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EQ Health and Wellbeing: Methodological issues in developing a new generic preference-based measure for health and social care

SIA Conference
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Acknowledgement and disclaimers

- Development of the EQ-HWB was funded by MRC UK, the EuroQol Research Foundation, Netherlands and NIHR ARC Yorkshire and Humber.
- The work was undertaken by researchers at the University of Sheffield, University of Kent, University of Melbourne, NICE, National University of Singapore, University of Illinois, Institute for Clinical Effectiveness and Health Policy (Argentina), University of Technology Sydney, and University of Bielefeld (Germany). We would like to acknowledge the contribution of our patient and public group, our advisory group and the project steering group.
- The work would not have been possible without the input of patients, informal carers, social care users and members of the public.

The views expressed in this presentation are those of the author and not necessarily those of the funders, the Department of Health and Social Care, NICE or other contributors.



Outline

- Background
- Focus of new instrument
- Issues and methods
- Results
- Summary



Background

- Health and social care interventions can impact on health related quality of life (HRQoL) and broader outcomes such as coping, control and other wellbeing aspects.
- The impact of health and social care may fall on those connected to the service users e.g. informal carers (spillover effects)
- Extending the QALY project aimed to develop a new measure that could be used to assess the impact of both health and social care on all potential beneficiaries



Proposed extension

1. Reflect impact of health and social care interventions on:

- physical and mental health
- broader quality of life
- judged to be important by service users and those impacted by interventions

2. Amenable to:

- generating a long-version of the measure & a preference-based index
- being included in trials and routine surveys
- being used internationally

With input from a group of members of the public (patients, informal carers and social care users), a steering group (with academics and decisionmakers) and a wider advisory group (Brazier et al 2022)



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Methods



Stages of development

1. Identify potential dimensions
2. Identify potential items
3. Face validation of potential items
4. Psychometric validation of potential items
5. Select items
6. Valuation



Stage 1: Identifying potential dimensions

- Generic measure should be applicable across most of the populations of interest – health and social care users and informal carers

Targeted qualitative review of reviews studies based on

- selected conditions (using International Classification of Disease 10 Chapters),
- social care interventions,
- informal carers and
- primary studies from development of measures of health and social care, and informal care (Mukuria et al 2022)



Stage 2: Identifying items

- Generic measure items should be applicable across all groups (health and social care users, informal carers)
- Items should be generic and convey construct without too much information (preference-elicitation in mind)

Identification of items:

- Drew on terminology from qualitative review.
- Existing measures and item banks with new items developed where they did not exist. (Carlton et al 2022)
- Specific criteria used to aid selection (Peasgood et al 2021)



Stage 3: Testing face validity of items

- Large pool of items to test across the groups of interest
- Concern regarding international applicability

Face validity testing:

- Qualitative interviews with standardised protocol and training
- Each participant reviewed a subset of items to reduce burden
- Six countries (Argentina, Australia, China, Germany, United Kingdom, United States of America) (Carlton et al 2022)

Stage 4: Psychometric testing

- Large pool of candidate items to test across groups of interest

Quantitative psychometric assessment (classical and Item Response Theory (IRT))

- Survey across the 6 countries with focus on specific populations covering physical and mental health, social care use and informal carers.
- Majority online to reach specific groups. UK – recruitment via NHS
- Survey included other measures and single items to enable all assessment without being too long (Peasgood et al 2022)
- Also relied on separate assessment of other data to inform expectation of factor structure



Stage 5: Selecting items

- Pool of candidate items with evidence from 6 countries on face and psychometric validity
- Length of classifier restricted by valuation methods

Selection of items relied on:

- Public and Patient Involvement group selection
- Two rounds of survey with other stakeholders – one for profile, one for classifier – with evidence from Stages 3 and 4 summarised for stakeholders to consider in selection process.
- Ranking and international team preferences used to make final decision (Brazier et al 2022)



Stage 6: Valuation of the new measure

- Could potentially be long and containing both health and other aspects

Valuation

- Qualitative piloting comparing valuation of EQ-5D-5L and EQ-HWB-S using time trade-off (TTO) and discrete choice experiments (DCE)
- Feasibility study using EuroQol Valuation Technology (EQ-VT) protocol in general population sample. Online computer administered personal interviews with TTO and DCE and the same training and quality checks as EQ-5D-5L studies (Mukuria et al 2023)



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Results

Results(1)

1. Qualitative literature review to identify themes and sub-themes (Mukuria et al 2022)

- Extraction and synthesis resulted in 7 high-level themes and 32 sub-themes

2. Item identification (Carlton et al 2022)

- 687 items reviewed – 97 taken forward to face validation

3. Qualitative face validation (Carlton et al 2022)

- Patients, social care users and informal carers (n=170)
- 97 items tested. 47 retained, 14 modified, 3 added





Results (2)



4. Quantitative psychometric assessment in the six countries (n=4879)
 - Evidence of good performance across most items
 - Less definitive evidence for carers and for China
5. Item selection (Brazier et al 2022)
 - EQ-HWB profile measure (25 items)
 - EQ-HWB-S classifier (9 items)

EQ-HWB (Health and Wellbeing, 25 items)

[These questions are trying to measure how **your** life has been **over the last 7 days**

In the **last 7 days:**

	No difficulty	Slight difficulty	Somewhat difficulty
1. How difficult was it for you to see (using, for example, glasses or contact lenses if they are needed)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How difficult was it for you to hear (using hearing aids if you usually wear them)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How difficult was it for you to get around inside and outside (using any aids you usually use e.g. walking stick, frame or wheelchair)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How difficult was it for you to do day-to-day activities (e.g. working, shopping, housework)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. How difficult was it for you to wash, toilet, get dressed, eat or care for your	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vision
Hearing
Mobility
Daily activities
Self-Care
Enjoyable activities

None of the time Only occasionally Some of the time Often Most or all of the time

Accepted by others e.g. feeling like you belong to be yourself and that you belong

Worried about myself

Unable to do the things I wanted to do

Self-worth

None of the time Only occasionally Some of the time Often Most or all of the time

Physical pain?

23. Please tick **one** box to describe your experience in the last 7 days:

I had no physical pain

I had mild physical pain

I had moderate physical pain

I had severe physical pain

I had very severe physical pain

Control
Coping

over my day-to-day life

e.g. having the choice to do things or have

Loneliness
Support
Stigma/belonging

None of the time Only occasionally Some of the time Often Most or all of the time

Discomfort e.g. feeling sick, tired, or out of breath (not including pain)?

Please tick **one** box to describe your experience in the last 7 days:

I had no physical discomfort

I had mild physical discomfort

I had moderate physical discomfort

I had severe physical discomfort

I had very severe physical discomfort

Memory
Concentrating/ thinking clearly

Sad/depressed
Anxious
Hopeless
Frustrated
Unsafe

Pain
Discomfort
Sleep
Fatigue

EQ-HWB-S (Short, 9 items)

These questions are about the **last 7 days**.

Please answer all questions. There are no wrong or right answers.

Please select **one** response for each question.

In the last 7 days :	No difficulty	Slight difficulty	Some difficulty	A lot of difficulty	Unable
1. How much difficulty did you have getting around inside and outside? (<i>using e.g. a walking stick or wheelchair if you normally use them</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. How much difficulty did you have doing day-to-day activities? (<i>e.g. working, shopping, housework</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the last 7 days , did you:	None of the time	Only occasionally	Sometimes	Often	Most or all of the time
3. feel exhausted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. feel lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. have trouble concentrating or thinking clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. feel anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. feel sad or depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. feel you had no control over your day-to-day life? (<i>e.g. had no choice to do things or have things done for you as you liked and when you wanted</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Please select one response to describe how much physical pain you had in the last 7 days . Did you have:	
no physical pain?	<input type="checkbox"/>
mild physical pain?	<input type="checkbox"/>
moderate physical pain?	<input type="checkbox"/>
severe physical pain?	<input type="checkbox"/>
very severe physical pain?	<input type="checkbox"/>

Mobility

Daily activities

Fatigue

Loneliness

Concentration & thinking clearly

Depression

Anxiety

Control

Pain

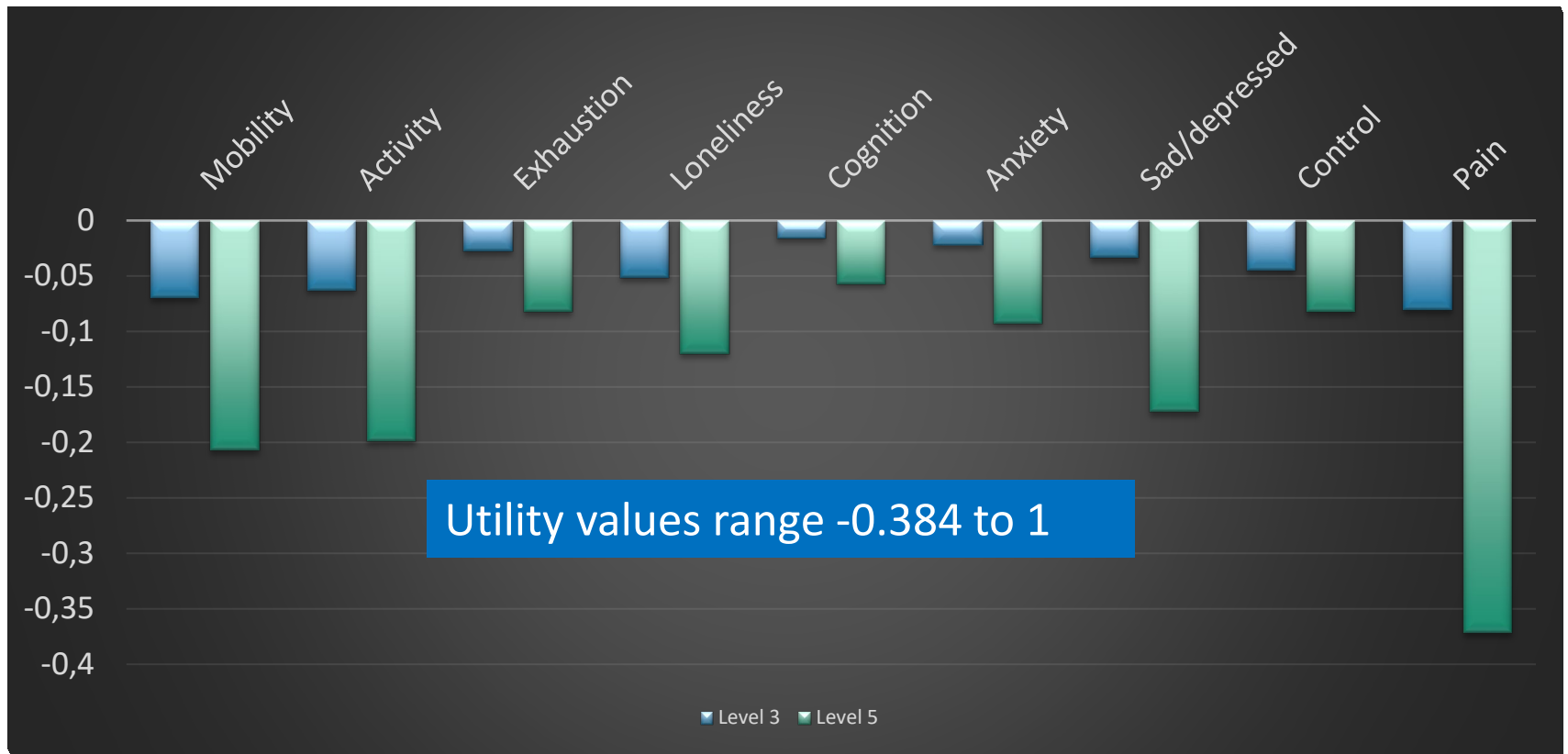


EQ Health and Wellbeing

- 7 day recall period (works better for some of the wellbeing items than 'today')
- Response options:
 - Difficulty (no/slight/some/a lot/unable)
 - Frequency (none of the time/only occasionally/sometimes/often/most or all of the time)
 - Severity (no/mild/moderate/severe/very severe)



Hybrid model (combining TTO and DCE data) disutilities for levels 3 and 5 (n=520)



Source: Mukuria et al 2023

Did we extend the QALY?

- Measurement:
 - Covers physical and mental health and other aspects of quality of life (wellbeing), based on judgement of service users and potential beneficiaries and other stakeholders
 - As a generic measure – some specific aspects may be missing e.g. being treated with dignity which may be more important in social care
 - More evidence required on performance of measure in social care and for informal carers
- Valuation
 - Weight given to all dimensions but restricted set of items
 - Also relatively larger weight given to common health dimensions



Current status

- EQ-HWB has ‘experimental’ status (meaning the measure can change) – free to use following collaborator agreement with EuroQol Group who hold IP status
- A number of studies on-going to assess the psychometric properties of the measures (rather than items) in different populations including proxy response.
- Evidence for move towards ‘beta’ version (1-2 years?)



Summary

- Measuring outcomes in the context of health and social care includes outcomes beyond HRQoL and beyond the immediate beneficiaries of services
- EQ-HWB has been developed to allow for use across different groups in health and social care.
- Methods aimed to address some of the issues in developing a generic preference-based measure.
- Further work ongoing.



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Simone Kreimeier
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EuroQol
Research
Foundation

CLAHRC

Funders

UK Medical
Research Council
(MRC)

University of Kent

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Institute for Clinical Effectiveness and Health Policy (IECS)

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EuroQol Research
Foundation

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References

Brazier, J., et al. (2022). The EQ Health and Wellbeing: overview of the development of a measure of health and wellbeing and key results. *Value in Health*.

<https://www.sciencedirect.com/science/article/pii/S1098301522000833>

Carlton, Jill, et al. (2022) "Generation, Selection, and Face Validation of Items for a New Generic Measure of Quality of Life: The EQ Health and Wellbeing." *Value in Health*

<https://www.sciencedirect.com/science/article/pii/S1098301522000109>

Monteiro, A. L., et al. (2022). A Comparison of a Preliminary Version of the EQ-HWB Short and the 5-Level Version EQ-5D. *Value in Health*, 25(4), 534-543.

Mukuria, Clara, et al. (2022) "Qualitative Review on Domains of Quality of Life Important for Patients, Social Care Users, and Informal Carers to Inform the Development of the EQ Health and Wellbeing." *Value in Health*

<https://www.sciencedirect.com/science/article/pii/S1098301521032277>

Peasgood, T., et al. (2021). Criteria for item selection for a preference-based measure for use in economic evaluation. *Quality of Life Research*, 30, 1425-1432.

Peasgood, Tessa, et al. (2022) "Developing a New Generic Health and Wellbeing Measure: Psychometric Survey Results for the EQ Health and Wellbeing." *Value in Health*

<https://www.sciencedirect.com/science/article/pii/S1098301521031922>