UNIVERSITY OF BIRMINGHAM

Beyond the QALY – in what direction?

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Symposium – Outcomes beyond the QALY, Erasmus University Rotterdam, March 2012

Outline

- What do we mean by the QALY?
- Why go beyond the QALY?
- In what direction?
- Capability wellbeing and ICECAP
- Discussion: some thoughts for the afternoon

What do we mean by the QALY?

What is a QALY?

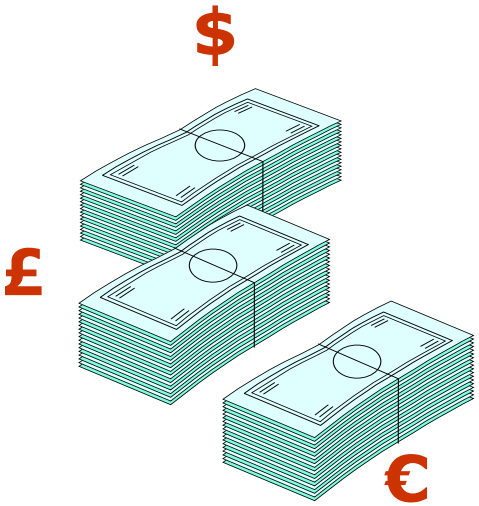
- … rather, what type of QALY am I going to focus on?
- Assume
  - Basic understanding that QALY is a measure of life years adjusted for quality during those years
  - Used in economic evaluation with aim of achieving efficiency

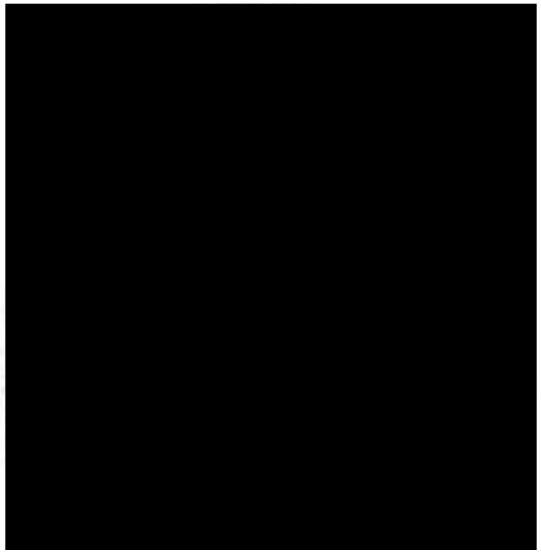
What type of QALY?

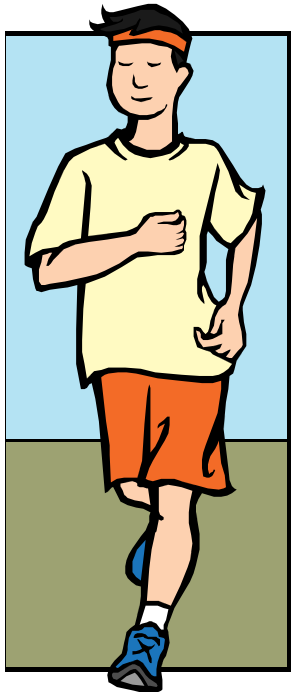
- Health focused
  - i.e. using health status (or health-related quality of life (HRQoL) to adjust life years
- Patient focused
  - i.e. health status for patient
- Extra-welfarist
  - i.e. valued using population preferences rather than direct patient preferences

Why go beyond the QALY?


$
£
€
Benefit

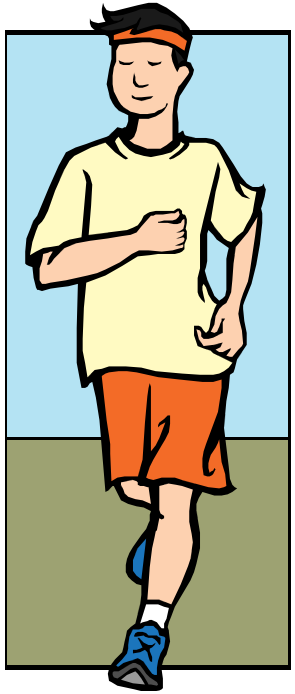






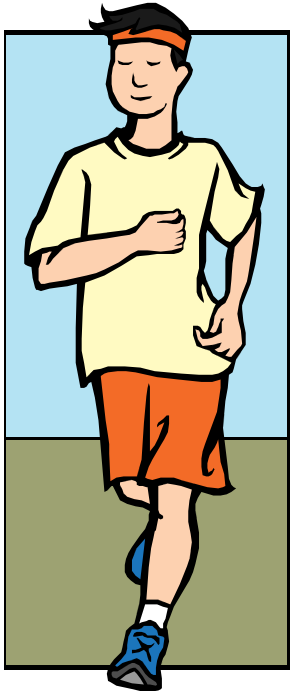
QALYs

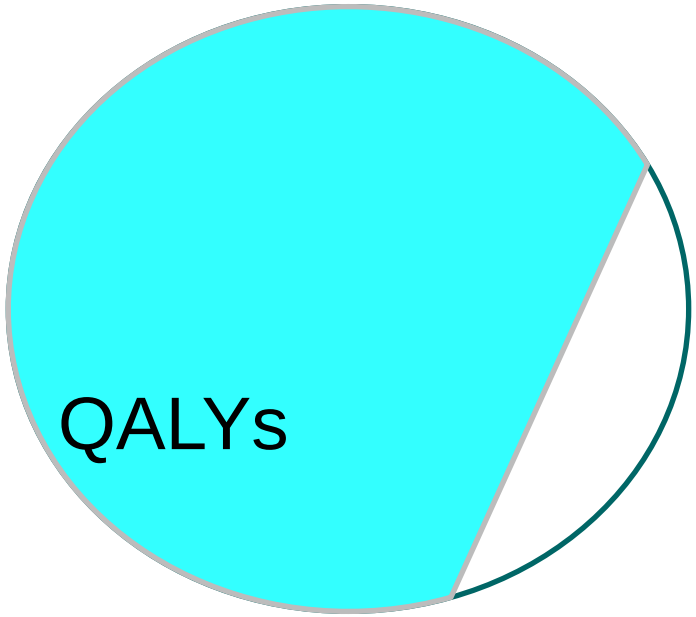
Health

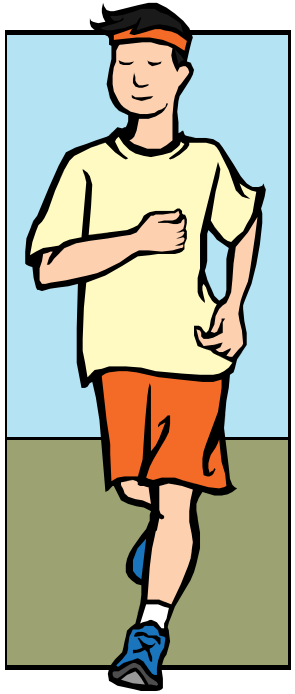


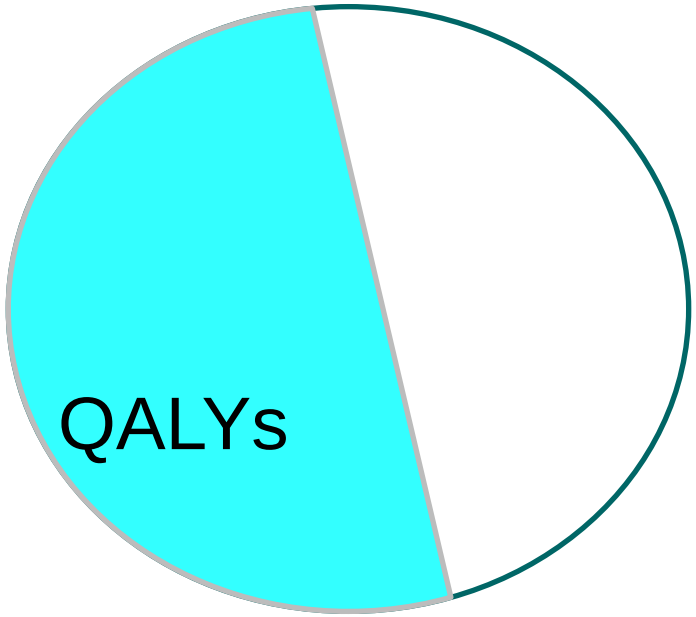
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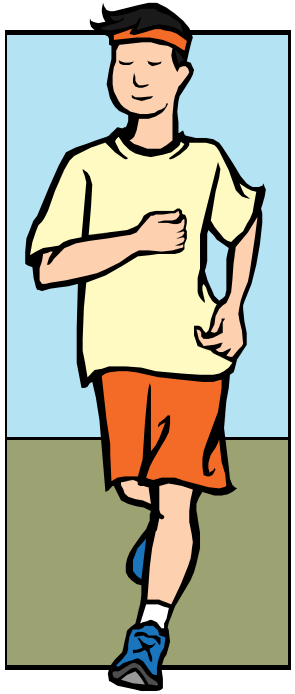
QALYs

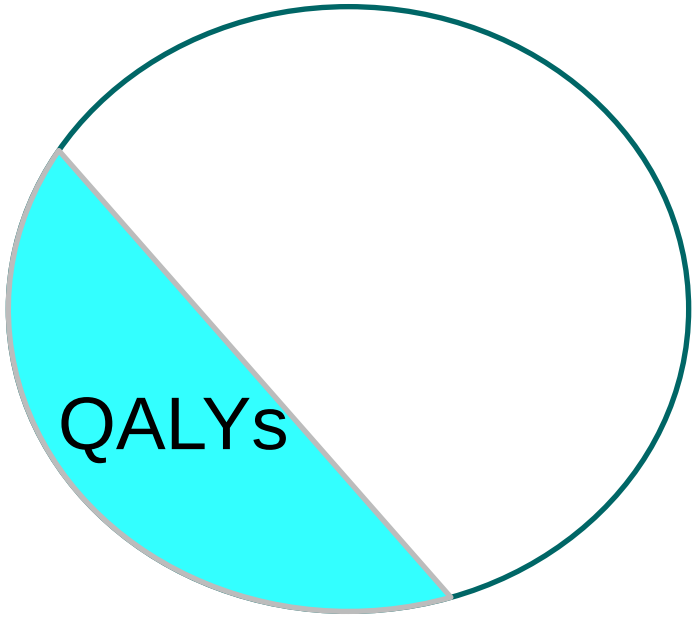


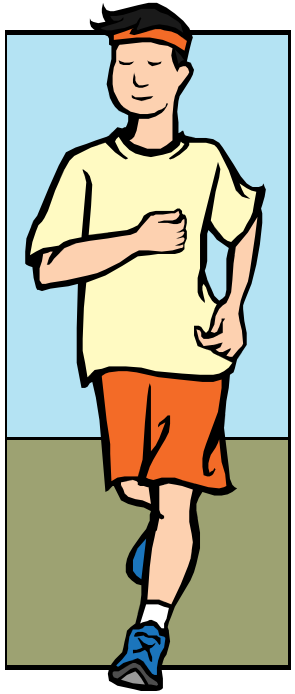

QALYs



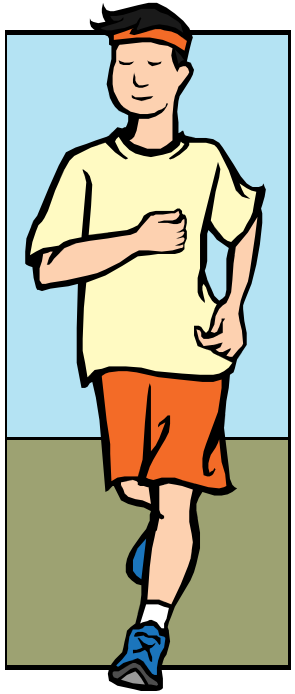

QALYs



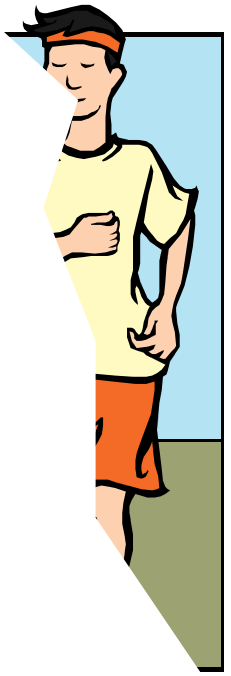

QALYs



Health

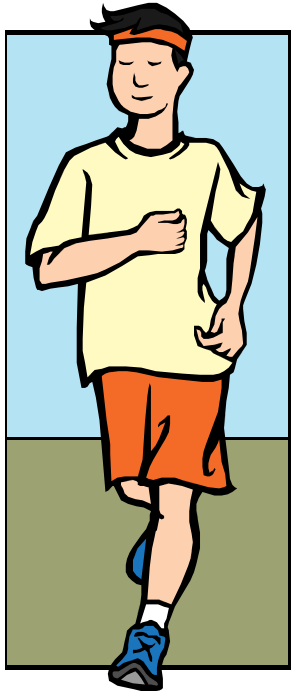


Health

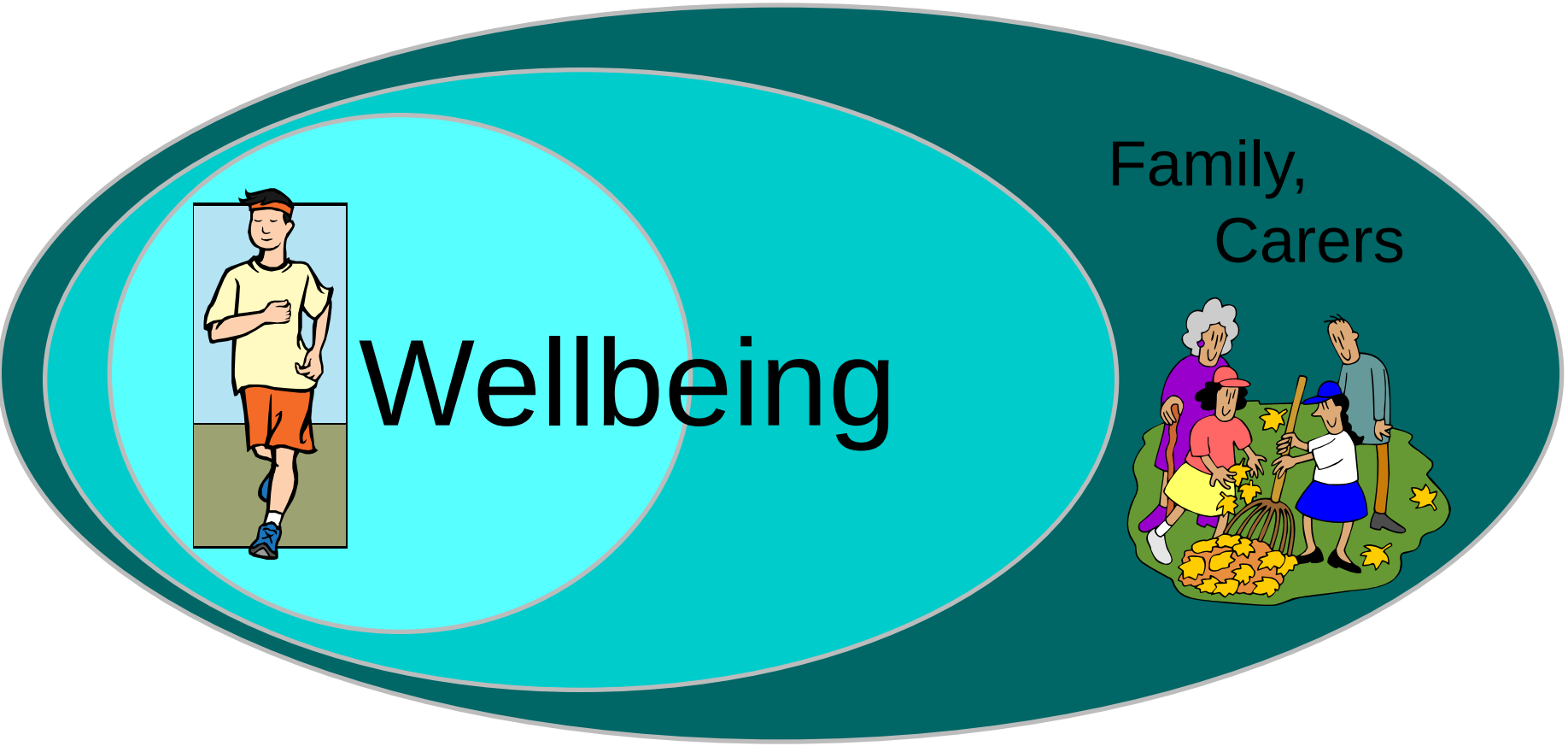


Beyond health



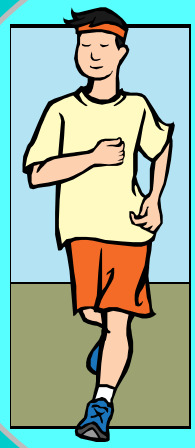


Beyond the patient



Society

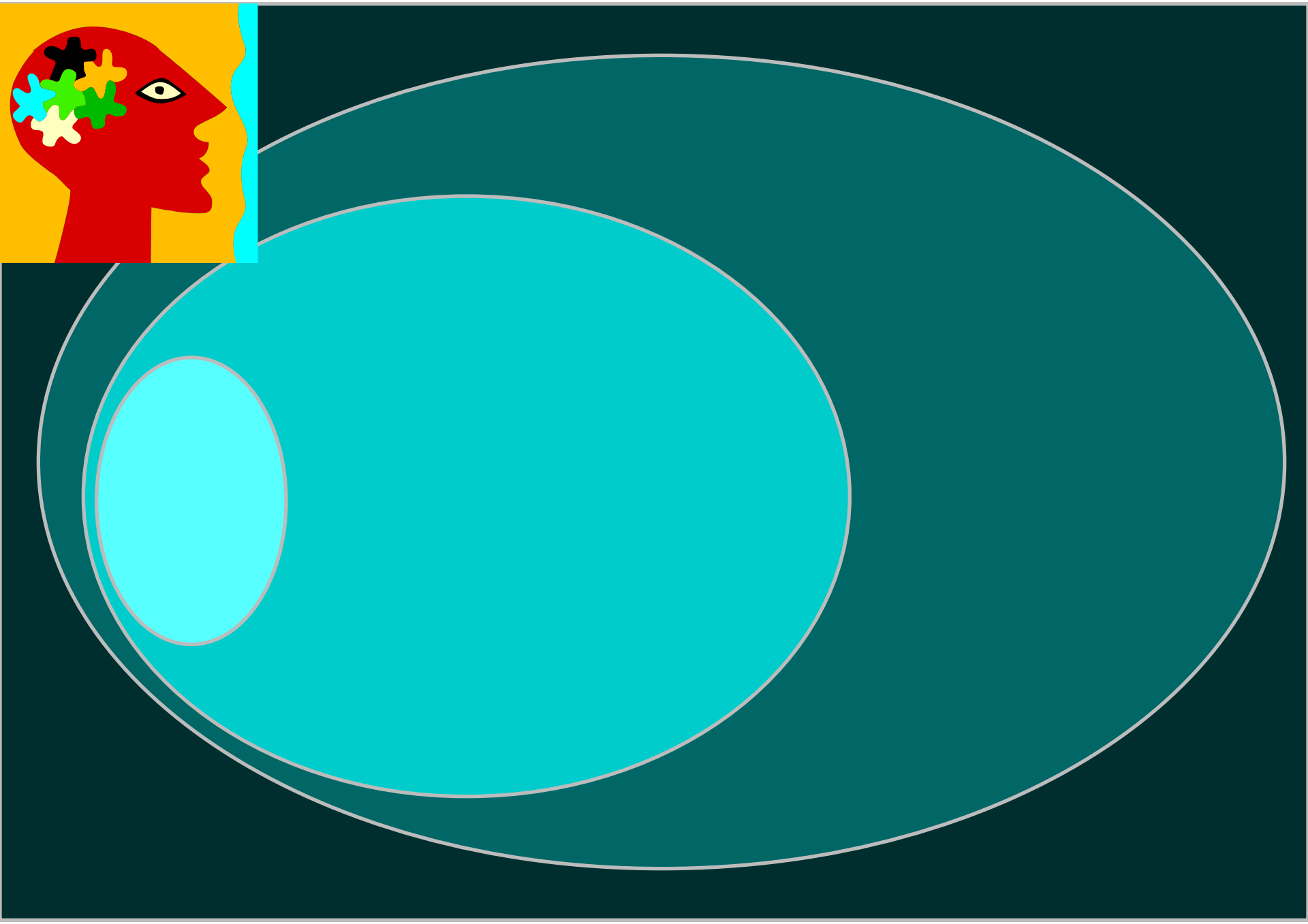
Family,
Carers



Wellbeing

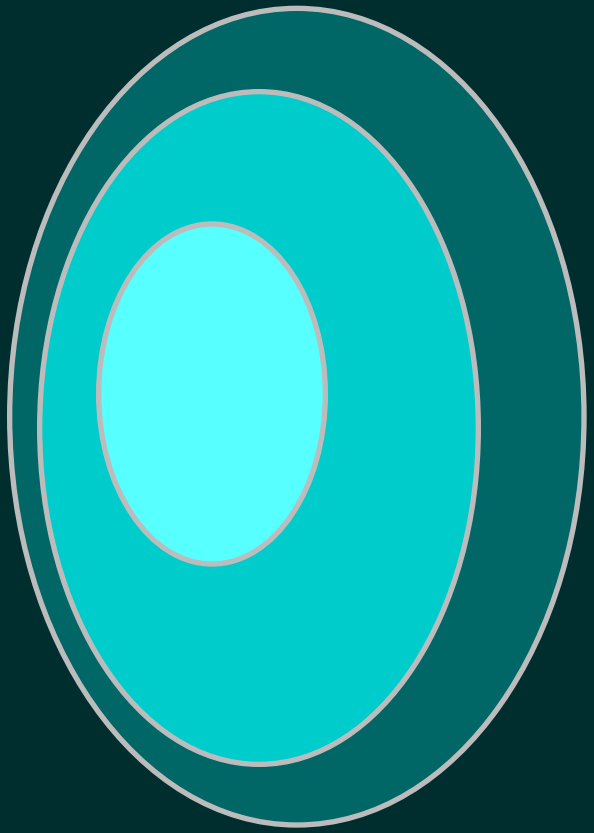








Society



In what direction?

i.e. what evaluative space is important?

Beyond the QALY?

- Beyond the (current) QALY?
  - Better measures of health?

Beyond the QALY?

- Beyond health?
  - Wellbeing?
    - Subjective wellbeing/utility/happiness
    - Capability wellbeing
  - Health plus additional sectoral measures?
    - e.g crime
    - e.g. education

Beyond the QALY?

- Beyond the patient?
  - Who?
    - Carers?
    - Families?
    - Society?
  - How?
    - Wellbeing?
    - Sectoral measures?
      - e.g. carer specific measures

Basis for going beyond the QALY

- Capturing everything?

Basis for going beyond the QALY

- Capturing what is important?
  - Capturing what is philosophically/theoretically important?
    - Utility/happiness/SWB – Mill, Bentham, economists…
    - Capability – Sen, Nussbaum, human development…
  - Capturing what decision makers want?
    - Health – economists perception?
  - Capturing what is important to people?
    - Do we know…?

Basis for going beyond the QALY

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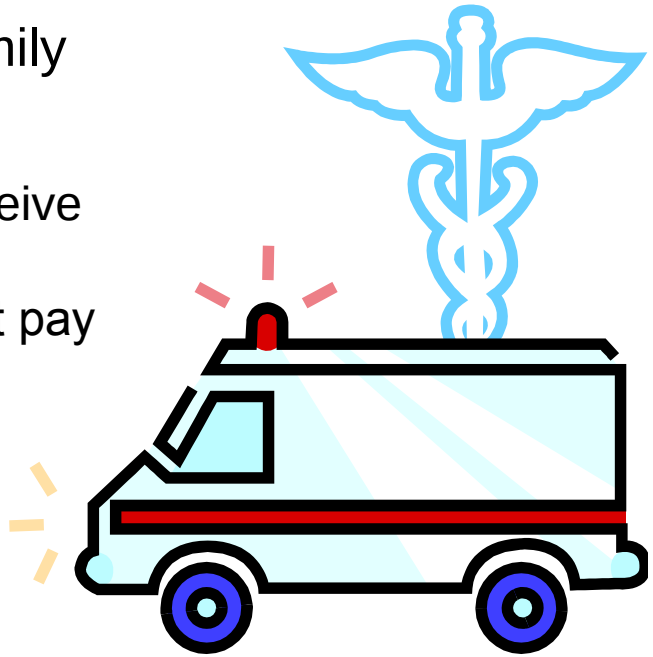
Capability

What is the capability approach?

- Developed in the work of Amartya Sen
- What is important is not utility (happiness), but functionings & capability
  - Functionings – what an individual does or is e.g. well-nourished, healthy, socially respected,
  - Capability – what an individual is ABLE to do or be, whether or not they then choose to do or be that
- People will adapt to poor circumstances – therefore assessing their happiness with a situation does not take account of how they have adapted to that situation

Why capability rather than functioning?

- Low-income family in US
  - Unable to receive health care because can't pay for it



- Jehovah's witness family in the UK
  - Choose not to receive health care for religious reasons
  - But healthcare is freely available

Functioning indicates similar levels of achievement of well-being; capability shows the difference

Nature of capability approach

- The capability approach is deliberately broad, advocating the use of multiple aspects of capability
  - E.g. Nussbaum's list of 10 'central human capabilities'
  - life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; and control over one's environment.

Capability approach

- ‘a broad normative framework for the evaluation and assessment of individual well-being and social arrangements, the design of policies, and proposals about societal change’ (Robeyns, 2006) (p. 352)
- ‘It differs from the standard utility-based approaches in not insisting that we must value only happiness (and sees, instead, the state of being happy as one among several objects of value).’ (Sen, 1993) (p. 48).

Empirical evidence of importance of capability?

- Grewal et al. (2006) found that older people in the UK appeared to be concerned about their (lack of) ability to meet particular functionings
  - qualitative work using in-depth interviewing to talk to informants about what was important to them in their daily lives
  - no distinction in the questioning between functioning and capability
- Ability to function a major theme emerging from the findings
  - E.g. inability to achieve enjoyment because of poor health
  - E.g. inability to feel secure because of worries about their partner's health
- Loss of capability clearly important to informants because it stopped them achieving important functions in their lives

ICECAP

ICECAP measures

- Measures of capability wellbeing
- Draw on capability approach as outlined by Sen/Nussbaum
  - But not perfect representations of it
- Also draw on many lessons learned through the QALY approach
  - But differ in important respects

Key characteristics

- Descriptive systems based on extensive in-depth interviews
  - Regarding relevant attributes
  - Regarding meaningful language
- Valuation based on aggregated population values obtained using Best-Worst Scaling
- Values anchored at ‘full capability’ (1) and ‘no capability’ (0)

Current measures

- ICECAP-O
  - For older people
- ICECAP-A
  - For the whole adult population
  - Has potential to be used for patients and others
- ICECAP-SCM
  - For people at the end of life

ICECAP-O

5 questions, each with 4 response categories.

1024 possible ‘capability wellbeing’ states.



ABOUT YOUR QUALITY OF LIFE

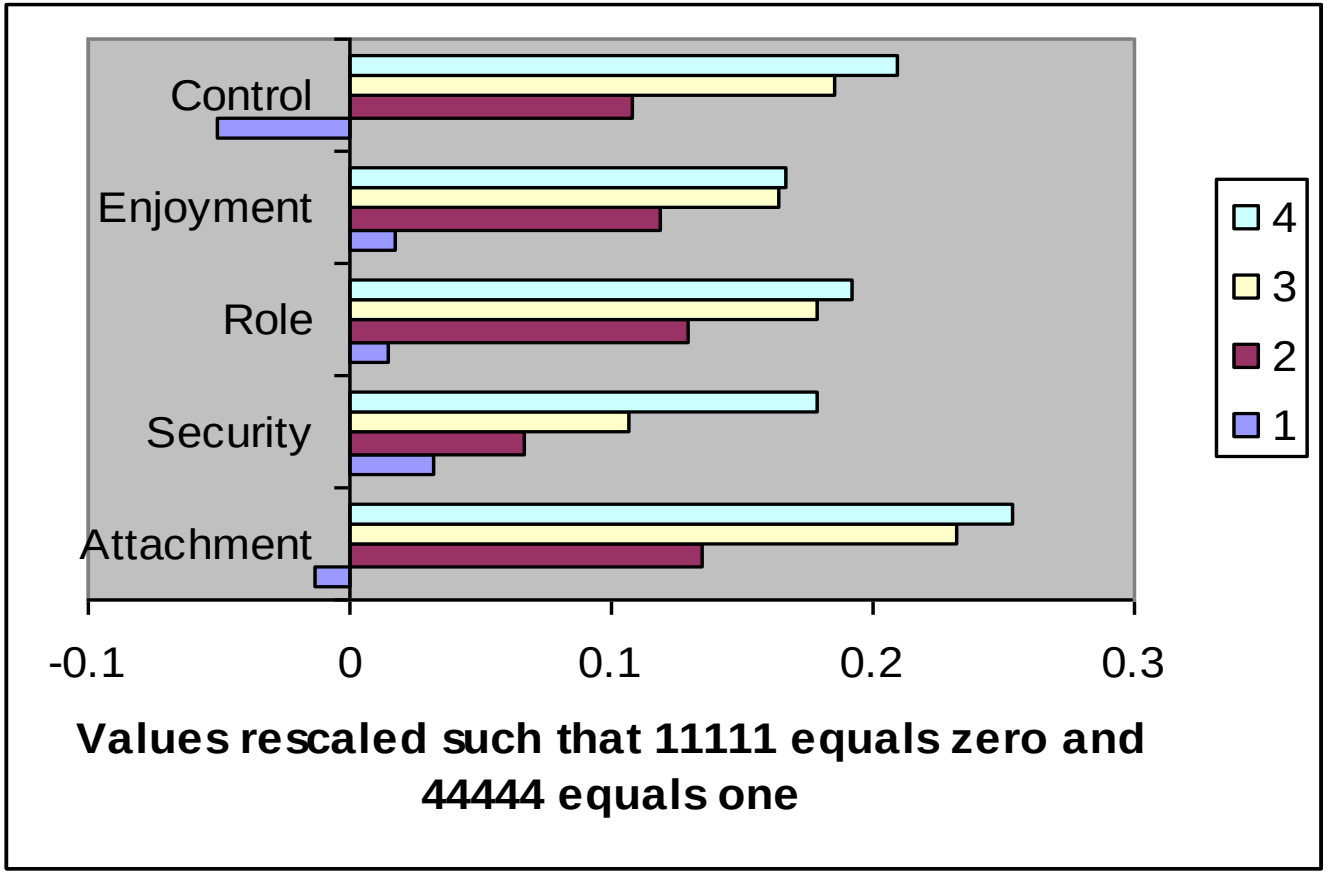
By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship		
I can have **all** of the love and friendship that I want		4
I can have **a lot** of the love and friendship that I want		3
I can have **a little** of the love and friendship that I want		2
I cannot have **any** of the love and friendship that I want		1
2. Thinking about the future		
I can think about the future **without any** concern		4
I can think about the future **with only a little** concern		3
I can only think about the future **with some** concern		2
I can only think about the future **with a lot** of concern		1
3. Doing things that make you feel valued		
I am able to do **all** of the things that make me feel valued		4
I am able to do **many** of the things that make me feel valued		3
I am able to do **a few** of the things that make me feel valued		2
I am unable to do **any** of the things that make me feel valued		1
4. Enjoyment and pleasure		
I can have **all** of the enjoyment and pleasure that I want		4
I can have **a lot** of the enjoyment and pleasure that I want		3
I can have **a little** of the enjoyment and pleasure that I want		2
I cannot have **any** of the enjoyment and pleasure that I want		1
5. Independence		
I am able to be **completely** independent		4
I am able to be independent in **many things**		3
I am able to be independent in **a few things**		2
I am **unable** to be at all independent		1

Tick one box only in each section

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ICECAP-O index values



- No capability on all attributes: value 0
- A little capability on all attributes: value 0.556
- A lot of capability on all attributes: value 0.868
- Full capability on all attributes: value 1

ICECAP-A

Similar format.

Aims to tap into the domains of importance to general adult population.



ABOUT YOUR OVERALL QUALITY OF LIFE

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in **ONE** box for each of the five groups below.

1. Feeling settled and secure

I am able to feel settled and secure in **all** areas of my life	4
I am able to feel settled and secure in **many** areas of my life	3
I am only able to feel settled and secure in **a few** areas of my life	2
I am **unable** to feel settled and secure in **any** areas of my life	1

2. Love, friendship and support

I can have **a lot** of love, friendship and support	4
I can have **quite a lot** of love, friendship and support	3
I can only have **a little** love, friendship and support	2
I **cannot** have **any** love, friendship and support	1

3. Being independent

I am able to be **completely** independent	4
I am able to be independent in **many** things	3
I am only able to be independent in **a few** things	2
I am **unable** to be at all independent	1

4. Achievement and progress

I can achieve and progress in **all** aspects of my life	4
I can achieve and progress in **many** aspects of my life	3
I can only achieve and progress in **a few** aspects of my life	2
I **cannot** achieve and progress in **any** aspects of my life	1

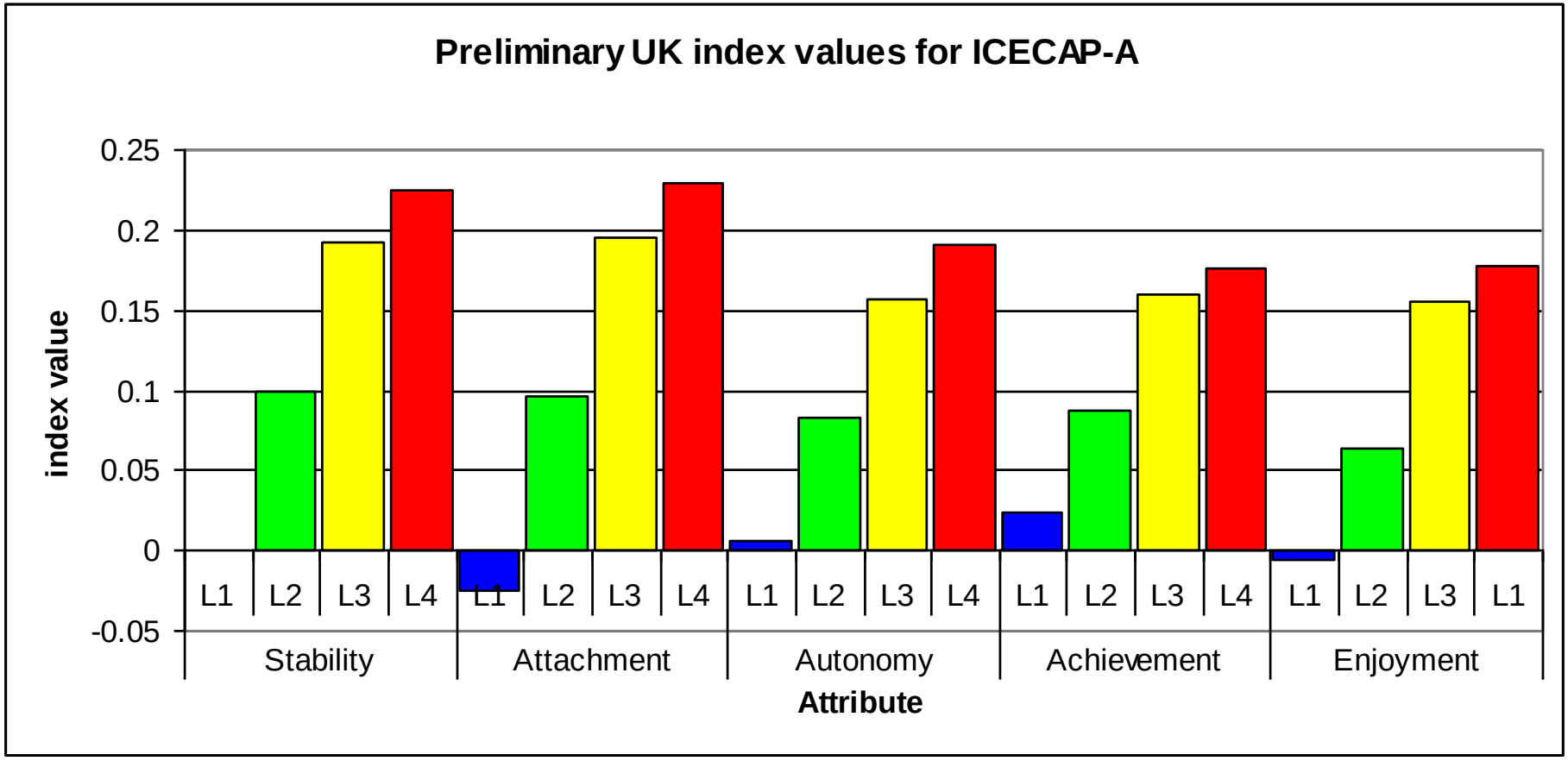
5. Enjoyment and pleasure

I can have **a lot** of enjoyment and pleasure	4
I can have **quite a lot** of enjoyment and pleasure	3
I can only have **a little** enjoyment and pleasure	2
I **cannot** have **any** enjoyment and pleasure	1

Please ensure you have only ticked **ONE** box for each of the five groups.

Preliminary values

- No capability on all attributes: value 0
- A little capability on all attributes: value 0.43
- A lot of capability on all attributes: value 0.86
- Full capability on all attributes: value 1



ICECAP-SCM



- **1) Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
- **2) Being with people who care about you** (Being with family, friends or caring professionals
- **3) Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
- **4) Emotional suffering** (Experiencing worry or distress, feeling like a burden)
- **5) Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
- **6) Being supported** (Having help and support)
- **7) Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)

Using the measures

- ICECAP-O and ICECAP-A are downloadable from our website: www.birmingham.ac.uk/icecap
- They can be self-completed by the patient themselves (although a proxy may be used in some cases).
- The profile score, e.g. 44333, is linked to a 0-1 index value, where 0 is no capability and 1 is full capability.

Included in more than 50 studies



Using ICECAP: A Capability approach to Resource Allocation

- Efficiency assessment?
  - Essentially the same approach as we currently pursue in economic evaluation
  - Maximising gain in capability across the whole population
- Distributive assessment?
  - Drawing on alternative approaches - associated with multidimensional poverty
  - But also drawing on longitudinal concept of QALYs

CapRA: efficiency assessment

- Maximisation of capability gained
- Years of full capability (equivalent)
  - Sum of capability over time
- Cost per (equivalent) year of full capability gained

CapRA: distributive assessment

- Important to increase the capability well-being of those in poverty (below minimum level)
- Concern with absolute shortfalls in capability
  - Interpretation of need as absolute deprivation in what able to do or be in life
- Use of multi-dimensional poverty measures associated with Alkire & Foster
- Doctoral work – Paul Mitchell

Multi-dimensional poverty

- Identification of those in poverty – "dual cutoff"
  - Identifying a poverty level for each dimension
  - Identifying the number of dimensions in which a person must be in poverty
- Aggregation
  - Censoring of those who don't meet criteria for poverty
  - Methods of varying complexity to account for depth & breadth of poverty

Extension of MDP to sufficient capability

- Utilisation of measured capabilities (ICECAP) rather than factors such as education, income
- Drawing of 'poverty' thresholds (e.g. 33333 – 'a lot' of capability) of sufficient capability
- 'Censoring' of individuals above threshold (i.e. given value of 1)
- Recalibration of values below threshold to give Sufficient Capability Score

Extension of MDP to sufficient capability (2)

- Introduction of longitudinal element by multiplying SCS by time to give (equivalent) Years of Sufficient Capability (YSC)
- Compare interventions in terms of gain in YSC?
- Compare interventions in terms of cost/YSC gained?

Discussion: thoughts for the afternoon

- Increasing consensus that the QALY does not capture all the benefits of health care
  - Increasing dissatisfaction?
  - Especially in some clinical / social care areas
- Less consensus about what it IS important to capture
  - Illustrated by the variety of perspectives represented by today's presenters

- Choice of evaluative space is a value judgement
  - Competing options that need to be justified
- Tools within non-health evaluative spaces are less worked up
  - Fewer options
  - Less information about validity etc.
  - Less clarity about use

- Plurality of research avenues within normative health economics is “a good thing”
- Vested interests in the status quo
  - Going beyond health…
  - … can be a brave choice!
- Looking forward to an interesting afternoon and hearing about some of these brave choices

Acknowledgements

- Terry Flynn
- Hareth Al-Janabi
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- ICEPOP Advisory Group
- ICECAP-A Advisory Group
- EconEndLife Advisory Group


www.birmingham.ac.uk/icecap