psychischen, physischen, sozialen und emotionalen Lebensbereichen.“

M. Bullinger 1996

Methodological Approaches

Paper-and-pencil
questionnaire

Interview

Self-assessed

Computer

Online

Assessor-assessed

Proxy, professionals

MEASURING THE QUALITY OF LIFE OF CANCER PATIENTS

A CONCISE QL-INDEX FOR USE BY PHYSICIANS

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(Received 1 November, 1980)

QUALITY OF LIFE INDEX

Study No. _____ / _____

Age _____

Sex M₁ F₂ (Ring appropriate letter) _____

Primary Problem or Diagnosis _____

Secondary Problem or Diagnosis, or complication (if appropriate) _____

Scorer's Specialty _____

SCORING FORM

Score each heading 2, 1 or 0 according to your most recent assessment of the patient.

ACTIVITY

- During the last week, the patient*
- has been working or studying full-time, or nearly so, in usual occupation; or managing own household; or participating in unpaid or voluntary activities, whether retired or not 2
 - has been working or studying in usual occupation or managing own household or participating in unpaid or voluntary activities; but requiring major assistance or a significant reduction in hours worked or a sheltered situation or was on sick leave 1
 - has not been working or studying in any capacity and not managing own household 0

DAILY LIVING

- During the last week, the patient*
- has been self-reliant in eating, washing, toileting and dressing; using public transport or driving own car 2

HEALTH

During the last week, the patient

- has been appearing to feel well or reporting feeling „great“ most of the time
- has been lacking energy or not feeling entirely „up to par“ more than just occasionally
- has been feeling very ill or „lousy“, seeming weak and washed out most of the time or was unconscious

Fig. 2. The format of the final version adopted.

Methodological Approaches

**Paper-and-pencil
questionnaire**

Interview

Self-assessed

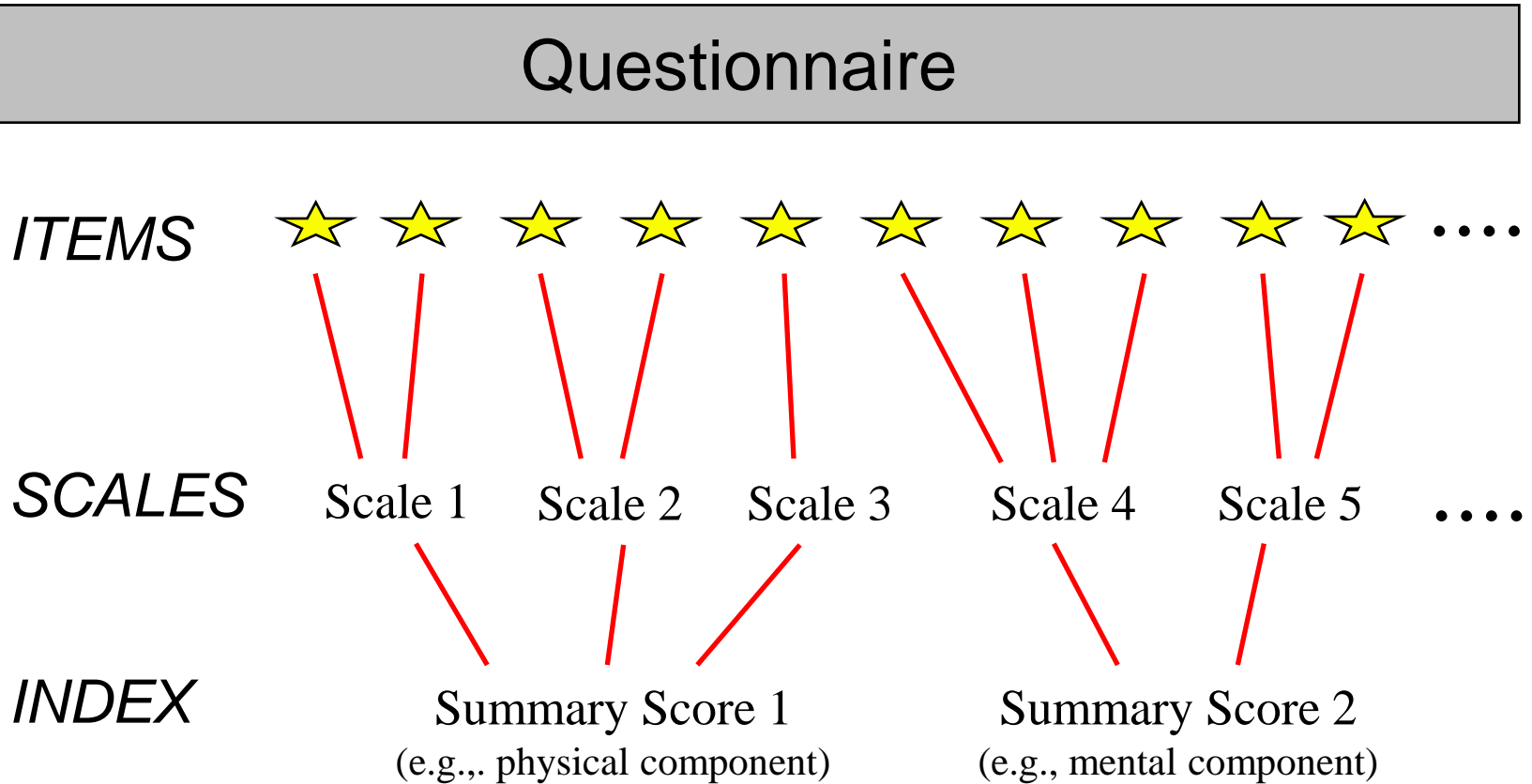
Computer

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Structure of a standardized questionnaire



Short Form 36 Health Survey / SF-36 (extract)

	Excellent	Very good	Good	Fair	Poor
1. In general, would you say your health is:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

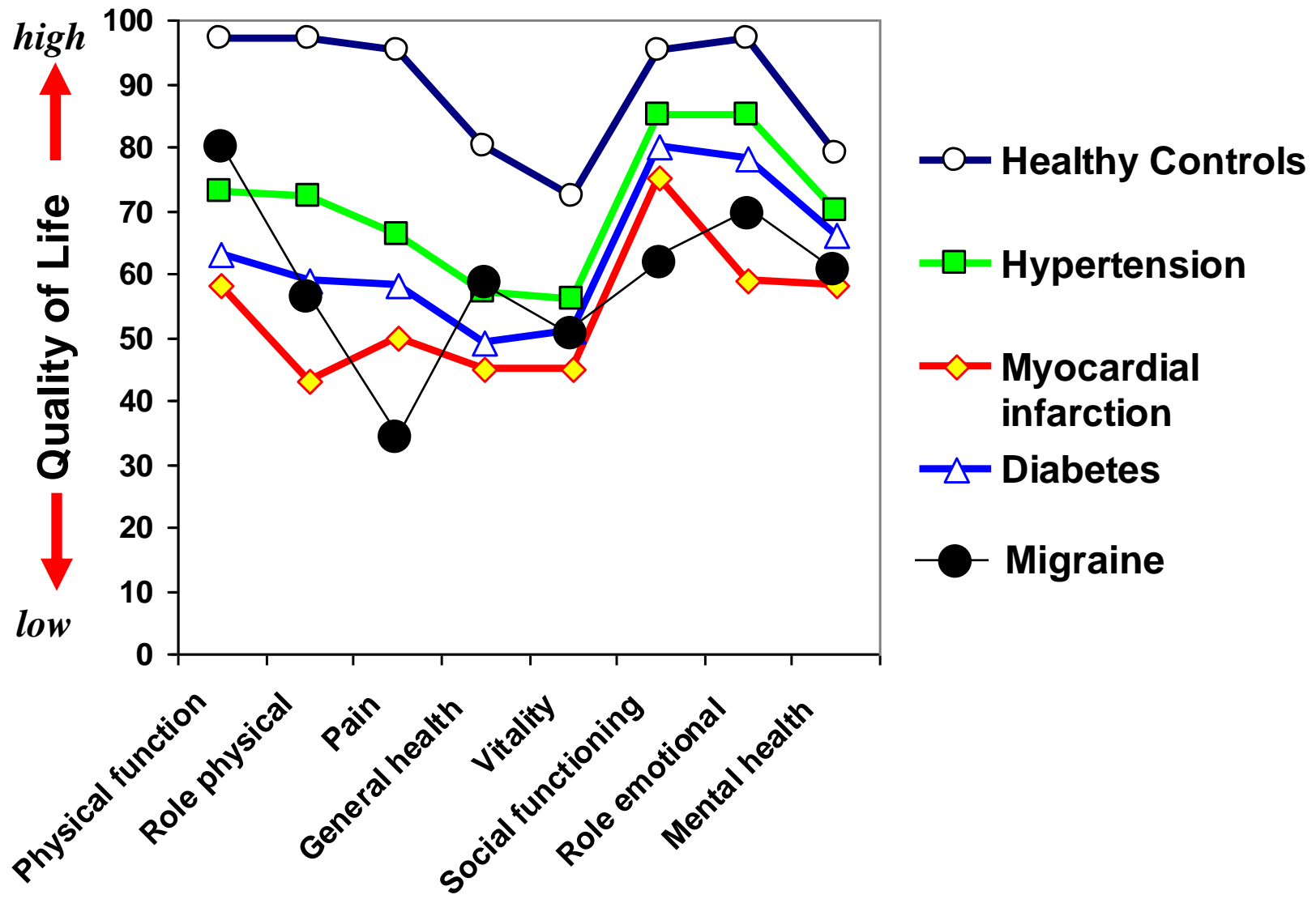


3. Does your health now limit you in these activities? If so, how much?	Yes, limited a lot	Yes, limited a little	No, not limited at all
- Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Short Form 36 Health Survey / SF-36

Items, Scales, Summary Scores

- **36 Items, different response formats**
- **8 Scales**
 - **Physical functioning**
 - **Role limitations-physical**
 - **Bodily pain**
 - **General health perception**
 - **Vitality**
 - **Social functioning**
 - **Role limitations-emotional**
 - **Mental health**
- **2 Summary scores**
 - **Physical component summary**
 - **Mental component summary**



Types of Quality of Life instruments



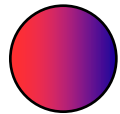
Generic instruments (SF-36, ...)

SF-36 Health Survey		Nottingham Health Profile		Sickness Impact Profile	
Section	Items	Section	Items	Section	Items
General Health	5				
Vitality	4	Energy	3		
Bodily Pain	2	Pain	8		
Mental Health	5	Emotional Reaction	9	Emotional Behavior	9
Role-Emotional	3				
		Sleep	5	Sleep + Rest	7
Social Functioning	2	Social Isolation	5	Social Interaction	20
Physical Functioning	10	Physical Mobility	8	Mobility	10
Role-Physical	4			Ambulation	12
				Body Care + Movem.	23
				Eating	9
				Work	9
				Home Management	10
				Recreation + Pastimes	8
				Alertness Behavior	10
				Communication	9
Σ	35	Σ	38	Σ	136

Types of Quality of Life instruments



Generic instruments (SF-36)



Disease-specific instruments



PSORIQoL

(example items)

true not
true true

I am embarrassed about my appearance

I have to be careful what I wear

I am always conscious of flakes on my clothes

I constantly have to look after my skin

I always hide my skin from people

Generic „versus“ specific instruments

Generic

- Comprehensive, focus on broad aspects of QoL
- Comparison of results across a wide range of conditions and interventions
- Validation, normative data, minimal (clinically) important difference

Specific

- Tailored to important aspects of a condition
- Responsive to subtle treatment effects
- Acceptance (patients, clinicians)

In der letzten Woche
habe ich mich krank gefühlt.

nie



selten



manchmal



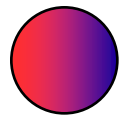
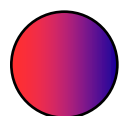
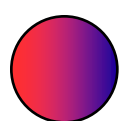
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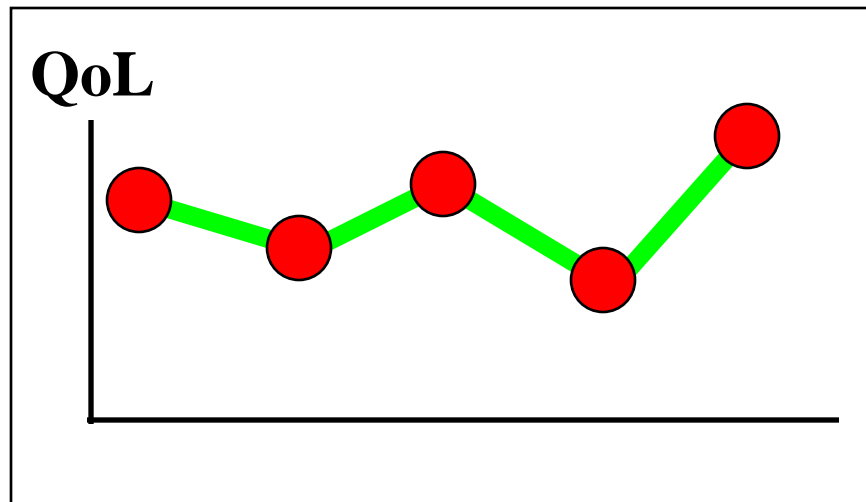


Types of Quality of Life Instruments

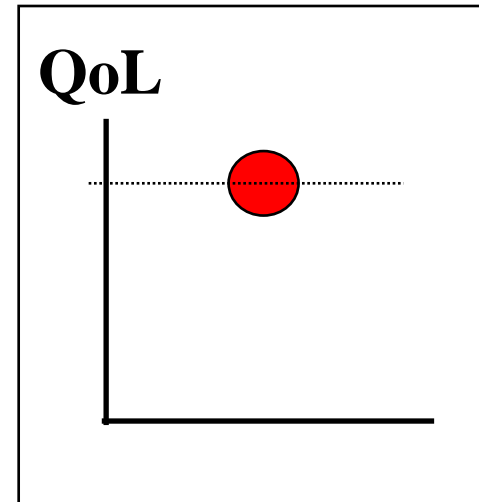
-  **Generic instruments (SF-36)**
-  **Disease-specific instruments**
-  **Preference-based instruments**

Quality of life measures

PROFILE



INDEX



EuroQol EQ-5D Questionnaire

By placing a check-mark in one box in each group below, please indicate which statements best describe your own state of health today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

Available German translations of preference-based QoL instruments

Instrument	Acronym	Valuation Method*	# Dim. # States	# Items	Source
Short Form Health State Classification	SF-6D	SG	6 9000	10	Brazier et al., 2002
Quality of Well-Being Scale	QWB-SA	?	4 1215	72	Kaplan et al., 1997
EuroQol	EQ-5D	TTO, RS	5 243	5	EuroQol Group, 1990
15D	15D	RS	15 > 10⁹	15	Sintonen, 1995
Health Utilities Index	HUI	SG, RS	7 24000	15	Torrance et al., 1996

* **SG: Standard Gamble; TTO: Time Trade Off; RS: Rating Scale**

Potential problems with preference-based QoL measurement...

- **Comparability of results obtained with different instruments?**
- **Whose values?**
- **„a QALY is a QALY is a QALY“?**
- **Transferability of results from other countries?**

Types of Quality of Life Instruments



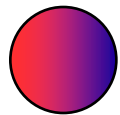
Generic instruments (SF-36)



Disease-specific instruments



Preference-based instruments



Individualized Quality of Life instruments

Summary points

Quality of life is an individual construct and measures should take account of this

Many widely used measures are not patient centred because of the ways in which items were generated, because a questionnaire may restrict a patient's choice, and because of the weighting system used

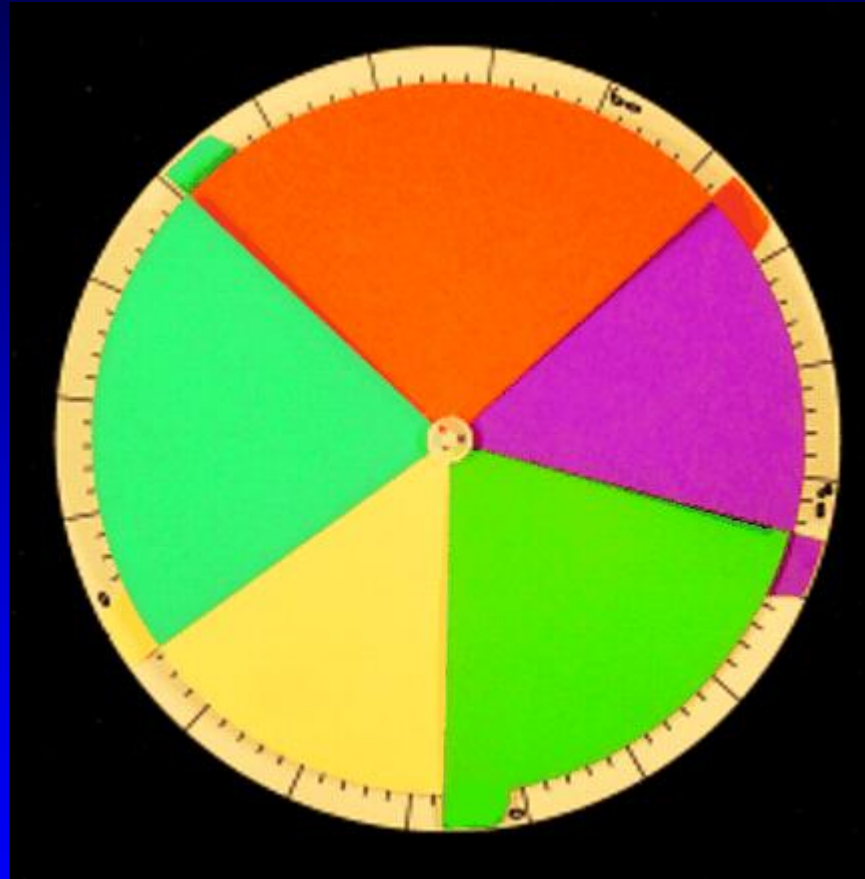
These limitations compromise their accuracy and usefulness because they do not measure what constitutes quality of life for all patients

It is possible to measure quality of life in a patient centred way using individualised measures

Some of the newer standardised measures may be more patient centred than their predecessors but further research is required

Individualized QoL measurement

(subject nominates domains, subject provides weights)



Individualized QoL measurement

(subject nominates domains, subject provides weights)

Schedule for the Evaluation of Individual Quality of Life

- *SEIQoL (O'Boyle et al. 1993)*
- *SEIQoL-DW (Hickey et al. 1996)*

Patient Generated Index

- *PGI (Ruta et al. 1994)*

Measure Yourself Medical Outcome Profile

- *MYMOP (Paterson 1996)*

Direct Valuation Methods

- *Standard Gamble*
- *Time Trade-Off*



Potential problems with individualized QoL measurement...

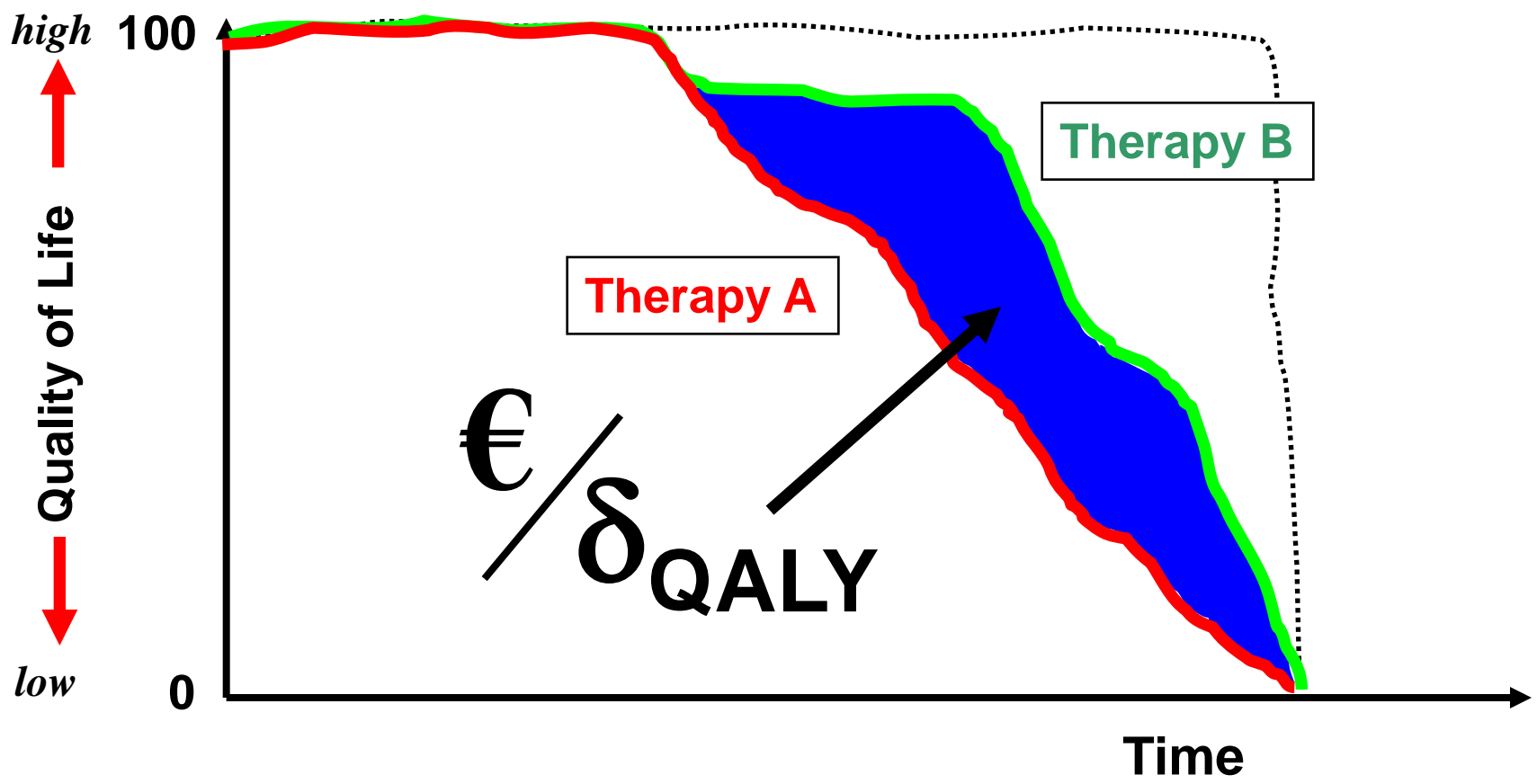
- **Long administration time (interview)**
- **Comparisons between subjects („apples and oranges“)**
- **Comparisons between groups (e.g. in RCT)**
- **Regression to the mean**

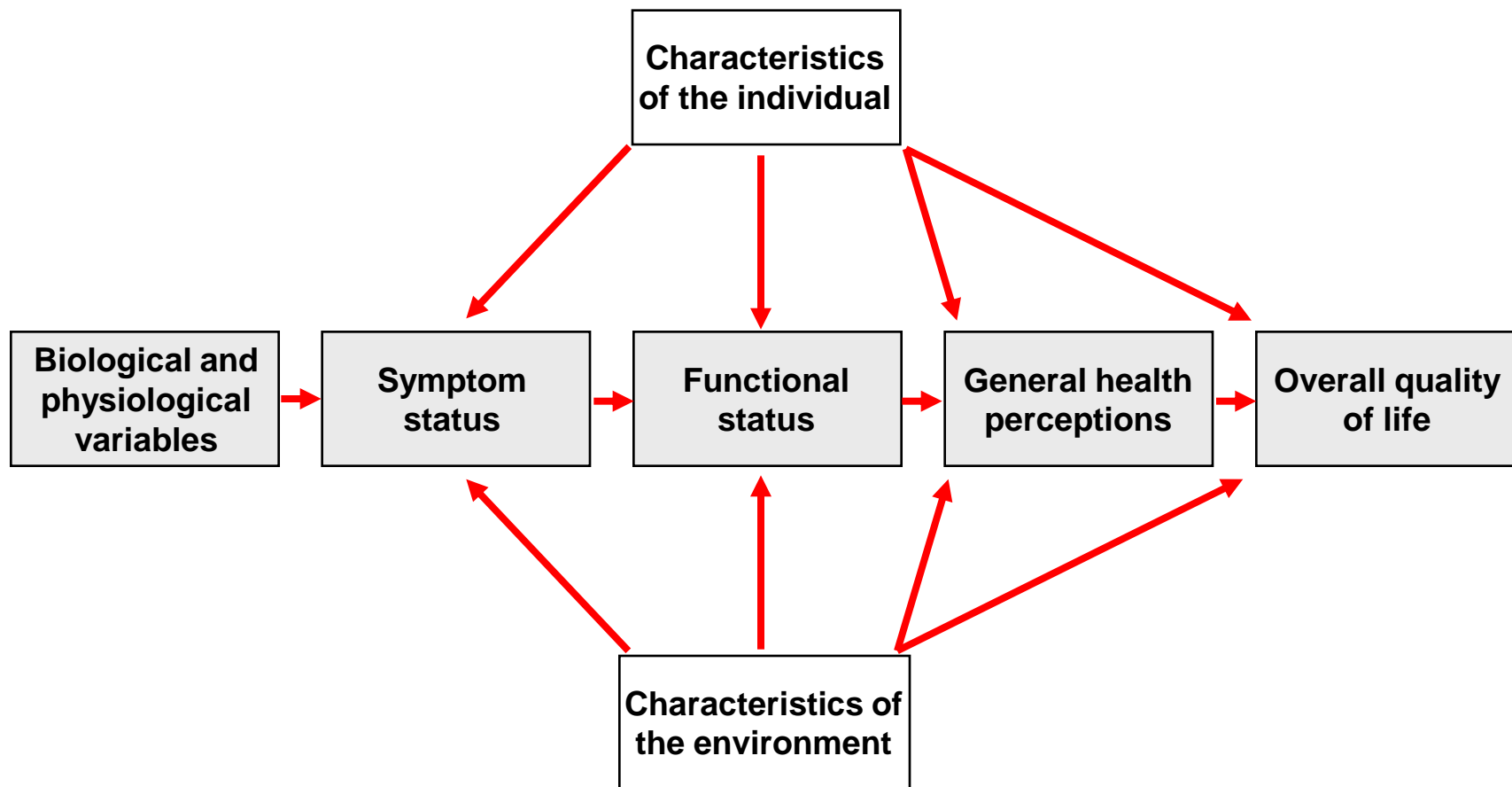
Summary

- 1** Common methodological approach: standardized self-rating questionnaire
- 2** Generic, specific, preference-based and individualized QoL measurement
- 3** Open questions in preference-based and individualized QoL measurement

**Thank you for
your attention!**

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Intra-class correlation of preference-based QoL instruments

(3 patients groups in medical rehabilitation, Gemany, Moock & Kohlmann 2008)

		15D	HUI 2	HUI 3	SF-6D	QWB-SA
Musculoskeletal	EQ-5D	0.37	0.55	0.54	0.40	0.26
	15D		0.55	0.46	0.68	0.48
	HUI 2			0.80	0.54	0.39
	HUI 3				0.46	0.36
	SF-6D					0.42
Cardiovascular	EQ-5D	0.39	0.50	0.61	0.46	0.44
	15D		0.52	0.44	0.51	0.53
	HUI 2			0.77	0.44	0.47
	HUI 3				0.40	0.47
	SF-6D					0.43
Psychosomatic	EQ-5D	0.41	0.63	0.55	0.29	0.30
	15D		0.60	0.41	0.65	0.61
	HUI 2			0.68	0.54	0.42
	HUI 3				0.31	0.29
	SF-6D					0.46