

DROP DEAD: IS IT TIME TO REMOVE 'DEAD' FROM HEALTH STATE VALUATION?

Virtual ISPOR 20th May 2021

Conflict of interest statement

I have no conflicts of interest to declare

I am an employee of the National Institute for Health and Care Excellence (NICE), London, UK

Moderator: Jacoline Bouvy

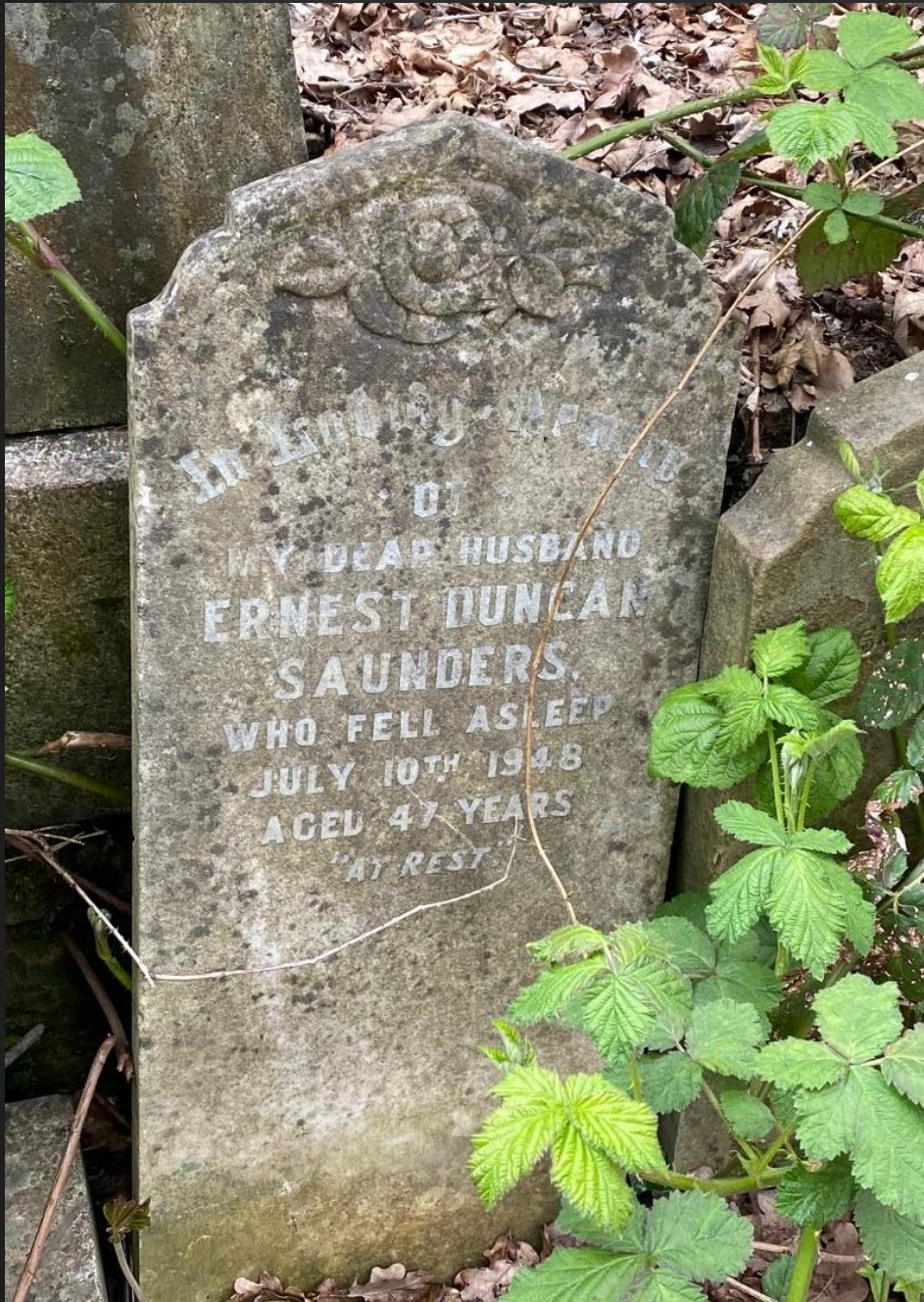
Panellists: Mathias Barra
 Chris Sampson
 Bram Roudijk

The problem with dead in health state valuation

Health state valuation: 1=full health, 0=dead

The use of dead in valuation studies
'10 years in this health state is equal to x years in full health, followed by death'





Alternatives
to dead?



Before the panellists present their arguments:
first polling question

‘Dead’ should have no role in health state valuation

- a. Agree
- b. Disagree

Are decision-makers indifferent between states
'worse than dead'?

- a. Yes (and they should be)
- b. Yes (but they shouldn't be)
- c. No (but they should be)
- d. No (and they shouldn't be)

What is the best candidate for an alternative anchor state to 'dead'?

- a. Worst health state imaginable
- b. Worst state defined by a measure
- c. A state 'as bad as being dead'
- d. Minimum endurable quality of life
- e. Unconsciousness
- f. Sleep
- g. Something else
- h. N/A: there is no realistic alternative
- i. N/A: no anchor state is necessary

Are current methods for valuing negative health states adequate?

- a. Yes
- b. No
- c. Unsure

‘Dead’ should have no role in health state valuation

- a. Agree
- b. Disagree



Drop 'dead'?

20th of May
2021

10:00 AM



Mathias Barra

HØKH – Akershus University Hospital HF

&

BCEPS – University of Bergen

(Liv Augestad and Kim Rand)

VIRTUAL
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Perspectives on death and the
QALY, problems with death, and
selected empirical findings.



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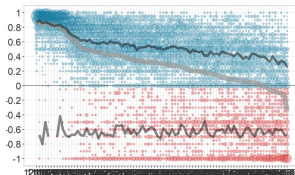
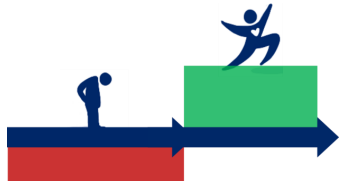
Conflicts of interest

- I declare that I have no known conflicts of interest, financial or otherwise.
- I am an employee of The Health Services Research Center, Akershus University Hospital HF, and Bergen Center for Ethics and Priority Setting in Health, University of Bergen, which receives funding from a variety of sources including the EuroQol Research Foundation and the Research Council of Norway.
- I received no funding in relation to this presentation.*



In fact, I had to pay a fee to deliver it.

Agenda



- Super quick intro to QALYs and time trade-off
- The TTO-task and how “negative” values arise?
- Why troublesome?
- Can they be ignored – some empirical evidence?

QALYs: The Basics

Milton C. Weinstein, PhD,¹ George Torrance, PhD,² Alistair McGuire, PhD³

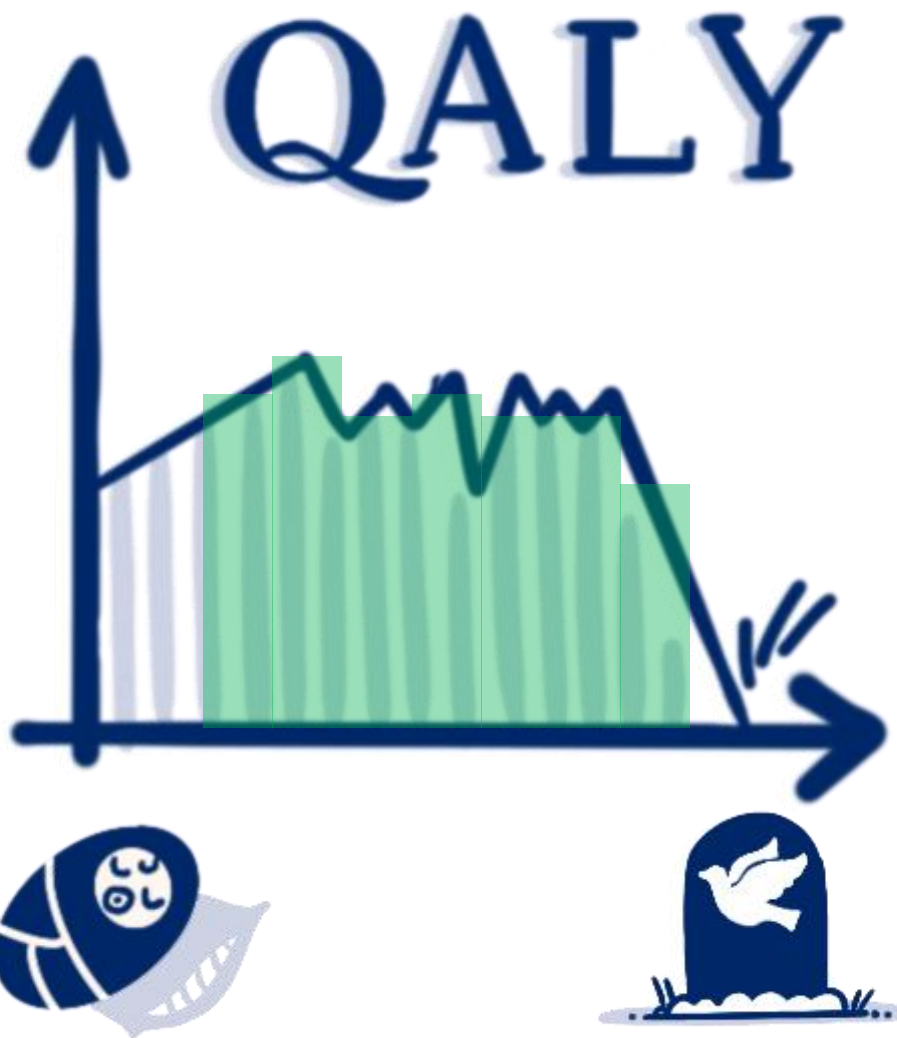
¹Harvard School of Public Health, Boston, MA, USA; ²McMaster University, Hamilton, ON, Canada; ³London School of Economics, London, UK

Keywords: quality-adjusted life-year, cost-effectiveness analysis, preference, utility, standard gamble, time trade-off, taxonomy, theory.

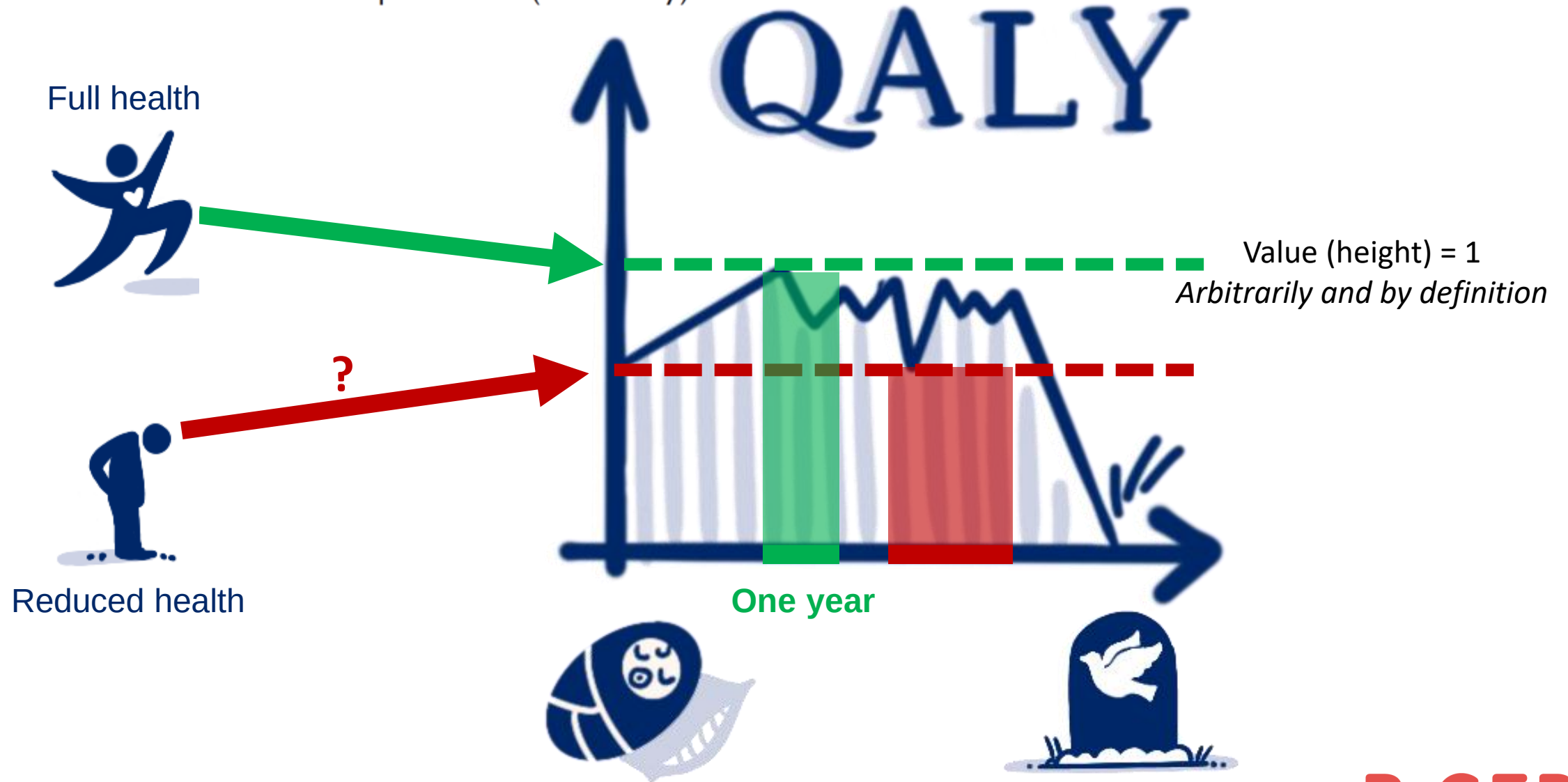
Table 2 Underlying assumptions of the conventional QALY approach

1. A resource-allocation decision must be made.
2. The outcomes of the alternatives can be specified in terms of health states, changes, and durations.
3. Resources are limited, and each alternative has resource implications (costs).
4. A major objective of the decision-maker is to maximize health of the population, subject to resource constraints.
5. Health is defined as value-weighted time (QALYs) over the relevant time horizon.
6. Value is measured in terms of preference (desirability).
7. Each individual is risk neutral with respect to longevity and has utility that is additive across time.
8. Value scores (preferences) measured across individuals can be aggregated and used for the group
9. QALYs can be aggregated across individuals; i.e., a QALY is a QALY regardless of who gains/loses it

QALY, quality-adjusted life-year.



5. Health is defined as value-weighted time (QALYs) over the relevant time horizon.
6. Value is measured in terms of preference (desirability).



What is valued during a **Time Trade-Off*** task?



Value (height) = ?
Objective



Value (height) = 1 QALY/year
Definition



Fixed duration



Free parameter



* I will **not** talk about SG, VAS, DCE etc, as TTO is **the theoretically correct** method

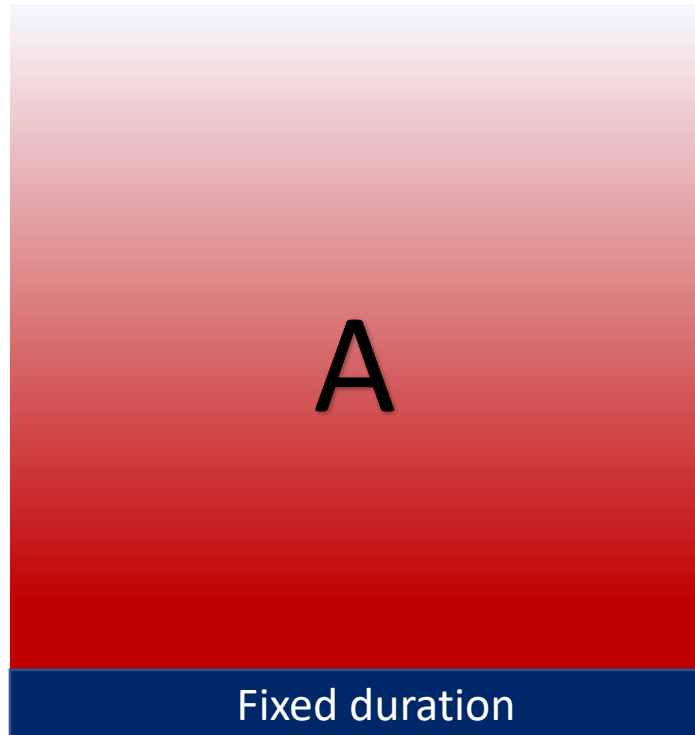
What is valued during a **Time Trade-Off** task?



Value (height) = ?
Objective

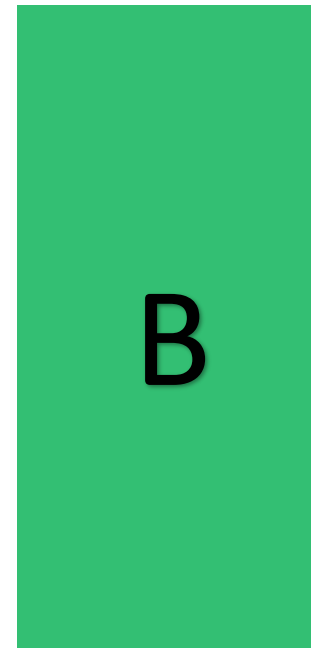


Value (height) = 1 QALY/year
Definition



Fixed duration

>



Like so?



What is valued during a **Time Trade-Off** task?



Value (height) = ?
Objective



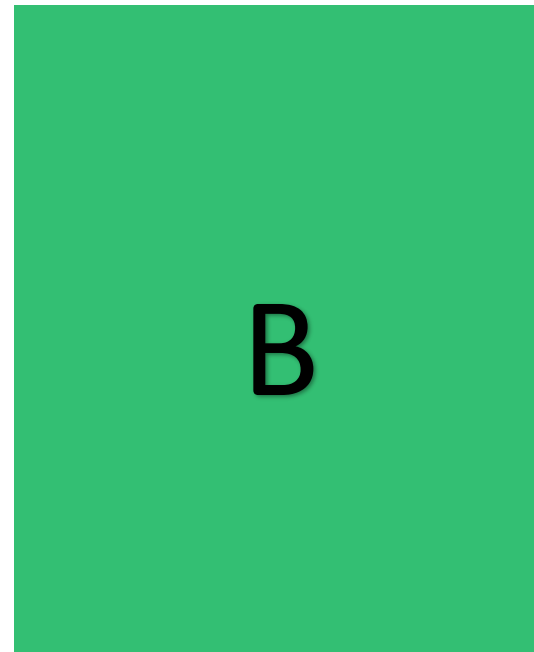
Value (height) = 1 QALY/year
Definition



A

Fixed duration

<



B

Like so?



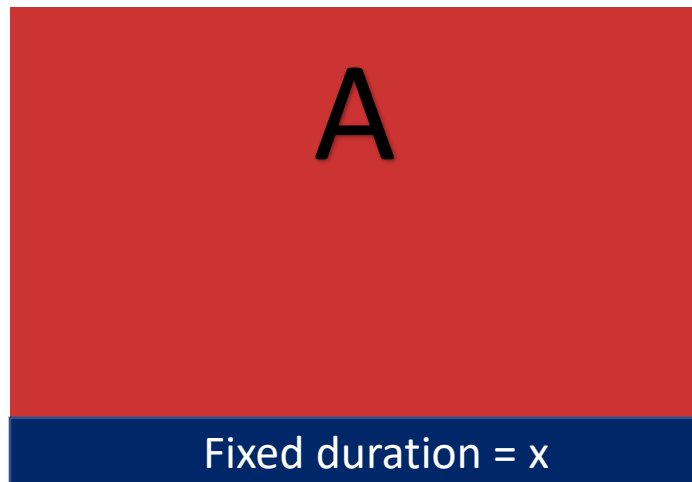
What is valued during a **Time Trade-Off** task?



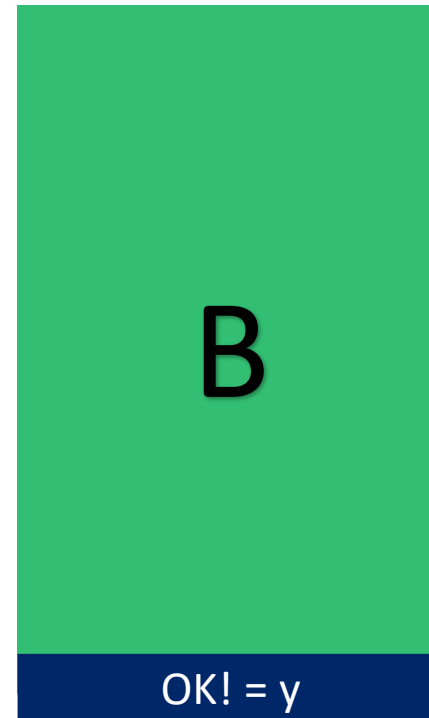
Value = y/x



Value (height) = 1 QALY/year
Definition

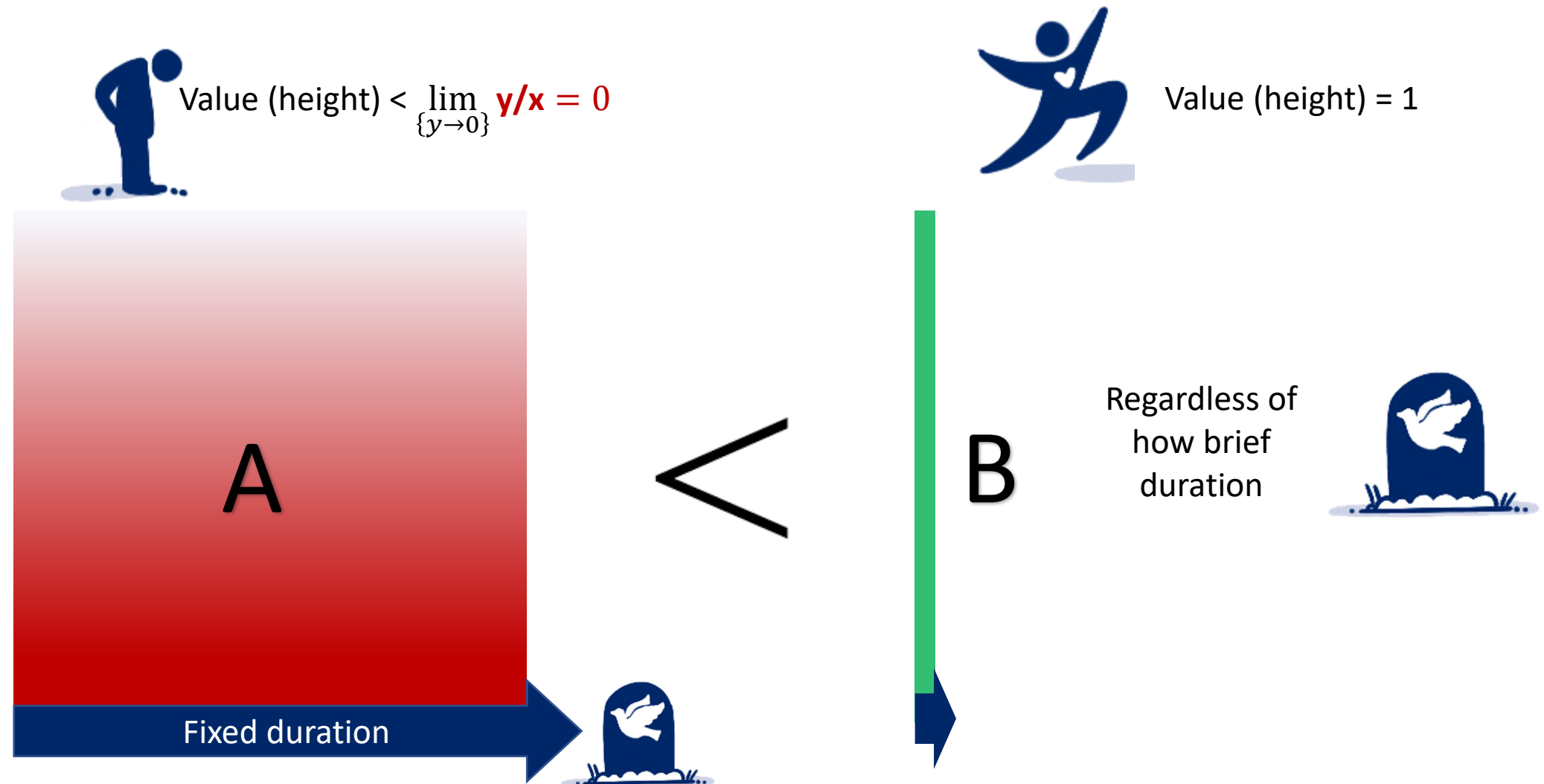


Fixed duration = x

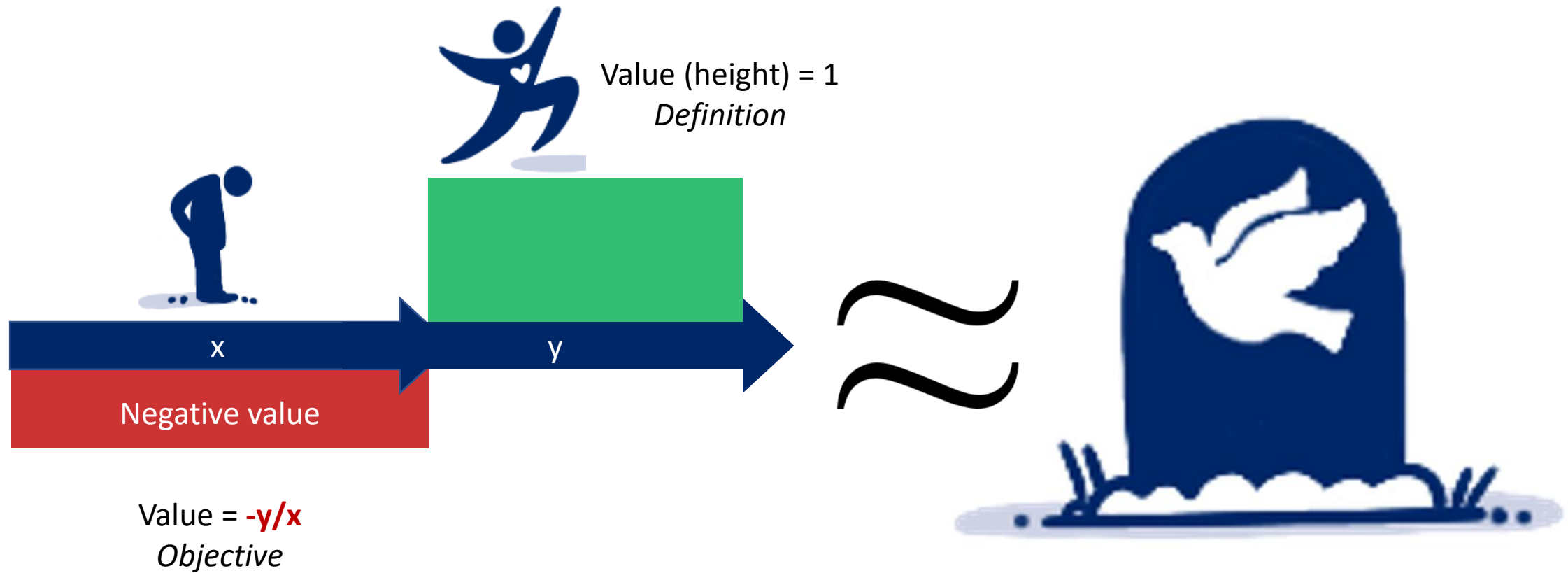


OK! = y

But, **sometimes**:

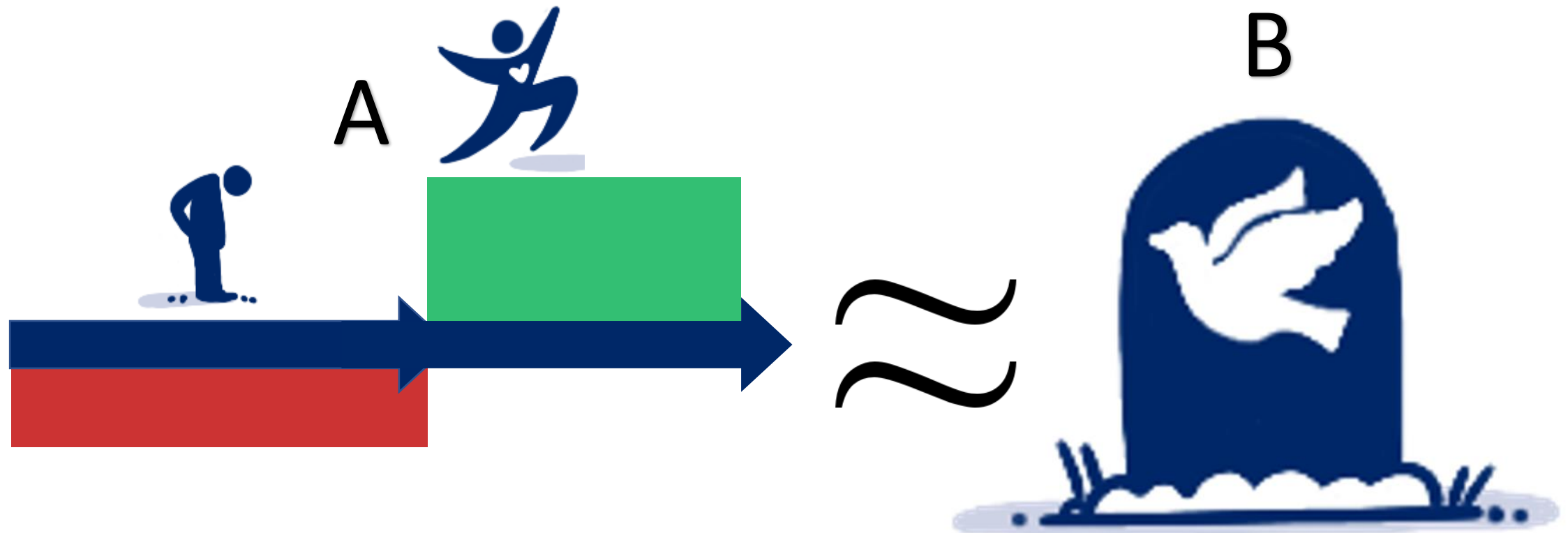


And, even, '**WTD**'* states



* **Worse-Than-Death**

Cannot be avoided* – theoretically, but...



- * 7. Each individual is risk neutral with respect to longevity and has utility that is additive across time.



Problematic?

‘dead’ vs ‘(immediate death)’

- Do respondents perceive “being dead» as a “health state”?



Cab be highly problematic

- Death is psychologically demanding.
- Invoking death: fear and anxiety.
- ‘Dying’ vs. ‘being dead’ vs. ‘death’.
- If ‘dead’ is a “health state”, a respondent may attribute non-zero value
- Instructions **do not** specify “death” as proxy for “zero time”
- Hard question: “**irrelevance**”

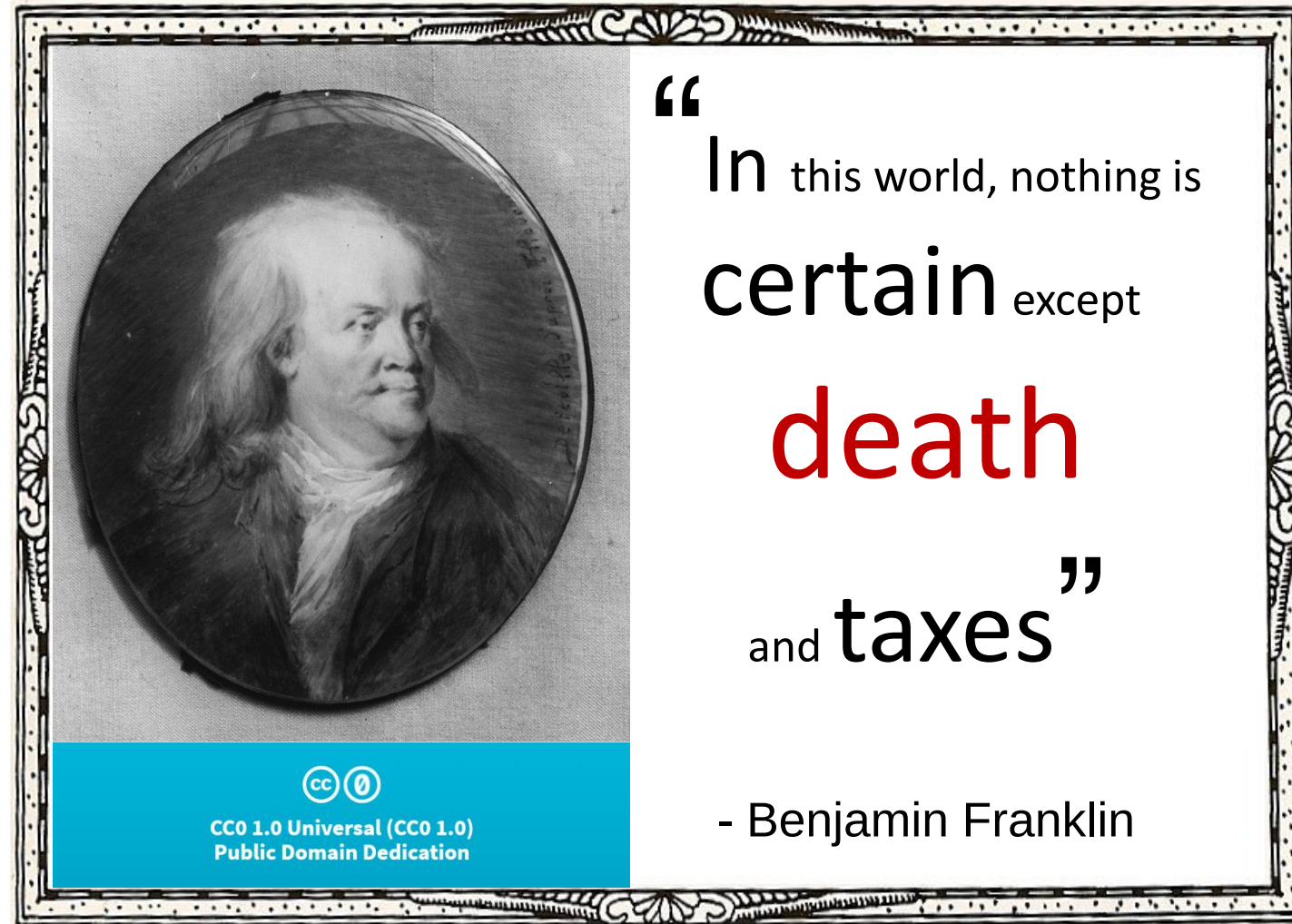
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So far

- We 'know' WTDs exist for some respondents, but not zero-states
- We know values are impacted by elicitation protocols.
- Important question:
Can values be TRUSTED?

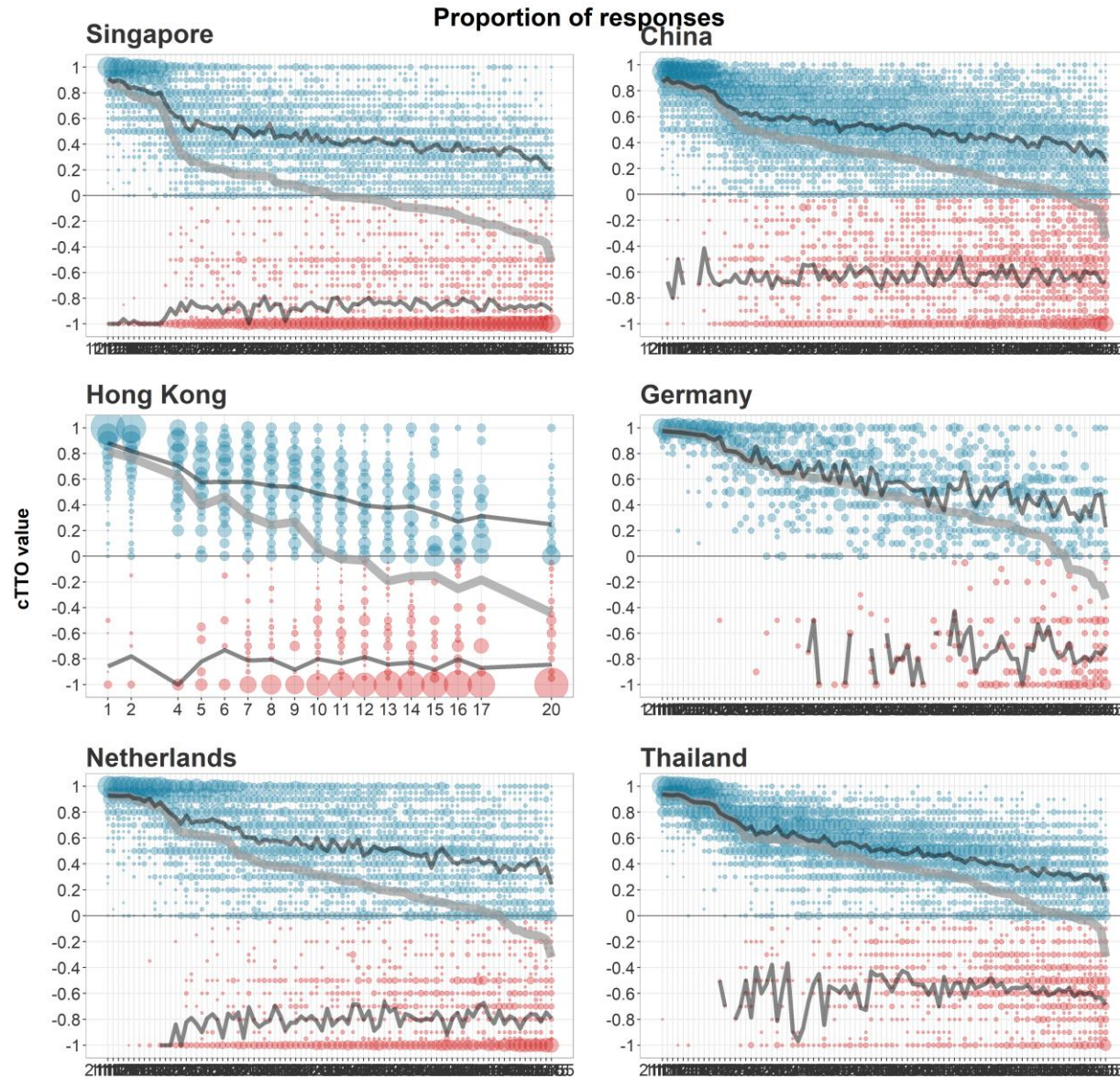


That is, what happens here?



That is, what happens here?





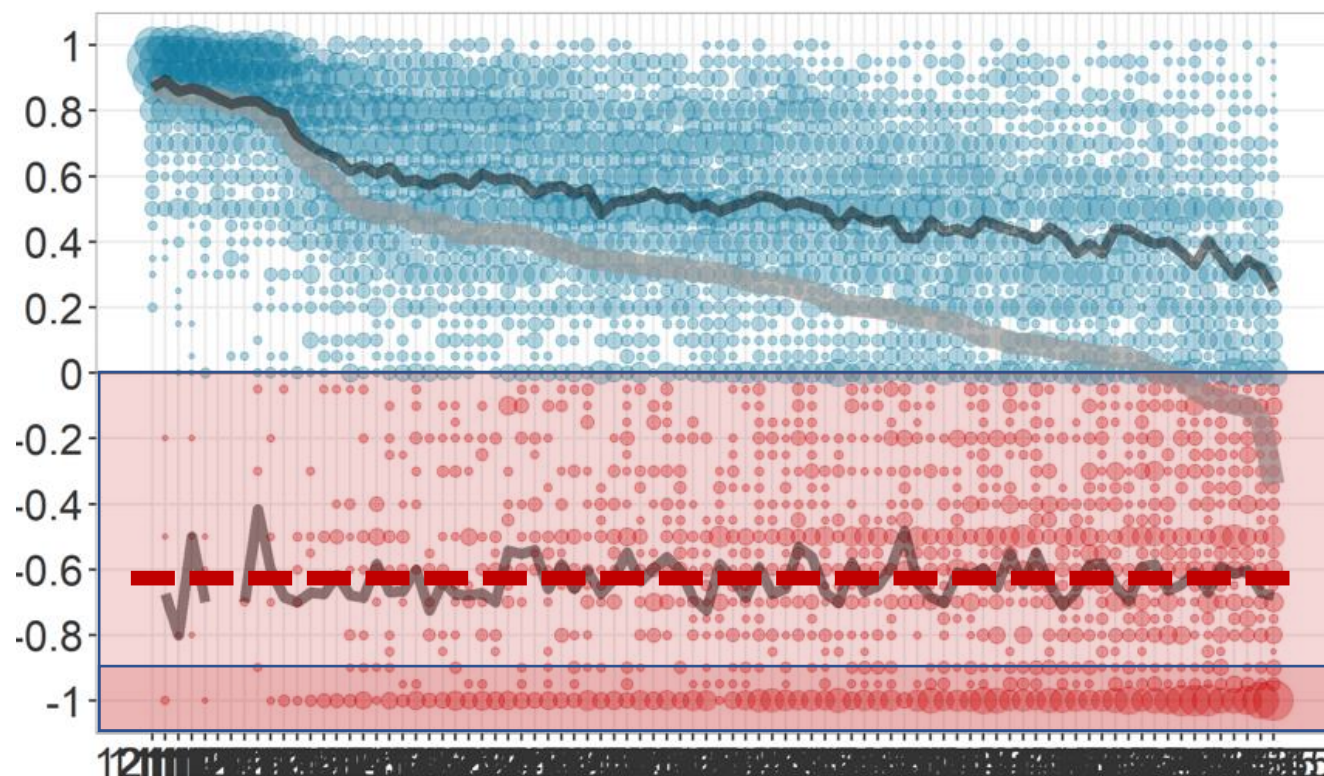
THIS IS YOUR HEALTH STATE VALUE DATA?

YUP! YOU POUR THE DATA INTO THIS BIG PILE OF LINEAR ALGEBRA, THEN COLLECT THE ANSWERS ON THE OTHER SIDE.

WHAT IF THE ANSWERS ARE WRONG?

JUST STIR THE PILE UNTIL THEY START LOOKING RIGHT.





There seem to be no association – **no information** – between health state severity and mean value taken over negative values. Share of all values that are negative distinguishes.



Table 1:

	Dependent variable:			
	val		val.alt	
	Original data	Random sample	Original data	Random sample
MO_2	0.035*** (0.010)	0.032*** (0.010)	0.039*** (0.010)	0.103*** (0.011)
MO_3	0.039*** (0.010)	0.039*** (0.010)	0.103*** (0.011)	0.147*** (0.010)
MO_4	0.101*** (0.011)	0.103*** (0.011)	0.147*** (0.010)	0.015 (0.009)
MO_5	0.146*** (0.010)	0.147*** (0.010)	0.017* (0.009)	0.053*** (0.011)
SC_2	0.015 (0.009)	0.017* (0.009)	0.053*** (0.011)	0.116*** (0.010)
SC_3	0.053*** (0.011)	0.053*** (0.011)	0.118*** (0.010)	0.147*** (0.010)
SC_4	0.116*** (0.010)	0.118*** (0.010)	0.143*** (0.010)	0.024** (0.010)
SC_5	0.147*** (0.010)	0.143*** (0.010)	0.026*** (0.010)	0.055*** (0.010)
UA_2	0.024** (0.010)	0.026*** (0.010)	0.056*** (0.010)	0.136*** (0.010)
UA_3	0.055*** (0.010)	0.056*** (0.010)	0.138*** (0.010)	0.139*** (0.010)
UA_4	0.136*** (0.010)	0.138*** (0.010)	0.138*** (0.010)	0.021** (0.009)
UA_5	0.139*** (0.010)	0.138*** (0.010)	0.022** (0.009)	0.051*** (0.011)
PD_2	0.021** (0.009)	0.022** (0.009)	0.052*** (0.011)	0.196*** (0.009)
PD_3	0.051*** (0.011)	0.052*** (0.011)	0.199*** (0.009)	0.247*** (0.010)
PD_4	0.196*** (0.009)	0.199*** (0.009)	0.247*** (0.010)	0.036*** (0.010)
PD_5	0.247*** (0.010)	0.247*** (0.010)	0.038*** (0.010)	0.080*** (0.011)
AD_2	0.036*** (0.010)	0.038*** (0.010)	0.078*** (0.011)	0.211*** (0.010)
AD_3	0.080*** (0.011)	0.078*** (0.011)	0.209*** (0.010)	0.260*** (0.010)
AD_4	0.211*** (0.010)	0.209*** (0.010)	0.261*** (0.010)	0.074*** (0.011)
AD_5	0.260*** (0.010)	0.261*** (0.010)	0.021* (0.011)	0.021* (0.011)
ctyNL	0.074*** (0.011)	0.071*** (0.011)	0.006 (0.011)	
ctyNO	0.021* (0.011)	0.021* (0.011)		
ctyUS	0.008 (0.011)	0.006 (0.011)		
Observations	17,617	17,617		
R ²	0.675	0.675		
Adjusted R ²	0.675	0.674		
Residual Std. Error (df = 17594)	0.370	0.370		
F Statistic (df = 23; 17594)	1,590.067***	1,585.560***		

Note:

*p<0.1; **p<0.05; ***p<0.01

 Random sample

All negative values in dataset substituted with a **randomly sampled** negative value.

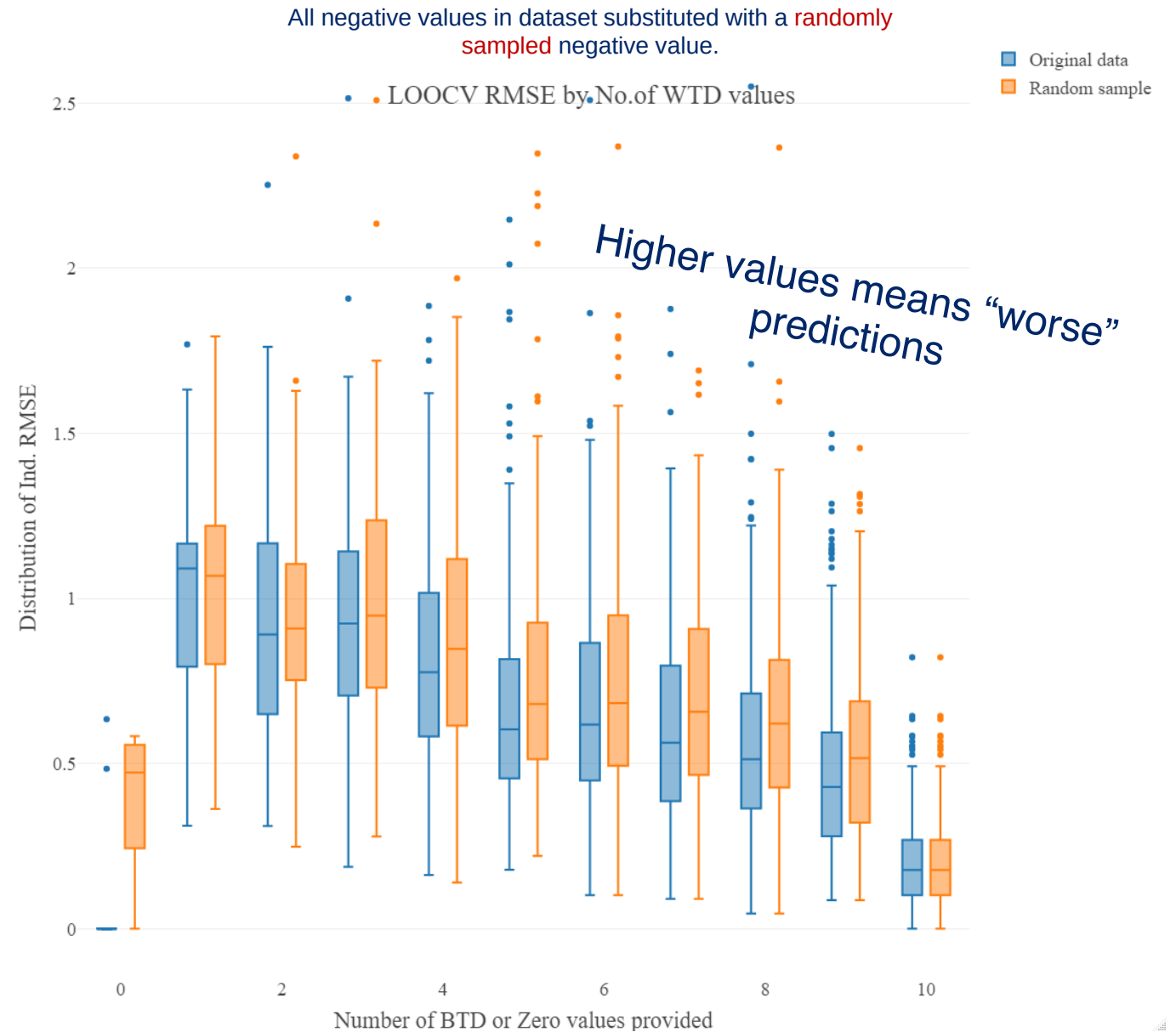


Also when **only “non-censored”** respondents are included.

However,
when I consider each
individual respondent



The jury is out...





THANK YOU

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@SEVPRI1



THE CASE IN FAVOUR
Drop Dead

#ISPORAnnual
#DropDead
@ChrisSampson87

Chris Sampson

ohe.org

VIRTUAL ISPOR
20 MAY 2021

Conflicts of interest

- I declare that I have no known conflicts of interest, financial or otherwise.
- I am an employee of the Office of Health Economics, a registered charity, which receives funding from a variety of sources including the EuroQol Research Foundation and the Association of the British Pharmaceutical Industry.
- I received no specific funding in relation to this presentation.

What is the role of 'dead'?

- The role of 'dead' is poorly defined
- The way we talk about states 'worse than dead' is problematic
- 0 QALYs $\neq$ 0 QALYs $\neq$ 0 QALYs

1.

The bottom of the QALY scale?



2.

A reference state for the valuation of other states?



3.

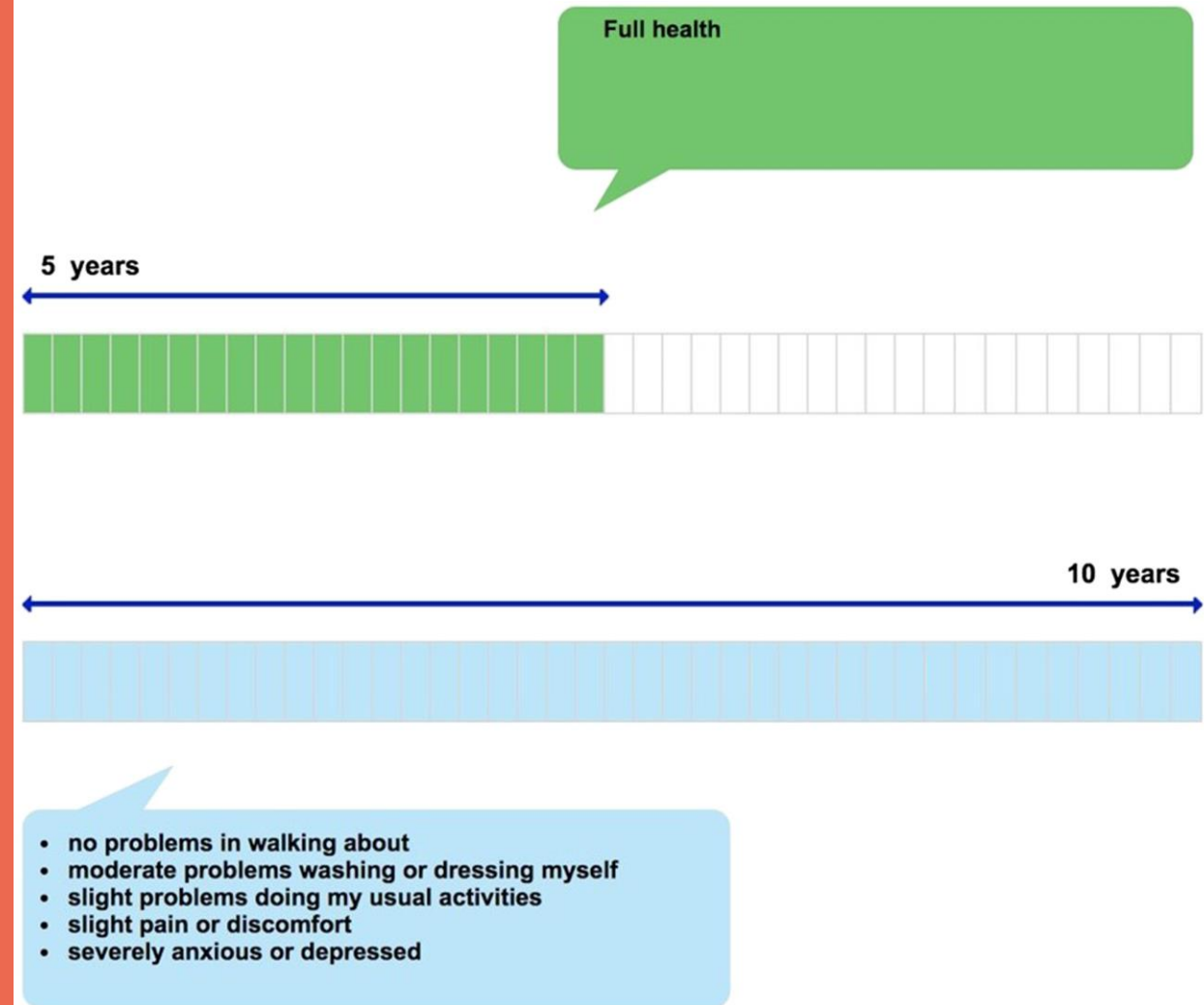
A useful shorthand for 'no health'?



Dead in TTO

*“Which would you prefer, 5 years in full health in Life A followed by **death**, or 10 years in the blue health state followed by **death**?”*

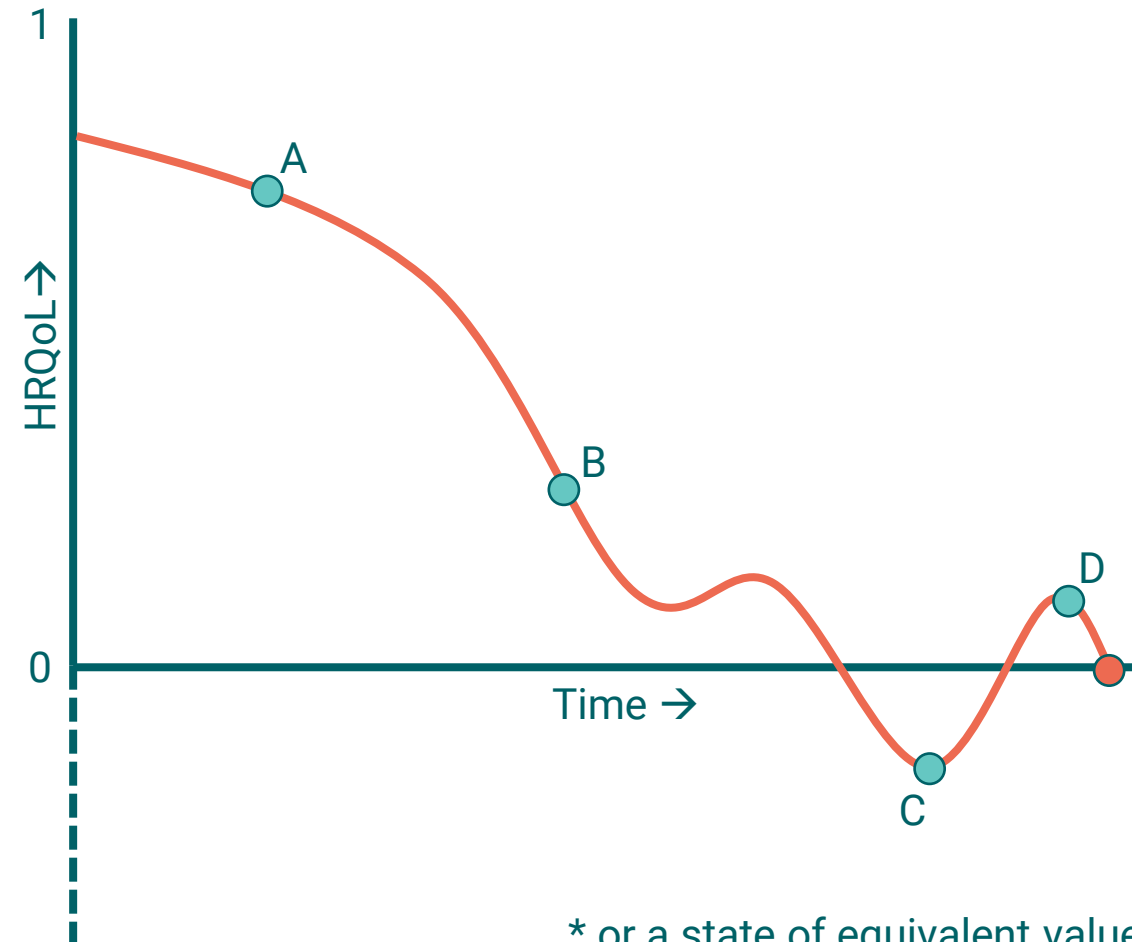
*“The health state may even be so bad that you would rather be **dead** at once than have to spend 10 years living with those health problems...”*



The problem with 'dead'

- Dead vs death vs dying
 - What does it mean to value 'dead'? ([Devlin et al, 2004](#))

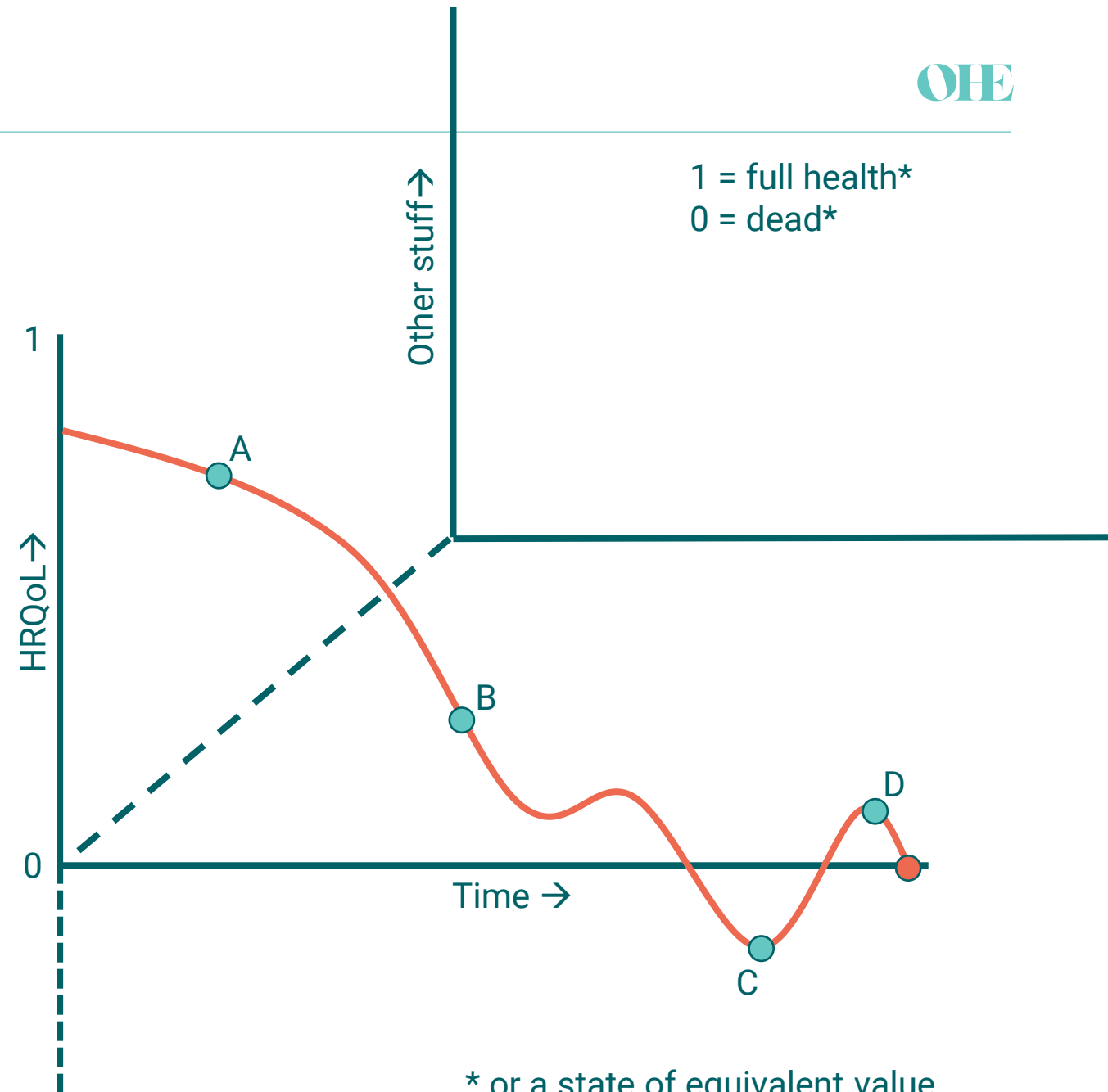
1 = full health*
0 = dead*



* or a state of equivalent value

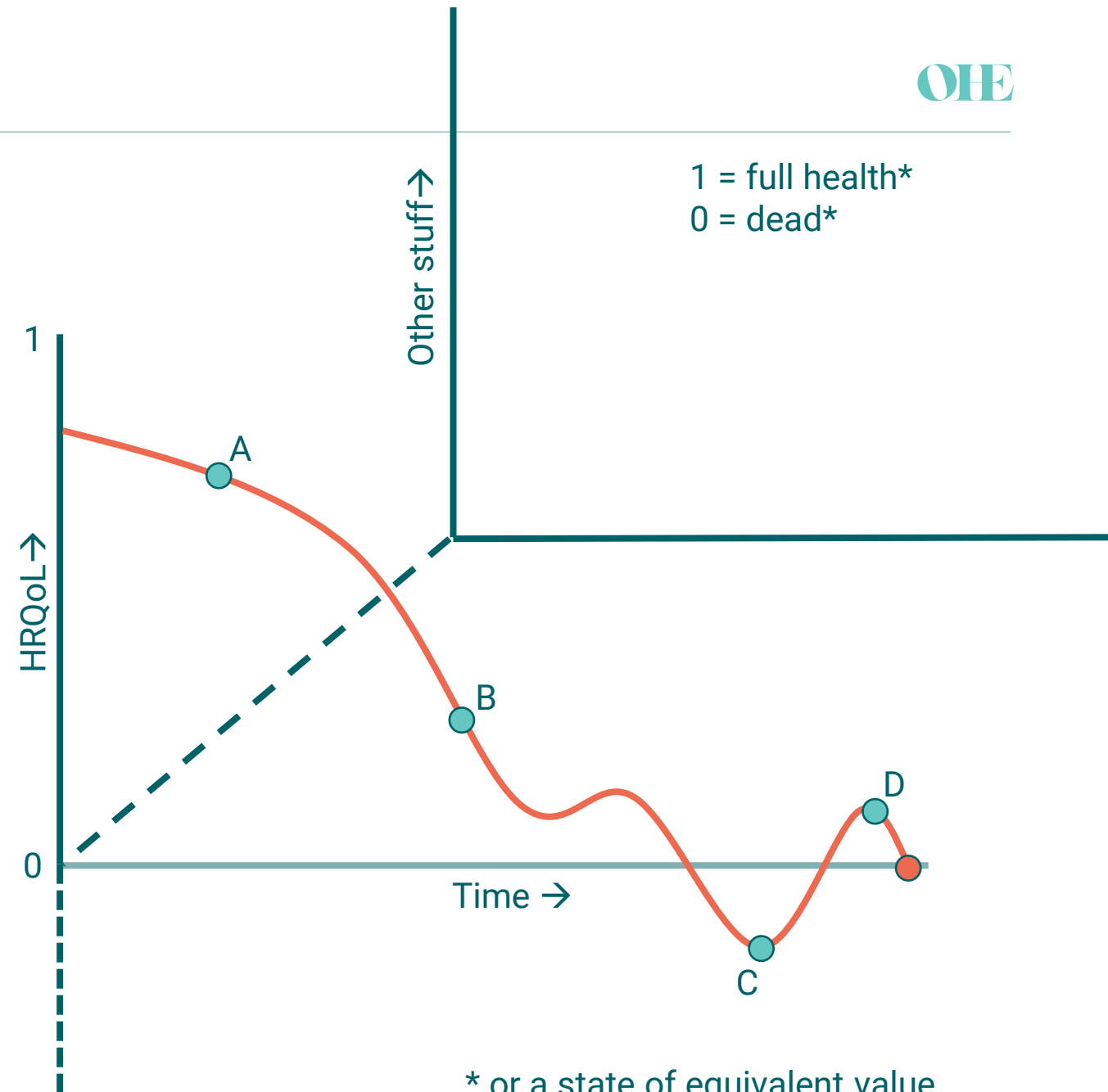
The problem with 'dead'

- Dead vs death vs dying
 - What does it mean to value 'dead'? ([Devlin et al, 2004](#))
- Invokes considerations beyond health
 - Time preference, probability of survival ([Sharma & Stano, 2010](#))
 - Views on euthanasia ([Augestad et al, 2013](#))



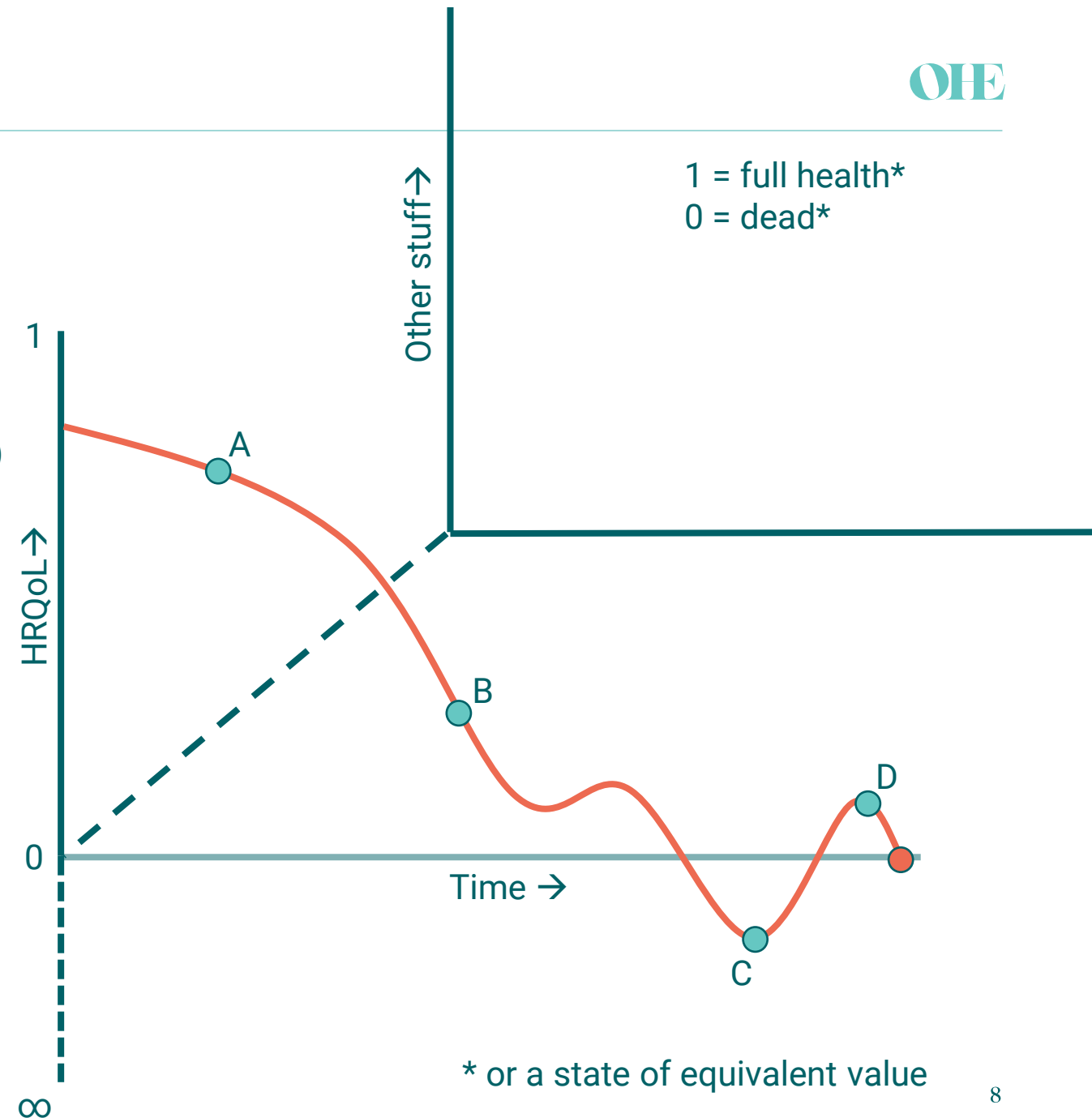
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- Indefinable with respect to time



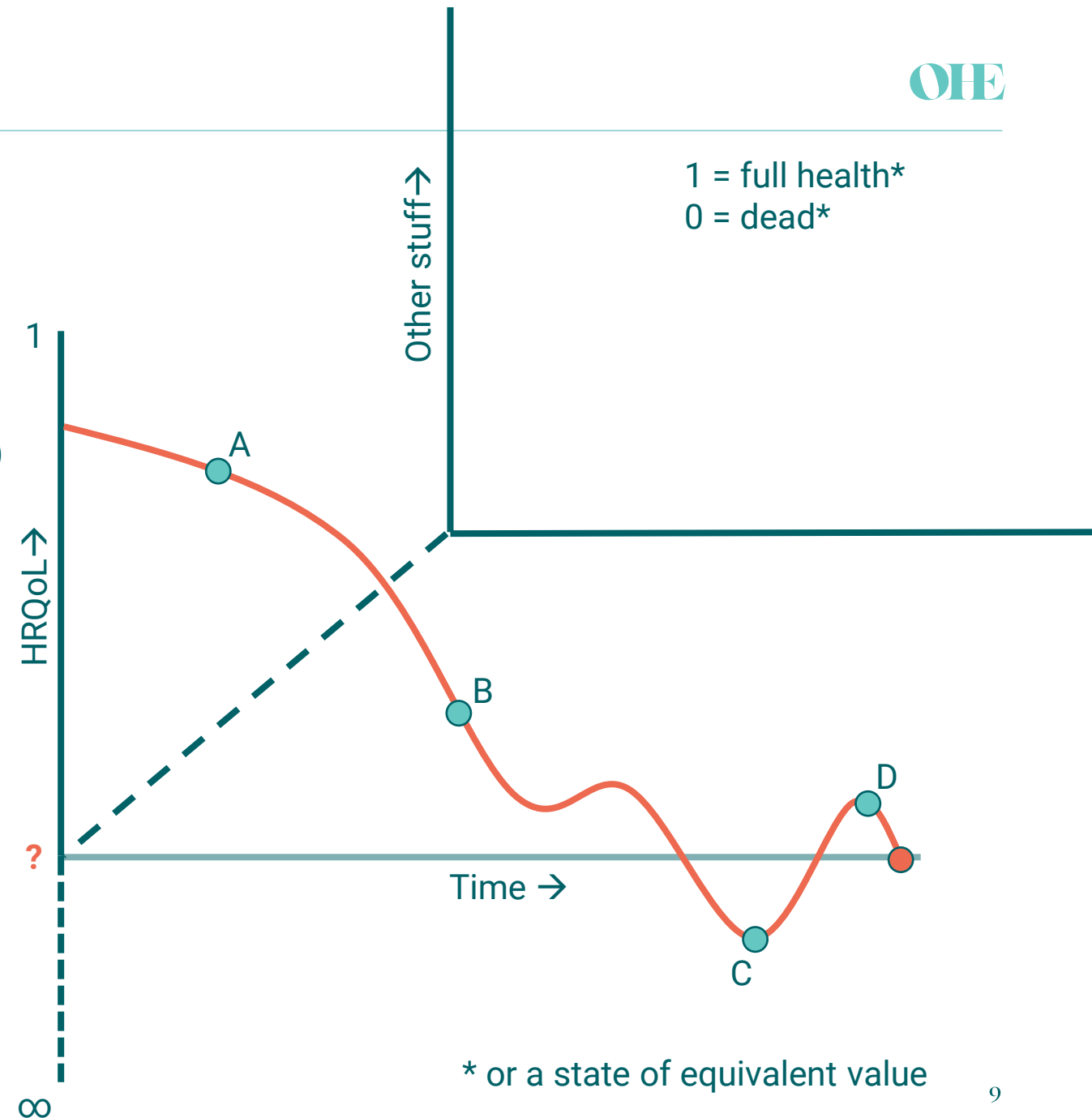
The problem with 'dead'

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- Indefinable with respect to time
- The negative scale is limitless



The problem with 'dead'

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- Invokes considerations beyond health
 - Time preference, probability of survival ([Sharma & Stano, 2010](#))
 - Views on euthanasia ([Augestad et al, 2013](#))
- Indefinable with respect to time
- The negative scale is limitless
- Health state "of equivalent value to being dead" is hard to conceive
 - EQ-5D-5L state 55511?



Do we really need 'dead'?

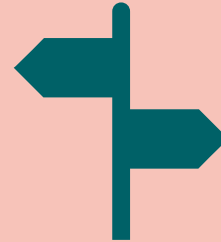
Scale measurement

'Dead' is not necessary to construct a meaningful scale of health state values



Utility

'Dead' is not required to elicit preferences / utilities



BTD vs WTD

We do not need to know whether a state is better or worse than 'dead'



CEA

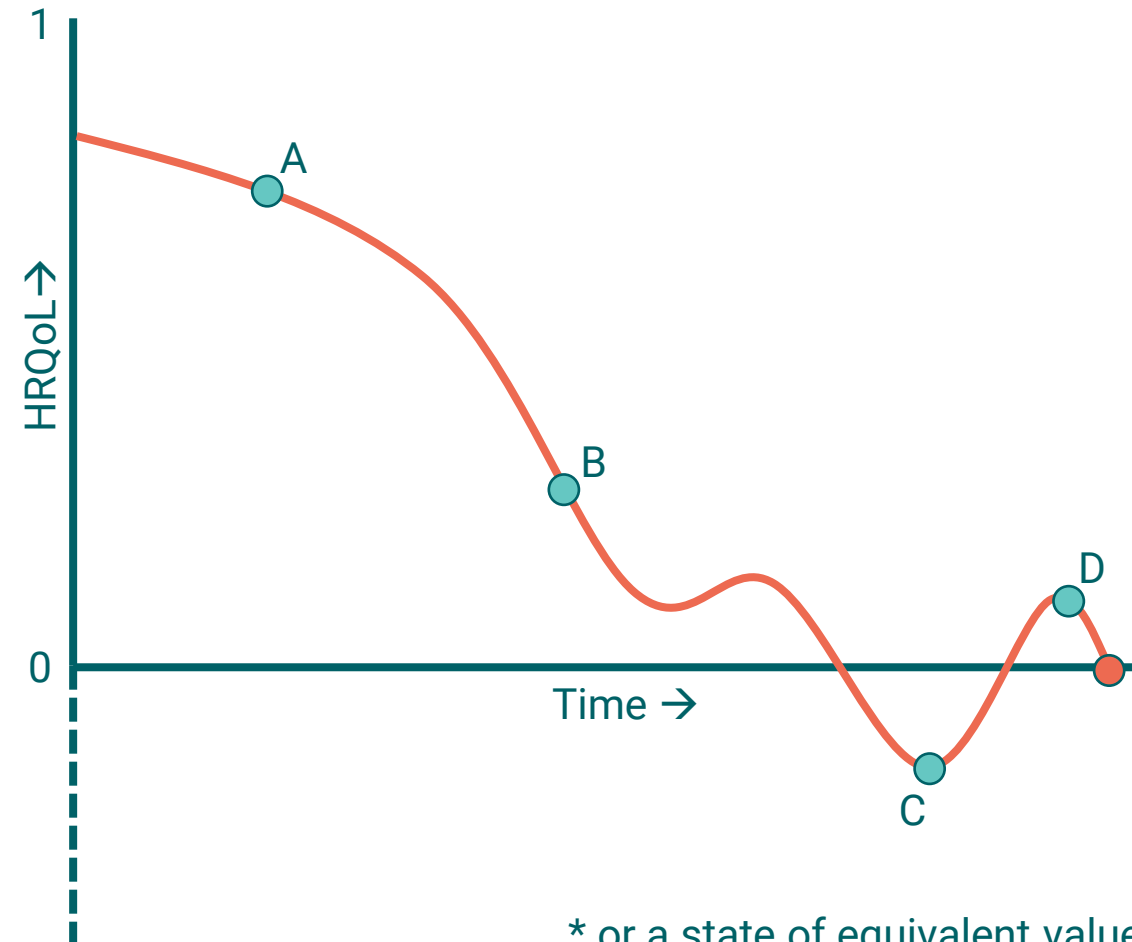
The 'dead' state necessarily generates no value in time, regardless of its role in health state valuation



Why we don't need 'dead'

- Zero can be anything

1 = full health*
0 = a very bad state

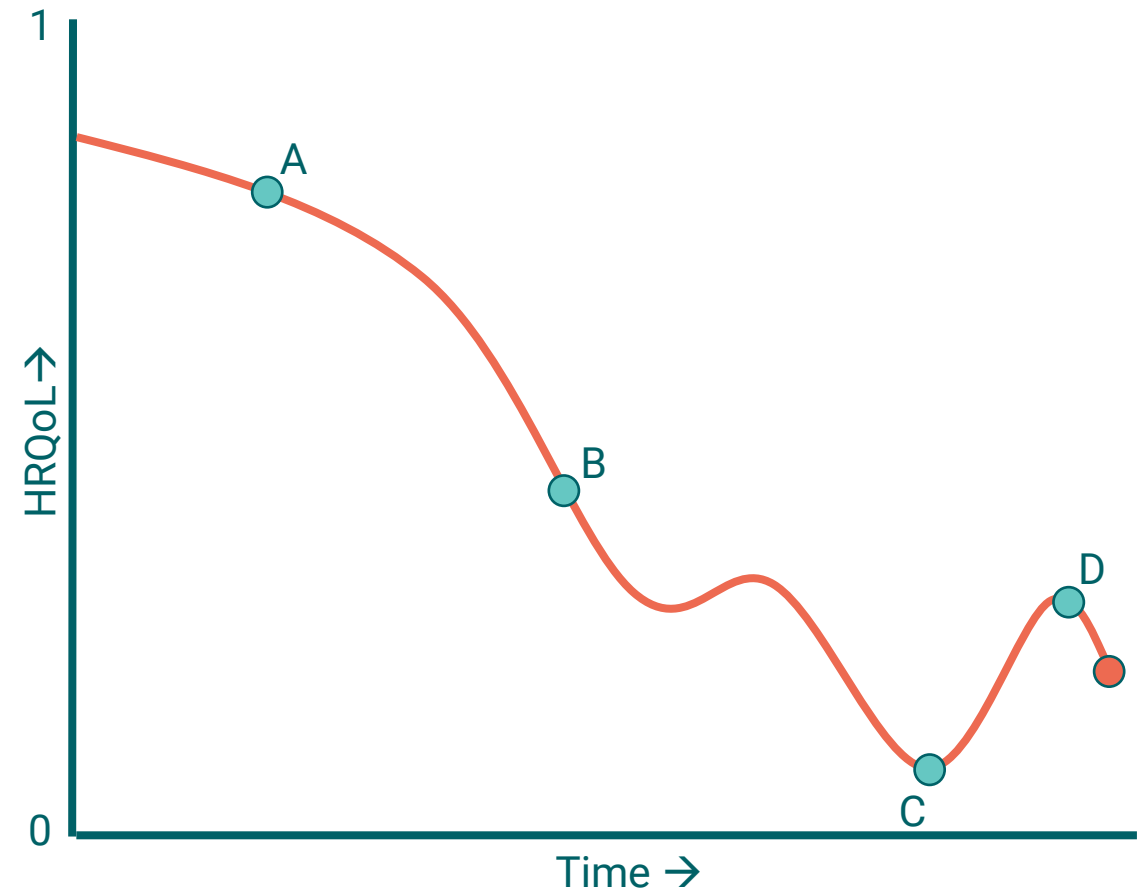


* or a state of equivalent value

Why we don't need 'dead'

- Zero can be anything
- Ratio scale > interval scale
 - Requires an absolute zero

1 = full health*
0 = a very bad state

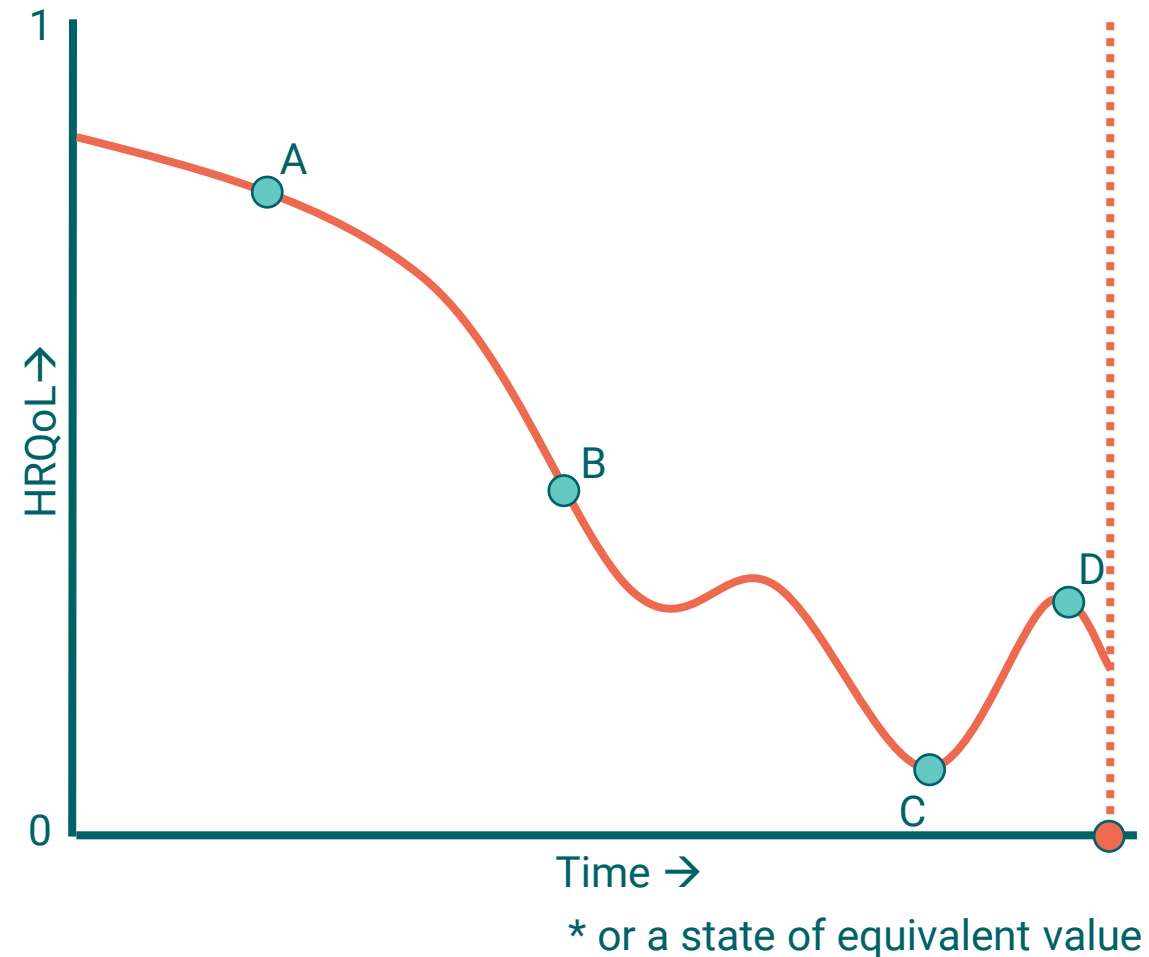


* or a state of equivalent value

Why we don't need 'dead'

- Zero can be anything
- Ratio scale > interval scale
 - Requires an absolute zero
- 'Dead' can still be zero
 - And it must ([Roudijk et al, 2018](#))

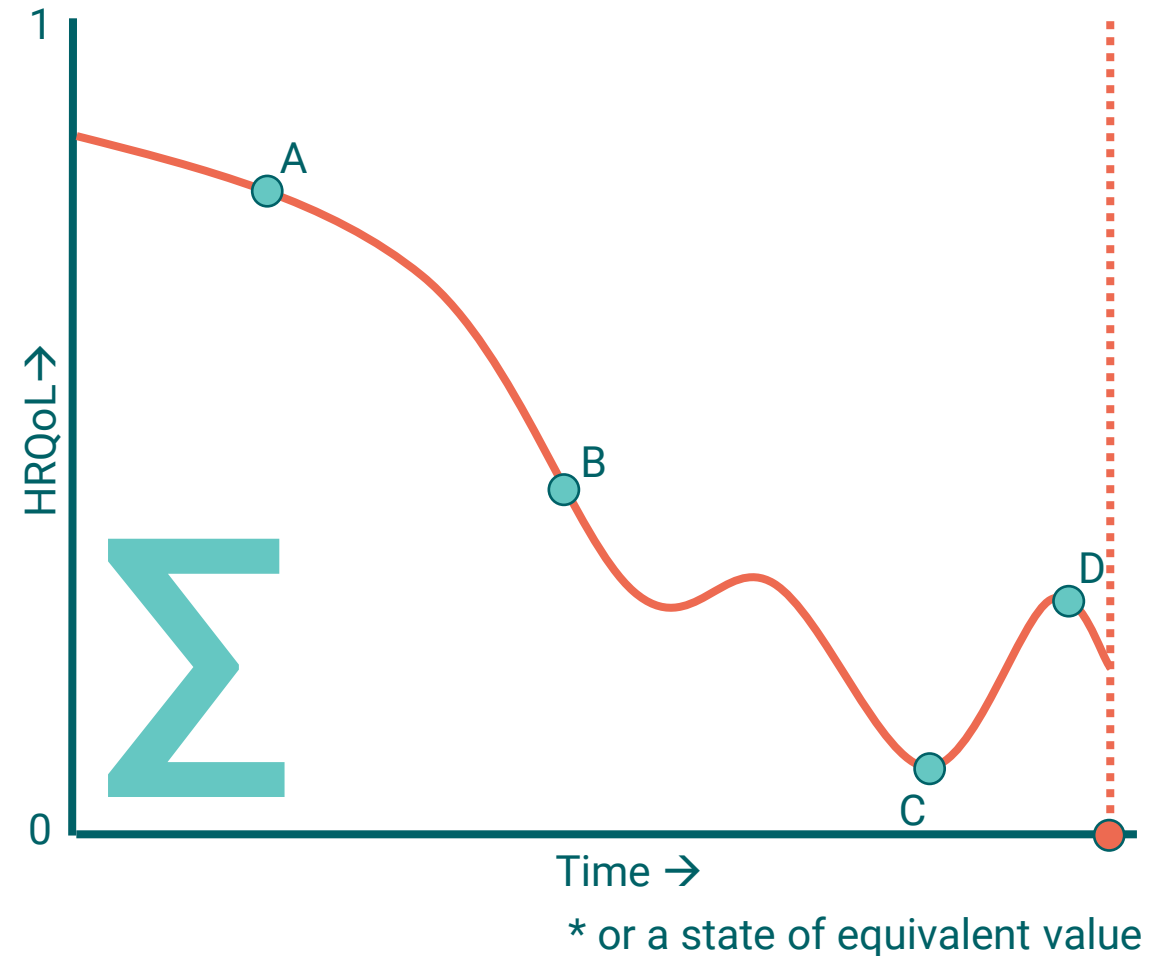
1 = full health*
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(and dead)



Why we don't need 'dead'

- Zero can be anything
- Ratio scale > interval scale
 - Requires an absolute zero
- 'Dead' can still be zero
 - And it must ([Roudijk et al, 2018](#))
- Resource allocation trade-offs are not health vs death
 - They are QALYs vs QALYs

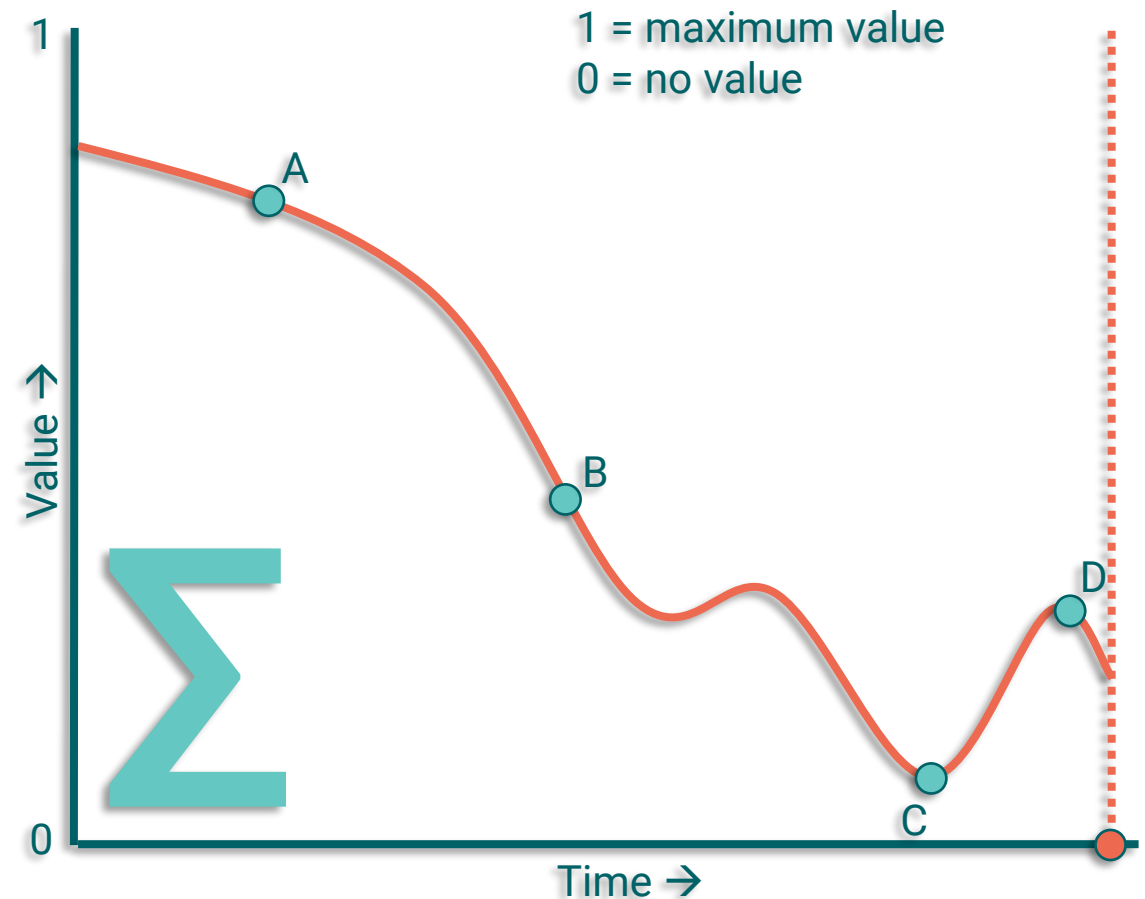
1 = full health*
0 = a very bad state
(and dead)



What we should do instead

- Dropping dead may make a big difference ([Sutherland et al, 1983](#); [Nord, 1991](#))
- Lots more research needed

1. Adopt an alternative anchor as an absolute zero
 - a) Worst health state imaginable
 - b) Worst health state defined by the measure (e.g. EQ-5D)
 - c) A minimum endurable health state
2. Redefine QALYs as a decision-making tool
 - a) Zero is a point where no value is created
 - b) QALYs may be rescaled
3. Keep calm and carry on estimating QALYs



Conclusion

Vote 'drop dead'!

- It isn't clear what we're seeking to achieve by referring to 'dead'
- Doing so seems problematic in theory and in evidence
- We don't need to use 'dead'

#ISPORAnnual
#DropDead
@ChrisSampson87

DROP DEAD

Is Anchoring at
'Dead' a Theoretical
Requirement in
Health State
Valuation?

Chris Sampson
David Parkin
Nancy Devlin

Is anchoring at 'dead' a theoretical requirement? it depends !

Bram Roudijk*

Peep Stalmeier**

***EuroQol Office, Rotterdam**

****Radboud University Medical Centre, Nijmegen**

We declare no conflict of interest.

what are the issues?

health scale anchors

- Dead-----FH
- Worst-----dead-----FH

drop dead altogether

- Worst-----FH

Approach

- 5 reasons to drop dead
- analyse them in turn

Approach

- Zero points
- Distance travelled = duration x speed
- quality adjusted life year (QALY) = duration x weight
- For which HS is value equal to zero

Proposition 1

- anchoring health state values at 'dead' is not required by scale measurement
- interval or cardinal scale assumptions so anchoring on dead is not necessary
-



Proposition 2

- QALYs do not require a distinction between states better or worse than dead
- But QALY's require a distinction between states in which you would rather live longer in, or states for which shorter durations are preferred to longer durations.



Proposition 3



- cost-effectiveness analysis does not require that 'dead' has a value relative to health states;
- what is the zero HS? Ratio scales have absolute zero.
- 'dead' is practical (Decision Analyses), unambiguous (stakeholders, epidemiology)



Proposition 4

I'd rather be dead, than wet my bed (Harry Nilsson)



Proposition 4



- using 'dead' ... causes problems ... studies difficult to conduct and interpretmany arbitrary choices
- ☹ arbitrary choices, freedom of social sciences 😊
- but using other anchors, will life be easier ?

Proposition 5

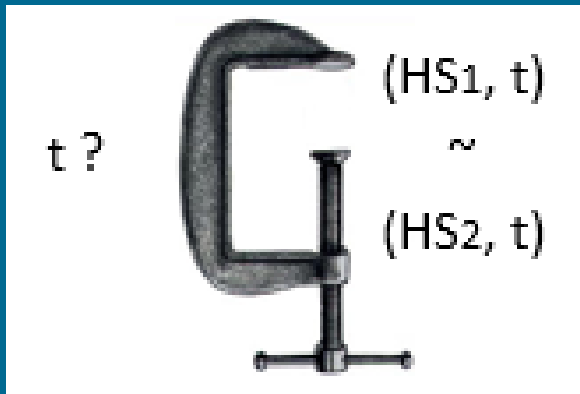
- alternative anchors to dead (sleep, unconscious)
- the anchor should have meaning in duration ??
- Well defined, easily understood?
- value of anchor depends on duration



How about the zero points?

- for QALYs, zero points are needed
- $\text{QALY} = \text{weight (HS)} \times \text{duration}$
- duration intuitively is 0 at zero seconds
- but for which HS is weight zero ?

Zero condition for duration

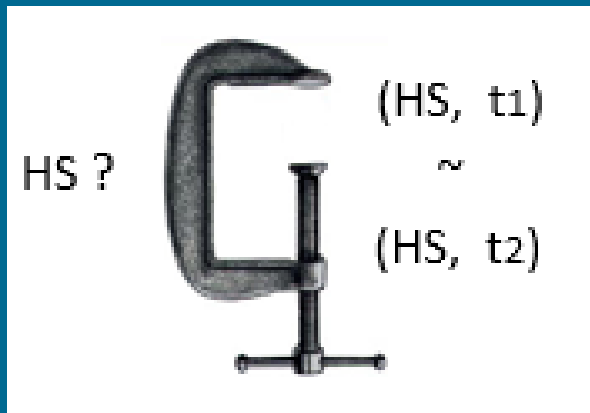


$t ?$ $(HS_1, 0)$
 $\sim$
 $(HS_2, 0)$

All episodes followed by dead

Miyamoto, et al. 1998

Zero condition for health



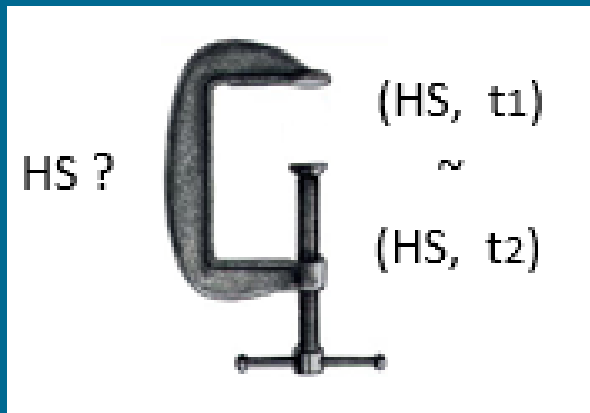
HS ?

(HS, t1)
~
(HS, t2)
t1≠t2

All episodes followed by dead

Roudijk, et al., 2018

Zero condition for health



HS ?

(HS, t1)

~

(HS, t2)

$t1 \neq t2$

a) dead

b) sleep

c) worst imgn

All episodes followed by dead

d) unconscious

Discussion

- if dead is a zero point, dead is not just something theoretical
- if dead is a zero-point, the propositions need to be reconsidered



The End