Υποκειμενικοί δείκτες υγείας και ποιότητα ζωής

Στάθης Κοντοδήμας

What is health?

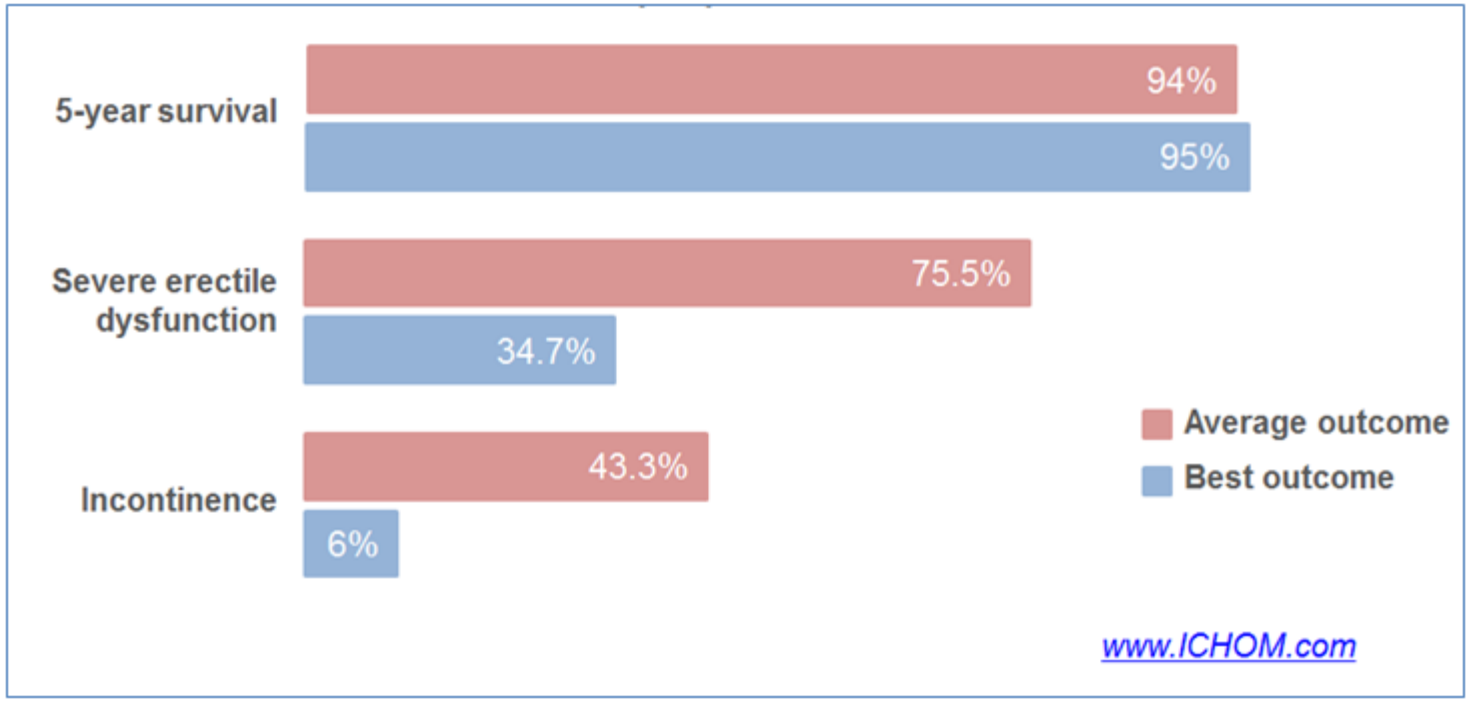
- **Good health is…*not bad health***
  - ‘Absence of disease’
- **Good health is…*a positive thing***
  - ‘Total physical and mental well-being’
- ***Good health is not an optional aspiration***
  - ‘ The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition ’
- **Good health is…two-dimensional**
  - ‘A long life and a happy life’
- **Good health is…*multidimensional***
  - ‘A long life plus an ability to do all the things that one wants to do’
- **Good health is a …*subjective concept***
  - ‘What makes me happy is not the same thing that makes you happy’
  - ‘What made me happy yesterday is not the same thing that makes me happy today

When is health care successful?

- When patients state that their well-being is better as a result.
- Health systems seek to improve people's well-being and their ability to play an active role in society.
- Yet health systems know very little about how often they achieve this.
- Cure and survival rates give only a partial picture of health system performance.
- The success of health systems is typically measured by survival rates, or rates of cure, after treatment.
- Often, though, differences in clinical outcomes between the best- and worst-performing providers of care are small.
- It is only when we measure outcomes reported by patients themselves – such as quality of life – that important differences in the outcomes of care emerge

Prostate cancer outcomes

- Clinical outcomes are not enough



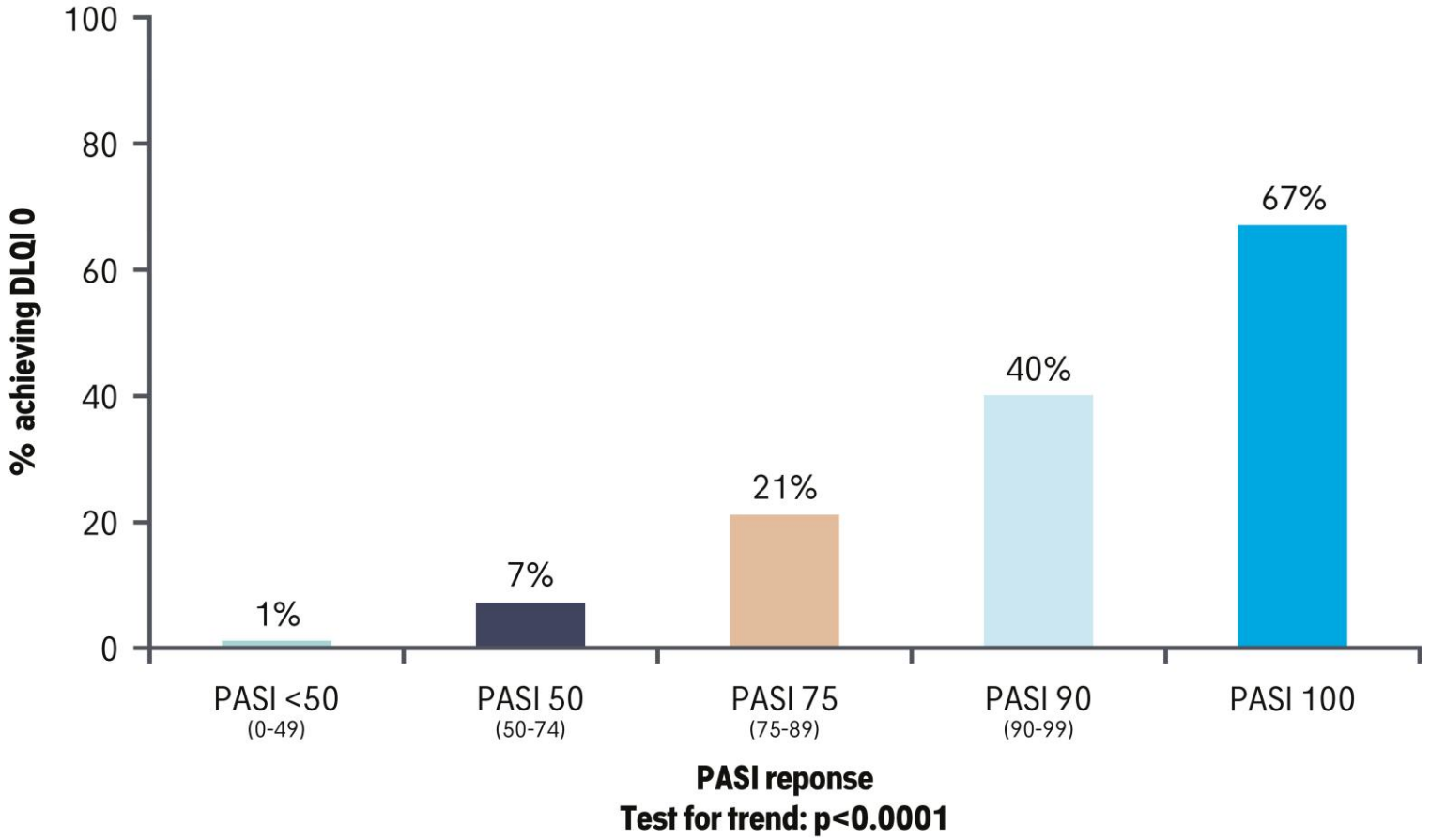
Differences in quality of care for prostate cancer become apparent only when patient-reported outcomes such as incontinence or sexual function are examined.

- Patients, clinicians and policy makers all stand to benefit hugely from these outcomes of health care

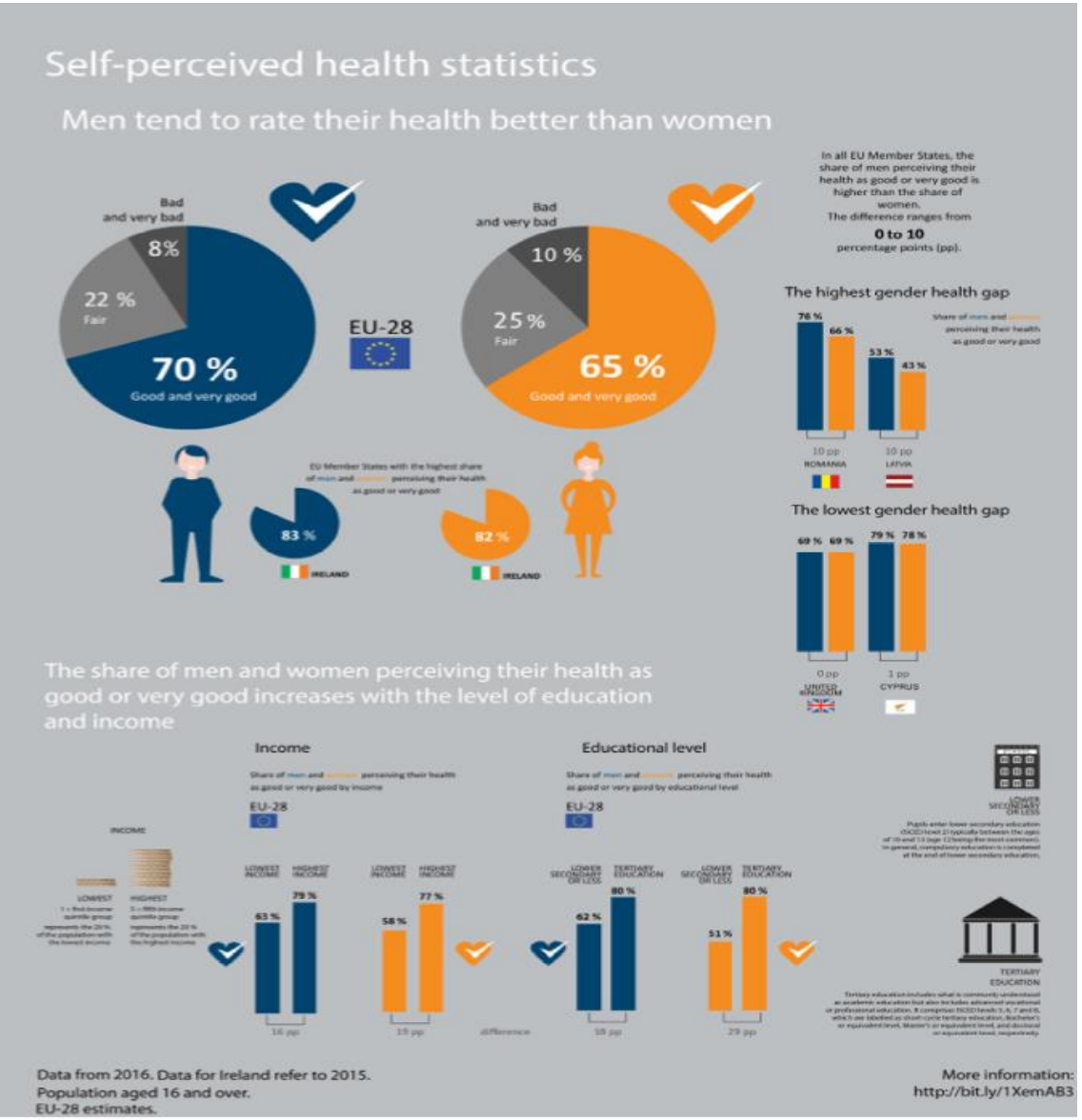
Quality of life correlates strongly with PASI

DLQI 0 and PASI response

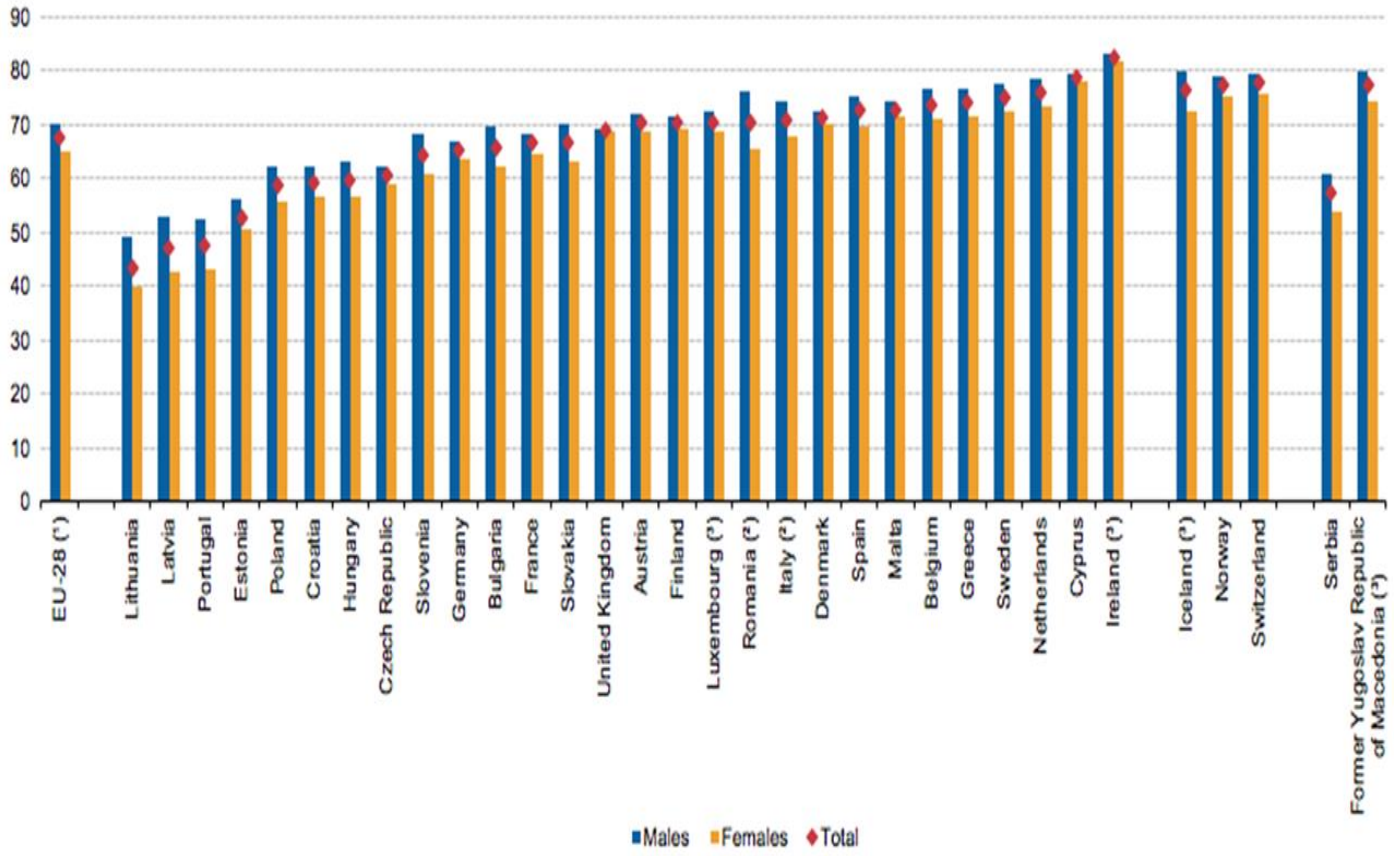
Subjective : No impact on QoL



Self perceived health care



Share of persons aged 16 and over with very good or good self-perceived health, by gender, 2016 (%)



(1) Estimates.
(2) Provisional data.
(3) 2015.
Note: Ranked on the overall share of persons with very good or good self-perceived health.
Source: Eurostat (online data code: hlth_silc_10)

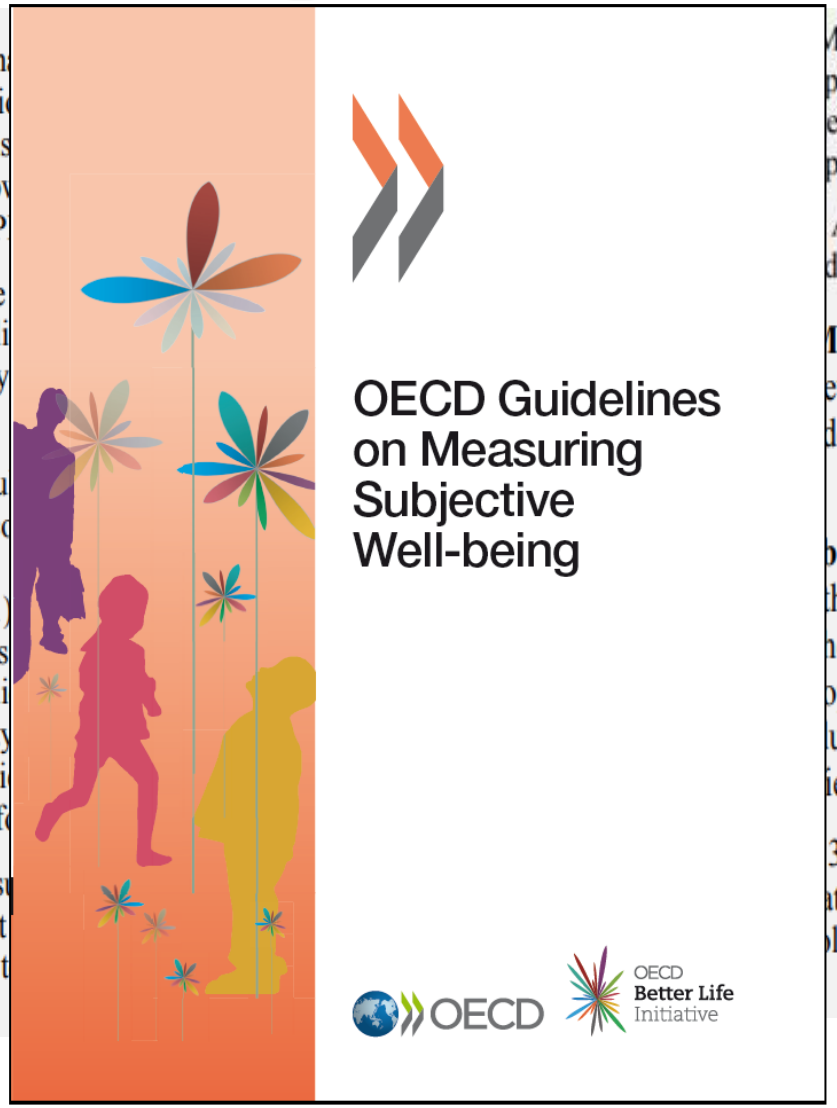
International Society for Quality of Life Research (ISOQOL) Recommendations for minimum standards for patient-reported outcome measures

1. Conceptual and measurement model: A PROM should h
describing the concept(s) included and the intended populati
should be documentation of how the concept(s) are organis
including evidence for the dimensionality of the measure, hov
concept, and the relationship among concepts included in the P

2. Reliability: The reliability of a PROM should preferably be
comparisons, but may be lower if appropriately justified. Reli
variety of methods including internal consistency reliability
response theory. Each method should be justified.

3. Validity – 3a. Content validity: A PROM measure shou
content validity, including evidence that patients and experts c
relevant and comprehensive for the concept, population,
application. This includes documentation of as follows: 1)
methods used to solicit and confirm attributes (i.e., concepts
patient-reported outcome relevant to the measurement appli
participants included in the evaluation (e.g., race/ethnicity
economic status, literacy level) with an emphasis on similariti
the target population; and 3) justification for the recall period f

3b. Construct validity: A PROM should have evidence s
including documentation of empirical findings that support
expected associations among measures similar or dissimilar t
outcome.



M for use in longitudinal research study should have evidence of
pirical evidence of changes in scores consistent with predefined
es in the measured patient-reported outcome in the target
plication.

A PROM should have documentation to support interpretation of
d high scores represent for the measured concept.

I: A PROM measure translated to one or more languages should
ethods used to translate and evaluate the PROM in each language.
de evidence from qualitative methods (e.g., cognitive testing) to

burden: A PROM must not be overly burdensome for patients or
he PROM should be considered in the context of other PROMs
he frequency of patient-reported outcome data collection, and the
opulation. The literacy demand of the items in the PROM should
ucation level or lower (i.e., 12-year-old or lower). However, it
ied for the context of the proposed application.

3), "ISOQOL Recommends Minimum Standards for Patient-reported
tient-centered Outcomes and Comparative Effectiveness Research",
l. 22, No. 8, pp. 1889–1905, http://dx.doi.org/10.1007/s11136-012-

Specific versus generic measures

- Generic measures
  - Aim for a broad assessment of health related QoL
  - Can be used across all different conditions
  - Examples: Nottingham Health Profile, SF36, COOP WONCA charts, EQ-5D, HUI
  - Can be insensitive to some problems
  - OR can be very long as they try to look comprehensively across the whole of health

Specific versus generic measures

- Specific measures
  - Aim for a narrow assessment of health related to a particular condition
  - Can only be used for that particular condition
  - Examples: Dermatology Life Quality Index, Beck Depression Inventory, Arthritis Impact Measurement Scale (AIMS)
  - Are more sensitive to the particular condition under investigation
  - Cannot be used to compare across conditions
  - GENERALLY NOT HELPFUL FOR ESTIMATING QALYs

Profile versus index measures

- Profile measures
  - Aim to provide a profile of an individual's health
  - Questions can be summed into sub-categories
  - Profiles can be clustered by disease or condition group
  - Examples: Sickness Impact Profile, Nottingham Health Profile, SF-36
  - GENERALLY NOT HELPFUL FOR ESTIMATING QALYs

Profile versus index measures

- Examples of profile measures
  - Nottingham Health Profile
    - 13 dimensions, 45 items
    - Physical mobility, pain, sleep, energy, social isolation, emotional reactions, employment, social life, household work, sex life, home life, holidays, interests, hobbies
  - SF-36
    - 8 dimensions, 36 items
    - Physical functioning, vitality, social functioning, bodily pain, general mental health, general health perceptions, role limitations – physical, role limitations - emotional

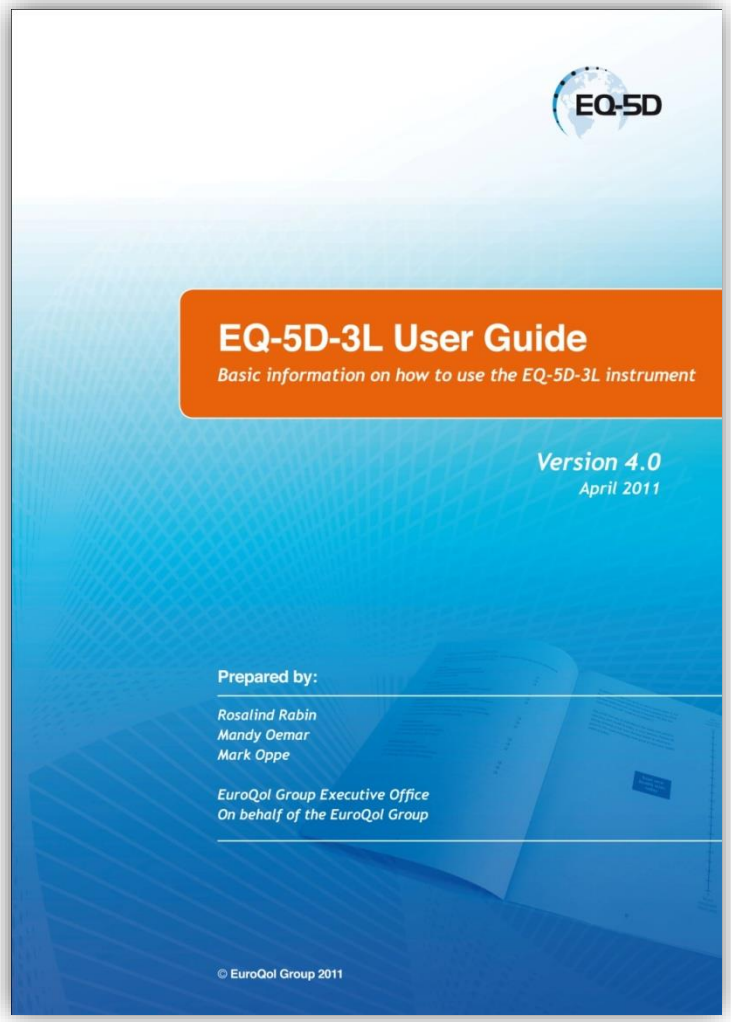
Profile versus index measures

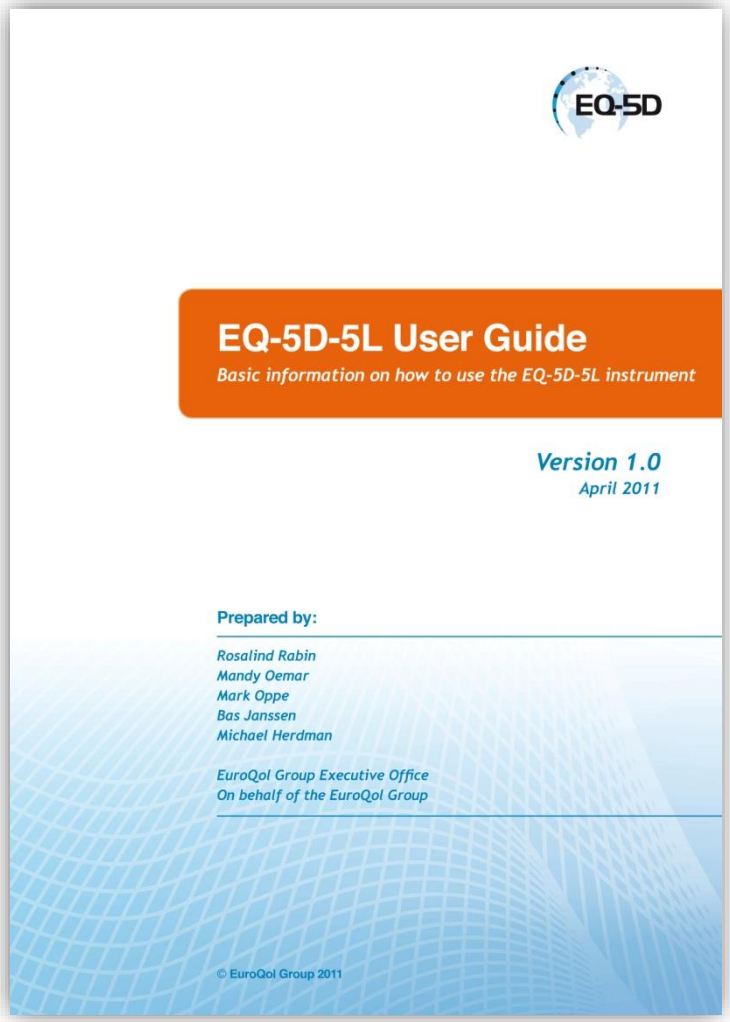
- Index measures
  - Aim to provide a single index value representing an individual's health
  - Aims to be comprehensive but trade off between number of dimensions and ability to obtain an index value
  - Incorporates social preferences / weights so that the index numbers are "meaningful"
  - Examples: EQ-5D, SF-6D, 15D, HUI

Profile versus index measures

- Examples of index measures
  - EQ-5D
    - 5 dimensions, 3 items
    - Mobility, self care, usual activities, pain / discomfort, anxiety / depression
  - HUI2
    - 7 dimensions, 7 items
    - Sensation, mobility, emotion, self care, cognition, pain, fertility

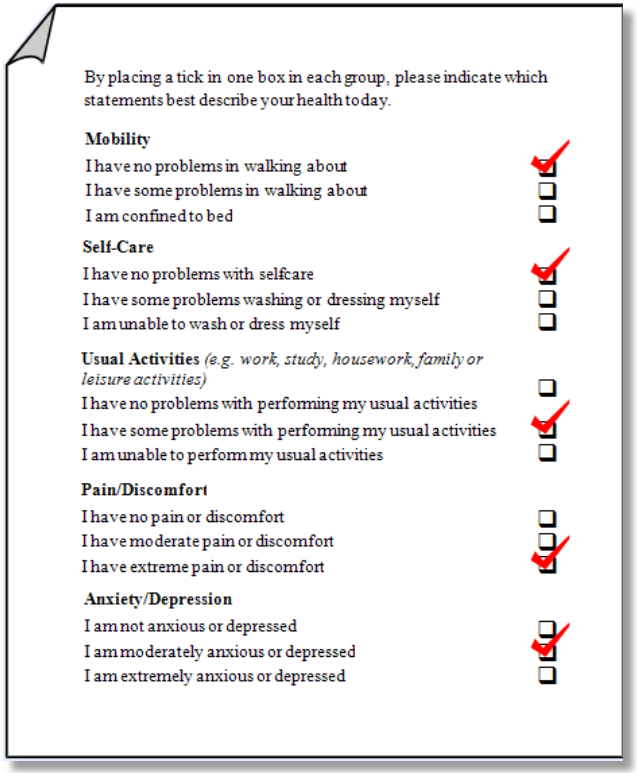
EQ-5D User Guides





EQ-5D Paper version

EQ-5D-3L descriptive system



By placing a tick in one box in each group, please indicate which statements best describe your health today.

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

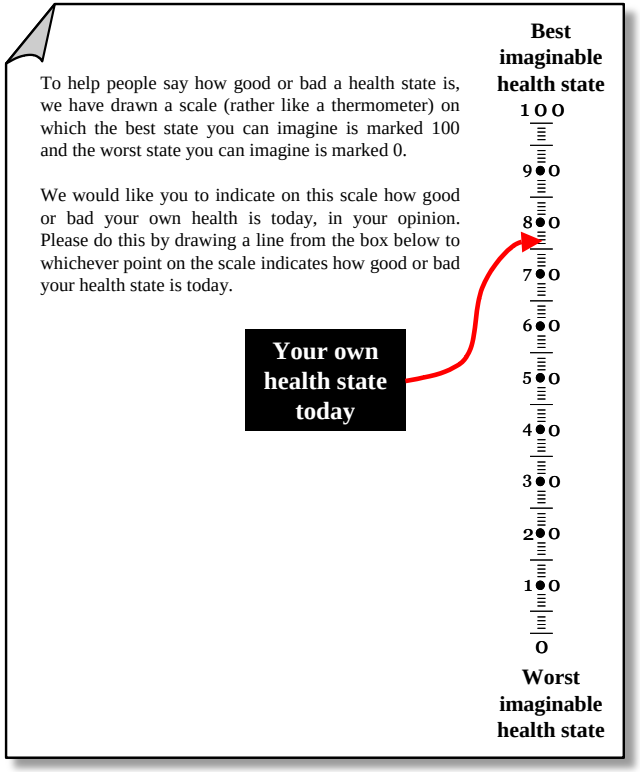
Self-Care
- I have no problems with selfcare ☑
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

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 ☑

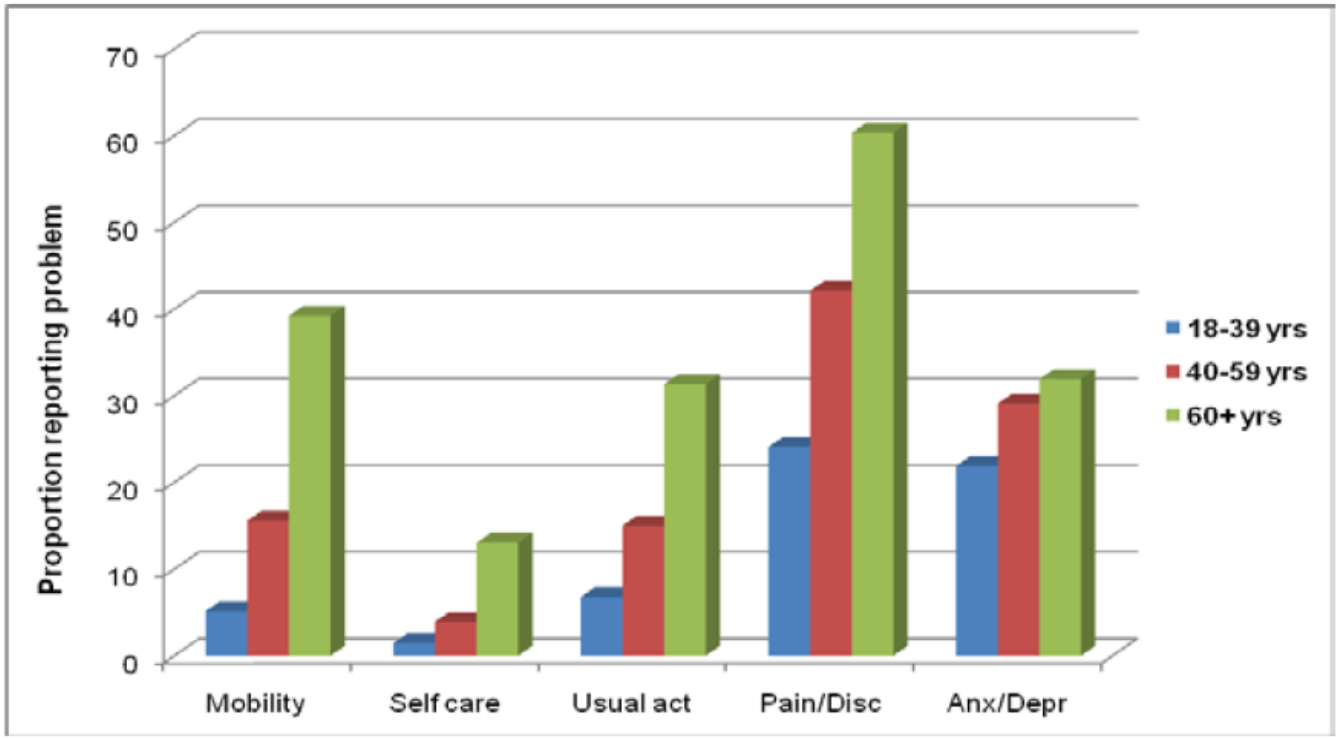
Anxiety/Depression
- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☑
- I am extremely anxious or depressed ☐

EQ-5D-3L VAS



Example of EQ-5D RESULTS PRESENTATION: PROFILES

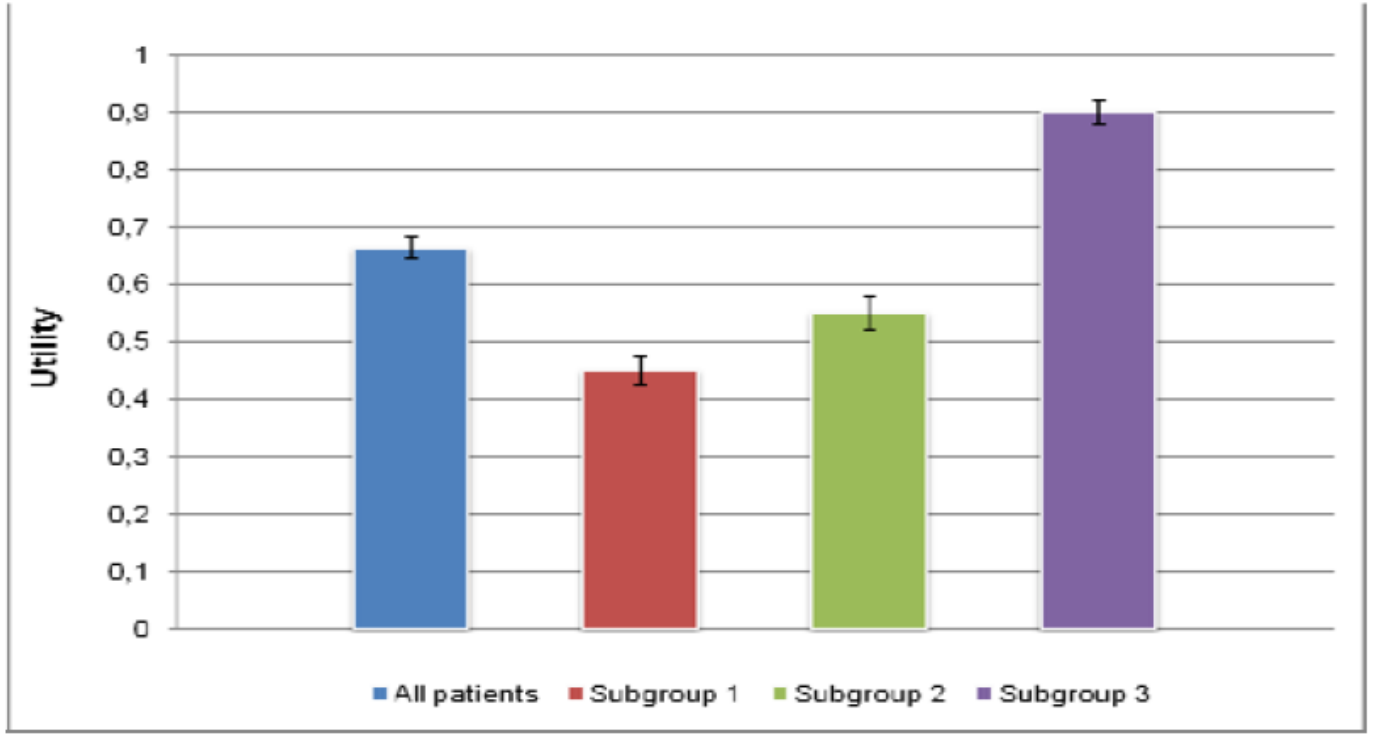
Figure 2: Profile of the population (% reporting problem)



https://euroqol.org/wp-content/uploads/2016/09/EQ-5D-3L_UserGuide_2015.pdf

EQ-5D INDEX: RESULTS PRESENTATION

subgroups.



https://euroqol.org/wp-content/uploads/2016/09/EQ-5D-3L_UserGuide_2015.pdf

QALY league tables

Intervention	$ / QALY
GM-CSF in elderly with leukemia	235,958
EPO in dialysis patients	139,623
Lung transplantation	100,957
End stage renal disease management	53,513
Heart transplantation	46,775
Didronel in osteoporosis	32,047
PTA with Stent	17,889
Breast cancer screening	5,147
Viagra	5,097
Treatment of congenital anorectal malformations	2,778

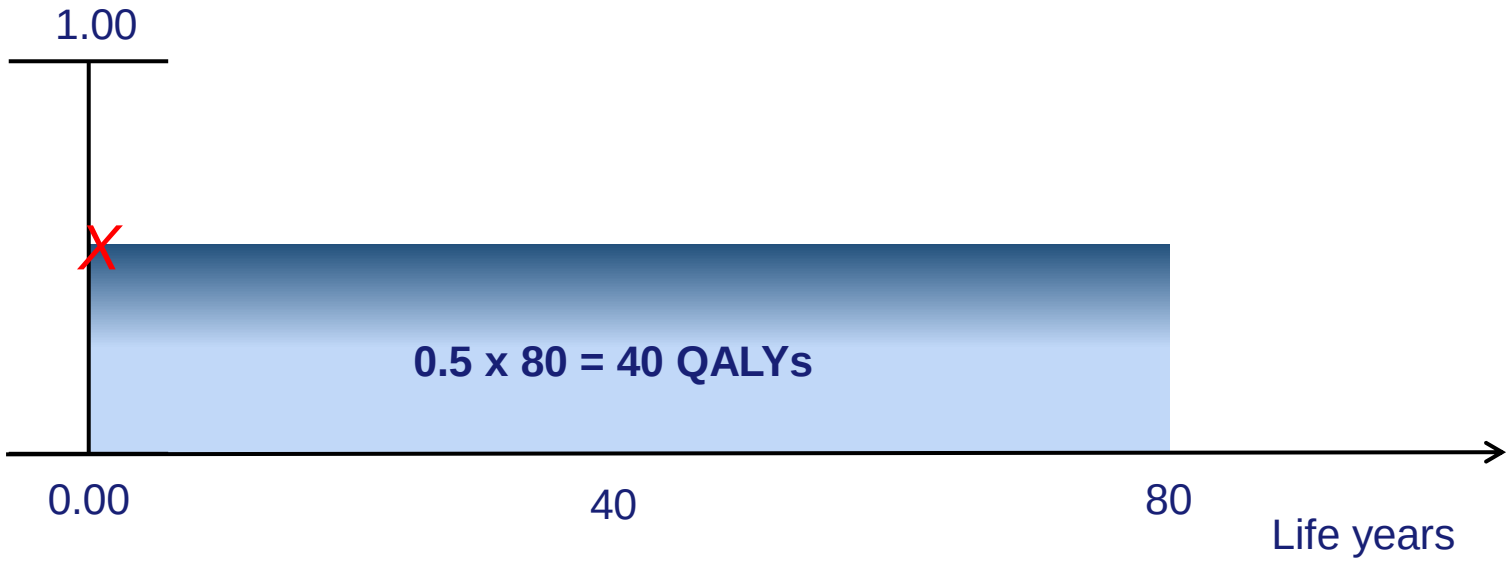
Table 5. Cost-utility ratios obtained in different context

Disease	Cost (€, 2007)
CER Knee arthroplasty (Min)	824.87
CER Knee arthroplasty (Av)	1,275.87
CER Knee arthroplasty (Max)	2,827.17
CER Hip arthroplasty (Min)	4,231.19
Higher recommended Spain (hepatitis treatment)[a]	6,783.07
CER hip arthroplasty (Av)	7,396.12
Critical care[b]	19,756.55
Congenital anomalies[b]	25,379.13
Genito-urinary diseases[b]	28,525.71
Spanish threshold	30,000.00
CER hip arthroplasty (Max)	48,186.64
International threshold	50,000.00
Injuries/exposures[b]	66,265.79
Digestive diseases[b]	89,348.43
Cardiovascular diseases[b]	92,629.31
Malignant neoplasms[b]	152,652.84
Anemias[b]	153,988.48
Allergy/immunology[b]	214,824.95
Infectious diseases[b]	649,038.17
Hematology-non cancer[b]	3,621,573.48

[a]Source: Sacristán et al[32].
[b]Cost-utility analyses published from 1976 to 2001, with ratios converted to 2002 US dollars.

Quality Adjusted Life Years (QALY)

- Example
  - Blindness
  - Time trade-off value is 0.5
  - Life span = 80 years
  - 0.5 x 80 = 40 QALYs



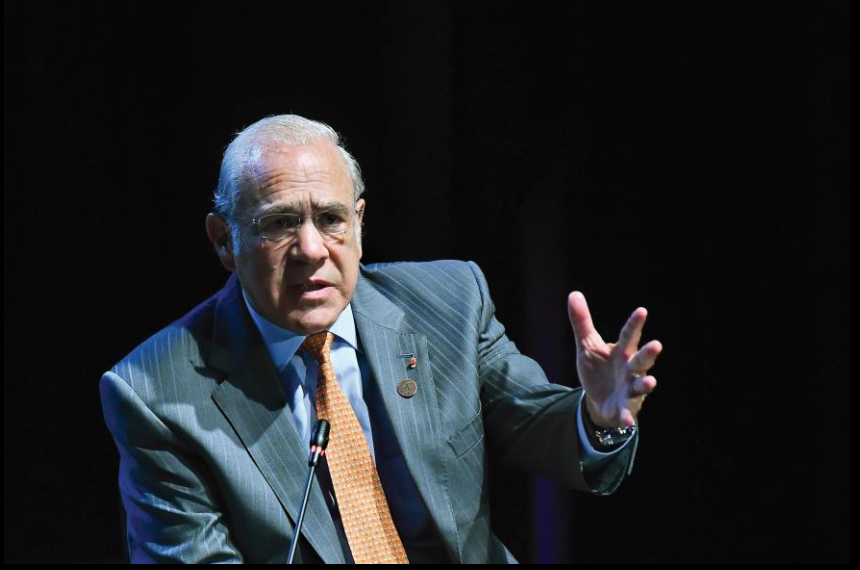
Collection of PROMs at a system-wide level is lacking

- NHS in England introduced routine measurement of PROMs in 2009 for all patients receiving four elective procedures

Table 1.1. PROMs programme in the NHS England

Treatment	Condition-specific PROM	Generic PROM
Knee replacement	Oxford Knee Score	EQ-5D (including EQ VAS)
Hip replacement	Oxford Hip Score	EQ-5D (including EQ VAS)
Varicose vein removal	Aberdeen Varicose Vein Questionnaire	EQ-5D (including EQ VAS)
Hernia repair	No instrument	EQ-5D (including EQ VAS)

Source: Health & Social Care Information Centre (2015). Note: EQ VAS = EQ Visual Analogue Scale



“Asking patients to assess the results of their care is perhaps the most important single step we can take to improve health care.

It will change the culture and mindset among clinicians and throughout health systems.

Getting this right will require political commitment at the highest levels”

Angel Gurría is the Secretary-General of the OECD.
Michael Porter is the Bishop William Lawrence University Professor at Harvard Business School and founder of ICHOM

PaRIS

Patient – Reported Indicators Survey

The next generation of OECD health statistics

PaRIS will…

Accelerate and standardise international monitoring, in population groups where patient-reported indicators are already used.

- **Priority groups** will be patients who have experienced stroke, heart attack, cancer, hip and knee surgery, and mental illness.
- **Close collaboration** with international partners such as The Commonwealth Fund and the International Consortium for Health Outcomes Measurement will ensure state of the art indicators and surveys.

Develop new patient-reported indicators in critical areas of health care, where none currently exist.

- **Priority groups** in this case are patients with complex, long-term conditions such as diabetes or dementia and – in particular – patients with several conditions.
- **We will survey these patients and carers directly**, and publish new international benchmarks of health system performance.


What is PRO


What is PRO

Foreword

The case for Health-related Happiness Research

Everybody wants a satisfying life for themselves and their children. Individually, people seek ways to achieve a more satisfying life and this quest is manifested in the soaring sales of 'how-to-be-happy' books and in the ongoing development of life-coaching businesses. Collectively, people call on governments to improve the necessary social conditions for happiness; for example, 85% of the British agree with the statement that 'A government's prime aim should be achieving the greatest happiness of the people, not the greatest wealth'

To sum up: Subjective measures of health …

1. Crucial
2. Trendy
3. Complimentary to hard endpoints
4. Methodological challenges
5. Can inform health policy making
6. Can revolutionize delivery of health care
7. Can enhance efficient allocation of resources
8. Can put the patient at the center of the health care agenda

Ευχαριστώ για την προσοχή σας!