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ISPOR Workshop

INCLUDING CAREGIVER / FAMILY MEMBER QUALITY OF LIFE IN ECONOMIC EVALUATIONS – YOUR QUESTIONS ANSWERED

ARE EXISTING MEASURES FIT FOR PURPOSE?

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Poll: Is there a measure fit for estimating QALYs in caregivers?

How should we measure caregiver utility?

Generic measure of health – (e.g. EQ-5D)

Subjective well-being (e.g. happiness or life satisfaction)

Care giver specific QoL measures

- CarerQoL (Brouwer et al, 2006)
- Carer Experience Scale (CES) (Al-Janabi et al, 2001)
- ASCOT-Carer (Rand et al, 2015)

EQ-5D	Carer-QoL Brouwer et al, 2006	Carer Experience Survey Al-Janabi et al, 2011)	ASCOT-Carer (Rand et al, 2015)
Mobility	Relationships	Activities	Occupation (doing things I value or enjoy)
Anxiety or Depression	Mental health	Control	Control over daily life
Usual activity	Financial burden	Assistance (organisations)	Self-care - look after oneself
Pain or Discomfort	Problems combining care and usual activities	Fulfillment	Safe and secure
Self-care	Physical health		Social participation and involvement
	Fulfillment from caring	Getting-on (with care recipient)	Space and time to be oneself
	Support with caring	Support (family/friends)	Encouraged and supported
Health VAS	SWB VAS		

Valuation of carer measures

	Country	Valuation technique	Score range
Carer-QoL	Australia, Germany, **Netherlands,** Sweden, UK and US	On-line Discrete Choice Experiment, General public (500 per country)	0-100 non-QALY preference-based scale
Carer Experience questionnaire	UK	Best Worse Scaling, Postal survey of carers (n=162)	0-100 non-QALY preference-based scale
ASCOT-carer	UK	None available	

None are on a QALY scale – so what is the solution?

1) Use non-QALY scores in a cost-consequences analysis or MCDA?
2) Map between EQ-5D and one of the Carer QoL measures?
3) Use 'preference-based' mapping to estimate exchange rates between measures?
4) Develop a new broader QALY measure?

1) Use non-QALY scores in a cost-consequences analysis (CCA) or MCDA?

CCA leaves it to the decision maker to value a difference in carer QoL score (on an arbitrary scale) and compare to patient QALYs;

- No sense of differential impact by disease – e.g. is this worse than for any other condition?
- But different scales are not comparable and ignores duration of QoL for carer
- Assumes there is a standard trade-off between patients health and carer QoL

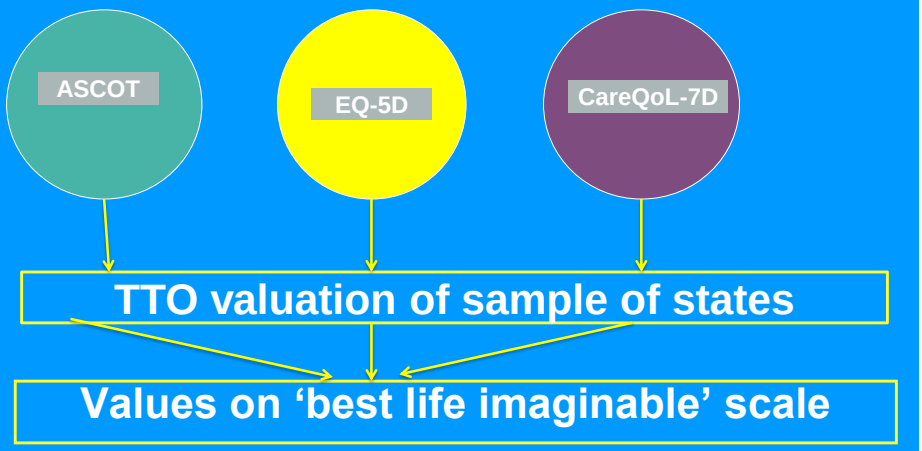
2) Map carer QoL measures onto preferred health measure (e.g. EQ-5D)?

- Regress a target measure (e.g. EQ-5D) on a source measure (e.g. generic or condition specific PRO) using data set collected from carers who completed both measures (target and source)

e.g. EQ-5D= f(ASCOT) and EQ-5D= f(CareQoL) problem solved?

- No since only modest conceptual overlap, so would fail to reflect non-health benefits.

3) Use 'preference-based' mapping to estimate exchange rates between measures?



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Preference-based mapping continued

Design:

- Representative sample of the population value states from each instrument
- Use preference-elicitation technique like TTO or SG with 'best imaginable life' as upper anchor
- Regress new generic TTO values on original values of ASCOT, EQ-5D and CareQoL scores (Source: Karimi et al, 2019)

Results:

New 'generic' TTO Value = 0.981 * ASCOT Tariff

= 1.022 * EQ-5D-5L Tariff

= 0.052 + 0.0094 * CarerQoL

- Exchange rate calculated by a simple solution using coefficients

EQ-5D-5L = 1.042 * ASCOT Tariff

= -0.052 + 1.082 * CarerQoL Tariff

6-11-2019

So use preference-based mapping?

i.e. Simply add the patient health related QALY to a CarerQoL QALY (using the best imaginable TTO/SG value as the gold standard)? But…

- Why does control/relationships/support matter for carers but not patients?
- Why does health matter for patients but not carers?

4) Develop a new broader QALY measure

- Address the limitations with the standard health related QALY
  - too narrow
  - misses important aspects of QoL for carers, patients including those with long-term conditions
- Enable patient and carer outcome to be combined?

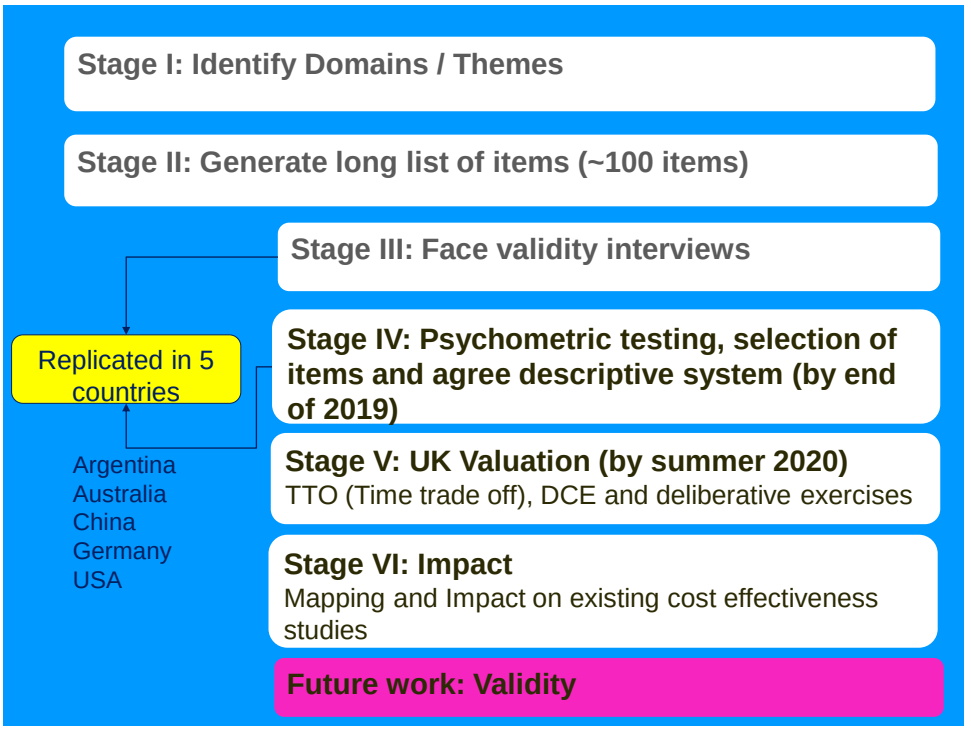
Extending the QALY project (E-QALY)

1. Reflect impact of health and care interventions on
   - physical and mental health
   - broader quality of life

   As judged to be important by patients, service users and others such as informal carers
2. Amenable to valuation
   - Generate a profile of scores and preference-based index for calculating QALYs
3. International study

- 6 countries (Argentina, Australia, China, Germany, UK, USA), with international advisory group in excess of 120

Funded by MRC, EuroQoL group and local NHS Research Collaboration



Preliminary domains and sub-domains

Conclusion

- ❑ Carer health related QALY measures rarely included
- ❑ Carer QoL measures broader than health – but why should they be so different to measures for patients?
- ❑ Carer QoL measures can't be used in economic evaluation in their current form
- ❑ Solutions:
  - Conventional mapping – insufficient conceptual overlap
  - Preference-based mapping – inconsistency between what we value for patients and carers
  - A single measure relevant to patients and carers?

Whatever the solution the opportunity cost of carer QoL benefits (with fixed public budgets) is reduced health for patients

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References

Al-Janabi H, Flynn TN, Coast J. Estimation of a preference-based carer experience scale. Med Decis Making. 2011;31:458–68. https://doi.org/10.1177/0272989X10381281.

Brouwer W, van Exel N, van Gorp B, Redekop W. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res. 2006;15:1005–21. https://doi.org/10.1007/s11136-005-5994-6.

Hoefman RJ, van Exel J, Brouwer WBF. Measuring care-related quality of life of caregivers for use in economic evaluations: CarerQol tariffs for Australia, Germany, Sweden, UK, and US. Pharmacoeconomics. 2017;35:469–78. https://doi.org/10.1007/s40273-016-0477-z.

Pennington B, Wong R. Modelling Carer HRQoL in NICE TAs and highly specialised technologies. http://nicedsu.org.uk/modelling-carer-health-related-quality-of-life/

Rand, Stacey E., Malley, Juliette, Netten, Ann and Forder, Julien (2015) Factor structure and construct validity of the adult social care outcomes toolkit for carers (ASCOT-carer). Quality of Life Research, 24 (11). pp. 2601-2614. ISSN 0962-9343

About E-QALY project:

Peasgood et al "Developing a new generic classifier of quality of life: results from the Extending the QALY (E-QALY) psychometric surveys" Paper Presentation, 36th EuroQol Group Scientific Plenary Meeting, Brussels, September 2019

Extending the QALY project collaboration with NICE, EuroQoL, June 2017

NICE to work with partners on developing new ways to measure quality of life across health and social care NICE, June 2017

See: https://scharr.dept.shef.ac.uk/e-qaly/about-the-project/

About preference-based mapping:

Rowen D, Brazier J, Tsuchiya A, et al. Valuing states from multiple measures on the same visual analogue sale: a feasibility study. Health economics. 2012; 21: 715-29.

K Stevens, John Brazier, Donna Rowen. "Estimating an exchange rate between the EQ-5D-3L and ASCOT.". The European Journal of Health Economics 653-61.