Diversity in values across the life-course

Joanna Coast
Outline

• Background
  • Current approaches in health economics
  • A life-course approach?

• Exploration of whether ‘what people have reason to value’ differs across the life-course
  • Examining existing capability measures
  • Issues in exploiting a life-course approach in capability measurement

• Final thoughts
Background (1): Current approaches in health economics
Current approaches in health economics

Health evaluative space

(Quality-Adjusted Life-Years based on health-related QoL)

Birth       Death
Current approaches in health economics

- Mobility
- Self care
- Usual activities
- Pain/discomfort
- Anxiety/depression

Birth → Death
Examples of EQ-5D questions

• **Usual activities**
  - I have no problems with performing my usual activities (eg. work, study, housework, family or leisure activities)
  - I have some problems with performing my usual activities
  - I am unable to perform my usual activities

• **Anxiety/depression**
  - I am not anxious or depressed
  - I am moderately anxious or depressed
  - I am extremely anxious or depressed
Changes to EQ-5D-Y

• **Usual activities**
  - I have no problems with performing my usual activities (eg. work, study, housework, family or leisure activities)
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Simplification of terminology
Changes to EQ-5D-Y

**Usual activities**
- I have no problems with performing my usual activities (eg. work, study, housework, family or leisure activities)
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Anxiety/depression**
- I am not worried, sad or unhappy
- I am moderately worried, sad or unhappy
- I am extremely worried, sad or unhappy

Simplification of terminology
Changes to EQ-5D-Y

• Usual activities
  • I have no problems with performing my usual activities (e.g. work, study, housework, family or leisure activities)
  • I have some problems with performing my usual activities
  • I am unable to perform my usual activities

• Anxiety/depression
  • I am not anxious or depressed
  • I am moderately anxious or depressed
  • I am extremely anxious or depressed
Changes to EQ-5D-Y

- **Usual activities**
  - I have no problems with performing my usual activities (e.g. going to school, hobbies, sports, playing, doing things with family and friends)
  - I have some problems with performing my usual activities
  - I am unable to perform my usual activities

- **Anxiety/depression**
  - I am not anxious or depressed
  - I am moderately anxious or depressed
Background (2): A life-course approach?
Notions of the life-course

- Age
- Generation
  - Historical context
  - Social norms
  - Generational links
  - Previous choices
Values & the life-course

• Values affected by contextual factors
  • Historical context
  • Parental influences

• Little evidence on ‘a temporal dimension about values’

*Hitlin & Paliavin, 2004*
Exploration of ‘what people have reason to value’ across the life-course (1):

Examining existing capability measures
ICECAP measures

- Capability evaluative space
  - Capability approach arose from in-depth interviews
  - Draw on capability approach as outlined by Sen/Nussbaum
  - Short measures suitable for valuation, and use in economic evaluation
- Developed in four phases
ICECAP development – all versions

- **Phase 1**: in-depth interviews to generate conceptual attributes for measures, analysed using constant comparative methods
- **Phase 2**: semi-structured interviews to check attributes and develop meaningful wording for measures
- **Phase 3**: valuation using best-worst scaling amongst general population
- **Phase 4**: assessment of feasibility, validity, reliability, sensitivity to change
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Evidence from ICECAP

- Values likely to be related to context
  - Industrialised 21\textsuperscript{st} century
  - Rapidly changing social norms
  - Values from parents, & earlier generations
  - Choices led to current situation

- ICECAP-O (& subsequently) noted lack of basic capability of nourishment

- Also related to age?
ICECAP-A v ICECAP-O

- Three attributes almost identical
  - Attachment, Enjoyment, Autonomy/Control
- Achievement (A) v Role (O)
  - Achievement seen as going beyond role
  - For older people, ability to achieve less important
    - Supported in ‘think aloud’ work
- Stability (A) v Security (O)
  - Greater emphasis on present among adult population
  - Reflecting greater uncertainty among older people?
ICECAP-A/O v ICECAP-SCM

• Greater variation in attributes of ICECAP-SCM compared to ICECAP-A/O

• Attributes relate to general wellbeing but also:
  • Health
  • Support
ICECAP-SCM – wording for measure

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)
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ICECAP-A/O v ICECAP-SCM

- Greater variation in attributes of ICECAP-SCM compared to ICECAP-A/O
- Attributes relate to general wellbeing but also:
  - Health
  - Support
- Reflects differences in focus: a good death, rather than a good life
Evidence on children’s values

- No ICECAP as yet
- Health (Stevens, CHU9D)
  - Being worried, being sad, being in pain, being tired, feeling annoyed, being able to do schoolwork, sleeping, being able to carry out daily routine, being able to join with activities
- Capability (Biggeri et al, FCWCCL)
  - Life & physical health, love and care, mental well-being, bodily integrity & safety, participation/information, education, freedom from exploitation, shelter & environment, leisure activities, respect, religion & identity, time autonomy, mobility
Exploration of ‘what people have reason to value’ across the life-course (2):

Issues in exploiting a life-course approach in capability measurement
Existing measures

ICECAP-A

ICECAP-O

Birth 18 65 Death
Issue 1: ICECAP measures for children

- Birth
- 18
- 65
- Death

ICECAP-A
ICECAP-O
Issue 1: ICECAP measures for children

Birth

Well-being

Well-being

Well-being

Well-becoming
Issue 2: an integrated framework

- Similar basis for descriptive systems
- Similar valuation mechanisms
- Similar anchors

ICECAP-Cs
18
Birth

ICECAP-A

ICECAP-O
65
Death
Issue 2: an integrated framework

- Similar basis for descriptive systems
- Similar valuation mechanisms
- Similar anchors
Issue 2: an integrated framework

ICECAP-Cs

ICECAP-A

ICECAP-O

Birth 18 65 Death

ICECAP-SCM
Issue 2: an integrated framework

ICECAP-Cs

ICECAP-A

ICECAP-O

Comprehension

Retrieval

Response

Judgement

I would give
tokens to
health gain

I would give
tokens to
‘a good death’
Issue 3: measuring end of life for children

Birth

Death
during
childhood
Issue 3: measuring end of life for children

Birth

ICECAP-SCM

Death during childhood
Issue 3: measuring end of life for children

Birth

ICECAP-SCM

Death during childhood
Final thoughts
Final thoughts (1)

- Focused here on differences in ‘what we value’ rather than ‘how much we value’
  - but also evidence of differences in values where we obtain these values for those at different stages of the life-course

- Issues are important for thinking about capability but also have wider applicability
  - E.g. shifts from CHU9D to adult HRQoL in measuring health and QALYs for economic evaluation
Final thoughts (2)

• Future research: recent Wellcome Award
  • To generate ICECAP capability measures for children and young people
  • To establish shifts between measures across the life course
  • To develop methods for capturing capability at end of life for children and young people

• Using both qualitative and quantitative methods
Acknowledgements:

ICECAP Research team
Hareth Al-Janabi
Cara Bailey
Alastair Canaway
Terry Flynn
Phil Kinghorn
Tom Keeley
Paul Mitchell
Rosanna Orlando

Advisory Groups
ICEPOP
ICECAP-A
EconEndLife

Collaborators
Kathy Armour, John Brazier, Stirling Bryan, Sam Clemens,
Ini Grewal, Elizabeth Hunyh, Louise Jones, Jane Lewis,
Alison Moody, Lucy Natarajan, Tim Peters, Jeff Round,
Kerry Sproston
Joanna Coast: Life-course approach to economic evaluation

www.birmingham.ac.uk/icecap

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ICECAP-A

5 questions, each with 4 possible responses

Aims to tap into what is important to the 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
   - I am able to feel settled and secure in many areas of my life
   - I am only able to feel settled and secure in a few areas of my life
   - I am unable to feel settled and secure in any areas of my life

2. Love, friendship and support
   - I can have a lot of love, friendship and support
   - I can have quite a lot of love, friendship and support
   - I can only have a little love, friendship and support
   - I cannot have any love, friendship and support

3. Being independent
   - I am able to be completely independent
   - I am able to be independent in many things
   - I am only able to be independent in a few things
   - I am unable to be at all independent

4. Achievement and progress
   - I can achieve and progress in all aspects of my life
   - I can achieve and progress in many aspects of my life
   - I can only achieve and progress in a few aspects of my life
   - I cannot achieve and progress in any aspects of my life

5. Enjoyment and pleasure
   - I can have a lot of enjoyment and pleasure
   - I can have quite a lot of enjoyment and pleasure
   - I can only have a little enjoyment and pleasure
   - I cannot have any enjoyment and pleasure

Please ensure you have only ticked ONE box for each of the five groups.
### 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
   - I can have a lot of the love and friendship that I want
   - I can have a little of the love and friendship that I want
   - I cannot have any of the love and friendship that I want

2. **Thinking about the future**
   - I can think about the future without any concern
   - I can think about the future with only a little concern
   - I can only think about the future with some concern
   - I can only think about the future with a lot of concern

3. **Doing things that make you feel valued**
   - I am able to do all of the things that make me feel valued
   - I am able to do many of the things that make me feel valued
   - I am able to do a few of the things that make me feel valued
   - I am unable to do any of the things that make me feel valued

4. **Enjoyment and pleasure**
   - I can have all of the enjoyment and pleasure that I want
   - I can have a lot of the enjoyment and pleasure that I want
   - I can have a little of the enjoyment and pleasure that I want
   - I cannot have any of the enjoyment and pleasure that I want

5. **Independence**
   - I am able to be completely independent
   - I am able to be independent in many things
   - I am able to be independent in a few things
   - I am unable to be at all independent

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