institute for
Medical Technology Assessment

Who's QALY is it anyway?

Loosely based on:
Versteegh MM, Brouwer WB. Patient and general public preferences for health states: a call to reconsider current guidelines. Social Science & Medicine. 2016 Sep 1;165:66-7

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1

Disclosures

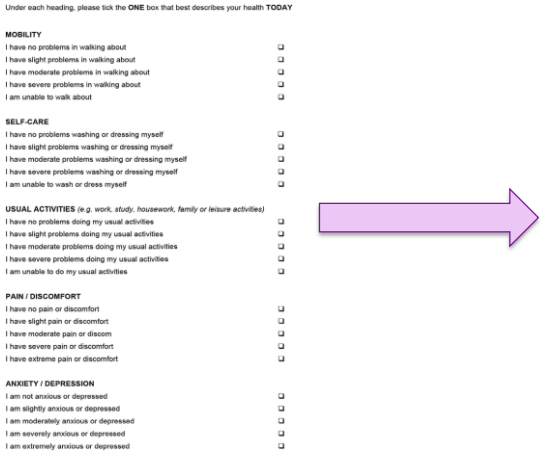
I have no personal conflicts of interest. I work for iMTA which receives grants from **Hospitals, Governments, EU, Industry, and foundations, outside this topic.** I am a member of the EuroQoL research foundation.

2

Who should value *health states*? Patients or the general public?

3

Current practice of health state valuation



Under each heading, please tick the **ONE** box that best describes your health **TODAY**

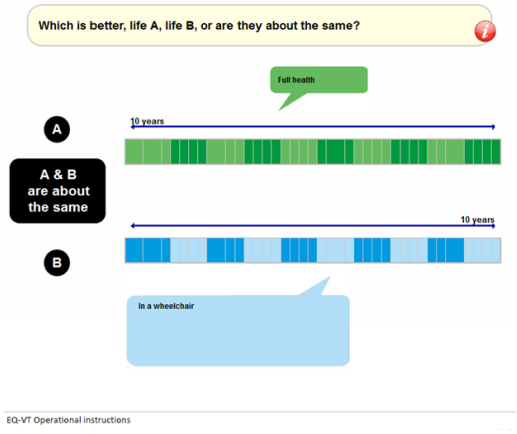
MOBILITY
I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about

SELF-CARE
I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe 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 doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN / DISCOMFORT
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discom
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY / DEPRESSION
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed



EQ-5D

EQ-VT TTO

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Veil of ignorance

5

1. Veil of ignorance

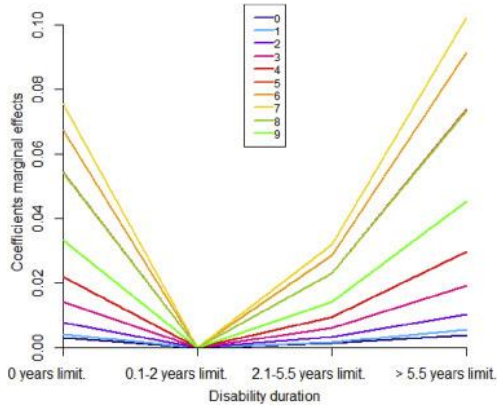
Societal choices should be 'impartial' not favoring particular groups or interests. Public preferences do not favor particular groups or interests.

A) Since the measurement of effect and the valuation of health states are separate, it is not easy (or possible) to exert influence

B) Behind our veil of ignorance, when deciding on a just society, we may want to know about the seriousness of a health condition from the perspective of individuals with first hand knowledge

6

Adaptation



de Hond A, Bakx P, Versteegh M. Can time heal all wounds? An empirical assessment of adaptation to functional limitations in an older population. Social Science & Medicine. 2019 Feb 1;222:180-7.

7

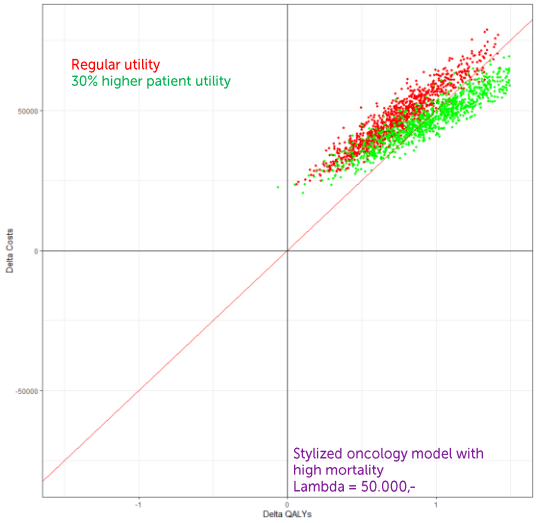
Adaptation

"No matter how sad the circumstances are in which disabled and chronically ill people adapt, we would seem to be **ignoring their laudable adaptation** were we merely to proceed as if they had not adapted. Yet, we may also doubt that we are fully respectful of disabled persons if we proceed simply on the basis of their own values, **forgetting the circumstances which caused them to adapt**.

Menzel P, Dolan P, Richardson J, Olsen JA. The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis. Social science & medicine. 2002 Dec 1;55(12):2149-58.

8

Excluding adaptation does not 'protect' patients from distributional consequences



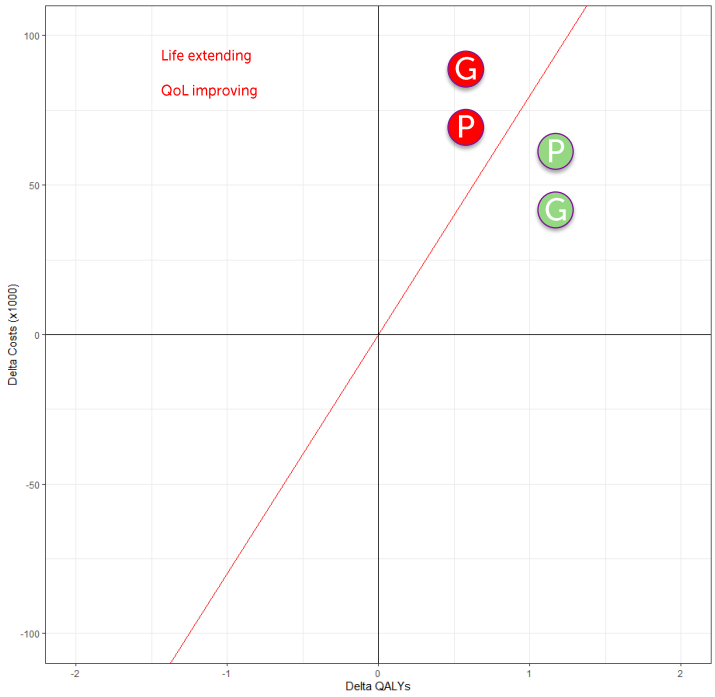
Where does this leave us for now

- Arguments that are in favor of general public values, do not rule out the use of patient values, they simply show the value of general public preferences
- There are good arguments to *want to* include patient preferences and openly discuss differences

Including patient preferences in appraisal

Conflicting scenarios currently also exist, we just don't know about it

When explicated, these conflicting results may be explicitly addressed in the appraisal phase.



11

Side note

12

Adaptation may equally affect how EQ-5D is filled-out and hence may impact QALY values

Under each heading, please tick the **ONE** box that best describes your health **TODAY**

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

Phrasing sensitive to adaptation, not objective measurement of functioning but experience of functioning.

13

Conclusions

- Current practice and historical arguments do not match well
- Valuation should be conducted from both a patient and a general public perspective
- It can be done (Swedish set)
- We would then have two types of QALYs for sensitivity analysis: patient QALYs and general public QALYs, and can assess disagreement, if any
- Personal opinion: the division between those making models and those measuring utilities does not do the field any good

14

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15