

Υποκειμενικοί και «Αντικειμενικοί» Δείκτες στην Υγεία

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Key Questions - outline

- **Clinical measures - critique**
- **Why measure subjective perceptions and health-related quality of life (HRQoL)?**
- **Conceptual / measurement models**
- **Types of measures - characteristics**
- **Where can they be applied?**
- **Key challenges?**

Health Outcomes

- ✓ Health outcome measurement has traditionally focused on survival periods, toxicity, biochemical indicators and symptom rates, and (more recently) a number of indicators of physical and psychological morbidity and social disadvantage
- ✓ Incorporate both **medical** and **patient's** perspectives
- ✓ Health status vs. Health-Related Quality of Life
- ✓ **Health status**: focus on morbidity
- ✓ **Health-Related Quality of Life**: encompassing physical health and functioning, social functioning, psychological and emotional well-being

How is health status and need usually assessed?

- The most commonly used type of health status and need assessment in health care is through **clinical indices** and **normative** or professionally defined **need**.
- Normative need identifies diseases and impairments **without considering the subjective perceptions of the subject**.
- Despite its usefulness and extensive use, the sole use of clinical measures is not free from **limitations**.

Shortcomings of Normative Measures

1. Lack of objectivity and reliability.
2. Neglects psychosocial dimensions and well-being.
3. Lack of consideration of health behaviours and compliance.
4. Unrealistic. Paradoxical approach; takes little account of limited resources.

“We cannot be endlessly generous and continue to be fair” (Acheson)

5. Serious conceptual limitations

“...essential for measuring disease...but not for health and treatment need” (Sheiham et al., 1982)

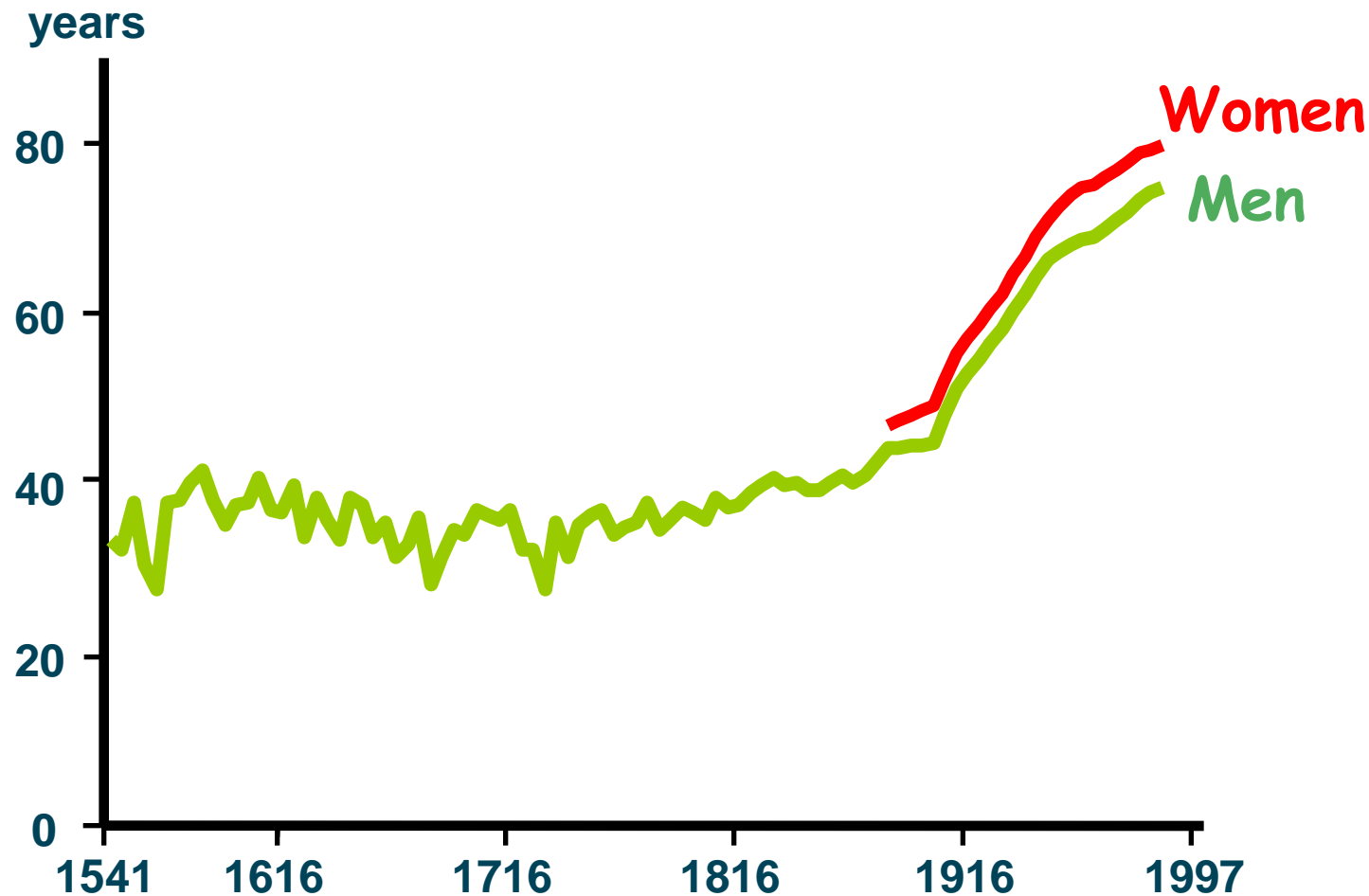
(Sheiham and Tsakos, 2007)

Interest in Assessing Subjective Perceptions

- ✓ Increasing interest about subjective perceptions of health (and oral health) has led to the development of a plethora of subjective measures of health and quality of life...
- ✓ Focus on measures for adults and elderly... with relatively more recently developing measures for children
- ✓ Most of those measures have been validated as well as adapted for use in different settings and cultures
- ✚ **WHY NOW? Which factors have led to this?**

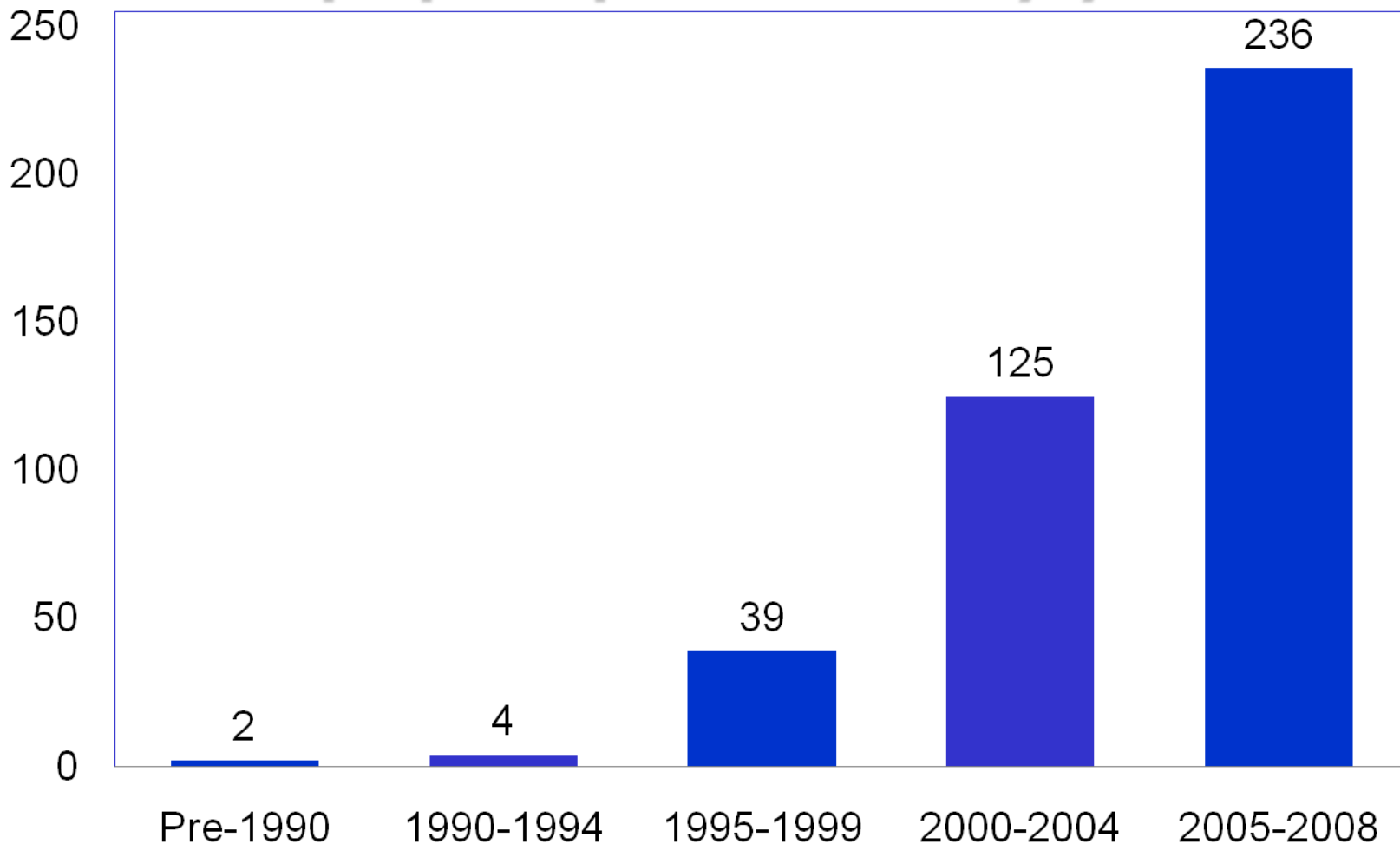


Major Improvements in Expectation of Life



England & Wales

Patient - based outcomes in oral health: Number of papers published by year



Different models of Health

A. Biomedical model

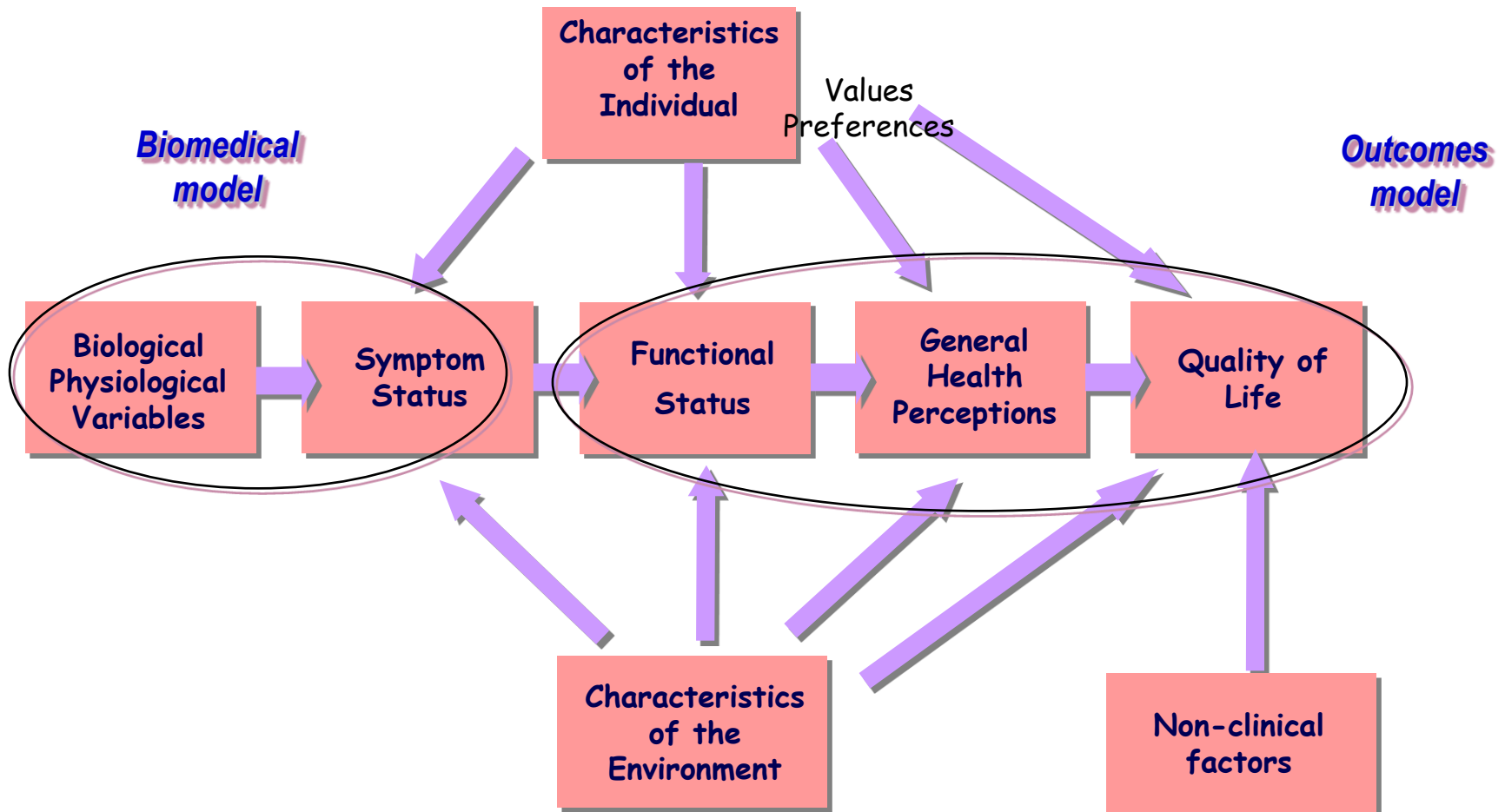
- ✓ Traditional approach - linear thinking (**reductionism**)
- ✓ Pathology, tissue damage etc.
- ✓ “find it and fix it” approach
- ✓ Emphasis on clinical data (disease-related)

B. Outcomes model

- ✓ Chronic diseases challenge biomedical model
- ✓ They have multiple causes, some in common (**Common Risk Factor Approach**)
- ✓ Value placed on self-reports (outcome-based)
- ✓ Emphasis on epidemiological data - broader determinants of health

Kaplan, 2003; Quality of Life Research

Outcome Measures Model (Wilson and Cleary, 1995)



Why use HRQoL measures?

- ✓ Important for assessing impacts of **chronic diseases**
- ✓ Physiologic measures often **correlate poorly** with functional ability and well-being
- ✓ Two patients with **similar clinical status** often have dramatically **different perceptions** about their health

Guyatt, Feeney and Patrick, 1993; Annals of Internal Medicine

- ✓ Intended outcomes of health care are primarily changes in patients' health status and quality of life (McCallion et al, 1993)

Why use HRQoL measures?

- ✓ Subjective perceptions and “Quality of Life” are underlying constructs in the provision of services
- ✓ Broader societal perceptions: court case for hip replacement and provision of care
 - Treatment provision determined by “an objective medical assessment of the patient's medical condition, the history and probable course of her illness, **the degree of pain she is in and/or the nature of her disability at the time**”. If the patient qualifies on that basis, then it should be available within the clinically necessary time at NHS expense, whether in this country or abroad, in a public or a private hospital.

Luxembourg, European Court of Justice ruling on the case of Yvonne Watt's hip replacement (2006)

Subjective Measures of Health

1. Single standing questions

- ✓ Self-Rated Health

2. Batteries of questions

- ✓ Pain and its effects on daily life
- ✓ Anxiety

3. Composite measures

- ✓ Health-Related Quality of Life (HRQoL)
 - Generic / Profiles (health status surveys)
 - Disease-specific (clinical trials)
- ✓ Preference-based measures

Generic HRQoL measures

e.g. SF-36, ADLs/IADLs, NHP, SIP, COOP, CASP-19

- ✓ Health **profile** covers a number of domains including physical, psychological and social well being
 - each domain gets a summary score

- ✓ Agreement about the **core set of concepts** that define health-related quality of life
 - physical health, mental health, social functioning, role functioning and general health perceptions
 - other dimensions that may be evaluated: pain, sleep, cognitive function etc

Characteristics of Generic HRQoL measures

- ✓ **Comprehensive**
- ✓ **General use** - not linked to specific diseases.
Ability to **compare** health outcomes **across diseases** and populations
- ✓ **Established reliability and validity** - widely applied
- **May not be responsive** to clinical status changes
- **Marginally relevant** for some conditions
- **Some do not provide a single score** - limited usefulness (?)

Characteristics of Specific HRQoL Measures

- ✓ Responsiveness (**sensitivity**) to clinical changes
- ✓ Greater **acceptance** by patients
- ✓ More **relevant** for health professionals and administrators / planners
- **Not comprehensive** measures of HRQOL
- **Cannot be used to compare** across diseases or healthy populations
- **Difficulty** attributing **broader perceptions** to **specific conditions** (?)

Preference-based measures

e.g. EQ-5D

- ✓ Based on preferences (subjective satisfaction or desirability that people associate with a health state)
- ✓ Represent strength of an individual's preference for different health outcomes
- ✓ Range from 0 (death) to 1 (complete health)
- ✓ Used to estimate quality-adjusted life years (QALYs)

Preference-based measures: Issues

- Focus on cure (rather than care)
- Measures that include time as a dimension are less favourable for older people (fewer benefits)
- Whose values count?
 - Public
 - Health professionals
 - Patients
 - Families
- Which methods should be used to obtain these values?

Uses of Health-Related Quality of Life Measures

- ✿ Political application (resource allocation)
- ✿ Theoretical role (important relationships)
- ✿ Practical application
 - research (clinical trials, health policy studies)
 - public health (population-based surveys)
 - clinical practice (focus on individual)

Locker, 1996



HRQoL measures have been used in:

- ✓ **Cross-sectional epidemiological studies, presenting the profile of functional, psychological and social impacts of disorders and conditions**
- ✓ **Studies assessing the relationship between clinical and HRQoL domains**
- ✓ **Intervention (Evaluation) studies assessing the effect of treatment, where quality of life is used as an outcome measure**
- ✓ **Studies for the assessment of treatment need, further facilitating planning of health services**



HRQoL measures: use in services

HRQoL indicators can ...

- ✓ bring out the necessary **subject-centred approach** and re-orient focus on health
- ✓ **complement** the use of clinical measures
- ✓ potentially provide useful information on:
 - **Prevalence** of the impacts of conditions on the daily life of people
 - **Needs assessment**
 - **Evaluation** of interventions

- ✓ **be relevant tools for health policy**

but still quite a few “open” issues

HRQoL measurement: challenges

Key challenges - “open” issues...

- generic or condition-specific measures?
- length of questionnaire vs. content: important domains?
- clinical - epidemiological setting
- which administration mode (self vs. interview)?
- What should be reported? How can it be interpreted?
- QoL is a dynamic construct - change over time

