Use of PROs in children
Development of a value set for the EQ-5D-Y

Koonal Shah, Office of Health Economics

Advances in Patient Reported Outcomes Research Conference
St Anne’s College, Oxford • 8 June 2017
Acknowledgements

• This presentation reports the methods and preliminary findings of two studies, both funded by the EuroQol Research Foundation
• The views expressed do not necessarily reflect the views of the EuroQol Research Foundation
• Both studies are currently in progress
• The studies are being conducted in collaboration with: Juan Manuel Ramos-Goni, Oliver Rivero-Arias, David Mott, Simone Kreimeier, Yan Feng, Ben van Hout and Nancy Devlin
EQ-5D-Y: state of play

• EQ-5D-Y – ‘youth’ version of the EQ-5D
• >40 language versions available
• Use is modest but growing
• Demand for use in HTA, but no value sets to support that
• Recent research has indicated that regular EQ-5D-3L value sets cannot be used for children and adolescents
EQ-5D-Y instrument

MOBILITY
☐ I have no problems walking about
☐ I have some problems walking about
☐ I have a lot of problems walking about

LOOKING AFTER MYSELF
☐ I have no problems washing or dressing myself
☐ I have some problems washing or dressing myself
☐ I have a lot of problems washing or dressing myself

DOING USUAL ACTIVITIES
(for example, going to school, hobbies, sports, playing, doing things with family or friends)
☐ I have no problems doing my usual activities
☐ I have some problems doing my usual activities
☐ I have a lot of problems doing my usual activities

HAVING PAIN OR DISCOMFORT
☐ I have no pain or discomfort
☐ I have some pain or discomfort
☐ I have a lot of pain or discomfort

FEELING WORRIED, SAD OR UNHAPPY
☐ I am not worried, sad or unhappy
☐ I am a bit worried, sad or unhappy
☐ I am very worried, sad or unhappy
Challenges in valuing EQ-5D-Y

- **Normative issues** (*whose preferences should we elicit?*)
- **Perspective issues** (*whose health should we elicit the preferences for?*)
- **Methods issues** (*how do we elicit the preferences, and on what basis do we make this choice?*)
  - VAS values *lower* for EQ-5D-Y than for EQ-5D-3L (Kind et al., 2015)
  - TTO values *higher* for EQ-5D-Y (Kreimeier et al., 2015) – possibly due to reluctance to sacrifice life years for children
- **Wording issues:** EQ-5D-Y and EQ-5D-3L are different instruments, but can we find a linking function?
Principles

• EuroQol protocol: EQ-5D value sets should be based on the preferences of the general public, not of the subgroup whose health is being evaluated
  • Reflects fact that HTA is intended to inform the broad allocation of resources across an entire population / health system
  • Public = taxpayers and potential users of health care
  • Consistent with recommendations of NICE and the Washington Panel
• But it may still be relevant to know about the preferences of children (as patients) (Versteegh and Brouwer, 2016)
• And child preferences may be relevant in other (non-HTA) uses of the instrument
Our research

Study 1: Latent scale DCE study

• Conduct a discrete choice experiment to obtain EQ-5D-Y values on a latent scale

Study 2: Anchoring study

• In parallel, test a range of methods for anchoring latent scale values at 0 = dead
Latent scale DCE study

- Internet survey
- 15 DCE (paired comparison) tasks per respondent
- Each task asks adult respondents to choose which they prefer of two EQ-5D-Y health states, considering the health of a 10 year old child

- UK general public sample (n=1,000; representative in terms of selected observable characteristics)
- Experimental design informed by priors based on pilot data (n=127)
- Data collected in March 2017
Question 1 / 16

Considering your views about a 10 year old child: which do you prefer, A or B?

A
- no problems walking about
- a lot of problems washing or dressing
- a lot of problems doing usual activities
- some pain or discomfort
- very worried, sad or unhappy

B
- some problems walking about
- some problems washing or dressing
- a lot of problems doing usual activities
- some pain or discomfort
- a bit worried, sad or unhappy
Preliminary findings

• ‘Having pain or discomfort’ and ‘Feeling worried, sad or unhappy’ appear to be the most important dimensions
  • Consistent with corresponding research on EQ-5D-3L / adult health

• ‘Doing usual activities’ appears more important than is usually the case in EQ-5D-3L / adult health research, whereas ‘Looking after myself’ appears less important

• Results broadly consistent across a range of data modelling strategies

• When asked whether their responses would have been different if the questions had been about their own health, respondents’ views were divided
Anchoring study

- Computer-assisted personal interviews
- Respondents answer questions both about their own health (using EQ-5D-3L) and about the health of a 10 year old child (using EQ-5D-Y)
- Two-arm design: random half of sample starts with adult questions and proceeds to child questions; ordering reversed for the other half

Considering your own health: which do you prefer, Life A or Life B, or are they about the same?

Considering your views about a 10 year old child: which do you prefer, Life A or Life B, or are they about the same?
# Anchoring study

1. Introduction and warm-up questions

2. Ranking (adult)

3. VAS (adult)

4. TTO (adult)

5. DCE with duration (adult)

6. Location of dead tasks based on PUF method (adult)

7. Half-way point – perspective switch

8. Ranking (child)

9. VAS (child)

10. TTO (child)

11. DCE with duration (child)

12. Location of dead tasks based on PUF method (child)

13. Debrief and background questions
Current status

• Pilot / cognitive interviews (n=9) undertaken in April
  • General approach found to be feasible
  • No clear preference for any one particular method
  • Some respondents felt uncomfortable/distressed thinking about death and severe ill health for children
  • Tentative evidence that preferences vary across techniques and between versions (3L/adult and Y/child)
  • Several improvements being made to improve the user-friendliness of the survey and interviewer materials

• Main stage interviews (n=300) planned for the summer
• Ultimate aim is to combine the results of the two studies to produce anchored EQ-5D-Y values
Thank you for listening

To enquire about additional information and analyses, please contact Koonal Shah at kshah@ohe.org

To keep up with the latest news and research, subscribe to our blog, OHE News

Follow us on Twitter @OHENews, LinkedIn and SlideShare

Office of Health Economics (OHE)
Southside, 7th Floor
105 Victoria Street
London SW1E 6QT
United Kingdom

+44 20 7747 8850
www.ohe.org

OHE’s publications may be downloaded free of charge from our website.